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**Journeys of Identity Construction After Traumatic Brain Injury: Elite Athletes Perform Their Stories
of Healing**

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Journeys of Identity Construction After Traumatic Brain Injury:

Elite Athletes Perform Their Stories of Healing

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A thesis submitted to the

Faculty of Graduate and Postdoctoral Studies

in partial fulfillment of the requirements

of the Degree of Doctor of Philosophy

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For Lily

Thank you forever

for your constant and loyal companionship

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Abstract

It takes time and effort for individuals to construct their identities after a traumatic brain injury. As a former elite athlete who sustained a head injury in 1997, I was interested in listening to the stories told by other former elite athletes who had also suffered head injuries. The purpose of this autoethnographic study was to explore how these athletes have constructed their identities after such a life-altering event. I asked: When elite athletes sustain traumatic brain injuries, what do the athletes' performances reveal about their journeys of identity construction? To collect data, I listened to four athletes' stories, two of whom, like myself, are Olympians, and two are former professional athletes. I talked to each of the athletes over four consecutive days, carefully observing their performances as they told me stories about their lives as athletes, their accidents, their journeys of recovery after their head injuries, and their lives now. On these four days, the athletes took photos with a digital camera to illustrate their perceptions of the lives they now live. I composed illness narratives from my observations, the athletes' performances, and their photos. These illness narratives were then analysed using a lens composed of Riessman's dialogic/performance analysis and Goffman's dramaturgy. The illness narratives and their analyses provide an in-depth study of these athletes' lives after head injury. The analysis revealed that the athletes, unsurprisingly, are still performers, their identities continue to evolve, and that, for the most part, they are comfortable coping with the consequences of their head injuries and content with their current lives. My hope is that these stories and the study of them offer inspiration for all survivors of head injury and their supporters.

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Chapter 1: Introduction – A Painter’s Fan

Research interests are often offspring of our own lived experiences (Clandinin & Connelly, 2000; Clark, 2007; Richards, 2008). I became interested in this research as a result of a particularly traumatic event and, like personal experiences often are, this one is close to my heart. The head injury I sustained on September 13th, 1997 was a turning point in my life, and it thoroughly shattered my comfortable and familiar, albeit always evolving, identity (Denzin, 1989). Not only did the injury stain my past, but it now paints the present, being the subject of both my MA and my PhD research. I have little doubt that it will also color my future (Bruner, 2002).

Here, I venture forth
offering thoughts on
the research journey.

Discover
on these pages
stories, ideas, and theory,
pieced together with
care.

I learned during the MA research process that it is important to me to reach out and increase awareness about head injury (Wilson, 2007). I continue that quest now by sharing illness narratives that I have carefully co-constructed with four elite athletes who are all survivors of a traumatic brain injury (TBI). Their invaluable contributions were to share

their stories of healing with me and to provide illustrations for their stories by taking photographs. I listened to and then reflected on each athlete's stories. I constructed the athlete's illness narrative by combining his stories of healing, the related photographs, and my own reflections. Then, I did as Riessman (2008) suggests: I conducted a dialogic/performance analysis. Next, I performed an analysis of narrative as described by Coulter and Smith (2009).

Four elite athletes performed stories about their pasts as athletes, their accidents, their rehabilitation, their identity construction, and their lives now. I consider elite athletes to be those who have represented their country internationally, or those who have played sports professionally. Tinley (2002) notes the arduous work involved to reach the top of a sport. He remarks that the athletes that reach these levels "do so as a result of a long term commitment to training and competing... No doubt, athletes must make severe sacrifices to reach the World class and professional levels within their sport" (p. 1). For these athletes, the intense focus on sport can "become a way of life" (Stephan & Brewer, 2007, p. 76). Drahotka and Eitzen (1998) believe that "Ex-professional athletes will always be known by their past (sports) identity" (p. 277). Taking these remarks into account, and to show my utmost respect for the accomplishments of the participants, I will continue to refer to these individuals as 'elite athletes'. I will not add the qualifier 'former' because I think that being an 'elite athlete' is an entrenched part of the participants' identities. They will always, in my mind, remain 'elite athletes' and I am tremendously impressed by their recoveries and new life journeys. It should be noted that the term 'elite' is by no means restricted to athletes. It

can refer to others who stand out for many different reasons, for example single mothers who hold down two jobs while caring for their children.

By listening closely to these athletes' stories and, at the same time, paying attention to my own, I have made an effort to begin to understand how we have constructed our identities. It is important to note now that, throughout this dissertation, I have used the term construct. However, at any point, this word can be substituted with the term reconstruct and will mean the same. Because I am a member of the culture I am studying, my own constructed story is included seamlessly as an interlude at the end of most chapters.

The research process was fascinating; I felt it essential that I venture into interesting and unique researcher-participant relationships. The process was complicated and tested my tolerance as I navigated through the uncharted waters of my research question: **When elite athletes sustain traumatic brain injuries, what do the athletes' performances reveal about their journeys of identity construction?**

To add fodder to my research, I also wondered:

1. What do the athletes' performances disclose about their understandings of the terms 'identity' and 'learning'?
2. How do the athletes, through their performances, describe their identities: who they felt they were before their accidents and who they are becoming after head injury?
3. When the athletes perform their stories, what do these performances convey about their perceptions of whether they have learned, and if so, how and what they have learned while (re)constructing their identities?

Two of the athletes, Terry Evanshen and Dave Irwin, were assisted by their partners while they were performing their stories. The partner's presence was necessary due to the memory impairments resulting from each athlete's injury. They reminded, encouraged, and guided the athletes. Although they were asked not to influence or lead the athletes, it was understandable that Lorraine Evanshen and Lynne Harrison had their own evolving understandings of the athletes' stories. Even though, as caregivers, they have been repositories of the athletes' stories, and they volunteered to assist Terry and Dave to convey their stories to me, I listened carefully to their comments. I am aware that, to some degree, my interpretations of their remarks may have coloured the illness narratives that I constructed from these athletes' stories.

Throughout the thesis, I have included my own story as interludes. My intention, by inserting these interludes, is to offer the reader glimpses of my experiences, to open the window leading to my story a crack. I hope that the reader does not regard these interludes as (un)needed "interruptions to the academic voice" (Kidd & Finlayson, 2009, p. 993). My reflections of the athletes' stories are in boxes and are sprinkled throughout their stories. I hope that these reflections "evoke, resonate, and illuminate meaning" (p. 993).

My Story Begins - Why This Research?

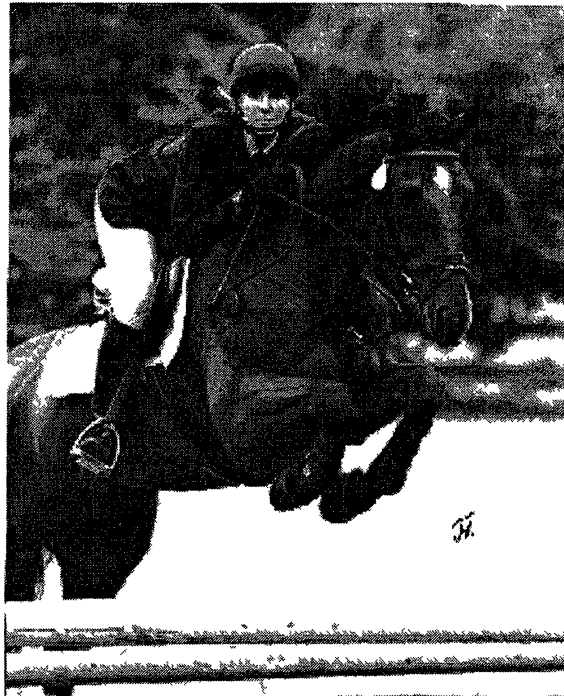
This research is entangled with my own life experiences and is therefore "shaped by [my] personal history, biography, gender [and] social class", in particular my life story of the past thirteen years (Denzin & Lincoln, 2005, p.6). The words of Yann Martel, in the Life of Pi, the 2002 Mann Booker prize winner, describe how my life has unfolded during these years:

...things didn't turn out the way they were supposed to, but what can you do? You must take life the way it comes to you and make the best of it (p. 101).

On September 13th, 1997, I was forced to “make a new story” when I fell from my horse at the European Three Day Event Championships, sustaining a traumatic brain injury (Josephs, 2008, p. 252). I had had a well defined identity, that of a successful equestrian athlete, that was obvious to me and to everyone around me.

After the accident, it became painfully apparent to me that, as Grealy (1994) eloquently writes:

Sometimes the briefest moments capture us, force us to take them in, and demand that we live the rest of our lives in reference to them (p. 78).



© 1993 Terri Miller

Riding my horse Gordon Gibbons in a competition

My ‘briefest moment’, the accident, immediately removed ‘equestrian athlete’- a crucial, central part of my identity - from me. My old way of life was all encompassing in all respects - mentally, physically and emotionally. It was

comfortable, secure, and familiar. Pillemer (2001) asks: "Can a singular event redirect a life course?" (p. 123). In my case, one did.

After the accident I was lost and adrift because, as is often the case after TBI, my athletic career had been curtailed (Echemendia & Candu, 2004). But, although mourning my old self and my old life took up all my time for a period after I was hurt, I eventually realised that I had to (re)define my notion of mourning so that I could move on and construct a new self and a new life. Behar (1996) describes mourning as I now see it, "not replacing the dead but making a place for something else...we allow ourselves to experience what we have lost, and also what we are....despite this loss" (p. 175). I still think often about my losses and I miss my life with horses with a passion. I yearn for that life daily. The insular, athletic life which used to be the only life I knew still fills me with both painful and lovely memories. However, although I still pay the utmost respect to these memories in (a healthy) relation to my past, I have moved on. Here, as Behar suggests, I have 'made a place' for my storied memories alongside those of the other participants.

I acknowledge that my own arduous journey after sustaining a head injury is the source of the researcher bias that the reader will no doubt perceive (Riessman, 2002b). Have I, as the researcher, "attempt[ed] to reflect rather than distort another's experience" (Vickers, 2002, p. 617)? I realize that, no matter how hard I try, it is impossible to remove the sound of my voice completely. However, I have tried: by conducting an autoethnography, I am letting my voice be heard as well as those of the participants. As Vickers (p. 617) cautions, I hope I did not impose my own themes and ideas on "the experiences of another" (Charmaz & Mitchell, 1997). Throughout the thesis, I have tried to be responsible to the voices of others, always mindful of the influence of my positioning as I shape "the production of knowledge" (Riessman, 2002b; Riessman, 2003, p. 6).

My experiences will

always

be part of

who I was,

who I am, and

also

part of who I am

becoming.

How This Study is Constructed

In this thesis I am a storyteller. I strive to show stories rather than tell them by enticing readers and drawing them into my stories, tempting them so that they are reluctant to let go and are anxious to turn the pages (Denzin, 2003; Lewis, 2006; Smith & Sparkes, 2009). I weave together the athletes' stories and my own story and I add personal insights (Josephs, 2008; Gannon, 2006). Evocative writing is a crucial component of this thesis because it touches readers emotionally, grabbing them and carrying them into and through the stories (Gannon; Rambo Ronai, 1998, 1999; Richardson, 1997a). Some story tellers are able to use only words to 'make' a story irresistible by linking experiences and making meanings across a minefield of unknowns (Polkinghorne, 1988; Josephs, 2008). But, to echo the words of Denzin and Lincoln (2000), I am a methodological bricoleur. I used different methods, including in-depth conversations, participant observation, field notes, and photos to more deeply explore and understand the experiences of the athletes.

Therefore, although writing has been a pivotal part of the research process, a "method of inquiry" and discovery, this thesis is messy and evocative (Charmaz & Mitchell, 1997; Guba & Lincoln, 2005; Richardson, 2000, p. 924; Sparkes, 2002). Sparkes comments that such a text makes "our 'findings' available to more diverse audiences" (p. 211). I use many forms of representation to enhance my written words and to construct the athletes' illness narratives, including both personal reflections and comments about the athletes' performances during the data collection process. These performances are, as Riessman (2008) describes, comprised of their body movements, expressions, and gestures, and reveal emotions and feelings. Carefully watching the participants perform prodded me to

interrogate, question, and challenge my own “taken for granted assumptions and perceptions of everyday life” (Goodall, 2008, p. 84). Using ideas suggested by Adams St. Pierre (1997), Holman Jones (1998a, 1998b), Richardson and Adams St. Pierre (2005), and Riessman, my poetry and the athletes’ photographs also augment the narratives. After constructing each narrative, I then analysed it “dialogically and performatively” (Sparkes, 2002; Riessman, 2008, p. 105). The actual writing process resembled a juggling act as I tried to keep story, performance and theory all in motion throughout the thesis (Holman Jones, 2005b).

Despite the use of these multiple representations offering the reader alternative ways to make meaning, this work should never be considered to be a finished product. Instead, it should be viewed as “tentative [, partial,] and incomplete, subject to reinterpretation, situated...” (Holman Jones, 2005a, 2005b; Riessman, 2002b, p. 210). I have drawn on these various means to accompany the words of my stories in hopes of disrupting readers’ routine ways of interpreting their surroundings and provoking them to think (Langellier, 2003). As Vickers (2002) demonstrates with her article, I believe this study is written ‘on the edge’, and so invites readers to reflect. Readers should heed these warnings. However, I hope that they find this work full of nuance and subtlety, in a word: tellable.

Tellability

The degree to which a story is tellable “results from not only its (detached) content, but also from the contextual (embedded) relevance of the story” (Norrick, 2005, p. 325). How tellable is this project? How will you respond to it? I like to think that my thesis is not only relevant to those from the culture of the head injured, but that it also has unique and interesting characteristics that rank its ‘extra-ordinary content’ attractive to all readers both

inside and outside the academic sphere. You can, if you like, glance at the stories superficially and enjoy them, as Norrick describes, on the “lower-bounding side” of tellability (p. 323). If you venture onto my autoethnographical pond and then skate over its shiny surface quickly, the stories appear smooth and clear. Few cracks will mar your path.

You are neutral, an observer.

But if you take the time and give in to the temptation to peer through the ice, you will discover that suppressed feelings and emotions lurk beneath it, embedded in the morass below. These feelings and emotions are barely visible, however if you choose to look more closely, you will have to sort through the endless interpretations that they make possible and that comprise the murky mess that you have uncovered. You began your journey imagining that there are many “alternative perspectives on the unusualness...[of this thesis as a] narrative event” (Ulatowska, Olness, Samson, Keebler, & Goins, 2004, p. 4). Then, when you have finished reading, you might have felt that you stayed past your welcome. You may have been uncomfortable, frightened of the understandings that you have pieced together (Smith & Sparkes, 2008c). You may think that what I have written is too personal and too revealing. Are you overwhelmed? You may be anxious to return to shore to find solace on firm, solid, and familiar ground, thankful to leave the unknown behind. Or, you may want to stay. Does the project slide towards the upper end of Norrick’s (2005) tellability scale for you? (I use ‘end’ loosely; I believe that, like the fabled rainbow, no end is ever reachable). Does its extra-ordinary content move you? Or do you think ‘So what’?

What Is It?

First, the constructed narratives, as well as the thesis' theoretical and methodological underpinnings, are pleated texts. As such, they are accessible to all and they “displace boundaries between autobiography and selected genres of writings” (Richardson, 1997b, p. 295). Second, the narratives are what Yardley (2008) describes as layered texts, each one filled with data and observations in an effort to provide multiple viewpoints and enable the reader to view the data and interpretations from various angles. Third, the athletes' constructed narratives are collages composed “of field notes, poetry, song, conversation, interviews, theories, performances” (Holman Jones, 1998a, p. 148). To fully describe this study I have chosen to use a metaphor that combines a pleated text, a layered account, and a collage. Opened at any point, this study appears as a range of complementary colours that meet the eye, each slightly different than its neighbours (a layered account). On the next page, one again finds complementary colours, a tone removed from where the fan was opened initially (a collage). Each page reveals slight nuances and different shades (a pleated text).

It is a painter's fan.

Definitions of the Terms Used – Painting the Test Stripes

Traumatic Brain Injury

A traumatic brain injury (TBI) is either a non-penetrating or penetrating injury to the head causing a “decreased level of consciousness, amnesia, other neuropsychological abnormalities, skull fracture, diagnosed intracranial lesions - or death” (Thurman, Alverson, Dunn, Guerrero, & Sniezek, 1999). Acquired brain injuries (ABI) encompass TBIs as well as head traumas that are disease, tumour, infection, or stroke induced (Webster, Dainsley, & King, 1999). A guide to severity is detailed by Leclerc, Lassonde, Delaney, Lacroix and Johnston (2001). They note that a severe TBI has occurred when there is a loss of consciousness lasting more than five minutes and post traumatic amnesia (PTA) lasts more than 24 hours. PTA can be defined in many ways, however all these definitions include the characteristics of confusion, disorientation, and “the inability to lay down continuous memories” (Ahmed, Bierley, Sheikh, & Date, 2000; Tate, Pfaff, & Jurjevic, 2000, p. 178). When PTA follows head injury, the sense of continuity of the ‘me’ self, as described by McAdams (2001, 2003), can be disrupted. I believe that, when traumatic events are experienced in life stories, the fissure of continuity that can occur in the ‘me’ self after such an event can be a factor that influences subsequent identity construction.

A fissure in continuity also impacted my parents’ selves. From listening to their tales of their traumatic experiences (I was not ‘there’; I was suffering from Post Traumatic Amnesia), I learned that a diagnosis of head injury brings grief, uncertainty, and a multitude of questions to family members. Lefebvre and Levert (2006) affirm this, noting that the experiences of loved ones are exacerbated by the lack of information available to interested

parties. This includes information on coping with patients' ongoing deficits. Typical lingering deficits are emotional volatility including mood, and cognitive disabilities such as "reduced mental speed, orientation, perception, concentration, language, memory, and executive functions" (Ribbers, 2007). As time progresses, survivors may deny that life has changed and that they must alter the role that they play. By storying the experiences of elite athletes, this thesis provides a qualitative resource of in depth support and information.

Although their statistics are dated, Basso, Previgiano, Duarte, and Ferrari (2001) underline the importance of traumatic brain injury (TBI) research worldwide. They note that TBI is a major public health problem: TBI is the main cause of death and disability in people under 40 years old. Worldwide prevalence of TBI varies from 67 to 317 per 100,000. These statistics confirm that this research will make a contribution to a significant percentage of the population.

Autoethnography

When a study is an autoethnography, the researcher's story is an integral and vital part of the data and is interpreted along with the stories of the participants. Vickers (2002) thinks that by including the personal in academic research, researchers find strength because their personal stories are an important, significant part of the research. Because the researcher is a participant as well as the researcher, autoethnography is a synthesis of ethnography and autobiography (Coffey, 1999; Ellis & Bochner, 2003; Ellis, 2004; Reed-Danahay, 1997). By incorporating the researcher's personal experiences, an autoethnography can add "blood and tissue to the abstract bones of theoretical discourse" when research is disseminated (Ellis, 1997, p. 117). Spry (2001) writes that "self-reflections

and cultural refractions of identity is a defining feature of autoethnographic performance” (p. 2). I believe that I have performed in this thesis because of the use of my story and my reflections in boxes throughout.

Autoethnography invites researcher reflection and introspection, so it has enabled me to unearth subtle nuances in my own story which help me to heal and to grow (Behar, 1996; Ellis, 2004). Behar remarks that the “exposure of the self who is also a spectator has to take us somewhere we couldn’t otherwise get to” (p. 14). Labelled as self-indulgent by some, Coffey (1999), Mylhalovivsky (1997), and Sparkes (2002) argue that it is not. To wit, Coffey writes that “an autobiographical voice in the text is not an excuse for an unattributed celebration of the self” (p. 127). Writing autobiographically has impacted me: I have found that the exposure of my self in this study has left me feeling vulnerable, a feeling that Denzin and Lincoln (2000) suggest will become a feature of 21st century research. This vulnerability is a risk of research but I believe that it is crucial to this thesis, brought on by my “changing and shifting emotional states” during the research process (Josephs, 2008, p. 265). Despite my increased vulnerability, I think that autobiographic writing has widened, stretched, and opened my past by providing a vehicle for me to first access, and then assemble the jigsaw pieces of my thoughts and memories (Behar, 2003).

Identity

Our identities are not permanent, rigid, and static, but they are actively constructed (Schneider, 2007). Experiences we accumulate through life mould us into identities that may temporarily suit us, but, as we continue to evolve these fleeting identities become history (Barresi, 2002; King, 2000; Raskin, 2002; Verkerk et al., 2004). One’s identities are an

ongoing story because our past and our present is continually interpreted differently by the 'I', the subjective thinker, during the 'I's' constant development (Holstein & Gubrium, 2000; James, 1963; McAdams, 2001, 2003, Smith & Sparkes, 2008b). Smith and Sparkes maintain that the 'I' is the process of constant identity formation, and the 'me' is the product of the continually evolving 'I'. At any given time, one's identity is at the intersection of the 'I' and the 'me' selves (McAdams).

Narrative identity.

I believe, as McAdams (2003) does, that "The self is many things but identity is a life story" (p. 187). This is reiterated by Sarup (1996), who reminds us that our identities are part of what we have experienced; they are not separate from what has happened to us. Individuals' fluid identities are shaped and influenced by their stories. These stories "weave together one moment with the next moment and the moment after that, capturing the ways we change as well as the ways in which we stay the same" (Verkerk et al., 2004, p. 36). Sharing our stories with others helps us to organize our experiences and learn about ourselves while we recount stories of these experiences, acquire new and personal meanings from them, and so (re)construct our identities (Baddeley & Singer, 2007; Bauer & McAdams, 2000; Holstein & Gubrium, 2000; Schneider, 2003; Singer, 2004). Schneider notes that stories are "artful, situated constructions" (p. 130) designed to assign meaning to experiences. When constructing constantly changing identities, "individuals craft narratives from experiences...and ultimately apply these stories to knowledge of self, other, and the world in general" (Singer, p.438). Individuals learn about themselves as they tell stories while constructing their identities because storytelling gives them the opportunity to make

sense of their lives. They can “step back and draw inferences and lessons from the stories they tell of their lives” (Baddeley & Singer, 2007, p. 178).

When they recount their life stories, individuals can explore and (re)construct their evolving identities in forward looking, purpose driven manners. Identities are continually changing, so individuals can discover themselves over and over again, both for their own interests and benefits and for those of others (McLean & Fournier, 2008). Bateson (2000) reminds that any life story notes change as well as sameness. Insights that individuals garner from their stories will help them to remember the past, (re)interpret present, and imagine the future as they (re)negotiate and (re)construct their current identities (McAdams, 1997, 2001, 2003; Mishler, 1999; Neimeyer, 1998; Polkinghorne, 1988; Raskin, 2002; Rimmon-Kenan, 2002; Schneider, 2003). Raskin thinks that because these stories will help them create new insights, they will contribute to their ‘I’ selves and so to their identities. Identity is not singular: “we speak – or sing – our selves as a chorus of voices, not just as the tenor or soprano soloist” (Mishler, p. 8).

Subjectivity.

I believe that individuals construct their identities narratively from the reflections of their subjective selves (Ricoeur, 1992). Narrative provides continuity because lived experience and the life-story a person shares are integrated to contribute to narrative identities (Ezzy, 1998). According to Ellis and Flaherty (1992), subjectivity (human lived experience) “is situated such that the voices in our heads and the feelings in our bodies are linked to political, cultural, and historical contexts” (p. 4). Similarly, Denzin (1997a) writes that subjective “interpretations are produced in cultural, historical, and personal contexts and

are always shaped by the interpreter's values" (p. 35). As I interpret the participants' performances, my interpretations may constantly change according to the different contexts in which I find myself (see also McAdams, 2003; Mishler, 1999; Neimeyer, 1998; Polkinghorne, 1988; Raskin, 2002). Not only are my researcher interpretations coloured by my own changing contexts, but the participants' lives may also be similarly shaped by culture, history, politics, or personal contexts and therefore these contexts may influence their stories. In sum, the subjectivity of the infinite possible imaginations of each athlete's identities are immersed in both the athlete's and the interpreter's political, cultural, and historical backgrounds and it is coloured by their values (Denzin, 1997a; Ellis & Flaherty, 1992). The reverse is also true: individual identities shape the cultural, historical, and political contexts in which they perform.

Performance serves as a "technology of subjectivity" (Hamera, 2006, p. 48), so while the athletes' performed their stories, they constructed subjective evolving and fleeting identities (Smith & Sparkes, 2009). I used the dialogic/performative approach to analyse these stories, so the athletes' dynamic "social relatedness completely precedes individuality, interiority and lived experiences" (Riessman, 2008; Smith & Sparkes, 2008c, p. 24). In other words, their subjective selves, personal identities, and stories are influenced by social identities derived "from cultural meanings and community memberships" consisting in part of athletic and head injury social identities (Charmaz, 1994, p. 269). As members of the culture of head injury, the athletes' social identities may lead to stereotypical assumptions and stigmatisation by others (Goffman, 1963). The athletes' identities remain tied to these social identities because the pain and uncertainty, and also stigma, that can accompany such

an illness becomes part of the person one is at the time (Mattingly, 2007). My own identities are no exception: I performed the analysis of the athletes' stories from a "unique vantage [point]" (Sparkes, 2002, p. 220) wearing a dialogic/performance hat coloured by my own subjectivity, touched by stigma, and influenced by my social identity of an elite athlete who had sustained a head injury (Charmaz; Denzin, 1997a; Ellis & Flaherty, 1992; Kelly, 1992; Riessman).

Learning

Lave and Wenger (1991) maintain that "learning involves the construction of identities" (p. 53). Antikainen (1998) reiterated the link between learning and identity by stating that "learning experiences are significant when they appear to guide [an individual's] life-course, or to have changed or strengthened his or her identity" (p. 218). Learning can result from "daily life activities" and occur incidentally and spontaneously without a teacher figure being present (Colardyn & Bjornavold, 2004, p. 71; Eshach, 2007; Folkestad, 2006; Livingstone, 2001; Taylor, 2006). I believe that lifelong learning processes contribute to the perpetually evolving identities of individuals. Law, Meijers, and Wijers (2002) maintain that individuals are continually challenged throughout the lifelong process of learning "1) to draw upon personal feelings; 2) to differentiate self from others; 3) to develop a personal narrative; 4) to represent experience in one's own terms; 5) to focus a point-of-view; 6) to build an inner life; [and] 7) to relate all to one's own purposes" (p. 432). After head injury, learning can be significant when, for example, an individual relearns how to decipher bus schedules, how to live independently, or how to take part in a particular volunteer activity. Relearning these activities may seem trivial to the uninjured, but can be tremendously

rewarding for survivors. My intention is for athletes' stories of healing to convey for readers how and what they have learned and are learning while (re)constructing their identities.

Performance and Performativity

According to Denzin (2003), performance is a method researchers can use to examine phenomena. While it may not seem conventional or traditional, performance can augment the stories storytellers share when they recount their personal narratives. Following Langellier (2009), Langellier and Peterson (2004), Peterson and Langellier (2006), and Riessman (2008), when the athletes narrate their stories, they will perform the characters that they were at the times of their stories. By using performance as the lens through which I interpret this autoethnography, I am also able to look at my evolving self as the main character in my own stories of healing. I can “dialogically look back upon my self as other.....as the polyglot facets of self and other engage, interrogate, and embrace” (Spry, 2001, p. 708).

Interviews are settings for performances: in this case, as the participants perform their feelings, emotions, and identities, I will attempt to ‘consume’ their stories of healing (Denzin, 2001; Langellier, 1989, 2001; Riessman, 2008). Denzin thinks that an ideal interview is one that is “reflexive, dialogic,... [and] performative” (p. 24). The athletes’ performances extend the understandings of their stories for me because while they performed, I found that they revealed “displays of identity, illness and health” (Riessman, 2002b, p. 6) that I observed, but that they may not have necessarily expressed verbally. Performing their stories enables individuals to convey meaning not just through telling, but meaning can also be observed in how they tell the stories: for example in their actions, their

body language, their facial expressions, and how their tone of voice varies throughout the telling (Carlson, 2004; Denzin, 1997b, 2003; Peterson & Langellier, 2006; Riessman).

Skultans (2000) notes that not only is every performance unique, but when the interviewee's performance is considered, the 'telling' of the story becomes important, not just the story as it was told. Hyden and Brockmeier (2008) feel that performance is an essential part of storytelling, noting that "telling a story is performing it, acting out a process of interpreting, constituting, and positioning one's experience" (p. 7).

The athletes' stories of healing are also performative (Langellier & Peterson, 2006). Langellier (2003, p. 446) defines performativity as a "personal narrative performance [that] constitutes identities and experience, producing and reproducing that to which it refers". As an example, consider the expression 'I invite you to lunch'. Stating this phrase "constitutes the performance of ..[inviting] by virtue of its utterance....[The word] does what it says" (Bal, 2002, p. 175).

Photography

Some of the athletes' performances may be partially constructed from the photographs that they take and partially from the ensuing conversations about these photos (Holm, 2008). While the focus of the study is the conversations I have with the athletes, the content of the photos of both the athletes' pasts and of the photos taken by them during the study provide material that may provoke further discussions and performances during photo-interviews (Kolb, 2008; Warren, 2005).

Stigma

Erving Goffman (1963) explains that the term stigma originated in Greece and was used “to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier” (p.1). Elaborating, he remarks that stigmatisation occurs when differences between individuals are evaluated “in negative terms” (Green, Davis, Karshmer, Marsh, & Straight, 2005, p. 197) by one of the individuals during their interactions. A more current understanding of the term considers stigmatised individuals to be those who have physical, mental, or psychosocial characteristics that fall outside of the local social and cultural norms (Green et al.; Islam, 2008; Link & Phelan, 2001; Scambler, 2004, 2009). Scambler (2009) notes that stigmatised individuals are often subject to “exclusion, rejection, blame or devaluation” (p. 441). The “nature of stigma may vary in different cultures”, not only affecting “what is stigmatized”, but also how it is manifested (Weiss, Ramakrishna, & Somma, 2006, p. 281). In all cultures, stigma targets flaws in individuals’ social identities because it labels them as different (Jacoby, Snape, & Baker, 2005).

Green et al. (2005), and Link and Phelan (2001) write that the components of stigma: labelling, stereotyping, separation, status loss, and discrimination occur in that order and result in stigmatised individuals’ feeling reduced power. A person may be labelled when others sense that the person’s characteristics are not what they would consider normal in the social setting to which they all belong (Green et al.). When people are labelled, they can experience disablism: “a set of assumptions and practices promoting the differential or unequal treatment of people because of actual or presumed disabilities” (Campbell, 2008, p.152). Disablism is an “exclusionary and oppressive practice”, subtly performed for the

disabled in the belief that these individuals are inferior (Deal, 2007; Scambler, 2009, p. 448). Labelled traits become stereotyped because they seem undesirable. When individuals have been stereotyped and labelled, they sense separation from their usual social and cultural situations. According to Green et al., the resulting status loss and discrimination can leave the stigmatised feeling less able “to participate fully” (p. 198). An individual may feel stigmatized, for example, because due to their injuries they are labelled as head-injured, stereotyped, in a cultural or social situation of less power, and separated from their usual situations because they are not able to participate fully (Green et al.; Scambler, 2004).

Goggin and Newell (2005) note that one in five individuals with a disability are living in the world today. When these individuals feel disablism or stigma, they may perform to appear more able and to “put forth [their disability and] their stigma as a difference rather than a failing” (Riessman, 2000, p. 113). If not already stigmatized, these individuals’ ongoing performances will help them to continue to hide an “invisible and potentially stigmatizing attribute”, so that disclosure remains an option for them (Riessman, p. 113).

Stories and Narratives

Narrative “eludes definition, blurs genres, and bleeds across boundaries” (Langellier & Peterson, 2006, p. 153). Polkinghorne (1988) and Riessman (2008) describe narrative as a story that is constructed and performed for the narrator and/or for others. Narrative imposes an organised pattern on human experiences and reshapes them into “meaningful episodes with a beginning, middle and end” (Leitch, 2006, p. 550). For many authors, the terms ‘narrative’ and ‘story’ are interchangeable. However, some claim that they are different and

that narratives emerge as constructions from stories (see Frank, 1995, 2000a; Paley & Eva, 2005; Riley & Hawe, 2005; Severinsson, 2003). In the case of this study, I construct illness narratives from the stories of healing the athletes tell me and from their performances as they tell me their stories.

Stories.

Even though Bruner (2002) believes that “narrative is murky, hard to pin down” (p. 5), others maintain that recounting their stories helps people to think about what is going on in their lives and aids them as they try to decipher the meanings of their experiences and impose order on them (Clandinin, Pushor, & Orr, 2007; Mattingly, 2004; Smith & Sparkes, 2009). Meanings emerge as stories are recounted to others and, by doing so, people reveal their lives (Mattingly, 2007). McAdams (2001) feels, as I do, that telling their stories enables individuals to make countless meaning while they endlessly (re)fashion their identities. They do this by “linking one stepping stone of experience with another” (Josephs, 2008, p. 251). While conversing with others, meanings appear as “braided narratives...[and] unfold from our conversations, supporting, challenging, and increasing our understanding” (Hollingsworth & Dybdahl, 2007, p. 147).

Stories of healing and illness narratives.

Because illness puts into question individuals’ identities and their senses of self, Stanley (2004) believes that illness narratives are an essential means for individuals to (re)create and (re)establish these elements and (re)gain a sense of belonging. When ill people hear illness narratives told by others, they may be more confident to tell their own stories and to make sense of what has happened to them (Frank, 2006; Mattingly, 1998).

Because illness can disrupt and damage people's worlds, Frank (1995) writes that telling their stories can help them sort out what is happening with their lives and alleviate the damage illness may have caused. Sakalys (2003) maintains that "...personal illness narratives provide a way to reclaim one's experience; if illness is a fragmentation of one's self and one's world, then narratives provide a medium through which.... to relate the events to one's life" (p. 231). Storytelling may help people to refocus their attention and assist them to reroute their lives in positive directions (Frank). The listeners of stories of healing may each derive various different meanings for the same stories. In sum, many authors (see Bury, 1982, 2001, 2004; Frank, 1995, 2006; Hawkins, 1999, 2007; Hyden, 1997, Robinson, 1990; Smith & Sparkes, 2002, 2004, 2008a, 2008b, 2009) recognise the value of telling their stories for individuals because recounting stories gives people a voice, they can articulate their experiences, and they can facilitate making meaning of their experiences by telling their stories. Hawkins (2007) describes a benefit of telling stories of healing and illness narratives:

... the creation of a story to be told to others is not just something that benefits the trauma survivor, but something of benefit for the larger society.... [survivors should] believe that each of them is a storyteller with a mission; that their responsibility as survivors is to bear the tale.

(p. 122)

Stories of suffering are often the precursors of stories of healing. Individuals' stories may turn into tales of hope and healing in spite of the illnesses and despair that preceded this evolution (Churchill & Schenck, 2008). Relationships formed to aid, assist, and support the ill may facilitate this transformation (Scott, Cohen, DiCiccio-Bloom, Miller, Strange, & Crabtree, 2008). The authors of stories of healing may then seek to use their experiences to

help others by rearranging their stories so that they become what Frank (1995) describes as quest narratives. Individuals evolve as they heal and, as time marches on, often become more willing to help others and recover “a connection to [their] life purpose” (Adame & Knudson, 2008, p. 160). Frank maintains that when living quest narratives, individuals find something positive to take from the illness experience, and then use this to help others.

Illness narratives provide “a density of texture, a depth of personal meaning, and an insight into the experience of illness not readily available through other means” (Robinson, 1990, p. 1173). However, I think Robinson is referring to illness narratives composed of words alone: by incorporating the athletes’ photographs and performances I believe I am able to offer even richer illness narratives, narratives that are co-constructions, pieced together from the athletes’ stories of healing as recounted by them to me, photographs taken by the athletes, and their performances as observed by me as they told their stories.

Riessman (2008), quoting Salmon, notes that all narratives are co-constructions:

All narratives are, in a fundamental sense, co-constructed. The audience, whether physically present or not, exerts a crucial influence on what can and cannot be said, how things should be expressed, what can be taken for granted, what needs explaining, and so on. We now recognize that the personal account, in research interviews, which has traditionally been seen as the expression of a single subjectivity, is in fact always a co-construction.

(Salmon, cited in Riessman, 2008, p. 31)

Voice

Hertz (1997) believes voice to be “how authors express themselves within an ethnography” (p. xii) to reveal their “will, intent, and feeling” (Charmaz & Mitchell, 1997, p. 193). It can be challenging for researchers to work out how to represent their voices when they are composing a postmodern text because they “are not just one single person, a unitary

author but rather a multitude of possibilities, any of which might reveal itself in a specific....situation” (Charmaz & Mitchell, 1997; Lincoln, 1997, p. 40; Waterhouse, 2007). However, Holman Jones (1998b) warns that too “many voices....rattle the bones of description and analysis without clothing them in the pulse and blood of flesh” (p. 422). In the illness narratives I have written, I believe that the participants’ voices coordinate with their performances, as well as my own, to embody their experiences as they tell their stories (Langellier & Peterson, 2006).

As the author of an autoethnography, I hope that, as well as communicating my own experience of healing from head injury, I am able to convey the experiences of others so that all of our voices are prominent in the text (Guba & Lincoln, 2005). As Charmaz and Mitchell (1997) do, I can use all I can of my “imperfect human capacities to experience and communicate something of others’ lives” (p. 194). This includes my voice. So, with my imperfections and the use of multiple forms of representations in the form of story, performance, researcher comments, and participants’ photos, I believe that I am able to co-construct the thesis with the participants so that the participants’ presences are felt throughout (Guba & Lincoln; Richardson, 1997b, 2001; Richardson & Adams St. Pierre, 2005). Guba and Lincoln describe that in my position, my voice is “manifest through aware self-reflective action, [but there are] secondary voices [present]...illuminating theory, narrative, movement, song, dance, and other presentational forms” (p. 196). By conveying the athletes’ stories to a wide audience, I am offering them opportunities to let their voices be heard (Wilson, 2007). The athletes may have found that, since their head injuries, their voices have been silenced and their stories of healing may have been unrecognized. I have

become a witness for them because I have listened to their stories (Frank, 1995; Sparkes, 2002). As Kirkpatrick (2008) explains, I am a witness because I have listened to their voices with a “narrative approach [that] values the individual experience and voice and puts a human face on the experience” (p. 62). I know that I will only ever be a witness; the ‘experts’ of this project are the athletes (Richards, 2008).

Struggling for air,
I am
overwhelmed, almost
drowning in the stories
offered
by athletes willing to help.
I
thank them.

.....Interlude.....

As time passes, our evolving identity (McAdams, 2003) is engraved with the experiences, memories, and beginnings and endings that we experience as we venture through life creating our life story. Time marches stoically forward, oblivious to the etchings, stains, and hiccups that are imprinted on our many selves by major life events. Sometimes the etchings scar so deeply that they alter the shape of a person. The stains either spread or fade as time relentlessly soldiers on. I have had a huge hiccup in my life. I am both etched and stained by its cause: a Traumatic Brain Injury (TBI). I know though, that I am emotionally healthier now than I was before the hiccup.

.....

On September 13th, 1997, I was competing at the European Three Day Event Championships at Burghley, England. I was both respectful of and somewhat daunted by the competition's demands, but, at the same time, I was full of anticipation. My quest is to finish the course cleanly. But, when I tell the story of that day, life as I had known it abruptly comes to an end.

I am in the start box of the cross country section of the speed and endurance phase. I feel the weight of the expectations that are always present in any team situation, and I am focused on the job that lies ahead of me. I know it will not be easy. My coach holds my horse Gordon and circles him as I was counted down. On 'go', we gallop towards the first fence, then the second, and the third. Obstacle four was a difficult challenge for so early in the course. After jumping a fence on top of a steep bank, my plan was to jump the narrow part of the next fence, the most direct route. But, while attempting to jump it, Gordon caught his front legs and down we went. As we fell, we were instantaneously etched and stained by trauma.

.....

I wonder what if. What if I had completed the course? What if I hadn't fallen? I had been hard pressed to imagine a future without riding. What if I had continued to ride in international competitions? What would the future have held?

....

Oblivious to everything, unconscious, I fly peacefully over England in a helicopter. I make it to the hospital long before my parents. They have been snared by a tangled traffic jam on the ground. Construction has slowed traffic almost to a standstill; it is a sea of disorder and chaos. Only one thought occupies their minds—quickly, get us to the hospital, quickly ... now. They are frantic and find themselves outside of and beyond the "normal" scope of reality. Sick with worry, endless scenarios are playing nonstop in their heads: what happened, is she alright? They had been at the competition when I fell at the fourth fence. Unbelievably, a neurologist was at the next fence. He had found his way to my side in no time and then he had assisted and guided the ambulance crew as they prepared to airlift me to hospital. Goodbye Burghley.

(Smith, 2008, p. 4)

Chapter 2: Literature Review – Painting the Test Stripes

Chapter Plan

Before I begin reviewing the literature, I would like to aid readers by outlining the chapter. I start with an overview of theories of identity, using an article by Smith and Sparkes (2008b) as a template. I review the six approaches that they introduce: the psychosocial, ontological realism, the inter-subjective, the storied resource, the dialogic, and the performance of identity. I go into detail reviewing the performance approach because this is the theory I have chosen to use.

I follow this with an overview of studies on the impact of illness on identity. There are two subsections: TBI, epiphanies, and ruptures in identity, and identity construction after life altering illness or trauma. I then review stigma. This is followed with a review of types of illness narratives, which I feel is central to this work. The main section of the review explains why I chose to use the model introduced by Frank (1995). I discuss the value of illness narratives for professionals. In subsections, I explain why theorists think that illness narratives are valuable teaching tools, and I review performance and illness narratives. I then explore the value of telling illness narratives for patients, and the importance of illness narratives for family, caregivers, and other supporters. Next, I review photography. I recall studies that use photo-elicitation, photo interviewing (which includes photo novella and photo-voice), and auto-photography. I find the section on photography most appropriately placed in the methodology because it outlines previous research. I follow with a section on the role of learning in identity construction.

I conclude this review by explaining how my search for a study focus led me to decide to perform this particular study for my PhD research.

Scanning the Colours: Theories of Identity

Smith and Sparkes (2008b) provide a comprehensive overview of the primary theories of identity. Reviewing the work of a multitude of theorists, they outline how they believe that these views loosely fall into six perspectives. They envision their understandings forming a continuum labeled ‘individual’ at one end and ‘social’ at the other. The psychosocial can be found on the left, then moving towards the right, ontological realism, followed by the inter-subjective, the storied resource, the dialogic, and the performance of identity at the right end of the continuum. Smith and Sparkes place McAdams (1990, 1993, 1996, 2001, 2004) at the psychosocial, or more individually oriented, left end of the continuum. In support of McAdams’ stance, Bauer and McAdams (2000) point out that “a mere assemblage of facts in a life story does not point to the person’s identity; identity emerges as the person ascribes personal meaning to those facts” (p. 278). I feel that this statement by Bauer and McAdams would be interpreted differently had it read ‘as the person ascribes meaning’, leaving out the word ‘personal’. The remark would then suggest that the meaning was shared, socially, or culturally constructed, and would place this work further towards the right of the continuum. Singer (2004) also subscribes to an individualistic view, writing that individuals’ constantly changing identities are constructed from individualistic knowledge producing experiences. He maintains that “individuals craft narratives from experiences, tell these stories internally and to others, and

ultimately apply these stories to knowledge of self, other, and the world in general”, in the process constructing their evolving identities (p. 438).

The following researchers also adopt a psychosocial view of identity. In their study of 70 adults, McAdams, Diamond, St. Aubin, and Mansfield (1997) describe identity as internalised: “an internalized and evolving life story, a way of telling the self, to the self and to others through a story” (p. 678). In support of this psychosocial view of identity, Labouvie-Vief, Chiodo, Goguen, Diehl, & Orwoll (1995) found that individuals’ definitions of their identities became less social, more individualistic, and “more differentiated and more internal” (p. 412) as they aged. This is reiterated by Dollinger and Dollinger (2003), who studied photos taken by various individuals. These photos reveal that as the individuals aged, their lives became more inward looking, therefore emphasizing individual rather than social tendencies.

A different perspective, ontological realism, is also an individualistically oriented view of identity and is placed in the same position as the psychosocial on the continuum. This view regards selves and identities as predetermined: “housed primarily within an individual and something he or she is endowed with” (Smith & Sparkes, 2008b, p. 9). The nature of the self, according to ontological realists, is described by but “it is not created by” our stories (Vollmer, 2005, p. 189). Similarly, Vollmer believes that the biological composition of individuals is the source of the self.

Somewhat more socially oriented, the work of Bruner (2002) and Nelson (2001) lies to the right of the psychosocial conception of identity, at the inter-subjective point on the continuum. Nelson writes that stories are never totally original because “many contain stock

plots and character types that are borrowed from narratives that circulate widely in the culture” (p. 72). According to Smith and Sparkes (2008b), the inter-subjective account is neither ‘thickly individual’ nor ‘purely social’. Because our characters are as much culturally as individually constructed, Smith and Sparkes deem both to be equally important when using an inter-subjective perspective.

For example, in a 1996 study Kvernmo and Heyerdahl find that “behaviour and attitudes were significantly associated with both family and regional contexts” (p. 453). Also in 1996, Shorter-Gooden and Washington conclude that racial identity was an important factor in the identity of young African-American females. Baumeister and Muraven (1996) wonder whether society is “the sum or product of identities, or is it the source of them?” (p. 405). They concluded that society and culture form an umbrella under which the self lives, and so adult identity was a combination of “the basic nature of selfhood and the sociocultural context” (p. 415).

When employing a storied resource, culture is viewed, according to Smith and Sparkes (2008b, p. 16), as speaking “itself through a person’s story and body”, so the social and the individual both play a part in identity (Riessman, 1993). In this case, however, the societal and cultural influence is even stronger than it is in the inter-subjective perspective (Smith & Sparkes). As Smith and Sparkes explain, “a person employs established and intelligible narrative resources available to them within a culture to construct an identity and sense of self, which then becomes personalised, and refers over time to the unique circumstances of a particular life” (p. 19). Personal narratives are understood as being situated among their local societal discourses and so reflect their socio-cultural context

(Riessman, 1993; Smith & Sparkes). Examples include Hinton and Levkoff who find in a 1999 study that cultural resources and ethnic identity, together with personal factors, “may influence the kinds of stories family caregivers tell” of their family members afflicted with Alzheimers (p. 453). Cain (1991) studies how a group of individuals, through joining AA, learned to understand themselves as non-drinking alcoholics instead of drinking non-alcoholics. She found that their transformations and their new understandings of themselves were facilitated by telling personal stories in the cultural milieu of AA’s system of beliefs and in the social environment of its meetings.

Moving further to the right again on the continuum is the dialogic approach to identity. In this case, “[r]elatedness and collective voices..... [both] precede individuality and personal voices in accounts of dialogical selves and identities” (Smith & Sparkes, 2008b, p. 20). I believe that Somers’ (1994) understanding of identity is dialogical because, although Somers calls the narratives to which I am referring ontological narratives, she explains that this type of narrative is “above all, social and interpersonal” (p. 618).

The performance approach I discuss next is the approach I will be using in my study.

The Performance of Identity

In a performance approach, which can be used in conjunction with both the storied resource and dialogistic perspectives, Smith and Sparkes (2008b) explain that ‘storied selves’ are performed and “social relatedness completely precedes individuality, interiority and lived experiences” (p. 24). Performance deserves special attention because it reaches wider audiences and opens the door to more meaning making. For example, Douglas and Carless (2008) remind us that when they performed songs about their research, although it

was satisfying and productive to reflect on their journey in this way, their performances were not only about themselves, there was a 'bigger picture' that (they hoped) their performances reflected. When individuals perform off the stage, the 'audience' can more fully appreciate their experiences because performance enables experiences to "surface as painful, derisive, sympathetic, sharing, ambivalent, [and] contradictory", notes Oikarinen-Jabai (2003, p. 577). The result is that performance becomes central to the story being told (Denzin, 2003; Gray, 2003; Oikarinen-Jabai, 2003, p. 577; Smith & Gallo, 2007). As Oikarinen-Jabai also points out, performances of stories can open "a path for us towards the borders" (p. 576), providing us with a site, Denzin writes, "where felt emotion, memory, desire, and understanding come together" (p. 13).

Gray (2003) writes an informative article about approaches to performance. He distinguishes performance types in two different ways, the first type of the first approach being one where the primary concern of researchers is to precisely represent their findings. An example is Jackson (1993), who emphasized the scholarship and the "intellectual context of the enactment" – the intellectual replication of researchers' (multiple) conclusions in a performance (p. 41). Another example is Stucky (1993), who used the term 'natural performance' to refer to instances that are actually performances of everyday acts. Natural performance, Stuckey wrote, "resembles documentary film in editing, framing, and re/presenting a 'slice of real life' " (p. 177). So Stucky's phrase 'natural performances' refers to performances that try to replicate life as it is experienced, or, in the case of research findings, that try to accurately represent the findings.

The second category of the first approach suggested by Gray (2003) for the use of the term 'performance', is to describe the 'messy' performance texts that Denzin (1997a) outlines. Evocative and dramaturgical, these texts "create spaces for the merger of multiple voices and experiences" (p. 91). Messy texts, Guba and Lincoln (2005) maintain, are not linear and binary, instead they try to break through these constraints that are inherent in traditional research methods to portray infinite aspects of the human experience.

Gray's (2003) second approach differentiates types of performance in a manner that I feel is most in keeping with my understandings. In this approach, he considers that performance falls into three types, dramatic performances being the first, the most formal, and the most obvious. Researchers involved with theatrical performance belong to this camp. In 1990, Pollock writes about her experiences working with students on a dramatic performance about mill communities in her area that is based on a novel by Hall, Leloudis, Korstad, Murphy, Jones, and Daly (1987). The project was an introduction to performance for many of the students; the act of performing the play paved the way for them "to question historical materials, to imagine alternative perspectives, to speak through 'other' voices", in sum, to learn (p. 34). Also in support of performance, Paget (1990) describes how, when people read scientific texts, they garner only the facts. In contrast, she thought that a performance encouraged the audience to feel and emote. By so doing, audiences sensed that they were closer to, and more involved with, the facts.

Next, Gray (2003) gives as an example of semiformal performances, those that may have been in part "deliberately orchestrated", such as an interview with the media (p. 255). As another example, in a study of breast cancer survivors, Langellier (2001) compares the

transformative and stigmatising properties of the ‘tattoo’ of mastectomy with the “active agency of getting a tattoo on [a survivor’s] mastectomy scar” (p. 147). I believe, as Langellier appears to have thought, that each tattoo is a ‘deliberately orchestrated’ performance of identity. Tattoos symbolize the ‘spoiled’ and often stigmatized ‘scars’ on identities with which individuals may be labeled with after mastectomy. I also suspect that the tattooing is an act that may be interpreted as a flaunting of the fact that the person has had a mastectomy, and therefore may be a sign of rebellion against the stigmatization that may accompany mastectomy.

Third, Gray (2003) lists the influential aspects of our lives, for example our race, gender, and culture, that we perform as we live our lives. I would add to Gray’s third type these performed aspects of identity: our emotions, feelings, gestures, and thoughts that facilitate us to gain an understanding of others that is more involved than one that is situated as, Battisti and Eiselen (2008, p. 1) note, only at a “rational and cognitive level” (Riessman, 2008). It is these facets of our evolving identities that I use in combination with Gray’s description when I refer to performance throughout this thesis. Langellier (2009) echoes this view of performance, describing performance as “the gesture of hands and postures, glances and gazes, inflections of voice which are the bodily techniques of speaking and listening to reveal or conceal, empathize or avoid, come or stay apart” (p. 153). Peterson and Langellier (2006) remark that, when performance is considered, stories are constructed in the process of being recounted; they are ‘done’. In other words, when the athletes tell their stories, an active process takes place, one of not just telling, but also of doing: of sharing, making, and performing.

Examples of this interpretation of performance include Scott (2008). In a study of women who are bulimic she finds that, when their illnesses were active, these women performed what she recognized as stigmatized, bulimic identities. When recovering, the women showed, through their performances, that they remained aware of the disordered identities that they had performed in the past. Collett and Childs (2009) use Goffman's (1959) performance-based dramaturgical approach to study families, and they list the benefits of the detailed observations that are inherent in this approach.

Performance facilitates meaning making. In a study where they try to enhance understanding in social situations, Battisti and Eiselen (2008) discover that a performative approach deepened their own understanding while researching the experience of being in a focus group. It allowed them to collect data that would add substance to the meanings that they made. Smith and Gallo (2007) describe performance ethnography, and include a performance text created by Smith to disseminate her research on the parents of children with genetic conditions. Smith finds that presenting her study in this way helps the 'audience' to more fully appreciate her study.

Performance exposes changing identities. Watson (2007) studies the developing identities of two student teachers and notes how their everyday, ongoing, and performances enhance the narratives the teachers produce as their identities evolve in their new roles of beginning teachers. Hull and Zacher (2007) reiterate Watson's findings, but this time in a job training program that they feel is a "prime context for identity construction" (p. 71). During their study, they observe "performative moments, [which were] especially intense events or periods in social relationships during which the enactment of self is foregrounded"

(p. 79). Wagner and Wodak (2006) explore how women “live, understand, and ‘perform’ success” (p. 385). They find that when the highly professional women they study perform their positions they are ‘playing the game’ of their success and power. The women’s performances reflect this; these performances show that the women work hard, they impress people, and that they are prominent figures. Noy’s (2004) interests lie in what he perceives is occurring as tourists recount stories of their travels. When he examines narratives of back-packing adventurers, he finds that the identities of the back-packers evolve as they perform their stories.

Performance reveals pride in ethnic identity and so serves to conserve ethnic cultural practice among immigrants. Baptista (2009) writes that Portuguese transnationals situate themselves both in Newark, NJ, and in their cultural home of Portugal by cooking bacalua (salt cod) to perform and express their cultural identities. Sharp and Boonzaier (1994) explain how they believe that ethnic identity formation is performance based. They find that the ethnic identity present in the Nama of South Africa is a “carefully controlled performance....a highly self-conscious statement of ‘who we are’” (p. 1). Delgado (2009) explores Latino performance in academia, wondering how his Latino identity impacts his “credibility and authority” (p. 162). But, although inclusion at the faculty level is sometimes less than should be expected in his place of employment, he finds that his ethnic identity should not matter since in academia “we are not performing monological scripts but performing roles that are parts of larger and evolving plays” (p. 162).

Performances hints at desires. Herrera, Jones, and de Benitez (2009) study street youth in Mexico, finding that the youths’ desire to understand their lives and to be socially

acceptable is reflected in their attempts to control their bodies. The youth had learned to perform strategically to attain this control through their dress and actions. These performances differed according to the audience. Strategy is also called for when disabled athletes must perform tactically because the Able may make assumptions about their skill level. In a study of wheelchair rugby by Lindemann (2008), he discovers that disabled athletes sometimes desire to perform more disability. In this way Others assign “disability as a static marker of identity”, and the athletes can then have more able players assigned to their team (p. 98). Such performances of disability reveal the competitiveness and desires of these athletes, a competitiveness that may seem, to some, to be at odds with their physical disabilities. However, I believe that performed competitiveness may be a legacy from their lives prior to being disabled. Unfortunately, these individuals, used to being the Other that people looked up to, now perform the marginalized Other.

Performance confronts stigma. The bodily control that Mexican street youths perform in the 2009 study by Herrera, Jones, and de Benitez, is also an attempt by the street youth to challenge the stigma imposed by their social deviance. This challenge is accomplished by changing different, non-permanent looks such as their dress and posture, even though the youth are unable to change some permanent aspects of their selves that contribute to their stigmatization, such as tattoos and piercings. Lindemann (2008) challenges the stigmatisation of homeless individuals by employing them to sell a newspaper about their culture. By enabling the homeless, Lindemann’s project shows “the newspaper’s vending interactions as performances of a contested ‘authentic’ homeless identity that...transforms the stigma of homelessness into a ‘selling point’” (p. 41).

Performance uncovers emotions. When she researched adoption stories, Holman Jones (2005b) finds that she believes telling these stories allows the storytellers to experience again and again the pleasures of the adoption process. Holman Jones then offers a beautifully written, emotionally laden account of her own journey to adopt a child. Kawale (2004) studies the role of the performance of emotion in the lives of members of sexual minority groups. She finds that the performance of emotion “is a key feature of performing sexuality.....[it] paradoxically contributes to the invisibility of minority sexualities in everyday places” (p.565). Audiences absorbing the performance of illness narratives are often the receptors of emotion. Mattingly (2004) notes that, when performed, narratives of healing are often told emotionally so the emotions of the narrator as well as those of the audience actively shape the story that is being told.

Reviewed next are studies showing that performances by the ill may reveal the impact that illness has had on their identities.

The Impact of Illness on Identity

Bury (2001) finds that chronic illness often precipitates identity issues because it causes a major upheaval in a person’s life. According to Charmaz (2002), when serious illness calls into question one’s self and identity, self and identity are no longer ‘givens’ and must now be redeemed and refashioned. In a study of chronically ill men, she concludes that identity dilemmas arose when the men lost “valued attributes, physical functions, social roles, and personal pursuits through illness and their corresponding valued identities” (p. 269). The men associated death with their personal identities, although they did cling to their original identities as long as possible. In a study of asthma sufferers, Adams, Pill, and Jones

(1997) find that when individuals try to meld their ‘illness’ identity into their ‘image of themselves’, they are apt to feel conflicted and unsettled. This conflict arises because there are fundamental differences in their identities as they now perceive them to be and their identities as they hope others perceive them. In 1987, McCabe and Green note that once a person “recognizes the gap between the achievements hoped for prior to the injury and his [or her] post-injury capabilities, he [or she] may adopt a passive response and give up” (p. 119). Mathieson and Stam (1995) find that the rebuilding of identity is made more difficult if survivors are denied voice because then they are liable to feel that their evaluation of their illness experience is not necessary and of no value.

Although identity loss is a common result after a life-altering injury, research shows that survivors, in the end, tend to reach levels of greater self-awareness, as Charmaz (1995) discovers in a study of chronically ill individuals. She writes that these individuals may eventually find themselves reaching positions in which they are more in-tune with themselves and in which they can adapt because they become “prepared to incorporate the illness experience into [their] narrative[s] (p. 301). Similarly, Mathieson and Stam (1995) find that if ill individuals become well again, “the illness experience moved from the foreground to the background” (p. 300). Ylvisaker, McPherson, Kays, and Pellett (2008) suggest that this may happen well after an individual’s continuity of life and identity is shattered by a head injury. A review of these studies is next.

TBI and Ruptures in Identity

In a summary of research on illness narratives, Hyden (1997) concludes that most researchers agree that when one’s ongoing life is disrupted by serious illness or trauma,

one's identity is also disrupted. During the healing process, identity issues may cause us "to change the premise upon which we plan and evaluate our lives" (p. 52). According to Pillemer (2001), TBIs can suddenly redirect individuals' life plans by powerfully affecting their "behavior, attitudes, and self-concept" and etching indelible scars onto their evolving identities (p. 126). Stanley (2004) writes about the impact of head injury, explaining that one can disrupt "not only the individual's physical integrity", but also an "individual's identity and sense of self in the world" (p. 355). In a 1989 study, Langellier finds that identities realized during the unsettling narrative memories of life after trauma such as a TBI can be "multiple, fragmentary, and unfinished" (p. 31). Personal narratives can bring to the foreground these ruptures that are sometimes caused by illness or injury and are often experienced, Sakalys (2003) feels "as a disintegration of self, as an interruption of one's biography, and as a silencing of one's voice" (p. 228).

Bury (2001) uses the term 'biological disruption' to describe such a rupture in identity, an event that can disturb and threaten "relations between body, mind, and everyday life" (p. 264). Pillemer (2001) describes 'momentous events' as "distinctive, circumscribed, highly emotional and influential" (p. 123). When individuals experience such events, how they interpret the meanings of these events ultimately influences the life choices they subsequently make and also how successful these choices are. Although the above studies by Bury and Pillemer do not refer to athletes, I think that the terms 'biological disruption' and 'momentous events' describe the impact of the catastrophic head injuries they each have experienced on the lives of this study's participants. I believe, however, that the terms 'turning point' or 'epiphany' can be used to effectively label defining moments that all of

the athletes described as undergoing some time after their injuries. Denzin (1989) understands the events associated with these terms as altering “the fundamental meaning structures in a person’s life” (p. 70).

I think that, in the case of the experiences of the athletes in this study, their turning points occur long after their ‘moments of crisis’, which I consider to be the head injury experience itself. However, in each athlete’s case, he or she experienced an ‘epiphany’ *because* of such a moment. How do individuals experience epiphanies and turning points that occur some time after their injuries, illnesses, or retirements?

TBI and epiphanies.

James Joyce defines an epiphany as “a memorable phase of the mind itself” (1944, p. 211). Following the thoughts of Joyce, McDonald (2008) describes an epiphany as an “experience made significant and enduring by the ascription of personal meaning” (p. 89). It is a vivid, sudden, and abrupt personal transformation (McDonald; Miller & C’de Baca, 2001). When he listened to the life stories of four participants who each had a ‘self-identified epiphany’, McDonald found several themes. The one most relevant to this study of identity construction is that McDonald adds yet another voice to those who believe that identity is evolving. He maintains that epiphanies “do not represent the final goal or endpoint in a journey toward self-becoming”, but rather, they are better described as notable moments on a never-ending journey (p. 112). Stevens and Doerr (1997) discover that, to their surprise, AIDS diagnosis was a positive event or an epiphany for ten percent of those diagnosed when they studied thirty eight low-income, racially-diverse women. These women used their diagnoses in a forward-looking manner to restructure their lives and, I

believe, to construct their identities. Their finding adds fodder to McDonald's assertion that epiphanies are not endpoints. Wainwright and Turner (2004) claim that fateful moments following the retirement of, or injury to, a ballet dancer, can be responsible for substantial repercussions in the dancer's life. Therefore, these events can have significant consequences to the evolving identity of the dancer. But is retirement or injury an epiphany? I believe not. I understand epiphanies to "leave mark's on people's lives" (Denzin, 1989, p. 70). However, Schulz (2001) remarks it is more characteristic of a turning point that "the trigger is loss" (p. 73). After such a trigger, individuals (re)shape themselves (Wainwright & Turner). Both Wainwright and Turner, and Wainwright, Williams, and Turner (2005) describe the dancers' retirements themselves as epiphanies, whereas I would characterize them as turning points. The dancers' lives have shifted. They may now call into question what they felt was important in their lives. Are the same things now important?

Next, I review the literature on identity construction after life altering illness or trauma, and I examine how individuals approach constructing their identities subsequent to such an event.

Identity Construction After Life Altering Illness or Trauma

When Rimmon-Kenan (2002) studies how individuals cope with the disruption resulting from serious illness, she finds that individuals can have trouble accepting that they may have to construct a brand new identity and envision a different future, one unforeseeable prior to experiencing the trauma. Chamberlain (2006) conducts a study of sixty people and through unstructured interviews heard about their experiences of recovery from TBIs. She observes that survivors of TBI often have changed minds and bodies leaving

their identities “unsettled and uncertain” (p. 408). However, Wood and Rutterford (2006) find that “very long term psychosocial outcome following serious head injury may be better than expected from data reported at earlier stages of recovery” (p. 72). The results from these studies imply that time is an important consideration to take into account when determining the extent of recovery after head injury.

While telling stories of their pasts, individuals can make meaning retrospectively by interpreting their past experiences to try to better understand their present situations, to construct who they are now, and to imagine their identities of the future (Chase, 2005; Neimeyer, Herrero, & Botella, 2006; Nelson, 2001). Nelson reminds us what people believe is central is a part of their evolving identities. Future identities are called designated identities by Sfard and Prusak (2005) and present “a state of affairs...[that is] expected to be the case” (p. 14). In this study, the traumas that the athletes to be studied have experienced and their evolving subjectivities may reveal that their ‘designated identities’ have changed. Prusak (2003) finds that, as their designated identities changed, the participants in her study tell different stories of life choices they expect to make and paths they expect to follow.

Freeman (1993) discovers that each time one revisits the past, a “new relationship is being created between the past and the present...designed to give greater form to one’s previous - and present - experience. The text of the self is thus being rewritten” (p. 30). Freeman calls this concept ‘rewriting the self’: one’s past is continually being understood differently in light of changing interpretations. In the present study, as the athletes perform their pasts, the writings of Bruner (1987), Nelson (2001), and Verkerk et al. (2004) suggest

that these pasts may constantly be accorded different meanings as the athletes subjectively make sense of who they are now through the performances I will observe.

In a study conducted of immigrant women, Anderson (1991) shows that milieu is important and concluded that researchers of identity construction must take into account the location at which selves are constructed. In contrast, Myles (2004) finds, in a study of the treatment of the loss of sense of self after head injury that, after TBI, identity construction may be difficult in any milieu because many survivors deny that they have changed since they were injured. This denial, as well as being an unawareness of changes, may also be an indicator of avoidance of the “emotional distress that accompanies awareness of them” (p. 490). I agree with Myles and I believe that for each athlete in this study, the degree of support that he or she receives, the severity of his or her head injury, and his or her stage of recovery is more important than the milieu of rehabilitation.

Myles (2004) also finds that of all trauma, TBI is “particularly likely to lead to loss of sense of self because it can result in impairments in any and all areas of functioning (physical, cognitive, emotional, and social)” (p. 490). Myles concludes that individuals who possessed a clear and definite self-image before their injuries – perhaps elite athletes? – are more likely to lose their sense of self and their pre-injury identity. In a study of cancer and dementia patients, Gillies and Johnston (2004) find that many survivors try to reclaim their identities “through references to an earlier life where pride in one’s achievements provided a contrast to their current, increasingly frequent reminders of decline” (p. 439). Vickery, Gontkovsky, and Caroselli (2005) study quality of life after acquired brain injury (ABI). Their results indicate that the attribute of self-concept is perhaps linked to quality of life.

While studying stroke patients, Ellis-Hill and Horn (2000) conclude that the strokes had disrupted the participants' sense of coherence of their current and past life paths. Because "their future had become unpredictable", it was unlikely that they would construct the future identities they had envisioned, causing them anxiety (p. 286).

My MA thesis contributes to the knowledge of identity construction after life altering illness or trauma. During my Master's course work, I became interested in how individuals approach identity construction after head injury. In the study, I explore how creative involvement can bolster the self-esteem of survivors of ABI (Smith, 2004). The findings indicate that, through creative involvement, which appeared to increase the self-esteem of survivors of ABI, other aspects of their diminished identities, such as self-confidence and sense of self, were also positively impacted. It is important to address these diminished qualities because if they are reduced, others may feel that they can inflict stigma.

Stigma: I Don't Like THAT Colour

An individual's identity has a bearing on how he or she is regarded and treated by others. So, if an individual has undergone a traumatic event in the past, the results of that traumatic event will no doubt influence his or her identity and how others interact with that individual. As Neimeyer, Herrero, and Botella (2006) write, "we come to see our selves in part as we are seen. In this sense [one's identity]...is always extensively coauthored by relevant others" (p. 130). Although others may influence the construction of an identity positively, Goffman (2006) notes that this influence could also be negative, because others may inflict a stigma on the individual. Mattingly (1998, p. 98) elaborates about stigma:

The disabled suffer not only a dramatic shattering of life stories through accident or disease, not only the imperative to revise their lives to suit those bodies, they also

confront a society which views them as less than a normal member even though they have left the sick role.

Stigma, as Mattingly suggests, and Goffman (1963) and Kleinman (1988) previously noted, is an unwelcome part of illness because illness can 'mark' a person in the eyes of others. Goffman remarks that the athletes of this study may seem 'different' because the attributes that we observe "are incongruous with our stereotype" of what is expected from an athlete who has competed at high levels (p. 3).

Verkerk et al. (2004) explains that identities are formed from our own sense of who we are - our self-concept - as well as from influences and opinions of others. Mathieson and Stam (1995) find that major illness and life-altering trauma impose 'biography-altering facts' on our lives such as "altered relationships, a curtailed sense of agency, and a changed vision of the future" (p. 300). They conclude that these 'facts' contributed to individuals' altered self-perceptions. As a result, the athletes may find themselves stigmatized: they may exhibit characteristics due to their injuries that are not positive "turn those of us whom he [or she] meets away from him [or her], breaking the claim that his [or her] other attributes have on us" (Goffman, 2006, p. 132). Coleman (2006) notes that because "stigma stems from differences" (p. 143), some of the attributes that the athletes project since their accidents may result in a perception of stigmatization.

Charmaz (1983) writes that stigmatization can result in a loss of self, self-esteem, and self-worth so it can impact individuals' subjectivities when they are ascribing personal meanings and understandings to the constructed identities that they perform. In a 2001 study, Lai, Hong and Chee examine how 400 psychiatric out patients and 100 mental health workers perceive stigma. They find that stigma negatively impacts these individuals' "self-

esteem, relationships, and job opportunities” (p. 111). Stigma may be interpreted by the stigmatized as others’ assertions of who “they now should be” (Charmaz, 1995, p. 658). Any stigmatized individuals may find themselves pre-empting stigma: anticipating reactions from others that they sense are making unfounded assumptions about their disabilities.

Alternatively, Goffman (2006) finds that they may use their stigmas as excuses for lack of success. I agree with Frank (1995) who leaves little room for self-pity. He writes that although individuals are not responsible for their illnesses, “Goffman shows that they are responsible for how they present themselves and manifest the signs for their illness” (p. 32).

Lekas, Siegal, and Scrimshaw (2006) note that even when stigma is only subtly directed towards individuals, these individuals can feel embarrassed when they have a disease. They are therefore “more likely to discern stigma in their everyday interactions and to report feelings of shame” (p. 1179). Charmaz (1999) writes that individuals may have feelings of ‘worthlessness’ brought about because they sense themselves as ‘worth less’. She adds that social circles wind closer and closer around the stigmatized, so that these circles become restricted to “the person’s most significant others” (p. 368).

Deviations from cultural norms can stigmatize. Ellis and Flaherty (1992) mention that many current cultural contexts are rife with “prevailing definitions of health...and stigma” (p. 4). However, it should be noted that, in a study of the cultural variations in the understanding of TBI, Simpson, Mohr, and Redman (2000) conclude that the experience of TBI transcends culture; they discover that stigma is inflicted after head injury by all cultures. Riessman (2000) studies thirty-one women in India, childless by choice, who were stigmatized because of their childlessness. She finds that women who were not necessarily

infertile but had chosen not to have children were stigmatized because they were “openly contesting the importance of motherhood” in India (p. 131). Allotey and Reidpath (2007) study individuals who had epilepsy in Cameroon and explore their experiences within their cultural, social, and environmental context. They find that the label of ‘epileptic’ restricted these individuals and “reduced their ability to perform traditional roles, affected their social value and excluded them from their communities” (p. 431).

Stigma may be perceived or felt, or both. Several studies, including one by Adams, Pill, and Jones (1997), support the notion that if the athletes believe that their disabilities are the first thing that others see, they may feel discredited and sense, or perceive, stigma. According to Charmaz (1983), who studies how chronically ill individuals suffer a loss of self, these individuals can feel devalued by others and hence negatively reappraise their sense of self as they feel increasingly isolated. These negative appraisals of their sense of self may develop because they feel that others may have expectations of them that they may not have met, and therefore, I believe, they may invite stigma. These individuals’ self concepts may be disrupted by these appraisals because they may be unaware of the selves that are visible to others until these others reflect the perceived stigmatized selves back to the stigmatized.

Adding to Charmaz’s (1983) findings, Galvin (2005) studies the impact of the experience of disability on people’s self-perceptions and explored what she describes as ‘disabled identity’. She concludes that the perceived positions of others contributed significantly to how individuals with disabilities judge themselves, and that the “negative attitude of others greatly contributed to the development of negative self-perceptions” (p.

397). Adams, Pill, and Jones (1997) also comment on people's self-perceptions in their study of asthma sufferers' attitudes. They find that individuals with a 'disabled identity' may be what Goffman (1963) refers to as discredited: they may "assume that their stigma or disability is immediately evident to others" (Adams, Pill, & Jones, p. 192). Stigmatization has an effect when, as Charmaz (1983) finds, "the ill person either feels forced to accept the discredited definitions and/or feels that these definitions further weaken the foundation of an already shaky self" (p. 182).

Gillies and Johnston (2004) study individuals with dementia and cancer. They find that advanced illnesses invite stigma because such illnesses "significantly challenge the person's ability to maintain [a 'healthy' outward] display and his or her identity is at once compromised and changed" (p. 440). When a person is no longer able to project a 'healthy' front, Kelly (1992) remarks, in his study on the impact of radical surgery on self and identity, that stigmas are initiated because the person's differences are now "appraised by others as undesirable" (p. 397). Ordinary and regular aspects of the individual are "called into question" because illness brings attributes to the person's identity that others perceive as negative (Kelly, p. 410). This stance is supported by Goffman's (1963) theory of stigma. He notes that individuals with disabilities can appear to others to have a 'spoiled identity' and are then judged accordingly by those others. In a study in which the narratives of twenty-seven cancer patients were explored, Mathieson and Stam (1995) find that all but two of their participants reported that they had felt stigma. This finding caused them to wonder how "individuals actively negotiate their identities in the face of stigma" (p. 297). They conclude

that the patients, in their revised narratives constructed after their diagnoses, had no choice but to include stories about the stigmas that they felt.

Sometimes however, a diagnosis of illness can reduce felt stigma. In a study that explores whether chronic fatigue syndrome (CFS) and fibromyalgia were stigmatizing, Asbring and Narvanen (2002) interview 25 women. Their results show that the women mainly felt stigma before being diagnosed. Because the symptoms of these diseases are vague and diffuse, they are difficult to comprehend by non-sufferers. Upon diagnosis, the women felt validated and their feelings of stigmatization were reduced. Dinos, Stevens, Serfaty, Weich, and King (2004) study forty-six individuals with mental illness with the intent of describing its relationship to stigma. They conclude that stigma “may influence how a psychiatric diagnosis is accepted” (p. 176), and that in some cases, stigma can be reduced with diagnosis because it enables people to access services that they may have been unable to access prior to diagnosis. My understanding of what these researchers believe is that when diagnoses reduce stigma, what really is happening is that the individuals who are ill now have a valid medical reason for their complaints, so they are better armed to control the impressions they make and to access services that they need.

In the cases above, a medical diagnosis reduced felt stigma, but often a medical diagnoses of stigmatizing illness can heighten felt and imposed stigma. In the case of the research done by Lai, Hong, and Chee (2001), the label of mental illness left the study’s participants more “vulnerable to stigmatization” (p. 111). Lekas, Siegal, and Schrimshaw (2006) study women suffering from HIV/AIDS and undergoing antiviral therapy. It appears to the authors that, although the drugs made HIV/AIDS a “more manageable disease” (p.

1165), stigma was felt in the same way as it was experienced by a group of women who had not taken the drugs. However, when the stigma was enacted - performed by the women through their actions – felt stigma did lessen slightly.

Hsin, Yang et al. (2007) note that current models of stigma tend to have a social focus as opposed to an individualistic view. In both the cases of felt and enacted stigma, Green, Davis, Karshmer, Marsh, and Straight (2005) examine how stigma affected the social lives of individuals with disabilities. They find that, when following the parts of stigma listed by Link and Phelan (2001) - labelling, stereotyping, separation, status loss, and discrimination - “the severity of the consequences varied among [the] various components” (Green, Davis, Karshmer, Marsh, & Straight, p. 197). Jacoby, Snape, and Baker (2005) investigate how stigma impacted the social worlds of individuals suffering from epilepsy. They discover that when misperceptions resulting in stigma are addressed, these individuals are more accepted socially. Because epilepsy is now experienced as a ‘central’ part of their identity, it assumes a more integrated role.

Courtesy stigma, which I review next, is stigma that is forced on individuals who are close to someone who is stigmatized (Goffman, 1963). Such stigma can be felt by the partners, families, and friends of stigmatized individuals.

Courtesy Stigma

Green (2003) surveys the mothers of eighty-one children with disabilities in Florida, USA who were stigmatised. Her findings indicate that felt stigma “increases maternal distress” (p. 1361). Although this was a quantitative study, Green feels that her position as a mother of a child with cerebral palsy lends humanization to the study and helps her to

interpret the findings. I was interested to read that she believes that stigma “can be reduced by a pattern of frequent, positive, ordinary interactions between individuals with and without the stigmatizing trait” (p. 1372). Gray (2002) interviews the parents of thirty-three children with autism. He finds that mothers, as opposed to fathers, are more likely to experience both felt stigma as well as stigma enacted through “avoidance, hostile staring and rude comments” (p. 734). Koro-Ljungberg and Bussing (2009) explore the management of courtesy stigma by the parents of children with ADHD. They find that this stigma exacerbates the stress the parents already feel. Turner, Biesecker, Leib, Biesecker, and Peters (2007) study how courtesy stigma manifests itself in the parents of children with an illness called Proteus Syndrome (PS), and uncover how parents cope. Their coping methods include “attributing cause, assigning meaning to social exchanges, concealing, withdrawing socially, taking the offensive, employing indifference, instructing and learning from family, and educating others” (p. 2089). In a 2007 qualitative study using focus groups, Gonzalez-Torres, Oraa, Aristegui, Fernandez-Rivas and Guimon discover that eighteen patients and twenty-six members of their families perceive stigmas that leave them feeling isolated and avoiding the company of others.

A review of the literature on illness narratives is next. I use the participants’ performed stories of healing to co-construct their illness narratives.

Illness Narratives – Listening to the Colours Others Like

Clandinin and Connelly (2000), Leitch, (2006), Polkinghorne (1988), Schneider (2007), and Smith and Sparkes (2009), all remark that we make sense of and impose order on our lives by telling stories. Clandinin and Connelly note that these stories have, as any

event does or thing has, “a past, a present as it appears to us, and an implied future” (p. 29). Polkinghorne reminds us that time is not always experienced in such an orderly manner, “with a harmonious interplay of past, present, and future” (p. 120). As well as their temporality, stories are embedded with, and link together, the cultural background and the personal history of the storyteller, and also the context of both the story and the storytelling environment (Bury, 2001; Hardin, 2003; Smith & Sparkes, 2006). Hardin maintains that the manner in which stories are presented – in this case performed – “is always sculpted by the context in which they are told” (p. 536). How will I witness the athletes performing their stories? Will these athletes, as Frank (1995) and Smith and Sparkes (2009) suggest, with other theorists concurring, think ‘with’ their stories as they perform them, reliving their experiences of head injury and continually reconsidering the impact of these experiences on their lives (Frank, 2006; Hyden & Brockmeier, 2008; Riessman, 2008; Smith & Sparkes, 2006, 2008b)? Baily and Tilley (2002) alert readers that it is important to remember that, during performances and storytelling, an individual conveys the meaning of a story, not whether or not it is ‘true’.

The present study is composed of illness narratives, and is itself an illness narrative. In 1988, Arthur Kleinman introduces the concept of the illness narrative, and suggested that it is important for people to recount their illness narratives during and after illness. Kleinman explains that illness narratives “edify us about how life problems are created, controlled, made meaningful” (p. xiii). Subsequently, there have been increasing quantities of research exploring the appeal of relaying illness narratives or stories of healing. Many researchers feel that sharing stories is a valuable exercise for individuals who are suffering from any

form and are at any stage of illness (see Bury, 1982, 2001, 2004; Frank, 1995, 2006; Hawkins, 1999, 2007 & Hyden, 1997). Bury (2004) and Frank (1995) maintain that under adverse conditions such as life altering illness or injury, telling their stories serve as needed opportunities for individuals to dig deeply within themselves to explore the meanings that can be derived from their experiences of illness. Mattingly (1998) feels that storytelling is one way for people who have experienced illness or disability to “make sense of what has happened” (p. 6). Frank (2006) writes of the importance of illness narratives, maintaining that when ill people hear illness narratives told by others, they “become empowered to tell their own” stories (p. 423).

Next, I begin with a review of the meaning of the term ‘illness narrative’ that has been proposed by several theorists and I then discuss which definition I have chosen to use.

Types of Illness Narratives

Frank (2006) notes that illness narratives have been described and delineated in several ways. Frank (1995, 2000a, 2000b, 2002a, 2002b, 2004a, 2004b, 2005, 2006, 2007) proposes three types of illness narrative. A chaos narrative is disordered, disorganized, and seemingly without any regard for time. When living a chaos narrative, the ill imagine that life is never going to improve. A restitution narrative is lived by those who optimistically believe that the life they are living now will get better; soon they will live life as they did before. Individuals living a quest narrative find a reason to live progressively again as they realize a ‘sense of purpose’.

Bury (1982, 2001) also outlines three types of narrative. Contingent narratives tell of the practical aspects of illness, moral narratives explore the relationship between the social,

the illness, and the ill person, and core narratives “reveal the connections between the lay person’s experience and deeper cultural levels of meaning attached to illness and suffering” (Bury, 2001, p. 265). Bury then explains that each of these narratives can be progressive, regressive, or stable, which I interpret as similar to the typology that Gergen and Gergen (1984) outline. Bury, and Gergen and Gergen, explain that while a stability narrative remains essentially unchanged, a progressive narrative indicates a positive direction of evaluation, and a regressive narrative the opposite. I believe that Bury (2001) echoes the structure of Frank’s (1995) quest narrative when he writes that, if a narrative is progressive, patients tell stories which explain that they believe that illness is “a form of disruption that can be turned into self discovery and renewal” (p. 276). I also think that Bury’s contingent narrative is similar to Frank’s restitution narrative. Although the contingent narrative does not seem as optimistic as the restitution narrative, both concern the practical and medical aspect of illness.

Anne Hunsaker Hawkins (1999, 2007) describes a typology she calls pathography. Such a narrative, told from a patient’s view, links the illness and its meaning to the storyteller’s life in general (1999). She lists four types of pathographies. I believe didactic pathographies are similar to progressive narratives as outlined by Bury (2001) and Gergen and Gergen (1984), and the quest narratives that Frank (1995) describes. Angry and alternative pathographies, point out, in either angry or non-confrontational (alternative) ways, the deficiencies of the health care system. The fourth type, ecopathography, is, according to Hunsaker Hawkins (1999) “a testimony to the capacity to transform [the illness] experience in ways that heal” (p.129). I believe that an ecopathography is

commensurate with Frank's (1995) quest narrative, Bury's (2001) progressive core narratives, and Hyden's (1997) view of illness narratives.

To discuss and analyze the athletes' illness narratives, I use Arthur Frank's (1995) types of illness narratives. That being said, I believe that the athletes' narratives do not necessarily fall cleanly into one category or another. As I have shown above, Frank's system ties into elements of the types of illness narratives proposed by other theorists I reviewed.

I now delve into how listening to individuals' illness narratives may help the professionals that are caring for them.

The Value of Illness Narratives For Professionals

It is understandable that in many studies of illness, disease, and disorder, researchers use narrative to make meaning. These researchers also show how important illness narratives, either of patients or of health professionals themselves, are for health professionals. They have found that, by exploring the stories of patients and their health professionals, they are able to show how these stories could enhance the understanding of these patients' illnesses by their doctors. To examine how the social setting of two hospital wards impacts the personal experience of a hospital stay in the case of one patient, Edvardsson, Rasmussen, and Riessman (2003) study a hospital's atmosphere by listening to the patient's stories. Their findings of this individual case show that while one stay is healing, the other is 'horrifying', suggesting to them that further study of ward atmosphere was necessary.

Haidet (2007) comments on a fascinating analogy between patient care and jazz music. Jazz is improvisational, remarks Haidet, and so too is patient-physician

communication. The main point he makes is that improvisation is often needed by physicians to respond suitably to “patients’ unique illness narratives” (p. 164). These improvisations facilitate handling the complexity of real world communication issues in many biomedical health care settings. Improved communication – professionals listening to patients’ stories - can educate these professionals.

The following research outlines the importance of narrative for enriching the knowledge of professionals and shows how stories can augment the doctors’ learning processes.

Illness narratives are valuable teaching tools.

Ogur and Hirsh (2009) seek to uncover the various manners in which medical students learn ‘longitudinally’ while caring for patients throughout their illnesses as opposed to only after diagnosis. The researchers review narratives written by the students and find that their learning about the patients’ illnesses is broader and deeper than it would have been had they only been responsible for the patients’ care part of the time. They discover that the experiences left the students feeling ‘deeply connected’ to their patients and that they had had a ‘real role’ in their care. Ogur and Hirsh also note that, by writing reflexively, the students developed “a detailed understanding of the health care system, with its strengths and gaps” (p. 849). Kumagai, Murphy, and Ross (2009) investigate how the stories of diabetes patients affect medical students’ “understanding of diabetes and its management” (p. 315). Subsequent interviews with the students reveal that they feel that listening to the stories was very useful for physicians. The students learned that there “was more to diabetes than the ‘scientific’ knowledge acquired through lectures; the stories challenged their

assumptions about having or working with people with diabetes and allowed the students to see the world” (p. 315) through these individuals’ eyes. In the case of pharmacists, Bissel, Ryan and Morecroft (2006) find that the pharmacists should “appreciate the insights” made available to them by patients’ narratives. For other examples, see Ben-Ari and Dayan (2008) and Edvardsson, Rasmussen, and Riessman (2003).

Another study sheds light on the personal lives of health professionals. In this study Ben-Ari and Dayan (2008) listen to the stories of nine female mental health professionals who had had violent personal relationships and who currently work with battered women. They wanted to better understand these women’s stories, and so proposed to explore both the personal and the professional aspects of the women’s lives, in particular how the self moved between them. Ben-Ari and Dayan found that the women built two stories, one about each life, leading them to think that the women conceptualized themselves as two different selves, feeling unable to join the two together. This method seemed to be the only way that the women could ‘make sense of their lives’.

Riley and Hawe (2005) speak about a drawback they found in their narrative research on the experiences of health professionals. They examined the diaries of community development officers who were “engaged in a primary care and community development intervention” (p. 226) with the intention of advancing new mothers’ physical health. They found that while narrative analysis of these diaries could shed unique light on “the complexity of community intervention implementation” (p. 226), the time required to analyze and present the data was excessive. This finding led the authors to see the need to rethink their strategies in the future.

Performance and illness narratives.

Following the ideas of Riessman (2008), observing patients' performances is another way that doctors can try to foster constructive relationships with the patients. Childress (2002) notes that body language should be a nonverbal cue for a doctor trying to establish a healing relationship with a patient. Thomas (2008) studies how both the form and the content of illness narratives can be used to analyze the transcripts from interviews with cancer patients. She comments on how performance enlightened her in the case of one woman, whose "talk is frequently interspersed with laughter and merriment...[She] sustains this performance of her positive and undisturbed identity" (p. 429).

The Value of Telling Illness Narratives For Patients

Patients also derive benefits from telling their stories. Sakalys (2003) feels that by recounting their illness narratives, to nurses in this case, the patients' abilities to make sense of their illness situations were enhanced and they were able to "reclaim ...[their] illness experience from the medical metanarrative" (p. 228). Scott et al. (2008) build a model to explore how positive 'healing relationships' between clinicians and patients evolve and then are maintained. They elicit stories of healing relationships from both patients and their doctors. Their findings show that developing a positive relationship involves several processes that, not surprisingly, are common to all the patients' healing relationships, one being that the creation and respect for a "nonjudgmental emotional bond" with a doctor is imperative to the success of such a relationship (Scott et al., p. 315). Bailey and Tilley (2002) hear stories from individuals who suffered from Chronic Obstructive Pulmonary Disease (COPD), their family caregivers, and their nurses, to understand how the patients

used storytelling to make sense of acute episodes of this disease. They found that, in the case of one patient, storytelling provided a way to “communicate distrust of the nurse’s ability to recognize the seriousness of distress and implications for its potential course” (p. 574). So, by telling their stories, patients can relay sensitive information, information that they may otherwise not feel comfortable communicating to others. These others may include their families, caregivers, and other supporters.

The Importance of Illness Narratives For Family, Caregivers, and Other Supporters

I believe that illness narratives not only help patients and their doctors forge closer and more holistic relationships, but they can also assist family members, caregivers, and other supporters to better understand journeys of healing. There is, to my mind, a dearth of scholarly literature exploring how these individuals understand illness and, more particularly head injury, through the narratives of patients. This remains a missing but important part of the knowledge about head injury.

There have been studies on the caregiving role in general. For instance, Hanks, Rapport, and Vangel (2007) examine how “perceived burden, caregiving relationship satisfaction, beliefs about caregiving, and mastery with caregiving” (p. 43), are appraised by caregivers. They find that many caregivers for the more severely injured felt dissatisfied with their caregiver roles, specifically noting that these caregivers were overburdened and not comfortable with their competency. In contrast, in an earlier study, Noonan and Tennstedt (1997) explore “the association between meaning in caregiving and the psychological well-being of informal caregivers” (p. 785), finding that, if caregivers looked for meaning, they were more likely to report positive beliefs about their caregiving roles.

Illness Narratives or Stories of Healing?

I believe that illness narratives, when lived by survivors of all types, vary in the degree of optimism. But it seems that all of the participants in this study see themselves moving towards something positive, so I want to highlight ‘healing’ not ‘illness’. Stories of healing and illness narratives are not fused, but they are closely linked. They may overlap, but then they may diverge and veer apart. They may cross paths at any time.

Some individuals may be stuck in a chaos narrative from a tellers’ perspective. Some may be stuck in restitution from either survivors’ or loved ones’ perspective. This study tells all sorts of stories, but the stories told by the athletes can be shown to help ‘fix’ broken stories. Therefore, I consider the stories performed by the athletes stories of healing.

I will now discuss one facet of the athletes’ performances, photography, and the methods that theorists have used to incorporate photography into their studies.

Photography: Composing a Pallet

In this study, I analyse the photographs as part of the athletes’ stories using the techniques ‘photo-elicitation’ and ‘photo-interview’ that Kolb (2008) and Warren (2005) outline. Photos are used as a resource in this study: the athletes will refer to both existing photos and the photos they take during the study as they construct meanings. My hope is that the photos they have taken will have helped them to augment their stories. Lastly, these photos have assisted me to make meaning and to add substance to the athletes’ performances because, as Harrison (2002) experiences, “the visual is a means of accessing data” (p. 858).

Photo-Elicitation

According to Warren (2005), if using the method of photo-elicitation, individuals are not viewing and commenting on photos they have taken themselves, but rather the researcher chooses photos that were taken in their pasts. The method photo-interview differs from photo-elicitation because the participants of a study using photo-interviews not only take the photos, but they, not the researcher, then choose which photos to talk about (Warren). Whether photo-elicitation or photo-interviewing is used, images, such as photos, drawings, or any visual images, are employed as stimuli to aid individuals as they recount their stories (Harper, 2002; Hurworth, Clark, Martin, & Thomsen, 2005; Warren, 2005). Harper, as well as Hurworth, Clark, Martin, and Thomsen note that the use of photos may prompt participants to respond differently than if words alone are used.

I believe that photo-elicitation has been suitable for use in this study. The photos of the athletes' pasts, as well as the photos that they took during the time I spent with them, have given the athletes a reference point to start from when they were asked to share their stories. Viewing photographs taken of them as active athletes may help the athletes, as Bach (2001) maintains, to 'unlock' their memories, to reconstruct events from their pasts, and to recount their stories and communicate their experiences (Gauntlett & Holzwarth, 2006; Holm, 2008). Remembering, reminds Harper (2002), is "enlarged by photographs" (p. 23). Harper seems to agree with Bach (2001) who writes that photos themselves "do not preserve meanings" instead, they "help to unfreeze memories" (p. 7). The athletes may or may not realize, when they look at the photos they take of themselves, that, as Warren (2005) explains, the photos may reveal their current and past "feelings, beliefs, [and] opinions" (p.

864). Mitchell, DeLange, Molestane, Stuart, and Buthelizi (2005) believe that, as well as drawing on the voices of people who may be oppressed, photos can “make sure that those voices are heard” (p. 257). Holm (2008) thinks that if photos were translated to text, the picture seen would not be as “full, lively and complex” (p. 2).

An example of photo-elicitation is a study by Bennett (1995), who listens to stories and looked at photos with fourteen nurses in rural Victoria, Australia in the 1950’s and 60’s. Through their stories and the accompanying photos of their pasts, Bennett heard the nurses elaborate about their jobs, their working relationships, and their nursing experiences, with the goal of allowing them to reveal, in depth, parts of their nursing identity before their stories were lost. Using photos, Bennett helped the nurses to remember routine activities and to recall detail so that their narratives were richer than if interviews were the sole source of data. One of the nurses commented, as she was viewing the photos, that without them “you do forget all these little bits and pieces you did” (Bennett, 1995, cited in Hurworth, Clark, Martin, & Thomsen, 2005, p. 55).

Kolb (2008) reminds us that this traditional view of photo-elicitation is but one method in which the participants are not the photographers. He notes that Warren’s (2005) definition of photo-elicitation, outlined above, is in contrast to how photo interviewing is used in the studies that follow below.

Photo Interviewing

In the following studies, the participants themselves are the photographers. Clark-Ibanez (2004) uses both researcher photos and photos taken by participants in her study of two elementary schools. Clark-Ibanez finds that the students’ social locations within a

charter school and a public, inner city school impacts their interactions with their teachers. She elaborates on the photo-elicitation interview (PEI) techniques she used to interact with the students. In one instance she used researcher-produced photos, in the other, the students took their own photos, which she later used as “interview stimuli” (p. 1509). Others, Warren among them, call this method photo interviewing because the photos are taken by participants. In other words, photo interviewing, and related methods such as photo novella, described next, utilise participant-directed photography.

Photo novella.

Photo novella enables the members of a community to take photos and tell stories with the hope of enlightening “policy makers about issues of concern at the grassroots level”, provoking community enhancement, and increasing community knowledge (Barraza & Robottom, 2008; Wang & Redwood-Jones, 2001; Wang, Cash, & Powers, 2000, p. 81). Barraza and Robottom (2008) discuss a study of environmental sustainability issues in which they used participant-directed photography as the main means of data collection. The study by Bennett (1995), which I give as an example of a photo-elicitation study, may also be considered a form of photo novella because it encouraged the participants, rural nurses, to paint an ordinary, everyday picture of their nursing lives. Photo-voice, according to Warren (2005), is a newer term for the photo novella.

Photo-voice.

In the following studies, as occurs in the studies of photo novella mentioned above, a camera is put in the hands of the researched. The groups that use photo-voice tend to be marginalised, silenced, and less powerful. When they are given a camera, these powerless

and oppressed individuals are empowered (Hurworth, Clark, Martin, & Thomsen, 2005; Molloy, 2007). Molloy comments that photo-voice is often used for groups involved in social action.

An example of a photo-voice study that is not community based is one by Loeffler (2004), who asks fourteen outdoor education program participants at a college to interpret photos they had taken during their outdoor activities, and then to discuss the meanings that they found in the photos with him. By reviewing the photos and the subsequent interviews, he found three themes: “spiritual connection with the outdoors, connections with others through outdoor experience, self-discovery and gaining perspectives through outdoor experience” (p.536). He notes that the study’s results encouraged further exploration of this use of photography.

Many studies that use photo-voice are of oppressed communities and the individuals belonging to them. Radley and Taylor (2003) give cameras to hospitalised patients in an effort to uncover the role of “the physical setting of the ward” in their recovery (p. 77). The patients were then interviewed to explore why they had taken particular photos. The researchers found that, by taking the photos, the patients had recorded parts of the hospital setting that were relevant to them. The researchers arrived at their findings by analysing the data gathered from conversations about the photos. Subsequently, Radley, Hodgetts, and Cullen (2005) study how homeless people see their daily lives by giving them cameras and asking them to record a typical day. The homeless people were then interviewed using the photos as prompts. Using the photos and the interviews, the researchers showed how different individuals experience homelessness in various parts of the city. Beilin (2005)

researched family farmers in south-eastern Australia and asks them to take pictures to explain their relationships to “the landscape, to the local...conservation groups, and to the imperatives of contemporary production systems” (p. 56). She finds that the photo-elicitation methodology that she used empowered the farmers to articulate their values and understandings.

In a photo-voice project studying African Americans who had lower income levels, the researchers, Carlson, Engebretson, and Chamberlain (2006), were able to “generate a social process that resulted in active grassroots participation in a community-campus partnership” (p. 836). After participants had taken photos in their community of things they wanted to change as well as things they wanted to remain the same, their stories were heard and then analysed along with the photos. By performing this analysis, the researchers uncover how to help these individuals move out of “helplessness towards authentic engagement and participation” (p. 836). In another photo-voice project, Wang, Cash, and Powers (2000) enabled male and female residents at a shelter to take photos of “their everyday health, work, and life conditions as a way to document their struggles and strengths” (p. 81). The participants’ stories and photos were analyzed, and the analysis was then used to recommend practices for subsequent photo-voice studies with vulnerable populations.

In sum, whatever specific form photo-interviewing takes, all of the forms incorporate the three phases that Kolb’s (2008) study does: involving the participants, sharing photos with them, and then analysing the resulting data. Hurworth, Clark, Martin, and Thomsen

(2005) write that photo interviewing invites and encourages active participation by study participants.

Next, I review another method of using photographs in a study, a method called auto-photography.

Auto-Photography

The difference between photo-elicitation and auto-photography lies in the fact that, when using auto-photography, the photos taken by the participants explore the question ‘Who are you?’ It is a method often used in quantitative self-esteem research, for example in studies by Dollinger and Clancy (1993), Dollinger and Dollinger (2003), and Noland (2006). By asking the participants to take photos, Rhodes and Fitzgerald (2006) found that the researcher was able to capture “everyday from the ground up” (p. 356). As Noland (2006) explains, photos enable individuals to illuminate “the construction of the self” (p. 3) and help researchers to tactfully approach the “personal subject of identity” (p. 4). As part of her doctoral dissertation, Noland (2000) used a non-traditional approach to auto-photography. She gave cameras to twelve women from India who were US residents living in a college town in Ohio with the purpose of the girls taking photos to illustrate who they were. She added more participant involvement by having the participants, not herself as the researcher, choose and explain their photographs. This enabled the participants to identify what was important to them.

In the following studies, Dollinger and Dollinger (2003), and Noland and Jones (1998), also used auto-photography. Unlike Noland (2000, 2006) however, there is no indication that the participants themselves viewed the photos and discussed them with the

researchers. Dollinger and Dollinger quantitatively studied 844 adults between the ages of 18 and 54. The participants were asked to take pictures that illustrated who they were and to write an accompanying commentary. The older the participant, the more the photos showed “greater uniqueness, interiority, and seriousness of purpose” (p. 277), which the researchers interpreted as more individuality. Using a quantitative approach, Noland and Jones (1998) explored how to evaluate the self-esteem of adolescent girls. Their participants were “50 seventh and eighth grade female students from two middle schools in Los Angeles” (p. 5). The girls were given disposable cameras and asked to take pictures that describe who they are and who they were not. The photos indicate positive self esteem and that the girls are thinking about their futures.

The next section is relevant to sub-research question three and reviews work on how learning and identity construction are related.

The Role of Learning in Identity Construction

I noted earlier how Lave and Wenger (1991) describe learning: “learning involves the construction of identities” (p. 53). Antikainen (1998) finds this to apply to his study when he explores what education and learning meant to “the lives of Finns” (p. 217). When he questioned what the role of education was in the lives of these individuals, his findings indicate that learning is valuable in “various transitions of life-course and breaks of identity” (p. 230). Mahiri and Godley (1998) wonder how personal views of oneself are impacted by the importance assigned by society to “writing and other literary practices” (p. 416). Their single case study reveals that, for this particular case, “identity was [strongly] influenced by societal values for writing and literacy” (p. 432). Isrealite, Ower, and Goldstein (2002)

examined how school experiences and the interactions that accompany such experiences impact the identities of hard-of-hearing (HH) adolescents. In this case, they found that students wanted to be identified as HH, and so needed “a critical mass of peers with whom they can identify” (p. 145). For these adolescents, “the perceived quality of their social experiences may influence identity development” (p. 136). McCarthey (2001) studied fifth graders with the purpose of understanding the role of students’ “literacy perceptions and practices in shaping identity” (p. 125). Her findings re-affirm the results of other research: “that literacy can affect our sense of self” (p. 143).

Why do I feel that the current research is important?

The Search For a Study Focus – Finally Deciding on a Colour

I believe that, prior to this study, journeys of identity construction of elite athletes after they have sustained head injuries had not been explored, in particular by a member of the same culture. As a survivor of a severe TBI, a 1996 Olympic athlete, and a PhD student in education, I find myself in a unique position. I became curious about a research topic that I felt was begging to be explored, so I listened to the stories of athletes like myself, former elite athletes who have sustained TBIs. The study is autoethnographical because I have included my own story. I wondered how other athletes who have sustained TBIs have tried to reclaim “a voice that bodily trauma...[has] caused to be silenced” (Frank, 1998, p. 336). I now had a focus, so I decided to listen carefully to the athletes’ stories, probing and questioning them to examine how they have constructed their identities since their injuries. Researching and writing this thesis, Freeman (1993, p. 188) suggests, is my attempt to “take what was and make something new”.

This work is a collection of illness narratives performed by my culture for academia, but also for a wider audience, including individuals who have sustained head injuries. My intention is that this collection of analyzed stories will cause its readers to pause and to think. This text should be beneficial and inspiring for the survivors of any life-altering illness or injury, not just head injury, to absorb. I wonder how it will impact you?

...Interlude....

.....It was a time of fear and uncertainty for my family as bewilderment surrounded them. They wrestled with the uncertain future we faced. During that confusing time, Chaos managed to ensnare them with its tentacles.

*Total confusion
for four months
there was
no longer
an order to time.*

Chaos

My parents remember the six weeks I spent in Nottingham, England while I was at the Queen's Medical Center. Initially, I lay in an induced coma. I was diagnosed with a severe Traumatic Brain Injury. My parents were also with me when I was flown home to Canada accompanied by a doctor and a nurse. "We prefer negotiation," my personal medical team had replied when asked by my parents whether I would be medicated to subdue me on the flight. At home in Canada, I was fed an extra hospital dinner each night by my father, who traveled to the Ottawa General Hospital every day on his way home from the office, because he found me too thin. My mother walked with me for hours around the hospital in a successful bid to

discourage the doctors from medicating me to keep me quiet. I don't remember any of this .Nothing. Post traumatic amnesia (PTA) kept me from knowing what was happening. Looking back, I am thankful that the PTA lasted as long as it did, thereby sparing me memories of an endless and discouraging time. Even though I was thirty four years old, my parents unconsciously called to action their dormant but instinctive parental roles. When summoned, these roles naturally and spontaneously rose from their long hibernations, springing to life and surging into overdrive.

(Smith, 2008, p. 5)

Chapter 3: Theoretical Framework - Selecting the Brush

I believe that “understanding complex lives requires more than one theoretical lens” (Riessman, 2003, p. 23). That being said, Catherine Kohler Riessman’s work (1990, 1993, 2000, 2002a, 2003, 2008) is the central component of the theoretical framework of this thesis. I combine her dialogic/performance narrative analysis, outlined in Riessman (2008), with Erving Goffman’s (1959) dramaturgical analysis. Goffman maintains that life is a stage on which individuals perform their evolving selves for others (Borgatta & Montgomery, 2000). Selves shift and change during these performances “in the course of social interaction” (Holstein & Gubrium, 2000, p. 24). Then, I composed the thesis using methods suggested by Laurel Richardson (1993, 1997a, 1997b, 1999, 2000, 2001). I feel as Richardson did in 1993. She commented then: “I write because I want to find something out. I write in order to learn something that I didn’t know before I wrote it” (p. 87).

Performance

.....And Storytelling

Goffman (1959) describes a performance to be any activity by an individual that “serves to influence” (p. 15) audiences in daily life. Similarly, Alexander (2005) considers any expressive human activity to be a performance. Although she feels that not much attention has been paid to the presentational aspects of storytelling, Riessman (2003) points out that a lot can be gained from close observation during conversational data collection. Individuals embody their stories because they are not only told “about the body but through it” (Frank, 1995, p. 3). When interpreted in this way, embodiment, giving tangible form to

ideas, can be considered a performance. How individuals want to be known by their audiences is reflected in how these individuals perform their stories for others and so reveal their preferred identities (Gee, 2000; Goffman, 1959; Riessman, 2002b). Gee notes that individuals' performances are associated with their identities. I observed the athletes embodying and performing their identities while they shared their stories with me, therefore conveying meaning not just through the telling of these stories, but also through the manner in which the stories are told.

As the athletes performed for me while I was collecting data, I found that I agreed with Langellier and Peterson (2006), who comment that "voice and body coincide in performance" (p. 157). However Riessman (2003) maintains that "Scant attention has been directed to the presentational features through which illness experiences are reflected" (p. 6). She believes, as I do, that the telling of stories can be regarded as performances because, while relaying stories vocally, storytellers unconsciously reveal additional information about their experiences and their identities. I think that identities, which I consider are constructed dialogically during social interaction, are not something people 'have' but they are "something people perform or do" for others (Holman Jones, 2005b; Riessman, 2002b, 2003; Smith & Sparkes, 2008b, p. 25). When I watched the athletes perform for me, I concurred with Riessman (2003) that "one can't be a 'self' by oneself" (p. 7).

As they told me their stories, each athlete performatively re-created "a self that was in jeopardy due to the effects" of the head injury (Frank, 2000a, p. 136). Because this was done through movement and body language, many parts of their stories, Riessman (2003, p. 6) maintains, remained "unspoken, inferred, shown and performed in gesture, association,

and action” (see also Daiute, 2004; Goffman, 1959; Langellier & Peterson, 2006; Radley & Chamberlain, 2001; Riessman, 2008; Smith & Sparkes, 2009). When individuals’ performances of their stories include these gestures and movements, these performances are another “means for identifying personal subjectivities...that distinguish...[their selves] from other selves” (Daiute, p. 113). Goffman’s (1959) dramaturgical approach uses a theatrical metaphor of the interview situation for analysis (Myers & Newman, 2007). The metaphorical theatres in the case of this study involve actors (interviewees, interviewers, and caregivers), stages (the interview situations), and scripts. Myers and Newman explain that a script outlines the “norms, rituals, expectations of how one should behave” (p. 11) as an athlete who has sustained a TBI. In this case, the audience consisted of the athletes, the caregivers, me as the interviewer, and the readers of this thesis (Goffman). In my role as a member of the audience, I planned to listen carefully to the athletes while observing their performances. Do individuals hide behind their performances (Manning, 1991)? In the case of this study, I don’t think that they did because I believe that, in most cases, the athletes’ performances were unconscious and spontaneous.

Goffman (1959) writes that during conscious performances, “when an individual appears before others in social situations he will have many motives for trying to control the impression they receive” (p. 15). This is particularly the case for the participants of this study when they perform for other members of society. At these times, they attempt to avoid being stigmatised because of their head injuries (Goffman, 1963). Goffman cautions that individuals should carefully consider their performances if their social position has changed:

When the individual does move into a new position in society and obtains a new part to perform, he is not likely to be told in full detail how to conduct himself, nor

will the facts of his new situation press sufficiently on him from the start to determine his conduct without his further giving thought to it.

(p. 72)

I wove my observations of the athletes' performances throughout the illness narratives I constructed. I believe that the performances are crucial elements of the constructed stories so I used them to enhance the data and then subsequently I considered them during the analysis.

....*And Photography*

Riessman (2008) maintains that we “have to make arguments in words about images,...[so that we can] contextualise and interpret them in light of theoretical questions” (p. 143). She later adds that in photos, researchers should look for “meanings related to their research questions, philosophical positions, and biographies” (p. 179). In the case of this particular study, I did not incorporate her in-depth and detailed methods of interpreting participants' photos. By adding photographs to the stories, I simply used them so that it is possible for the understandings that the readers of the thesis arrive at to be ‘thicker’. The use of photos gave the athletes another tool to add to the depth of their descriptions of their lives past, present, and future. As Bell (2006) describes, the athletes' photos provided opportunities for them to enhance my understanding of their lives today.

.....*And Writing*

I continue to evolve as a writer because, as I noted earlier, I found that the process of writing about the athletes' stories of healing and about their performances was a method of analysis in and of itself (Richardson, 2000). Ricoeur explains that, as the author I was “the craftsman, the maker of the work” (Valdes, 1991, p. 7) and the narratives that I co-

constructed with the participants from their stories was for me a “method of inquiry” (Richardson, 2000, p. 923).

I agree with Richardson (1997b) that writing is:

.....a theoretical and practical process through which we can (a) reveal epistemological assumptions (b) discover grounds for questioning received scripts and hegemonic ideals – both those within the academy and those incorporated within ourselves, (c) find ways to change those scripts (d) connect to others and form community and (e) nurture our emergent selves.

(p. 295)

a) Revealing epistemological assumptions.

An interpretation of life as it happens is not linear. According to Ronai (1992), it is not “clearly demarcated [because] linear story lines cannot be used to describe lived experience” (p.104). Both layering and the painter’s fan metaphor I use for this thesis better mimic how life plays out. The structure of the painter’s fan reveal my epistemological assumptions, inviting a “circular process of interpretation that blurs and intertwines both cognitive and emotional understandings” by the readers (Ronai, p. 104). A painter’s fan, similar to a layered account, tells tales of authors’ introspections to be interpreted by readers because, as the author, I incorporate an infinite number of points of view (Ronai, 1995). By reading a story written in this way, Ronai (1992) maintains that a reader who is self-aware will undergo a “process of self-examination involving conversation with oneself” (p. 103).

b) Discovering grounds for questioning received scripts.

I heard stories from the participants. I didn’t question while I was listening, but throughout the process of writing and interpreting the texts I discovered that I was probing what I had listened to and I was continually developing new interpretations of what I had been told. I found myself entrenched in a hermeneutic circle (Ricoeur, 2006). I interpreted,

then I understood, then, armed with these interpretations, I understood the text differently. I am confident that the interpretations the readers will discover while reading the illness narratives will facilitate the emergence of meanings for them (Riessman, 2008; Sparkes, 2002).

c) Changing the scripts.

Authors can hint at a multitude of meanings that become apparent to readers when the authors' texts are viewed from different angles. In so doing, authors can reveal 'unexpected' scripts because they are able to employ all sorts of voices and many forms of representation, one being performance. Some are articulated by the authors' own selves and some by those of their participants. Engaging a painter's fan, as I have, hints at these 'unexpected' scripts when these researcher and participant selves tell their stories (Gergen & Gergen, 2000).

In the case of this study, when the athletes' illness narratives and my analyses of them are read, because these selves each have their own voices, the voices may convey impressions that are "conflicting, disjointed, and ambiguous in character" (Ronai, 1998, p. 407). Ronai explains that these many "impressions then 'write' on readers, merging with the readers' impressions to create for readers their own lived experiences" and their own interpretations (p. 407).

d) Connecting to others.

I believe my own position is complicated because I am a researcher studying my own culture. When I began this study, I imagined that I would be teetering on a two-dimensional continuum, researcher at one end and native at the other. However, having now

experienced this particular research process, I agree with Ronai (1992), who maintains that this is too simplistic a way to describe my “various role conflicts and multiple levels of absorption” (p. 122). Simplicity aside, it is an analogy that still resonates with me. While collecting data, I found myself traveling repeatedly along this continuum, sliding ad infinitum into and then leaving the end that is labelled researcher so that I could visit and then return from the other end called native. I was “in a constant state of flux; it is the dialogue between the facets that act to fulfill the tasks of particular roles” (Ronai, p. 107). In the role of researcher, I whispered encouragement to the me that performed the role of the native. I believe that my native self will always struggle with the difficulties performing some tasks, difficulties that were imposed by deficits leftover from the accident. Performing the role of native I offered cooperation and support to the researcher me, the one who is captivated by the research topic.

Nurturing our selves.

Stories inspire me. Particularly to this study, I was encouraged by stories about individuals who have sustained TBIs while they are, or after they have been, international or professional athletes. A survivor of head injury myself, readers will soon discover my interests include researching head injury. To convey this passion I have tried to write an evocative text in which I am “standing within what I study...and writing about the experience” (Bochner & Ellis, 1996, p. 19). Hyden and Brockmeier (2008) maintain that “For people to tell stories about their illness is a way to create meaning and cope with their particular experiences” (p. 7). It has been so for me.

I am eternally thankful for the support given to me by my family and friends during the various stages of my own rehabilitation. My supporters allowed me to (re) learn how to nurture my self: to make choices, to voice opinions, and to be as independent as I could be at any given time. Their actions rehabilitated some core elements of my personality. Rehabilitation helped me to realise anew that I am responsible for the construction of my own self. I can once again freely make choices and I am able to sculpt my life according to what I think and feel. I easily offer opinions which I share with others who consider them respectfully, and I am completely independent.

During the research, I was always concerned about understanding the study's participants. A life changing event such as head injury is first a catastrophe but then can have positive outcomes (Denzin, 1989; Severinsson, 2003). Denzin maintains the experience can become an epiphany, a reason for change and growth. Severinsson writes that recovery from such an event can be empowering when it leads to a meaningful life. I believe that it is especially important for individuals who have lived such a disruption to realise that what they are experiencing in terms of their evolving selves is not abnormal. People are continually in the process of nurturing the selves that they will forever be becoming. Human "subjectivity and human agency [recognised as crucial parts of the self are] central to the issue of neurotrauma" (Medved & Brockmeier, 2008, p. 55), however survivors are sometimes believed to be incapable of both by their well-meaning caregivers.

...Interlude....

Where is Claire?

I don't know, nor do I care, about much as I languish in a state of nothingness imposed by post traumatic amnesia. My memories of the four months

after my fall are only snapshots. Most are out of focus. I have lost a lot of them. I drift in and out of being "present." I am absent most of the time. I live in the "now."

Who am I?

I am shown things to help me to remember, to remind me. My dog comes for a visit. I welcome him. I astound everyone by effortlessly lifting the huge Golden Retriever onto my bed. Then I lurch down the hall and introduce him to my new world, the only world I that I remember. I live in the present.

Where am I?

I am at a hospital. I stagger around its corridors. I go into other patients' rooms. I greet staff.

How am I?

I am fragile. My balance is bad. I have no memory. I think I'm fine. No one else does. For now I am content. I am fed, exercised, and cared for. I am told what to do. Please eat. I am just like my horse Gord.

What happened?

I have had a traumatic brain injury.

Prognosis?

Excellent ... "In a year you won't know anything happened."

Reality?

I will be out of touch with mine for another two years.

Now, I become Restitution.

(Smith, 2008, p. 5)

Chapter 4: Methodology – The Primer Coat

Before I outline the methodology I used, I will discuss my own positioning while collecting the data. What are some of the influences I felt I needed to consider as I tried to position myself for optimal data collection?

Sliding Between Many Researcher Positions: Choosing How and What to Paint

While collecting data, I carried my identity with me “like [a] tortoise shell into the research setting” (Riessman, 2008, p. 139). I was always immersed in the process: I felt almost submerged while collecting data from each participant. However with each participant, my researcher positioning varied, sliding along a continuum labelled at one end ‘daily interviews’, sliding to ‘house guest’ at the other. Reinharz (1997) agrees that this fluctuating degree of researcher closeness may have had an impact on the selves I brought to the particular research situation and so also coloured the data I collected. I wondered how, in each case, my “social location, subjectivity, and frameworks of understanding” that I brought to the study influenced and “enter[ed] into ...[my] analysis of another’s narrative account of illness” (Riessman, 2004, p. 311). So, I paid attention to where each particular research situation located me and to the unique situation surrounding each participant. As Alvesson and Skoldberg (2000) comment, there is “no one-way street between the researcher and the object of study; rather, the two affect each other mutually and continually in the course of the research process” (p. 39).

I believe that my researcher position would, in each case, influence the narrative I constructed and then analysed. Data collection was in one sense staged. First, my conversation guide offered carefully planned topics which, I now realise, placed invisible,

silent boundaries on the discussions. Second, the seating arrangements were relatively inflexible because they were dictated by the limited range of the voice recorder. I question whether this subtly and transparently staged setting influenced the selves I witnessed? Third, I am aware that as much as I planned to begin each session anew, I brought conversations from previous days with me to the session each day, as well as what I had learned reading about the athlete's past. Sometimes, I wanted to begin again, probing the participant from a new and completely different angle to try to uncover different, previously unrecognized meanings. Not only were the athletes' pasts and injuries destined to colour my viewpoint, but previously conceived ideas about head injury abound. These unavoidable preconceptions no doubt contributed to my own interactions and interpretations, but I am sure that the athletes also experienced these preconceptions from others as a form of stigma.

I wonder if I can ever be sure whether I positioned myself optimally in the case of each participant while collecting data for this study (Behar, 1996; Dickson-Swift, James, Kippen, & Liamputtong, 2006, 2007, 2008; Ellis, 1999)? Dickson-Swift, James, Kippen, and Liamputtong (2007) believe that, in their study, they heard untold stories. I think I did too. I question how I received these stories. Did I demonstrate the emotions the storyteller expected to see? I believe that I did show my vulnerable self (Ellis). Behar asks if:

.....as a storyteller opens her heart to a story listener, recounting hurts that cut deep and raw into the gullies of the self, do...[I], the observer, stay behind the lens of the camera, switch on the tape recorder, keep pen in hand?

(p. 2)

Given my research design, it was not surprising that I found that, in my role as researcher, it was impossible, with every one of the athletes, to maintain a 'traditional' researcher distance or, as Goffman (1961) suggests, a 'role distancing'. Instead, as the athletes told their stories,

I realized that I wanted to listen closely, carefully, and empathetically in order to give them support and confidence and also to be able to co-construct illness narratives that best reflected their stories of healing (Kleinman, 1988). I saw no need to separate the self I was, one that was “creative, inspirational, vulnerable, sensitive, unpredictable, [and] mystical”, from the research I was undertaking (Douglas & Carless, 2008, p.4).

The relationships I formed with the athletes were based on similar, very uncommon experiences, with the result that they were unconventional research relationships (Johnson & Macleod Clarke, 2003). The relationships may have been unusual, but Coetzee and Rau (2009) did find that when researching trauma, the commonality found in similar experiences can forge a bond between the researcher and the researched. They note that if such a relationship is positive and healthy, it can impact “how experience is re-membered and narrated” (p. 1). Fortunately, although having the common experience of head injury was at times stressful, I believe that in the end my own journey of healing enhanced “my connection with my research participants” (Rager, 2005b, p. 24). However, I consciously did not assume our experiences were similar, so I hope that my perceptions of the athletes’ journeys of healing were not influenced by my own experience of head injury. Dwyer and Buckle (2009) weigh the challenges of being an insider during research. I was initially challenged because I wondered before I got started whether I would be able to reveal my own self, the one that had been made fragile by head injury? I intended to do that during the research process with each participant, and in the end I did, and I am happy that I did. This revelation aided me when I asked the athletes to disclose, share, and perform their stories of healing for me (Rager, 2005b; Tillman-Healey & Kiesinger, 2001). I find that I agree with

Rager, who writes that emotional connection is an essential component of the qualitative research process.

At the same time as I was encouraging the athletes to share their stories, it was essential to the narratives I was constructing that I maintain my own reflexive self-awareness (DasGupta & Charon, 2004). Each participant was different, causing me to carefully ponder my ever-changing, multiple, and shifting researcher positioning, and then perhaps to change my performance within each evolving position (Pini, 2004; Reinharz, 1997; Riessman, 2008). Following Reinharz, it was important for me to consider my positioning, because my positioning was bound to “shape or obstruct the relationships that [I could]...form” during the interview process (p. 4). What did I do to situate myself each time as I experienced and reacted to the participant’s stories (Douglas & Carless, 2008)? How could I best locate myself to construct an illness narrative from each athlete’s stories? Although I did not consciously ponder these questions in each research situation, I now realize that I kept a variety of possible influences in mind while positioning myself as I spent time with each participant.

Researcher Vulnerability and Emotional Response

Even though I recognize intellectually that conducting research is possibly threatening to the researchers and that the data collection process may be an emotionally stressful experience for them, I was nevertheless somewhat surprised that the support I gave to the athletes left me feeling vulnerable myself (Etherington, 2007; Johnson & Clarke, 2003). Lewis (2008) notes the importance of empathy to qualitative research, “the capacity to think and feel into the life of another person” (p. 64). I agree with Dickson-Swift, James,

Kippen, and Liamputtong (2007): I think that if the participants feel vulnerable, we (researchers) should “be prepared to show our [own] vulnerabilities” to demonstrate that we are sympathetic (p. 342). Researchers may feel vulnerable and emotional because research requires the “exposure of the self who is also a spectator” (Behar, 1996, p. 14). Happily, exposing ourselves to participants can possibly “take us somewhere we couldn’t otherwise get to” (Behar, p. 14). Although I frequently felt overwhelmed and also often emotionally drained, the research process did enable me to learn more about myself (Behar, 1996; Dickson-Swift, James, Kippen, & Liamputtong, 2007, 2008; Ellis, 1999; Ellis, Kiesinger & Tillman-Healey, 1997; Johnson & Clarke, 2003). As Ellis describes might happen, I felt vulnerable when I revealed my self and my experiences to others. Much of this was because in the end I wanted the reader, as good writers of fiction do, to “feel the feelings of the characters, smell the smells, see the sights, hear the sounds, as though you were there” (Ellis, p. 676). In order to do this, I had to collect data that originated in the hearts of the participants, which often left me feeling vulnerable. Despite the sometimes stress provoking interactive data collection process, the experience I had garnered collecting data from the same population for another study prepared me for what I faced (see Smith, 2004, 2005, 2007a, 2009).

Participant Vulnerability

Conscious as I was about my own well-being in the various research settings, I was also aware of the possible impact of the data collection process on the emotional well-being of the participants. How susceptible did they feel during those times (Johnson & Clarke, 2003; Rager, 2005b)? I was never sure how they were affected by sharing their stories but it

is “not difficult to imagine that reflecting [on a life altering experience] is likely to be a distressing experience” (Johnson & Clarke, p. 430). It was of paramount importance to me as the researcher that I respect each athlete as an individual. So, although I considered some options for writing up my research, I felt that by writing four individual stories and analyzing them separately I was less likely to discount any individual’s data and I could show the respect I had for each athlete as an individual (Kidd & Finlayson, 2009). Because I shared my own story with them during our conversations, I could build rapport, indicate to the athletes that I felt we had an experiential base that perhaps included some commonalities, and nurture comfortable and constructive research relationships with them (Dickson-Swift, James, Kippen, & Liamputtong, 2006, 2007, 2008; Dwyer & Buckle, 2009; Rager, 2005a, 2005b). Regarding her study, Rager (2005b) thinks that because she and the participants had a common and stressful experience with cancer, it helped her to build a stronger connection with them. Dwyer and Buckle (2009) explore an interesting position, that of researchers being both insider and outsider, not one or the other. They note that acceptance is often “more rapid and more complete” (p. 58) if the researcher is an insider.

The Importance of the Storytelling Process to the Athlete

The process of telling their stories was of value to the athletes. It gave them the opportunity “to be listened to by a person who really did want to hear their story” (Dickson-Swift, James, Kippen, & Liamputtong, 2007, p. 334). By recounting their stories of healing to me, the athletes were able to (re)visit their pasts, (re)arrange their presents, and (re)imagine their futures (Bruner, 1990; Clandinin & Connelly, 2000). According to Clandinin and Connelly, the past and the present contribute to the construction of future

identities. So, while they were constructing and telling their stories of healing, the athletes made new meanings, and, at the same time, remembered ones they had previously made (Bruner; Smith & Sparkes, 2009). By recounting stories of their sporting pasts and their head injuries, the athletes gained insight and understanding into their lives in general through meaning making. They gathered “meaning from an event that applies to greater areas of life than specific behavior; with insight, there is often some kind of transformation in the understanding of oneself or others” (McLean, 2005, p. 684). I will always wonder how the athletes saw me while they told their stories and made meaning from them: did they see me as an individual who had also sustained a head injury or was I an academic to them (Pini, 2004)? I believe that their views of me may have influenced parts of their performances, but I think that in the end the data I garnered from these performances about their past, present, and future selves would not have changed (Clandinin & Connelly, 2000).

Research Context and Environment

As I entered each research environment, I was very much aware that its context was unique. The participants’ stories took place against distinctive backdrops painted with each storyteller’s cultural, historical, and social colours (see Frank, 2004a, 2004b; Georgakopoulou, 2007; Hardin, 2003; Josephs, 2008; Langellier, 2003; Madison, 2006; Peterson & Langellier, 2006; Riessman, 2003, 2008; Smith & Sparkes, 2008c, 2009). Hardin notes that stories “are always sculpted by the context in which they are told” (p. 536). The stories and the contexts in which they are told, Madison believes, reflect how the athletes’ cultures have changed: they were competing athletes, now they are survivors of head injury. The context of each research situation provided some of the uniqueness that was discernable

in the relationship I had with each participant. The emotional and physical proximity of each research environment was also unique and so, to a large extent, contributed to my positioning. I was fortunate because in the case of Dave Irwin, I was invited by him to be a guest during the interactive interview process (Ellis, Kiesinger, & Tillmann-Healy, 1997). Smith and Sparkes (2004) write that Smith, as the primary investigator, conducted interviews in the athletes' homes during their study. Because of this research environment, each participant in that study was encouraged "to tell their life story in their own way and in their own words" (p. 615).

Significance of Head Injury to Each Athlete's Current Life

I believe that the significance of head injury to the participants' current lives also impacted my evolving relationships with them. Sliding along a continuum, I found Dave Irwin's experiences with head injury at one end, they are the central elements of his current life. His head injury is the focal point of the restitution narrative he currently lives. Dave challenged my thinking and so made it hard for me to establish a relationship in which we were both comfortable. This was in part because he believed that my own injury had been insignificant in comparison to his. I wonder if Dave's reaction to my injury was his competitive nature revealing itself? Terry Evanshen's experiences are all bathed in head injury because the severe memory deficits he has been left with permeate his present life. The injuries sustained by John Beedell and Jim Kyte are less significant to their current lives, although John no longer drives due to his injury. At the opposite end of the continuum from Dave Irwin, Jim suffers some lingering deficits such as dizziness and nausea but he does not let them interfere with his life now.

In sum, these are the many factors that I needed to consider to optimally position myself in each research environment. In her examination of her own positioning while conducting research in rural Australia, Pini (2004) elaborates on her use of reflexivity to ponder the identities she became during the research. My own partial and incomplete knowledge of the participants was gathered from the many researcher positions I assumed and is, I am sure, influenced by these multiple positions. I do feel that the data I collected from these varying positions enabled me to, as Oikarinen-Jabai (2003) eloquently writes, “create forms through which experiences can be reversed, enlightened from fresh perspectives...., and shared with audiences and readers....I make use of the human capability to empathize, to place myself in different positions, to dance with my shadows” (p. 578).

The Participants

Finding four
former elite athletes
who are survivors
of
head injury
was
difficult.

Participant recruitment was an emergent process, in part because there are only so many former elite athletes who have sustained head injuries. The study strayed from my original (too) tightly knit design: although the athletes whom I recruited had sustained life

altering head injuries, these injuries had occurred as a result of accidents long after they had retired from sport. My original plan was to recruit athletes who had been injured while competing or training for their sport. There was only one athlete, Jim Kyte, who had been injured when he was still a hockey player. His injury, however, was sustained not while he was playing hockey but in a car accident during the drive home after practice.

John Beedell, Terry Evanshen, Dave Irwin, and Jim Kyte readily accepted to participate in this study. When I first met each of them, I gave him a recruitment text and, in the cases of Lorraine Evanshen and Lynne Harrison, a recruitment text for caregivers. These documents consist of a brief description of the study and an invitation to participate outlining what the roles of the athletes and of the caregivers would be. Before I started to collect data, the athletes, and, if present, the caregivers, all signed consent forms.

The Plan For The Conversations

Keeping my always fluctuating positioning in mind, I asked the participants to share stories with me during informal, in-depth conversations (see Appendix for conversation guide) which were interactive interviews (Ellis, Kiesinger, & Tillman-Healy, 1997). These interviews were, as I had hoped they would be, “reflexive, dialogic, [and] performative” sessions because they “transform[ed] information into shared experience” (Denzin, 2001, p. 24). The unstructured interactive interviews offered the participants opportunities to “tell their stories in their own ways to someone whom I hoped they would view as an attentive listener” (Mishler, 1999, p. 21). I believe that telling stories is an essential tool used by humans to relay information that they wish to communicate (Bingley, Thomas, Brown, Reeve, & Payne, 2008; Riessman, 2008; Smith & Sparkes, 2008b). Bingley, Thomas,

Brown, Reeve, and Payne, and also Riessman, expand on the notion of ‘telling’. They write that telling a story is a way to describe, remember, argue, reflect, share, justify, persuade, perform, or entertain. Telling can even be used, Riessman cautions listeners, to mislead. During the conversations with the participants, I was an ‘active listener’, and I made suggestions. I performed in this way to “attempt to assist the participants to tell their life story in their own way and in their own words” (Smith & Sparkes, 2004, p. 614). I understand my own story better after listening to the stories of the athletes (Ellis, Kiesinger, & Tillman-Healy, 1997). Upon reflection, which occurred as I was with each athlete, I believe that the participants’ stories can be viewed as co-constructions of their collaboration with me in my role as researcher (Riessman, 2002a).

During these conversations I tried to uncover the athletes’ personal viewpoints of constructing their identities by listening to the athletes’ stories and observing their performances as they told me their stories (Riessman, 2008). The conversations lasted from one to two hours in length over a period of four consecutive days. I originally planned to spend five days with each athlete, but four turned out to be sufficient.

I talked to the athletes at various times during the day; these times were not usually scheduled until we had finished talking the previous day. Sometimes I didn’t schedule times; with Dave Irwin, when the time seemed right I would run and get my tape recorder. The only athlete for whom I had to take into account residual deficits was Dave. I had anticipated that more of the participants would have greater deficits, so I had planned the schedule over consecutive days to allow for deficits the participants may possibly have as residues from

their head injuries. These could include attention deficit, fatigue, and memory issues (van der Naalt, van Zomeren, Sluiter, and Minderhoud, 1999).

How the conversations unfolded, and consequently in which direction I would carefully steer subsequent conversations, varied from athlete to athlete. I quickly realised that in order to collect the data I was after, I had to loosen my grip on my carefully but fairly rigidly planned conversation guide. The first meeting was always one of introduction and casual conversation, held to blur the boundaries between us so that the participants would be inclined to lead me in directions that would enable me to uncover more data (Finley, 2005; Madriz, 2000). I designed this meeting keeping Madriz' suggestion in mind: I wanted to spend as much time with the participants as was needed so that they recognized that, throughout our conversations, I would strive to pay close attention to their feelings and voices. On this day I began to elicit stories from the athletes by nudging them to tell me stories about their pre-injury lives. I wanted to know how they then perceived their pre-injury identities and how they described the events of their pasts. During this time, I told them my own unscripted story and I shared my personal and social experiences, as Ellis, Kiesinger, and Tillman-Healy (1997) suggest. By doing so, I was attempting to position myself as close to the athletes as I could. The first day's conversation was more or less the same for each participant and allowed me to carefully observe the athlete. On subsequent days, I explored the research questions, changing the manner in which I introduced the conversations according to previous days' conversations and performances.

Second, I observed the athletes' performances while we were conversing (Riessman, 2008). Because every performance was unique, the 'telling' of the story became important,

not just the story as it was told (Langellier, 1989; Peterson & Langellier, 2006; Riessman; Skultans, 2000).

For the third type of data, each of the athletes provided me with a photo of his athletic past. Employing the methodology photo-elicitation, I used these photos to provoke reflection and elicit memories. Photo-elicitation draws “out memories of [each participant’s] history” (Harper, 2000, p. 729). Bach (2001) feels that viewing the photos encouraged the athletes to “acknowledge what has previously been resisted and repressed” (p. 2).

Fourth, I provided each participant with an easy-to-use digital camera. I asked them to take pictures to describe their daily lives and their identities now. I used the photos to illustrate the illness narratives that co-constructed with the participants (Bach, 2001; Holm, 2008; Warren, 2005). These pictures helped the athletes to make “‘visible’ different parts....of [their] stories” (Bach, p. 2). According to Harper, the pictures also aided them to “re-create [their] unexamined, taken-for-granted perceptions” of the identities that they have (re)constructed (p. 729). We looked at the photos together and discussed them in reflective conversations that were photo-interviews (Hurworth, Clark, Martin, & Thomsen, 2005; Kolb, 2008; Warren). Hurworth, Clark, Martin, and Thomsen maintain that photos can encourage people to open up and can promote discussion of “either the familiar [and also perhaps] the unknown” (p. 54). My intention was for the athletes to be able to use the photos to comment on their lives and their identities. I believe that the athletes thought that the photos did just that. It seems to me that when the athletes looked at the photos they had taken of themselves, the photos revealed “their [current and past] feelings, beliefs, [and] opinions” (Warren, p. 864). I believe that the photos complement the illness narratives that

the athletes and I co-constructed because of the inclusion of photo-interviews as part of the interactive interview process (Bell, 2006; Warren, 2005). I agree with Bell, who writes that photos can help “make visible...[and] give voice to silenced or stigmatised illnesses” (p. 32). If the athletes photographs had people in them, I had these people sign consent forms.

Fifth, I kept field notes in a journal outlining my impressions and thoughts during the emergent data collection process (Creswell, 2002). My field notes, because they provided me with a way to privately chronicle my research journey, enabled me to jot down my thoughts so that I could explore and reflect on them after the data collection was complete (Coffey, 1999; de Carteret, 2008). I like de Carteret’s description of her field notes: “a spiral moving outwards from unjoined thoughts” (p. 236). I found that my unjoined and scattered – both literally and figuratively - field notes eventually became tighter and made more sense. As time marched on the jotted thoughts began to slowly coalesce.

The five data sources discussed above: the athletes’ stories, their performances, the conversations they initiated, the stories and performances surrounding the athletes’ photos of the past and the present, and my journal notes were the primary sources of data. I also encouraged the athletes to give me artistic data, as suggested by Eisner and Powell (2002), if they felt that art was an effective way to convey their thoughts and emotions and augment their stories. I had hoped that, by enabling expression using alternative methods, the athletes’ stories would enrich “the domain of expression [and] ...the capacity to realize new worlds” (Gergen & Gergen, 2002, p. 23). But, as it turned out, none of the athletes used artistic means to embellish their stories.

The Constructed Illness Narratives

To make more sense of my conversations with the athletes, I read and reread the transcripts and then organised them using Nvivo. These consecutive informal conversations, together with the photos taken by the athletes and my field notes, yielded the thick and descriptive narratives (Nelson, 2001; Richardson, 1997a, & Verkerk et al., 2004). To write the narratives, it was necessary to link the various stories told to me by each participant. Telling their stories was a means of connection for the participants: Frank (2006) explains that the storytelling provides “people with an ability to recognize and connect what was disparate” (p. 421). Mattingly (1998) describes what co-constructing these narratives involved for both me and the participants: “confronting obstacles, taking risks, facing enemies, overcoming dangers and the like” (p. 70). Each time I (re)visited the transcripts of my conversations with the athletes, I found that the data “reflectively [built] on one another” (Denzin, 1997a, p. 226), the result of which being that the illness narratives that I constructed of the athletes’ stories of healing are rich and detailed descriptions of complex lives realized over time (Nelson). As Bergen (2005) writes in the Giller Prize winner *The Time in Between*, “each successive story [is] like a piece of thread, and [I collected] those pieces” to construct the illness narratives (p. 39). Before adding my reflections, I sent the athletes their constructed illness narratives for member checking, in case I had misinterpreted what they had told me (Janesick, 2000).

By layering the athletes’ stories with my reflections as I constructed the illness narratives, I was, as was Robinson (1990), able to inject the stories with insight, personal meaning, and texture. I wove together each athlete’s stories into an illness narrative that

shifts “forward, backward, and sideways through time, space and various attitudes in a narrative format” (Ronai, 1992, p, 103).

I found that I became increasingly introspective as I wrote this dissertation. I had conversations with myself; I was self-aware and reflective in my role as a participant. As I wove my own story through the participants’ stories, I found that layering helped me to explore my fluid position and the many roles that are a part of me. I could reflect on my shifting subjectivities and my ever-evolving thoughts and impressions that, as they changed, added to all the knowledge that I have gained while meeting with each participant.

A Painter’s Fan (Revisited)

In order to expose readers to multiple understandings of knowledge I have presented them with an array of representations presented in multiple literacies. To show the study’s subtle variations, nuances, and versatility, I have sprinkled the written text with poetry, field notes, and photography (Holman Jones, 1998a, 1998b). These multiple literacies not only represent a collage, but they appear in the text both as layers representing some of the interpretations that readers may make of the text and as subtle variations and tints on my painter’s fan.

The study’s seemingly autonomous and dynamic evolution fascinated me. I began with a rigid plan, but I soon realised that such a set notion can block what naturally unfolds in life. Having let go of my fixed agenda, it often seemed to me that the study constructed itself; it had a life of its own. As I wrote, I was pointed in various directions to pursue new ideas that I gleaned from the participants during our conversations. I felt welcomed by the study, my own creation, so I took possession of

this authorship of the interpretation of others' lives. I surrounded my constructed stories with theory. When I wrote, the story seemed to be crafting itself; I found new ideas that grabbed me, peeking through the words, wanting to be exposed. So, I have exposed them. In doing so, I inevitably have offered even more glimpses of myself (my self). These glimpses, exposed and unwrapped, have evolved into integral parts of the stories from which this dissertation is built.

I have constructed this text as the study was: evolving, changing, and shifting. I hope I have also effectively, and in a cohesive and nonintrusive manner, conveyed the theoretical background supporting my findings.

In the role of a survivor of head injury, I sometimes grapple with how I appear to the participants. Dave Irwin did not believe that I was hurt badly. Terry Evanshen praised me for work that he believes will be truly beneficial to others. By undertaking this research, I believe I have made the best of a life changing event that certainly did not fit into my life plan.

Interlude...

Finally, four months after the fall, post-traumatic amnesia finally left me and I reentered the same world that healthy people experience. The progression of my recovery was lost on me. I still had no idea what I had been through and what had happened. Everyone around me noticed that I started remembering the people, places, and events of the previous days. At the same time that I reached this milestone, I was admitted to the head injury rehabilitation program at St. Vincent's hospital in Ottawa, and so I became a patient in yet another hospital for the next two months. During long days that flowed into each other, I underwent intensive therapy of all sorts—physical, speech, occupational, and cognitive. I was under constant supervision; someone was with me all day, making sure that I followed a "normal" routine, that I ate, and that I went to my therapies. I wore an armband alerting the nurses to my movements so that they would always know where I was. It squawked loudly when I left the confines of the ward. The staff on the ward only began to trust me in the month before I was discharged. At that point they finally had sufficient faith in me to allow me to venture out on my own and find my own way around the hospital. At long last, I was able to sample just a small taste of the freedom most take for granted.

When I was released from hospital, a marathon of outpatient therapy began. It took a year in total to complete the hospitalization and outpatient therapy. Therapy creates artificial situations to teach about real life and how to go about solving its problems. It taught me some things well. What therapy didn't teach me was that I was no longer the same person I had been. So, when therapy ended I believed that I had re-entered the real world, and I assumed life would resume as I had lived it before I was hurt. I thought that life as I was now going to live it was the same as the one that had left with an astounding crash on September 13th, 1997. In my

mind, my life had not changed. I was still going to train and compete with my horses. The painful truth, which I did not realize, let alone accept, was that my life was now different. But, for the time being, I lived life as I imagined it and as I wanted it to be¹. Wisely, my "team" avoided a huge battle by letting me figure out on my own that life had to change.

Off I went.

Smith, 2008, p. 5

Chapter 5: The Athletes' Stories –

The Colour of Each Room

I think that the athletes' illness narratives can best be read keeping in mind a term introduced by Arthur Frank (1995), "thinking with a story" (p. 23). Frank maintains that stories should be read or listened to with empathy and understanding for the experience that the patient has undergone. Consumed in this way, the athletes' illness narratives and incorporated narrative analyses may be reflected on and lived in by readers long after they are experienced. As is suggested by Bleakley (2005), they may impact readers' lives and foster "empathy for a patient's experience of illness" (p. 534).

The thesis, my own story, and the four illness narratives I have co-constructed with the participants, are emergent due to each storyteller's evolving identity. These evolving identities were apparent in the athletes' performances as they told their stories (Langellier, 2003). I have done what Gergen and Gergen (2000) suggest: they explain that the notes I have included in boxes throughout each narrative about the athletes' performances should provide "the audience with possibilities for a rich engagement with the issues, but leaves them free to interpret as they wish" (p. 1030). As the researcher, I am relying on the readers of this study because I thrust responsibility on its audience to bear some of its weight. The readers must make their own meanings and understandings from "their unique vantage points" (Sparkes, 2002, p.220). They will do this after digesting the co-constructed illness narratives (Richardson, 1993), the narrative analysis (Riessman, 2008), and the analysis of the constructed illness narratives (Coulter & Smith, 2009). In these narratives, Smith and Sparkes (2009) explain that I show rather than tell, using thick description, reflections, and

photography, how the athletes hinted about their backgrounds and their current lives as they performed their stories which have become the co-constructed illness narratives you will now read. These were composed keeping the athletes' performances in mind. Denzin (1997a) writes a wonderful description of autoethnography, commenting on its compatibility with performance: an autoethnography is "a performance text....turning inward waiting to be staged" (p. 199).

I have detailed the photo-interviews I held with the athletes (Kolb, 2008; Warren, 2005). Riessman (2008) maintains that we "have to make arguments in words about images,...[so that we can] contextualise and interpret them in light of theoretical questions" (p. 143). She later adds that researchers should look for "meanings related to their research questions, philosophical positions, and biographies" (p. 179). In the case of this particular study, I did not incorporate her in-depth and detailed methods of interpreting participants' photos. Instead, I am trying to "communicate participants' views of their worlds with more primacy than language alone" (Warren, 2005, p. 861). Photos lessen the gap between the readers and the participants and, according to Bell (2006), they "do more than [just] show, or tell" (p. 42). By adding photographs to the stories, I am using them to contribute both to the 'thickening' of the understandings arrived at by the readers of the thesis and to the meanings made by the participants (Bell; Warren).

In what order should I present the illness narratives? To name but a few possibilities: I could have placed them in order of the length of time that had passed since their injuries, or their ages (younger first, or older), or the severity of their injuries, or the impact that they perceived their injuries still had on their lives, or the order in which I saw them and

composed their narratives. With so many possibilities and without a clear idea of ordering that spoke to me, I eventually fell back on an alphabetical order. Within this order, I have organised each illness narrative slightly differently to provide assistance to the readers as they decipher how my sometimes disorganised but always interesting experiences varied while I was spending time with the participants (Gannon, 2006; Ronai, 1998, 1999). Some may find that these stories are, as Gannon points out that ethnography sometimes is, close “to the art of fiction” (p. 477). In my attempts to reflect on the time I spent with each athlete I have constructed their narratives using my impressions and observations gathered during data collection. In so doing, I hope I have portrayed each athlete with “complexity, thoughtfulness, and insight” (Warr, 2004, p. 586). My personal reflections that revealed themselves both during and after data collection are included in the form of boxes inserted throughout each story. My storytelling voice plays the leading role in these narratives, so, as Sparkes (2002) suggests, my “academic voice is stilled.... No citations, no references, and no scholarly interpretations are provided” (p. 85). Richardson (1997a) recommends using a format that facilitates the narratives’ accessibility to a wide audience. I hope that this format does just that. My intention is that the stories, my reflections, and the narrative analyses imbedded while the narratives were co-constructed are read together. I hope that they tease out the experiences of identity construction after head injury for the participants and bring to life my time spent with them.

My autoethnographic presence will be noticed in two ways as readers consume the stories. First, as already mentioned, I have sprinkled my comments throughout the stories in boxes of text. These insertions are reflections that reveal some of my musings about what I

have observed and heard. Taken as a whole, I believe that they may be a partially composed attempt to come to terms with my own head injury and what it really means to me. Second, at the end of each story, I have reflected on the time I spent with each athlete and considered these questions: How did I feel in the presence of the athlete? What did I experience while spending time with him? How do I think our conversations went? How did his stories impact me? What have I added to my thoughts about my own experience while with this athlete? These autoethnographic reflections can be viewed as an insertion of me into this research in two ways: me, as the researcher, but also me as a participant and a member of the culture of head injury.

...Interlude....

I am fixed.

Riding again

Back to life

as it should be

I am better

Things are the same.

Over the next two years, I slowly, in a circuitous manner, became friendly with the new me. I was unable to break free from my old life because I did not realize that I was not who I had been. I was convinced that my comfortable, familiar lifestyle with the horses was the place for me to be now. I tried for more than a year to make my old life work again. I moved to North Carolina, which was my winter home for many years pre-injury. I rode again, which was of paramount importance to me while

reestablishing who I was. Throughout this time, I did not really understand the significance of the trauma I had experienced and the changes it would impose on my life. Such understanding requires insight, and I was not healed enough to have insight². So I rode. I also traveled to competitions, this time as a spectator. I finally became well enough to face life as it now was. I realized that my life had irrevocably changed, and I realized that I was not the same person who I had been before my injury³.

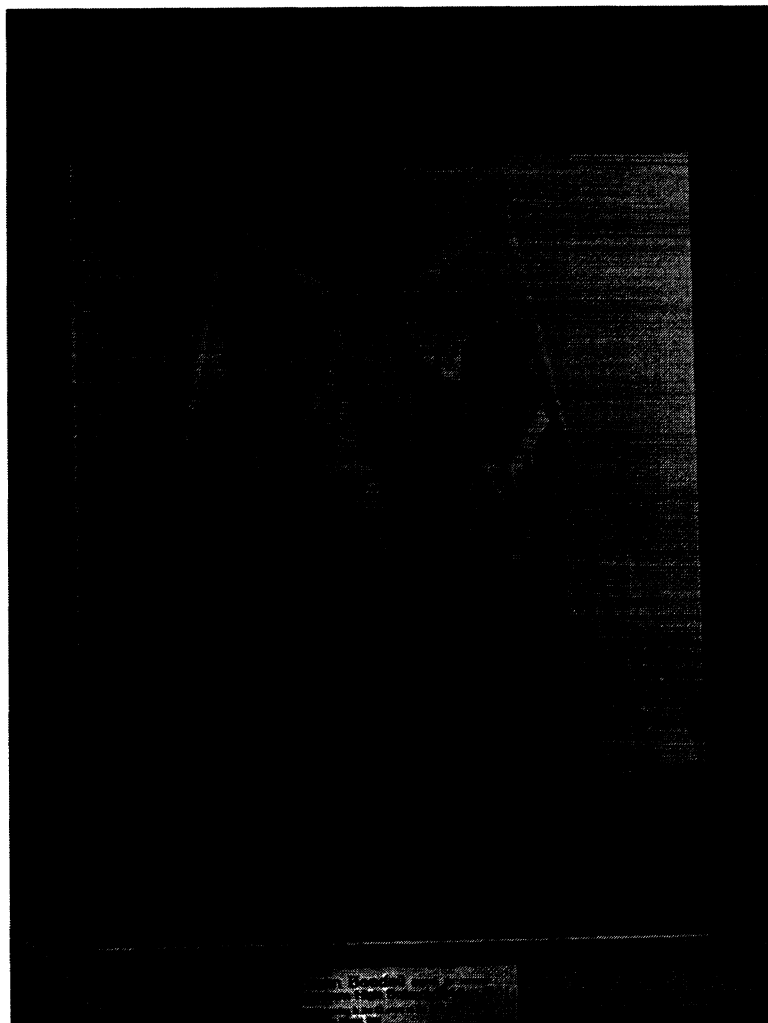
*I became aware
that I had fallen
from a position
of respect, friendship
and admiration
to one of pity.*

*Pitied by all
admired by none.
An instant and
unwelcome change.
Who am I now?
I wonder.*

I eventually realized that everyone who was part of my old world saw a huge label on my forehead. "Head Injured" it said. A large percentage of the elite equestrian athlete culture I had been part of pre-injury were unable to see the new person before them. To this day, people from my old life automatically package me into their laymen's perceptions of what head injury is. I didn't know, at the time, what

was happening⁴..... My life hadn't turned out the way it was supposed to —at all. I had been an athlete: dedicated, motivated, tough, driven, successful, and respected. Falling on my head was a life changing event, causing me and my family endless grief, mourning, and loss. I am no longer the same person; the person I was before the fall is gone. But, although I am different, I am still dedicated, motivated, and driven. Thanks to these qualities, I have recovered almost completely. I finally recognized that, despite my valiant attempts, a return to my old lifestyle was not possible. I had no choice but to accept what life had chosen for me. I moved back to Canada.

(Smith, 2008, p. 5)

John Beedell

John Beedell represented Canada at the 1958 World Championships and the 1960 Olympics in C2 canoeing in which two people are paddling. John always paddled on the left. Twenty years ago, when he was fifty-five, he fell off a ladder while building his cottage and sustained a traumatic brain injury. At the time of his accident he had been teaching Outdoor Education and Science at a private school for twenty years.

The following narrative was constructed from transcripts, participant observation, and field notes from my conversations with John Beedell in August, 2008.

Prelude

When I called John to see if he was interested in participating, he was eager to meet me and learn about the project. He lives in Ottawa, so I stopped by his apartment one day to pick him up and take him for a coffee. John was fascinated by the ideas I had for the study. He was eager to help and offered immediately to participate.

When I met John to introduce myself and my research, his performance indicated his interest and enthusiasm. He was waiting for me at the front door of the apartment building and then listened intently to what I had to say as we sat opposite each other at the local coffee shop. As I told him about the study, his bright eyes never left my face.

Pinning him down for four consecutive conversations was a little difficult; it was July and he had trips planned to various cottages for the summer. We settled on a week that suited us both at the end of August.

From what John had told me the first time we met, I knew that he was always busy. So, when I dropped John off at his apartment building, I wondered, as I always did when I left, what he would be up to next. He always seemed to be heading off somewhere on his bike.

The first day of the four we met, I rang to be let into the building and took the elevator to the floor on which he lived. As I exited the elevator, I saw him waiting outside his apartment door for me. He first showed me around his apartment. He had made use of

every nook and cranny of the small space. Bookshelves lined the walls, and in the few places where there were no books, there were paintings. John had a card table set up for me to work on, so I unpacked my tape and digital recorders, and opened my notebook and we started talking.

John lived in the same building but in a smaller apartment before his accident, and after he was discharged from hospital, he moved right back. Eventually, he moved to a larger apartment. There was an enormous amount of stuff that he had accumulated in the apartment, so I have no idea how he would have stored all of his things in a smaller space.



Childhood

John's performance during the conversations we had was one of interest and helpfulness. He volunteered bits of information that were extras. John spoke clearly at all times and he went into great detail after thoughtfully considering what I had asked him to tell me about.

John began by telling me his story. He started right at the beginning:

I was born in New Zealand....when I was 3 we left New Zealand and my Dad, who was a ship's engineerwanted a land job when I came along. This was the time of recession in the 1930s, so he had gone to London where he had gone to University to see if he could land a job there. Mom packed me up after he had left, we headed for England, but, by the time we got to England, Dad had a job down in British Guiana (now known as Guyana) in South America. So my Mom stayed in England long enough to have my sister and then we followed him down when my sister was 4 or 5 months old and of course you only travelled by ship then.

John remembered a lot from the time of the 2nd World War and told a fascinating story of how his family had arrived in Canada.

We were 60 miles in the jungle, up the Demerara River which is famous for Demerara Sugar and El Dorado Rum and so we lived there for 5 years until I caught malaria. [It was] during the war, they had to get me out so we were on a bauxite [aluminum ore] boat, the Nazis were after us in U boats so we had an experience in St. Thomas in the Virgin Islands. We were entertained by Danish friends of friends, we had a wonderful time, they took us around the beaches and we then left after 2 days on the bauxite boat. We came up to Arvida, Quebec and we found that these people who had been so nice to us in St. Thomas were taken and shot as spies.....we don't know whether the Nazis had captured their relatives in Denmark and then the Nazis had made these people be spies or they just liked the exciting life of being spies. They would radio the subs every time a bauxite boat left and then the subs would try and sink [the boat]. To this day, we don't know whether they didn't bother radioing or the subs [just happened to] miss us, but the ship we were on was sunk on the way back down.

I asked John how old he was when this happened, he replied that he “would have been eight years old at that time”. I wondered whether he actually remembered this time, or whether his memories came from stories that he was told. He firmly believes that “I remember it, I do remember it. I remember British Guyana clearly”. Apparently he remembers the snakes well too, and recounts that “you didn't worry about the big snakes, they could only crush you. The little snakes though were poisonous”. He continued his story:

But Dad still had a year in his contract and Mom and Dad had to go down for another year. Fortunately, they did not go back down on the boat they came up on [which sunk on the way down]. They came up on the Lady Hawkins when they finished in British Guiana [the second time]. The Lady Hawkins was sunk in the Bermuda Harbour going back down, so in both voyages, we just missed fate. Anyway, I stayed for a year in Montreal while my Mom and Dad were down. I saw my first snow because I hadn't seen snow in New Zealand, we had lived in England, hadn't seen any snow there, and there wasn't any snow in British Guyana, so I can remember going to the corner of the veranda...I was left with some people in Montreal, I picked up the snow, it changed to water, I thought it was magic. I can still see it happening in my hand now.

John spent a year “in Montreal, then when Mom and Dad and my sister came back up from British Guyana, we moved to Kingston”.

I am amazed by the detail of John's memories of this time. How much did he actually remember, and how much had he been told later in life by his parents? How many of his stories were the product of stories that he had been told and had been 'dressed up' over years of telling? I have no idea, but the stories were fascinating. John was the first participant who went into such detail. Terry Evanshen and Dave Irwin talked only very briefly about their childhoods. Subsequently, Jim Kyte has told me stories of his childhood and hockey days in great detail.

Identity

It quickly became apparent to me while I was talking to John that he was many things. To name but a few, he was an Olympian, a teacher, a learner, a father, a grandfather, and a survivor of Traumatic Brain Injury. When I asked John to talk to me about his identity fairly early on in our conversations, I asked him how he would describe himself. He immediately said that “First and foremost, I am a teacher”. He misses teaching because he loves to help children learn.

The thing I miss most is the exposure to [the kids], I mean you have a group of kids. There are good ones, there are bad ones, they are a group of people so I guess I miss the exposure to them. I miss.... the preparation of teaching because whenever you did either science or in athletics, you prepared yourself and I suppose I miss that.....

I was curious to hear how John defined identity. Without taking any time to think, he told me that it was “How you are looked upon by other people”. After thinking a bit longer, he talked more about what he thought:

We make our identity by what we do, our job, everything like that, who we associate with and, so my identity at one time that was I was a good teacher, I had been a good athlete, you tend to try and build on those concepts. When I was a teacher I don't think I ever talked to anyone about the fact that I had been in the Olympics but the fact that I could still run and things, I certainly showed that....

John does not believe he lost his identity as a high school teacher right away after his accident.

I had teachers come in and visit me, it was just remarkable and I really appreciated that, so I didn't lose my identity as a teacher at that time, even though I knew I would not teach again. But at that time.... often they would say, well it will be good when you come back which was not reality but you tend to grasp that and hope that, yes, that will happen.

Although deep down John knew that he would not teach again, he could not imagine what his identity would be if he were not a teacher. John told me that currently “I am still in a way a teacher because I associate with REACH which helps disabled people [by supplying them with lawyers] and I still go over to the school, like I was over today and met some people that I have taught”. He hopes his identity “is still a helper, I help in the ski marathon that I used to participate in, go over and work in the office, I help with REACH. They put me on the board.... I was helping in my school in the library until I became obsolete because of computers.....”

At the end of the conversation, John reiterated how he felt about his identity: “when

the Olympics come on, I was part of that but mainly I think of myself as a teacher”.

When I asked him how he would describe himself as an athlete, he saw no difference between ‘former athlete’ and ‘ex-athlete’.

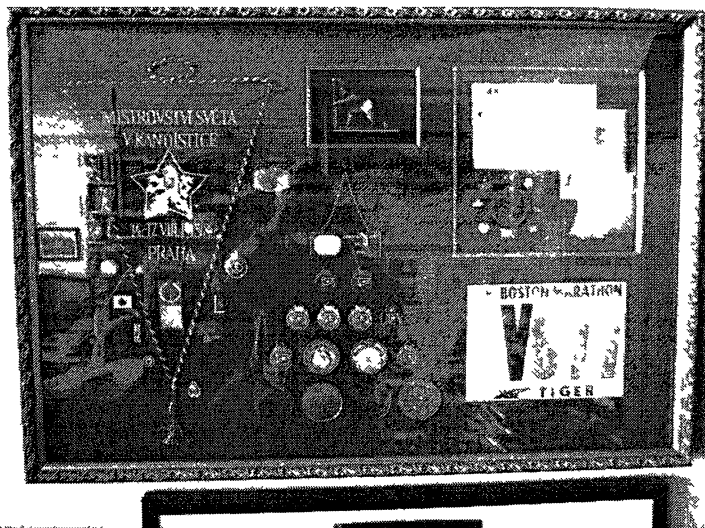
John has an understanding of identity that is similar to that of Terry Evanshen. Although I did not explicitly ask Terry to define the concept, our conversations led me to believe that he identifies himself in terms of what he does, not who he is inside. Terry identifies himself with how people see him, as a motivational speaker. John identifies himself in the same way, in terms of what other people see and the image that he projects.

An Athlete

When the Beedells moved to medium sized Canadian city, John became involved in sports while he was at school there, “mainly baseball and things like this. I started running and really it wasn’t highly organized sports and I did some canoeing, but very little”. Staying in the same town, he attended university in engineering. One summer he went north as a student and “got involved with the..... canoe club up there, they were a racing canoe club”. John recounted that when at university a couple of years later, the university “and I both realized that I wasn’t going to be an engineer”. John then moved north to work for a large mining company and at that point he “got totally involved in the sport of racing canoes andstarted winning national canoe championships....with a partner”. His C2 partner throughout his canoeing career remained constant and is someone with whom John has remained in casual contact over the years.

Sports at the international level were very different in those days because training was done in conjunction with full-time work. John told me that he and his partner:

...were based completely in Sudbury.....back in the 60's we were not subsidized at all..... so any training you did yourself and we had phone calls from our coach in Toronto or something like that.....He came up once in a while to see what you were doing....that was about as close as you got to him...He sent a list of things to train, how to train, but just checking once in a while, so it was very, very low profile coaching..... It wasn't highly organized the way it is now.



John made a collage of his athletic accomplishments. He told me when we were discussing his identity that canoeing was only a small, unimportant part of his life. All the same, when I said that I was thinking of leaving out the picture of the collage because I could not seem to take one without a reflection of the background in the glass and also because he repeatedly told me that this part of his past was only a small part of his life story, John adamantly told me it should be part of the story. Words were not enough to describe his canoeing experiences. I think he was secretly prouder of his Olympic accomplishment than he let on. Interestingly, the picture we chose in the end has John reflected in the glass.

In order to train every day, John would get out of bed “at 5:30 in the morning to get down before I went to work at Inco and I had to be there for 8 o’clock. So we would get up

early, train, then get out to work in time and then train after work too”. Training took about three hours a day. In addition to canoeing, they did “weight training especially in Sudbury, it iced over early, so we did a lot of running, a lot of weight training”.

John’s experiences were so different than those of the other participants. For them, training took up the entire day. Dave Irwin, when training in Europe, had time for little else. When Jim Kyte was playing professional hockey, the sport and the travel required between cities to play different teams took up all his time. I found that when I was involved showing horses, days were often not long enough to get everything done.

Sport consumed our days.

The World Championships

John told me that “the first big thing we went to was the [World] Canoe Championships in Czechoslovakia in ‘58”. John and Joe didn’t take their own canoe, they “just used one of theirs”.

Elite sport in the days when John took part in it seems to have been much more casual than sport today. It appears that athletes sometimes had to borrow equipment, but organisations from host countries were very willing to lend it. Today, I don’t think that athletes would dream of competing without using their own equipment.

John remembered that they flew

.....across the Atlantic in an old Constellation with the fire breathing engines and we were late by the time we got into Brussels and then we were to fly to Prague but we were too late so they put us up at a hotel for the night. We then went back to the airport, there was a Russian T104 jet and it was a converted bomber, I mean you

could see it was a converted bomber, they had seats that were just sort of strapped but to take off in this jet when we were used to the prop planes, it was just simply amazing, it was just woosh.....it was sure fast compared to the prop planes.

John stayed in Prague for the entire two weeks of the championships. He remembers “landing in Prague, [it] was Communist at this time, we were met by a man with a Tommy gun, we gave him our passports as we got off the plane, they gave them back to us when we left after 2 weeks”. During the World Championships John told me that they

....were entertained by one of the Czech canoe clubs. They had 20 along the Vltava River. They were very good to us but they had been canoeing for years.....and the Russians were there too who were the top canoeists during the 60s and so we would train with the club and the actual races, which were canoe and kayak, took up the 2 weeks that we were there.

The Olympics

The qualifying races for the Olympics took place at Mooney’s Bay in Ottawa. John and his partner always raced

....1000 metres, a kilometre. But at that time, there were also 10,000 metre races and we did not do those but that was the standard which they have eliminated now.... They didn’t have any shorter races like they do now. They have a 500 now too in the Olympics.

In order to qualify John and his partner “competed against all people that were in Canada that wanted to race in the Olympics....we raced the 1000 metres in flat water”.

When John and Joe left for the Olympics, they flew from Montreal directly to Rome “with the entire Canadian Olympic Team....I think there were about 60 of us in 1960“. John enjoyed watching other sports and told me stories of what he had seen.

When you weren’t canoeing, they allowed you to go [and watch]. I went to the Olympic venue in Rome, being a New Zealander, I was able to watch Snell win his 800 metre. Another New Zealander who was racing the 5000, the most spectacular race I have ever seen because this New Zealander in the 5000, he had a withered arm

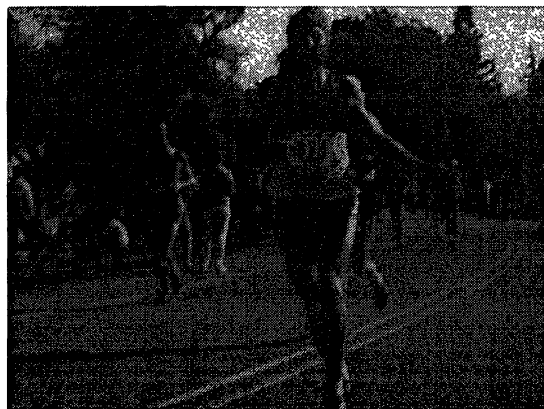
which literally dangled from his shoulder. 5000 I think is 15 laps of the oval race, at about the 3000 metre mark he suddenly sprinted ahead and got about ¼ of the length of the oval ahead, ...[then] a distance runner from East Germany and he must have been 6 feet and he came lumbering after this little New Zealander and he was within 2 or 3 feet at the end of the race but the New Zealander won it, just the most spectacular race I have ever seen.

John's characteristic of trying his hardest to reach the top rose to the surface in Rome. He told me "You feel you are a part of the whole group of people that all are aimed at winning, you may not win, but you aim for it".

I am sure that this is the same attitude that enabled John to recover optimally. He still strives to live his life fully by doing all the things that he wants to do. He does not let any of the lingering remnants from his accident get in his way.

Sports After Canoeing

Sports have always played an important role in John's life. When he finished canoeing he ran two or three marathons a year, a total of twenty. He ran the Boston marathon once, finishing in three hours twelve minutes. His fastest time was three hours six minutes. He expressed frustration that he had never broken three hours, but said in his own defence: "it's like running a four minute mile".

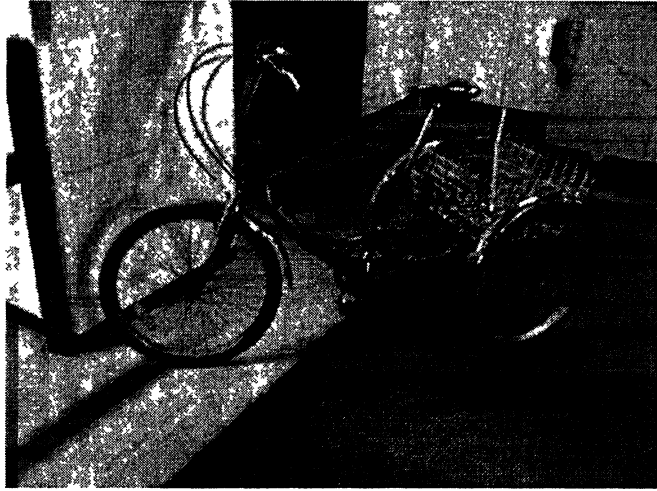


He also cross country skied, racing in the Gatineau 55 in 1988. While talking to me, he thought about his involvement in sport, reflecting that “I’ve always liked athletics. So you try to keep your body in shape and sports were an easy way to do it. I never did like just sitting around, pushing weights or anything like that. I liked sports where you did something”.

I think John’s active life helped him to recover optimally. Rather than being ‘forced’ to do the rehabilitation, it was more than likely easier for him to be active than if he had been told to keep quiet and rest.

Sports are still important to John. He swims daily in the pool downstairs: “that is at least giving me some swimming and when I’ve gone up to my sister and brother-in-law up in the Lake of Bays, they have a sailboat so I have been able to sail up there”. He has a large tricycle, which is his summer mode of transportation. The first one he had – he has had three stolen! – was bought for him by his son. Initially he thought “I don’t need a tricycle. You immediately, as soon as you think of a tricycle you think of a little kid, but I realized it was a life-sized one”. He calls his bike his BMW (Bike My Way). He told me that he has not driven a car since his accident because he would never forgive himself if he were the driver and had an accident: “I would always feel it was my fault”.

John’s bike lets him “escape to the outdoors anytime....I still relate to the outdoors”. He figures that he puts about 1000 miles a year on his bike, regularly going “out to Mooney’s Bay and out to Dow’s Lake, I just like the exercise....I probably bike ride if it’s a reasonable day”. John took a picture of his bike parked in the garage:



I later took a picture of him riding his bike:



John uses his BMW as his only private mode of transportation. He is amazing; it doesn't faze him at all to bike to the other side of Ottawa to help out at the Canoe Club. He bikes all over the city. I think that the adjustment for him to stop driving was made fairly easily because of his athletic past.

A Teacher

When John started to canoe, he had done “some recreational boating, sailing and things like that but I had never gotten into competitive canoeing so I followed through and that took me to the World Championships [in 1958] and the Olympics [in 1960]”. A year after the Olympics, John canoed in the 1961 North American Championships. He then realised that there was no money or future in canoeing, so he had “better get back to reality”. Reality, for John, began with a conversation with his sister, who encouraged him to apply to teacher’s college. After thinking about it, John decided to give it a try and then started college immediately. John soon found out that he was passionate about teaching and he still is; he told me “I loved teaching and I suppose I was very involved with teaching and sports were just minor things”.

I wondered at this point whether John really meant minor, or whether he meant extra-curricular. Sport seems to have figured largely in his life thus far. He did not take part in sport simply for enjoyment; he canoed at the international level. He then ran the Boston Marathon for which it is difficult to qualify.

John was fired from his first teaching job for two reasons. The first was that he didn’t speak French. He asked a French student in his class to teach the French lessons. Understandably, when the inspector found out, “he flipped”. John broke another rule as well. He would hang all the students’ art works up on lines across the classroom. He said that “it wasn’t because I was radical or anything”. John thought that by only putting up the best, “you are sidelining so many people and I thought everyone deserves to show what they can do and if they compare it to others and they themselves say ‘look, I could do better’, they

would learn more than if I just put up the best”. Since John was only supposed to put up the best art, he “got fired for that too”.

I think that this shows John was ahead of his time. Most teachers would probably have simply transmitted information to the students, but John helped the students to learn from each other.

John then began teaching at a private boys school. The school became co-ed a few years before his accident. At the school, there was a link between his teaching life and his sporting past because at the school “athletics were a very important part of schooling, so....the running definitely was something that I could do, because I ran with the boys”, which he felt developed more closeness between him and his students. He taught science and outdoor education. John believes that he was a good teacher in part because he had been selfish, a characteristic that helped him while he was canoeing. He told me that “you realize what motivates kids and a lot of that is a type of selfishness....you sometimes have to use that to get them to work harder”.

We talked about John’s outdoor education trips and the value he finds in that form of learning.

When reflecting back on when you are in the outdoors, you are not in the same teaching environment as you are in, say, in a schoolroom situation. First of all, there has to be a lot of pre-trip work as to what we expect from them, how they should be prepared as far as cooking outdoors, clothing, depending on whether it is winter or spring or fall so it is a different situation. And you get instant learning with outdoor education because if they don’t do what you recommend, they are going to feel the effects immediately. If they get wet, they know they are going to feel cold.....

John told me about the parallel he has noticed between outdoor education and recovery. He explained that “in outdoor ed, there is a consequence, if you do things right, there is a

consequence, a good one. If you do things wrong, it ain't so good. And also, with your recovery, if you do things right, there is a consequence; you learn how to do something".

John felt that Outdoor Education, like recovery, gives lots of opportunity for real life learning.

It wasn't in a classroom situation, we did the pre-tripping in a room or something but it wasn't a classroom. And so we would give out material, tell them to read it andyes you have to re-teach out there. But this is the same situation like in a teaching situation, you present material, you hope that they learn it, then you give them tests in time and in outdoor ed, you pre-teach them and then [they experience] reality, something is happening and it's different than regular learning.

Part of the reality that John exposed his students to was the preparation work for the trips.

They began with planning.

We had all kinds of equipment, we had cooking equipment and axes, saws and things like that and they would, we would all get together, the group that was going to go and we would go over what food we wanted to takewe would go and buy our own stuff and we....., that was a little more difficult because we would have to arrange [it so that] there would be time off school to go and get things....

John's students told him what they thought they needed: "We certainly had some things that were a must.... they couldn't say we want steak or something like that, but we would have a list of things and then they would choose from a list of what they thought they would like to take along". John let them organise and plan, but at a certain point he would "bring them back to reality and say do you think we might need matches?"

John next explained what happened on a trip, recounting that:

....at the place [we went] there were sort of lean-tos, open lean-tos where they were closed on 3 sides and a floor and then a large open fire-pit on the front and we would divide into 3 groups. One was responsible when we got there to put up tents and to get everyone's bedding inside in case it rained and then it wouldn't get wet. There was another group that was in charge of cooking and there was another group in charge of clean-up. So you found that it was just like life, you had to work

together..... Then we would change the next meal, so this way everybody got an experience at each group of things.

John's teaching style encouraged collaboration by having the students work in groups to accomplish tasks.

John seemed proud of the fact that his outdoor education classes were “related to life and reality [because] someday you might find yourself in a situation where you [just] have to exist. It may be accidental, it may be planned, but it is certainly something that can [happen]”. When John goes back to the school at which he last taught for alumni meetings, he is sometimes approached by men who say to him “Sir, remember when we were out at twenty-five below zero....”.

A Survivor of Traumatic Brain Injury

In August of 1988, John was working on a cottage that he had started building after he left his wife. He fell down the hole where the stairwell was going to go down into the basement. Luckily, someone was working with him at the time and called an ambulance. John was taken to a large hospital. He was unconscious for eighteen days after which he was moved to another hospital and then to a rehabilitation hospital. There, he recounted that they gave him

physiotherapy, speech because I seemed to have to learn to speak again and certain things like thatthey got me talking again and walking and I finally left there, I was able to get around with a cane which had legs on it and I periodically go back for any review of therapy and things like that, but other than that I haven't been in a hospital since.

John still lives with some reminders of his injury. He has a tight feeling in his legs, walks with some difficulty, and writes awkwardly. Before the accident, he was right-handed,

but that hand is now gnarled and twisted because his fingers were never set. During the time that he was unconscious, “they didn’t repair them so by the time they found out they were broken, they had already set so I had to change to my left hand so it was utter slavery”. He now writes with some difficulty with his left hand.

I asked John if he ever felt stigmatized. He has felt pity in the past, but he told me that most “people ...usually don’t divulge if you have changes. I hope that any changes are for the better but I don’t know”. A less obvious leftover from John’s sporting days is that his life as an elite athlete supplied him with a striking contrast to his uncertainty of what people thought of him after the accident. John is sure that his Olympic experience is the element responsible for the respect that people still accord him. He believes that this is because “I achieved a certain goal; I had gone to the Olympics. You still get people that say, you went to the Olympics, so it definitely does give you a different stature”.

The Dark Side - Depression

When he was first released from hospital, John believes that he suffered from severe depression for about a month. He told me that while he was in the hospital, “there was always someone there and you are always going to therapy or doing this, doing that, it is when you are alone that you can get into depression”. That is exactly what happened to John. When he left the hospital, John’s time was his own to fill, so he became very depressed. This period was a turning point for him.

My eyes were crossed, I had speech slur, you suddenly are almost starting over again. So you have to draw on what you still remember and zero in and say I’m going to do this but as I said before that happened, I got very discouraged. I am sure I even thought of ending my life, you know, you get so depressed.

John thinks that when he came out of the depression, “everything started to make a little more sense”. To overcome the depression, he described that “finally I just took myself and I shook myself and I said look, you cannot do the things you used to, accept yourself the way you are and try and improve. After I had done that, things started to happen”.

I think that the depression felt by John is relatively common occurrence after such a life-changing event. You eventually come to the realisation that life will not be the same, no matter how well equipped you are and how much therapy you have undergone. It is understandably very difficult to adjust to new identities that have been imposed by an accident.

When he felt able to continue with life, John explained to me that “I felt a focus, I felt that I could make certain achievements. I suppose I even thought I’d run again, but you know, reality has come to that too. So you go through and again you are drawing on things that you learned in sports”. Only the best are able to climb the steep ladder to reach the top in sport because it requires determination, tenacity, doggedness, and it is always a struggle to succeed. Because these characteristics were already a part of him, John was able to use them to help him after his accident. He explained to me that “my epiphany was shaking myself and saying, look accept yourself and do as much as you can, don’t look at what you used to do”. He told me that “the accident changed my life of course”. But it also helped him because he suddenly realised

....that you don’t necessarily have to do the things you used to, you can adapt to change and you can adapt to pushing aside things that you thought were the most important things in the world and you can substitute and you have to persevere a bit but after you persevere and it’s happening, then you realize that the perseverance was worthwhile.

This epiphany in John's recovery made it possible for him to learn again.

John's realisation of his changed abilities reminds me of Jim Kyte's 10-90 rule. Jim realised that he could not force the healing process to proceed as quickly as he wanted it to. Jim's 10-90 rule is a similar manner of relating to change as John's realisation of the importance of adaptation. Realising that change can't be forced was an epiphany for Jim. 90 percent of what happens is not under your control, so, as John remarked, you have to adapt to change.

A Learner

After hearing John's stories of his teaching experiences, in particular the outdoor education trips that he made with his students, I was curious to hear how he understood learning. John used his accident and the learning that he undertook after it as an example to illustrate his ideas of learning. John described the parallels he observes between how he perceived himself after his accident and childhood.

Suddenly you cannot do all the things that you used to do. And suddenly you think back in a way I am like a child that we always say do your best and there is always going to be people that can do certain things and others can't and suddenly you are, you are suddenly down with everyone else, you suddenly have to realize that you are in the position that many children are as they grow up, they have to realize that they can't all be doctors, that they can't all be engineers, that there have to be a range of people in our existence. So you suddenly have been demoted from what you could do into a different world.....

John feels that learning has to have meaning. For him, his accident was the reason he was learning.

You had to know where you were going with that learning. You just couldn't start to assimilate facts... you had to have a reason to try and certainly the reason I had was to re-learn things that I couldn't do anymore that had been damaged.... I guess I looked back on teaching students and [I was] thinking I'm back to basics again, I've got to practice.....I knew how to assimilate knowledge, at least that didn't disappear,

and so I dedicated myself to re-learning things that I had trouble with after my accident.

When John was depressed, he also felt discouraged when he became aware that after a serious accident “you first of all realize you can’t do the things that you used to be able to do and even learning to walk again, you have to go through, you suddenly realize that your limbs don’t function the way they used to”. He knew that when recovering from such a serious injury “you know you have to try and you may fail but when you get success, you pat yourself on the back, you really do”. He compared his recovery to outdoor education classes, telling me:

In outdoor ed, there is a consequence, if you do things right, there is a consequence, a good one. If you do things wrong, it ain’t so good. And also, with your recovery, if you do things right, there is a consequence, you learn how to do something. For examplewalking along the walls.....you use as many crutches as you can and the wall is a crutch but at least it teaches you to try and get your balance and to, like I leave my cane back there and if I do feel a loss of balance, then I do reach for something or I fall..... it’s very similar to teaching.

John seems to have been able to transfer his thoughts and methods of teaching to his recovery. Regardless of whether one is recovering from injury or not, John feels that learning is continuous in life, that people learn all the time, without even realizing it.

A Father

John has three sons who all live in Ottawa and whom he sees regularly. His eldest son is a photographer who “is all over the world. He is very dedicated to his work”. The next son is a lawyer with two sons, and his youngest teaches outdoor education at the same school as John did. John’s youngest son has three children, two girls and a boy. John said his

son “has been recycled” because he is doing the same thing that John had done. John told me that he admires his sons

..... in their own ways, like my eldest son is a photographer and he is very dedicated to his work and goes to extremes in many ways and...[he often puts himself in] danger.....And I admire my lawyer son, I think he is very dedicated to his profession and he is an honest lawyer and my son who is a teacher, again I admire him in the way he is approaching life

His family were very supportive and helpful during his recovery from the accident. John said that “they visited often which was great..... I was still learning to walk better and so they would take me for walks and things like that, so they were supportive in every way. If I needed groceries, they would get them for me”. He still spends a lot of time with them now and mentioned that “the lawyer one, he and his wife and one of their boys were swimming with me yesterday downstairs. I see them quite often”. John took a picture of his youngest son’s family. John asked them to pose for him on the lawn



All of the athletes participating in this study have terrific family support. Terry Evanshen's wife and daughters helped him to find out who he is now after his accident, Dave Irwin's partner Lynne Harrison took charge of his rehabilitation, and Jim Kyte's wife persisted during his recovery time, when Jim himself admitted he had not been very nice to be around.

John was close to his parents. I found it fascinating and appropriate that when he took a photo of a photo of his parents, his image is reflected in the glass as it is in the photo of his canoeing awards:



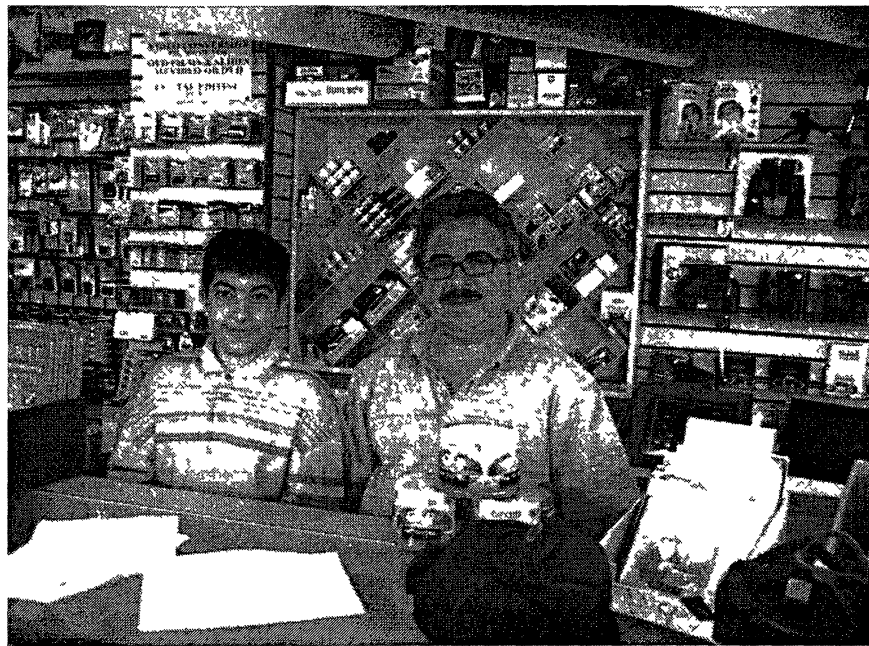
John took the photo of his parents because, he thoughtfully said:

.....they have been the inspiration to me, they were both alive when I had my accident and they certainly helped me a lot, my Dad was an engineer and he was also a pianist and so he gave me exposure to classical music very early which has spilled over into the CDs that I like and I did try piano when I was able to, but never approached his skill and my Mom, who.... near the end of her life..... came to live here in another apartment and she lived to 98, she just died about 6 years ago now, but she taught me in the kitchen, if you use something and you don't need to use it again, put it away. She had the most neat kitchen

A Friend

John spends a lot of time with his family and with his ex-wife and so considers them friends. He mentioned a few other friends, one being a lady who used to be in his apartment building and is now in a retirement home. He visits her regularly. During the winter, when he is not with his family at their cottage, he plays bridge in the building's games room

One of the pictures he took was of the owner of a local camera store, an Iranian who left his country, and his son John told me that he “has been an inspiration to me and also his son....who is still in public school but he's a sharp little guy”.



I thought Jim's choice of friends was interesting. He picked a person that he admired, rather than a friend that he did things with. I want to know why the camera store owner was an inspiration, and why he was impressed with his son. I did not delve more deeply into the reasons for these choices

A Day in the Life of John Beedell

When John was released from the hospital, he got an apartment in the building in which he still lives. His picture of his living room reflects the life of an active, interesting, and interested man. In the foreground you can see the table and chair that he set up for me to use.



John took a picture of the balcony of his apartment from which he has a magnificent view of the city:



The balcony is packed full of plants and there are also racks on which he hangs his laundry to dry. He took the photo because it shows “I have always had a bit of a green thumb and so it is my way of having greenery around and that tree at the end, I bring in during the winter”. His laundry also appears in the photo; when talking to me about this photo, John mischievously smiled and told me that “you’re not supposed to [hang laundry out], but I don’t hang it over the edge....”.

John’s day begins with a swim: “the swimming pool is about a 75 foot pool.....I guess so I swim a couple of lengths, do some exercises and then swim again....I do that for half an hour”:



After swimming, he eats the same breakfast every day, consisting of “porridge, toast, an egg, and one cup of coffee”. If it’s a nice day, he then goes for a bike ride.

When I bike ride, it is out to Mooney’s Bay, it is probably 10 or 15 km I suppose and I often call in at the Rideau Canoe Club and see if I can be of any assistance there. I go out there if they have races, like dragon boat races, I help them judge, do things like that but I am not participating in the active competitive canoeing anymore.....I can’t do it but at least I can see it”.

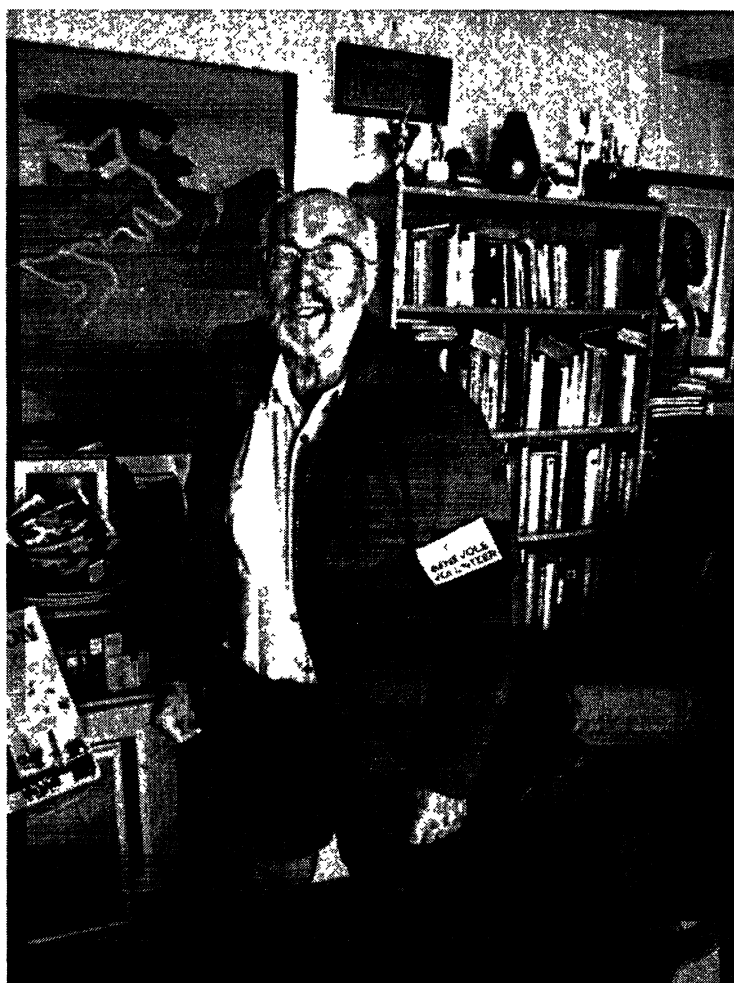
John may go to a movie at the Bytowne Cinema when he gets back from his bike ride. When the Ottawa Chamber Music Festival was on, he pedalled madly from one venue to the next, catching eighty-one concerts in two weeks! He attends the Ottawa Symphony concerts at the National Arts Centre. Before his hand was crippled in the accident, he played piano. He loves music and has a large collection. He proudly told me that he had thirty-five feet of CDs and took a picture of some of them:



John's daily routine reminds me of the disciplined days that athletes lead. When he canoed, his days were long: training, working for Inco, then training some more. It seems to me that the regimented time schedule he kept then has continued. His days were full then, and he has a daily routine now; he does not seem to have spare time.

Traveling is now part of John's life. He shared pictures of himself in a number of countries: in Iceland, Antarctica, Norway, British Guyana, New Zealand (his mother, age 80 at the time, took him to see where he was born), England, and Rome (he re-visited this city, where he had participated in the Olympics, a couple of times). In April of 2009 he is joining a trip lasting two and a half weeks that will take him to Senegal, the Canary Islands, Cape Vincent Island, Gibraltar, and Spain.

John volunteers during a local ski marathon and had me take a picture of him wearing his official jacket:



Reflections on Life Now

I referred to John's stories again and again as I tried to understand his reflections about his injury, his life, and his athletic past. John does think of himself as disabled, particularly after watching the Olympics on TV,

.....because of what I was able to do when I was not disabled. You can still live that life. Like I have been watching the Olympics over the last 2 weeks and you definitely think often I was there so you reach a different plane.....I can still look back.... I look up at that picture right behind you there, that was one of my egocentric things, I took all of my medals and things like that and I put them all together.....

Leftovers From Elite Sport

John appreciates the legacy that sport has left him with, and believes that "sports are a good preview to life". He recognises that sport "gives you a purpose and gives people a purpose to work together, play together, to focus on a very real thing that is enjoyable to do. And so I appreciate sports from that aspect and let's see I guess I'm the same in loving animals". Pets have been an important part of John's life in the past; he finds that dogs help one to learn how to approach others.

Most dogs love people and they love you because you are kind to them animals teach you a mode of approaching people in general. We sometimes are so prejudiced in colour, race, all kinds of things.....a dog approaches people with a clear conscience and they accept you if you are kind to them....

I next wondered whether he felt that his sports background had been a sort of 'training ground' for the recovery he had undergone. John said that it had. He elaborated, telling me that

....certainly in athletics, if you want to excel, you train, you have a focus, you know where you are going, you know how much time you have to put in training and things like that. I think that after my injury I used some of those concepts.....you know your speech is slurred, that you are going to have to work on it and train it again so, yes.... I certainly did bring them into the recovery from my injury.

I think that all the athletes I have talked to have recovered to the extent that they have because of the disciplined hard working life that they have carried over from their sporting pasts. They have all reached back to their lives in sport for these skills.

I then asked him for a specific example. He told me that when he was re-learning walking,

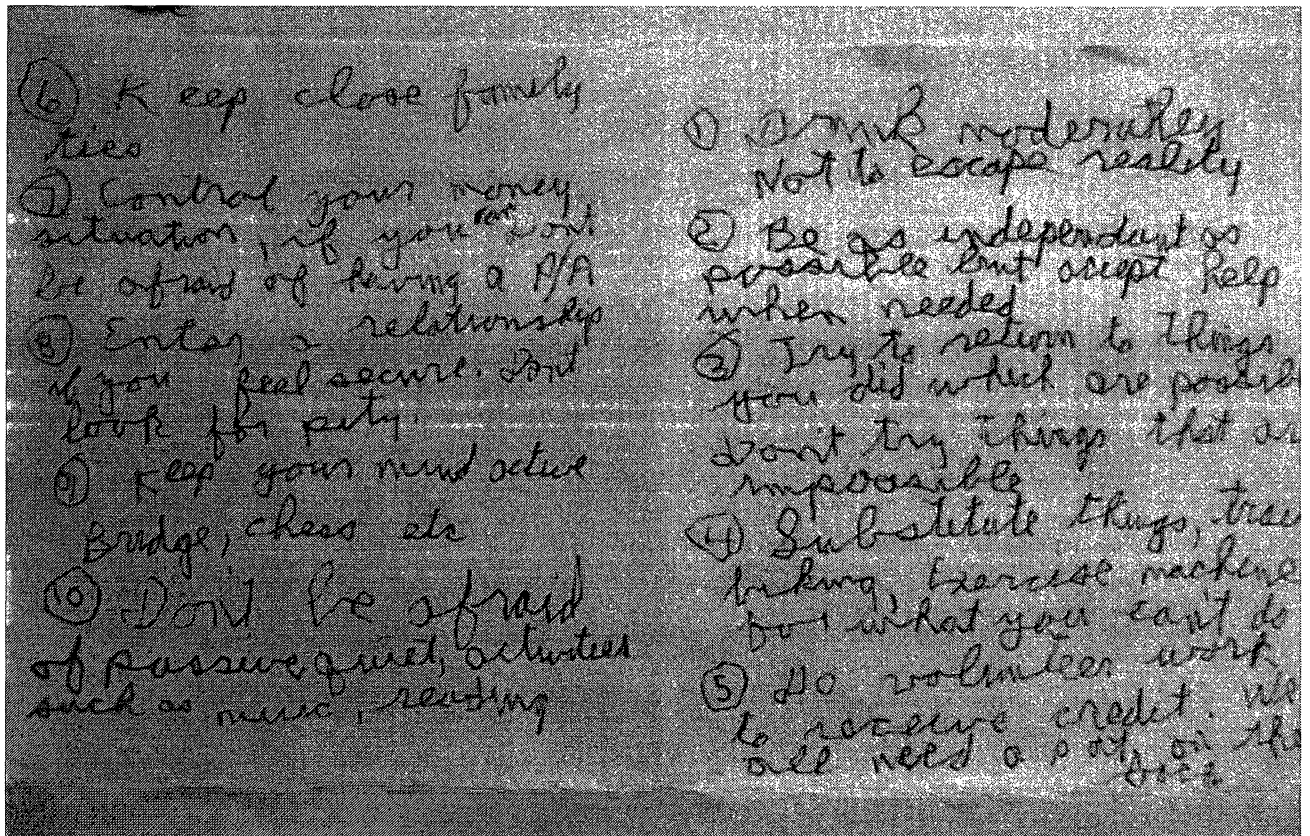
I wanted to give up the cane completely... I haven't of course, but you train yourself, you say, okay walk....balance as far as you can and you do it until you have to reach for a wall or something.....when you are athletically training, you always, time is the element there and you try and improve your time. In the same way you try and improve your distance you can walk after your injury, so.... they are the same concepts.

Striving to be the best at canoeing was a challenge; John later challenged himself by running marathons. He continues to challenge himself, now with lengthy bike trips, such as one he took recently when he biked fifty kilometres out to Cumberland to see a farm he used to own.

The List

When I arrived to talk to John on the third day, he said that “I woke up in the middle of the night and I got thinking of what we have been talking about and I got up and I wrote down about a number of rules I thought for athletes who have had brain damage, skull fracture or something and I listed them”.

I was touched that he had taken the time to write out his thoughts given his great difficulty writing. He had obviously thought them through; I don't think he had had an opportunity to discuss them with someone. I believe that, as he told me about each point, he was deriving new meaning and learning about himself in a new way that was revealing lots of new meanings to him.



He discussed each of these points in more detail with me. He shared what he had written out loud and, as he did so, he elaborated on each point.

The first one I thought of was drink, if you must drink, drink moderately, not to escape reality.....Just because I think many people escape through alcohol and it's, I know, I hope I have no problem myself. I drink a bit, but moderately and I know that it's easy to escape reality by drinking, that's why I thought about that.

[2.] Now, be as independent as possible but accept help when needed. That is just a general thought.

[3.] Try to return to things you did before which are possible but don't try to do things that are impossible.

[4.] Substitute things, travel, biking, exercise machines, for what you can't do..... I substitute with my biking and my swimming.

[5.] Do volunteer work to receive credit. We all need a pat on the back. While we were athletes, we got medals and things like this, and pats on the back.

[6.] Keep close family ties. If you isolate yourself and you don't continue your relationship with family, it can be disastrous.

[7.] Control your money situation if you can. Don't be afraid of having a PA [power of attorney]

[8] Enter a relationship if you feel secure, don't look for pity.

[9] Keep your mind active with such things as bridge, anything that keeps you thinking.

[10] Don't be afraid of passive, quiet activities such as music and reading, which I have.

.....So those are my thoughts in the middle of the night.

Who John Has Become

John became depressed when he realised that he was disabled and couldn't "do the things [he] used to do". When he overcame his depression and was able to live with the changes in his life, he saw himself as a different person, an improvement over how he was prior to his accident.

I know I was a better person after because I suddenly realized that you can't do all the things that you used to doI suddenly realized that here I was a handicapped person and that so I could appreciate their level of ability of whatever they could do. Before I did not appreciate what handicapped, sorry, disabled, people can do.

He knows that he now approaches other disabled people with more understanding: "I can't remember how I treated disabled people before my accident. I hope I was kind but I wasn't exposed to them that much but I know now that I am disabled that I do approach them in a different way than I used to". He is now "more appreciative of people [in general] for just what they are and not what I expect they can do".

John confided in me that: “You always sort of wish that you hadn’t had the accident, but I accept it now”. His characteristics have also changed since his accident, he thinks for the better.

I hope I am kinder, more open to understanding people. I suppose we always think we are good, I hope I am good, so I guess the basic thing is I don’t know for sure, I really don’t know how I can describe myself. I just hope that I am what I think people are, if they are kind to me, I hope I am kind to them.

When I questioned John on his use of ‘hope’, he said that he was indeed kind to others.

What were the factors that he thinks helped him to evolve into the person he is now?

First of all, the accident. Then I think the depression that set in and [then] the relief from that tension, by saying look, accept yourself the way you are and work from that mode not from that you think you can do everything again. There was a time you [think]oh good, I am getting back to where I was but you never do.... I guess just the fact that I got into, into volunteer work and things like that and I found I got a great deal of satisfaction for all of these things which I had never thought of before and so I continued and that has brought me back to the person I am now.

When John realised that he could no longer do the things that he used to be able to do, he felt released and able to evolve into the person he is now. He added that “hurry has gone out of my life, which is really nice”.

Does John mourn the loss of the person he used to be? The only part of himself that he really misses is that he is not able to do as many sports as he once did. Other than that, he said “I don’t miss me [from] before”.

John has established a life that is enviable. He rides his BMW to all sorts of events around town. I believe that he sees more and does more than many people his age who have not had a head injury.

Closing Thoughts

John shared with me that he had enjoyed the whole interview process. He found it therapeutic to talk to me, “happy that it was happening”. He told me that he was “finding that it is very interesting to meet you and to sort of look back on my life since I’ve had my accident and how I’ve shaped it and tried to give some direction to it”. He commented that the conversations we had had “showed me what I rely on to make my life complete now and I can rely on the bike to get around and I rely on the pool for exercise, I rely on the people I associate with to have a circle of more acquaintances”. John enjoyed the picture taking process.

It made me recall or try and recall all of the things that had made an impression on me and had directed me since my accident. And certainly the pool, the bike, these things are part of my life now and music and books and so, yes it was very good to zero in on them.

I pondered what my impressions were after talking with him for four sessions, and then commented to him that “you are very busy and you are very optimistic and you do a lot and they all contribute to John Beedell as he is now”. John Beedell did not just survive his accident, but he is now thriving after his accident.

Reflections

When I first arrived at John Beedell's apartment, I felt anxious and unsettled in the formal setting he had arranged. I wondered whether the formality would compromise the casual nature of the conversations I hoped to have, but this turned out not to be the case. In the end, time I spent with John was comfortable and relaxed. I was left with a wonderful impression of John and the life he had lived as he entertained me with detailed stories full of description about his younger days, his time in recovery, and his current life.

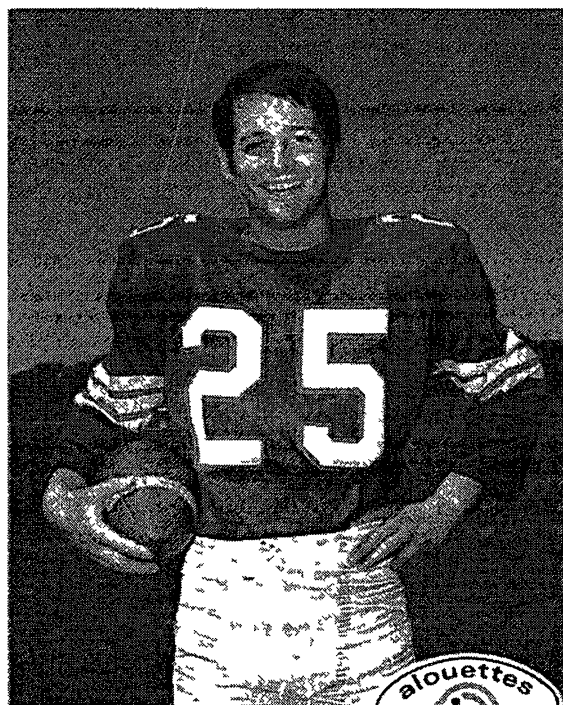
It was interesting to me that despite the 'proper' setting, I felt more at ease while spending time with John than I did with the other participants. I was comfortable with Dave Irwin, but this was more due to his partner Lynne's graciousness than to Dave's demeanor. I was at ease with the Evanshens, but I think Terry's memory limitations, and his performances of the perfect Terry, prevented him from talking freely and openly even though he told me that his life was 'an open book'. The formal nature of the conversations with Jim Kyte was to a large extent due to the setting, the office setting 'draping' its formality over the conversations.

I found it fascinating that, despite his superficial description of identity, deep down John had a more insightful notion of its meaning. It was easier for him to write his thoughts down, so he did. I don't think that when he constructed his list he associated the points he made on it with his 'I' identity. In his words, the list was composed of his thoughts 'in the middle of the night'. The list gave me a glimpse of his feelings and beliefs.

I thought about my own experiences after talking to John. I also find it much easier to write things down, and I find lists develop all on their own in the middle of the night. What part of our memory enables us to retrieve these lists? Why do I find it easier, at all times of the day, to write rather than speak? Some of this is memory

related. But, I also think that, regardless of whether one has memory deficits or not, writing helps organization, allowing one to rearrange thoughts and feelings as they are committed to paper. I believe that the word 'committed' has taken on a new meaning in the age of computers. Writing floats while it is being crafted, molded, and shaped on a computer. It then sinks into a disk where it can be stored in many ways, under different names. A written artifact then magically rises to the surface when summonsed. A hand written note, as John's was, is less permanent. It can be torn up, misplaced, or crumbled. Is this why I photocopied John's note several times? I thought for a long time, and finally realised that John's list was his 'I' self.

Terry Evanshen



Terry
EVANSHEN
Montreal Alouettes • Flanker

Terrence Anthony Evanshen was born on June the 13th, 1944 in Montreal. After high school where he played as a wide receiver, he won a football scholarship to Utah State University. As a star receiver in the Canadian Football League he played for fourteen seasons, from 1965 to 1978 With a record of ninety-two touchdowns, he caught 600 passes, fumbling the ball only three times. Terry was on the Montreal Alouette Grey Cup winning team in 1970 and was an all star seven times. He was inducted into the Football Hall of Fame in 1984 (W-Five, 2001; Argonauts Hall of Famers, n.d.). Terry sustained a severe Traumatic Brain Injury in a car accident in 1988.

The following story was constructed from transcripts, participant observation, and field notes taken during my conversations with Terry and Lorraine Evanshen February 20 – 23, 2008.

Recruitment

I was nervous calling the Evanshens the first time. My heart beating faster than it should, I heard the phone picked up on the second ring. Lorraine, whose voice sounded efficient and organized, was friendly and interested as I chatted with her about my research. After telling me that she thought that she and Terry would like to take part, she added: “but you have to talk to Terry first”. Terry was not in, so we arranged that I would call back at 8:30 the following morning. I did so, and I was taken aback when Terry answered the phone. I had no idea how the memory issues he was left with would enable him to remember our conversation. June Callwood’s (2000) book about Terry’s experiences, *The Man Who Lost Himself*, had prepared me for a man who thought only in the present.

When I heard Lorraine prompting Terry in the background I felt reassured because I then knew that she was listening to Terry’s side of our conversation. Terry talked to me about his involvement as a participant and asked me some questions. I believe that he had prepared ahead of time when he knew I would be calling today. Terry told me that he and Lorraine had discussed their participation, and that they had agreed to take part because they felt that the study would benefit all survivors of head injury. Lorraine then took the phone to probe a little further into what their time commitment would be and then suggested a series of days about three weeks away. She told me that either Saturday or Sunday every week

were ‘family’ days: the Evanshens made sure that on one of the weekend days they made no other commitments.

The day I met Terry and Lorraine, I had driven from Ottawa to their home near Toronto. The roads were clear and dry for February and the weather was sunny with a clear forecast for the week. I was able to think about the interview process. Although my head was already crammed with questions that I wanted to ask both of them, I added a few new ones to my repertoire during the boring, solitary four hour drive. When I got closer, I was thankful for the detailed directions Lorraine had given to me over the phone. I turned right off the paved highway onto their gravel road as she had directed me to do, and I saw the farmhouse ahead of me on the left. It was an old, carefully restored stone house, sitting on a small hill and overlooking rolling fields.

Terry and Lorraine were available for four consecutive days, not the five I had planned. Because it was qualitative research I had anticipated that the study would be emergent, and it already was. I realized then that I had to be prepared to be flexible so that I could accommodate each of the participant’s needs and schedules. Terry and Lorraine were being flexible too and generous with their time; they spent a couple of hours in the morning of each of these four days talking to me about their experiences.

I drove a short distance along a neatly shovelled driveway, parked the car next to a Jeep, and walked towards the house. I knocked on the door that appeared to be the most used: rubber boots were lined up in the doorway. Terry opened the door immediately. He was impeccably dressed in tidy gym clothes consisting of perfectly fitting track pants and an

exercise jacket which fit as if it had been made for him. The image projected by Terry's manner of dress was complemented by his flawless grooming. His hair was combed perfectly, not a hair was out of place, and his face was beautifully tanned.

I later learned two things about Terry from Lorraine: that Terry was always perfectly turned out, and that he had lots of clothes to choose from, but he always dressed in either one of two outfits. He looked about 50 years old: one of the first things I asked him was how old he was. He told me 63. I was amazed.

Lorraine was at the kitchen sink; she washed her hands and came to meet me. I was immediately impressed by the powerful and authoritative aura that surrounded her. At less than five feet, she is a dynamo. At the same time, she comes across as understanding and compassionate. Terry obviously loves Lorraine very much and he is openly appreciative of the support she has given him, telling me at one point that "Thank goodness that we knew each other from the very beginning when we were kids, [otherwise] it would have been very, very trying [for Lorraine], I can see that right now".

The First Day

Lorraine first led me into the living room. I looked at the formal space consisting of two sofas separated by ten feet of carpet, and I then asked her if we could use a room with a table between us for the recording equipment. She suggested the dining room. I knew that it would be the better choice because its arrangement meant that we could easily engage in what I hoped would be informal conversation facing each other in close proximity. I could put the recorder on the table. All the same, I would have preferred a setting with a less

formal atmosphere. But we made the dining room work. Each day, we sat around the table, Lorraine first offering me a coffee before we got underway.

As I looked around the house while being shown it by its proud owners, my main objective was to find a room with a casual seating arrangement and a relaxed, open atmosphere. In such an atmosphere I would feel at ease asking personal questions to elicit stories, and I hoped that Terry and Lorraine would feel open and feel like sharing their stories. I knew that finding the right space was even more important from the participants' perspectives. At this stage, however, why would Terry and Lorraine know that?

A few years ago, I read June Callwood's (2000) book about Terry and Lorraine's experiences, *The Man Who Lost Himself*. An inexhaustible social activist, June Callwood has written several books (see Callwood, 1986, 1988, 1995) on topics about which she felt passionate. My story takes place in Terry's life now, and probes in different directions than does Callwood's book. I am grateful to her for introducing me to Terry through her book and for providing such a well researched, caring, and heartfelt glimpse into his recovery. Terry was interested to know why I had picked up June's book.

Terry was the first participant in the study, so the time I spent with the Evanshens was the first opportunity I had to don my researcher hat. The first day, I was unsure of my tape recording equipment, so to reassure myself I checked it constantly to make sure it was working. I was very 'on edge'. I am sure that my nervousness was apparent to Terry and Lorraine, but they really outdid themselves so that I would feel at ease. Each day, they were ready and waiting for me when I knocked on the kitchen door. I think my ingrained punctuality pleased them. The dining room table was set up for what closely resembled 'a meeting'. I found the seating arrangement

was perfect from the point of view of being close together and being able to lean on the table casually. For me however, the setting was never casual enough. I felt very much in the role of the researcher, unable to discard the researcher hat. I wanted Terry to sit back in an armchair and throw his feet over the armrest, but in retrospect, I don't think his performance would script such an action even if it was just his own family in the room. I doubt that Terry ever let himself leave the perfect exterior behind that he presented to everyone. Terry was showing to me and performing for me the perfect self that was the only self that he knew. The dining room, somewhat too formal a setting for our conversations, and the conversations themselves, mirrored the immaculate, perfectly presented Terry.

I remembered that, at the time I read Callwood's (2000) book, I was just emerging from what I now know is a typical phase of head injury rehabilitation: you don't want to have anything to do with anyone who has sustained a head injury. You want to identify with people who are healthy and who project what appears to you to be a healthy self. I think that I cautiously purchased and subsequently read the book to learn more about head injury and how such an injury had impacted another individual.

When I was reading the book, it didn't occur to me that because Terry had been an elite athlete his story would particularly resonate with me. I reflected on my position both as the researcher and as a fellow survivor of head injury.

In order to get to know the Evanshens before delving too deeply into their lives, I began by asking Terry how he felt about sharing his story with me. He told me what I already knew: that each person who was injured would respond to his or her injury differently and also that there was an infinite number of ways that the brain could be injured. Then, referring to his own story, he noted that if "I feel that you want to do something good

and will do something good, then of course I would fully cooperate and my life is an open book so talking about it is okay with me”. He often relies on his instincts and ‘how his heart feels’. He told me “If I don’t feel that you are sincere with your questions, I may not answer them. I can’t tell you, I go by how my heart feels and then I just go with that.”

Each day as I was driving home, I believed that Terry’s heart had felt good that day. He always seemed to me to give a lot of thought to his responses to my questions, even though he told me afterwards that he never knew what he would say before he said it.

Terry was the one who broke the ice. First off, he told me how much he felt that this study was needed, and he complimented me for taking it on. Even though he had never met me, he said he felt the “greatest respect for me” for doing the study.

As I listened to him, Terry’s comments about the study and its importance felt incredibly affirming to me. I had been feeling insecure as I embarked on what I saw as a huge undertaking. Would I be able to do it? How would the research process impact me as a fellow survivor of head injury? I immediately felt that I understood Terry, his motivation, and his drive. I wondered whether I would understand the other former athletes in the same way. I believe that Terry sensed a kindred spirit and that, although he was already very willing to be in the study, his desire to help me by participating became even stronger.

The conversation began as I had planned it. Initially, I directed a lot of my energy towards making sure that Terry felt comfortable. To do this, I asked him to tell me a story that described how he retained some of his characteristics from football. What emerged from

this story was how committed he had been to the sport. As a football player, it had been crucial to him to be the best, and he believes that same commitment has been a vital part of his recovery since his accident. I found his story interesting because it revealed that, while he was playing, he had continued to work hard to be the best at football in spite of the recognition of others that he was incredibly talented. Terry feels that this talent allowed him to perform extraordinarily every time he played.

While telling me this, Terry leaned even more forward in his chair to emphasize what he was saying. During his performance of his self at that moment, his eyes never left my face and his voice was strong and very clear.

Terry was always aware that talent on its own was not enough, and he emphasized the hard work that made it possible for him to use this talent:

... I know that what my body did in my first life was very unusual, I did things that nobody did before. And so therefore I was at a level of performance... very few people ever got there and how did I do that? I worked at it every single day.

I had read stories that speak of the hard work done by Terry in his former life as a football player, work I that I felt was indicative of his intrinsic motivation. I suggested that this same motivation that compelled Terry to work hard had allowed his brain to recover to the degree it had. Lorraine agreed with me, but she underlined motivation's negative aspects as well. She noted that with this level of motivation you are never going to allow "someone to say you can't do it, like with Terry sometimes I say to him okay you have worked today to exhaustion, okay, it's time to stop". Terry's answer is "But I'm not exhausted though". Lorraine then has to remind him "But your brain is exhausted".

Denial of exhaustion is a typical reaction for survivors of head injury before these individuals become self-aware, before they finally accept that one is more tired after such an injury and frequently must rest. This denial can become problematic, particularly when paired with motivation and drive. I was able to suggest to Terry that he was intrinsically motivated because I know what it's like – I too am intrinsically motivated. I know that this motivation was the underlying factor that enabled me to be successful in sport. Importantly, were I not so motivated, I don't think I would have recovered to the extent that I have. Throughout our conversations, I found both Terry and Lorraine not only to be full of their own thoughts, but also open and receptive to new ideas. I don't think they had considered Terry's intrinsic motivation an important influence during his incredibly successful climb back after his accident. I could easily imagine Terry not wanting to rest. I am the same way.

Comparing Notes

I always find it comforting , reassuring, and reaffirming to chat with another survivor of head injury. Many moments arise to 'compare notes' and to find common ground. I hope that Terry and Lorraine felt the same way because, in the end, it turned out that they spent more than six hours with me over the course of four days.

Comparing notes on head injury and rehabilitation was a tool that I thought would 'break the ice' between the Evanshens and me. I began by confiding in Terry that I did not do as well in conversations as I had previously. I told him that "I write, I love to write. But with the computer now what you write first doesn't look at all like the end product. And I need that time to figure out, where my thoughts are..... you can't think on your feet as fast".

Terry wholeheartedly agreed, commenting:

Without question, without question. That is one of the most difficult things to accept. I know I am having difficulty today. I'm trying to explain it to you, why don't you see this. In my head, I see it but you don't see it and I can't figure out why you don't see it.

Lorraine jumped in, saying that this was very frustrating for Terry not to be able to put his thoughts into words. But, she also finds that sometimes she also gets frustrated if she feels that Terry is taking a long time to say things.

I find it revealing that Lorraine brought up this point. When I was reviewing the taped conversations at the end of each day, what Terry had told me was longwinded. While we were sitting around the dining room table talking, his performance was very neat, tidy, and organized, both in the delivery of his conversation and also in his appearance. However, listening to the tapes later each day, I often had to listen several times to Terry's seemingly well-articulated thoughts.

Each time, I had to concentrate to understand the gist of what he was saying. In most instances, I decided that Terry had taken a long time to say what could have been said in just a sentence. For example, Terry explained to me what Lorraine meant when she said that he was in his own world:

For me to be in my own world it means that I am trying to do the best that I can do to be myself. To find myself, what kind of character am I developing? What am I showing? I am really not interested in your seeing me as a recluse, I am not arrogant, self-centred, yes I'm self-centred. You know why I'm self-centred, because I'm trying to follow the ABCs of whatever it may be. Doing the driveway, What are you doing that for? Because I've got the rhythm. Well okay, he's cuckoos. He's trying, okay, because I have a rhythm I get into it and I get it all done and I'm not tired. My brain is focusing on each - am I doing that right, am protecting my shoulders, watching my tennis elbows,.... I'm in my own world, I'm going to clean the driveway until it's clear...

I found this explanation unnecessarily long winded and complicated. I feel that it could have been condensed into a couple of sentences. However, at the time that Terry told me the story, he made it seem believable, logical, well-thought out, and organised.

That first day, at the end of our conversation, I showed Terry and Lorraine some photos of me competing with my horses so that they would have a point of reference and a mental picture of me competing when I talked about my first life. Terry showed me his humble side again when he told me that “I have the greatest respect knowing how difficult it is, how hard you have to practice, how in tune you have to be with your animal the both of you have to do it at the same time takes a tremendous amount of teamwork and I really, really appreciate that”. Terry seems so willing to credit others when he sees how hard they work. I greatly appreciate that he recognizes the difficulty of my sport. A prominent memory that I took away from my time with the Evanshans is Terry’s graciousness and his ease at helping others to feel good. He includes others in his conversations by letting them feel important and asking questions about what they have done.

I expected to meet a man who was as proud of his achievements as Terry appeared to be, but I didn’t expect to meet someone who was so quick to note and applaud the achievements of others. Terry immediately gave me credit for what I had done. I was delighted that he really seemed to be anxious and interested to hear my story. It was invaluable for my own self-esteem and confidence that someone who had been at the top of his sport was curious about what I had accomplished. Terry’s eye contact was always excellent, so when he looked me in the eye and told me that he wanted to hear my story, I really felt that he was sincere. I must add that not only was Terry generous with his compliments to me, but throughout the time I spent

with the Evanshens he did not hold back with his loving comments about Lorraine, at one point telling her in my presence: "thank you very much Lorraine for putting up with me and I'm not afraid to say that because it is the absolute truth".

While viewing photos taken of me riding my horses, Lorraine brought up another point. She wondered how I felt when I was in the company of people from my old world, confiding in me that she and Terry sometimes feel lonely when they are with athletes from Terry's past. She said that "one of the sad things, you know, he spent so long in the sport and gave so much but yet when he sits amongst them, you know, his colleagues and [former] friends and players that he can't really feel, you know, into it with them". She explained:

.....[his former colleagues] certainly are glad when they see him....[But] to sit down and have a full-out conversation like they would have years ago doesn't really happen. I think they kind of wait to see what he's going to say before they start in on what they are going to say.

I knew exactly what Lorraine was referring to, so I told them about my relations with the equestrian athletes I had known when I was riding before I was injured.

People competing at high levels in any sport don't have much to talk about except their sport, so when I had that connection, we would go out to dinner at the end of the day and.... but I didn't have anything else with those people. I have one very good friend from before my injury who is still my friend but most of them were horse people and I have nothing else to talk to them about. Nothing, nothing in common.

I told Terry and Lorraine at one point that I was very happy in my new life. It seems to me that I had been stripped of the blinkers I had been wearing as an equestrian athlete, and my whole field of vision had grown so that my life included many more things. I now was taking part in a wide range of activities and I had met so many new and interesting

people. Lorraine, surprisingly to me, agreed, saying that, during their old life

....we never stopped and it was ughhh.....[but] sometimes things happen for a reason. And I, I struggled with that for a long time but sometimes I sit down by myself and I say you know what, maybe this accident happened to Terry for a reason. Maybe it was God's way or whoever's way of showing him that he must slow down because it was just always work, work, work, work, work, work, work.

Before I drove away the first day, I gave Terry and Lorraine two articles I had written about my head injury experiences about one and a half years after I was hurt. They were happy to have been shown the pictures and they told me that they looked forward to reading the articles. I also gave Terry some homework: I lent him a digital camera, and I asked him to take pictures to describe his perception of his evolving identity now.

At the end of the day today, I realized how lucky I am that I am going to spend three more days talking to Terry. This is the first time that I have talked to another survivor who had been an elite athlete and was injured. I have already recognized in myself some the qualities that had brought Terry to highest echelons of sport: intrinsic motivation, a hunger and drive for excellence, and a tenacious reach for the top. I was amazed to see how we thought similarly about the time commitment, the all-encompassing lifestyle, and the single mindedness that sport at a higher level demands. Terry too seemed pleased to have the opportunity to 'compare notes' with me. I felt that this first conversation opened the door a bit wider and so helped Terry and Lorraine to feel comfortable. I had the chance to get a closer glimpse of Terry which helped me to create a story about our conversations that is a textured, many coloured, in-depth painting of his life.

Our Subsequent Conversations

When I arrived to talk to the Evanshens the next morning, both Terry and Lorraine came to meet me at the door, seemingly eager to get going and also curious about the direction of today's conversation.

I wondered what they had talked about after I left the day before. Did they rehash the day's conversation? How much of it, and for how long, did Terry remember it? Had they wondered out loud what today would bring?

We sat again at the dining room table, sipping coffee. I began by saying how interesting I found it that what had surfaced immediately on the first day was how isolated we both felt from our old familiar worlds. We were both coping with living in the new world of head injury in which we had unwillingly been immersed and would now reside in forever more. These feelings were the unwelcome and unfortunate outcomes from our injuries that were felt strongly, by not just Terry and me, but also by Lorraine. In our first life, we had both been living in the rarefied, exclusive closed environments of elite sport. Not to be able to maintain relationships with people from these environments was painful. This isolation had taken us all a long time to come to terms with.

I found that I had come away from the first day wanting to delve into how Terry and Lorraine managed to make their relationship work. Lorraine has been there for Terry since he was hurt. Now, she is used to how he is and knows how important his routine is to him. So, his routine suits both of them. Lorraine has time to do her own thing while he is at the gym in the morning. His routine includes helping Lorraine in the kitchen. It is a relief to her that he helps her so much with the day to day chores of living especially because she does

work part time at a hospital. Although I don't know Terry at all, I found him, at the level at which we were interacting, pleasant to talk to, if a bit rehearsed and distant. This all fit in with the immaculate physical 'presentation' of Terry Evanshen. It turned out that it was not rehearsed; according to Terry, he had no idea what was coming out of his mouth until he said it



Terry reading my articles

I was flattered when Terry told me that he had read the articles that I had given him and that he had highlighted several points that he wanted to discuss. Resonating the most with me were Terry's thoughts on what I had said in the second article, one I had written almost three years after the accident. In the article, I had said of my healing process "I think we are nearing the end". Terry picked up on that, pointing out to me that we will never be finished with the healing process. I agreed with him but I told him that, at that time, I was sure that I could still heal and be as good as new.

Memory

I have very slight memory issues, but I knew that Terry's are much more severe and are a factor both he and Lorraine have to be constantly aware of. So, it made sense for me to try to understand exactly how his memory was compromised. They confirmed what I had read in June Callwood's (2000) book, that Terry has no memories at all of his life prior to his accident and that he relies on others to tell him what it was like when he played football. Lorraine explained that "we would show him some [pictures] of himself as a ball player and stuff. And he looks and he says, oh I guess I wasn't that bad. But the memory of it, you know, it's just not there for him".

When I asked Terry to give me an example of how his memory works, he explained that he could remember that I had been there yesterday, sitting at the dining room table and talking with him and Lorraine. He could not, however, remember what the conversation had been about. Then, he leaned forward on the table, his blue eyes looked directly at me, and he told me that if I made a sweeping summary for him of what we had talked about, our conversation "would come back" in more detail. When he heard a brief outline of a conversation he had had the day before, Terry told me that he could then mentally paint a picture of what was talked about which would "allow him to get back in the rhythm". Lorraine commented that over a period of time Terry would forget that our conversations had ever taken place. Terry offered another example of his memory problems by telling me about his routine when he leaves the property. He makes himself answer a series of questions before he drives away: Where am I going? When do I have to be there? Why am I

going there? What do I need to do? How am I going there? He always makes sure he has written directions with him.

I was still having trouble understanding how Terry's memory worked and how he could carry on a conversation. Terry explained it to me again.

Somebody will say something that will trigger something in my head. And my doctor has taught me, if that happens just go with the flow, you are developing a new memory bank and so you allow your deeper character from your past to awaken.

When Terry is talking to someone new, he tries to turn the conversation so that it becomes what he describes as rhythmical.

You know a little bit about me, you'd have to talk to me about it and I'd pass it off like it's nothing and then I'd say, what about you, what do you do and then I'd turn the conversation to you and allow you to say and then I would get into a rhythm of talking to you. I'd talk about you, not me.

Learning about his memory deficits has been an important part of Terry's ongoing construction of his new, post TBI identity. Terry has had to learn how to take part in conversations with his compromised memory. By turning a conversation around, Terry has learned that he can let the other person lead the conversation and talk about themselves. He has learnt to compensate during conversations so that his memory deficits are less apparent.

I can't imagine living with Terry's deficits, although I can somewhat relate to some of them. I am frustrated by my memory. I repeat myself a lot. I tend to blame that on memory problems, but I honestly think that sometimes I am lazy and I could remember if I thought a bit more before opening my mouth and speaking. I wondered, as I drove to the Evanshen's house every day, what Terry had remembered of our conversation the day before. I know that I tend to interrupt when in conversation, but I also know that I do so because I don't want to forget a point that was just brought up and on which I want to comment. I have noticed

during our conversations that Terry listens well. His performance leaves the impression that he is focused and appears to be intently paying attention. He has not interrupted me, although Lorraine commented to me that he does usually do so.

If Terry has to leave an unfinished conversation, he will ask before he goes “would you please pick up the conversation when I come back because I’ll forget”. When Lorraine and Terry talked the evening after I had questioned Terry on how his memory works, Lorraine recounted to me that she had reminded him that

.....you can’t say you don’t remember anything, you know, because there are certain things that seem to flash back with [you], you know, maybe not clear as a bell but certain things that kind of flash back that we sometimes are surprised at.

Terry spends a couple of hours each morning reading the newspaper, time that he considers well spent because he gathers information that will come in handy when he is talking to people. He explained that reading the paper helps him expand his brain “so that when I am in front of people in a social gathering if a word clicks in, then I remember part of the story in the newspaper or an event and I can talk about it”. Lorraine thinks that “there must be a certain part of his brain.... that tends to retain information that he reads in the paper that seems important to him as a person”. She thinks that “he’s gotten better at remembering some of those things that he’s read”. Terry seems to have adjusted well to the limitations imposed by his memory, and he has learned how to cope so well that, to anyone who meets him casually, these limitations are not apparent. Terry knows that he “can’t go back and say remember last year, it’s not there, so I have to go with what I did today for tomorrow”. He talks about what he read in the paper that day, not about events in his past, not even about events in his recent past. He doesn’t retain those memories.

Terry does not remember anything emotional. He told me that “I remember cities, I remember teams, I remember companies, but any emotional contact within that company I don’t remember at all”. Lorraine commented that the loving man Terry once was is gone. For example, she told me that Terry has learnt how to hug, but she told me that “the hugs are what I call shallow hugs...And its not just with me, but it is with everybody, you know”. Terry’s loss of emotional capability also showed up in other ways. Lorraine finds that “he’s not really good if I start to cry about something, he’s not real good. He’d rather probably walk away or just what ever, no, he’s not really good about that”. She also described for me how Terry had “very, very, very little empathy toward anything and anybody after his accident. He cared about no one but himself”.

I applaud Lorraine for trying her best to understand Terry’s needs and weaknesses, and I admire her for accepting that he has to ‘act’ out being the warm, friendly person he used to be. Lorraine and her daughters Tracy and Tara find that Terry’s hugs are now devoid of any real feeling and emotion. He does however appear to make, and says that he makes, the effort to be the old Terry who was warm and emotionally connected. That Lorraine had stayed with him during the turmoil following the accident and then continued to be his most ardent supporter despite his emotional deficits continues to astound me.

What I found to be the most amazing example of Terry’s memory function, or lack thereof, was Lorraine’s description of Terry watching a football game.

This is where I say that things that are so....imbedded in that brain...., Terry still to this day can call a play before it happens, he can look at you, know the stats on the field before the ball is even snapped, he can say what’s gonna work, what’s not gonna work, he’s very, very sharp when it comes to a game. He follows it, he follows it to a tee, and it is amazing to me and like, we all look at each other and say

jesus he should be out there like coaching or something. He's so good at it. And yet the other smallest of things can be so fuzzy for him and hard to do, but the football it's there. It's there, it's there, that's it.

Wherever this knowledge resides in his brain, he is able to access it – and nothing else from his previous life - when he watches a football game on television.

I was amazed after listening to the story that Lorraine had told me about Terry watching a football game since his injury. I was fascinated to learn that, somehow, his incredible knowledge of the game survived his extreme memory loss. Why is this? Is it testimony to the years of his life that he had spent playing the game? Is it revealing of all his hard work? His skill level was so high, both naturally and because of his dedication and hard work. I wonder whether, if he had had another skill he practiced with the same devotion and talent as football, would he also have retained that knowledge? At the end of the discussion, when I felt that I had begun to understand Terry's memory deficits, I found myself thanking my lucky stars how fortunate I am to not be left with the severe memory impairments that Terry will live with forever.

Other Deficits

Lorraine told me that many of Terry's characteristics are still the same. During our conversation, she reminded Terry that "there are quite a few qualities of yours that you still have. For instance your motivation, you mention often that you have a passion for perfection and intolerance of failure". But there are also many factors that indicate how Terry has changed. Lorraine and Terry both recognize that Terry has severe deficits in addition to his memory problems. Because of his memory loss and other limitations, Terry knows that "I have to concentrate on every single thing I do when I do it". To compensate

for this deficit, Terry told me that “I try to finish one project [at a time. I go] from A to Z”.

Because he can only focus and concentrate on one task at a time, he is not able to multitask.

Lorraine, who knows Terry’s limitations better than anyone, told me that:

...he has to do one thing at a time or he’s stuck. Or he gets really confused. And if you ask him to do two things and I know that is unfair of me sometimes, I say Terry I want to do this and then I say something else and then I walk away and I say no that wasn’t fair because you know what, he is going to get confused and he’s not going to know which one to do first, so I have to just do one thing at a time. Give him one thing at a time.

Before his accident, Lorraine recalls that Terry could do fifteen things at one time. Today, his old drive is still there because he has learnt to stay with each task and concentrate on it until he has mastered it.

I think it must be very difficult for Lorraine to respect Terry’s limitations. I suppose that she has lived with him long enough that any adjustments she makes happen unconsciously and automatically. I am sure that she now knows how to interact with him well enough that she can accommodate his deficits without even thinking. It would be so much easier to be able to ask him to do several things at once.

Perfection.

As a result of this concentration on the task at hand, there are many things that Terry must do perfectly. For instance, when he shovels the driveway in the winter he shovels every last morsel of snow: Lorraine says that it is “done to perfection”. Lorraine gave another example of Terry’s perfectionist tendencies. The immaculately mowed lawn in the summer has not a blade of grass out of place. He mows every three days to retain the lawn’s perfect look.



Terry shovelling the driveway

Lorraine believes that his perfectionist leanings have gotten worse since his accident. Terry reported to me that: “I’m very meticulous about what I do now”. Apparently he was before his accident too, but Lorraine finds that this tendency is now carried to a fault. As is common after such a severe head injury, some of Terry’s characteristics, especially the ‘bad’ ones, became amplified. Terry let me know that he likes to be told exactly what is wanted. He will then go and do it, not “as quick as you want it, but I will get it done. But when I finish the task it will be done exactly the way you want it done, or I won’t do it”.

Terry played football to perfection, and he approached his recovery and now his chores, as well as his gym routine, in the same way. Lorraine commented that “if you could see him at the gym, I kid you not, like a lot of the men say to me, Lorraine, he is so good, I mean he is far better than any of us. And he still feels he has to prove something”.

I can relate to Terry's exaggerated desire for perfection. In my own situation, I tried never to be late before I was injured. Now I am always five minutes early. I know though, that Lorraine feels that Terry is still the same person and that she is so lucky that he is able to be with her on a daily basis. Terry always tried to be perfect in his appearance, demeanor and work ethic before his accident. Now his desire for perfection extends to mundane, everyday tasks.

Lorraine and Terry both think, and I agree, that this characteristic of wanting to be the best is the same factor that, along with his natural talent, helped him to become a great football player. Terry added a comment about playing football: "I have to be in the rhythm, I have to be in the proper flow otherwise I make a mistake and you are going to see it and I don't want you to see it". Lorraine responds, somewhat sarcastically, saying "God forbid if he would ever make a mistake". She then told me how difficult it is for Terry to say that he is wrong. Terry feels that making a mistake is "a waste of time".

I wonder whether Terry was familiar with the concept of 'flow' when he was playing football. When athletes are 'in the moment', they experience 'flow' when everything happens automatically without conscious thought or effort.

Fatigue is another residual issue from his injury that Terry must deal with.

You know what happens, that from the moment I wake up in the morning I have to focus 100% on exactly what I'm doing. Then come 4 o'clock in the afternoon, I'm tired, my brain is tired. Physically I can work 24/7 but my brain is totally exhausted because I'm concentrating on every single thing. I lay down for an hour and I listen to some soft waves and I get up in an hour and I'm refreshed. And I can start all over again. It took me many years to get that and now I know I need it.

I have also found that I must give in to the fatigue that is a result from my head injury. It helps tremendously if I rest for a while in the afternoon. It is hard to accept but it is there, an unwanted legacy from my injury.

The Story of Terry's Epiphany

During our conversations, Terry referred repeatedly to the epiphany that he had experienced. At the time of this experience, he had been watching the baseball pitcher Nolan Ryan while Ryan was being interviewed. Ryan was asked the question 'Nolan, how do you approach baseball?' When Ryan answered the reporter, Terry feels he experienced a revelation.

So I'm watching him and I wanted to hear what he has to say and so he reached over and he takes the baseball, gets in the pitcher stand and he winds up and he says this pitch, this moment is a total commitment to every single windup, I try to put everything that I have into each and every pitch that I throw.

Terry shook his head in amazement and remarked to me: "How simple a question can that be and his answer will stay with me the rest of my life". Terry realized that, as an athlete, he had been as extraordinarily focused and driven as Nolan Ryan had been. Terry's answer would have been the same had he been asked the question. Ryan's comment had opened a door so that Terry could catch a glimpse of who he had been as a football player. The door quickly shut, and Terry no longer could 'see' the Terry from the past. But he had 'remembered', albeit for only a brief moment, how he had approached football. This memory stays with him today and he now recognizes that this particular memory had been an epiphany for him. It was at that moment that the new Terry connected with the old Terry. Having this realization enabled Terry to begin to draw on his innate focus, drive, and motivation during therapy sessions. Ryan's explanation drove home the point to Terry that

to “build a new Terry one day and one moment at a time...you better start listening to what they are trying to teach you”. Another learning opportunity presented itself that day: he finally was open to learning how to construct the new Terry.

When Terry told me the story about his turning point, this point in his life was obviously so important that it stuck with him. Although there were many things that he could not remember from week to week, this comment from Ryan had resonated with him and he had remembered the story exactly as it had happened. How does Terry’s memory work? It appears to me to be not at all straightforward.

Although Terry had experienced this turning point inspired by Nolan Ryan’s comment and had remembered the experience clearly, this was also the moment at which he became aware that he was not able to touch the Terry from the past. Before Terry accepted this prognosis, before he realized that he had to construct a new identity, he “felt useless, no worth, what the heck am I doing, I don’t know who I am, who that guy was...he’s done some wonderful things...but that was some stranger that I no longer know”.

A Story About Learning.

It was obvious to me from Terry’s stories that Terry realized that he had continued to learn during his journey of recovery, and would keep learning throughout his life. Terry explained how he had learned how to compensate during conversations for his memory deficits. He had (re)learned how to follow a familiar daily routine: go to the gym, read the newspaper, then do tasks (given to him by Lorraine one at a time to avoid confusion) around the farm.

Terry had undertaken an avenue of learning early in his recovery when he was given a job at the local hospital by his doctor. There, he could learn and then practice social skills such as (re)developing ease at being around people. For about a year, for three hours a day and three days a week, Terry greeted patients and escorted them to a treatment room. To get to the hospital without getting lost, he had a map which he stuck on the dashboard of his Jeep. He talked to patients while holding a card on which he had written what he would say to each of them:

Hello

How are you?

Your name is?

Is this your first time here?

This job provided Terry with lots of human contact, in it he (re)learned how to feel at home around other people. His memory deficits meant that he had to review the card before he greeted every single patient.

Terry has learned to use compensatory lists and these lists have become an integral part of his life because they take the place of his memory. When Terry has things to do, he carries a list and checks off items as he completes them. For example, Terry derives great satisfaction from his six trips to the gym each week. At the gym, he knows “exactly what [he] is doing”. He makes sure that he follows a routine; he has a list with him. I “carry it around and check it off”, while doing his exercises in the same order every day. He told me that “For me to do what I can do, I have to follow a routine. That’s what drives me”.

Terry feels he learns by thoroughly reading the newspaper every day. As part of his routine, Terry spends three to four hours reading it when he gets back from the gym.

Although Terry's newspaper reading routine drives Lorraine crazy, she is thankful because, whether or not he retains some information, "at least he is making the effort to learn what's going on in the world.



Terry reading the newspaper

It is impossible to understand exactly what Terry is learning. Lorraine, who knows him best having experienced his former life and now living his new life with him, says that although she doesn't know "what his whole head is all about... I just hope that some of the things that are important in his life, he is learning how to deal with them and how to cope with them just like I do on a daily basis, you know". I asked Terry to describe how he has learned, and he told me that he experiences "real life learning". Lorraine jumped in and said that Terry's learning was "daily living". She felt that because he is so repetitive and consistent, doing the same thing each day of the week, he unconsciously learns how to make the next week a tiny bit better. I feel that this is another leftover from the enforced routine of elite sport.

When Terry first came home from the hospital, Lorraine told me he was in bad shape.

He would get frustrated and he would say, I can't do this and I can't do that, but as time grew, I could see his willingness to learn a little better and then I also knew that there were certain tasks he could do and there were certain tasks he couldn't do. I was all prepared to help him with the ones he couldn't do but I refused to do, help him with the ones that he could do.

If he had trouble doing a task she knew he could learn to do on his own, Lorraine would tell him “tough, that's going to take you an hour and it should only take you five minutes but I know you can do this”. Hard as it was to watch him struggle, by not doing the job for him Lorraine helped him to learn new tasks and to relearn old ones. Terry appreciates that when he came home at last from the hospital, Lorraine allowed him to learn and “gain experience, be silly – without saying he was stupid”. He thinks that by doing so, she opened the door so that he could “grow again, at whatever stage he was capable of re-growth”.

As I watched Terry, I wondered what went on in his head. He must be learning and remembering some things, but how does his brain work? How much does he learn each time he does something? Is his learning cumulative, or does an experience's uniqueness make it stick in his mind? When something extraordinary happens, is he able to retain what he was learning at the time because of the extraordinariness surrounding the experience?

Lorraine mentioned how Terry has learned to be helpful in the kitchen. She had recently made a lot of meat pies for a school bazaar; she really appreciates Terry's help with the pastry.

He helped me and like we made 30 meat pies and believe me, it took us the day before the day of but like they were his pastry. You see he's got the strength in his hands and all that and so it's, well I don't want to say it's easy for him but it's a lot easier for him than it is for me to be able to mush your dough and all that. I'm telling you he's a really, really good pastry maker.



Terry helping Lorraine in the kitchen

A Story of the importance of family support.

I told Terry and Lorraine that I believed family support was essential. They agreed, revealing at that point that they had attended a local head injury association's meetings for a time shortly after Terry's return home from the hospital. However, they found that the lack of family or other support available to most of the people in attendance was too hard for them to handle. Lorraine in particular was very affected.

Claire, we left those places and we just, we would get in the car and we were practically crying..... where are these people going in their life? What is going to happen to them? And sadly, like I will tell you this, but I remember all of those people quite well that were in that group and do you know that I see them at the mall walking around in another world.

Terry and Lorraine felt so discouraged that they stopped going after attending a few meetings.

I think that this is unfortunate that they stopped going to the meetings, but I understand how these meetings affected them. The Evanshens would be assets to the local head injury group. Because Terry has a lot to offer to other survivors, I think that, in his presence, other survivors may realize that they can do better and therefore they will aim higher. He was an icon in his former life and can be now again, both through his speaking engagements and as a mentor to others in a similar predicament.

The Evanshens are very family oriented, and so both recognize the importance of family. Terry feels that his family gives him solid ground to stand on. He made its importance clear to me when he commented that “I’ve got my daughters and my wife and I go forward now”. Terry is sure that the extent to which he has recovered is in large part due to family. He is lucky, as I was, to have such support. We talked about other survivors, some of whom do not have familial support, and it appears that he is extremely grateful to his family, and that he does not take them for granted. When he talks about Lorraine, he says that he knows that “if I didn’t have someone who totally understood me and understands the situation, it could be pretty difficult”. Terry explained that the position that partners and caregivers are in enables them to let go, but that position can also keep them holding on too long in fear of what may happen if they do let go.

If you are really drawn to the person who has been injured...and you are really into every single thing... they will hold onto you for a long time. [But you] need to release the person to be their own person again...[you can’t keep telling them] you can’t do that.

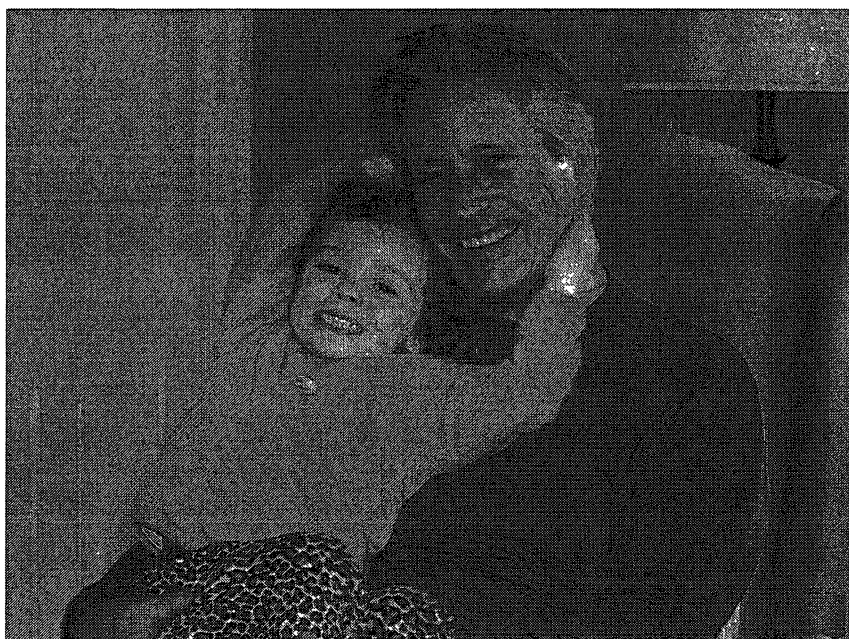
Loved ones must let individuals go, they can't keep holding on forever. Families also must understand that survivors are not necessarily the same people that they were soon after head injury or as they were before they were injured. I had a similar experience of unconditional acceptance with my parents. I mentioned to Terry that we were both so fortunate "because you need that support and you need them to be able to recognize, that's the way you used to be, you're not going to be the same but they can still cherish and respect the new person". Terry agreed. He said again, as he had several times already, that he and his family both accept that the old Terry Evanshen is gone.



Terry's wife, Lorraine

The Evanshen's daughters.

June Callwood's book mentions Terry and Lorraine's three daughters. Naturally, I asked about them. Tracy lives about half an hour way with her four young children. Her youngest child is still at home so she is a full time mother. Then they talked about Tara, who, with her husband, is building a house right next door to Terry and Lorraine. Until the house is completed they are staying with Terry and Lorraine with their young daughter Trinity. Trinnie, as she was called by Lorraine, frequently added to the background noise on my tape recorder by running full tilt through the dining room.



Terry with his granddaughter Trinity

I then asked about the third daughter, Jennifer. Lorraine told me that she had passed away four years ago of brain cancer. Terry performed differently when he was talking about Jennifer; it was the only time during our conversations that he leaned back in his chair and he moved farther away from Lorraine. Through this performance, he was unconsciously

showing me that he and Lorraine don't deal with grieving the same way at all, and I wondered whether they may still have disagreements about that. Lorraine really doesn't want to talk about Jennifer, while Terry says that he "talks with her all the time".

I thought that the coincidence of Terry's head injury and Jennifer's brain cancer was truly awful, and it took me a long time after I heard this to be able to have it no longer on my mind. Why were these people given this to deal with along with the tragedy of Terry's accident?

A story about how Terry constructed a new identity.

A few years ago, an opportunity arose that enabled Terry to share his story of recovery. It opened the door to his new life further and helped him to begin constructing his new and always evolving identity, an identity he feels proud of and for which he is respected. Before telling me this story, he spun his life-altering experience, from which I am convinced that many people would not have recovered, in a completely positive direction when he asked me "how many people in their whole lives get a chance to live a second life?" I found it amazing and commendable that Terry was able to turn his less than desirable past experience of severe head injury into a forward-looking future.

It soon became clear to me that Terry's second life as a motivational speaker (although he feels that he is more correctly described as an inspirational speaker) is a key part of who he is forever becoming. His speaking engagements continually provide him with many occasions to feel respected and worthy. He seems content now with his second life and he recognizes that he is lucky to have found an outlet for a talent that he didn't know he had. It all began when an athlete whom he knew from his football past heard him speak very

early on and told him “Terry, you know you had the luxury of entertaining people in your first life”. Terry said yes he did, and the athlete then remarked that people

....remember it 30 years later as if it were yesterday. Now you, you have the ability to entertain the possibilities in each person, that they listen to you and they say, I can do that, I can really be better, so they look at themselves internally in a better light.

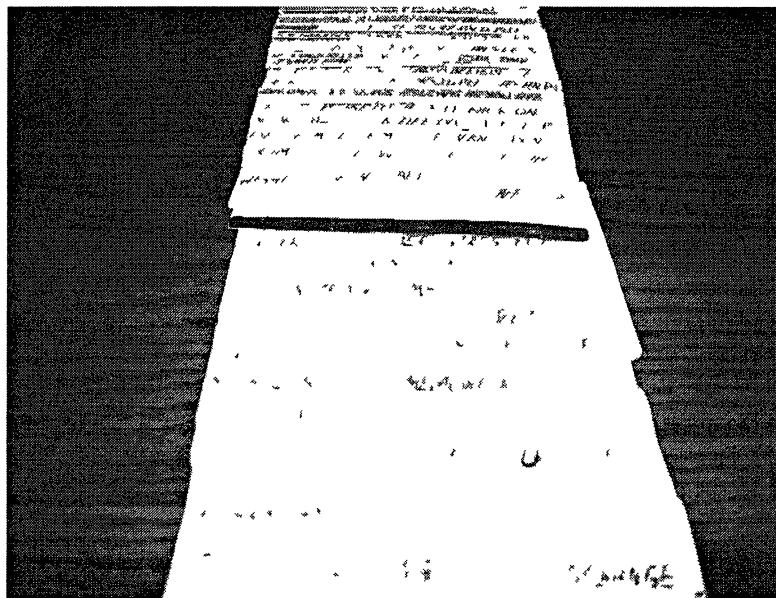
Terry learned from this individual that he could use his experiences in a positive way to help others.

I said to Terry that, as an athlete, he had had to “struggle[d] all the time to live up to something, to improve this or that, and that hasn’t changed yet, I bet”. Terry concurred, but he told me also that “I know I have, I had a talent”. When he played football, he had crowds of fans clapping and cheering him on. I told him “It is the same thing with your speaking now. So maybe you are subconsciously grasping at that because it can provide you with confidence, self-confidence, and self-esteem, just like when you played football”. Terry replied that because everyone was listening to him, he felt in control. He told me that “once I’m on stage, that’s my world”. I thought about what he had told me and I realized that Terry still considered himself on stage. That hadn’t changed from Terry’s football days. Concurring, he said, that “it has grown, but now I look forward to being in front of people..... I know I can touch people around the world”.

Control seems to be important to Terry. I feel he struggles to be in control of his own life since his injury. When he was playing football, he controlled the play. He is able to still control his fitness and how he looks. He feels in control when he is speaking publicly. It is important for him to experience control over his own life again.

Terry tells me about his inspirational speaking experiences.

If people tell their stories over and over again, they realize new meanings and learn from them. These previously unrecognized meanings emerge while they are recounting their stories for others. But, for Terry, his memory deficits prevent this learning. He told me that “if I tell a story one time or 10,000 times, it’s like the first time. So I never get bored with myself”. Terry never gets bored, and, although I am sure that he is gaining insight each time he tells a story, he does not retain any facts or thoughts for any length of time. For his inspirational talks, he has made 113 cards that he reads from during each talk. He told me that he completely relies on his cards; if he were to lose them, his world of speaking would fall apart. Each card is a picture, with different coloured highlights which help him to visualize what he is talking about, although even with these highlights he reads directly from each card with no variance from one talk to the next. He told me that “every single word in my talk is on my cards”.



Terry’s highlighted cards

The index cards are his “security blanket, I can unfold the story but if I don’t have the cards....”. Lorraine thinks that

....at this stage of the game he sees that first sentence on the card and he is able now to continue on to the end of that card and then the next card. And there have been a few times that..... where all of a sudden he’s lost. But he’s been able to get back into it, you know.



There are 113 cards. Each card is numbered on the back.

For the first couple of years that Terry was speaking, he would have to read every word on each card, his eyes never looking up from the card. Then, Terry surprised me by telling me that he had started to feel emotion when he talked.

When I started doing the cards, everything was in white. And so, I would have to read every word on the card and I wouldn’t have eye contact with [the audience] so for at least almost 3 years that I would look at, I would say to myself, I have got to start looking at people and so when I started to feel emotion when I was saying something I wanted you to feel that same emotion that I am feeling.

What I find interesting after hearing Terry talk about his speaking engagements and his cards is that although Terry is using the highlights on the cards to differentiate between emotions and starting to feel these emotions, he cannot rely on his feelings to show emotion naturally. I wonder if Terry was unconsciously trying to learn about feeling emotions by colour-coding his cards?

Lorraine knows that Terry has not regained the emotional capabilities he had before his accident. I think that Terry knows this too, although he is looking back to his football days for the tools he uses for his emotions. The emotional prompts on the cards are coloured in the same way as his football plays were coloured in his days as an athlete.

So in my, in my, in my days when I played I knew.....colours.... quarterbacks now ...have to look at 3, 4, 62 blue to the left, I have automatic recognition of colour and numbers even without counting, to catch a ball I did not know that I had this other talent. Here we are how many years later, decades later, I realize that I can get.... colours and I can emote myself again. So as I would get to a certain colour I would emote the thought.

After Terry had finished explaining this process to me, Lorraine informed me that “everything goes back to the football days”. She feels that this is due to the fact that Terry has still got some of the same characteristics as he had before his accident: “You know, names in the limelight, in the newspapers, on the television, all that stuff, it all is part and parcel of who he is and what he continues to be today”. Terry’s head injury caused no end of change, but Lorraine feels that Terry’s need for his name to be out there is a characteristic that has stayed with him.

When I called to speak to Lorraine a couple of months after the data collection was completed, Terry answered the phone. He performed the interested Terry even over the phone. He seemed to remember me, and I recognized that he was using some of

the same memory tools he had told me about during our conversations. He unconsciously revealed that he didn't know who I was when he asked whether the article I had written had come out yet. Throughout the conversation, he performed the Terry that Lorraine had told me about: the Terry that wanted the limelight.

I asked Terry if he was afraid of failure. He told me that he was when he first gave his inspirational talks. As I mentioned previously, he couldn't take his eyes off the page because he was afraid to get lost, so he couldn't look at his audience. His audiences' respect for him was something he needed; if he got lost he was afraid that he would lose their respect. Terry told me a story about one time about three months ago when he was speaking, and he spent about an hour after the talk on question and answer, a time when he always puts his cards down. He then spoke to people on the way out. He said goodbye, picked up his bag, and walked to the parking lot.

I'm just getting into my car and this fellow comes up and he says, are these yours? Oh, I said oh my God my cards, my heart almost left my body, where are my cards. He says I was watching today...and he says you just got busy and nobody picked them up so I just picked them up and I just wanted to make sure you had your cards.

I wondered, after re-reading this transcript, whether anyone has ever photographed each and every card so that the world won't end should Terry ever lose his cards.

Lorraine sometimes goes to Terry's talks with him if they are within driving distance, but she does not attend the talk itself. She says that he is very comfortable talking now, and "you know what, he needs his own separate identity and that, that's his cup of tea so to speak and I don't need to be so involved in it". She knows, and it was obvious to me,

that Terry derives great satisfaction from his talks. He knows that each person listening is a different person, and that therefore they will each take something different from his talk. He proudly said to me “How often do you get that opportunity to talk to people and affect so many people all at the same time?” He then made reference to his less than perfect memory, saying that speaking publicly “gives me energy and again it makes me want to do more especially when I don’t remember last week. I just remember being there, good people, great questions....”

How Terry feels when he is speaking.

When I asked Terry what he ‘got’ out of the public speaking that is a large part of who he is now, he answered long-windedly:

I don’t know what that talent was in my first life but I knew I was talented. Probably more than anybody that played the game at that time, or up until that time. I was very special in what I was as a character on the field. Not knowing what that character was, I now realize in my second life that that character that was there in my first life has somehow come back in my second life. When I am in front of people en masse and I’m looking at them and I can see in their eyes that they are listening and I am touching their souls.

The End of Our Conversations

The last thing I did with Terry was go over his pictures with him. He had followed the directions to the letter. He had taken pictures describing where he lived, what he does every day, and pictures of people who are important to him.

I found it telling that none of the pictures responded to the directive: pictures of what you see yourself doing in the future. Terry lived only in the present, his past was inaccessible. I had not realized until I saw his photographs that his future was as baffling for him to imagine as his past was for him to revisit.

Before I left, I gave Lorraine a nice pink azalea. I gave Terry a hug, in part to thank him profusely and in part to see if I could sense the lack of emotion. I couldn't but I don't know him. When I went out the door, I turned to see Terry smiling at me appreciatively. Perhaps he was silently thanking me for the azaleas I had bought for Lorraine. Lorraine had packed me a lunch for the trip, another testament to her thoughtfulness, and, as I had come to realize over the previous days, her generosity and her French Canadian background.

What I remember most of all about Lorraine was her comment to both Terry and me one of the first days I was there. She thought that we both were too hard on ourselves, giving our deficits from our head injuries too much recognition and too much power in our lives.

She remarked that:

...you and Terry, you can't be so hard on yourself all the time, you really can't. You know, every once in a while I say to him, take that right hand, touch your left shoulder and give yourself a little pat because you know what, you really have come through what you've come through pretty darn good you know and be just thankful for what you've got.

Recovery requires perseverance, understanding, and support. I think that we should both be thankful and lucky to have not only the familial support that we have, but also the perseverance, tenacity, and intrinsic motivation needed for optimal recovery.

Reflections

As I reflect on the time I spent with Terry and Lorraine Evanshen, I wonder what they really thought. Because Terry was such an adept performer, did I listen to his 'real' thoughts? I believe that Lorraine was accustomed to how he was during everyday life and that she knew that Terry's actions (including his performances for others – I wonder how he performed if only his family was present?) were a part of him. Terry let no one see who Terry really was except perhaps his family. However, I am not at all sure he even let them have a glimpse. He was on stage the whole time. Terry's memory is very compromised, but he (almost) had me fooled. His proficiency at hiding his memory deficits led me to believe that he routinely was able to conceal his difficulties remembering. It was yet another aspect of Terry that he kept to himself, under the mask he always wore. But was he really wearing a mask? Or, was I in fact experiencing the 'real' Terry? To explore this, I would have liked to spend time with Terry by himself. Lorraine is a lovely person and seems to be an ideal caregiver, but it seemed to me that there was always a window – Lorraine – between Terry and me. The glass was never clear but stained with Lorraine's comments. It was an interesting situation – Terry wore his mask, and Lorraine performed the part of a stained glass window, behind which he sat.

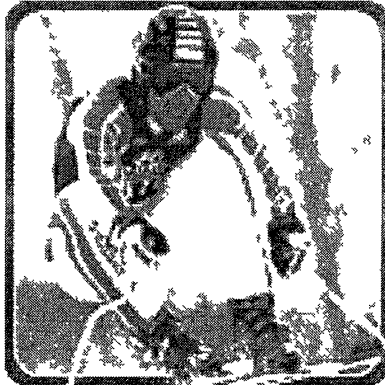
Initially, I was a little stressed in the Evanshen's presence, Terry being the first participant of the study. I also think that I was in awe that I was talking to someone who had been as well known in the sports world as Terry had been. But I felt very welcomed every day and the Evanshens frequently applauded my research. Their interest in the project made me feel both more at ease and more confident that this study would be helpful to others. After the first day, I felt completely at ease around Terry. I no longer feel intimidated; I think I have developed, evolved, and learned so that I have reached a point at which I am comfortable interacting with other survivors. I was not in a hurry to leave the Evanshen's company for two reasons.

First, they were so accommodating, and second, because I now know that it is all right that I feel lucky that my own ordeal with head injury and its long, difficult, never-ending aftermath has worked out so well.

I marvel at the peace that the Evanshens have made with Terry's injury. I am sure that they found, as I did, that the adjustment that have to be made after life changing injury are initially unacceptable. Terry was an example for me that a major and disruptive life-changing event does not have to lead to unhappiness. The Evanshens introduced me to the notion of adjustment. I learned from them that modifications may have to be made to accommodate huge life changes, but that the initial chaotic time of mere existence can certainly evolve into a happy and fulfilling life. Terry and Lorraine seemed content. They have created a life that is comfortable for them.

In my own case, I did not realize that I had no choice but to acknowledge the changes my head injury had made to my life, so my first move was to try to go back to my old lifestyle and make it work. Only when I realized that I would never fit in as I once had did I accept that I had changed and it was necessary to build a new life. As the Evanshens seemingly have done, I have 'made peace' with the monster called head injury.

Dave Irwin



Dave Irwin is one of the team of four successful downhill ski racers called the Crazy Canucks. The Crazy Canucks broke ground during the 1970's with their wins, raising awareness of alpine skiing in Canada. In 1975 Dave won the Men's Downhill in Schladming Austria. He was on the Canadian Downhill Ski Team for 11 years and competed at 2 Olympic Games: the '76 and '80 Olympics. With Dave's success came his induction into

five different Canadian Sports Halls of Fame

(<http://www.cbc.ca/sports/story/2001/03/24/irwin010324.html>).

Weeks before each Olympics, Dave had crashed and sustained concussions. Although his crash at Wengen, Switzerland in '76 resulted in a severe concussion, he competed at the Olympics, in Innsbruck, Austria, finishing eighth. He fell again before the '80 Olympics which were held in Lake Placid, New York, suffering another concussion. At that time, a concussion was not considered severe and the effect of the cumulating damage that can result from several concussions was not known. After each concussion, Dave was able to go right back to skiing. In 2001, long after his days as a Crazy Canuck, he sustained a severe head injury when he fell while skiing at Sunshine Village in Banff, Alberta.

The following story was constructed from interview transcripts, participant observation, and field notes taken during the time I spent with Dave Irwin and Lynne Harrison April 20th – 24th, 2008.

Recruitment

I feel very lucky to have the opportunity to include Dave and his partner Lynne Harrison in this study. The senior program director of ABI (acquired brain injury) of the Ontario Neurotrauma Foundation, with whom I had discussed the study, emailed me that she had seen Dave and his partner Lynne and described the study to them. Lynne and Dave had told her that they were willing to be participants. So, I emailed Lynne and we arranged for a time in April that was convenient for all of us. Dave's story molded naturally as I was writing it into a shape formed by the days that I spent in Canmore with him and Lynne. By using our conversations each day as starting points, I describe Dave's past as a Crazy

Canuck, his present life, and his thoughts on what the future will bring. Although this story ends when I leave, I know that Dave's story will continue.

Sunday April 20 In The Afternoon

There was a snowstorm (at the end of April!) when I flew in to Calgary late Saturday night, making the driving terrible. The roads were snow covered and icy. It turned out that my rental car had no four wheel drive, so I spent the night in Calgary with a cousin and drove to Canmore Sunday morning. Because Dave was just heading out to go skiing, I talked at length to Lynne as she painted on a huge three foot by four foot canvas squeezed next to the dining room table.

When I got to Canmore, my first impression of Dave was of him looking forward to a day of skiing. I met him as he was heading out the door around 11 am – he was friendly, joking, and light, and dressed to ski. He greeted me enthusiastically and looked me right in the eye; he seemed to be examining me as we talked. My impression after watching Dave's performance turned out to be right: I was looking at someone who was eager and willing to be in the study.

Lynne's unique paintings are large acrylic, colourful paintings of Aboriginals and Inuit. During the time that I was there, Lynne was preparing for an upcoming exhibition. She was open and frank about Dave, their relationship, and her role now. I wondered what her life had been like right after his head injury? How does she think she has changed as a person from living through the experience?

Dave's Accident

Lynne began by telling me a story about how Dave was injured. On Friday March 25, 2001, while he was skiing at a local ski hill Dave had lost his balance and fallen, suffering a severe axonal brain injury. She explained that this type of injury involves shearing on all of the many layers of the brain. After being given oxygen, he was airlifted to a nearby hospital. They stabilized Dave there, and then he was flown to a larger hospital. At the time, Lynne was working at the front desk of the local health unit. She “didn’t even hear the helicopter land”, and so knew nothing until someone called her about an hour later. She then heard that Dave had had a terrible accident.

Lynne first met Dave in a small town in British Columbia in the spring of 2000, less than a year before his accident. He asked her to marry him in August of 2000, so she moved to his place in a nearby town in December, three months before his accident. When Lynne had a premonition telling her that she better move in with Dave quickly, she had acted on it. She remembers feeling that “I would soon go through the most difficult thing I had ever gone through”. Since the time he was injured, it has never occurred to her to leave.

I love him and I wanted him to get better. I always felt that he would and then it took a lot longer than I thought, initially in the acute phase....the first time I brought him home for a weekend.... [when] I turned him around in the cul de sac, he didn’t know our house or anything. How could I leave somebody like that? I couldn’t have put him in a long-term care facility which is what would have happened if I hadn’t stayed, ...he wouldn’t be doing nearly as well, like he is doing really well....

When Dave was still in the hospital, Lynne used to arrive for visits with a pile of “pre-school pictures and go through them” because he was like a baby and had to learn to walk, talk, everything again. When it was time for Dave to go home, Lynne quit her job so

that she could stay home and take care of him. She is critical of the rehab provided by the hospital, telling me that:

...they don't look at brain injury in a holistic way. It is about making you survive the accident through the acute days, providing some rehab, but there is nothing for the psychology. And there is no psychological counselling for the family, you know, like Dave's kids really didn't get much, anything really, you know. And they should be providing that, because with the rate of failure of families and relationships after brain injuries.....

But Lynne was determined to care for Dave and she still is working towards the goal of helping him to recover as much as he is able. She knows that at the time of his injury this was a long term commitment and it now continues to be one. She shared with me that when Dave first came home "I cashed in all my RRSPs (Registered Retirement Savings Plans) so I could take care of him". She realizes that "not too many people do that sort of thing, but lucky for me I was in a situation where I could do that". When Dave first came home, "he was allowed 15 minutes of speech language pathology every week...he had no short term memory [so by] the time the next week rolled around he wouldn't remember what he'd learned". Lynne knows that for Dave the whole experience "is just horrible and I can't imagine. I can't even imagine, I mean I've lived with Dave now for, I've known him for 8 years and lived with him for 7 and I can't imagine...".

Although she is now spending more and more time 'doing her own thing', she says she is still very protective of him, "almost like how you would be with your children. But I also know that, I am lucky, I know he is getting better so I have to let go". She added "it is time for me now to actually have my life now...".

I believe, after listening to Lynne as she painted, that Lynne knows that not only does she have to let go for her sake, she owes it to Dave to let go. It is extremely difficult for caregivers to actually let go, even though they may intellectually acknowledge that letting go is for the best.

Lynne Talks About The Positive Aspects Of The Accident

Lynne regards Dave's accident, albeit a horrendous experience, almost "like it was a gift because you know he was so busy...he used to have eight balls in the air juggling....". She notices a tremendous change in him, finding him "more laid back than he was ...[He is] more humble, he is more relaxed, he is more easy going, and I think it was just, I think there is a lot of pressure when you are someone really well [known]". She remembers that in the past,

....Dave used to be very wary of people because he always wondered what they were up to. You know, why are they here, what are they after? They don't like me for who I am, they are here because of who I was, not because of who I really am. You know, I think that in itself really got to be tough too, along with everything else.

Dave was never sure whom he could trust. Many people saw him as an icon and watched his every move.

I was incredibly lucky. I believe that the Dave I met, because I was not only there in the capacity of a researcher but also as a house guest, was for the most part friendly, welcoming and in no way wary.

It was very difficult for Dave to know who his real friends were. According to Lynne,

....there is an awful lot of pressure, no matter what you do, someone is watching you, commenting or making decisions or judgments, this or that, or if you didn't say hello because you are busy doing something at the grocery store they think you are a snob...

Lynne and Dave's sister both believe that now, because of the accident, Dave can let go of "all that stuff and now he can just be Dave.... that's what [we] think personally."

Stigma

Even though Dave can now just be Dave, both Lynne and Dave feel stigma, although it is perhaps not recognized as such by Dave. Lynne finds, as I do, that people sometimes think that you should be the same every time they see you, whether or not you have experienced a life-altering event. Lynne pointed out that "you are not who you were, I am not who I was yesterday, so what, how can you judge somebody", comparing them to how they used to be? "Basing everything they know about Dave on..... how he was 3 years ago or 4 years ago", some people expect Dave to still be at the same stage of recovery that he was at when they last saw him. Other people, knowing that Dave has had a head injury, place certain stereotypical behavioural expectations on him. People's reactions to the changes they notice in a person that they have not seen in a while are often unexpected and unfair, in particular when that person has sustained a profound, sudden, life-altering injury. Lynne has experienced this when people see Dave for the first time since his accident. She says that they often don't realize that

...it may take him a little longer to get to the information but it is all there, so if you have to spend more than a minute talking to him, if you sat down with him for an hour or two and had a real discussion, you would be amazed at where he is at.....

Despite people's reactions to the fact that she is still with Dave, she maintains that she feels "honoured actually that I've been given this opportunity to help Dave and that by helping Dave, I can lead by example and help other people". She recognizes the stigma for what it is, and, when she senses it, she can use her knowledge of it to educate those who

unconsciously impose stigma on her and Dave. Lynne is convinced that her experiences can benefit others.

Other people will look up to me and see what I'm doing.... I've had people email me and say ... 'my husband and I have talked and if either one of us ever get a brain injury we just hope that we can be like you'. I mean isn't that amazing, isn't that fantastic?

Lynne feels that she has made the right decision staying with Dave. She said to me: "I have made a choice that this is the path I'm on it is an opportunity to just walk in what I feel is a good way. If other people pity you or whatever that's their problem".

I hope that Lynne is spending time doing her own thing as well. It seems to me that she spends a large part of her day doing things for Dave. Her life seems to revolve around his accident. She is in the process of writing a play, in partnership with Dave's sister, about Dave's life.

Sunday Evening

When Dave came home from skiing he was tired, as Lynne had predicted. The first thing he always did after he had changed was carefully mark down on his calendar each time that he had skied so that he could keep a tally of the days. He then knew that today had been his 82nd time this year. Testy, tired, and hungry, Dave yelled at Lynne a couple of times before dinner. She had warned me before how he was when he came home and how he sometimes was when he had not yet eaten, telling me earlier that "usually by 7 o'clock, if he hasn't had dinner he's a little cranky. He can be a little cranky; as soon as you feed him he is fine". Lynne justified his mood by saying that "He is like most men, most men are like that. They start getting cranky when they are hungry". Lynne has lived with Dave since his

accident and has not left his side, supporting and sticking by him. Yet she knows that “I still don’t really get it.....I get it better than most people do, there’s times I still don’t get it and you only can get it if you have a brain injury. I said to Dave you know what, I am not going to go get a brain injury so I can get it”.

I was nevertheless surprised and amazed that Lynne was patient and put up with Dave’s yelling and treatment of her, even though she knew the cause of his testiness. I guess I admired Lynne for being accepting enough to allow him to treat her in that way; she explained to me that she tries so hard to always understand. Lynne affirmed my assertion that it is impossible to know what it is like to live the life of a survivor and to go through the process of recovery if you are not the one who was injured.

Given Dave’s fatigue and his horrendous mood, I decided to wait until the next day to have a conversation on which he would hopefully be focused, so that I could actually begin the data collection process. All the same, since I would be having dinner with Dave, Lynne, and the friends Dave had skied with that day, I had them all sign consent forms. This sticks in my mind because Dave initialled each page after he had read it carefully. I then showed him how to use the camera and explained the types of pictures that I would like him to take. He appeared to like the assignment, and told me “before I had my brain injury I was photographically inclined... I probably have thousands of pictures, 5000 pictures, and I was quite good”. After Dave had carefully studied the camera’s instruction sheet that I had given him, he proceeded to take pictures most of the evening. Since he included pictures of his friends, they each signed a consent form as well. The first picture he took (he took many!) was of his partner, Lynne Harrison:



Dave also took several pictures of the guests that came for dinner, Richard and Ruth Columbia, friends that Dave has known for twenty years. Ritchie often skied with Dave, and had that day. It was interesting for me to observe how easily and comfortably the Columbias interacted with Dave.



I fell asleep feeling a little uneasy because I had yet to 'interview' Dave. I had been given the perfect room. It was on the lower level of the house, so it was private. I spent many hours sequestered there during the days that followed, pouring over the data that I had collected and figuring out in which direction to guide the next conversation.

Monday April 21st

The Dave Irwin Foundation

Lynne started to paint as soon as she got up in the morning. As she worked she talked to me about the *Dave Irwin Foundation*. I had read about the foundation on its website, <http://www.daveirwinfoundation.org/mission.html>. The mission of the foundation is to help people to become more aware of acquired brain injury (ABI), thus contributing towards its prevention and improving the quality of life of Canadians living with brain injury. One of the Foundation's main objectives is to fund scholarly research and explore new programs to help survivors of brain injury rehabilitate. By funding further academic research, the foundation hopes to contribute to knowledge acquisition.

Through their annual *Dash for Cash* event and with the help of industry sponsors, donors, and publicity, the *Dave Irwin Foundation* tries to increase awareness and knowledge of head injury, which will hopefully lead to its prevention. The *Dash for Cash* is a fun ski 'race', attracting people of all levels. Lynne explained that "the race course is a GS [Giant Slalom] race course but it is so simple that anyone can ski it backwards". *Alpine Canada* is the organisation that regulates ski racing in Canada and oversees Canada's four million recreational skiers. One of the things that *Alpine Canada* has done for Dave is to include the

event under its insurance umbrella; the participants are all members of *Alpine Canada* for the race day after signing an *Alpine Canada* waiver.

Raising public awareness through events such as the *Dash for Cash* will hopefully increase education about head injury. By educating people about brain injury, Lynne explained that the *Dave Irwin Foundation* will help them to understand that “five years after your accident you are totally different than you were one year after your accident [and now you are different again] and guess what, it is not contagious”. When people see Dave now, seven years post-accident, she told me that sometimes “people are funny.... if they don’t understand it so they think it is contagious, so they don’t want to talk to someone with a brain injury because whew, I don’t know, kind of scary.”

While Lynne chatted at length about the Foundation, I heard the passion in her voice. I believe that the Foundation provides her with an outlet for her energy; she is able to use some different skills than she uses for her painting. I will later discuss how she taps into these same organizational skills with her involvement with her and Dave’s business, Mountain Image.

I am amazed at Lynne’s energy level. She is extremely active and keeps busy. At the time that I was visiting, she was training for an ultra marathon in the Sahara desert, she was painting for an upcoming exhibition, she was writing a play about Dave with his sister Dot, and she was running Mountain Image.

Dave came into the kitchen in his dressing gown during this conversation. He sat down on one of the bar stools surrounding the island counter, put his feet up on the counter, and relayed his thoughts on the foundation, and on increasing the number and the amount of the donations that it receives. He explained that the foundation “can’t just do it with \$50,000

a year. That is nothing.....as I told my board, we need a million bucks a year. And where are we going to get it from? We need to think of another [way], something to get us money.”

At this early stage of the data collection, I found Dave’s performance fascinating. I was not seeing Dave’s public persona, instead, last night and again this morning, I was being introduced to Dave at home, the one that most people did not get to meet. Dave was natural and relaxed. Was this because he was in his home environment, or would he have been comfortable talking to me in any situation?

Memory

Since the three of us were already chatting, I decided it was time to steer the conversation towards the purpose of my visit: exploring Dave’s ongoing identity construction since his accident. During our informal conversation, which lasted almost an hour and a half, I turned on the recording device I had brought with me. Lynne continued painting and only contributed when she really felt Dave had forgotten something, or to steer the conversation a little so that I could get the information I wanted. She was a perfect example, as Lorraine Evanshen had been, of an individual in the caregiver role that I had described when I was planning the study.



Dave's picture of Lynne painting Monday morning

I asked Lynne, in Dave's presence, to describe her understanding of how Dave's memory works. Lynne explained that when Dave came home after being in the hospital for two months, she had not moved anything, leaving the house exactly the same as it had been before his accident, so that "he could slowly discover his house again...it was all really critical". Lynne told me that "His long term memory is amazing".

If you ask him if he had lunch he might forget that he had lunch today, well not so much anymore, he is better now but he might not remember what he had or he comes back from skiing and you say, okay, did you see anybody when you were skiing and he'll remember a few but he won't remember everybody. But there was a time when he wouldn't remember anybody...when he wouldn't remember that he went skiing.

Dave's memory is always improving and Lynne continues to observe him remembering things that she thought were gone forever. She believes that the biggest problem with Dave's memory is that he can't initiate a memory. She mentioned that "he will know you were here and then in a few weeks he might sort of not remember until I initiate the memory because

he can't always initiate the memory". If Lynne prods Dave or shows him pictures, he can retrieve a memory that he cannot access until given a prompt. Lynne feels that as time goes on, Dave's memory capabilities will grow so that he will remember more and more. Dave nodded in agreement: "I know that, of course". At the *Dash for Cash* this year, people were saying to Lynne "he didn't recognize me last year but he recognizes me this year".

I have firsthand experience with Dave's memory problems. When, six months after I had spent time with Dave and Lynne, I attended a head injury fundraiser at which Dave was speaking, Lynne was delighted to see me. However, when she told me to go say hi to Dave, she cautioned me that I would have to remind him who I was and that I had stayed with them. I began by talking to Dave about his dog Buddy, then I chatted about his friends at the coffee shop. I may have imagined it, but I believe he remembered who I was.

Dave can't consciously remember new things at this stage of his recovery. He told me that he can't "wrestle with my memory and think oh, I'll remember this later. I can't do that yet". I wondered how he remembered things that he felt were important. When I asked him, he thought about the question, and then answered:

.....often it is pictures, physical like painting pictures, often it is that way.....[but] it can just be a voice picture or it can be a sound picture, it doesn't have to be a physical pictureit can be a picture with voice and all that so it can be many things..... a picture is what I use to remember things.

Dave's remark revealed to me that he employed creativity to remember things. The importance of this comment became clear later when I realized how creative Dave was, something that was confirmed by Lynne. As I will explain later, the business he started before he was injured, Mountain Image, was born from this creativity.

Interestingly, although he says he has little short term memory, Dave did remember thoughts he had had, in order to tell me the next day, a sign that his memory is improving. He told me that he had spontaneously remembered something.

Actually a memory unfolded yesterday for me..... it was just me working for the first time with a memory. And it was just me going well okay Dave you are recovering and this is just something else you are recovering. Like you are working a little on memory now, but not a lot and maybe what you should do is really focus on that, the memory. It is just starting to work.

He added that this memory was “a big picture, a fuzzy old big picture....[so] I went and opened the shades”.

How great it must feel for Dave to finally be able to open the shades. As it had been when I was talking to Terry Evanshen, I thought how different and difficult life would be if one could not count on one's memory. I relay Dave's stories about the Crazy Canucks next, unlike Terry, Dave remembers his time as a well-known athlete very clearly.

Dave told me that along with his problems with daily memory, he remembers nothing of ten to twelve years before his accident. He doesn't know why he can't remember this time. He feels that “it should have come back” because it was there before. “After my injury, probably that is gone forever. But before....., I used to have it, where did it go?”

The Crazy Canucks

Dave can still access his memories of his time as a Crazy Canuck. These memories are vividly present, so this period seems extra important to him now. He remembers this pivotal period of his past at least as well as someone who has not had a head injury. I had planned before our meeting to show Dave pictures to see what memories he had of this time

and to prompt him to tell me stories, however, this was not necessary. His memories of this time seem to be clear and he entertained me with elaborate tales of his life as a Crazy Canuck.

Dave's stories of this time were fascinating. He started at the beginning, telling me tales of how the adventure unfolded. At age 15 or 16 he had been picked for the national team. Four downhill racers: Ken Read, Steve Podborski, Dave Murray, and Dave Irwin, traveled to Europe in 1975. Naturally, I asked how the name Crazy Canuck had originated. When Dave hurdled down a hill during a race at Wengen, Switzerland, Patrick Lange, a sports journalist, looked at him and said "Crazy Canuck". Dave told me that then he "legally coined the name within a week....I put four owners: Ken, Steve, me, and Murray". Dave described a typical series of days during the racing season:

Usually every week we are at a new race or a new event, so that means every week you are traveling.....then you are there at the resort for say 5 days, and there is a couple of days of travel that's when your time off is, that's your holidays....., we'd have at least 2 or 3 days of training and one day of rest. Two or three days of training would be very different from the day of the race.

The team traveled together between races in an old Volkswagen van with a malfunctioning heater. The driver and the passengers in the front were boiling hot while the passengers in the back were freezing.

The Crazy Canucks prepared for each race with detailed thoroughness. Before each race, the team members

....had to go out and look at the course, physically size it, memorize it and I used to memorize it, not just down the course because that can't give you enough, you gotta look up the course and memorize it that way and then you look at it sideways and memorize it this way and memorize it that way. So you have 4 memories of that particular spot where this piece of ice is and how it is slanted and where it is soft and where it is hard and all these little things you have memorized.....

I was interested to hear how they had trained differently on each of the days leading up to a race.

The first day of training is very, very, very different from the last day of training because the first day of training you are trying to familiarize yourself with say all that's there, what's new, what's exciting, what athlete is there,then you are trying to get familiar with the snow type, what's the snow like this year, is it hard or soft..... then the next day you go out and look at the race course and try to memorize the race course, what's changed.....then the next day or that day you have your first training run so that is pretty importantthe last training day then you are [seeing] what can you do to win and you just try to prepare yourself for the next day which is the race day and the most important day of the week.

A Typical Day Now

I asked Dave what he did on an average day now The first thing he brought up was the fact that he had skied eighty-two times this season at Sunshine resort near Banff, which is typically open about one hundred and fifty days a season. He hopes that before the resort closes for this season he will have skied over one hundred days. On those days, skiing takes up most of his day. Dave's dog Buddy is important to him and a great companion to him, so he spends time each day talking to Buddy and letting him out of the house on his leash.

When I asked Dave to take pictures of what was important to him, three pictures were of Buddy: Buddy lying down and sleeping and Buddy on his leash sitting on the picnic table.

For this picture, Dave had woken him from his sleep so that he looked at the camera:



Does cooking play a part in Dave's daily routine? When I asked him, he informed me that he hadn't "learned how to make dinner again yet". Although he does not cook now, he told me that he enjoys eating well and says that he 'tastes' good restaurants. He believes that "you can look around and try and find good restaurants, but you've actually got to go there and taste it to know if it is a good restaurant". Before his accident, Dave's kids were with him half the time and he always cooked when they were with him. I had not yet asked him any questions about learning, but he volunteered that cooking involves learning. He said that in "the 10 year period before my accident....I cooked and prepared and did this and did that and learned, learned, learned".

The Coffee Shop

He then informed me that he had forgotten what I had asked, so I reminded him that I wanted to know what he did on a typical day. He told me all about the coffee shop he goes to, the one he makes "his constant hit" of the four or five in the area and the place where he spends time each morning. He thinks that "Coffee is good for your brain if you are injured....it gets your mind fired up and you go, go, go". He invited me to go to the coffee shop at that point. We had talked for over an hour and a half so I was more than ready for a break. As we walked, he was proud to show me how much of the sidewalk he had taken responsibility for shovelling in the winter. He shovelled the area from in front of his house to the corner. This space included the sidewalk in front of about six neighbouring houses.

As we walked, Dave explained that there are other reasons he goes to the coffee shop. He uses his trips to the coffee shop as a form of rehabilitation. When we got there, I noticed that Dave was able to talk to many people at once. When I came back in after going

outside to take a picture, Dave had gone over to another table and was chatting with people sitting there. When he first went to the coffee shop after being injured, he said that he could only talk to one person at once, so

...I sat down with [one person], talk, talk, talk, three, four, five minutes and got up and walked away. Went back in and talked to somebody else, three, four, five minutes, got up and walked away. I did that and that for a week and I said you know what, I can do that, [so now] I can now talk to two.... people and then I started handling three people and sitting down with them and that was a bit of a problem. I still worked at it but I was at two [people] and acknowledged going to three.....is a little more complicated because you have got three bits coming at you so you have to remember a little quicker.....But it is a monstrous task going to two people or more now if I see five people at the table it doesn't matter.

Dave knows that the coffee shop is a test because there are many other people at different tables, all creating noise and other distractions. Now, he finds it easy to talk to any number of people. Dave took several pictures at the coffee shop.

The coffee shop seems to be a perfect environment for Dave to practice his skills. It was busy and noisy, so there would always be lots of distractions for Dave as he progressed through rehabilitation. I found it very interesting to see how aware he is of some of his deficits, yet he was completely unaware of others. He had not yet healed to that point.

Dave asked me to take a picture of him standing outside the coffee shop:



Dave then took a picture of his friend Ed sitting at a table inside:



Lynne thinks Dave's daily trips to the coffee shop are good for him because "he is seeing people daily, they are giving him positive feedback,... he is learning how to interact with people, he is learning to remember". As I will elaborate later, Lynne did comment that during the summer months, Dave spends almost too much time at the coffee shop.

While at the coffee shop, I noticed that Dave was known to a lot of people there. I think that there are many regulars who quietly and unobtrusively observe how he is changing. I chatted to several people, listening to their stories of seeing the differences between Dave right after his injury and Dave now. They seemed proud of him and full of admiration. He has plenty of supporters; he took pictures of many of his coffee shop friends. The coffee shop is part of his identity.

One of Dave's pictures was of his friends Darren, and Shannyn, the owners of the coffee shop:



The Trail

After we had walked back from the coffee shop, Dave showed me the trail running behind his house that he had spent a lot of time working on. Part of Dave's routine used to be that when he returned from the coffee shop he would work on his trail. He had cleared the trail and in some low areas had built it up so that it would not flood. Lynne had told me that the trail was an outlet for Dave's creativity.

That's his creative side.....he was like that before his accident. He used to do stuff like that all the time. And since his accident.... it is a physical release for starters – it's creative, it's problem solving because he is trying to work on making the elevation a certain way. Dave's one of these guys that if it wasn't for people like him, we'd still be swinging from the trees. He is a real eccentric and he's a real out of the box thinker and he is still very much so.

Dave explained the work he had done in detail and we walked along the trail so that he could show me where he had planted some shrubs and trees. He seems very proud of the trail:



Dave stopped working on the trail when his neighbour complained. Lynne firmly believes that working on the trail was helpful for Dave at the time.

[It] gave him a goal, he is goal oriented, he gets the goal done, he builds the trail, it gives him something to wake up to, to have to do everyday. Something to give him a reason for living and it is a positive thing of course....So that was really good for those 3 years.

She feels that the complaint was not altogether a bad thing. She told me that it was “almost like a little push to find something else. Okay, you are ready to do something else now”. At the present time, she thinks that Dave is ready to look for something else to ‘sink his teeth into’. She senses that he is ready for the next stage of his rehabilitation, to set another goal for himself.

Seeing the trail offered me a glimpse of the creative side of Dave. It was clear to me that planning and constructing the trail was a learning experience for him and an outlet for his creativity.

Part of Dave's routine now is that he sometimes heads to the library when he leaves the coffee shop to get ideas for his business, *Mountain Image*, which designs and produces logos for pins and other souvenirs for several Western ski resorts. Lynne is now managing the business. She thinks that Dave is almost ready to go to the office, telling me that "he could come to the office a couple of days a week and if we gave him specific projects to work on he would be great".



One of the pictures that Dave took for me was of his empty desk at Mountain Image. I felt Dave's sadness after seeing this picture and I thought that it revealed the fact that Dave was particularly impacted by this loss from the accident.

I wondered how and when will Dave come to terms with the changes and losses imposed by his head injury? How will his future plans, when he had worked out what he wanted them to be, involve Mountain Image?

Tuesday Morning April 22nd

Today Dave and Lynne headed to Calgary, an hour away, for an appointment. So, I was surprised when Dave was prepared to chat before they left in the morning. I quickly went to get my tape recorder. When I came back, he had put his feet up on the counter as he had the day before. I questioned him about the colours he had painted the interior of the house. He told me that he had researched what the colours meant before he painted the house when he moved there before his accident. The living room was yellow, which I assumed was that color because yellow feels bright and warm. But Dave felt that there was more to it than that. He told me about his choices, saying that yellow

.....brings out something in everyone that visits the house because that yellow makes you talk, open up your heart, makes you talk about everything..... that colour brings out conversation, conversation, conversation and that's what that colour does. Very big research on that.

So that he could show his choice of paint colour, Dave asked me to take a picture of him in the living room when he returned Tuesday afternoon. There is a painting of him ski-racing in the background.



The dining room was painted burgundy because the colour also” brings out the conversation but you are conversing about different things...I know it enlightens people”. I pointed out that the big windows joined the inside of the house to the mountains outside. Dave agreed, saying it “makes us part of the mountains, we are part of the mountains”. The kitchen cabinets surround another large window, having the effect of inviting the mountains into the room. To emphasize this connection, the cabinets were all a natural stained wood

Friends

The phone rang and Dave answered it It was Richard, who had come for dinner Sunday night. Dave has known Ritchie for over twenty years. When Dave first knew Ritchie, he was skiing, and had lots of ‘friends’. Lynne had told me earlier that before Dave was hurt

....there were only a couple of really close friends that he had anyways and then he had his accident, and of course once you have the accident, you know those people that would phone you from Calgary and say they wanted to go skiing, the ones that wanted to brag

about skiing with Dave Irwin...[but] as soon as you are released from hospital, these people dropped off like flies.

Lynne's comments reinforced my experience and that of most people who have had a head injury. Each person, injured or not, has only a few real friends that stick around through thick and thin, as I discussed above when talking about stigma.

Dave seems to have realized this; he told me that because of the accident “now I don’t have any friends so I am now building friendships and ...[it] doesn’t matter what happens they are still friends”. Dave appreciates that his real friends are helping him heal.

[Friends and family are] critical as you probably found out and I know and all that...you can’t heal just by yourself. It is all you, it is all the other people’s energy around and how big the energy and all that and I hope he gets better, I hope he gets better. Well this guy’s doing great and like he’s going to live. And you know what, that brings this down to up there and you will feel much better.

I agreed with what Dave said to me: “you don’t need lots of friends, as you get older you only need a few good friends, a few friends that you built a relationship with”. It seems that the new friendships he is building are real friends. I was able to chat with Dave’s friends when I went with him to the coffee shop on Monday and again on Thursday when I dropped by on my way to the airport in Calgary. At that time, I talked to Ed and then to Darren. Dave’s friends seemed to genuinely care about him and commented insightfully about the progress they had seen that Dave was making in his recovery. One of Dave’s pictures was of his friends in the coffee shop:



When Dave hung up the phone after explaining to Richard that he would not be skiing today because he had to go to talk to his lawyer, he sat back down at the kitchen island and put his feet back up on the counter and I spent time listening to him talk about learning.

Learning

I was curious to hear about Dave's understanding of learning. What does he consider learning to be? He told me that he thinks that everyone learns all the time, and that his learning curve has been particularly steep since his accident. Dave's response to my question was that learning was

....a vision, the vision is take one step at a time to get there. And the best thing about learning is having the vision before you take the steps, it is hard to take your steps before you have your vision because then you take four times more steps getting there but if your vision is very focused you can walk there straight in a line.

Dave shared that he believes that one learns all the time, telling me that "learning is a funny thing, you do it all over the place....as you recover, you have got to learn every step and learn, and learn and learn, so learning and recovery are very, very closely matched". However, he maintains that, although learning and recovery are almost the same, they are

not the same. He explained to me that he thought that in order to recover, you have to learn, but that most people learn without having to recover.

I believe that Dave explained his view of learning well. I found it very interesting that some of the qualities left over from skiing showed through when he defined learning. According to Dave, learning required 'a vision and a focus'. Anyone involved in high level sport knows that both are necessary to survive the long arduous climb to the top. Although Lynne feels that his understanding is only intellectual, at least he was drawing on his past experiences to build a definition.

I later asked Lynne about Dave's comments about learning. She feels that he is still "integrating stuff. Sometimes when he talks about stuff it's more intellectual than it is integrated because he is not quite yet at a place where he puts all the stuff into practice even though he can intellectually talk about it".

Dave felt that, in order to learn, "thinking about something is very important...it is very important to think, think, think..." He believes that when you think about something it means that you are able to make a plan. He told me that you have to plan or have a vision so as to be able to walk in a straight line towards your goal and to learn while doing so. Dave's planning of his life has changed now that he is no longer in a skiing 'niche'. Dave finds his life both simpler and more complicated than it once was. It is now "kind of broad and all that but it's, it's simpler because it's my life and it is more complicated because it is my life". Dave has had lots of practice planning; he told me that he has had to plan throughout his life. He had to plan "how to be the best skier in the world, planning how to own or operate a mountain image business, make it grow, grow, grow, owning... real estate, so I've had lots of planning experience all the way through". He feels planning is key: "if you really

don't know what you are doing, that is hard". When I asked Dave whether he had problems making plans now, he said, no, he didn't: "I've had lots of planning my whole life... now, [I'm] planning how to make my life grow."

Dave pointed out to me that his life is now an open book and he will "learn along the way". The open book that Dave describes suggests that he knows that his identity is always changing and that learning contributes to his evolving identity. He explained to me that "who I am changes all the time. It always did and it always will. Because every day I'm different, every day I learn....". He is always thinking about and trying to figure out what his next step will be. Lynne told me that she believes that in the last few months Dave has been searching for what to do with his life. She knows that this is a decision that he must make for himself. She told me "I can't figure it out for him and I certainly can't, I don't want to spend eight hours a day helping him figure out what he wants to do". She thinks that he is "looking for the next phase..... what to do next and so it is a good struggle because he, ultimately he has to decide what he is going to do. I can certainly make suggestions but it's up to him to follow through and find out what works for him". As Dave works through the process of figuring out what he wants to do, he will be continually contributing to his evolving identity.

Identity

The conversation that we had about learning had revealed that Dave was searching for his identity. I asked Dave what he thought identity was. He told me he thought that "It is who you are, who you are trying to beit's an image, it's a name, it's a thought, it's..... Like the Crazy Canuck, it is a bit of a name but not much more. It's an image". How had he

thought of himself when he was a Crazy Canuck? He said to me that “I will always be a Crazy Canuck. I was an athlete and I made sure I was good at it and I would do it and ...do the best...and win”. When he was no longer a Canadian Team ski racer, he said he was still “an athlete and [he] became a shop, business owner, developer ... and then I became a Dad”. When I asked him to talk to me about who he was now, he told me “I am not Dave Irwin anymore. I can’t be.” I asked him again who he was now. I found that his response offered me a glimpse at the fractured identity that he had been left with after his head injury. He revealingly answered: “Who is Dave – I don’t know, he is just a guy, okay he is a guy who skis all winter, goes to the coffee shop all summer, that’s it”.

I found this statement sad. When Dave was telling me who he was, it was almost as if he had ‘downgraded’ himself to being ‘just a guy’. For Dave, being a Crazy Canuck lives on. He seems stuck in the past, unwilling to let it go.

I sensed that Dave could talk more about his evolving identity and his changing goals. So I persisted, repeating the question “Who is Dave Irwin now?” He answered that he feels that the big thing now is that he is “...just a recovering guy and that’s it and the big thing is recovery”. He shared with me that “that’s what I’m working on now, my focus is recovering,oh I don’t know, I’m getting better, better, better and I am still getting better every day and I’m feeling better”. Dave knows that he still has a way to go: “I know I’m not yet finished my recovery but a lot of people would say I’ve recovered now even though I haven’t”. He is aware of the fact that he will never be exactly the same person that he was before: “I am going to recover back to the way I was somewhat but I won’t recover who I was, I can’t “.

When I asked Dave what he preferred to be called: an ex-athlete or a former athlete, he replied that there had only ever been four Crazy Canucks and he was one of them: “how can I become an ex-Crazy Canuck.... I am not a former Crazy Canuck, I am a Crazy Canuck”. Whatever his future may hold for him, when he is asked who he is, he will always say that he is a Crazy Canuck. This is part of his former ski-racing identity that is still and I believe, as Dave does, that it will always be a part of him.

Dave told me that he was still deciding what to do next because his goals in life are no longer the same. I wondered what his injury meant to him now. Dave replied that it had changed his life.... “I used to have a life as Dave Irwin, now I have a life as Dave. Just a guy”. The injury has stripped him of his identity. All the same, when he is skiing, people recognize him, something that appears to be important to him. He told me that “a lot of people seem to know me when I’m up there, I don’t know if it is because I am a famous skier or what but they seem to know me”. He told me “I actually said that today to Lynne, I got called Dave twice by the staff and it was people I didn’t know so it seems to be changing”. I asked him what he feels contributes to the person he is today. Dave said the “coffee shop, [and the] ski hill”. He added that he has “some other goals and aspirations but I am not reaping them yet so it doesn’t matter”. I couldn’t get him to elaborate.

I commented that I thought that what had happened to him was a large part of who he now is. Dave said that “maybe, maybe not, it’s my past and my past is a big part of who I am. That’s it, nothing I can do, nothing I can control...”. “No”, I responded, “you can’t, but to lose 10 to 15 years of your life, that is huge”. Dave then gave me a hint that he was aware of the enormity of the consequences of his accident.

It's gigantic and I know that, it's amazing how big it is, it's amazing how much of a hold it is, but I have to now kind of build it back together. I don't know yet if I am going to build it back together or just build something new. I don't know yet what will happen. Probably something new.

Dave told me that right now, his goal was to recover "that's my goal right now is to recover.....[I] will be someone that is 110% of who I am, that's just a guess. I don't know exactly....".

Pins And Magnets

I changed the subject completely and asked Dave to talk to me about some of the magnets that were on the fridge in the kitchen and had been produced by Dave's company *Mountain Image*. Lynne had told me that Dave

....creates in his mind. He is always creatively looking for new ways for us to develop souvenirs. He is constantly doing doodles of different ideas and things that he should be looking at. In his mind he is extremely creative, extremely creative.

I asked Dave how the pins were created and then made. How had they come up with the designs? He told me that "when you design a pin, you've got to do a couple of things. One is.....how many colours can you go to?"

Dave took a picture of some of the fridge magnets that *Mountain Image* has produced:



Dave's creativity was evident when he explained that they had to work out how to get all the images that they wanted into the pin in the upper left corner of the photograph.

There I have the Canada flag with a red Banff underneath with a white Banff and a red frame and so it fits into the leaf and sort of ties into the leaf and then you got a bear in one red beside the flag and the moose in one red beside the flag and they don't really interrupt the flag too much.

Dave was very involved in telling me about designing each pin, but Lynne told him that now he really must get ready to go. I spent the day listening to my tapes, sifting through what we had talked about and figuring out where to begin the next conversation.

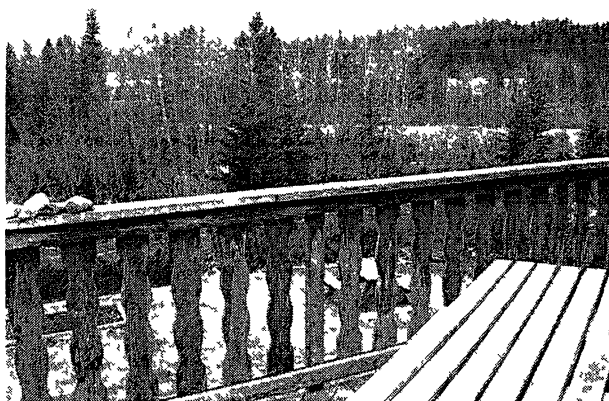
I found that, in order to 'capture' Dave at his most cooperative, I had to throw my conversation guide out the window. He was at his best first thing in the morning, which is not uncommon after head injury. On Wednesday, after his trip to Calgary, he just left in the morning, off to the ski hill.

Wednesday April 23rd in the Evening

Wednesday evening was not a good time to talk. Dave was tired from his trip to Calgary the day before so he headed out the door to go skiing. After dinner, he seemed ready to chat, so I asked him to talk about the pictures he had taken. He had followed the instructions to the letter and so had taken pictures to illustrate his identity now. Dave had checked off each point in the instruction sheet when he had taken the pictures that satisfied my request, so he had included all the pictures that I had asked him to. These were pictures of where he lived, what he did each day, what he saw himself doing in the future, and pictures of people that were important to him.

The first few photos were of Lynne. When Dave said that he had thought about what he wanted before he met Lynne, he had decided that what was missing in his former

girlfriends was a brain, and “Lynne [not only] has a brain ..she has done a huge job taking care of me”. He admits that he didn’t know how much he’d love her because she was bright and intelligent. He had then taken some pictures of Richard and his wife Ruth as an example of people that were important to him. These pictures also showed the colours he had chosen for the living and dining rooms, so we talked some more about his reasons for these choices Following those shots was one of his house and then one of the view of the mountains:



A picture of me and Lynne was next; he took it to show that the wood in the kitchen “makes the right feeling in your mind and brings the world inside....it is all one big picture”. Another picture was of Lynne with the mountains in the background. Then there were three pictures of Buddy: “yes, he is a big part of my life....and he’s around all day and I’m around all day...” Dave then told me about the next series of pictures. Six of these were of the coffee shop and its regulars. These pictures were followed by the one of his empty desk at *Mountain Image* that I included earlier. Then there was another of Lynne, another picture of Buddy, this time on the picnic table, and then several pictures of the walkway he had built, including some of the trees he had planted along it:



Thursday April 24th in the Morning

When I talked with her while she painted Thursday morning, Lynne neatly summarized what I had seen during my time with Dave. She thinks he is ready for the next step, but, like him, she does not know what this step should be. She told me how he spent his days now, and started by saying “I think he is a little bored right now.....he is skiing, but he knows skiing is almost over this season and I think he is coming into this phase where you.... he’s going to spend a lot of time at the coffee shop”. Up to this point in his healing process, the seasons of the year had dictated how Dave will spend his time. She said:

..we actually have a few phases. In May, we have the dandelion phase.... Dave will spend 12 hours a day for about 3 weeks out picking dandelions out of our yard. That’s the dandelion phase. Then.... usually around this time of year we also have the sweeping of the street gravel phase. So Dave will spend a few days sweeping up the gravel on the street which was put down during the snow and then he puts it into our drivewayIn the fall we have the raking leaves phase where he goes around and rakes all the leaves for us..... And then in the winter he shovels snow.

Lynne is confident that when Dave fully accepts the changes that have been necessitated by his injury and then learns how to incorporate them, he will successfully negotiate his way through his now altered life. She emphasizes that he “is not a different person, he’s still got all the same characteristics, there are a few different ones that are probably better than he was before....I think he when he is finished all of this thing, he is a better person than he was before”. She thinks that when he is ready to come to terms with what happened to him, he will find what to do next. She knows that Dave struggles with this. He is thinking about his future all the time but he is not sure what direction to head in, explaining:

...where is my next step, that is harder for me to do. I can’t tell you what my next one and my next one and my next one is going to be because I know I haven’t analyzed that totally yetbut I know I am going to have to do it but I don’t quite yet know whatgetting my life back here in Canmore.... that is my big, big job right now, getting used to Canmore.

The drive and the intrinsic motivation that had propelled him to the top as a skier peeked through when he told me: “When I was an athlete I had to train myself to win. Well now my winning is not a World Cup, my winning is life.... So now I have to train, train, train myself to win life”.

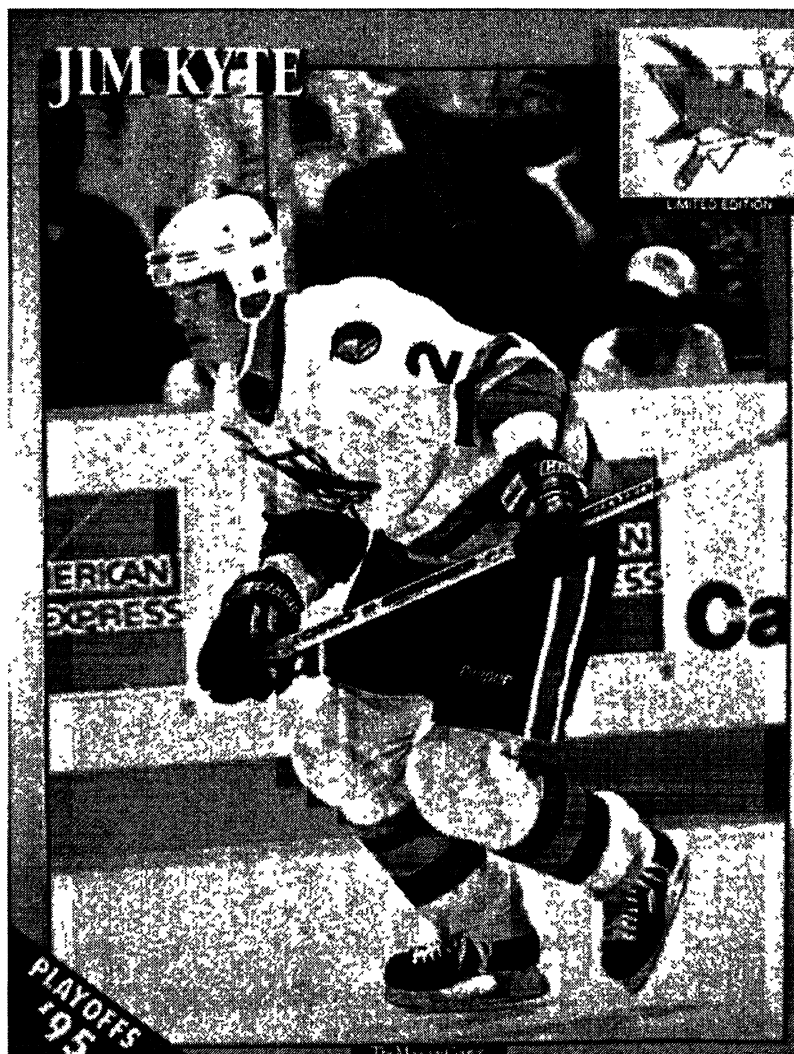
Reflections

Dave's partner Lynne was welcoming and open during our conversations, the result being that I felt very comfortable in her presence. But, when I was talking to Dave, I always felt that there was a wall between us. Dave tried his hardest to be helpful and he seemed to be open during our conversations. I think what made me feel a separation was his remark to me on the first day. He said: 'Your injury was not nearly as bad as mine was'. I felt immediately put on the defensive, and I had trouble looking past this comment. He didn't ask about my own head injury, but he made an assumption about my experience, one which I believe he made too quickly without knowing the facts. Maybe he was envious because I have found a way to make my life full and enriching again. I was back at school and doing research. I am perhaps too harsh in my judgment of Dave because his understanding and experience of head injury at the time I was talking to him made it impossible for him to believe that I could do such things after a 'real' head injury. As a result, even though Dave was very forthcoming about his own story, I always sensed that he felt superior and thought "she doesn't really understand". So, although the conversations went well, I didn't feel that there was any closeness or real understanding between us. Perhaps Dave was not as adept as Terry had been at asking me to share my story? Nevertheless, I was disappointed; I had hoped that we could have made more of a connection because of our similar experiences. I first perceived Dave's 'superiority' the first day we talked. I then wondered how I could bridge the gap between us after having my hopes dashed that the commonality of head injury would be somewhat of a bond. I had previously talked with Terry and Lorraine Evanshen; my experiences during that period of data collection were completely the opposite despite the fact that Terry always performed wearing a mask. While spending time with Dave, neither the head injury nor my sporting past were enough to let me close enough so that I could put myself in his shoes.

The relationships I had with the participants were all different from the onset so I had a unique plan for each period during which I would collect data. However, in every case, the plan seemed to evolve, change, and develop all on its own, often causing me to wonder why I had made a plan at all. Despite the evolving 'Dave' plan and my own difficulties adjusting to it – I am a person who always plans everything ahead of time - I did feel that the conversations with Dave yielded excellent data regardless of the wall I sensed between us. The wall never tumbled down even though Dave went out of his way to show me his daily life.

I was affected, saddened by Dave's stories of the present. His daily life seemed so much less than his past life. He had not yet reached the point in his healing where he has found a reason to make his life fulfilling again, and so seems to be bored and at a loss as to what to do with himself. I think that he is extremely lucky to have Lynne as his partner, as someone who is always there to look out for him and help him on his journey of healing. If only all survivors of serious injury had the support that Dave and I have.

Jim Kyte



Jim Kyte is a former National Hockey League (NHL) hockey player who was the first, and, is still to this point the only legally deaf person to play professional hockey. After playing a year for the Cornwall Royals of the Junior 'A' hockey league, he was chosen by the Winnipeg Jets as the twelfth overall pick in the 1982 NHL Draft. A reliable defenseman, Jim stayed with Winnipeg for eight years and, following that, was a member of four other

teams in the NHL – Pittsburgh, Calgary, Ottawa and San Jose. He then played for a year with the Kansas City Blades of the International Hockey League (IHL) in Kansas City, Missouri. While he was playing professional hockey, Jim founded the *Jim Kyte Hockey School for the Hearing Impaired*, which was in operation from 1986 to 1993. After playing for sixteen seasons, he was forced into retirement after sustaining a head injury in a car accident on October 27th, 1997 while driving home from practice in Kansas City, Missouri.

Jim is currently the Acting Chair of Marketing & Management Studies in the *School of Business*, at a local college. This job more than fills his days, but Jim kindly squeezed in four sessions with me over the period of three weeks. The following story was constructed from transcripts of the conversations, participant observations, and field notes of our conversations on October 14, 16, 17 and 30th, 2008.

Family

Jim has no trouble remembering his anniversary. He is lucky with dates; he eloped to Jamaica and married his wife Nancy on May 10, 1993. It then so happened that his “twin boys, Hayden and Wyatt were born on May 10, 1994”.



Hayden



Wyatt

Then, “on May 10, 1995 my son Owen was born”. Owen is autistic. Jim’s attitude with his kids is remarkable, explaining to me that his viewpoint is that we should let our kids “be the best that they can be”. He thinks that “we shouldn’t be holding them to a standard, an artificial standard, or a perception of what perfect might be in your mind and I just have a different set of expectations [for] Owen”. Jim believes that right now “it is up to us to advocate on his behalf and to ensure that he has been given an opportunity to get an education and by the end of the day it is up to him”.



Owen

Jim Kyte Today

The first day Jim and I met at 7:30 am in a coffee shop close to the college. Jim, as I soon learned was his style, at least for our meetings, was a couple of minutes late. He was then terribly apologetic for making me wait. His hearing aids were not that obvious to me despite his shaven head. Although Jim speaks with a thick tongue and a bit of a lisp, I would not judge his speech as being that of someone who is hearing impaired.

As an Acting Chair at a local college, Jim runs his department using skills he has retained from his hockey days. He shared with me that “I’m very team oriented and I have a good relationship with everybody and I treat everybody as a team member....I don’t think I know more than anybody else in the department”. He expects everyone in the department to be a member of the team. Jim explained:

You are only as good as the people that you surround yourself with....I have to do my job and I want everybody else to do their jobyou have to be able to understand why are you here, what is the mission of the department, of the school of business, and fit into the college framework.....at the end of the day we are here for the students.

We arranged to meet in Jim’s office at the college for subsequent conversations, since the noise level of the coffee shop was a bit high. His office was a bright corner space lined with windows in what certainly seemed to be a prime location. Each time we met, Jim’s performance was of someone very accessible: his body language was open – he did not cross his arms and he leaned forward in his chair - and he always had a smile on his face. Although he looked directly at me for the purpose of reading my lips, I suspect, after observing his open body language and welcoming performance, that he would have looked at me in this manner even if he had not been hearing impaired.

When Jim is in his office, he has an open door policy, he finds it crucial that he is always available to others. By leaving his door open, “when I am working away....anybody can come in at any time....that is just my philosophy as a manager....I think it is important that I am accessible to people ...they shouldn’t have to make an appointment with me”. When I was there, Jim’s office appeared to me to be one belonging to someone with too much to do. He is embarrassed by its state, and he told me that “I like to be organized and I don’t think it is organized and sometimes I’m searching for papers and it makes me really frustrated but by the same token it’s a lot better than it was”.

I am very grateful to Jim that he spent the time talking with me. When I looked around his office, it was always obvious that he had plenty to do, making me even more appreciative of the time that he gave me I thank him most sincerely for his contributions.



According to Jim, his office looks just like his father's used to look. Jim reiterated his belief in having an open door policy while telling me about his father.

He was a dentist and his office paper was just piled, almost a foot high, literally, like ten to twelve inches of paper on his desk. And I don't know if this is hereditary or whether it's just I just get so busy and I just go, go, go, go and I don't, I don't know if I need a filing system or I just need to lock the door and get myself organized every day because I do have an open door policy and people come all the time.....I encourage it because I think it is very important to have communication with people.

When he was hired for the job he holds now, Jim knew that getting the job was a real opportunity: “[so] I worked really hard and I was prepared, I read like mad, I educated myself, ran into a few stumbling blocks but one thing [is] I'm not afraid to ask questions”.

The pictures shown above are the only ones that Jim took. He first told me that he was protective of his and his sons' privacy, but then he proceeded to send me their photos anyway. He explained that his life was “an open book”, but he felt that taking pictures of his family was invasive, that his family life was private. When I explained the reason I was including photos, Jim blamed his hectic lifestyle for the lack of photos, admitting that at one point he had left the camera in his car when it was at the repair shop for the weekend.

How did Jim's identity evolve and lead him to this position? I'll start at the beginning.

Growing Up

Jim Kyte was born and raised in Ottawa, the third child in a family of six. His father became hearing impaired after contracting the Whooping Cough as a youngster. At that time, the disease was believed to be the cause of his hearing loss since “there was no history

of hearing impairment in my father's side of the family previous to him". However, when Jim's older brother was having some trouble in school, his hearing was tested and he was also found to be hearing impaired. Then, Jim was tested at age three with the same result. At that point, "they knew that it was genetic". Despite this fact, Jim's three sons have no hearing problems. Having been hearing impaired all his life, when Jim is asked "all the time, what's it like to be deaf? [I tell them] I don't know. The reason why is because I don't know what I am missing."

Hockey

The development of Jim's hockey skills began early. He remembers:

.....all the kids in the neighbourhood played hockey.....I wanted to fit in with the rest of the kids so I played hockey too. I played all types of sports but I was tall and I was gangly and I don't know if I had a chip on my shoulder, seem to have something to prove, but I worked extremely hard so I was the only 7 year old to play with the 8 year olds on the competitive team.

Jim continued to do well at hockey. He did have one hiccup when he was cut from the team at age fourteen. The incident remains vividly clear in Jim's memory because it gave his father the opportunity to teach him a valuable lesson.

I figured I was going to be on the team and so I stopped working hardAnd kids have a certain way of reacting but it really depends on how the parents react and a lot of parents would get really upset when their kid gets released particularly an established player; and my dad said, well I hope you learned your lesson, you weren't working, you looked like you assumed you had made the team and I'm not surprised you got cut.

I can't relate to Jim's lack of drive, but, having learned his lesson, I certainly can relate to the tenacity Jim displayed after that phase. When I was competing with the horses, I learned early that the only way to get to the top was to be incredibly motivated, persistent, and single-minded in working towards a goal.

This lesson became somewhat of a turning point for him. Jim seemed to have learned it well; from that point on he always put 110% effort into hockey. Now, Jim puts the same degree of effort into his work and everything else he does.

After playing one age group ahead every year until the age of fifteen, Jim was “drafted by the Hawkesbury Hawks to the Central Junior Hockey League (CJHL) and so I moved to Hawkesbury when I was sixteen”. Jim was then drafted by the Cornwall Royals, a team in the Ontario Hockey League (OHL) which was a Major Junior ‘A’ hockey league. Jim spent a year with the Cornwall Royals before the National Hockey League (NHL) drafted him “in the first round in 1982, I was Winnipeg’s first pick.....I was twelfth overall in the 1982 draft”.

I just kept playing and playing and people kept drafting me and no one was more surprised than I was when I heard that I was projected to be a first round pick of the National Hockey League draft. I was just enjoying it and playing to the best of my capabilities and I thought well maybe I might get a scholarship opportunity to the United States..... then lo and behold I got drafted to the NHL and I started playing when I was eighteen.

After playing for Winnipeg from 1982 to 1989, Jim was traded first to Pittsburgh and then to Calgary, where he broke his ankle. After missing most of the year while in Calgary, he became a free agent and signed with his home team, the Ottawa Senators. He played only four games for the Senators.

A Day in the Life of a Hockey Player

As a former athlete myself, I am intrigued by the day to day lives of athletes in other sports, so I was fascinated by Jim’s stories of life as a hockey player. My life as an athlete was in no way glamorous day-to-day and I heard Jim tell me stories that implied that his life as a hockey player was also a day-to-day grind. He then explicitly told me so.

I first asked Jim about practice days. He explained how practice was for his team.

[Practice was] pretty regimented.....During the regular season....a typical day you wake up at 8, you are on the ice at 10, you have to be there an hour before practice, you get there at 9, you have to be on the ice from 10 to 12, a two-hour practice. Afterwards you would work out.....you may have a special team activity as well, sit down with the coach, talk as a team, go over team systems, review penalty killing power plays, your own personal play, maybe watch some video and then after you generally are done at 2 o'clock, between 2 and 3 and that would be a practice day.

On a day when the team had a game, the day proceeded differently.

You would get up at 8 o'clock, if it was a home game, you'd get there for 9, you would have a pre-game skate from 10 to 10:30, maybe quarter to 11, just a light skate, should be a light skate anyways to just get the blood flowing....get the body going and then after that you would have any treatments for that day, and then you would leave and go to a pre-game meal a lot of carbo [carbohydrate] loading, you'd have pasta, vegetables, mostly just pasta.....then I would be in bed, I would want to go to bed at 1 o'clock because really you don't win games in the morning, but you want to peak for the evening when your performance is, so I would sleep every afternoon for 3 hours from 1 to 4. I would wake up and generally games would be at 7 or 7:30, I like to be at the rink 3 hours before game time. It is a little bit early but I like to get there early and read the game notes, tape my stick, make sure my equipment is right, you go through the whole mental preparation, look at the line match-ups.....

When I asked Jim what he missed most about hockey, he immediately said "The camaraderie in the dressing room" that was part of any practice or game.

I am sure that the camaraderie in the dressing room that Jim misses is the same as the aspect of my sport that I miss most: opportunities to chat with friends while on quiet walks on the horses through the woods, and the nightly casual dinners when conversation would center on the day's activities and upcoming competitions.

Jim had a reputation as a fighter when he was playing hockey. Because I have no knowledge of hockey, I asked him to explain to me how he had become known as a fighter.

People would think of me as a physical defenseman, I didn't fit the mold of an "enforcer". An enforcer is someone who goes out there and instigates a lot of things, I would play so physical though that the enforcer would come after me because I was

making it difficult for the other teams' skilled players. If I can make Glenn Anderson or Mark Messier or Wayne Gretzky think for a half second about me coming at them and delay their decision-making or to think about getting hit, rather than thinking about the puck, I've done my job.

Mental Preparation for Hockey Games

Most elite athletes and many athletes at lower levels use mental training developed for their particular sport to prepare for a game or performance, as Jim appears to have done. He remembers that "before every game, from a mental image and preparation, you would go through things in your head and you would do mental images to things you wanted to happen, we wanted to see happen". Jim would research

...the nuances of the players that you are playing against,..... [as a defenseman I would have to know] what kind of moves.... what kind of plays they like to do on the powerplay if you are a penalty killer. Some teams have set plays and you just have to be aware of them.

He felt that mental preparation was a necessary complement to augment each player's physical preparation.

The only other athlete that I talked to that did any kind of preparation of this kind was Dave Irwin. Dave would study the shape and slope of the terrain in minute detail just as Jim carefully and thoroughly studied the team against which he was playing. Terry Evanshen, the only other participant who had been a team player, made no mention of mental tactics because his injury took away all his memory of his football past. Even so, I suspect that during the time he played football, from 1965 to 1978, mental training was not yet used in sport.

Identity

Jim Kyte's Public Identity

Jim mentioned that as an NHL player, you were also an entertainer. He told me that

“you are actually, as an NHL player you are an athlete but you are also a professional entertainer is what you are”. If the fans did not find a game entertaining, they may not pay to come to the next game. By the same token, how the players treated the fans was very important. Jim explained that as a player, you are

....a commodity, if you can bring something to the team when the team wants you, if you don't bring anything to the team, then they will find somebody else who can and you have to accept that as an athlete. So you have to make sure that you are a commodity that someone wants to buy and wants to use and get value out of. And the way to do that is to compete and be in shape and be ready to play.

Jim brings up a major difference between team and individual sport. When you are competing on your own and for yourself your only responsibility is to yourself. If you do badly, you have no one to blame but yourself, and your performance affects nobody but yourself. This is true unless you have sponsors or you are representing your country. Jim, as a professional team player, had responsibilities both to his teammates and also to the owners of the team who were paying his salary.

Jim felt it important as a player to establish ties with the team's community through volunteer work. Because of this belief, he explained how he had been as a hockey player.

I was always very involved in the community, always involved with charity work. I think I would be regarded as someone that was good for the community and always had time for the fans to sign autographs or take photos. You will find in most people who are physical players on the ice are some of the nicest players you want to meet off the ice. We seem to get our aggression out on the ice.

Jim is currently giving back to hockey and the community that surrounds it in many ways.

I was involved with the Ottawa District Hockey Association, I'm a Co-Director of the Volunteer Division for the World Junior Hockey Championships, I coach minor hockey, so I'm involved in the community.....I attend many charity events whether it be golf tournaments or charity auctions or whatever the case may be, so I would think that people consider me, I would hope that people consider me as a good guy for the community and appreciate where I was.

Jim's Identity as a Hearing Impaired Hockey Player

Jim was the first, and is still to his knowledge, the only officially hearing impaired player who has played in the NHL. Because of his hearing impairment, he wasn't able to hear people calling for the puck, so Jim relied on sensory systems that other hockey players don't need to use because they can hear.

I just used different tools, I used my eyes a little bit more than someone else, I became a positional player, I did a lot of the talking on the ice, my teammates would listen to me instead of vice versa..... if you like go to another NHL game,you can hear the players call for the puck and they'll be talking to each other,[to help me] the goalie would put his hand up in the air to let me know whether it is icing or not

Jim used the glass surrounding the rink as a tool to help him: he would look at the glass and the "reflection [would reveal] where the fore-checker was behind me because I didn't hear where they were skating, and I may not have had the time to look over my shoulder to have a quick shoulder check to see where he was, little things like that".

When one considers how difficult it is to play sports professionally, it is amazing that as a hearing impaired player, Jim was so good that the teams he played with changed their strategies in order that he could play. He must have been a valuable player. I imagine that it would have been easier for the teams to use someone who played maybe not quite as well but was able to hear.

Jim's Identity as a Member of an NHL Team

Being a NHL player was far from glamorous. When the team travelled, Jim remembered that "It's a business trip. One hotel looks the same as another. And then you are there to compete.....as an athlete you can't let the highs get too high and the lows get too low, you have to try to keep an even keel all the way through". Jim explained that "it's a

short distance from the penthouse to the outhouse”. Critics may be complimentary, but they could turn quickly and easily condemn a player judged to be playing badly. Jim commented that the media “like to focus on the negative....if you have a good game it generally isn’t in there but they are really quick to point out bad games”.

Sent Down

Jim explained to me that in the early 1990’s there were two leagues right below the NHL, the International Hockey League (IHL) and the American Hockey League (AHL). The IHL “was a better league than the American League from a talent perspective, [the players] were a little bit older, former NHL players coming down at the end of their career or up and coming superstars who hadn’t been drafted yet”. Jim was still bothered by his ankle injury so, after the NHL lockout in 1994 he went to a new team in the IHL in Las Vegas. His year in Las Vegas was followed by a stint for the San Jose Sharks of the NHL “that turned out to be a great experience”. After sixteen seasons as a professional hockey player, Jim’s career was winding down, so after only a year in San Jose, he went to the Kansas City Blades of the IHL. It was in Kansas City during the exhibition season before his second year there that Jim had the car accident that ended his hockey career.

Head Injury

The Car Accident

Jim remembers his hockey career ending car accident, on October 27th 1997, vividly. He described it to me in great detail.

I was literally a half mile from the rink, if that, and so anyways, I was in the middle lane and I don’t remember, I just remember something black coming at me, so what had happened, according to witnesses, the car came up the off ramp, blew the stop sign and hit me on the driver’s side door.....my car slid from the impact sideways,

thankfully there was no one beside me.... hit the curb, and then starting flipping down the sidewalk. Witnesses say the car flipped at least three times.

Jim explained to me why he was not injured physically but did sustain a head injury.

Because I didn't see it coming and I would think because I had just finished a really hard workout and I was relaxed that when I got hit I was kind of jello. I'm just assuming and but there is no real damage on the inside of the car.... But the passenger seat headrest of the Honda Civic was twisted almost more than 190 degrees so they theorized that my head hit the headrest, I don't know.

When Jim was still at the accident scene, the first thing he wanted to do, and then did, was call his hockey team. When people came over to the smashed-up car, Jim immediately asked whether they had a cell phone: "I actually called the rink because whenever you get hurt on the ice, the first person to come see you is the trainer, he comes out on the ice.... I figured I probably needed a trainer. So I asked to use the cell phone and I called the rink". He was taken by ambulance to the hospital where they x-rayed him and didn't find any broken bones. He remembers that "I was discharged to my wife and that's what I remember about the day, it was just before Hallowe'en too.... So that's what I recall".

Hockey Team Involvement

When Jim was discharged from the hospital into his wife's care, his hockey team was helpful. A lot of his team members visited. He recalls that "the team sort of took care of me in the beginning, first I was having headaches...., I was on muscle relaxers and pain medication and then I went to ENT (ear, nose, and throat) guy". An ENT doctor was involved because of Jim's hearing impairment. The visits from his teammates soon ended. Jim told me that at the time he was understanding and that he still is.

I found that one of the hardest parts of my own recovery. People's lives are involved and busy; they keep going and soon you are left by the wayside. Jim seems to have been much more understanding and forgiving than I had been.

Jim explained to me that he simply reminded himself that everyone has busy lives; they all just keep moving forward in those lives and doing their own things.

Jim recalls that at the team Christmas party “Dan, the owner of the team, comes up to me and gives me a big speech about how you know I really care about my players, don’t worry about anything, take care of your family and I can help you”. It was reassuring for Jim to hear this since he was in the second year of a three year contract. But then, the unthinkable happened.

January 1, I got a letter terminating me because there is a little clause in the minor league contract “if a player suffers a season ending non-hockey related injury, they have the right to terminate the contract”. So we fought against that saying well the season is not over yet, how do you know I’m out for the season? According to their doctors, they said, I wouldn’t be back, etc.....I never thought I was finished, I thought, you know, I’ll be back and then this whole thing happened with the team and I said, well they just gave me the motivation to get back a little bit earlier, maybe I will just kind of try to get healthy.

For a long time, Jim was unwilling to accept how serious his head injury was and that the reality was that he would continue to feel its physical legacies forever. Today, he is more than ten years post injury and is still living with some deficits that are assumed to have been caused by his accident.

After the Accident

Four days after the accident, Jim took his kids out for Hallowe’en: “my kids were really excited...I lasted about half a block then went home, I was just too dizzy, I was

tired...”. For the next nine months, Jim was constantly tired and spent most of his time lying on the couch. Also, for a long time Jim had headaches every waking moment. He was extremely frustrated which was understandable given how long his recovery was taking.

Emotionally I was, I think I was pretty dead emotionally. I just tried to think logically, hey I can't do anything, I have to rest, I have to get healthy.....I just focused on trying to get better. I went to my massage therapy, I took my medication, I did everything I was supposed to do and between that I was very tired, I got tired very quickly, I slept a lot, I and then when I wasn't sleeping, I had 3 young kids in the house that I tried to engage with them but in the beginning on a very limited basis. Then as things progressed, the bumps and bruises and aches and pains and whatever from the accident subsided but you know the headaches and the nausea and the vertigo....they weren't going away.worse at times because I would get up and I would hit my head on something which made it worse. So I got very frustrated by the lack of progress.

Jim's wife Nancy thinks that Jim's personality is not the same as it was before the accident. Jim recalls that in the first year after the accident “I was a jerk to my wife. I didn't take it out on my kids....[but] I wasn't a nice person to be around, I had a very short fuse, and you take it out on the people that are closest to you. Unfortunately she bore the brunt of it”. Then, during the latter part of this year, his son Owen was diagnosed with autism. Everyone's attention turned to Owen, which “kind of diverted all of my attention away from me and really just focused on him. A backhanded welcome distraction: the focus wasn't on me anymore, it was really all about Owen and what could we do for him...It was healthy for the family”. At the time the family's main concern was “What are we going to do about our special needs child?”

I understand the place that Jim was at. Recovery and rehabilitation take so much time and energy away from not just survivors but also from their families and supporters. I believe that the emphasis and spotlight put on survivors is not

necessarily a good thing; when the focus is diffused, it can relieve the pressure and stress on survivors by taking the attention away from them.

Jim saw a world renowned concussion specialist in June of 1998 because he was still having some pretty serious issues as a result of his injury. Jim was told by the doctor that “he would never clear me to play again. My career was over in hockey, I guess I sort of suspected things were not looking too good but that sort of put the nail on the coffin, put the mallet in too, [I thought] oh my god, it is over”. When Jim heard this, his “range of emotions went from numbness or indifference to rage”. But, only a short time after hearing this news, he found his attitude changing. He recounted to me that he learned as a result of his initial recovery that although “I never gave up....I recognized that I couldn’t push, like I was almost pushing myself too much and it was always one step forward, two steps back”. Jim finally had to admit that “this is a bit of a different animal, you are going to have to slow down ...get better in the long run, this is the strategy, so I had to buy into that strategy...”. This proved to be another turning point. He realised that recovery from head injury could not be rushed.

This seems to have been the point at which Jim really became aware of the extent of his injury. Jim seems to have accepted the fact that he would never play again very soon after he was told so by the doctor. Only when survivors acknowledge that life must change are they ready to contemplate other options for careers. Even given his acceptance, I find it remarkable that he was also able to accept that the reality of how long the healing process would take.

Jim quietly worked at reconciling himself with the decision made by the doctor who told him that he would never be cleared to play hockey again. Jim admitted to me that, although he “didn’t put out a press release saying I was retired, I just faded away”, he nevertheless took a positive stance and remembered that he was open to a new career. He explained why he believed that his attitude was so positive.

I had a doctor tell me you are not allowed to play again, versus 30 general managers saying you are not good enough to play anymore, why don’t you just go away, why don’t you just retire....was that easier or was it harder? I knew, if I was 24 when it happened it might be hard. I realized that I had played a long time, I knew that hockey was just the first career I was going to have.

I believe that Jim may have been unconsciously relieved that he was given an exit from hockey, although I know he would have chosen a less traumatic route given the option. Retirement from an athletic career is hard to accept, even if one has prepared oneself, as Jim had done. I compare the timing of Jim’s accident with my own. Both happened when in retrospect, it had been time anyway to consider other career options. When my forced retirement did happen, it turned out to be a blessing in disguise, albeit a bit too injurious. I am sure that many top athletes remain involved in sport simply because it seems too difficult to make a career change.

Residual Problems

Jim still lives with some lingering deficits that are the result of his car accident. He told me that “I still suffer from dizziness at times, still suffer from vertigo.... my memory still is not....the sharpest”. Jim has memories of his earlier childhood but he does not remember a period in his teens and early 20’s.

I feel fortunate that there is no period of my life that I just don't remember. I remember from seconds before the accident. My only memory loss is of the four months after my accident. Each participant's memory was impacted very differently. Terry has no memory prior to his accident and chronic memory issues in his life now. Terry's memory of his whole pre-accident past appears to be gone forever. Jim has a period of his past gone forever. Dave had no memory of the ten or twelve years before his accident, but remembers prior to that point well. His memory of the present is mainly there for him to retrieve if he is given prompts.

Jim elaborated about how his memory works.

It's not my early childhood, I seem to have a pretty good memory of that, but it is fleeting, I can't really pinpoint as to the period of my life that is missing, but just stories that I think I should remember and I have none, because they are funny stories or they seem to be fairly significant social events that one would remember, but I don't remember them.

These pre-accident memories are irretrievable even if Jim is prompted; they seem to be gone forever. He remembers most of his post-accident life really well, but explained that "there are certain things here and there that I just don't remember".

Jim finds that when he speaks, sentences are sometimes jumbled. He gave me an example: "sometimes I would say 'look run dog' [instead of 'look at the dog run']". When I am speaking, I will actually mix up the words and my thoughts and what I am trying to say". Jim explains that "I will say words backwards or say sentences....., my word thought processing coming out of my mouth gets a little bit mixed up as to what I am thinking about". And, as he describes "I know still today if I am tired or whatever, I word search. I word search trying to find the right word or I mix my words up". It came up several times in our conversations that Jim might like to coach some day. But, he admitted that he recognises

that “[I] don’t know if I have the skills anymore, the skills that mentally have to be razor sharp to be an NHL coach”. These residual problems led to a diagnosis of permanent post-concussion syndrome.

Jim finds that writing gives him time to think. He explained:

When you are writing, you write things down and then you can re-visit it and re-read things and correct mistakes that you have made previously or shaped words or thoughts and ideas a little better other than when you speak, so once you speak, it comes out and that is what it is, but in writing you get the opportunity to edit it and massage it, so I started to write.

I can relate to Jim’s speaking problems and his preference for writing. I have similar problems. Sometimes when I want to say something, what I formulate in my brain is quite far removed from the words that leave my mouth. It is much easier to write on a computer where it is easy to change things. I told Jim that when I write, the final product is completely different than what I first wrote. Jim also finds it easier to write than to speak. At times during his recovery he had a hard time speaking clearly and expressing his thoughts. This continues to be the case.

How Jim Thinks He Has Changed

Before he was hurt, Jim thinks that he was “ much more jovial,...I guess I was funny....I liked to dance a lot, I used to play practical jokes on people, I would be kind of, sort of not a court jester, but I guess much more outgoing personality”. His character is no longer as easy-going as it once was. Jim recalls that his wife Nancy also noticed these changes in him after his accident.

She said my personality has changed, I think it has changed, it has gone back a little bit but right after the accident obviously I was ornery, I was unhappy, I was a very, like nothing would bother me before and I had a very short fuse....that year after the accident just, everything seemed to be on hyper drive.

While Jim was talking about his accident and his sporting past, at no time did his performance indicate that he was stuck in the past. He seems to be always looking forward. Secondly, Jim never physically leaned back, never crossed his arms, never lost eye contact with me, or gave any other unconscious performance that he was uncomfortable talking about his injury and the period that followed it.

A 10-90 turning point.

Jim's father used to tell him that "you control what comes out of your mouth, so 10% of life is what happens to you and 90% is how you react to it". Jim gave me an example, explaining "I can get upset, I can punch the wall, I can do whatever, but it doesn't change anything". During his recovery, Jim remembered that the 10-90 rule and told me it "kind of resonated with me.... in the morning when I wake up, I decide whether it is going to be a good day, or a bad day... [I decide] how I relate to my wife, my children and other people".

Jim first learned to use the rule when he was cut from the team at age fourteen. He used it again in his recovery when he felt that he was not getting anywhere. At that time, Jim consciously learned to say to himself "today's going to be a good day. I am going to have a good day today and that I think was kind of a turning point in my recovery". The 10 – 90 rule also helped him when he was learning how to cope with his son Owen's autism. He had no control over the diagnosis, but he did have control over how he would react to it. At the time, Jim realised that he had many choices: "for example you become the overnight expert, you advocate on his behalf, you do a whole bunch of things".

Jim remembered the significance of the 10-90 rule at a pivotal point during his recovery. There was a period during which he felt out of control. He told me "I couldn't

control my headaches, I couldn't control my vertigo, I couldn't control my memory loss, I couldn't control how tired I was.... because I couldn't control those things and it was very different, it was a very frustrating experience". He thought about what he had learned from his father "and then I just had that epiphany about the 10-90, I think that is a very pivotal point in my recovery is the recognition of what those words mean". It wasn't until this point in his life that Jim felt he really experienced what the rule means. Jim recognised that although ninety percent of his healing was under his control, there was still ten percent that was not.

Our Conversations

Learning

Jim is a teacher so I was very interested to hear how he defined learning. He thought a moment before describing learning.

Learning is anything new that you learn whether that is a new term, a new word, a new way of screwing in a light-bulb, if it is different and you haven't been exposed to it before, it is learning. So that's my general definition of learning is that being exposed...recognizing, understanding, is that it is different, whether that's an experience, mentally, physically, emotionally is a learning experience.

Jim thinks that everyone learns differently.

Now mastering it, that's a different level, a high level of learning, but just learning in general is something new that you recognize as new and you understand it and whether you can explain it or there are different modes of learning, so people learn auditory learners, tactile learners, there's visual learners, but different ways of learning that people learn from.

I thought that it was very interesting that Jim was the only participant who has brought up Mastery and had defined it as a different level of learning. I wonder why none of the other athletes, all having performed at the top of their game, had brought up Mastery? I'm not sure whether I would bring it up either.

Jim believes in lifelong learning. He thinks that one learns continually from everyone around, telling me that I “learn everyday that I come into the office, I learn from my secretary, I learn from my colleagues, I learn from students walking in, I am always [learning].....the day that I think that I learned it all, I’m going to be in trouble” in this job. He also thinks that life is too busy for people to care – or to learn – unless they can relate to you. He brings relating forth when he talked about his teaching:

There might be hundreds of thousands of people out there with MBAs but none of them can buy the experience that I have had in my pro-sport or my athletic career. The experiences that I have been exposed to.....the recovery, everything, you can’t buy that. You can’t get that in the textbook, you can’t get that in the classroom.

By bringing his sport experience with him into the classroom, Jim can use it to relate to the students and “talk about certain areas, rather than just talking about the theory and then you can apply it in the classroom, it is much more [real]”.

I agree completely with Jim on this. First, there are few human experiences outside of high-level sport that require such an elite level of performance. By bringing these experiences with him into the classroom, the students will have a living example to learn from. Second, actual experience is much more valuable than only theory. Because Jim combines both, I am certain that he creates an excellent learning environment for his students.

Jim feels that pushing himself as a hockey player to be the best by trying his hardest was a learning experience for him, and that that learning experience has helped him to become who he is now. He thinks that it is easy to be complacent because “Everybody is very comfortable in their own little circle”. According to Jim, learning only happens when you bravely venture further because “you only learn when you go outside that circle and go

outside that comfort zone....I have never been afraid to go outside that comfort zone”.

Jim explained to me that his mistakes now have different consequences than when he played hockey: “if I make a mistake here at the office, well only myself and maybe my secretary might know about it”. In contrast, when he was playing hockey, he commented that “If I make a mistake in a hockey game, twenty thousand people in the stands and maybe a million more on TV see that mistake and it is played over and over again on the nightly news”.

Jim believes that one must be brave in order to face the mistakes that occur while one is learning. Mistakes help one learn. I agree with Jim that professional hockey is a difficult venue to try to push one’s boundaries and learn. Even if a player is brave and tries to learn, the career consequences can be devastating if that player makes mistakes while learning.

Jim maintains that education is valuable. He is extremely grateful to be in the position he is in without having sought formal education.

I’ve always believed in the value of education...I know that I’m very fortunate to be in the position I am now, without that piece of paper..... thankfully some people have given me that opportunity to excel and trust the fact that because of my life experience and some of the other things that I have been given a little bit and I have been able to show that I can execute and perform.

Jim is doing his job without a formal education. He does not hold the piece of paper that you are given upon the completion of a degree. He knows that it is the one thing that he is missing. It is valued above experience by society and it is the one thing that would make his job secure.

Jim emphasized that he firmly believes in learning and reiterated that “it is an

essential part of who I am”. He knows that his learning experiences have opened the door for him to continue to evolve as a person, telling me “I am not stagnant.....because I continue to learn new things every day and I am open to those learning experiences”. His interest in learning led him to his job at the College.

I think Jim’s attitude about learning speaks volumes. I am sure that Jim also learned all the time when he was playing hockey. Whether in athletics or in life, learning is necessary to move forward. As Dave Irwin noted, if you know where you are heading with your learning, you can walk towards that point in a straight line without a lot of zigzags along the way.

Jim’s Job

During his hockey career, Jim was realistic. He knew that he would not be playing hockey forever so he took university courses to prepare him for life after hockey, telling me that “I took courses and I went to university during the summer and I chipped away...”. Jim realised that “the most important thing in my body wasn’t my hands or my legs, it was my brain”. He has always been aware of the fact that “when you are an athlete you are one injury away from the end of your career. So I always liked to be a little bit proactive rather than reactive but I just choose to keep myself engaged because I knew hockey was my first career”. At the time, he already realised that, when athletes retire from a career in hockey, they are still young enough to pursue at least one other career. To cope with the change such a retirement would bring, he made a plan.

You have to plan..... a lot of athletes think that they don’t have anything valuable to bring to the workforce or they don’t realize the skill set that they have honed and developed as an athlete and how applicable they are to other facets and other industries and other jobs that they can do.

Jim felt that the skills he learned and honed as a hockey player would be useful and needed in the workforce. This knowledge prepared him for retirement, but he knew that many former players were less ready simply because they didn't recognise this fact. Jim was aware that hockey players had plenty of skills they had learned that they could also use in their next careers.

I recognized a special opportunity to train because you see a lot of my colleagues who played pro sports didn't have a plan for after hockey.....they didn't go to University they [think there is a]a perceived skill-set that might be lacking, [but]..... I think athletes have a different skill-set that most people don't have.

Jim's strategy paid off personally. He used his education as well as skills he had learned as a hockey player to become the Acting Chair of the Marketing & Management Studies in the School of Business at the college where he teaches.

From 2000 to 2004, Jim wrote a column for the daily newspaper. The column was an opinion piece on hockey, from outdoor recreation hockey to the NHL. Through working on the column, he learned the skill of writing concisely. Jim reminisced that when he was composing the first draft of his first column, he had reached the required length before he had begun to make his point.

Jim was teaching courses in the School of Business at the college when he was asked by the new Dean in the fall of 2001 about starting a sport business program. He pulled together an advisory team comprised of leaders of sport in the area, a team on which "there was a real balance between professional sport and high performance sport". Jim then spent a harried two weeks putting together a business plan for the three semester program, which was geared towards students who already had a degree or diploma before starting. The plan was approved by the Board of Governors in March of 2002 and the college said to Jim "we

would like you to run with this”. The Dean wanted the program up and running that September. Jim described the next year as a whirlwind in his life while he was getting ready for the first year of the program.

I had to market it, had to find the students, had to find the teachers, pick the textbooks, so I worked on the fall semester during the summer, wrote the winter semester during the fall and wrote the summer semester during the winter and still taught and ran the program and did everything else, so it was a crazy, crazy. But I did it, because I’m just, I’m results-oriented, I guess.

My brief experience of Jim sees him as relishing challenges and seeking them out. I wonder what the Dean saw in Jim that prodded him to ask Jim to take on the project of designing a new program for the School of Business at the College.

Jim’s Explanation of Identity

I wondered how Jim would define identity. First and foremost, he thoughtfully related that when he was playing hockey, “I identified with being a player because that is what I did for a living and also that’s what I lived and breathed because you needed to train, you needed to educate yourself from that perspective”. He talked about identity in terms of how others saw him.

Public identity is how people have a perception of me. So on the icethis guy is a mean SOB and I wouldn’t want to go in a corner with him but the people in Winnipeg would say the same thing about me being on the ice but he was a really good guy in the community cause he does so much charity work and deals with kids, he has a hockey school for hearing impaired kids, he visits hospitals, he does everything else, that he is actually a really good guy off the ice and a good, good person.

I then wondered how Jim viewed himself. He described himself for me: “I enjoyed doing a lot of things that my fellow team mates didn’t.... I enjoyed art, I enjoyed reading, I didn’t watch soap operas,....I played cards with the guys no question, but I knew that hockey was a

short term career". There are a number of characteristics Jim refers to that seem to be leftovers from his hockey past.

I think that I'm driven, I'm very competitive, I hate to lose, I hate to not accomplish something or goal that I have set myself to do.....maybe I have bitten off more than I can chew with this job and the World Junior Championships and having a full life outside of work, maybe I don't know if it is a time management issue but or it is just a fact that I have a very full life at the moment..... I have always considered myself to be pretty sharp mentally, that's just me.

Jim looked at his identity in terms of what others thought. His musings about how he perceived himself seemed to focus on superficial qualities, not on what he thought, or how he felt, or on his beliefs. His next thoughts are only a bit more introspective.

Stigma

Jim feels a certain amount of stigma because he is hearing impaired. However, the stigmas he remembers most are those that are associated with being an athlete

.....because you don't get a second chance to make a first impression..... you size up people in the first 4 seconds just based on their appearances. [For example] athletes.....are dumb, ... some people have a stereotype of being: oh he is an athlete, he is not an academic, he can't be very smart, he is just an athlete.

He can also relate to the preconceived notions of others. In his case, people make assumptions about his hearing, saying to each other:

...oh he is deaf, he can't do this and he can't do that, he can't hear very well, he can't hear anybody skating behind him or you are speaking to him and you know he can't hear and I tell this to people all the time, if I sit down, any meeting we start, people don't know me, I say, I'm legally deaf over here, if you are going to speak, ...speak loudly and if you have a habit of speaking with your hand over your mouth, please refrain from doing that because I read lips.

Jim's Opinions and Perspectives

Throughout our conversations, Jim offered many opinions and perspectives that he has learned from his various experiences in life. From sports, he has learned that “what you did yesterday has no bearing on what happens today”. He told me repeatedly during our conversations that “it is a quick trip from the penthouse to the outhouse”. He learned this first early on when he was only a child and cut from the hockey team.

I learned a valuable lesson that you have to work hard all the time...from that very painful lesson, I was given an opportunity to come back to the team. They had an injury and you know I seized the moment and I never ever [took anything for granted] from that point forward, no matter what I do, because of that valuable experience. [It was] painful, but my parents didn't protect me from it...[and] I never, no one would ever outwork me in anything that I did. So whether it comes to this job that I'm in now or you know, I will always put the hours in, I always do whatever it takes.

Now, he works incredibly hard at the jobs he has earned and numerous other commitments, one of which is his job as the co-director of volunteers for the World Junior Championships which starts on Boxing Day in 2008.

Jim mentioned ‘the five P’s many times during our conversations. When I asked him what they were, he explained that they are “the keys to success in my opinion”: perspiration, preparation, positive attitude, perseverance, and passion.

Number one is Perspiration – you have to work hard...two is Preparation, you have to work smart...number three is Perseverance, you are going to be tested so you have to be able to persevere through certain things and believe in yourself...four is Positive attitude, no one wants to be around someone who is negative all the time...and number five is Passion; if you have passion for what you do, the other four “Ps” come easy.

It seems that these five characteristics are those that he gained as a hockey player and now experiences again in his job at the college.

I asked Jim if he mourned the person he was as a hockey player, before his accident. He said that no, he didn't, "Because it doesn't serve a purpose. It is wasted energy". Jim looks at life as a series of experiences, "whoever is upstairs gives you a set of tools and it is up to you to do the best you can with the tools you are given". Hockey was only one in a series of experiences, so Jim looks into the future; he doesn't dwell on his past as a player.

You could come into my house and you wouldn't see any hockey photos up. You would never know that I played 17 years of professional hockey. That was my old life, I had to move on to a new life and this strategy fell naturally into place. We had to keep looking to the future because the past was finished and you can't live in the past..

A Lasting Perspective

Jim now has a job that he has to prove himself at, just as he had to prove himself at hockey as a player, then proving himself over and over again that he was a worthy player despite his hearing impairment. His mindset is one that belongs to a winner. Because of his hearing impairment he remarked that "I've always had to prove people wrong, I've always had that mentality that you don't think I can do something, just watch me. I had that before the accident and I have that now".

After spending at least four hours talking to him, Jim's fabulous attitude was very apparent: it is one of an achiever who takes nothing for granted and is not afraid to fight battles. His performance, exuding confidence, emphasizes this attitude.

Jim tries to live his life:

.... as an example of someone who has had some things to overcome and I haven't let them hold me back. I may be different from some of the other brain injured persons because I have always had to overcome things in my life and overcome a stigma attached to the fact that I was hearing impaired and some people think that [I] couldn't do x or y because of the hearing impairment so I have always had to prove people wrong.

I am impressed with Jim's stories about his past. To be in the position he is in now at the college is a testament to the hard work he appears to do while working towards any of his goals or following any of his many pursuits.

Reflections

Jim Kyte was the last person that I interviewed for this study. By the time I got to Jim, I was feeling confident about the whole interview process. However, each interview experience was unique, and each one affected me differently. When I look back and reflect on the experience of interviewing Jim, I think that he impressed me with his past and present achievements. First, Jim was a professional athlete. I think that is the reason why I was so in awe both of Jim and of Terry Evanshen. Jim and Terry could both make money while playing their sport, doing what they loved. I was fascinated by Jim's stories of his time playing hockey, and I think I heard him tell his best stories when he was recounting this period of his life. Second, Jim told me several times during our conversations about things he had learned from people both before and after his recovery from head injury. His interest in learning and taking courses while he was an athlete was remarkable, as was the fact that he had redirected his life so successfully after his professional hockey career and after sustaining a head injury. But, despite the fact that Jim appeared to be willing to help at all times, I didn't really experience a connection between us. This may have been because we sat in Jim's office, a place central to the workings of his 'team'. Each time we met, he had an hour set aside for me. When the hour ended, Jim stood up, performing for me that he had to move onto the next item on his agenda. I understood this, but he was the only participant with whom I felt as if we were on a schedule.

I felt pressured to ask all my questions within a certain time period, and I also felt that I was disrupting his time with his 'team'. I was not as impacted by Jim's stories of healing as I had been with some of the other athletes' stories, and I found that I felt less empathetic towards him. Was it because I was hurt when I was competing at the highest level, and Jim's accident happened when he was on his way out after

playing professional hockey for a number of years? Did I feel that Jim had been lucky because, although accidents are far from being welcomed events, his accident had occurred at the best time, during the twilight of his career? I'm not sure: maybe it was because what I saw before me was a seemingly well-recovered individual in a dream job? Regardless of how I felt when I reviewed the experience, Jim fit perfectly into the study. His stories would have complemented those told to me by Terry Evanshen had Terry been able to remember his football days.

Chapter 6: Analyses of Narratives –

Applying the Paint

In Chapter Five, I co-constructed the illness narrative of each participant. I composed these because, as Smith and Sparkes (2008c) explain, I am a storyteller. I reflected on the time I spent with each athlete and wove these reflections into each emergent narrative (Coulter & Smith, 2009; Polkinghorne, 1995; Riessman, 2008; Smith & Sparkes, 2008c). I believe that these narrative analyses are more accurately described as interpretations because ‘analysis’ reminds me of a researcher performing from afar. In the case of this study however, Kidd and Finlayson (2009) remark that I am interpreting “meaning.....from my own [nearby] place in....[a similar] world” (p. 986).

Following the narrative analysis, readers are led to the analysis of narrative. Chapter Six consists of a dialogic/performance analysis of each of the illness narratives (Coulter & Smith, 2009; Riessman, 2008; Smith & Sparkes, 2008c). This analysis has been performed according to the following factors: the narrative’s context, its textual organisation, my researcher positioning and influence, the type of the story, the photographs taken by the athlete, and the described identity performances of the athletes. While performing the analysis, I referenced many theorists, including work by Charmaz & Mitchell (1997), Coulter & Smith (2009), Frank (1995), Kolb (2008), Langellier (2003), Polkinghorne (1996), Reinhartz (1997), Riessman (2008), Smith and Sparkes (2009), Sparkes (2002), and Warren (2005).

....*I wonder?*

In the following analyses of narrative, I examine and interpret the illness narrative that I constructed for each participant. All of the participants, except for me, are male. The wording of the questions reflect this. For each story, I looked through the theoretical lens discussed earlier and I was guided by the following questions, some of which are variations of those suggested by Riessman (2002b, p. 8):

- **Type of story:** In what kinds of stories do the athlete's *performances* place him?
- **Physical positioning:**
 - **Who** orchestrated the physical positioning of the athlete, caregiver, and researcher in the environment while the athlete was *performing* stories?
 - **How** were these individuals positioned?
 - **Why** do I think that [the athlete or the caregiver] set up the environment in this way?
 - **What** did the positioning reveal about the athlete? If the athlete set up the environment, was the positioning part his *performance* of his stories? In what way?
- **Researcher Positioning:** How do I perceive that my membership in the same culture, that of former elite athletes who are survivors of head injury, impacted the stories the participant chose to tell? How do I think that my

cultural affinity influenced the way that the athlete *performed* his stories for me?

- **Memory:** If the athlete had memory deficits resulting from his injury, how did the athlete *perform* them?
- **Control:** Does the athlete's *performance* indicate that he is trying to control our conversations? If so, how?
- **Stigma:** Does the athlete perceive any stigma directed towards him? If so, does the athlete *perform* stigma while relaying his stories? If so, how does the athlete *perform* stigma?
- **Understandings:** How do the athlete's *performances* reveal his understandings of 'identity' and 'learning'?
- **Learning:** Does the athlete think that he learned on his road of recovery? If so, how do his *performances* relay that learning? What does he believe that he learned? How did he learn?
- **Identity:** What are the verbal and *performance* (beyond the spoken word) identity claims made by the athlete? How and when does the athlete describe and *perform* his past, current, and imagined future evolving identities?
- **Changes:** How does the athlete think that he is different or the same as before he was injured? How does he, through *performance*, express these differences?
- **Photographs:** Why did the athlete take a particular picture to illustrate a particular aspect of his identity? How is the picture part of his *performance*?

- **Turning point:** Did the athlete experience a turning point or epiphany? How did he *perform* while telling me about it?

The analysis of each narrative explores these questions in the order that seemed appropriate in each case. Consideration was given to the following:

The Influences of Context and Discourse

Discernable throughout the illness narratives are their contexts: the cultural, social and historical lenses through which the stories were told to me by the athletes (Frank, 2004a; Georgakopoulou, 2006; Hardin, 2003; Josephs, 2008; Langellier, 2003; Madison, 2006; Peterson & Langellier, 2006; Riessman, 2003, 2008; Smith & Sparkes, 2008b, 2009). Both the participants and their audiences, the readers of the stories, are not immune to the influences of society because, as Riessman (2008) writes, “larger social structures insinuate their way into individual consciousness and identity” (p. 116). I have no doubt that the athletes shaped their stories so that when they performed them for me, the stories and their roles within these stories “conform to [their] cultural ideals” (Daiute, 2004, p. 113). Now, the audience, guided by what they have read, will make their own unique meanings, meanings that are shaped in part by their own social, historical, and cultural backgrounds (Riessman; Sparkes, 2002).

Structure

In this thesis, I have organised, constructed, and then written each illness narrative to reflect the structure of the conversation I had with that participant. I viewed structure as emerging from the interactive interviews, not as something that the storytellers or I imposed on the transcribed conversations (Frank, 2000b; Riessman, 1993, 2008). Structure was

visible in two different ways : one, as the themes that I uncovered and that reflected the lived experiences of the athletes, and two, as the positioning of the interview settings as they were designed by the participants. The sessions ranged from quite structured in the cases of Terry Evanshen and John Beedell to not structured at all in the case of Dave Irwin. I discovered, as did Richardson (1997a), that writing was a large part of the process of analysis. I found that a less predetermined structure in the writing process enabled me to highlight “moment-to-moment nuances” as well as performances that occurred in the interactive interviews (Georgakopoulou, 2007, p. 64).

Response

...of the researcher.

The conversations I had with the athletes enabled me to co-construct meanings as we conversed and then again as I performed a narrative analysis. I believe that these narratives reflect the “alive and fluid” interactive conversations I had with the participants (Corbin & Morse, 2003; Coulter & Smith, 2009; Ellis, 2004; Ellis, Kiesinger, & Tillmann-Healy, 1997; Riessman, 2003, p. 23). According to Ellis, Kiesinger, and Tillman-Healy, interactive interview processes are used by researchers “for getting an in-depth and intimate understanding of people’s experiences with emotionally charged and sensitive topics”, such as recovery from head injury (p. 121). Corbin and Morse point out that an interactive interview can invite participants to seek the friendship of the interviewer, but they warn that such a situation should be entered into cautiously by both the researcher and the participant. During an interactive interview, a researcher may share his or her own stories in an effort to

get closer to the participant. I shared my stories to try to create an environment that fostered empathetic listening and response by both the participant and me.

...of the participants.

Perhaps due to their injuries, the participants have not experienced life as a consistent, cohesive process, so they do not have the possibility of having fluidly developing identities that have evolved steadily over the years. They have all experienced ruptures, or perhaps they now see them as epiphanies, in their life stories (Denzin, 1989, Wainwright & Turner, 2004). Consequently, when the athletes told their stories, they all mentioned that the process of narration lent, as Ezzy (1998) points out, “a sense of connectedness and temporal unity” to their lives that they had not been aware of previously (p. 245).

Photographs

I used photo-interviews (Kolb, 2008; Warren, 2005) to discuss each athlete’s photos with him. The athletes’ performances during these interviews became part of their stories, as did the photos. Because the photos are interwoven with the constructed stories, I commented on the relevance of each athlete’s photos and pondered the significance of photos taken by that athlete as parts of the analysis of the particular aspect of his story.

Analysis of John Beedell’s Illness Narrative

John was fascinating to interview. His stories were well thought out and he was a gracious host when I came to his apartment to talk. John repeatedly insisted to me that he identified himself as a teacher, that the elite level athletics he had successfully taken part in were ‘just for fun’. This despite the fact that he had competed at the canoeing World Championships in 1958, the Rome Olympics in 1960, and he had run the Boston Marathon!

Performance

John Beedell, at age seventy-five, was the oldest participant in the study. Each time we met, John performed in such a way that structured our conversation and relationships conventionally. John's norm was revealed during his performances (Bial, 2004). The value system he expressed through these performances subtly indicated to me where he believed he should be positioned in society as a whole. I wonder whether John's charming performances were obvious only to me because I was looking out for them? Or, did his family, his friends, and the people he casually met day-to-day appreciate his delightful performances, ones that reflected his values, as much as I did?

John brought order and structure to our conversations immediately. For example, when I asked him on the first day to tell me about his teaching life, he told me he wanted to start at the beginning. After John had structured the first day's conversations, he performed the need to be taken seriously by ensuring that each of our conversations followed in logical and sequential order on the days that we talked (Riessman, 2008).

Positioning of Athlete and Researcher

John set up quite a formal 'front', one that he imagined would be most appropriate for our conversations (Goffman, 1959, 2006; Bial, 2004). Goffman describes that a front consists of a setting, an appearance, and a manner. He defines a 'setting' as the part of a front that remains more or less the same and is required for the performers (John and I) to begin performing. It is the "expressive equipment...intentionally or unwittingly employed by the individual during his performance" (p. 22). The setting of the front that John prepared for his performances was visible in the way he thoughtfully arranged the room, putting a

chair and card table facing the sofa in his living room for each of our conversations. The placement of these formal 'stage props', as well as revealing his thoughtfulness, also, I think, reflected his traditional assumptions regarding how an interview should be conducted. His 'manner' during the interviews further hinted at the formal way in which he expected that our conversations would unfold (Goffman, 1959). John took a photo of the living room to illustrate where we had talked. The setting also foreshadowed the roles we would 'appear' in during these conversations (Goffman). By presenting a 'front' and a 'setting' and performing in a particular 'manner', I think that John was trying to control my impressions of his appearances and his world. I think that perhaps he was trying to order his world and his appearances according to how he thought I should see them (Goffman).

Performance continued.

John's front and his rituals, parts of his performances, served to reveal his cultural background to me (Goffman, 1959). As outlined by Goffman, I believe that these performances make up part of his 'personal front' because they follow him wherever he goes. His 'personal front' was discernable in his manners, clothing, body language, the music albums in his personal collection, and his love of the Ottawa Chamber Music Festival. John took photographs of his music collections to illustrate his love of music.

I believe that all of John's performances of his selves: athlete, teacher, survivor of traumatic brain injury, learner, father, and friend, were sincere and they indicated that he knew himself well (Goffman, 2006; Park, 1950). This observation is supported by Park's remark that "everyone is always and everywhere, more or less consciously, playing a role....it is in these roles that we know ourselves" (p. 249). The role that I witnessed John

performing most sincerely and consistently for me was of an individual who knew he had recovered optimally from head injury.

Type of Story - Quest

John was depressed for a time after his head injury when he first came home to his own apartment. At that time, he was beginning to realize the changes that the head injury would bring in his life due to his altered “life situation, rehabilitation, and [the not yet previously experienced] recovery process” imposed by the accident (Strandberg, 2009, p. 279). Eventually, John learned to cope by becoming more proactive in setting recovery goals and by learning that despite these goals, as Shotton, Simpson, and Smith (2007) remark, his recovery would be “slow and gradual” (p. 862).

In time, John accepted his new limitations and rose from his depression. These changes, necessitated by his injury, were, Frank (1995) suggests, “significant vocational and personal changes” to his life (p. 116). He was given an adult tricycle of which he took a couple of photos. He now doesn’t drive a car but rides his tricycle everywhere. He enjoys many of the same things he did before his accident but he also has some new interests. Over time, John learned to see his head injury as an opportunity to make new meanings and welcome new opportunities (Frank, 2005; Shotton, Simpson & Smith, 2007; Wlodkowski, 2004). In agreement with Frank (1995), I believe that John is performing that he is now living a quest narrative. It seemed to me that he has managed to hold “chaos at bay”, because he recognized when coming out of his period of depression that the changes imposed by his injury would eventually result in a different but, most importantly, certainly not a diminished person (p. 115). John’s performances indicate that he was able to rekindle

an important part of human nature within himself. As Wlodkowski points out, John (re)realised how essential he felt it was “to be curious, to be active, to initiate thought and behavior, [and] to make meaning from experience” (p. 143). Shotton, Simpson, & Smith recount a study in which individuals arose out of depression following brain injury when they realised that they were in control of their healing: there was no luck involved in the process. I believe that the results they refer to are similar to those experienced by John.

Understandings

....of identity.

The context of John’s day to day life was in part culturally formed and in part formed by the setting in which we talked. I observed that the stories he told me were recounted for me through the filter of the person he considered himself to be at the time of the current story. So, as Hoskins (2000) suggests may happen, the stories provided clues to his evolving identity. Despite the influences I assumed his many stories had on his identity, John had a very clear notion of who he will always be: a teacher. As Flood (2000) remarks, and John’s performances showed, narrative has the power “to refigure both the past and future” (p. 207). In John’s case, as important as his stories of his life as an athlete were for him, his stories revealed that he felt his primary identity was that of a teacher. His emphatic declaration that he was a teacher was made by John several times despite the multitude of diverse experiences that he had accumulated over a long life. Many would have considered these experiences significant enough to have coloured their identities more influentially (Polkinghorne, 1996). Singer (2004) feels that all the experiences accrued during a life contribute to one’s narrative identity. Despite Singer’s remark, it seemed that John will

always view his world through an internalized narrative in which his athletic past takes a back seat. Therefore, he will forever think of himself as a teacher and a helper, not so much as an athlete. He showed his love for helping others by taking a photo of his friends, a father and son who had immigrated to Canada and who run the photo shop he frequents. He told me how he helped his own family by taking them to swim at the pool in his building, and so he took a photo of the pool (Kolb, 2008; Warren, 2005). I saw more than that: to me, the photo revealed a place to which he had access and could therefore use to help others.

John did not mention his 'I' self, a self explained by McAdams (1996, 2001), when we were discussing John's concept of identity. The list that he composed for me of his 'rules' for people that have sustained a head injury was indicative of his 'I' beliefs and feelings although he did not verbalise these ideas as such.

....of learning.

As Riessman's (2003, 2008) performative/dialogic narrative analysis takes into account the influence of context and discourse, so too did John's teaching. During classroom lessons, John taught the theory behind outdoor education. He then took his classes on field trips that provided environments in which the focus of the management of learning "is shifted from the teachers to the students" (Colardyn & Bjornavold, 2004; Eshach, 2007, p. 173; Folkestad, 2006; Gerber, Marek, & Cavallo, 2001). The work of Folkestad as well as that of Colardyn and Bjornavold reiterates that learning during field trips, not in a classroom, is not explicit, but that students learn through "doing, playing, practicing" (Folkestad, p. 139).

Learning is influenced not only by the interactions between the teacher and students, but also the interactions between the students themselves. Eraut (2007) and Folkestad (2006) note that meanings become shared as students learn and interact: the outdoor education field trips run by John provided opportunities for interaction, therefore the students may have developed new meanings. These learning environments also encouraged intrinsic motivation in the students, an aspect of learning whose importance is emphasized by Wlodkowski (2004). The students' intrinsic motivation was nurtured because the field trips took place in a setting in which they were compelled to take the initiative to practise the skills that they had learned in the classroom.

As well as offering an environment for practical learning and the development of intrinsic motivation (Wlodkowski, 2004), these trips were set up by John to encourage the students to think critically and reflectively. By providing a learning opportunity outside the classroom, John was helping students to learn how to reflect because these trips promoted "active, persistent, and careful consideration of any belief or supposed form of knowledge in light of the grounds that support it" (Dewey, 1933, p. 9). The value of Dewey's statement is reiterated by Van Woerkom, Nijhof, and Nieuwenhuis (2002), who write that it is important for students to learn to "think critically about the whys" when they do things (p. 375).

The students could also, on these field trips, learn about their own beliefs, knowledge, and points of view, and also work out how to respect those of others (Brookfield, 2004; Eshach, 2007; Law, Meijers, & Wijers, 2002). Brookfield points out that when individuals can recognize "the assumptions that undergird their thoughts and actions" (p. 341), they are learning to think critically. Eshach reminds us that these assumptions,

which I believe consist of the students' existing, conscious beliefs and knowledge, in other words, their 'I' selves, may influence what they learn and how they perform while they are learning. I agree with Law, Meijers, and Wijers, who feel that post-modernity has increased attention on the "critical, creative power of the 'I'" (p. 432). They believe that in this era, the 'I' has become "more completely the maker of 'me'" (p. 432). It seems, then, in light of these theorists' views, that the students unconsciously developed their evolving identities, which is the combination of their 'I' and their 'me' selves, as they accumulated new experiences on the trips they took in John's outdoor education classes.

Closing Thoughts

John is making the most of his life now, travelling frequently and crossing the city on his bike often. He realizes his limitations and has learned to work within them, cope with them and adapt to them (Shotton, Simpson, & Smith, 2007). His days are full: he enjoys travelling, exercise, music, and the company of others. I can't imagine how his life could have been much more full before his head injury.

Analysis of Terry Evanshen's Illness Narrative

I believe that Terry performed in a conventional sense, as if he were on a stage, all the time 'in everyday life', and that these performances revealed his authentic self, the self he believed himself to be (Aubert, 2009; Goffman, 1959). Because of his severe memory deficits, Terry was accompanied by his wife, Lorraine, during all of his performances. Lorraine played a critical role in Terry's rehabilitation and continues to be the central figure in his life today (Man, 2002; Jumisko, Lexall, & Soderberg, 2007). I believe that Lorraine's crucial role stems from her readiness to care for Terry. As Jumisko, Lexall, and Soderberg

explain, a family member's willingness to care for a loved one "is derived from their feelings of natural love and the ethical demand to be responsible for the other" (p. 353).

Negotiating the Location for Conversations

When I first arrived, Terry and Lorraine led me to the living room where they had thought I could best conduct the interviews. They did not realise that I wanted to have casual conversations with them, not the proper and formal interviews they envisioned. The Evanshens had a ritualistic view of interviews. They believed that the space should be formal; they imagined and expected a more conventional interview setting than I considered to be ideal (Bell, 2008; Goffman, 1959). As Bell (2008) explains, ritual can be traditional: "understood as carrying on ways of acting established in the past" (p. 128). I was interested in listening to the Evanshens' stories, but I also wanted to interview them interactively (Corbin & Morse, 2003). Ellis, Kiesinger and Tillman-Healy (1997) elaborate, explaining that because I used interactive interviewing, the Evanshens and I were able to derive a multitude of meanings together. I could perform my story for Terry and Lorraine while they performed theirs (Corbin & Morse; Ellis, 2004; Ellis, Kiesinger, & Tillman-Healy; Mishler, 1986; Riessman, 1993). As both Ellis and Mishler point out, during the interactive interview process, Terry and I could co-construct Terry's illness narrative as we developed a relationship.

In the end, we sat at the dining room for the interactive interviews. It seemed to provide a setting a bit more conducive to encouraging the type of conversation I was hoping to engage in and also more favourable to the performances I wanted to observe (Goffman,

1959). Goffman believes that the setting of an interview is the stage for the performance, and as such remains more or less the same for the duration of the performance or interviews.

Researcher Positioning in the Conversational Space

The first day we talked, both Terry and Lorraine asked to hear about and see pictures of my own athletic past. Because they were the first participants in the study, their questions and interest in my story helped me to feel comfortable and competent so that I felt, as Voloder (2008) writes, in the realm “of the familiar” in my researcher role (p. 27). To achieve this positioning, I recounted the ‘essence’ of my experiences for them (Medford, 2006). That gave us, together with our common knowledge of sport and head injury, a starting point from which to find common ground (Lewis, 2006; Medford, 2006; Voloder).

I wanted a more casual ‘setting’ than the dining room table that we had settled on but I knew that none was available. I think that such a setting would have helped me to better blur the line between Terry the conscious performer and Terry the person. It could also lessen the power differential that I feared would be present if I was primarily seen in my role as the ‘researcher’ (Etherington, 2007; Khawaja & Morck, 2009; Sarason, 1999). I agree with Etherington, who maintains that researchers must emerge from the protection offered by their objectivity. But Khawaja and Morck point out that when I emerged during my conversations with all the participants, I needed to remain aware of my positioning because a researcher’s positioning always “influences the research process” (p. 28). In this case, my positioning remained more ‘apart’ than I believed ideal. Partially because of the final choice of setting, I feel that I was unsuccessful at blurring or preferably erasing any line between the Evanshens and me. I will forever question whether another setting would have

contributed to, or altered, Terry's polished performance in any substantive way. The whole time I was there, I found it impossible to peer under Terry's mask to find Terry the person. I believe that his 'perfect' performance metaphorically represented his desire to 'run the show' called his life, perfectly.

Terry Performs

Initially, I wondered if Terry's conscious performance was his attempt to control me by 'forcing' an impression of himself on me. He certainly seemed to believe in the part that he was playing as well as in the Terry he was portraying (Aubert, 2009; Goffman, 1959, 2006; Worthen, 2004). Worthen's remarks caused me to wonder whether I should have questioned Terry's authenticity. But I truly believe that Terry's performance was authentic, and that Terry did really believe in himself and his own performance. I wondered whether he ever let anyone glimpse at the multiple Terrys that I am sure were hiding under the mask he performed in. I have a feeling that Terry did not let anyone, except perhaps his family, peek behind his mask. Regarding Terry's photos, Aubert notes that photos can "establish a working distance between subject and viewers" (p. 5). I think that Terry tried to do just that. Terry's photos seemed to be perfectly composed, orchestrated, and staged. They appeared to reveal that Terry continued wearing his mask while having his photos taken.

Carlson, Engebretson, and Chamberlain (2006) note that photos and stories can be used to "influence others" (p. 840). Terry's performed stories, and his photos displaying his performed selves, were ritualistic in the sense that they were performances of someone used to being the center of attention and therefore influential (Goffman, 1959). I think that this was due to his past as a football star; some of his reactions indicated that he certainly missed

being in the limelight as he had been in his football days. Do others, as Goffman (2006) suggests may happen, think that his head injury and memory deficits make him different? Terry is no longer in the limelight, but Lorraine affirmed my suspicions about Terry wanting the limelight. She commented that things were always 'all about Terry', a legacy from his football past that had become stronger after his head injury. Perhaps he had started playing football as a young person to use it as a vehicle to reach for the limelight, although at the time his reasoning was unconscious.

I observed Terry's 'front', the part of a performance that consistently functioned in the same manner, in the model of attention that he was during our conversations. I was an audience of one: he leaned forward in his chair, eyes on my face at all times (Goffman, 2006). His performance seemed to indicate that he was fully 'in' the conversation. Only when the conversation touched on how Terry and Lorraine each handle their daughter Jennifer's death in their daily lives did Terry register his difference with Lorraine. He performed this difference by leaning back and crossing his arms (Goffman, 1959; Riessman, 2008).

Control - Terry's presentation of himself.

Terry's turnout or presentation of himself was always immaculate (Goffman, 1959). I suspect that this metaphorically describes the degree of perfection to which he tries to complete tasks (Riessman, 2002a, 2003). Lorraine reaffirmed my impression: she told me that Terry is always impeccably dressed and that he completes everything she asks him to do as perfectly as he possibly can. Is Terry's perfect dress and detailed grooming a descriptive metaphor for how he prefers his everyday life to be? I think so; I believe that Terry's

turnout reflects his desire to appear confident and authoritative in his daily life after head injury (Maquire & Stanway, 2008). Maquire and Stanway studied nine individuals with an average age of twenty-two, finding that their style and turnout hinted at their desire for confidence, as I believe that Terry's impeccable turnout did.

By turning himself out immaculately, Ricoeur (1984) suggests that Terry hints at a personal characteristic that contributes to make his daily patterns "as a whole meaningful" (p. 170). Terry goes to the gym every day. Are these daily trips and his structured days another indication of his desire for perfection? I think they are, but I also believe that Terry projects himself as the 'image of perfection' in body and dress in order to control one small part of his world, his body (Charmaz, 1999). Although he was also a perfectionist before his accident, Lorraine commented that he is much more so now. Terry's performances of detail and perfection after his accident are perhaps unconscious attempts made by him to regain some small part of control of his life.

Perfect photography.

I feel that Terry continued his performance and was 'on stage' in the photos he had Lorraine take of him (Goffman, 1959; Riessman, 2008). During the photo-interview, held during our last conversation, he did not have me discard any photos (Kolb, 2008; Packard, 2008; Warren, 2005). I concur with Packard (2008), who found that photo-interviewing "reduces the authority of the researcher at least to some degree and raises the voices of the research participants" (p. 63). I felt that I augmented the co-construction of Terry's story by listening to his ideas – he wanted to keep all the photos. While taking them, Terry had precisely followed the directions I had given him: the photos visually recorded his current

evolving identity, and so showed him performing everyday tasks (McAdams, 2001, 2003). Terry was posing in each photo in what I believe was a ritualistic ‘presentation of the self’ as Goffman (1959, 2006) theorises. I think he felt compelled to pose with ‘stage props’, for one photo he was wearing his glasses, dressed immaculately, and sitting at the table while reading the paper, and in another he was dressed for colder weather than it actually was while shovelling snow. I agree with Goffman (1959), who suggested that by composing the photos in this way, he was conveying “some coherence among setting, appearance, and manner” in his daily life (p. 25).

Lorraine, the Caregiver

I listened carefully to Lorraine, Terry’s wife and caregiver, during our conversations because she seemed to be an ideal example of a partner who had stayed through thick and thin. Lorraine bore the brunt of the responsibility for his rehabilitation. Klonoff, Koberstein, Talley, and Dawson (2008) point out that families are faced with turmoil if a family member sustains a head injury. Rotondi, Sinkule, Balzer, Harris, and Moldovan (2007) note that needs change during the family’s ongoing upheaval and the injured party’s rehabilitation. Such change requires preparation and planning for the future (Man, 2002). It was essential that Lorraine stay healthy during Terry’s initial rehabilitation, and it still is now because she is his primary caregiver. The emotional, physical, and psychosocial state of caregivers, as well as the minimisation of their day-to-day stressors, is crucial to the wellbeing of TBI survivors (Hanks, Rapport, & Vangel, 2007; Koerner & Kenyon, 2007; Rotondi et al.). Jumisko, Lexall, and Soderberg (2007) write that additional stress may be felt by caregivers because some survivors of head injury need a lot of attention paid to them, and so therefore

are time-consuming and energy draining. Rotondi et al. feel that meeting a caregiver's needs "will reduce stress, promote better adaptation to injury-related difficulties, and improve outcomes" both for survivors and their caregivers (p. 15). I don't think, however, that Lorraine had tried to access any services or counselling for her own well-being. I also don't know if such services were available to her.

Identity

Who is Terry Evanshen? Terry's memory losses and his continuing inability to retain information cause him not to be able to assess many parts of his current and former selves. He cannot reflect on his post-injury experiences and selves "in relation to [his] past" selves (Gracey et al., 2008, p. 645; Lysaker & Hermans, 2007). Lysaker and Hermans suggest that access to the selves of his past would lead Terry to a better quality of life. Because of the complete loss of his pre-injury identity and his continuing severe memory problems, Gracey et al. (p. 627) prompt me to wonder how he has made "sense of, or construe[d][himself] after brain injury". According to Moss, Parr, Byng, & Petheram (2004), after a sudden, severe, and permanent disability, a person may have to "learn to think differently" (p. 753). However, it is unclear to me what Terry's thinking processes were, so it is not apparent to me if he thinks differently now. I do know, from his description of the epiphany he underwent when listening to Nolan Ryan, that he always tried his best when he played football. This characteristic is, if anything, worse now, judging from his lawn mowing and snow shovelling.

Nochi (1998) finds that survivors may possibly live any or all of three regressive narratives of the self listed by Gergen and Gergen (1984). First, they lose a clear

understanding of themselves. But, in Terry's case, because of his memory deficits, he only lives in the present and avoids the self-comparison of current and pre-injury selves that Gracey et al. (2008) comment many survivors can't avoid. In his present life and in his (imagined) future, he understands himself as a motivational speaker. Second, when survivors compare themselves to who they were, they feel diminished. But, how can Terry feel diminished since he can't remember his past? A study led by Lavalley & Robinson (2007) found that the gymnasts they studied had to "distance themselves from their pasts" in order to establish their retirement identities (p. 119). Lastly, survivors sense that others view them as less than who they were. Terry has experienced some stigma, but, according to Lorraine, because they generally keep to themselves, they avoid the scrutiny of others (Admi & Shaham, 2007; Lai, Hong, & Chee, 2001). Admi and Shaham explain in their study of people with epilepsy that outsiders often view chronic conditions as having a greater impact than do people with these conditions. Outsiders may feel threatened: they may wonder if the stigmatised are contagious.

Type of Narrative – Quest

One of Terry's responses to his injury has been to use his experience to help others. Terry told me that he is "reaching and touching people today to become better human beings". That he does motivational speaking is evidence of the quest narrative that he lives and it hints at how he currently perceives himself (Frank, 1995; Riessman, 2002b). Frank defines a quest narrative as "the ill person's belief that something is to be gained through the experience" (p. 115). The act of speaking in public, has, according to both Terry and Lorraine, had a very positive impact on Terry's self-esteem (Gardner, 1983). When

speaking, Terry uses his experiences to tell others about his journey, and also to shed some light on head injury for those who are unfamiliar with it. He hopes to enlighten his audience, some of whom are perhaps uncomfortable in his presence because of their lack of knowledge.

Frank (2006) looks at how stories are told as opposed to delving into their content. After reading Frank's article, I consider Terry's quest story also to be a story of 'strategic health' because through his motivational talks he helps not only others but also himself (Frank). This type of story describes "how to get, for oneself, health that other people will miss out on because they lack necessary strategies" (Frank, p. 425). Terry is getting something for himself through his motivational speeches because they have allowed him to identify himself as his own person and they help him to feel that he exists separately from Lorraine.

Terry is very fortunate to have Lorraine in his life. Her constant presence enables Terry to be exactly how he wants to be. I sense that whatever Terry's life brings, she is there for him. Perhaps if the opportunity for public speaking had not arisen, Terry's life would be much more geared towards himself. His existence is, after all, according to Lorraine, 'all about Terry', although to outsiders it seems to be much less self-serving than Lorraine says it is. I believe that, and Lorraine agrees, that he was also 'all about Terry' before his injury. According to Frank (1995), he could fall into three categories, chaos, restitution, or quest. But, in what category would Terry fit were his quest not discovered in his public speaking? I wonder whether he would have looked elsewhere for another 'quest'?

Learning

The severe memory deficits that Terry was left with make it difficult to learn new skills or to relearn old ones (Marsick & Watkins, 2001; Strandberg, 2009). In Terry's case, learning opportunities occur over and over again because Terry's memory does not allow him to remember for long what he has learned. So, what was he really learning? It seems that Terry has been able to learn strategies for his day-to-day activities, including strategies that enable him to function with his severe memory deficits. For instance, he has learned how to turn conversations around so that he is the listener asking questions, not the person talking and answering questions. Terry learns when he is faced with a new challenge in his daily life and he discusses how to approach it with Lorraine (Eshach, 2007; Livingstone, 2001; Taylor, 2006). Terry is learning from life experiences but I was unable to discover how Terry can manage his own learning with his severe memory deficits.

Terry took photos of the cards he uses for his talks on which he has written every word of his motivational speech. Following the ideas put forward by Riessman (2002b, 2003), he can make "claims about himself" because he can rely heavily on his cards (Riessman, 2003, p. 5). So, he is able to perform the 'perfect' Terry when he gives his talks. In this case the performance is for a larger audience: the cards enable him to perform 'perfection' for the listeners.

An Epiphany

Terry experienced an epiphany, a "sudden, abrupt, and positive transformation [that]...was profound and enduring" (Denzin, 1989; Jarvis, 1997; McDonald, 2008, p. 90). Denzin writes that such an event can mark a life. Terry's epiphany occurred when he heard

Nolan Ryan, a baseball Hall of Famer, speak about his concentration and focus during an interview on television. Because it briefly gave Terry access to his past, Ryan's comment made a lasting impression (Denzin, 1989; Hyvarinen, 1998). The epiphany that Terry underwent had the effect of allowing him to relive what the experience of playing football had meant to him. It showed Terry how "the fundamental meaning structures" in his current life were the same as those in his past by allowing him to remember how he used to be, albeit only for a moment (Denzin, 1989, p. 70). Watching Ryan's interview gave meaning to Terry's lost experiences by providing a brief window of memory for Terry to look through before the window slid shut again.

Terry's perfectionist tendencies of today were made meaningful and given context because he was able to briefly glimpse the perfect football player he had been after hearing Ryan. Despite his memory problems, the experience had been so meaningful that Terry had remembered it clearly (Denzin, 1989; Loyttyniemi, 2001). As Loyttyniemi explains, life experiences are best remembered when they have 'profound meaning'. Remembering Ryan's words, vividly but certainly not elaborately, illuminated part of the old Terry that had previously been inaccessible to him (Hyvarinen, 1998; McDonald, 2008). McDonald points out that an experience like the one Terry underwent helps individuals "to gain insight and perspective" (p. 90). I found it interesting that he was able to describe the epiphany to me despite his memory limitations. Was he able to remember this event because, as McDonald suggests, the epiphany helped him gain insight and perspective? It was one of the only memories to stay with him.

Memory

Although Terry speaks clearly and his conversations appear logical at the time, when I looked at transcripts of the conversations at a later date and tried to make sense of what he had said, I realised that a lot of what he had told me was difficult to decipher. Terry's memory deficits are significant. He did tell me that he didn't know what he was going to say until he was speaking, and that certainly seemed to be the case when I read the transcripts of our conversations. Terry claims to remember nothing from the time before his accident, but he does, in fact, retain some bodily memory of his football days. These memories are evident when he watches football games and can predict the next play (Culbertson, 1995; Kleinman & Kleinman, 1994). While watching football on television, Culbertson suggests that Terry's mind seems to remember "as if possessed of a life independent of will or consciousness" (p. 169). At these times, as Venken (2009) reminds, Terry exhibits bodily memory through his non-verbal performances; his body functions as a 'keeper of the past'.

Riessman (2002b) maintains that "language is viewed as a resource" by narrative analysts (p. 5). Terry's resourceful use of language came into play when he told me that he used language to steer conversations away from himself. In the role of the active conversationalist, he found that he was able to manage his identity, that of a Hall of Fame football player who had sustained a head injury, and conceal his memory problems. Cloute, Mitchell, and Yates (2008) note that survivors of head injury sometimes use concealment as a strategy to manage such a loss of identity. Terry could ask questions and avoid answering them, therefore using language as a resource to hide his memory deficits. Engineering conversations in this way enabled Terry to be in control so that he would not feel 'othered'

or stigmatised. Instead, this situated him in a position of domination and power, not one of subordination, despite his memory deficits (Goffman, 1963; Johnson, Bottororff, Browne, Grewal, Hilton, & Clarke, 2004). Johnson et al. explain that othering can be perpetuated because the practice serves to “reinforce and reproduce positions of domination and subordination” (p. 254). To avoid feeling subordinated and ‘different’ because of his memory, Terry tried not to place himself in situations in which othering would occur.

Ricoeur’s (1984) hermeneutic circle is a spiral encompassing both the apprehending of one’s world “and the advance of self-understanding in the presence of new worlds” (p. 171). I believe that Terry has figured out the world he now lives in and he understands himself in this world despite his severe memory deficits. I believe that, because his world is simplified and he follows a fairly regimented and self-imposed routine, he is certainly able to hide these deficits well. I think that his compromised memory has contributed significantly to his world, making it smaller and more manageable, leaving Terry free with no need to make decisions that influence his movements. I think, after listening to and observing Terry, that Terry does not expose himself to new worlds.

Stigma

I was interested to hear if the Evanshens had felt stigma (Goffman, 1963), and, if so, how it had manifested itself. After head injury, Nochi (1998) remarks that survivors’ social worlds are influenced by their interactions with others. According to Admi and Shaham (2007), stigma is associated with “biased attitudes derived from ignorance, helplessness, and fear” (p. 1178). Terry told me that he sometimes “feels people looking at him sideways” (Smith, 2002, p. 317). From that comment alone, I know that he experiences stigma and that

he perceives, through the way that these people regard him, that he is different than they are (Smith, p. 317).

Lai, Hong, and Chee (2000) believe that stigma originates in perception. People, as Lorraine observed, may not accord Terry the same degree of respect as everyone else because they notice that there are differences based on their preconceived notions of head injury. Unfortunately, disability “often overshadows personal identity” (Lai, Hong, & Chee, p. 113). Who Terry used to be is no longer important and, sadly, nor is who he is now. People are often unsure of how to interact with Terry; they feel uncomfortable because they don’t know how to react to him (Admi & Shaham, 2007; Lai, Hong, & Chee; Goffman, 1963). As a result, the Evanshens can feel stigmatised, but I believe that Terry and Lorraine have internalised the stigma they feel and now sometimes feel othered (Johnson, Bottoroff, Browne, Grewal, Hilton, & Clarke, 2004; Lekas, Siegl, & Schrimshaw, 2006). Admi and Shaham point out that self-perception can play a role in how stigma is experienced. Perhaps Terry and Lorraine perceive themselves as ‘different’ and unknowingly perpetuate stigma? As Johnson, Bottoroff, Browne, Grewal, Hilton, and Clarke note, othering, and I believe stigma, can “reinforce and reproduce positions of domination and subordination” (p. 253). Does Terry feel less powerful as he did as a football star? My suspicion is that he does, as witnessed by his constant attempts at control. To counter stigma, Rotondi, Sinkule, Balzer, Harris, and Moldovan (2007) explain that it is important for the stigmatised to be “accepted ‘as who you are’ by family in particular, but also friends, and to be involved with each as they had in the past” (p. 22).

Closing Thoughts

Terry's photos revealed something that I found interesting. None of his photos look forward, toward the future. For most of us, Clandinin and Connelly (2000) remark that life "is filled with narrative fragments, enacted in storied moments of time and space, and reflected upon" (p. 17). But what about Terry? He lives in the present because his memory deficits do not give him access to his past. In addition to his missing past, the photos seem to show that he just lives day-to-day without thinking about the future. I wonder whether Terry thinks about the future? If he does think about the future, how does it present itself?

Analysis of Dave Irwin's Illness Narrative

While I stayed as a guest with Dave Irwin and Lynne Harrison in Canmore, Alberta, I observed that in their daily life they manage to live without constant reference to Dave's head injury. Dave is not sure what he would like to do next; he is not yet ready to adapt his lifestyle to accommodate the residual deficits from his head injury so that he can begin to resolve, as Charmaz (1995) aptly writes, "the lost unity between body and self" (p. 657).

Type of Narrative - Restitution

Frank (1995) maintains that when someone is living a restitution narrative, the plotline is straightforward. Individuals believe that "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (p. 77). Dave's restitution narrative is evident in his skiing schedule. He carefully marks down each day that he has skied; his goal is to ski at least half of the days that the hill is open. Lynne recognises that Dave skies as often as he can in an attempt to re-establish his old lifestyle. Dave's stories seemed to be testimonies,

described by Felman (1992) as bits and pieces of memory that have flooded the individual before these memories have been fully comprehended, remembered, or understood (cited in Frank, 1995). Dave is just beginning to understand the impact of the injury and has not yet accepted the changes it has made to his skiing life. Evidence of the narrative type that Dave lives can be seen in one of the photos that he gave me, a highly doctored photograph of him 'pretending' to race soon after his injury. His pride of this picture was visible in his performance when he showed it to me; he stood tall, smiled broadly, and then posed next to it and asked me to take his picture (Riessman, 2008).

Lynne knows Dave is frustrated by doing nothing meaningful each day, so she has begun to quietly encourage him to find something that he really wants to do. However, following Charmaz (1999), his head injury still "dictates daily life. It shapes lasting meanings. Suffering can seep into and transform the self. Suffering can lead to either development or diminishment of self" (p. 366). I believe that Dave still suffers. He has not fully accepted the changes to his lifestyle that the injury necessitated and he is at a loss when trying to decide what to do with his life (Shotton, Simpson, & Smith, 2007). Dave is still at the stage that Shotton, Simpson, and Smith describe, when the survivor still hopes someone "will 'wave a magic wand' and everything would be as it was" (p. 862). When he was injured, Dave experienced what Charmaz (1983) explains is a "a crumbling away of [his] former self [image] without simultaneous development of [an] equally valued new [one]" (p. 168). His currently lost self is palpable in the photo he took of his empty desk at *Mountain Image*.

The illness narrative I constructed from Dave's stories is highly influenced by the contextual backgrounds of his stories. His first stories were steeped in the culture of high level ski racing and the more recent were coloured by his experience of head injury. It was apparent in the stories of his past that the stories were influenced historically and socially by his identity as a Crazy Canuck (Smith & Sparkes, 2008a, 2009). His more recent stories reflect that he, and Lynne even more so, both noticed and felt the stigma attached to head injury (Frank, 2004a; Goffman, 1963; Riessman, 2003, 2008). According to Goffman, Dave now possesses "an undesired differentness" (p. 5). Despite feeling this stigma, Dave is aware and proud of social influences on his current life; he included many pictures of his friends in his life at home and his life in the coffee shop (Riessman).

Is Dave's story truly one of only restitution? I believe that his story may be one of restitution with glimpses of quest, but one that still leans readily towards chaos. Frank (1995) describes a chaos narrative as revealing "vulnerability [and] futility" in the individual's life, as Dave's story does (p. 97). Dave showed me that he realized that he was going to have to search for another focus in his life. I sensed his reluctance to do this. Although he knew that he would have to accept his changing life, befitting a quest narrative, he also did not let go of the futility and frustration he felt, a characteristic of a chaos narrative.

The Site for Most Conversations

My conversations with Dave were extremely casual when I compared them to the organised daily schedule that the Evanshens live by, a schedule that emerged when Terry, Lorraine, and I planned the time for the next day's meeting. During the days I spent talking

with the Evanshens, I had time to digest the conversation and ready myself for the next day. In contrast, I talked with Dave in unplanned conversations, whenever and wherever I could capture his attention, usually first thing in the morning in the kitchen of his house.

Participant positioning.

Dave's performance was the same every day at this time, evolving naturally when he positioned himself at what Lynne told me was his regular morning location (Reissman, 2002a, 2003). He sat at the counter island in the kitchen wearing his bathrobe with his feet up on the island and his hair ruffled, clutching a cup of coffee. Dave did not seem to attempt to keep me at arm's length during our conversations. This was observable in his performance which included his extremely casual attire and posture. From this unconscious, nonverbal performance, I believe that Dave was indicating that he felt comfortable and 'at home' in my presence (Reissman, 2002). I also sensed, however, that Dave was continually trying to put me in a position of less power. Had he, as an article by Khawaja and Morck (2009) suggests, felt less confident about his ability to place me in this position, or felt instead that he was being placed in the position of the Other, I think he would not have presented himself as casually for our conversations. I believe that perhaps he felt that his athletic career had been greater than mine, so in order to assert this claim, he felt it necessary to place me in positions less powerful than his own.

Caregiver and researcher positioning.

While Dave and I talked, Lynne painted quietly. By remaining in the background and performing her own task, she was able to be attentive at all times to our conversation. She did not interrupt save for the few times she felt that Dave had missed something important.

Dave was aware of this and also, perhaps unconsciously, proud of Lynne as I believe his photograph of her while she was painting attests.

Lynne and Dave invited me to stay at their house so I was a guest. At the same time I could be a variety of researcher selves, as Reinharz (1997) points out, each one independent because of the location of my bedroom in the basement of the house, and the fact that I had rented a car. Although I had imagined that I would be an outsider, I found that I was treated as, and felt as if I was, a friend, a position in which Ellis (2004) remarks qualitative researchers desire to find themselves.

Performance

Bruner (1990) suggests that my conversations with Dave in the kitchen formed “a sense of the canonical and ordinary as a background against which to interpret and give narrative meaning to breaches in and deviations from ‘normal’ states of the human condition” (p. 67). I believe his daily morning performance was an assertion of his ‘normality’ in spite of his head injury (Reissman, 2008). Although he is still healing, the ‘normality’ of Dave’s daily routine was in stark contrast to his days a few years ago when each and every moment was dedicated to recovery from head injury. I believe that Dave positioned himself at the kitchen island, and then took and chose the photos he did in the photo-interview that was our final conversation, because he was performing the ‘normality’ of his daily life (Holm, 2008). Holm suggests that photography can be performance, both as “a form of investigation and a form of representation” (p. 2). I think that these pictures, and the performances within them, indicate that Dave was making sure that I, his audience, knew that he was not only ‘normal’ but also that he was not a stigmatised person. Perhaps Dave

desired to show that he had power over me because he felt he had been a greater athlete and had experienced a worse head injury (Eakin, 2008; Goffman, 1963; Kolb, 2008). I believe, judging from the quantity of photos that he took, that Dave feels empowered when given the camera. As was apparent in the case of Kolb's participants, the camera aided Dave to make explicit his perspective for me and eventually for the readers of his story.

Understanding of Learning

I liked Dave's view of learning and recovering. He told me that he did not think learning and recovery were the same and then proceeded to explain why. He believes that one has to learn while recovering but that learning can also take place without individuals having to recover. Although Dave is clear about his thoughts on learning and recovery, I sense that he thinks he will be 'finished' recovering at some stage, a typical response from an individual living a restitution narrative (Frank, 1995). Frank explains that a restitution narrative has a simple plot: when individuals are ill they assume that over time they will recover to be just as they always were. When I talked to Dave, he was six years post injury, and he was just beginning to realise that he was not living a restitution narrative, that he will not recover completely but instead he will always be recovering because his head injury has changed his life forever (Parsons & Stanley, 2008; Frank). When I spent time with Dave, he was only then becoming aware that his injury would not follow a restitution storyline. Lynne, the person who is closest to him and who has stayed with him since he was injured, knows that Dave has had "difficulty adapting" to the consequences of his life altering injury (Parsons & Stanley, p. 231). Dave has not yet come to terms with the fact that, as Parsons

and Stanley found in their study, “Things are different now” (p. 231), and that in order to be content in his life, he must accept this.

Because of the multiple impairments Dave has been left with, he will forever be (re)learning and internalising routine skills, interpersonal behaviours, and intra-personal attitudes (Gardner, 1983). In a study by Parsons and Stanley (2008), learning was an important occupation as the participants adapted to their new lives with brain injury. The skills Dave uses to learn may be culturally and socially specific to the life he leads now, a life which involves his evolving post-injury self. However, by necessity, this life is now continuously moving farther away from his former ski-racing self (Daiute, 2004, Frank, 2004b; Hardin, 2003). Frank comments that a person who is suffering is still sculpting his or her own life, as Dave is now doing. Daiute explains that “telling one’s story creates one’s self-concept” (p. 112). In this case however, does Dave want a ‘head injured’ self-concept as he shapes his life? I believe he performs that he does not: he seems to be trying to perpetuate the Dave that was a skiing hero.

Before.

Dave explained to me all the learning he used to do when familiarizing himself with a ski course; he had to accumulate and memorise knowledge critical to all aspects of the race, for example how to complete the course quickly and safely (Folkestad, 2006). He knew exactly what line he was going to ski. The head injury he sustained in 2001 changed what he needed to know and how he learned.

After his accident.

Following head injury, old knowledge is sometimes no longer of any use. Not useful is Dave's practical knowledge of ski racing, outlined by Livingstone (2001) as knowledge that stresses "direct experience in various situated spheres" (p. 4). Dave's meaning perspectives are not the same after his accident. These include, according to Mezirow (1985), his pre-injury "structure of cultural and psychological assumptions", which he had drawn on before his injury to "assimilate and transform new experience" (p. 21). This knowledge is of little use to him in his new life because his new experiences are no longer relatable to his pre-injury knowledge.

Memorization is now not an option as a learning tool that Dave can use. Strandberg (2009) explains that memory impairments prevent individuals from easily learning things and then remembering them. Soon after his injury Dave began learning without realising it, although he told me that he now knows that during that time he was reaffirming many old skills as well as learning new ones, as happened in Marsick's and Watkins' (2001) study. His learning since his accident has been learning as Livingstone (2001) describes: tacit, incidental, and spontaneous. Lynne shared with me that it continues to be so to this day. I believe that, by including photos of his friends, Dave was hinting at the learning he had undergone at the coffee shop that enabled him to carry on conversations with these friends. Skiing, which Dave did not relearn but did remember, was for him, as Venken (2009) notes, a bodily memory, a legacy from his past.

Learning new skills is helping Dave to cope with a multitude of possible post-injury deficits including, Shotton, Simpson, and Smith (2007) suggest, "cognitive impairments,

emotional disturbance, interpersonal difficulties and behavioural problems” (p. 857). These may occur in part because, for Dave now, both making interpretations and the expression of these interpretations, seem to be more difficult. Mezirow (1994) writes that a meaning scheme is “the constellation of concept, belief, judgment, and feeling which shapes a particular interpretation” (p. 223). Dave has lost his ability to formulate each interpretation he makes with the help of a meaning scheme. He now seems to be unable to access some of his pre-injury beliefs and feelings, ones that may have contributed to the shaping of his meaning schemes and his morality (Collinson, 1996; Verkerk et al., 2004). Verkerk et al. explain that morality is one element of an individual’s identity.

Dave’s Understanding of Identity

Dave will always consider himself a ‘Crazy Canuck’. Ezzy (1998) remarks that when people build their identities “Both memories of the past and anticipations of the future are symbolically organized and manipulated to provide a coherent self-concept that serves to direct current actions” (p. 241). I believe that Dave’s search for identity is made more difficult because he is missing a large piece of memory, the ten year period immediately preceding his accident. Because of this hole in his memory, Dave is at a loss to know who he was right in the time before he was hurt, and so is clinging to his old identity of a Crazy Canuck. Being a Crazy Canuck forms an important part of his past that he refuses to let go of. It is the part of his life as a skier that he remembers. He emphasised over and over that he will always be a Crazy Canuck, which indicated to me that being one is a hugely important part of his *idem*, or, as McAdams (2004) describes, his ‘me’ self.

Rimmon-Kenan (2002) notes a life changing event can rupture the continuity of a life story. As an example, she explains that in general, after cancer diagnoses, individuals' pasts seem to no longer be part of their bodies. In Dave's case, his pre-injury existence as a skier was severed. But, although it seems that he can no longer live a skiing life as he did in the past, he still tries to perform his ski-racing self and so skis more and more often. I believe that because he used to perform a skiing lifestyle, he is attempting to exert his autonomy by being the same person he used to be. According to Frank (1995) this is typical behaviour for someone living a restitution narrative. I think that Dave believes that he will be 'fixed' or 'cured' when the right medicine is found. One advantage to Dave's frequent skiing is that he is becoming less reliant on Lynne. Strandberg (2009) writes that although significant others are initially important supporters, over the longer term survivors of TBI themselves become the parties that are responsible for the services they need. But significant others are, according to Strandberg, the initial "driving force in the training and preparation for the life-situation after the injury" (p. 292).

Self-esteem.

Gardner (1983) lists intra-personal characteristics as those relating to the inner aspects of a person. Collinson (1996) and Verkerk et al. (2004) appear to agree that a healthy intra-personal identity suggests a capacity for reflection and introspection, an understanding of one's self, and indicates maturity. Dave's intrapersonal self, including his sense of self, self confidence, and self-worth, had been shattered by the accident. Ricoeur (1999) notes that self-esteem has two components: "the ability to act on our intentions and the ability to produce, by our own initiative, efficacious changes in the course of events" (p. 51). Dave

seems not to have not yet (re)established any confidence in himself nor has his self-esteem improved. I believe that Dave is at a loss because he has no real intentions; in the course of a typical day he does not have a plan involving any significant activity other than skiing. Dave poignantly illustrated this loss of purpose and direction in his life with the photo of his empty desk at *Mountain Image*.

Dave's course of events in a day contains few situations in which his self-esteem would be bolstered. Perhaps he skis as much as he does so that he raises his self-esteem. I suggest that clearing his trail also heightened his self-esteem. If Dave worked at *Mountain Image* part time, as Lynne thinks he is ready to do, I believe that he could bring to fruition his ideas for new designs for pins and logos, and potentially improve his self-esteem. He took a photograph of pins he had designed as an illustration of our conversation and of the importance of the pin designs. Perhaps Dave doesn't play an active role at his office because he thinks that he will no longer would be 'the top performer' there.

Control

Rimmon-Kenan (2002) found that in her case, which occurred when she contracted an autoimmune neurological disease, the need to control had "itself been controlled by the unpredictability [of illness]" (p. 10). Was this the case for the participants as they (re)constructed their identities? I found the opposite seemed to be at play; I believe that both Terry and Dave needed to be in control, perhaps due to their diminished stature or perhaps the stigma associated with their injuries (Goffman, 1963). The participants strived to be in control of the impressions that they made on me, presenting themselves on stages, as we all do and as Goffman (1959) theorises. Terry Evanshen always performed that he was in

control; this was visible in his impeccable turnout. Dave also tried to be in control; some of his performances were unconscious attempts at regaining the control he had lost after the accident. These performances took the form of endless grammatical corrections while I was speaking. Lynne had warned me that this would happen. As well as pointing out that I make countless grammatical mistakes, Dave commented on how many times I said ‘umm’ during our conversations. Upon reflection, although irritating, Dave’s concern with my use of language stressed importance of language; as Ricoeur (1999) claims, “although not everything is language, nothing in experience arrives at meaning unless it is borne by language” (p. 48). I wonder, in the cases of both Dave and Terry, if they may also always have performed perfection before their injuries?

Stigma

Coleman (2006) remarks that stigma is a “special and insidious kind of social categorization” (p. 145) that occurs when people, as they are wont to do, generalize the stigmatised person’s behaviour as stemming from one particular event. In the case of Dave, the event is his head injury. Any stigma or othering perceived by Dave and Lynne place Dave in a space that is in direct contrast to how Dave Irwin, the Crazy Canuck skier, was looked upon before his accident. At one point, Lynne talked to me about the stigma towards Dave that she notices. Although Lynne experiences stigma, she is not certain that Dave picks up on it. People who have seen Dave since his accident have various reactions, sometimes they have stigmatising expectations of his behaviour that are based on stereotypical understandings of head injury. Kit (2009) explains that a stereotypical view of head injury can occur when individuals expect to observe cognitive deficits in a person who

has experienced a head injury. These individuals may then, as Goffman (1959) writes, apply “untested stereotypes” to that person, stigmatising them (p. 1). Individuals can be stigmatised if, Coleman (2006) explains, they represent “a view of life; a set of personal and social constructs; a set of social relations and social relationships; a form of social reality” that the person who is stigmatising finds abnormal (p. 141). Quite possibly, the way an individual now behaves is in contrast to how the person who is imposing stigma understands ‘normal’. When Dave comes in contact with people he had last seen in the earlier parts of his recovery, these people sometimes expect him to still be back at the same point in his recovery that he was at when they last saw them (Bury, 2001). This may occur even though, as Bury points out, the sufferer (Dave) may be experiencing “altered relations of body, self, and society brought about by illness” (p. 274).

Goffman (1963) reminds us that when an individual is stigmatised “He is reduced in our minds” from a “whole and usual person to a tainted, discounted one” (p. 3). Dave has been unwittingly reduced to a fractured individual. Part of Dave’s ‘me’ self is that he sustained a significant head injury while skiing. As well as stigmatisation, Dave feels ‘othered’ due to the marginalisation and exclusion he often experiences (Kleinman, 1988; Johnson, Bottorff, Brown, Grewel, Hilton, & Clarke, 2004). Being othered, can, according to Johnson, Bottorff, Brown, Grewel, Hilton, and Clarke, reinforce the position of subordination that Dave already feels.

Closing Thoughts - A Changed Person

Dave is now struggling because he has realised that he faces a decision about what to do. Skiing was his life and occupied most of his time. Now, skiing can no longer be his main

focus, so he must search for a new source of experiences to give meaning to his life. At the same time he must learn to adapt to this new life, a difficulty which was overcome in Parsons' and Stanley's (2008) study. In that study, two participants' recovery was facilitated by, among other factors, learning. Shotton, Simpson, and Smith (2007) comment that some survivors – I suspect that Dave may be one - may find it extremely stressful “to confront a life that is likely to have lost some previously valued meaning” (p. 857). Ashe, Taylor, and Dubouloz (2005) note that in their study, the ability to cope with life-changing illness was made possible through evolved meaning perspectives, or changes in “feelings, values, and beliefs” (p. 280). But Dave has not yet come to terms with the changes imposed by his accident. Thankfully, Strandberg (2009) maintains that “outcomes and recovery represent a prolonged process, which is probably never ending, but over time, it can become an integrated part of life” (p. 293). I wonder if Dave will ever be able to integrate the changes he is experiencing that were imposed by the head injury? How will he adapt to this new life? At the time I spoke with him, his new life seemed to be difficult for him to become accustomed to.

Analysis of Jim Kyte's Illness Narrative

Jim Kyte seems not to be constrained by his lasting, albeit minor, impairments, which, according to Shotton, Simpson, and Smith (2007), can typically include vertigo, dizziness, and some trouble verbalizing. His intrinsic motivation, energy, and passion, revealed during our conversations, seem to have helped him to move fluidly between the culture of hockey professionals, the culture of individuals who have sustained head injuries, and the culture of academia (Deci & Ryan, 2008a, 2008b; Vallerand, 2008; Wlodkowski,

2004). Deci and Ryan (2008a) describe intrinsic motivation as occurring when “the activity itself is interesting and spontaneously satisfying” (p. 15). Intrinsically motivated individuals derive positive feelings from performing an activity, not from the rewards received when an activity is performed. According to Wlodkowski (2004), learning can be an intrinsically motivating activity if people are given choices so that their learning is personally relevant. I believe that Jim has moved from the intrinsically satisfying position as a professional hockey player to one that is also motivating: an educator.

Positioning

Our first meeting was in a coffee shop. I found it interesting that Jim wanted to conduct the interactive interviews in this casual setting, rather than in a more formal venue as had been the case with Terry Evanshen’s initial suggestion and John Beedell’s living room setting (Corbin & Morse, 2003; Ellis, Kiesinger & Tillman-Healy, 1997). I think that I was taken aback by the coffee shop: because I was interviewing him during working hours, I must have expected the conversations to be more formal than they were. However, I believe that Jim was on the right track when he suggested the casual setting of the coffee shop. Ellis, Kiesinger and Tillman-Healy remark that the relaxed setting of the coffee shop - “the dynamics of the interview situation” (p. 122) - would contribute positively to the understandings that both parties derived from the conversation. However, on subsequent days, because the coffee shop was too noisy and too distracting, we met at Jim’s office at the college. I don’t think that continuing the conversations in Jim’s office was an attempt made by Jim to control these conversations. Corbin and Morse explain that the opposite is true: the more casual a setting is, the more control interviewees have because they are “the central

actors.....telling their stories” (p. 339). It was fascinating to experience how different locations can impact how conversations proceed and meanings are made.

Performance

Jim performed successfully as a hockey player because he was autonomously motivated, a type of motivation that occurs when intrinsic motivation is combined with extrinsic motivation. Individuals then integrate this drive “into their sense of self” (Deci & Ryan, 2008a; Deci & Ryan, 2008b, p. 182). While playing hockey, Jim performed for an audience of hockey fans all the time; a large part of the job of playing a sport professionally is to entertain the audience (Daniels, 2006; Kelly & Hickey, 2008; Parry, 2009). According to Parry, the stereotypical view of life as a hockey player is an individual living a glamorous lifestyle, in which skill is combined “with devotion to family, charity work and a place in popular culture” (p. 212). Jim certainly fit this stereotype. But, despite the importance to any professional hockey player of maintaining the identity of ‘a hockey player’, Kelly and Hickey note that “an elite performer has a private life and a public life” (p. 384). Jim emphasized throughout our conversations that his private life was of primary importance. Jim did tell me that however idyllic the ‘lived value’ of a hockey player’s life appears to be, when examined more closely, his performance as a hockey player can be summarized in these words: a means to support his family.

Jim did not initially perform the part of a teacher. However, I did observe that several of his performances were “less of particular skills than of recognized and culturally coded patterns of behaviour”, behaviour that I believe are conventional for a teacher (Carlson, 2004, p. 72; Riessman, 2008). Carlson notes, and Goffman (1959) agrees, that

during these performances Jim's teacher 'front' meant that some elements of his performance stayed the same throughout the times we spent together. As an observer who is not a teacher, I believe that Jim's performance of being a teacher included leaving his office door open at all times, so that he would always be available to both staff and students. Although I regard this behaviour as stereotypical of a teacher, it may have been school policy. When I gave Jim the story I had written about him, he returned it edited as a conventional teacher would. In this sense, Jim's performance while at his office was ritualistic (Goffman). I believe that he performed in the manner one would expect of a stereotypical teacher. Carlson (2004) writes that our lives are structured by our performances. To wit, Jim 'wore' his teacher self as a mask that made certain rituals essential parts of his performance, although I found that, unlike the mask that Terry Evanshen wore, it was never difficult to peer underneath Jim's mask.

Identity

As can be expected, Jim's hockey career ending injury was unwelcome and unanticipated (Hyden & Brockmeier, 2008). But, although the head injury required a significant length of healing time, it did not leave him with cognitive or psychosocial deficits or in circumstances that would not allow him to pursue a new career (Chamberlain, 2006; Steadman-Pare, Colantino, Ratcliff, Chase & Vernich, 2001). Chamberlain remarks that what sometimes happens, and what Jim experienced, is that head injury can be 'invisible' to others. Steadman-Pare, Colantino, Ratcliff, and Vernich found that one of the factors governing the quality of life of survivors was that they had employment.

Fortunately, Jim had prepared for his retirement from hockey: he had had the foresight to realize that one day, his hockey career would come to an end so he had taken courses in preparation for this inevitable change in his life (Tinley, 2002). Tinley remarks that the changes encountered upon retirement from professional sport can cause emotional upheaval as these individuals “face the daunting task of redefining their personal identity” (p. 1). For the golfers in the study undertaken by Douglas and Carless (2008), retirement caused significant ‘personal trauma’. Although Jim was ready for his retirement, his head injury ended up being a large part of his journey towards a new career, a part he had unintentionally embarked on. So, between his hockey and teaching selves and careers, he was obligated to make what Frank (1995) calls “significant vocational and personal changes in....[his] life”, and, as a result of his injury and during his recovery, forced to make these changes happen (p. 116).

Despite the changes his injury forced him to make, Jim elaborated on the fluidity between his hockey ‘selves’ and his teaching ‘selves’. He remarked on the experience he had accumulated during his time as his hockey ‘selves’, and how these experiences had enabled him to become his teaching ‘selves’ without a major search for new direction in his life. (Gergen & Gergen, 1984; Loytteniemmi, 2001; McAdams, 2003; Myles, 2004). Jim was spared from what Myles found in his study of the adjustment of survivors of head injury to change: that many survivors deny change after their injuries and so “begin to experience loss of sense of self” (p. 487). Loytyniemmi remarks that life transitions, in this case head injury, only become so “when they are given that meaning” (p. 200). Jim did not allow his injury to

be a 'life transition': at the time, his retirement was imminent, so, in any case, he was on the way to a new vocation.

As he performed during our conversations, Jim revealed who he had become at the time of each story – a hockey player, a parent, a teacher. Fittingly then, each self I saw was “a product of the scene [being performed], not a cause of it” (Goffman, 1959, p. 252). Jim now describes himself as a teacher. The positive self-esteem I witnessed may have been due to his success as a teacher. When he became a teacher, the sense of life-validation he had felt from fans as an admired hockey player returned again. Once again he felt successful, now performing in his role as an educator. Tinley (2002) remarks that when athletes exit from sport, “there is potential for [them] to experience a variety of emotional feelings different from those they had become accustomed to as an athlete”(p. 1). He adds that they may experience “depression, confusion and loss of identity” (p. 2). Jim seems, to a large extent, have dealt with these negative emotions.

Photography.

Unlike the other participants, Jim had no interest in taking pictures to visually portray his identity. He performed his position by questioning the need for this part of the research several times: each time I told him that it was up to him whether he took photos or not. I thought a lot about why he had resisted taking photographs. I believe he felt protective of his family and thought that taking pictures of them would invade their privacy. He believed, as Aubert (2009) recounts, that the photos would transform their private life into public knowledge. Jim took photos of his children, but he took few other photos. I was disappointed. During the photo-interviews with the other participants I had encouraged them

to 'engage' with the photos they had taken by telling stories about them (Chalfen, 1987; Kolb, 2008; Miller & Edwards, 2007; Warren, 2005). Warren feels that when photography is used in this way, participants may feel that they have more say in the research. In Jim's case, he didn't seem to acknowledge the benefit outlined by Warren. Kolb notes that a discussion with the photographer about photos taken, encourages participants "to share insights and perspectives" (p. 1). Again, Jim forfeited this opportunity. As I noted in his story, he was protective of his family, so he may have felt that taking pictures of his life was an invasion of their privacy. As Barthes (1981) explains, the image seen in a photograph is never far from the scene or individuals that have been captured by the photo. Although he provided me with photos of his family simply to put faces on their names, Jim did not want the scenes of his life and identity available to others. He did not have anyone take pictures of himself either.

Stigma

Within the context of elite athletics and disability, stigma consists of devalued evaluations and expressions that are socially and culturally defined, and then imposed (Atherton, 2007; Link & Phelan, 2001; Goffman, 1963, Hsin Yang, Kleinman, Link, Phelan, Lee, & Good, 2007). Atherton remarks that stigma, in the case of his study for deaf people, can result in a perception of being disabled. Hsin Yang et al. found that stigma "exerts its core effects by threatening the loss or diminution of what is most the stake" (p. 1524), in Jim's case, his value as a hockey player despite his deafness. Berger (2008) writes that stigma assigns stereotypical meaning to disabilities, such as inferior and abnormal. Stigma perpetuates itself: Nochi (1998) explains that stigma can occur when the stigmatized assume

that others have the power to stigmatise them, and Link and Phelan (2001) maintain that others feel more powerful when they stigmatise.

Jim was stigmatised because he was a ‘dumb’ professional athlete, and because he was deaf. In their study, Simons, Bosworth, Fujita, and Jensen (2007) studied 538 college athletes. Their comments about the athletes in their study reflected “the dumb jock stereotype; low intelligence, little academic motivation, and receipt of undeserved benefits and privileges” (p. 1). Holzemer et al. (2007) describe the impact of a diagnosis of HIV/AIDS. Deafness in the case of Jim, as in Atherton’s (2007) example, can lead to assumptions by others, thereby possibly adding to any suffering individuals are already going through. I agree with Weiss, Ramakrishna, and Somma (2006), who maintain that stigma “contributes to a hidden burden of illness” (p. 277). Lutz and Bowers (2005) note that some experience their disability daily. For example, as a hockey player, Jim’s deafness was incorporated into his game because rather than using only their voices to communicate, Jim and his team members included other means into their play.

Narrative Type

After Jim’s career-ending hockey injury he was, in a sense, reborn into life as a teacher and an acting department head at Algonquin College, befitting a quest narrative as described by Frank (1995). He ‘rose to the occasion’ forcibly presented by the head injury, and used his experience as a professional hockey player to begin a new career (Frank). Jim eventually developed a sport business program at the college at which he was already teaching. All the while, it seems that his life unfolded, as Gergen and Gergen (1984) write, in “coherent sequences, cross-time patterns, and overall directionality” (p. 173).

Jim's lived quest narrative is progressive, as outlined by Frank (1995) and Gergen and Gergen (1984). They describe the type of narrative Jim is living as the expectation that something positive can be retrieved from the experience of head injury. As his narrative moves forward over time, on the whole he positively evaluates his experiences (Gergen & Gergen). Jim recounted his unfolding progressive narrative (Gergen & Gergen) and performatively let me view some of the selves he has been (Frank, 2000b), as the framework outlined by Riessman (2008) suggests. Both the selves he is now, and the illness narrative I have written, are the co-constructions assembled from the stories he has lived.

Turning Points

....control.

Jim needed to feel that he was in control, as do many individuals after serious injury, and just as many athletes do when ageing. Phoenix and Sparkes, (2006) remind that ageing often does, and injury sometimes can, lead to a loss of independence. When Jim was in his first stages of recovery, he was frustrated because he could not control his dizziness, vertigo, and memory loss. He feels that his first turning point occurred during his long recovery when he realized that his recovery would take time, that he had no control over his lingering symptoms, and that he would have to relinquish control over the tight time line he had set for his recovery. It was not yet time to regain control over his life, a life in which he felt was being controlled by, Allen and Carlson (2003) explain, "an external and intangible force" (p. 194). Jim felt that others had power and control over him. He needed to establish an internal locus-of-control so that his beliefs were positive, about, as Izaute et al. (2008) elaborate, the

“amount of control...[he] could exert over...[his] environment” (p. 762). Jim’s 90-10 life exemplifies an internal locus-of-control.

...the 90-10 rule

Jim’s second turning point occurred during his recovery. All of a sudden, he realized what the 90-10 rule that he had been taught by his father meant and so he invoked it. This turning point had the characteristic of an epiphany in that it was a cumulative event enabling, as Denzin (1989) describes, a ‘personal transformation’. Jim now looked at each day afresh and with a positive outlook, an outlook with which he had had trouble since his accident (Denzin; Loyttyniemi, 2001). Izaute et al. (2008) note that Jim’s changed outlook and internalised control often goes hand-in-hand with “greater emotional well-being” (p. 762).

Understandings of Learning

Jim believes that people acquire their knowledge throughout their lives by, Eraute (2007) summarises, learning from experiences that they have gathered through dialogue with others, their own thinking processes, and the things that they spend time doing. They can then, keeping Riessman’s (2008) framework in mind, perform this knowledge during subsequent interactions. Jim thinks that there are many types of learners and intelligences (Gardner, 1983, 2006). All of these intelligences enable individuals to “resolve genuine problems or difficulties that ...[they] encounter” according to the type of learner that they are (Gardner, 1983, p. 60). Jim supports Gardner’s view of intrapersonal intelligence, as do Jacobson, Mcduff, and Monroe (2007), who remark that “when emotional input is added to learning experiences, it makes them more memorable and exciting” (p. 7). Jim also

promotes Gardner's interpersonal intelligence because he encourages his students to work with each other so they can learn to make meaning by exploring, Wertsch (1991) explains, "voices, social languages, speech, and dialogicality" (p. 67).

Closing Thoughts

When I met with Jim, he was always optimistic despite his head injury and his hearing problems. He has a healthy outlook on the world; even with his injury he has found opportunities to excel, such as those he has found at the college at which he teaches.

.....Interlude.....

Three years after my injury, I summoned my dedication, motivation, and drive once more to create a new life for myself. I never in a million years thought I would be back at school. I had used my undergraduate degree in computing science to fund my riding, but my computing job was a means to an end. I needed to find something that captivated me, to find where opportunities for writing and research, thinking and pondering, trying out ideas, creating, and building would abound. I wondered: How can I incorporate my unique experiences into research⁵?

*I am better.
so forward to
graduate school
where I research
how to use art
to help others.*

Tapping into these experiences for inspiration, I questioned whether others felt the same sense of pride and increased self-esteem as I did from completing creative projects. I explored that idea in my MA thesis. Because TBI survivors easily feel frustrated by an endless regime of never ending and seemingly unproductive therapy, I examined how finishing a creative project could add to the participants' self-esteem. To satisfy my own creative leanings, I painted the conceptual framework onto a four by six foot board. As part of the final product, I painted my interpretation of the data as a large mural. My research found that completing a creative activity did indeed add to the participants' self-esteem. It also added to my own self-esteem:

*Now, doing my PhD
I am researching
Traumatic brain injury.
I read, I learn, I listen.
I have discovered
who I was meant to be.*

(Smith, 2008, p. 8)

Chapter 7: Exploring the Research Questions -

What do I Think of the Colours I Chose?

I learned quickly

that

There will never be

only

one 'answer'.

Only thoughts/musings/feelings

and explorations of

maybes.

Thematic Analysis Across the Illness Narratives

After I had done a dialogic/performative analysis of each illness narrative, outlined by Riessman (2008), I conducted a thematic analysis across the narratives so that I could further explore the evolved research questions. Polkinghorne (1995) and Coulter and Smith (2009) describe the individual analyses of each illness narrative, and this thematic analysis, as analysis of narrative. Phoenix, Smith, and Sparkes (2010) call using diverse types of analyses 'analytical diversity'. Coffey and Atkinson (1996) remark that researchers "can use different analytic strategies in order to explore different facets of our data". They add that by examining data from different viewpoints, "the more we may reveal – or indeed construct – their complexity" (p. 9). So, using field notes, transcribed conversations, photos taken by the athletes, and my experience as data, I made interpretations which evolved into categories

(see Graneheim & Lundman, 2004). From these I drew common themes that focused on *what* the athletes told me. Braun and Clarke (2006) explain that when using a thematic analysis, researchers, by “identifying, analyzing and reporting” data (p. 79), strive to find patterns or themes. Hsieh and Shannon (2005) point out that this manner of analysis is useful when a phenomenon is being described. They note that with this analysis, new insights emerge as categories and “flow from the data” (p. 1279). Hsieh and Shannon seem to equate thematic and content analysis; others, including Braun & Clarke, describe content analysis as being concerned with a more micro level analysis. Riessman (2008), Smith and Sparkes (2008c), and Williams (1984) offer further explanations of thematic analysis. I agree with the following remark made by Riessman: in the following analysis of this particular study, there is “minimal focus on how a narrative is spoken...on structures of speech a narrator selects, [the] audience ...[or] the local context” (p.54). Instead, in the case of this study, I explore the stories’ contents and I uncover common themes to shed some light on the research questions.

To whom does it matter

what I have found?

I don’t know but I

hope

that this project helps

others who live

with

head injury.

I begin with an exploration of the secondary research questions so that I will have more ideas for consideration when discussing the main research question.

1) What do the athletes' performances disclose about their understandings of the terms 'identity' and 'learning'?

a) Understandings of Identity

I understand identity to be fleeting, loose, and evolving. It is temporary. It is an ever-changing series of constructions. Alvesson, Ashcraft, and Thomas (2008) note that identity “loosely refers to subjective meanings and experience.....and thereby entwines feelings, values and behaviour and points them in particular (sometimes conflicting) directions” (p.6). My perceptions, observations, and interpretations of the participants' identities helped me to re-constitute the athletes, the subjects of my research, into characters that perform on the pages of this thesis. Warren and Fassett (2002) suggest that this thought implies that the athletes' performances are “a continuing process of acts” (p. 579).

I agree with Sarup (1996), who writes that our identities are part of what we have experienced; they are “not separate from what has happened” (p. 15). I was a little surprised that, in contrast to this view and the view of Alvesson, Ashcraft, and Thomas (2008) outlined above, the athletes had, for the most part, very concrete, permanent, and static ‘me’ selves views of identity (McAdams, 1996, 2001, 2003, 2004; Holstein & Gubrium, 2000; James, 1963; Neimeyer, 1998). Neimeyer reminds that athletes' views are traditional: the traditional norm for a view of the self is the notion “of a stable and essentialized self” (p. 135). McAdams (2003) thinks that one's identity of the present is inextricably interwoven with influential events of one's past, events likely to have bearing on the present ‘I’ (ipse)

and 'me' selves. I support McAdams' theory of identity. However, seemingly inspired by their pasts, the athletes suggested labels for themselves that, for all except John, related back to their athletic or their pre-injury empirical 'me' descriptions of their occupations (Neimeyer). Terry identified himself as a Hall of Fame football player and a motivational speaker, Dave was a Crazy Canuck, John was a teacher, and Jim was a hockey player, a professional entertainer, and a teacher. Jim's identity has progressed with time; he has only considered himself a teacher since his accident. Terry's identity has also progressed; he has only been speaking publicly since his accident. Everyone except Terry told me very detailed stories about their athletic pasts; their performances during the telling of these stories revealed to me that these pasts remain very important to them (McAdams; Riessman, 2008). Even John, who insisted to me that his athletic past was trivial, told me multiple stories about this time in his past. I am certain that if Terry had access to his past, beyond his bodily memory, described by Culbertson (1995) and Venken (2009), that surfaced when he watched football games, he too would have told me stories of his days as a football player.

Only John seemed to understand that one's identity consists of more than a label. Identity evolves, and as Riessman (2008) theorizes, John performed ideas that led me to believe that he thinks that how one feels and what one believes at any given moment are also part of one's identity (Bauer & McAdams, 2000; McAdams, 2001, 2003; Neimeyer, 1998; Raskin, 2002; Verkerk et al., 2004). For example, the list that John had compiled in the middle of one night during the time that our conversations took place speaks of some of his beliefs and opinions, especially those he has gathered since his head injury. I think that, as Verkerk et al. hint, John is aware that his identity is continually evolving, and I think that he

reveals this with his list. I concur with McAdams (2003), who writes that the “self is many things but identity is a life story” (p. 187). As Bauer and McAdams point out, “a mere assemblage of facts in a life story does not point to the person’s identity; identity emerges as the person ascribes personal meaning to those facts” (2000, p. 278). When John wrote down his list for me, I was able to see the ‘I’ part of John, the part that I think, in agreement with McAdams (2001, 2003) we all possess because we are human.

b) Understandings of Learning

When I asked the athletes to talk about their understandings of learning, they each used a different verb to describe learning as an action: to find, to satisfy, to understand, to move towards, and to explain. I believe that these verbs can also all be used to describe changing identities because, as they learn, individuals contribute new dimensions to their evolving identities. So, as the athletes performed their stories for me while they made new meanings and as they learned on their healing journeys, their identities also changed, grew, and developed (Alheit, 2005; Biesta, Goodson, Tedder, & Adair, 2008; Biesta & Tedder, 2007; Lave & Wenger, 1991; McLean & Fournier, 2008; Tedder & Biesta, 2007; Verkerk et al., 2004). Verkerk et al. suggest that by exploring the question ‘Who am I’, we can learn about our past, current, and future identities. Alheit finds that learning can occur as people tell stories because storytelling helps them to “reflexively ‘organise’ their experience in such a way that they also generate personal coherence, identity, and meaning to their life history” (p. 209). With this remark, Alheit also connects learning and identity. Tedder and Biesta note that, in effect, “life can (be)come an object of learning” as people make connections between their past and present selves (p.1). McLean and Fournier (2008) call learned

connections that are made through storytelling ‘autobiographical reasoning’. In the case of the participants in this study, the athletes had to learn, possibly through autobiographical reasoning for those without memory impairments, in order to live life as well as they possibly could given their injuries.

As they performed their stories for me, I believe that the athletes ‘(re)discovered’ and ‘released’ meanings from buried memories that will always be parts of their lives (Brady, 2000; Mahoney, 2007; McLean & Fournier, 2008; Polkinghorne, 1996). Mahoney makes a case that textual forms can be used to make meanings by creating “a context for a deep and emotional understanding of lived experience” (p. 574). I followed Mahoney’s suggestion when I co-constructed each athlete’s illness narrative. Brady reminds that the ‘creative co-construction’ of these texts facilitates readers to uncover meanings suggested by the athletes’ performances. Polkinghorne effectively and succinctly writes that a story “bestows meaning on life” (p. 159).

In order to live my life as well as I could, I went back to school three years after my accident. I consider my quest towards a PhD to be comparable to my life as an athlete: in that life I was always striving to be the best. When I could no longer reach for goals as an athlete, I found another lifestyle into which I could pour my energy. What goal will I have next?

The need to be in control.

Biesta and Tedder (2007) speak of education “as a major lever of empowerment” (p. 133). More specifically in the case of the athletes in this study, I believe education has, in a circuitous and indirect manner, empowered them by helping them to become autonomous

again. However, education may have left them initially feeling ‘out of control’ because they may have been taught basic skills out of context during their rehabilitation. Sometimes, learning is context-free and performed in a neutral environment. Individuals tend not to be able to easily make use of this type of learning until they are given directions on how to do so.

The athletes may have been left feeling not in charge and ‘out of control’ of the construction of their identities. They may have felt this way because their status as former elite athletes now feels lessened. I think that the athletes made small, barely noticeable efforts to show me that they still are in control. These performances were their attempts to bolster impressions of their identities, both as athletes and after head injury, that they tried hard to make on me (Biesta & Tedder, 2007; Kaplan & Maehr, 2007). Following Biesta and Tedder, I believe that the athletes may have lacked agency, which is “characterized by particular configurations of routine, purpose and judgment” (p. 113). Kaplan and Maehr define goal orientation theory as the whys and hows of people as they try “to achieve various objectives” (p. 142). In light of this definition, I think that perhaps each athlete’s lack of concrete goals in life caused him to try to impress me and show me that he is still in control.

The athletes’ present lives are a far cry from the positions of high achievement, power, and autonomy they had occupied as elite athletes before their injuries. In their pasts, the athletes were, explained more generally by Powers, Koestner, and Zuroff (2007), autonomously motivated: their goals and aspirations were freely chosen. I believe that, at the present time, the athletes try to overcome the lack of autonomy, self-determination, and free

choice that they now feel by trying to exert control over their surroundings, in particular over the people in their lives (Deci & Ryan, 2008a, 2008b; Pintrich, 2003, Powers, Koestner, & Zuroff). During their time as athletes, Deci and Ryan (2008b) show that the intrinsic motivation that the athletes had employed in their sport may have been integrated “into their sense of self” (p. 182). As Guay, Ratelle, and Chanal (2008) suggest might happen, the athletes are now trying to (re)locate the motivation they had used to meet an “optimal [sporting] challenge” and employ it as they attempt to resume control of their lives once again (p. 235). Ratelle, Guay, Vallerand, Larose, and Senecal (2007) believe that their autonomous motivations led to their achievements as athletes. I suspect that this autonomous motivation played a part during their recoveries. I wonder how it will play a part in their new lives?

Pintrich (2003) writes that the athletes may have had various subtle ways of trying to exert control over me, the researcher, so that they could feel more autonomous and reassure themselves that they were in control. Dave Irwin corrected my grammar endlessly. Terry Evanshen internalized his need to control. Because he was always groomed and dressed to perfection, I think, following Pintrich, that he was trying to influence the impression he made on me through his behavior at that time. John Beedell created the perfect ‘arms length’ conversational space, although I question whether this was done because of a need to control or was it simply reflective of the way he was accustomed to doing things. Jim Kyte did not try to control me but his need to control something in his life after his injury was reflected in his attempt to hasten the speed of his healing.

I think that each athlete's need for control is reflected in the types of photos that each one took. Terry and John's photos followed my requests to the letter, showing me that they were used to following instructions. This is indicative of Terry's need for perfection. I think John's orderly photos reveal how, as a teacher, he would expect his students to behave. Dave's photos were not as structured, but neither is his current life.

2) How do the athletes, through their performances, describe their identities: who they were before their accidents and who they have become after sustaining head injuries?

a) The athletes' performances of their evolving identities as they remember them to have been before their accidents

As previously discussed, with the exception of John Beedell, the athletes still identify themselves in part in reference to their athletic pasts. They all consider who they had been as athletes as a major part of their evolving identities now. In the case of John, the experience of rowing at the Olympics was only one part of his varied athletic life. The Olympics came at a time in his life after which he had to let go of canoeing in order to pursue an occupation through which he could support himself.

All the athletes, except Terry whose memory deficits made it impossible, performed long stories about their time in sport, conveyed to me against a backdrop painted with, as recommended by both Hoskins (2000) and Riessman (2008), its remembered context and culture. Dave Irwin performed a particularly detailed scene of traveling in an old VW van with his fellow Crazy Canucks: the front passengers were boiling hot and those in the backseat froze. I wonder if my memory of his performance is imagined: I remember him

crossing his arms (to keep warm?) when telling me about those drives. His stories may have seemed unbelievable had they been told less passionately and without the embellishments of performance as outlined by Gray (2003).

Vallerand et al. (2003) define passion in such a way that appropriately describes how Dave and the other athletes performed their sporting pasts as they relayed their stories. He describes passion as “a strong inclination toward an activity that people like, that they find important, and in which they invest time and energy” (p. 757). Vallerand (2008) adds that when an activity is autonomously internalised in someone’s identity, harmonious passion leads them “to choose to engage in the activity” because they love it (p. 1). As I watched and listened to the athletes while they performed their stories, the passionate feelings that the athletes had towards their pasts was initially visible to me in their eagerness to share these stories by participating in the study. It then became apparent in the manner in which the stories were performed. The athletes’ immediately discernable passion forcibly indicated to me both how important their pasts and their prior involvement in elite sports still are to them. It was noticeable when the athletes performed their stories that they had integrated their passions for their sports into their identities at the time when they were competing. It was also clear, after hearing the stories, that the ingrained passion for sport and the autonomous motivation that had helped the athletes reach the pinnacles of their sports would always be a part of their identities (see Deci & Ryan, 2008a, 2008b; Guay, Ratelle, & Chanal, 2008; Ratelle, Guay, Vallerand, Larose, & Senecal, 2007 for more explorations of passion and motivation). Even Terry, who only ‘saw’ his passion through an epiphany, realised that the perfectionism the epiphany revealed was still part of him.

b) The athletes' current evolving identities: Who are they in the process of becoming?

Significance of head injury to each athlete's current life.

I believe that the significance of head injury to the participants' current lives also impacted, and continues to impact, their evolving identities. Sliding along a continuum, I found Dave Irwin's experiences with head injury at one end; they are the central elements of his current life. His head injury is the focal point of the restitution narrative he currently lives. Dave challenged my thinking and so made it hard for me to establish a relationship in which we were both comfortable. This was in part because he believed that my own injury had been insignificant in comparison to his. I wonder if Dave's reaction to my injury was his competitive nature revealing itself? Terry Evanshen's experiences are next; they are all bathed in head injury because of the severe memory deficits he has been left with that permeate his present life. The injuries sustained by John Beedell and Jim Kyte are less significant to their current lives, although John no longer drives due to his injury. At the opposite end of the continuum from Dave Irwin, Jim suffers some lingering deficits such as dizziness and nausea but he does not let them interfere with his life now.

Their lives now.

Since their life altering injuries, all the athletes, except for Dave Irwin, have moved on. Dave is still living what Frank (1995) describes as a restitution narrative; he is the one participant still struggling to construct his identity. Sadly, he doesn't know where he is next headed. When I asked who he currently is, he said 'just a guy'. As Gracey et al. (2008) question, how do individuals make sense of themselves after injury? They note the impact that such an injury can have on an individual and his or her stories, suggesting that meaning

and doing “are linked” for these individuals and that it is important “to focus on meaning and activity together” (p. 643). The journey Dave must undertake as he is searching for his identity is influencing the story he lives today. I noticed two factors that I believe will guide the story he will live: the importance that skiing still is in his life and the presence of his company *Mountain Image*.

Moss, Parr, Byng, and Petheram (2004) note that it takes time before individuals learn how to construct themselves - their identities - after head injuries. During the time period preceding such a construction, one’s sense of self can reach a low point, leading to diminished psychosocial functioning and a less positive outlook for the future (Gracey et al., 2008; Lysacker & Hermans, 2007; Muenchberger, Kendall, & Neal, 2008). Muenchberger, Kendall, and Neal explain that individuals can feel a “pervasive sense of difference” (p. 985) if they try to return to their pre-injury occupations. Excepting Dave, the athletes had made sense of themselves by, according to Gracey et al., (re)developing a healthy “outlook on life, emotional experiences, motivation, lifestyle and uncertainty” (p. 642). Most importantly, each athlete had accepted, as Moss, Parr, Byng, and Petheram found in their study, that it was futile to attempt to be the same self one was before his or her accident.

Once again with the exception of Dave, the athletes had all experienced turning points that helped them to move on, away from their injuries, towards new lives. Also contributing to their evolving identities were their responses to stigma and to familial support. Some felt that their injuries had been blessings in disguise.

Turning points or epiphanies.

The athletes' turning points and epiphanies seem to have suddenly and abruptly influenced them. According to Pillemer (2001), life can sometimes be punctuated with a "distinctive, circumscribed, highly emotional and influential" event (p. 123). The terms turning point and epiphany are equivalent to some. Here, I explain how I distinguish them.

Terry Evanshen's glimpse at his past was an epiphany for him. It left what McDonald (2008) calls a meaningful mark: he recognized that he had retained his pre-injury characteristic of always striving for perfection. I understand Terry's epiphany to have been of the type Denzin (1989) refers to as cumulative because it was realized after he had accrued experiences during the time period since his injury. In the case of Terry Evanshen, these experiences were unconsciously accumulated.

In their study of patients with breast cancer, Thomsen and Jensen (2007) describe turning points as "emotional and important events" (p. 349). John Beedell sunk into a depression when he first came home. His turning point was his realization that he would have to accept himself the way that he was now, post-injury. Jim Kyte's turning point took place when he became aware that healing from head injury took time and he would have to be patient and wait. It appears, as illustrated by the cases presented above, that the athletes' turning points occurred at times when they each realized that in order to heal, they would have to make personal changes that would be, as Loyttyneimi (2001) explains, transformational. An epiphany enlightens and makes one aware, but does not invite change. The turning points that the athletes experienced allowed their lives to finally move forward, helping them to progress beyond what Frank (1995) calls a restitution narrative, the

narrative that one athlete, Dave Irwin, still lives. They no longer lived in hope of a recovery that would make life just as it had been before (Frank). In sum, I believe that these turning points allowed each athlete to evolve the typology of the story he was living, perhaps from living a restitution narrative to living a quest narrative. They could begin to realize that life post-injury could have what Frank calls a “sense of purpose” (p. 117). They could each live a renewed life with new meaning.

Stigma.

The athletes all told me that they wear the stigmatizing label of ‘head injured’ as part of their identities. In the case of Jim, he also owned the stigmatizing label of ‘deaf’.

Goffman (1963) explains that people are often considered ‘less’ because of stigma. Green, Davis, Karshmer, Marsh, & Straight (2005) think that individuals in the same position as the athletes are, sometimes feel ‘less’ when they encounter people who know of their injuries. The label ‘head injured’ was usually not used by the athletes when identifying themselves. However, it was frequently a label forced on them by individuals who, by imposing this label, felt in a position of more power. According to Link and Phelan (2001), in order “for stigmatization to occur, power must be exercised” (p. 363). Scambler (2004, 2009) agrees, as does Campbell (2008), who both emphasize that people are treated unequally by those seeking power when they are stigmatised. Similarly, Deal (2007) and Scambler (2009) note that disablism is felt when others perceive you as inferior. Warren and Fassett (2002) explain that when one is ‘separated’ by disability, he/she is liable to become ‘shaped’ by the label ‘disabled’ and suffer disablism when people “levy power in unjust and unequal ways” (p. 582). Interestingly, Berger (2008) notes that disability can be both empowering and

disempowering. The players with disabilities he interviewed for his study viewed themselves as athletes, pure and simple” (p. 672). I believe that these athletes felt empowered: they reframed “what appears to be lacking as something replete with possibility” (p. 673).

Jacoby, Snape, and Baker (2005) explain how stigma was maybe partially responsible for reducing the athletes’ feelings of social worth. In their eyes, stigma “is part of chronic illness because individuals who are chronically ill have less ‘social value’ than healthy individuals” (p. 172). In Jim Kyte’s case, however, stigma may have been directed at him not because of his head injury, but either because he had been a ‘dumb’ professional athlete or because he was hearing impaired. According to Terry and Lorraine Evanshen, the stigma that they feel is due to Terry’s injury and is one of the reasons that they keep mainly to themselves. After my own injury, I perceived stigma from the horse community so I began to live a new life and socialize with a new group of friends. Slade, O’Neill, Simpson, and Lashen (2007) report, in their study of infertility, that when individuals disclose their illnesses to others they are not likely to feel increased support but instead, they may feel more distressed. However, they found that individuals are less likely to perceive stigma from others who are knowledgeable or are not afraid to offer support to them. To this end, the goal of the *Dave Irwin Foundation* is to educate people about head injury and its meanings so that stigma about head injury is not perpetuated. Koro-Ljungberg and Bussing (2009) studied parents of children with attention deficit hyperactivity disorder (ADHD) and found that it was important to tailor education individually to each case. By doing so, they could teach the parents how to more effectively cope with those performing the stigma. Weiss,

Ramakrishna, and Somma (2006) suggest that context specific research for both disease and culture will serve to better manage stigma in a given location.

The partners of survivors can feel courtesy stigma when it concerns family members, a stigma that Larson and Corrigan (2008) explain is sometimes called family stigma. Both Lorraine Evanshen and Lynne Harrison felt family, or courtesy, stigma directed at them because they lived with survivors of head injury. The following study points to the use of strategies to manage courtesy stigma. Koro-Ljungberg and Bussing (2009) note that when it is felt, courtesy stigma should be handled with care so that “existing negative identity markers” are not perpetuated (p. 1175).

I believe that the stigma that Jim Kyte felt may be described as aversive disablism, which Deal (2007) writes is a “subtle form of prejudice” (p. 93). Campbell (2008) notes that disablism may have caused “assumptions and practices” (p. 152) to be directed Jim’s way because he was hearing impaired.

Familial support.

The illness narratives I constructed reflect that the athletes are socially dependent on others: they exist dialogically in relation to these others (Gee, 2000; Holman Jones, 2005b; Riessman, 2003; Shotton, Simpson, & Smith, 2007; Smith & Sparkes, 2008b, 2009; Sparkes, 2002; Williams, 1984). Smith and Sparkes (2008b) describe narrative as being dialogical because of the “larger socio-cultural matrix” (p. 6) that shapes identities and selves. According to Williams (1984), more often than not stories, and illness narratives, “are bounded by and constructed in relationship with various individual people and organizations” (p. 250). Shotton, Simpson, and Smith remark that they believe that

dialogical support, both professional and familial, encouraged the survivors of head injury in their study to forge on determinedly. Personally, I feel experience is often shared, or dialogical. Holman Jones notes that this shared experience can be safe but it can also have a “luminous and calloused skin” (p. 3), which I believe is made more so by traumatic experiences.

Becker and Charles (2006) depict family as I would, as a “set of norms and practices” about, among other things, “giving support” (p. 101). The stereotypical ‘happy’ family provides support and guidance for one’s choices in life. The readers of this study will note that Jim, John, Terry, Dave, and I all appear to have tremendous support from family and partners. John Beedell took a picture of his daughter-in-law and her children to illustrate their significance in his life. I was witness to the supportive caregiver roles performed by the partners of Terry and Dave. Rotondi, Sinkule, Balzer, Harris, and Moldovan (2007) express that it is important to survivors that they are accepted ‘as they are’ by family and also by friends. Not only that, but these theorists also note that survivors strive to be involved “as they had in the past” with their friends (p. 22). In the cases of the participants, both Terry and Dave and their partners found that their lives were quieter than they had been. Dave seems to have gathered new friends that seem important to him, while Lorraine Evanshen shared that they now keep to themselves much more than before Terry was injured. Is this due to stigma? It would be interesting to explore how other members of supportive families feel about the isolation often felt after head injury.

Noonan and Tennstedt (1997) studied the well-being of caregivers to frail elders. They discovered that when the caregivers looked for meaning in their caregiving

experiences, they found it. Jumisko, Lexell, and Soderberg (2007) note that family members who care for survivors of head injury “struggle with their own suffering” (p. 353). But, although Hanks, Rapport, and Vangel (2007) also found that stress, burnout, increased responsibility, and lack of support are often experienced by caregivers, Lorraine Evanshen and Lynne Harrison did not express that they were experiencing these outcomes and I did not observe that their performances were indicative of these detrimental possible side effects. The importance of Lorraine to Terry and Lynne to Dave is evident in the photos both athletes took of their partners.

A blessing in disguise.

Lynne, Dave Irwin’s partner, and Lorraine, the wife of Terry Evanshen, both commented that in some respects, each partner’s head injury had been a ‘blessing in disguise’. Both men had been very busy filling commitments in their lives as elite athletes. Their head injuries left them with new lives in which they now had slowed down and were no longer always in a hurry. What they had “initially perceived as a grave loss” could now be viewed as “something like a blessing in disguise” (Landau & Hissett, 2008, p. 12; Shaffir & Kleinknecht, 2005). Shaffir and Kleinknecht write that a loss can be viewed positively, “not as a dishonorable or an unfavorable event but as a blessing in disguise” (p. 730). Landau and Hissett comment that although lives of survivors and their loved ones may be unrecognizable from their former states, such conflict may well provide a welcome change. I feel the same way. My own injury opened the door to research and academia, one which I could never have imagined being open prior to my injury.

Jim Kyte's injury forced him into retirement, something that he would have had to consider very soon anyway. So, in the case of Jim his injury could also be counted as a 'blessing in disguise'. It meant that his retirement was now compulsory, however he had tried to minimize the impact of retirement by taking courses to prepare for the future. He had looked beyond what was his present life even though making a future plan is often not considered important by elite athletes at the height of their athletic careers (Drahota & Eitzen, 1998; North & Lavalley, 2004; Zikic & Richardson, 2007). North and Lavalley point out that athletes are generally unwilling to prepare for their retirement. Similarly, Drahota and Eitzen remark on the focus of professional athletes on the present: they found that the athletes were not encouraged to look ahead and plan for their future. The abrupt accident that Terry experienced was an unnecessarily harsh but time-related turning point that gave him no choice but to move on with his life. Zikic and Richardson studied the outcomes that may be seen from job loss in general. They discovered that these losses may be viewed positively when they are made sense of because they may present new opportunities.

3) When the athletes perform their stories, what do these performances convey about the athletes' perceptions of whether they have learned, and if so, how and what they have learned while constructing their identities?

a) How the athletes have learned

Colardyn and Bjornavold (2004) believe that lifelong learning takes place in everyone's life journeys, and that it doesn't matter how the learning occurs. Each athlete's learning journey was unique to them and, for the most part, grew from their own healing initiatives. According to Marsick and Watkins (2001) "learning grows out of everyday

encounters while working and living in a given [personal, social, business, and cultural] context” (p. 29). So, as does the context of identity, the context of learning bears some consideration. Marsick and Watkins continue, explaining that these contexts play “a key role in influencing the way in which people interpret the situation, their choices, the actions they take”. I believe that each athlete’s learning journey was the product of learning from many different settings and social, historical, and cultural contexts (Frank, 2004b; Georgakopoulou, 2007; Hardin, 2003; Josephs, 2008; Langellier, 2003; Marsick & Watkins, 2001). Langellier notes that people’s cultures emerge as they tell stories. As well as influencing stories, these cultures may also influence the contexts in which, as Marsick and Watkins explain, learning is situated. For example, Terry’s task in the doctors’ clinic was designed to take place in that context because there he could learn while he increased his social interactions. When Jim learned to play hockey, his learning took place among boys who were about the same age and I suspect that they were also from similar cultural backgrounds. Jim’s learning at home in the familial context must have been unusual because he was learning to cope with a hearing impairment shared by other members of his family.

As Hardin describes, not only do the participants each perform and learn in the research situation by drawing unconsciously on their own contextual backgrounds, but I too, as the researcher, have my own history, which I carried with me into the research situation. In all likelihood, my explorations of identity and learning were influenced by my background and the backgrounds of the participants. Frank claims that one’s identity depends on how one relates to others. In other words it is dialogical and is therefore

influenced by the context of the identities of others. I believe that Frank's thoughts can be extended to learning.

b) What the athletes learned

The types of things the athletes learned fell into two categories. First, they learned some skills through rehabilitation: *how* to do things that would enable them to live their lives as independently as possible. Second, they learned by *doing* these things, things that would give their lives meaning and purpose. It became clear to me that what the athletes had learned had enabled them to live their lives autonomously again. In most cases, they were, Marsick and Watkins, (2001) maintain, in control of their own learning.

For example, Dave was in control of his learning: he taught himself how to interact with more than one person at a time by placing himself in increasingly complex situations in the coffee shop he frequented. This learning was accomplished by interaction while performing an activity. Dave was aware that he was (re)learning skills that he had lost the capacity to do since being injured (Folkestad, 2006; Marsick, Watkins, Callahan, & Volpe, 2006). Dave's learning choice emerged as a result of his pre-injury interactions with others (Marsick, Watkins, Callahan, & Volpe). He realized that he wanted to expand his post-injury communication skills. Jim learned when he had to design, create, and then implement the new Sports Management program at his college. He felt fortunate that he was given this opportunity. Unlike many elite athletes, he had had the foresight as a hockey player to look ahead at his future and had taken courses in preparation for life after hockey. In his study, Tinley (2002) found that most athletes do not give enough thought to their lives after sport. He quotes one as commenting "It's counter-productive. You have to be so focused on the

task at hand, on doing your best. Nobody really wants to know what you'll do next. So you just don't think about it". Terry was unaware of what he was learning when he greeted patients at the doctor's office. He was unconsciously constructing, as Marsick, Watkins, Callahan, and Volpe remind, "the mental, emotional, and interpersonal frameworks for processing all of[his] experience into knowledge" (p. 796).

I believe that John became able to learn again when he reached his turning point (Denzin, 1989). At this time, he realized that in order to improve his situation, he must accept the new life that was imposed on him by his injury. So, he opened himself up so as to be able to learn how to live this new life. He learned how to ride a tricycle (his BMW) for transportation. This allowed him to participate in many activities that would not have been possible otherwise, such as day trips around the city and visiting the various sites of the Ottawa Chamberfest.

The main research question:

When elite athletes sustain traumatic brain injuries, what do the athletes' illness narratives reveal about their journeys of identity construction?

Now, finally, I explore the main research question. But, I am finding that:

My queries multiply,

regardless of

where

I am situated

in this study
and also in
life.

There are many colour swatches to choose from and then use to represent what I have discovered. I have selected swatches that are shades of gray because, as other qualitative researchers do, I believe that there exist no black and white ‘answers’. Readers have lots of choices when they consider and reflect on the main research question. After the narrative analysis and the analysis of narrative, eight themes rose to the top (see Braun & Clarke, 2006; Coulter & Smith, 2009; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005; Riessman, 2008; Severinsson, 2003; Smith & Sparkes, 2008c; Williams, 1984). These researchers refer to themes in a variety of ways: Graneheim and Lundman use the term ‘underlying meanings’, Hsieh and Shannon, and Braun and Clarke refer to themes as ‘patterns’ that they call categories, and Severinsson labels them ‘meaningful units’. These themes are:

1) Not surprisingly, the athletes are still performers

According to Riessman (2008), everyone performs all the time. All the same, I found it especially interesting to observe performances, albeit subtle and noncompetitive, in these former athletes while I was collecting the data. When I chose to use Riessman’s (1990, 1993, 2000, 2002a, 2003, 2008) and Goffman’s (1959) work on which to base the theoretical framework for this study, I did not foresee what now seems obvious to me: the use of a performance theoretical lens ties in nicely with the performances that were a central part of the athletes’ pasts. I believe that sometimes their performances were put on for me to

persuade me to think in certain ways about the stories that they were relating. For instance, I was convinced by Terry's performance of his desire for perfection. I think that it was an attempt to control the impression he made, one of the few things in his life he still could control (Goffman, 1959).

2) The athletes were all very willing to contribute to the study

All of the athletes were eager to help me in my position as the researcher, and they were all enthusiastic to contribute to the study (Dixon-Woods & Tarrant, 2009; Wendler, Krohmal, Emanuel, & Grady, 2008). Wendler, Krohmal, Emanuel, and Grady found in their study of patients with HIV that the patients all felt important because they knew that as survivors they had crucial and unique information to contribute. Their study's results are also applicable to the current study: all of the participants thought that because many people can relate to the sad truth of head injury, their contributions were worthwhile and relevant.

3) The athletes' identities continue to evolve

The athletes' identities keep growing in positive directions. As they began to complete small tasks successfully, their intra-personal identity, for example their self-confidence and self-esteem, grew (Strandberg, 2009). Gardner (1983) and Heider (1958) both indicate that as social interaction with others increases, people are rehabilitated interpersonally. This was the case in this study.

The participants' identity evolutions involved searches by them after their initial rehabilitation, searches that led them to find ways to lead satisfying and fulfilling lives. In the case of Dave Irwin, his search has not yet produced satisfactory solutions. All of the participants possessed seemingly innate drives to be the best that they could be after their

injuries. This drive seemed to me to be similar in nature to the drive inherent in their quests to excel as athletes.

4) Most of the athletes are comfortable with their head injuries

With the exception of Dave Irwin, the athletes seemed to be at ease with, and have made peace with, their injuries. This usually occurred after they had experienced epiphanies (Denzin, 1989; Jarvis, 1997; Loyttyniemi, 2001; McDonald, 2008). Loyttyniemi notes that such an event “often produces transformation” (p. 178); similarly, Jarvis explains that an epiphany reconfigures an individual’s “most deeply held beliefs” (p. v). I believe that an epiphany may also enforce or give substance to these beliefs. For example, Terry experienced an epiphany that seemed to explain his perfectionist tendencies as a football player, perfectionism that had remained with him in his post-injury life. Jim experienced two epiphanies, the second one reminded him of a lesson he had been taught by his father, and it helped him during his recovery. In sum, I believe that all the athletes had to accomplish this peace in order to construct their identities in a healthy, positive manner. Dave was still searching for what to do with his life; he seemed ‘stuck’ between a restitution and a quest narrative. I believe that this may be why Dave seemed to me to be so restless.

5) Most of the athletes are content with their current lives

The athletes are, again with the exception of Dave, satisfied with their lives now. I believe that this is, in a large part, due to their healthily constructed identities and the peace they have made with their injuries.

6) Familial support is important after head injury

In all cases, the athletes had familial support. It appeared to be a crucial ingredient of the wellbeing of all the athletes. For example, Dave and Terry had their partners Lynne and Lorraine who also served as caregivers. Less obvious is the case of the wife of Jim, who remains in the background but played an important role in his recovery and held the family together despite his injury. A similar role was played by the family of John. Lynne Harrison and Lorraine Evanshen, who were in the roles of caregivers, seemed both to be able to incorporate the healing journeys of the partners into their lives so that these lives continued to evolve in a positive manner (Stern, Doolan, Staples, Szmukler, & Eisler, 1999). The participants in this study are fortunate. Stern, Doolan, Staples, Szmukler, and Eisler explain that family members often struggle to come to terms with “an experience for which there are no clear and definite answers” (p. 354).

7) The athletes still have the drive to be the best

The athletes have not lost the desire to be the best. This legacy of their athletic pasts was apparent to me because they still strive for perfection and satisfaction in their current lives. This is evident in Jim’s autonomous motivation and his rise to the top of his current job (Deci & Ryan, 2008a, 2008b). Dave seemed to continue to be unconsciously competitive, visible when he compared the severity of our injuries, and declared mine to have been relatively minor.

8) My own evolution into a researcher/writer bears consideration

The evolution of my own story is, surprisingly to me, a ‘finding’ of this study. I have evolved into a researcher and a writer. I wear these hats proudly, although I have no idea

where wearing them will lead me. Along this research journey I have changed and grown, evolved, shifted, become more comfortable and happy in my own skin.

....Interlude....

I don't ride anymore. I haven't ridden for two years. I finally came to the realization, at long last, that I had to make a complete break to become healthy again. It was time to put the final touches on the new me. I am teased by memories and thoughts that occur more and more often: in the middle of the night, when I am driving down the road, when I am sitting at my computer.⁶

I miss riding. I yearn for it. I crave the smell and feel of horses.

Someday, I will journey forward with an open, inquiring mind, and carefully reacquaint myself with the healthy parts of my old life.

Soon.

Today, as I write, I realize it is September 13th again. The date arrives yearly with clockwork regularity to taunt me with haunting memories of the whole ordeal and to tease me with harrowing stories. It is the tenth anniversary of the day my life changed. For everyone involved, the memories of that day are slowly receding, but its significance is always there to remind us of that time. Today, as I decide what memories to commit to paper, the stories almost pester me, refusing to leave me alone.

Things will be better tomorrow.

Initially, I actively hid from the stories that have etched and stained me. I refused to acknowledge that I owned these tumultuous times. I dodged these memories as much as I could: tough, weighty memories filled with reminders of a time burdened with (un)realities, a time I was forced to spend in transition between lives. During that time in limbo, before I had found a new direction for my life, I spent an

inordinate amount of time avoiding eye contact with the new identity imposed on me by the TBI⁷. I denied being part of the TBI culture and I shrank from any contact with it. Although I tolerated my new identity⁸, I still certainly did not welcome TBI into my life.

*It was easier
To duck and hide
When I felt that
Assumptions were made
Before people knew
Who really I was*

(Smith, 2008, p. 9)

Chapter 8: Reflections -

How Do I feel About the Paint Job?

While conducting this research, I saw no need to separate the self I was, one that was “creative, inspirational, vulnerable, sensitive, unpredictable, mystical”, and also a survivor, from the research I was undertaking (Douglas & Carless, 2008, p.4). Richards (2008) remarks that people “who are ill or disabled can themselves succumb to a way of writing that simplifies their experience and objectifies themselves” (p. 1717). I don’t feel I have objectified myself. As Richards explains often happens with individuals who are disabled, I have been ‘othered’ in the past. This thesis is my effort to regain my voice and to be othered no more. Here, I explore how being the researcher as well as one being researched has impacted me. I describe my legacy and write about the impact it will always have on me. I offer glimpses of who I was, and I explore who I am becoming.

In Search of Myself

My old life with the horses.....

Every evening, I open the screen door to the barn to feed my boys. My main man Gordon is weaving back and forth at the thought of food. He leans dangerously far over his stall guard, stretching himself into the aisle. He then wildly circles inside his stall, shavings scattering and messing up my perfectly swept aisle. A couple of stalls further along, Sing’s bright and naughty eyes catch mine as he too leans into the aisle. He dances silently, waving his right foot in the air, pawing quietly for food. Just a minute boys.

There are five or six horses in the barn, usually they are geldings. I feed them their

individually prepared gourmet dinners. As they delight noisily in the grain, I heave Sing's hay into his stall. To get Gordon's, I walk outside and extricate a couple of flakes that are soaking in a tub. I carry the hay inside, walking awkwardly under the heavy weight and leaning forward to avoid the draining water. Lord, his allergies are a pain. I heave the unwieldy mass onto the rubber mat in his stall. I am only 'sort of' wet.

Goodnight boys.

I am amazed at the vividness of the experiences that seem to be recalled instantly. I am fascinated that these day to day events are the ones that have stuck close to me.

I clearly recall mundane details: positioning a tube of wormer down a horse's throat and depressing the plunger. Trimming whiskers almost daily. The routines before riding Gordon: lasering some acupuncture points on his legs and covering him with the Electromagnetic blanket for twenty minutes. While he is wearing the blanket, an allergy mask is positioned over his head. Kim sits by him, methodically pressing the mister when he inhales. Sometimes the masseuse stops by. It takes Kim, my indispensable helper, at least an hour to get him ready. Gordon goes off twice. In the morning, thirty minutes flat or jumping. Every four days, a gallop. Afternoon, at least a one hour walk.

After. Shampooing a sweaty horse. Drying him carefully, rubbing his belly and legs with towels after scraping off the excess water – I don't want any scratches, the infections that plague skin that is left too wet. Taking him out on the lawn for some grass. I now treasure these memories. I can still see my horse's lips growing longer, reaching for a delectable morsel. Before putting him back in his stall, I remove any droppings and rebuild the bank of shavings lining the stall. So that it is completely level, I run a pitchfork smoothly along the top. I sweep the doorway until there is not a shaving in sight in the aisle.

Done.

On to the next one, multiply this by five or six. It takes long and exhausting days to do all these duties, ones most often taken care of by a precious and carefully trained groom. I do these chores on the groom's day off, and I love the process.

I carefully keep these memories. I think of them often, and I will never let them go.

But -

I fell on my head. Be it a disaster or a hidden blessing, I now do research instead.

My new life after head injury.

I believe my unwillingness to separate my research and my self is partially due to the fact that over the course of time I have regained the capacity to be 'in the world'. During this period, which has evolved over the past thirteen years since my accident, I first watched the world spinning around me. In the past, sometimes I joined this world and the people in it. Sometimes I just enjoyed observing the changing colours. Now, as my wellness fluctuates, I experience these colours changing more frequently and differently than do the maple tree's leaves. My head injury now limits my physical scope. But, I don't believe that my injury has limited the scope of this thesis. Instead, it provided the unique opportunity for a member of this (luckily) uncommon culture to research her own.

I have learned that the changing seasons of my life and my injury demand attention and require close observation. I have come to think and reflect upon these times. I take pleasure in fresh, different, simple things now. Since my injury, I am experiencing more of the world. I enjoy just being in ways that never before caused me to pause during my frenetic life. I used to always be too busy. I was always on my way somewhere. I now question whether I was really too busy.

These days, I sniff the fresh country air, marveling at my fortune at having found the oasis I live in. I watch the daffodils I painstakingly planted when I was able to, now blanketing huge sections of the lawn in yellow every spring. I enjoy seeing plenty of new growth on the multitude of different, tiny trees I placed when I first moved. They are growing and will soon form a physical shield, shutting out the parts of the world which I don't want to discover my oasis. Many other diverse parts I invite in.

Today, I admire the spindle tree outside my office window. It is covered in pink berries but has lost most of its leaves. I can't remember how long into the fall the berries stay on. The lawn around the tree is carpeted in leaves. I don't bother raking them – I can't do it myself.

The colours of my life have changed more than for most people: be witness to a changing me as I remember and reflect on these pages as I empathetically share the stories of others. Changes as a result of my head injury occur less and less. But I will always be changing. I observe others more than (I think) they know. I watch them studying me. They notice that my memory, cognitive skills, emotional control, balance, and motor coordination have gradually changed over time. My own notes: my memory is selective. I compensate by responding and telling others right away so that I am not responsible for remembering. In terms of cognitive skills: I now have one speed. I can no longer multitask. I am now one track minded. When I focus on one thing, it is to the exclusion of other things no matter how important they might be. Emotionally, I handle things very well to a point, and then I overreact. I am still driven. I am creative. I don't think I was as creative before. If I was, I did not let my creativity show.

Am I overreacting now to the dystonia I have? I don't think it's an overreaction.

Because...

unfortunately, my balance and motor coordination have declined over the last four years. I have always had, but only to those that know me well, slightly detectable balance and motor coordination problems. Now, they have worsened and are related to the focal dystonia I have developed in my right leg. Pont-Sunyer, Marti, and Tolosa (2010) define dystonia as "involuntary contractions of the legs or arms resulting in twisting and repetitive movements or abnormal postures" (p. 22). It is sometimes experienced years after a serious head injury. Dystonia and my resulting limited mobility lead to a brave face most of the time, however I now find myself despondent over this legacy more and more often. What restrictions will my future hold? I have recently started using a wheelchair most of the time. Who will push it when I am old and gray? At these times I find it hard to cope. Why, oh why, after all the obstacles I have overcome, do I need to overcome another? It alleviates the emotional pain brought upon by dystonia somewhat when I bury myself in writing. This is only sometimes effective.

I sit at my desk in my lovely windowed study and I wistfully imagine taking a break to join nature outside. I could go for a run, or walk. OK, I'll ride on my scooter instead. Or not. I need someone there in case my aged scooter dies.

Some days, despite the weather outside, I find myself wallowing unproductively in my growing physical limitations. Although I can no longer run, ski, swim, or bike, these limitations somewhat approach being 'balanced' by my scholarly writing. As compensation, I try to contribute to the culture I find myself in. An example of this is this study. Every day,

I am thankful of the timing of this latest hurdle. Thank goodness that I completed my course work – it feels like eons ago but in fact is only four years ago – and that my data collection was finished a couple of years ago. I could not have handled these parts of the journey now without enlisting more help than I am comfortable doing.

I wonder how the participants would react to me now? Would my physical limitations change the impressions I made on them when I was walking well? I have a feeling that they may well, but I imagine not so much for those that have lived longer post injury. For those whose injuries occurred more recently, I believe that they experience new people more from their first impressions. These people may first see my difficulty walking and they may base thoughts that they have about me on that. What the participants would think when they see me now may colour their understandings of how I now am in all other ways. I wonder how my research would have changed to accommodate what I am physically able to do now? I feel so passionate about undertaking this research, yet it would now be far less manageable. I could interview using Skype, but how would a performance analysis have been possible if I didn't conduct face to face conversations? I couldn't observe how the athletes physically reacted to our conversations.

I enjoy watching the changing impressions I make on other people I meet. They view me tentatively if they know of my injury and have not seen me. If they have seen me but not in the last couple of years, they are appalled at the effect dystonia has had in this time. First, they wonder if only my physical being has been affected. Then, they always ask if they can help. I used to resist the help that I badly needed, but now I often answer 'sure, please!', and I am then 'pushed around' in my wheelchair. Thanks. Really. As time passes, despite these

physical limitations, most that know me, and also those just beginning to know me, have come to regard me as the same as they are. I feel I am intellectually at par. Those that knew me before tell me that they feel that I have not become less intelligent, but that I am not able to handle my intelligence as well as I used to.

This is probably right but

I am doing my PhD after a serious head injury.

My self as I am now – both being the researched and doing the research.

What has this research experience done to me? I am awakening to the fact that my time doing the PhD has passed. I must now move on. When this journey started, my friends thought I was crazy to restart my education. ‘Don’t you already have a BSc?’ They were not even taking my history into account. Although I will always be labelled as head-injured by some, most simply thought that I was out of my mind. ‘Why?’, ‘What are you proving, and to who?’, ‘Are you not too old?’

But, when I (re)started the education journey, it was for me, about what I wanted to do. Truthfully, I wasn’t ready all those years ago when I was riding horses. I hadn’t lived through the roller coaster of emotions that I have now banked. I have immersed myself in head injury. What would I have done if I hadn’t fallen? What if? The truth is, I don’t know. I think I am happy that I chose to do this. Surprisingly to me, I enjoyed the process of collecting data and interacting with others who have undergone similar experiences. I like to write and so crafting the athletes’ stories was not a chore.

What narrative type do I live?

I write knowingly, knowledgeably about others. I have pondered on and invited readers to question the stories I have co-constructed, as is appropriate of postmodern research. Anyone and everyone is welcome to voice their thoughts. But how about one more tidbit about me? Here, I blindly announce that I am living a quest narrative, without putting in a lot of thought. But wait, let me think about that. What are the attributes of such a narrative? As a quest narrative does, I have decided to “meet suffering head on” (Frank, 1995, p. 115). I speak from my own perspective, and I hold “chaos at bay” (p. 115).

But.... do I? I feel that these days I am not so far from chaos (Frank, 1995). I feel out of control. Number one, the defence of this thesis is looming. I am poised and alert, but also edgy and uncertain. What will I be required to do? Days roll together as I prepare. Number two, I am in fear of dystonia. Were it not for the sleeping pills necessitated by the head injury, I would lie awake at night wondering what was next in store for me. I have trouble being by myself these days, I think too much then. I normally love it. Usually, I love to think. Thinking these days is, however, to be avoided. Chaos is, according to Frank, ultimately “told in the silences that speech cannot penetrate or illuminate” (p. 101).

Currently, I feel impenetrable.

Chapter 9: Conclusion -

A Top Coat That Never Completely Dries

Regardless of the profound revelations and understandings that I have learned from examining stories of my own experience, I know that I continue and will continue to live in the struggle of complexity and unanswered questions, questions that change and grow, transforming my understandings as I discover new layers, new textures, new strands, and always, new knots on the underside of life's canvas.

(Glustein, 2006, p. 176)

The healing journey after head injury follows an arduous, never-ending path. I will forever be indebted to those who helped me find my way: Thank you for choosing to perform at such a crucial time in my life. On the convoluted journey I now find myself on, entitled 'The PhD Thesis', I am taking Stuart's (2009) advice: "...the best place to end [is]... with a beginning" (p. 99). So, I started at the beginning and tried to uncover new meanings in my own and others' stories of healing. Now, I (re)reference Hawkins (2007), whose quote appears in the introduction. To complement Hawkins' writings, I would like to say that I hope that the stories I have created will help not just survivors of TBI - not even just survivors in general - but that these stories will help all people learn from our journeys. I believe that the athletes and I should be regarded as storytellers 'with a mission'. To embark on my mission, I heard the stories of four other driven, motivated, single-minded individuals, who, like I did, coped with, and are still coping with, the aftermath of a life-changing head injury. These are the Olympians John Beedell and Dave Irwin, and the professional athletes Terry Evanshen and Jim Kyte. At this point, I would like to come full circle and end as I started this journey: Thank you again to these individuals for sharing your

stories; I believe that our co-constructed illness narratives and the analyses thereof will help others (Hawkins).

Overview

I reviewed my own background in Chapter One because the impetus for this research was my own head injury. I discussed why this past experience begged for an auto-ethnographical study and I provided a glossary of the terms I used in the study.

In Chapter Two, I looked closely at how various theorists have conceptualized identity and the performance thereof as outlined by Riessman, (2008), and Smith and Sparkes (2008b). I then reviewed the history of the term illness narrative and discussed why I believe in the importance of these narratives, as do many of the contemporary theorists I referenced. It became apparent to me that many of these theorists' conceptualise illness narratives similarly to Arthur Frank (1995), so I chose to use his illness narrative types for this study.

I detailed the theoretical framework in Chapter Three. The framework changed during the research process; this change in my theoretical lens occurred soon after I had conducted the interactive interviews and so completed the data collection phase of the study. In the end, I used a dialogic/performative narrative analysis based on the work of Riessman (2008) with a sprinkling of Goffman's (1959) dramaturgy. With this framework, I was able to explore *how* the athletes told me their stories. During the time I spent rereading the transcripts and the constructed illness narratives my research questions evolved , as Riessman (1993) explains might happen, to better incorporate this analysis and my changing interests.

I outlined the methodology I used to collect the data in Chapter Four. I explained that my main methodological goal was to (try to) erase the line between the researcher and the researched. I found that it was necessary for me to review my endlessly changing relationships with the other participants, so I reviewed the dilemmas I encountered trying to establish healthy and close researcher-participant relationships (Alvesson & Skoldberg, 2000; Reinhartz, 1997; Spaulding, 2008). To encourage such relationships, I used interactive interviews as detailed by Ellis, Kiesinger, and Tillman-Healy (1997) and used by Smith and Sparkes (2004) in their study of men who were disabled by playing rugby. The interviews took place in the athletes' homes, or, in the case of Jim Kyte, his place of work. These interviews were places where meanings were co-constructed between me and the participant (Mishler, 1999). The participants seemed to enjoy telling stories during these sessions, and all except Jim Kyte used the digital camera I provided to take pictures that would illustrate the illness narratives I wrote (Bach, 2001).

In Chapter Five, I presented the illness narratives I co-constructed with the athletes from the stories that they had told me. I embellished these narratives with photos. We talked about the photos that the athlete had taken on the last day of our conversations in photo interviews (Kolb, 2008; Warren, 2005). I then used the photos to complement the co-constructed narratives. I also included my own reflections and observations in the stories. Importantly, as Ellis and Bochner (2003) remark, "we can never capture experience" in the illness narratives we create (p. 228). What I have captured is simply what I observed at a specific point in time from my own particular point of view. Smith and Sparkes (2008c) describe me as a storyteller performing narrative analysis. When using narrative analysis,

Coulter and Smith (2009) maintain that the story is the analysis for the storyteller. They base this remark on Polkinghorne 's (1995) claim that narrative analysis “produces stories” (p. 6).

In Chapter Six, I did a dialogic/performance analysis of narrative (Riessman, 2008), of each athlete's co-constructed narrative. I explored the type of story, the positioning and performance of the athlete during our conversations, the context of the story, how the athlete revealed his or her memory limitations, the athlete's desire for control, and the stigma he or she felt. I also inquired about any learning the athletes had undergone, and any changes that they noticed in themselves. I leave the readers enough space so that they are able to muse and question and “make sense [of the narratives] in their own ways” (Coulter & Smith, 2009, p. 578). During the analysis of each narrative, I discussed the pictures that the athlete had taken, and why I thought that he or she had taken particular photos (Kolb, 2008; Warren, 2005).

Having analysed each narrative individually, in Chapter Seven I examined the themes that I had unearthed across the narratives (Coulter & Smith, 2009; Riessman, 2008). I then revisited the research questions and I detailed my interpretations of what I had found. Regarding the main research question, I found eight themes. One, the athletes are still performers. Two, they were all very willing to contribute to the study. Three, the athletes' identities continue to evolve. Four, most of the athletes are comfortable with their head injuries. Five, most of the athletes are content with their current lives. Six, familial support is important after head injury. Seven, the athletes still have the drive to be the best. And lastly, I found that my own evolution into a researcher and writer after sustaining a head injury myself merits consideration.

I reflect in Chapter 8. I talk of my past with the horses, how I feel now, and what difficulties I now face. I explore the impact that doing this research has had on me.

Now, in Chapter 9, the conclusion, I wrap things up for the readers. I have already completed an overview of the chapters. I will next discuss performance, and how I feel it contributed to the study. Then, in the following sections, I touch on the study's implications, the contributions I hope it makes, and I suggest some recommendations for future research.

Performance

I feel that my choice of a dialogical/performance approach to analysis, outlined by Riessman (2008), has lent a deeper, closer feel to the analysis for this study. Such an analysis has helped me to convey to the readers what I feel was revealed by the participants' performances of what they had experienced during their recoveries from head injury. As Riessman did in articles (2002b, 2003) about her study of men with Multiple Sclerosis, I explore how the participants think that their lives have changed after head injury. Would subsequent analyses, using different theoretical frameworks, help me to expose nuances that Riessman's dialogical/performance analysis may have kept under cover?

Carr (2007) feels as I do about the use of performance in illness narratives. She writes that: "Within the field of illness narrative scholarship I believe performance offers a means of theorizing beyond the written word. The body, central in performance, figures strongly in illness narrative and yet is often absent in the telling" (p. 217). I would like to think that, by creating illness narratives that include comments about the athletes' performances, I have brought their stories to life for the readers. I have tried to show how the performed telling of a story in the present can (re)configure stories situated in the past

(Mattingly, 2004). As Freeman (1993) writes, the past is being (re)written each time it is (re)visited. I hope that the study constantly changes for its readers with the help of descriptions of the athletes' performances as data. I would add to Freeman's comment that the athletes' changing performances play parts in (re)writing their pasts. Each time they performed for me, they may have been interpreting their pasts in new ways and understanding these pasts a bit differently than the time before.

A Tellable Painter's Fan

I believe that this thesis has evolved and, with the readers' interpretations, is forever becoming what I intended it to be, a painter's fan. It is a combination of a pleated text, a layered text, and a collage (Holman Jones, 1998a, 1998b; Richardson, 1997b; Yardley, 2008). Following Holman Jones, each illness narrative, as well as the thesis itself, is a collage of narrative, performance, photography, and reflection. The layered thesis, described by Yardley, provides multiple viewpoints. My hope is that, as Richardson notes, the co-constructed stories are accessible to all.

Opened at any point, this painter's fan reveals subtle nuances, all of which add up to a richly coloured tapestry of ideas painted with my own interpretations. I have tried to offer multiple viewpoints for readers to take in, digest, and then perhaps decide which they support. I hope that, while reading this text, they are forever arriving at meanings that they themselves have made. Because described performances, photographs, comments, and poetry have all been used to complement my written words, I believe that this thesis and the stories from which it is constructed are tellable offerings (Norricks, 2005), all suggesting many interpretations.

Future Directions

During the research process, I found but a few articles on caregivers of survivors of head injury. More specifically, I am interested in studying relationships between individuals who have sustained head injuries and their caregivers, in particular those people with whom the survivors had relationships before their injuries and are still with the survivors now as their main supporters. I wonder: Who are these people who give themselves over to helping others? What are their relationships with the person for whom they are caring? How have these relationships changed? What are the stories of healing that they have listened to? How were they impacted by their loved one's injury? What can I learn from these caregivers' stories? I would like to see research, as does Carr (2007), that seeks to discover "the systems of support - implicit and explicit - that encourage the reintegration of the ill.... into society". When trauma is articulated, does it "perhaps mute the inclusion of these crucial characters [(the caregivers)]... how [might] these voices.... complicate, tell and retell the experience in collective and useful ways [?]" (p. 217).

Three of the athletes in this study, have accepted their injuries and moved their lives forward, as I have mine. Dave Irwin has not yet reached that point. I wonder about the questions that face survivors as they learn to accept their head injuries. Vachon (2001) lists questions long-term survivors of illness may have, including "Why have I survived when others haven't" (p. 280)? Has Dave evolved to the point where he is wondering about his head injury in a similar manner? I hope that he finds a way to accept his injury, find a meaningful path to follow, and advance his evolving identity beyond feeling that he is 'just a guy'. Further research could explore, when survivors' deficits prevent them from returning

to their previous occupations, how these survivors (re)discover meaning and purpose in their lives. If it is necessary for them to make significant adjustments to their lives, how do they do so? How do they reconcile themselves with their head injury?

I wonder about disclosure, a problem with which I sometimes have to wrestle. For those left with deficits they are able to hide, how do they decide with whom to share their history of head injury? Why and how do they choose to share it? Why do they choose to hide it? I have found it easier not to disclose my injury to casual acquaintances, preferring to wait until I know them better. It is then less likely that they see me through the lens of head injury.

Personal Implications

Behar (1996) believes that qualitative research should break your heart: If it doesn't, she thinks that it just is not worth doing. In many ways, this research broke my heart over and over again. I returned to a time that I would rather forget because I thought I believed that experiences like mine often best remain "unspoken and unstoried", as Carr (2007) expressively states (p. 216). But, in order to maximize my closeness to the other participants, I told them my own story. I had to tear apart my own experiences, peer deep down into the cracks I exposed and then I had to lay bare my self who has experienced head injury. Because I am also a participant, you read about me too. It was at times painful to listen to the athletes' stories because my own experiences made it possible for me to really picture how it had been for them. Also, spending time with the participants caused me to often question my existing and readymade assumptions about head injury.

When I wrote the illness narratives for the participants and described their performances, I wondered if doing so would have been easier for someone less personally involved. I also questioned how open minded I was during data collection: did the closeness of my own experiences impede my observations? If so, how? I would like to think that, instead, this closeness was the source of my absolute admiration for the athletes' stories of healing.

Contributions

Now, the time has come to confront the question: Is this research useful? Instead of thinking 'So what, who cares?' I, perhaps selfishly, feel that it has been worth doing. This research has been personally valuable to me. Exploring the experiences of others in an autoethnography has opened the door for me to better understand what I have been through. I have developed knowledge in the field of autoethnography by exemplifying that, as Taylor (2008) has reinforced for me, autoethnographic research and this research in particular, has strengthened my notion that my experiences count too. Someone somewhere will benefit from my story. Richards (2008) explains that my "position as author is problematized by my very existence and perceived identity (whether it is my own perception or others'" (p. 1718). But I don't agree with Richards. I feel that despite my positioning, I have contributed invaluable knowledge because of this perception of myself. I am a survivor of head injury doing autoethnographic research.

In my unique researcher position, I have exposed readers to not only the stories of elite athletes who have survived head injury, but also to my own stories. As a survivor cognitively able to return to school, I have turned the research lens of this autoethnography,

which was originally pointing outward, inward as well. This has enabled me to offer what I feel is a unique perspective on head injury research: the research has been conducted by someone from the same culture. Specifically, I feel that by listening to these athletes and reflecting on their struggles, I can recount their stories, my story, and my reflections during the research process to let other survivors know that they are not alone. I hope individuals in general, but particularly those who have sustained head injuries, will learn from the stories of the other participants. By constructing illness narratives from the stories of these athletes, I hope that others can see the benefits of telling their stories of healing for others and for themselves. As Glustein (2006) did in his thesis, I have endeavoured to fill the pages with the participants' voices. To continue with this way of thinking about my research, I plan to produce a book that will be composed of the athletes' voices. It will be written for survivors and will share the athletes' stories of healing.

I have contributed methodologically by writing this thesis unconventionally. I continued the metaphor of the painter's fan, which I used to describe how I constructed the thesis, by naming the chapters according to how a house would be painted. I used Frank's (1995) types of illness narratives, but when I assign his narrative types, I question the types I give to two of the participants, and I also question my own. I added a chapter with a reflectively written, raw, story of my own travails. Did I want to write the chapter? No! Did it contribute to the thesis? Absolutely.

This study offers new knowledge because it employs ground breaking methodology to explore innovative questions. I have listened to and questioned the participants, spending extended periods with them to (partially) capture their experiences as well as I was able to. I

am aware, however, that my constructed stories will ever only be incomplete interpretations of that specific time in their lives. I have explored the photographic illustrations that they have taken for their stories. I have watched their performances of their stories and inserted comments about these performances throughout their stories.

The uniqueness of this study extends to its analysis. Using Polkinghorne's (1995) and Coulter and Smith's (2009) descriptions of narrative analysis – storytelling - and analysis of narrative, I have brought to the surface *how* individuals tell, or more appropriately to Riessman's dialogic/performance analysis, *show*, their stories, and also *what* these stories show. I hope that this study is useful to researchers in other areas of study who are interested in how narrative analysis and the analysis of narrative (Coulter & Smith; Polkinghorne) can be used to complement each other.

Another contribution of this study is that I believe that performing this study as an autoethnography enables all of us – participants, me, readers – to better appreciate the complexities of head injury. By showing how differently the participants, albeit a small number, have approached rehabilitation, I have extended the knowledge about some of the infinite range of possibilities available for those who survive a head injury. Although I feel I have contributed in this way, I am left wondering about the emotional support to survivors. This research showed that this support was lacking. However, the importance of family support was evident. The participants of this study all had this invaluable resource.

Developing a Theory

An outcome of this research is that I can suggest the following theory. It can be applied to those recovering from any life-altering illness or disability. The theory:

The path of recovery from serious injury is suggested by the path of life before the injury occurred.

I believe that this research of a select group: elite athletes who have survived head injury, contributes knowledge that is applicable to all survivors of head injury. As already mentioned, elite athletes have an innate drive that causes them to push themselves to the limit of their abilities, and beyond. This study shows that, for these athletes, working towards the goal of healing from head injury invokes the same sense of accomplishment for them as their work towards their athletic goals. The thread of working towards a goal continues throughout their lives. I suggest that this also applies to the general population of survivors of head injury: how individuals handle their lives prior to head injury resembles how they will approach life after injury.

A Finale

Others may judge this research. I think I have been clear about the study's purpose, my methods, and my interpretations so that the study resonates for most and is relevant to some (Finlay, 2006). My goal in this study was to give voice to a few former elite athletes who have sustained head injuries and are either struggling to come to terms with, or are settled into, their post injury lives. This study's readers will all form opinions on its significance to them: any interpretations found by them are possible. I once again remind the readers that I have only made suggestions.

What now?

I ask myself...

Perhaps more research

but first

I will write

again....maybe

a

novel?

.....(the last) interlude....

I find myself looking forward to the future with anticipation. Writing heals. Telling heals. Etchings and scars soften and eventually vanish over time. The stains are less noticeable. Time has helped them to fade.

I know that I am healthy and happy again.

But, even if I am happy in my life now, do I want my memories of this upheaval in my life to also soften, fade, and slowly, quietly, vanish?

The memories are fading. I grasp at these memories, keeping them close, not letting them go. I feel them slipping away; but I have discovered that I don't want to lose them.

So I write stories.

(Smith, 2008, p. 10)

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Endnotes

1. As Bury (2001, p.272) explains, I was trying to " 'normalise' in the sense of keeping [my] pre-injury lifestyle and identity intact." The "me" who my family, therapists, and doctors saw every day did not, at that point, match the 'me' I thought I was projecting. I truly believed that I was the same person that I used to be. King (2000) and Rimmon-Kenan (2002) note that after experiencing a major life trauma, individuals can have trouble accepting that they may have to construct a brand new identity and envision a different future, one unforeseeable prior to the experience of the trauma.

2. Insight takes self awareness, which is hard for anyone to attain. After a head injury, self awareness is an unusual addition to one's repertoire, normally rediscovered (or, more commonly, discovered for the first time) after years of reflective self-examination.

3. As I recount my narratives of that time, I see that they show my life during that time develop "as a drama of gradually unfolding awareness" (Hurwitz, 2000, p.2086).

4. Because I was situated within a cultural context rife with "prevailing definitions of health ... and stigma" (Ellis & Flaherty, 1992, p.4), I seemed "different"; the attributes that others observed were "incongruous with our stereotype" of what is expected from an athlete who has competed at high levels (Goffman, 1963, p.3). As a result, I found myself stigmatized. I may have exhibited characteristics due to my injury "that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that

his other attributes have on us" (Goffman, 2006, p.132).

5. My research, past and present, is, for me, yet another step I can take towards reclaiming my voice "that bodily trauma ... [has] caused to be silenced" (Frank, 1998, p.336). Everyone who has had a life changing moment in their lives wonders: how am I going to fashion a new person from the rubble left after the trauma (Grealy, 1994)?

6. I have learned that my beloved past will never be left behind, even as my current identity is shaped by new experiences and evolving relationships (Nelson, 2001; Verkerk et al., 2004).

7. Identity is always a work in progress, at this point in time, my post accident identity search was especially complex. My life had been redirected by a singular, pivotal event (Pillemer, 2001).

8. My present, ever-changing identity will always include my memories and stories of the past, not of "how it was, but how it is interpreted and reinterpreted, told and retold" (Bruner, 1987, p.31). I find that I am surprised, sometimes mystified, but generally satisfied with the person I have become (Frank, 2000b).

Appendix
Conversation Guide

Introduction:

Four informal interviews or conversations took place with each athlete/participant as well as with his caregiver if a caregiver was present. All of the participants were male. I talked with each of the participants over the course of four days with the purpose of exploring the following research questions:

When elite athletes sustain traumatic brain injuries, what do the athletes' performances reveal about their journeys of identity construction?

1. What do the athletes' performances disclose about their understandings of the terms 'identity' and 'learning'?
2. How do the athletes, through their performances, describe their identities: who they felt they were before their accidents and who they are becoming after head injury?
3. When the athletes perform their stories, what do these performances convey about their perceptions of whether they have learned, and if so, how and what they have learned while (re)constructing their identities?

This guide contains broad and open-ended questions from which more were developed prior to each conversation and more emerged as the conversations progressed. I found it necessary to use 'probe questions' such as 'Can you tell me a little more?', or 'Can you give me a specific example?' These probes were worded in such a way that they encouraged the participants to describe their experiences in more detail. I sometimes found that I had to word the questions in several different ways until the participant understood what I was asking.

Participant Information

Research Title: Identity Construction After Traumatic Brain Injury: Elite Athletes Perform Their Stories of Healing

Interviewer:.....

Interviewee:.....

Caregiver (if present):.....

Time:.....

Date:.....

Location:.....

Conversation 1

Objectives:

- 1) To meet the participant and gain his trust through informal conversation.
- 2) To foster rapport and obtain casual background information from the athlete.
- 3) To tell him about the study and to invite him to ask any questions.
- 4) To facilitate the development of trust, I will share my story with the athlete if he wishes
- 5) To observe how the athlete performs his identity before I begin encouraging him to tell me stories in subsequent conversations (sub-question # 1)
- 6) To ask the athlete for the photos I requested in the information letter.
- 7) To ask the athlete, over the next couple of days, to take pictures that describe his life now and what his sense is of who he is now (the caregiver may have to assist the athlete).
- 8) To ask the athlete to express himself in other ways if he would like (painting, poetry, collage) while he is telling stories.

Conversation 2

Objectives:

- 1) To hear stories of his past as an athlete that may reveal the athlete's perceptions of his pre-injury identity.
- 2) To uncover, through his performance, what the athlete implicitly understands 'identity' to mean.

3) To observe how the athlete performs his identity while telling his stories.

Guiding Questions:

a) Can you tell me about your past as an athlete. (Use photos of the athlete competing as prompts).

b) Tell me a story that you think describes who you were when you were an athlete.

c) I'd like to get a sense of who you are now, can you tell me a story that describes your sense of who you are now.

Conversation 3

Objectives:

1) To hear stories of the athlete's accident and how he sustained a TBI.

2) To understand how the athlete feels that the injury has changed his identity and life.

3) To observe how the athlete performs his post-injury identity.

4) To examine how the athlete's performance during this conversation reveals his unspoken emotions and thoughts about the changes in identity and life that he possibly has experienced.

5) To observe, through his or her performances, whether he considers himself to be an athlete, an ex-athlete, or a former athlete. To observe how and whether this differs from his comments when explicitly asked.

Guiding Questions:

a) Tell me a story about how you sustained a TBI? (How were you injured....)

b) Tell me a story describing how you think you have changed since your accident? (How has your sense of who you are changed since your accident?) (How would you describe the impact that your accident had on your identity?)

c) If you don't that you have changed, tell me a story describing how you are the same as you were when you were an active athlete.

d) Tell me a story of a typical day in your life:

- i) What are some special activities - fun and not so fun - that you do that are part of a 'typical day'?
 - ii) What are some special activities - fun and not so fun - that you do that are not part of a 'typical day'?
 - iii) Describe to me how you think that your day to day activities have changed since your TBI.
 - iv) What are the activities that are new to you, that you have undertaken since your accident?
 - v) Talk to me about those activities that you particularly enjoy and make you feel good when you are doing them.
- f) What factors of your life now do you think have contributed to your sense of who you are now?

Conversation 4

Objectives:

- 1) To uncover what the athlete understands 'learning' to mean.
- 2) To hear stories that describe how the athlete perceives that he has learned after his or her injury.
- 3) To explore how the athlete feels that learning has played a role in his journey of identity construction.
- 5) To observe how the athlete performs his or her identity when telling stories of his or her learning experiences.

Guiding Questions:

- a) Tell me a story that describes how you understand the term 'learning'.
- b) Do you think that you have learned since your injury?
 - i) If you did not learn:
 - Why do you feel that you did not learn? (Give examples of learning the athlete will have likely undergone during rehabilitation)
 - Tell me a story that describes how you are different now then you were initially following your injury.

Re-state the question.(Do you think that you have learned since your injury?)

ii) If you feel you did learn:

- Tell me a story about the learning that you have undergone.
- Tell me a story that describes the manner in which you think that you learned
- Tell me a story about what you learned.
- What are the reasons that you chose the avenues of learning that you did?
- Tell me a story about how you perceive that learning has played a part during the construction of your post-injury identity?

c) Tell me a story that you think describes other factors (activities, events, things) that you feel have helped you through your journey of recovery and your post-injury identity construction? I'd like to hear any stories that you would like to share about these other elements (activities, events, things).

d) Tell me a story about how the trauma that you experienced impacted you in the months right after your injury.

e) What are the factors that you perceive have contributed to your present identity (who you are now)?

f) How is your sense of who you are different now than right after your injury?

f) How do you think telling stories has helped you to sort things out (helped you to learn)?

g) How do you think that learning has helped you to constructed a post-injury identity and how has it helped you in your current life?

h) Talk to me about the photos you have taken and how they illustrate the person you are now. (Why did you take each particular photo?)

i) Tell me a story that describes what the trauma in your past means to you at the present time.

j) How has that meaning changed as your sense of how you are as evolved?

k) How do you think that learning has contributed to this change in the meaning of your trauma?

l) I'd like to hear stories about the photos that you have not yet talked about, and why you choose to take those photographs.