

Self-Care Narratives by People with a Traumatic Brain Injury

by

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A Thesis submitted to the Faculty of Graduate Studies of  
The University of Manitoba  
in partial fulfilment of the requirements of the degree of

MASTER OF ARTS

Department of Psychology

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### Abstract

Traumatic brain injury is one of the leading causes of death and disability in the North America, and can result in long-term physical and psychological consequences, which over time change brain injury from a medical problem to an issue of quality of life. Various self-care activities can significantly improve the quality of life in people living with a chronic health condition. However, research on self-care in these populations has focused on the physical aspect of self-care, often excluding other domains of functioning. There is minimal self-care research involving people who had a traumatic brain injury; however, it is important to understand how they experience and make sense of their injury and its consequences in order to develop more effective approaches to their rehabilitation and support systems. In this study, I interviewed adults with traumatic brain injury who had their injury at least two years prior to the study. Narrative analysis of their stories revealed that the participants faced the following difficulties: constructing an explanation for the injury, dealing with losses and limitations, feeling misunderstood and insignificant, and dealing with memory deficits and physical problems. The ways in which participants tried to overcome these difficulties was understood as self-care. It manifested in a variety of ways, including deliberate health-related behaviours, changes in one's way of thinking, emotional regulation strategies, and linguistic and paralinguistic means used in the narratives. I discuss ways to understand the findings using different theoretical models, such as illness narratives, social disenfranchisement, and social disability models. The results of the study strongly suggest that our understanding of self-care should encompass both physical and psychological health.

*Keywords:* narrative, self-care, traumatic brain injury

### Acknowledgements

I would like to sincerely thank my research supervisor Dr. Maria Medved for continued support, encouragement and invaluable advice she provided to me at all stages of this research project. I am also very grateful to my other committee members Drs. Diane Hubert-Murphy and Christopher Fries for their support and recommendations.

I would like to acknowledge the financial support I received while completing this study in the form of a two-year scholarship from the Manitoba Health Research Council.

In addition, I would like to thank the Manitoba Brain Injury Association for their cooperation and making this study possible.

Finally, I am honored to extend my gratitude to the participants of the study, who allowed me into their lives and shared their experiences.

### Self-Care Narratives by People with a Traumatic Brain Injury

A brain injury can suddenly and irreversibly change one's life in a matter of seconds. From one moment to the next, the person may suddenly experience pain, difficulties with attention, memory loss, and other unusual changes in themselves. Some of the impairments will subside, but many may stay with the person long after he or she is released from the hospital. With all these changes, a TBI survivor may feel like a different person, and will need to learn to adapt to and live with this new altered sense of self.

A traumatic brain injury (TBI) is defined as a nondegenerative, noncongenital insult to the brain from an external mechanical force, possibly leading to impairment of cognitive, physical, and psychosocial functions (Dawodu, 2003). Approximately 10 million people are affected by TBI in the world every year, leading to hospital admission or mortality; compared to all other types of injury, brain injury is the most likely to lead to death or disability (Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007). In terms of causes, worldwide the majority (almost 60%) of TBIs are due to road traffic injuries, 20-30% are due to falls, 10% are due to violence, and about 10% are due to workplace and sports-related injuries (Gururaj, 1995). In Canada, there were 16,811 hospital admissions due to TBI in the period of 2003-2004 or 46 admissions daily (Hyder et al., 2007). In Manitoba, people with TBI use hospital services 3.9 times more often than people without TBI; 60% of these services were unrelated to the TBI proper (Cameron, Purdie, Kliewer, & McClure, 2008).

Given the high prevalence and potentially serious consequences of TBI, it is not surprising that there is a large body of research on this condition. Of those studies,

however, only a limited number have been conducted looking at subjective experiences of individuals with TBI. Although the research in this area is growing, a good understanding of what living with a TBI means for these people is still lacking. The importance of such investigations cannot be understated; understanding patients' subjective experiences of the illness can provide useful insights into effective rehabilitation and long-term community care. The person living with this condition is the expert on the experiences and challenges associated with it. Even though he or she may not necessarily possess an expertise based on the factual knowledge about brain injury, these accounts provide us with the authenticity and first-hand knowledge of the lived experience. As authors of the stories, they allow others to have a glimpse of what living with brain injury is like. Making sense of these experiences is accomplished through construction of stories, or narratives. Narrative is, thus, an appropriate method to investigate lived and meaning-making experiences of these individuals as it allows exploring how they construct stories of life with the illness. I will discuss narrative further later in this introduction.

Lorenz (2010) argues that after the individual with TBI is released from the hospital, TBI ceases to be a medical problem, and becomes a quality of life issue. TBI survivors' quality of life is affected by the deficits and limitations of their condition along with their social consequences. However, it can be improved by a continuous process of self-care. This is things people do to adapt to their illness, as well as restore and maintain the sense of wellbeing. Research on self-care in TBI survivors is lacking, but it is an integral element of their everyday experiences of living with consequences of TBI. From the point of view of rehabilitation, emphasizing self-care is important, because it has been

shown to improve health status and quality of life, as well as decrease medical costs (e.g., Gammon, 1991; Stearns et al., 2000).

### **Self-Care**

According to the World Health Organization (2009) the concept of self-care refers to deliberate action that individuals, family members, and the community should engage in to maintain good health. This is a rather general definition. A variety of operational definitions of self-care can be found in the research literature, from broader ones, where self-care refers to behaviours and attitudes aimed at improving health and managing disease, to narrower ones, where self-care is understood as management of physical symptoms of a specific disease. Because the majority of self-care research has been done with people with chronic illnesses, for example, diabetes, asthma, HIV or arthritis, the most frequently used definitions of self-care are informed by the medical model of health. In other words, researchers tend to focus on behaviours related to managing physical symptoms and pay much less attention to emotional, cognitive, and interpersonal self-care strategies.

Another branch of self-care research focuses on older adults. Similar to chronic illness research, self-care is conceptualized as a crucial element of chronic health care (Ory, 2008). Adopting what can be called a disease-centered approach to self-care limits the attention health care providers and policy makers pay to the complexity of this phenomenon (Spenceley & Williams, 2006). It is easy to miss non-medical factors that influence effective self-care, like cultural beliefs about illness, quality of social support, and making meaning of the illness when research does not include them into their scope of investigation. These issues may serve as important barriers or facilitators of self-care.

For example, in their cross-cultural multi-site study of HIV-positive individuals, Reynolds et al. (2009) found that representations of the illness influenced self-care behaviours and outcomes. Perceptions of the seriousness, consequences, and especially controllability of the disease were related to the frequency and perceived effectiveness of self-care behaviours, as well as quality of life outcomes (Reynolds et al., 2009). One study revealed that self-care behaviours in participants with heart failure were affected by their psychological status, ethnicity, and comorbid conditions (Schnell-Hoehn, Naimark, & Tate, 2009). In their study, severe psychological distress, a large number of comorbid conditions, and being Aboriginal were negatively associated with the quality of self-care, while higher self-efficacy was linked to more frequent self-care behaviours in this population (Schnell-Hoehn et al., 2009).

Bayliss, Steiner, Fernald, Crane, and Main (2003) reported a number of barriers to self-care as experienced by individuals with comorbid chronic diseases. These factors included lack of knowledge, need for social support, aggravation of one condition by symptoms of or treatment of another, and financial difficulties (Bayliss et al., 2003). In fact, low income has been repeatedly reported as a barrier to self-care (e.g., Loignon, Bedos, Sevigny, & Leduc, 2009; Silverman, Musa, Kirsch, & Siminoff, 1999). In addition, several studies point to differences in self-care behaviours across different ethnic groups (e.g., Reynolds et al., 2009; Silverman, Nutini, Musa, King, & Albert, 2008). Gallant, Spitze, and Grove (2010) found variations in self-care activities in older adults with chronic conditions across four ethnic groups (African-Americans, Latinos, Asian-Americans, and American Indians). Based on these findings, the authors argue that

there is a need to include cultural values and beliefs related to health and illness management into research on self-care.

Although these studies are based on different chronic conditions, one may argue that within the larger definition of self-care, experiences of individuals with different chronic conditions have common elements that do not depend on particular physical symptoms. Paterson, Thorne, and Russell (2002) investigated decision making related to self-care in individuals with HIV, Type II diabetes, and multiple sclerosis. The authors reported that there were similarities in health decision making across conditions, such as a focus on healthy practices and nature and quality of available information; however, the specific characteristics of the diseases influenced the meaning and significance of these decisions (Paterson et al., 2002). In constructing their narratives, individuals with TBI are also likely to incorporate how TBI-related difficulties, like requiring special transportation because they are in a wheelchair, affect their lived experiences and everyday decision-making processes.

As seen from the literature, research on one condition can inform research on other conditions, and comparison of findings on self-care may illuminate elements that are characteristic of many chronic conditions. It should be emphasized, however, that since TBI survivors are a heterogeneous group in terms of location, severity, and specific consequences of the injury, living with TBI-related difficulties is not equivalent to having a specific chronic condition. Nevertheless, adjustment to these difficulties in everyday life has commonalities with adjustment to a chronic illness, and for this reason research on chronic illness is relevant to this population.

Because the majority of studies on self-care have focused on self-care as management of physical symptoms of a disease, there is a need for a more life-centered, as opposed to disease-centered, approach to self-care. Its underlying assumptions include “Self-care is about living life,” “Ill person is the best expert on self,” and “Illness as part of life” (Spenceley & Williams, 2006). There is a growing number of studies that use this approach; the majority of them use qualitative methods of investigation and look at experiences of self-care in individuals living with chronic health conditions. These studies often include in their conceptualization of self-care activities that are not directly related to management of physical symptoms.

Cicutto, Brooks, and Henderson (2004) used focus groups to study self-care experiences of individuals with chronic obstructive pulmonary disease. The participants in their study interpreted self-care in the context of meaning and purpose of life. Their self-care strategies fell into two broad categories: physical adjustment and emotional adjustment to the illness. Striving for a balance between living life and disease management was an important element of physical adjustment. In terms of emotional adjustment, the participants reported such self-care strategies as seeking social support from their family, peers, and health professionals, positive thinking, acceptance of their condition, and laughter (Cicutto et al., 2004). For the participants in this study, self-care was focused as much on maintaining emotional health as on symptom management.

In a study of self-care strategies of older adults with multiple chronic conditions, Leach and Schoenberg (2008) found that their participants used these strategies with the goal to remain in control of their health. The self-care behaviours in this study addressed three domains of functioning: management of physical symptoms, cognitive structuring,

and faith. To manage their symptoms, the participants reported focusing on diet, taking medications, exercise, and going to the doctor. Their cognitive strategies included being health vigilant, normalizing, and social comparison. In the spiritual domain, the participants emphasized prayer as a support strategy, gaining strength from God, and viewing church as a central part of their lives (Leach & Schoenberg, 2008). Thus, in this study, the concept of self-care was kept broad and flexible to allow for a variety of strategies the participants might include in their stories.

Finally, Plach, Stevens, and Keigher (2005) investigated self-care in mature women living with HIV and/or AIDS. In this study, self-care emerged as efforts to maintain physical health as well as sustain heart, mind, and soul. The participants used health-promoting activities, focus on wellness, and contending with symptoms as strategies to nurture their physical health. To take care of their emotional well-being, the participants reported drawing on inner strengths which they developed throughout their lives. They also changed their ways of thinking about life and death, and health and illness, adjusted their expectations for the future, and re-conceptualized the way they understood their purpose in life. Finally, faith in God was discussed as a strategy to nurture the soul (Plach et al., 2005). In this study, the individual is seen as a whole, body, mind, emotions, and spirit included. The authors argue that management of physical symptoms, although important, is only a part of the holistic approach to self-care in an individual with a chronic condition.

It is important to understand self-care from the point of view of the affected individuals, who may perceive self-care as including many domains of their lives, such as physical, emotional, cognitive, and spiritual domains (e.g., Votova & Wister, 2006).

When the concept of self-care is narrowly focused on disease management, it is easy to overlook other factors that facilitate recovery and adjustment to the illness. For example, optimism has been shown to be an important aspect of self-care. Fournier, de Ridder, and Bensing (2002) report that optimistic beliefs differentially influence symptom management depending on its perceived level of controllability. A more encompassing, holistic approach will be more effective in enhancing quality of life of individuals living with permanent impairments.

Although there are a few studies on self-care and stroke survivors (e.g., Guidetti, Asaba, & Tham, 2007, 2009), research investigating self-care in individuals with TBI is lacking. Guidetti et al. (2007) looked at the process of recapturing self-care shortly after a stroke or a spinal cord injury, when the individuals were going through rehabilitation. The meaning structure of this process included several elements: becoming familiar with the new body, trying to use the body in different activities, reclaiming control over their body, and everyday living, at the same time as feeling uncertainty in the continued recapturing process. The participants also described several contextual factors that were important for them: support from others, an unspoken expectation to be responsible for one's own self-care, extended time (i.e., needing an increased amount of time for self-care), a new daily structure, the therapeutic relationship as an enabling possibility, and a gradual change in challenge.

TBI presents unique challenges to self-care in comparison with other chronic health conditions. First of all, emotional and cognitive deficits caused by TBI can compromise the person's ability to use emotional and cognitive self-care strategies to adjust to their condition. This in turn limits the scope and efficacy of self-care strategies

available to them. Second, a compromised sense of self experienced by many individuals after a TBI would seem to hinder one's efforts to manage the difficulties, because it detrimentally affects motivation and certainty in one's ability to cope. In addition, Dill, Brown, Ciambone, and Rakowski (1995) argued that self-care responses to symptoms are influenced by one's current identity and personal biography. But the sense of personal identity is sometimes disrupted after a TBI (e.g., Nochi, 1998).

Obviously, one's experience of living with TBI is complex and affected by numerous challenges. Several aspects are related to one's ability to engage in and make sense of taking care of oneself, both physically and psychologically. They influence how narratives of living with the illness are constructed. Such aspects, which I will discuss in turn, include psychosocial, cognitive, and behavioral consequences of TBI, and loss of a sense of self.

### **Psychosocial, Cognitive and Behavioral Consequences of TBI**

People affected by a TBI experience a combination of physical, emotional, cognitive, behavioral, and social difficulties; our understanding of self-care needs to include these domains to facilitate rehabilitation and adjustment to the injury. Each patient has a unique pattern of impairments due to the nature and severity of the injury, the person's age, gender, genetic endowment, and other related factors (Crowe, 2008). Many experience sleep disturbance, which may lead to fatigue and sleepiness, exacerbate other symptoms, and slow the recovery overall (Orff, Ayalon, & Drummond, 2009). The person's body changes, becomes unfamiliar and may be difficult to control, yet the person needs to learn to accept and live with this new body. The most common neurological symptoms associated with TBI are headache, dizziness, poor coordination,

increased light and sound sensitivity, altered sense of taste and smell, hearing loss, and blurred vision (Crowe, 2008).

There are a number of common emotional difficulties occurring in the aftermath of TBI, with mood disorders being the most frequent psychiatric complication (Jorge, 2005). There seems to be consensus in the research literature that depression is the most common mood disorder seen in persons with TBI, with prevalence estimates ranging from 24% to 70% (Crowe, 2008). Depression is more likely to occur in the first year post-injury; however, its prevalence is elevated in this population for many years after the injury. Factors ranging from those related to the injury itself to social support and the presence of any physical symptoms affect the likelihood of developing depression (Silver, McAllister, & Arciniegas, 2009). In turn, depression impacts cognitive functioning, for example, resulting in decreased attention and poorer memory, and social reintegration through lack of motivation to engage in meaningful social interactions. As a result, affected individuals experience decreased overall quality of life (Jorge, 2005). Anxiety is another common emotional consequence; it is related to thoughts about the future, being a burden to one's family, and social isolation (Morton & Wehman, 1995). These mood disturbances interfere with the recovery and rehabilitation process, and negatively affect the individual's quality of life. In addition, people living with TBI often experience irritability, frustration, and disinhibition. These emotional difficulties are reported by family members as more stressful to deal with than any existing physical symptoms (Bennett & Raymond, 1997).

Yet social support from family members and friends is experienced by TBI survivors as a crucial self-care resource. For example, in a study by Fraas and Calvert

(2009), 87% of participants reported that strong social support was a crucial element of their recovery after the injury. The role of family members as a source of support became for them more important than before the injury; however, participants also felt that maintaining the social network of friends was more difficult (Fraas & Calvert, 2009).

In terms of cognitive functioning, Stratton and Gregory (1994) argue that all people after TBI have some degree of cognitive impairment; its intensity greatly depends on the severity and location of the injury. Studies consistently find impaired attention and memory after TBI (Salmond, Chatfield, Menon, Pickard, & Sahakian, 2005). However, Mathias and Coats (1999) emphasize that because studies use different methodologies, diverse samples in terms of severity of injury, as well as vary in time post-injury, findings on the cognitive abilities of people who have sustained mild to moderate TBI are unclear. Even though most symptoms subside within the first several months after the injury, residual cognitive difficulties may last for a lifetime. For example, Klein, Houx, and Jellemer (1996) found decreased memory and neuro-cognitive performance speed in adults several decades after their injury, even though the participants considered themselves fully recovered. Other cognitive difficulties associated with TBI include deficits in concentration, judgment, orientation, language, and self-awareness (Brooks, 1990). One of the potential effects these difficulties have on self-care is that they may limit effectiveness of psychotherapy for this population. This is because in order for therapy to be effective, clients need to be able to attend to the therapist, and to what is being discussed, reflect on it, remember what has been dealt with, and finally have the motivation to address their problems, which builds on one's awareness of impaired functioning (Bennett & Raymond, 1997). Access to mental health professionals can be

seen as a self-care strategy; the cognitive difficulties associated with TBI can be a hindrance to using this resource.

Almost half of all people who sustained TBI have been labeled as having reduced insight into their condition; it may be the most maladaptive of all cognitive sequelae, as it creates a disparity between how the person evaluates him- or herself and what others see (Schmitz, Rowley, Kawahara, & Johnson, 2006). This has the potential to create tension and stress in relationships (Flashman & McAllister, 2002). Through narratives, TBI survivors construct the meaning of living with their difficulties, and insight, or self-awareness, influences how these stories are constructed. What may look like reduced insight to others, is part of lived experiences for the affected individual, and is not necessarily experienced as a deficit. So, although lack of self-awareness widens the gap between the perspectives of a TBI survivor and those around him or her, each perspective has an equal value in understanding the process of living with a TBI.

People who sustained TBI in the frontal lobes and the limbic system often show personality changes including an increase in challenging behaviours, collectively known as a 'frontal lobe personality' (Mathias & Coats, 1999). Crowe (2008), in his review of research on personality changes after brain injury, discusses a number of proposed classifications of these changes. Even though researchers use different terms and bases for classification, they tend to divide all symptoms into two groups. For example, Prigatano (1992) calls them active and passive disturbances. Active disturbances include irritability, agitation, anger, impulsiveness, impatience, inappropriate social responses, rapid mood changes, suspiciousness, and delusional phenomena; passive disturbances include asponaneity, sluggishness, loss of interest in the environment, loss of drive or

initiative, tiring easily, insensitivity to others, over talkativeness, helplessness, and lack of insight or awareness of behavioral limitations (Prigatano, 1992). These difficulties necessarily affect one's social perceptions and interpretations of events and other people's thoughts and feelings. Perhaps, these new features of the affected person change how he or she makes meaning of their current situation and relationships, as narrative necessarily includes a reflection of one's personality. They may also influence how the person makes meaning of their changed sense of self.

The described changes in one's personality, as well as decreased or lacking insight into one's own abilities, are also likely to negatively affect one's social interactions. The negative impact that emotional deficits have on the survivor's interpersonal relationships can compromise the social support network. Since the latter is a commonly mentioned self-care resource for TBI survivors, these deficits present unique challenges for self-care in this population. As evident from the literature, TBI survivors often exhibit what others view as poor social behavior and communication (Crowe, 2008). Various factors contribute to poor social skills; for example, decreased sensitivity to emotional cues, disinhibition and poor self-monitoring of verbal and non-verbal behavior, impatience, and emotional lability (Stratton & Gregory, 1994). As a result of these changes, persons with TBI are at risk of becoming socially isolated (Morton & Wehman, 1995). As they may not realize the extent of changes in their social behavior, it may be hard for them to understand why others reject them. They become dependent on their families for numerous aspects of living, which creates a lack of opportunities to establish new social contacts. In addition, some TBI survivors are unable to resume their leisure activities or can only do so in limited ways. Restricted social life is thus an

obstacle for reintegration into the community, and more generally, social support and satisfying friendships are crucial for what might be perceived as a good quality of life (Morton & Wehman, 1995).

In summary, the consequences of TBI affect various domains of functioning and interact in complex ways among themselves and with factors such as the person's age, gender, comorbid conditions etc. to produce a unique pattern of impairment for each affected individual. To further complicate the situation, a considerable number of TBI survivors experience what Nochi (1998) called a "loss of self."

### **The Loss of Self**

From the point of view of the person, personality change may be experienced as a loss of continuity of the self. Individuals with TBI may feel that they are not the same person as they used to be before the injury (Nochi, 1998). Identity is thought to be constructed through narratives, or stories that we create about our lives; from this standpoint, memory is crucial for developing and maintaining a stable sense of self. However, TBI often causes memory loss creating 'blanks' in memory, and thus disrupts the continuity in the sense of self. This can make renegotiating of one's sense of self after the injury difficult or even impossible (Johnson, 1990).

Experiences of reconstructing self-identities by individuals with TBI have been reported in several studies using qualitative methodologies. Muenchberger, Kendall, and Neal (2008) conducted a narrative investigation and argue that identity adjustment after TBI is experienced by the affected individuals as a dynamic and cyclic journey, and if they achieve the balance between the new and the old self, this balance is also unstable and fluctuating (Lorenz, 2010; Muenchberger et al., 2008).

One has to wonder how this disrupted sense of identity affects TBI survivors' ability to take care of themselves in order to adjust to their condition and try to restore a sense of wellbeing. It may influence self-care on many levels, and only the individuals themselves can speak about how they live with these challenges and try to restore their sense of self at the same time as adjust to deficits. In the participants' stories about living with the consequences of their TBI, one might expect to hear interwoven story lines about dealing with possible memory loss, whether one's sense of identity is disrupted, and how the person tries to care for themselves at the same time as making meaning of these difficulties. It is interesting to see how these difficulties affect their ability to be effective at taking care of themselves, and if they do, in what ways, and how the participants try to deal with this. Some research has been done to explore how TBI survivors make meaning of their struggle with the disease.

### **Subjective Experiences of TBI Survivors**

From qualitative investigations of subjective experiences of individuals with TBI, there seems to emerge a general trajectory of these people's lived experiences over time. As years go by, TBI survivors have to face their condition, its challenges and limitations; as they get used to and adapt to those, they start to make sense of their new changed life and changed self. This journey is long and difficult, and some people do not reach a satisfying resolution as fast as others, if at all. Qualitative inquiries into these experiences help understand how this process unfolds and is experienced, as well as what factors facilitate or impede it. Importantly, knowledge of this trajectory is important to understand how self-care strategies and experiences change overtime and reflect the changes in one's self-perception in relation to the injury.

The first stage of this trajectory, not surprisingly, directly follows the injury; the person learns about the injury and its consequences. Shotton, Simpson, and Smith (2007) call this period “waking up,” which describes the survivors’ experience at that time both literally and figuratively. The major challenge at this stage is getting to know one’s changed self, including changed physical, emotional, and cognitive functioning. Brown, Lyons, and Rose (2006) use a metaphor and call this process “finding the bits of the puzzle.” The puzzle that needs to be put together is the traumatic event and their current condition.

Understandably, at the beginning of this process the person may be overwhelmed and feel like everything around and even their body is different. However, as they gain knowledge and start to understand what has happened to them, they become more used to their new situation and their changed life. It is the beginning of what Jumisko, Lexell, and Söderberg (2009) refer to as the process of the unfamiliar becoming familiar. One important feature of this process is the prevalence of negative emotions, such as anger, fear, and sadness. These negative emotions can in turn color the patient’s view of self-care; if they find it hard to accept what happened to them, taking care of this changed self may be an unwelcome challenge. Lorenz (2010) describes this emotional strain as “living with frustration and confusion.”

The second general stage of the trajectory can be understood as the process of making sense of the injury and its consequences and integration of the pre- and post-injury self. Brown et al. (2006) call this process “filling holes in memory.” This is the time when the process of coping with the injury and its consequences comes to the forefront of the survivors’ experiences (Shotton, Simpson, & Smith, 2007); this is when

they have to renegotiate the self-care strategies that are familiar to them to reflect their new challenges and needs. Thus, as the participants in Shotton et al.'s (2007) study shifted from hoping to return to pre-injury levels of functioning to realization that they need to learn to live with their limitations, coping evolved as well. Beliefs about TBI was one of the coping strategies discussed by their participants, for example, believing that they would get better helped them to keep a more positive outlook. Thoughts about the injury and its role in their lives influenced their expectations for the future, and reflected their attitude towards the current situation. For example, when the participants viewed their accident as something that sometimes happens in life, they were better able to accept it. Fraas and Calvert (2009) also discuss modification of coping as an important experience for their participants. Individuals may need to try several coping strategies before they find the one that works for them.

An important theme emerging in TBI survivors' stories is their strong motivation to get better. Because rehabilitation from a brain injury is a long and difficult process, irrespective of the extent of recovery, the person needs to have enough energy, perseverance, and positive thinking; Jumisko et al. (2009) refer to this as "finding strength." The participants in their study recognized that it was their responsibility to actively engage in their own rehabilitation (Jumisko et al., 2009). Consequently, individuals are very motivated to learn and master new self-care strategies to facilitate rehabilitation at this stage. Ultimately, the goal and the challenge of this stage of the trajectory is to integrate the old and the new, the past and the present, to create a sense of coherence (Lorenz, 2010).

In the final stage of the trajectory, the participants reach certain acceptance of their condition, and are able to reconstruct their sense of self; the person at this stage can be thought of as successfully completed rehabilitation. Unfortunately, not all TBI survivors seem to reach this stage. Those who do, however, will necessarily experience it in unique ways, which is the reflection of the idiosyncratic combination of pre- and post-injury factors.

The particular self-care behaviours people choose through their recovery trajectory and beyond are informed by their sense of self and the roles they ascribe to themselves. A lost sense of self may compromise one's self-care efforts, as they would not be supported by a coherent self-representation. There is a pressing need to understand experiences of self-care in this population, as it is likely to provide insights into their long-term coping with and adjustment to the limitations of their condition.

### **The Role of Narrative**

In the field of qualitative research, narrative refers to stories about people's lived experiences and events that are chronologically connected (Creswell, 2007). The concept of narrative includes three elements: temporality, meaningfulness, and sociality. Temporality refers to the idea that individual experiences are connected in multiple ways to social norms and pressures. Meaningfulness demonstrates that the content of stories does not necessarily represent objective reality, but rather includes things that are meaningful and important to the speaker. Finally, sociality reflects the process of narrative construction, which is situated in a particular context and presented to a specific audience (Harling Stalker, 2010). Telling stories is an indispensable tool for one's interaction with other people for a variety of purposes, including self-expression, transfer

of cultural knowledge, establishing relationships with others, as well as communicating one's experiences (Hall, 2011).

Narrative analysis has been used in social sciences to investigate people's lived experiences in a variety of settings and situations. For example, it has been used to study the illness and recovery experiences of both individuals with a variety of health conditions, and health care providers. There is significant value in using narrative research methods to learn about individuals' experiences in order to assess quality of health care. This approach can help identify the gap between the perceptions of quality of care between care providers and care recipients (Lees, 2011). More generally, narrative can be used to study illness and recovery experiences of individuals beyond the scope of health care provision, for example, to understand illness trajectories across lifespan, or daily experiences of living with a particular condition.

The person living with a chronic condition is the expert on the experiences and challenges associated with it. Therefore, if one wants to achieve a fuller understanding of what it means to live with TBI, as well as improve current health care to these individuals, it is imperative to include TBI survivors' stories into the discussion of self-care. They can bring a unique perspective to how these individuals understand their condition and the challenges associated with it. Through telling of stories people develop their understanding of life, construct a certain image they want others to see, and share their lived reality.

There has been no published qualitative or quantitative research investigating self-care experiences of individuals with TBI. However, given its prevalence and long-term consequences, it is crucial to understand the experiences of these individuals in the

domain of self-care, so that this knowledge can inform more efficient and person-centered health care provision and policy making. In this study, I conducted semi-structured interviews with TBI survivors who were invited to share their stories of adjustment to their condition. I analyzed their narratives from the point of view of how self-care manifests in them. The participants were encouraged to talk about their daily experiences and how their life changed after the brain injury. I was interested in hearing their accounts of life events both prior to and after the injury. Even though the participants were not asked directly about the meaning of self-care in their lives, it emerged from their stories and experiences of dealing with a variety of situations.

## **Method**

### **Participants**

The participants for the study were recruited from the local brain injury survivors' support group. The sample consisted of nine Caucasian adults, including six males and three females, in the age range from 35 to 55 years old. The time elapsed after the brain injury ranged from 2 to 43 years. Studies that include a diverse sample of participants with regard to the time since their injury are common in the research literature (e.g., Fraas & Calvert, 2009; Lefebvre, Pelchat, Swaine, Gelinat, & Levert, 2005). All participants lived independently in the community at the time of the interviews.

With the permission of the group facilitator and the group members I attended several meetings of the support group in order to get to know this population better, observe them and their interactions in a naturalistic setting, and introduce myself to potential study participants. My observations during those meetings were not used as data for the current study, as the ethics approval had not been received at that point. However,

it helped me in developing the interview guide for the study and provided me with background knowledge of some of the things the participants might talk about in their interviews.

After the ethical approval for the study was granted by the Health Research Ethics Board of the University of Manitoba, I distributed flyers with the information about the study among the participants. The group members who expressed interest in participating and met the study criteria were interviewed and received \$20 Tim Horton's gift card for taking part in the study.

### **Descriptions of Participants.**

These short descriptions of each participant serve the purpose of adding context and background for their narratives. They are based on the participants' demographic information, what they told about themselves during interviews, and field notes taken during and after the interview. They should help the reader to better understand the sample of participants and their unique circumstances. Personal and identifying information has been modified to ensure confidentiality.

#### ***Claire.***

Claire is a single white woman in her thirties with no children, living with her father. She has college level education and works part time. She sustained her brain injury at the age of nine as a result of a motor-vehicle accident, when the car she was travelling in was hit by another car.

I met Claire through the brain injury survivors' support group and she was the first participant in the study. Claire's interview took place at her house, according to her preference. It did not seem that the room was cleaned before the interview, and it smelled

of cigarette smoke. During the interview, Clair was lying on her couch, while I sat in an armchair. She appeared to be reserved, chuckled a few times, and seemed in a slightly negative mood. I found it a little difficult to establish good rapport with her. She was willing to talk about herself and her experiences, which included sensitive issues. She gave thoughtful answers to my questions, although sometimes she needed to be encouraged to keep talking or elaborate on what she had already said.

*James.*

James is a single white male in his forties with no children, living alone. Before his injury 2 years prior to the study, he worked as a truck driver. He does not remember whether he graduated from high school. His brain injury happened as a result of an assault when he tried to intervene in a crime in progress. At the time of the interview he was on disability and not working.

The interview took place at the office of the brain injury survivors' support group. James was excited about participating in the study and was eager to share his experiences and being listened to. He was open and talkative, and rapport was easily established and maintained. He often did not maintain link between statements and frequently changed topics without a transition.

*Carl.*

Carl is a divorced white male in his fifties, living alone. He has children and grandchildren, although he is not very close with his family. He did not finish high school. He sustained his TBI when he was 17 years old as a result of a motor vehicle accident, when the car he was riding in went off the road. Before the accident, he had a

job installing and repairing neon signs. At the time of the interview he was on disability and not working.

The interview took place at the office of the brain injury survivors' support group. Carl was cooperative and talkative, but his narrative was marked by pervasive negative emotionality, including anger and contempt. His speech was slightly laboured; he tended to go on tangents and include a lot of details into descriptions of events, which is why his interview took 1.5 hours instead of the planned one hour.

***Matt.***

Matt is a divorced white male in his fifties with no children, who lives with his mother. He has high school education. His brain injury happened when he was in his early thirties, as a result of a motor vehicle accident, when the car he was riding in went into a ditch. Before the injury, he worked as a porter at a large department store; since the injury he hasn't been working, and at the time of the interview he was on disability and volunteering at a non-profit organization.

The interview took place at the office of the brain injury survivors' support group. Matt was amiable but somewhat taciturn, and it seemed like he was slightly uncomfortable, although he was eager to participate in the interview. Later in the interview, when good rapport was developed between him and the interviewer, he became more relaxed. He appeared to be calm and rather imperturbable; he didn't seem upset or annoyed even when he was discussing unpleasant or sensitive topics. Frequently instead of answering the interviewer's question, he would talk about something else or continue his previous line of thought.

***Andrew.***

Andrew is a single white male in late forties, living with his mother. He has a high school level education. He sustained his brain injury as a result of a seemingly unprovoked assault when he was in his early thirties. Before the injury, he worked as a technician for an electrical company; at the time of the interview he was on disability and not working.

The interview took place at the office of the brain injury survivors' support group. Andrew was energetic, friendly, and open for discussion. He seemed to enjoy sharing his story with the interviewer. He was talkative, frequently going on tangents. Sometimes he would forget what he was going to say, which obviously annoyed and frustrated him. He smiled frequently, and appeared to be in a good mood, although he also seemed slightly agitated.

***George.***

George is a single male of mixed ethnic origin (Ukrainian and Aboriginal) in his thirties, living with his father. He has a child with a woman he was dating before his injury. He has a Grade 9 level of education. He sustained several head injuries; the most severe one was 10 years prior to the interview, as a result of a physical fight at a bar. Before this injury, he worked as a machine operator at a steel factory, but he was unable to return to work after his injury, and at the time of the interview he was unemployed.

The interview took place at the office of the brain injury survivors' support group. George was eager to participate in the interview and share his story. He was attentive, friendly, and open to the interviewer's questions. However, he seemed to be in a low mood. He expressed strong frustration and sadness when he talked about his inability to

play hockey after the injury, and not seeing his child because the child's mother's family was preventing him from it.

***Nancy.***

Nancy is a white female in her forties, cohabiting with her boyfriend. She has an adult son from a previous relationship. She holds Bachelor of Arts degree in Sociology. She sustained her brain injury at the age of 14 as a result of a motor vehicle accident, when her car rolled over and she was not wearing a seat belt. She held a variety of jobs, and at the time of interview she was working part time as a waitress.

The interview took place at the office of the brain injury survivors' support group. Nancy brought her boyfriend's dog to the interview with her, because she did not want to leave it home. The dog was often interrupting the interview by barking and growling. Nancy was in a very good mood, she was talkative, laughed often, and seemed to enjoy sharing her story. To introduce herself, she sang a song in which she changed the lyrics to reflect her life. She often used humor and irony when talking about her life.

***Brandon.***

Brandon is a single white male in his early fifties, living alone. He is divorced and has an adult daughter. He has a high school education. His head trauma happened 15 years prior to the study, when he fell from a ladder and hit his head on a concrete wall. Before the accident, he held a variety of jobs, such as security guard and landscaper. He has not been able to work after the injury, and was on disability at the time of the interview.

The interview took place at Brandon's apartment, as it was more convenient for him. His apartment appeared cluttered, and it smelled of cigarette smoke. Brandon and

the interviewer sat at a dinner table across from each other during the interview. He was cooperative and friendly, although not very talkative. The interviewer often needed to ask Brandon to elaborate. He appeared calm, and did not smile. During the interview, he stayed focused, paid attention to the interviewer's questions, and did not go on tangents.

*Shelly.*

Shelly is a white female in her early fifties, living with her common-law partner. They have three adult children together. Shelly has a Grade 9 level of education. She sustained her brain injury when she was eight years old, when she was hit on the head by a door in school. She has been on social assistance since she was 19 years old, held a variety of jobs, and at the time of the interview worked as a coordinator at a women's assistance center.

The interview took place at the office of the brain injury survivors' support group. Shelly was very open and friendly, and seemed to enjoy telling her story. She was in a good mood, smiled a lot, and talked about the importance of staying positive, accepting the injury, and learning how to overcome its consequences.

**Data Collection Procedure**

The participants took part in a one-hour semi-structured individual interview. The majority of interviews took place on the location of the support group meetings, at the local Brain Injury Association, and two interviews were conducted in the participants' homes according to their preference. The interview questions (Appendix B) were used as a guide. At the end of the interview, the demographic information was collected (Appendix C).

The interviews were digitally recorded in order to insure accuracy of interview transcripts. Field notes were taken to record the environment of the interview (where it took place, whether other people were present, if the environment was conducive to a relaxed mood of both the participant and the interviewer, whether there were any distractions during the interview, etc.), the participant's non-verbal behavior, and the interviewer's comments. The recordings were then transcribed using the conventions developed by Medved and Brockmeier (2004: Appendix D), which allowed recording acoustic characteristics of speech, such as tempo, pitch, emphasis, and pauses. The participants' names were replaced with pseudonyms, and any identifying information was removed to ensure anonymity.

### **Data Analysis**

The transcripts were analyzed using the narrative approach. First, each transcript was read and interpreted individually, whereby meaningful elements were coded and later analyzed. Second, the data from all the interviews were compared and analyzed together, for the purposes of finding overlapping as well as unique themes. The analysis included three levels: thematic, structural, and dialogic/performance analysis. Although they are discussed here separately for clarity, they likely overlapped during the analysis.

**Thematic analysis.** The sole focus of thematic analysis is the content on the participants' stories, as opposed to how or to whom the story is presented (Riessman, 2008). I analyzed the transcripts individually looking for emergent themes as related to self-care experiences. The participants' stories were interpreted to understand how their coping with various situations and challenges represented different aspects of self-care.

After that, emergent themes from all narratives were compared and organized according to the theoretical lens of the inquiry.

**Structural analysis.** At this level of analysis, the focus shifts to include not only the content of the story, but also how the story is told; that is, how the narrator uses language means to make an argument and persuade the listener to believe his/her story. The same story can be told differently, and each narrator will choose the expressive means, in this case, language tools, according to the effect he or she wants to produce on the audience. Within sentences, I paid attention to metaphors, verb tenses, repetitions, and other elements of speech organization. More generally, I focused on the plot of the story, how cohesive the story was, what the main point of the story was, and how it was expressed, as well as whether there were counter-narratives (a story line opposite in meaning to the main theme).

**Dialogic/performance analysis.** Narratives are not created in a vacuum; any story is actively constructed within the context of a social interaction between the speaker and the listener, being influenced by the characteristics of both (Riessman, 2008). At the dialogic/performance level of analysis, this active co-construction process is analyzed. Specifically, the focus is on how the narrative is influenced by the context of the interview, the participant's current life situation, and the influence of the researcher. In this case, the principal investigator is a White female graduate student with Eastern European background without obvious health concerns.

### **Validity**

There are many ways to assess validity of a qualitative research study. In my research project I followed the set of validity criteria proposed by Tracy (2010), which

she developed while drawing on existing validity criteria for qualitative research in the literature (e.g., Creswell & Miller, 2000; Lincoln & Guba, 1985). She suggested a set of criteria for quality that can be applied to all types of qualitative investigations, making them universal for this type of research: a worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethics, and meaningful coherence.

Having a worthy topic reflects the need of a research study to be relevant, significant, interesting, and making a unique contribution to the field. To meet this criterion, I selected the topic (self-care) that has not been significantly researched with brain-injured population. I also used the definition of self-care that is broader than the one used in the majority of studies that deal with this concept.

Rich rigor refers to a) having rich and abundant data combined with the researcher's understanding of multiple theoretical approaches, and b) conducting the study using rigorous methods specific to the qualitative approach the researcher is taking. In order to achieve rigor, I collected data from as many consenting individuals who met the criteria for the study as were available to me, and enriched their interview transcripts with coding of their non-verbal behaviour during the interview, as well as my field notes, which were completed immediately after each interview. I also made an effort to familiarize myself with a number of theoretical frameworks that can be used in analyzing the data, so that it could help me to notice complexity of the participants' stories. In addition, the interviews were read and closely analyzed several times to extract as much data as possible. I also tried to ensure that the claims made in this paper are supported by enough evidence from the interviews.

Sincerity is used to refer to authenticity and genuineness, when the researcher is honest and transparent about the process of inquiry and his/her personal role in the study. To achieve sincerity, I included a section on reflexivity at the end of the paper, where I address some of the issues and personal reactions I had during the study.

Credibility reflects trustworthiness and plausibility of research results. To achieve credibility, I provided thick descriptions of the participants, their experiences, and the stories they shared. Another way to improve credibility is triangulation, when a researcher uses multiple sources of data, different theoretical frameworks, or methods in working with the data. In this study, I extracted data from the content of the participants' narratives, the ways they presented themselves and their stories, and demographic as well as injury-related information.

Resonance is the term Tracy (2010) uses to describe the ability of the study results to affect the audience and promote empathy and identification with the participants. It can be achieved through clear, comprehensible writing that is targeted to a specific audience, as well as through transferability, which is the potential of the study to be relevant in other contexts and with other populations. It was addressed by providing detailed descriptions of the participants and the context of the interviews, so that other researchers can judge if the characteristics of this study are similar enough to their research to allow generalization of the findings.

The criterion of significant contribution refers to theoretical, heuristic, and practical significance of the study. I address the significance of my findings at the end of the Discussion section of the paper. It is my hope that the results of this study will contribute to the theoretical understanding of the concept of self-care, will inspire future

research that will build on my study, and will be helpful in the practice of rehabilitation for brain-injury survivors.

Being ethical is another criterion for a high quality study. To address procedural ethics requirement, I sought and obtained permission to conduct the study from the Health Research Ethics Board of the University of Manitoba. In addition, I was aware that ethical concerns could emerge at any point during the study, i.e., situational ethics requirement, and I made an effort to adhere to the ethical standard of conducting research throughout the process of participant recruitment, as well as collecting and analyzing data. I also made an effort to be as neutral as possible in my description of participants and their stories, to avoid blaming and marginalizing brain injury survivors, which is a danger due to their already marginalized status.

Meaningful coherence in Tracy's (2010) framework encompasses the following: whether the study achieves the proposed goal, the methods match the research paradigm, and the reviewed literature is connected with the results and the conclusions of the study. To address this criterion, I explained why the narrative approach is appropriate for my study, and used the methods consistent with this approach. In discussing the results of the study, I referred to the previous research that I reviewed before completing the study. I also tried to elaborate how my results answer the questions I posed at the beginning of the paper. I relied on my supervisor's expertise and other graduate students' suggestions on whether the study hangs well together and organization of the paper.

### **Findings**

The stories that made up the participants' narratives were analyzed from the point of view of self-care. Many stories reflected the participants' attempts to promote their

well-being or alleviate difficulties, both in physical and psychological functioning. The results of the study are organized according to the main issues the participants described. The following themes were prominent in the participants' narratives: coming up with an explanation, dealing with losses and limitations, feeling misunderstood and insignificant, having memory deficits, and living with physical consequences of the injury. Within each theme, I will describe the self-care strategies that emerged from the participants' narratives. Following this, the discussion section will explicitly consider these five themes in terms of their relevance to self-care among the TBI survivors.

### **Coming Up with an Explanation**

One of the prominent stories told by the participants was about trying to understand why their injury happened to them. Through their narratives, the participants developed their own explanations for the reasons why they sustained their brain injuries. The participants differed in how their brain injury happened: four participants were involved in motor-vehicle accidents, three participants suffered a physical assault, one participant had an accident at school when she was a child, and one participant suffered a fall.

The more recent the injury, the more difficulty the participants tended to have in coming to terms with it (although they all had their injury for a minimum of two years prior to the study). Related to this, for the participants with a more recent injury, the theme of making sense of the injury was more prominent in their narrative. Seven out of nine participants told a story about trying to come up with an explanation for their brain injury. The nature of the injury also seemed to affect the difficulty of creating a feasible story explaining the injury: the participants who suffered an assault seemed to struggle

the most with constructing a meaningful story of why their injury happened to them. In fact, two participants who suffered a seemingly unprovoked assault seemed the most stuck in forming a story explaining the seeming senselessness of their injury. They tended to experience significant anger and frustration when talking about their injury. Thus it seems that it is important to create a narrative about, or to endow meaning to, one's injury because it has an impact on one's emotional reaction towards the injury. Cognitive and emotional processes go hand-in hand, in that creating a satisfying story about the injury is a cognitive process, but the ease of coming up with an explanation, as well as the explanation itself, may lead to various emotional reactions in the participants, as demonstrated in the examples that follow.

A few participants' stories of their injury incorporated significant positive elements, such as, for example, feeling lucky to be alive and seeing their brain injury as something that gave them a chance to become a better person. Giving such meaning to their injury seemed to have helped the participants accept their injury, and created a more positive emotional disposition towards it. For example, Claire told a story about how she used to struggle to accept her injury, then realized it was something to adapt to, and later learned to appreciate how lucky she was:

C: I used to cry myself to sleep when I was a teenager [I: Oh], and say that, you know, um, hoping against hope that it was all a dream and I was gonna wake up (.) and everything would be normal (.) but, um, (2) ((clears throat)) that wasn't the case [I: Uh-huh] and I, you have to learn how to adapt. (.) Um (1) yeah (.) just adapt, and you know, I was one of the luckier ones, [I: Uh-huh] I was very lucky,

(.) I mean [I: How were you lucky?] you wouldn't know that I was- I had a terrible accident when I was a kid [I: Uh-huh] by just looking at me.

The meaning Claire attributed to her injury developed over the years, and the story she tells today seems to allow her to be more accepting of her injury and its consequences. In other words, for her, a story of transformation, and perhaps growth, over time was comforting.

Another participant, Matt, also regretted that the injury happened to him. However, he counteracted this feeling of sadness by including into this story such positives as receiving a settlement and not having major issues except for poor memory. Overall, he seemed to have found some balance between feelings of regret and appreciating the good things that happened after the injury.

Alternatively, not being able to create a story of one's trauma that would make sense to the person, or creating a story with a negative meaning had an adverse effect on the participants' reactions to the injury, and significantly contributed to their everyday struggles. Both Andrew and James sustained their brain injuries as a result of an unprovoked assault, and making sense of the injury has been a difficult endeavor for both of them. James's injury had a dramatic impact on his life, and even years afterwards he is desperate to understand why it happened to him. His exasperation is seen in a strong metaphor about death and the repetition of the word 'why':

J: I analyze things to death.

I: Mm-hmm, like what things?

J: ((sighs, points to his head)) Like this. I analyze (1) why did they do it, [I: Mm-hmm] and I try to figure out from their point of view, why they di- they had done

that to me. [I: Mm-hmm] And most times (.) I have a hard time thinking like that, I get very angry [I: Mm-hmm] at people that done this, [I: Mm-hmm] I try to understand why they did it and I can't.

I: You still can't.

J: No.

Lack of a meaningful explanation for his injury, and his inability to understand why it happened is associated with James feeling angry, frustrated, and sad. He describes a few strategies he uses to help himself manage the anger: he spends time on his own, makes an effort not to think about his brain injury, and reassures himself that he is a better person than those who caused his trauma. Later in the interview, he repeats that he is not a violent man, which sounds like a self-reassuring statement aimed at convincing himself – and the listener – that he would not behave on his anger. Because his trauma happened as a result of a seemingly random assault, coming up with a meaningful explanation is very difficult for James. This in turns fuels his anger, and he seems to be caught in a circle: he tries to find an explanation, but can't, he feels frustrated and angry, and then has to deal with those difficult feelings.

While struggling with creating a story, another participant, Andrew, was able to construct a narrative to explain why his injury happened to him. He told a story of how his injury had been orchestrated by people in the law enforcement system because they conspired against him. His search for the answer to the 'why' question lead him to the idea that it was done to him on purpose to stop him from solving crimes and helping people. This explanation might seem improbable to an outside observer; however, this is the story Andrew created to make sense of the random attack that left him impaired, and

to deal with the sense of unfairness. The emotional outcomes of telling this story for Andrew are feelings of anger, helplessness, and frustration, although unlike James's, they seem to be targeted and justified by the explanation. James and Andrew provide examples of how some strategies can fall short of creating a satisfying explanation for the injury, in that even though they lead to some meaning making, the psychological suffering is not reduced, or, in case of Andrew, is maintained by his story.

A few participants used the idea of a higher power in their explanations for the brain injury. From this perspective, using religious references as part of the meaning making process involves a turn to spirituality for caring for themselves. Some participants constructed stories that involved being thankful to this higher power for saving them from death. Others, like Shelly, told stories about how her injury happened to teach them something: 'God did it for a reason (.) and (.) the reason was the lesson now that I'm *learning*.'

Another participant, Andrew, took an opposite stance, utterly rejecting the storyline that God allowed his brain injury to happen for a reason:

I: So, let's go back to the minister. So, you met with the minister?

A: Right, and I asked him, 'How come so much has happened to me and I lived, and yet so little happens to other people and they succumb to their injuries?'

I: Mm-hmm.

A: And, uh, you know, he didn't have an answer for me, you know, he just put his arms out like this and said, 'Well, Andrew', he says, 'you know,' (2) and then he put hands together, ((claps his hands together)) he said, 'maybe the big', and he

looks at me like this, 'maybe the big guy has plans for you'. ((laughs)) What, live in POVERTY and half out of my mind till I die in like sixty years?

I: So, you didn't buy that.

A: No chance that I buy that.

Later in his narrative he angrily called God 'a sadist' for allowing his brain injury to have happened. Many other participants did not place importance on religion at all, as revealed by the absence of any religious references.

Several participants mentioned how they were moving towards becoming a better person, because they had to struggle and overcome difficulties brought on by their trauma. James told a story of trying to live according to his values even when life gets tough:

J: Everybody else, everybody is slowly dying. [I: Mm-hmm] It's how you look at it, how you present yourself to the world, whether (.) it's noble or whether (.) it's just a piece of garbage. [I: Mm-hmm] I feel like I have been dealt a piece of garbage hand. [I: Oh] I don't believe the world owes me, I don't believe I owe the world. [I: Mm-hmm] I believe (2) in myself, to be myself. I think you're lying, I'd confront you and tell you, I think you're lying, [I: Mm-hmm] but I'm also open to other people's thoughts and suggestions, always open.

For other participants, creating a meaningful story about their injury seems to have helped them to accept this life event, but it was relatively neutral in terms of its affective impact. For example, Carl sees his injury as 'one of life's little mishaps' which could have happened to anyone else, but happened to him 'because it was meant to happen'. Another participant, Brandon, assumed responsibility for his brain injuries,

saying that ‘they happened to me because, cause I did something that I shouldn’t have done’. He came to this conclusion by analyzing his behaviour prior to each injury and assuming that if he had changed his behaviour then, his injuries would not have happened.

Attempts at coming up with a satisfactory explanation for why the brain injury happened was a common element in many of the participants’ narratives. However, each story is unique, as the participants had to make sense of their own circumstances and had to rely on their cognitive resources, e.g., their reasoning abilities, which may have been compromised as a result of the injury itself.

### **Dealing with Losses and Limitations**

Many participants spoke of the losses they suffered as a result of their brain injury, and functional limitations they had to live with ever since. Frequently, that included losing the ability to work or to participate in favourite leisure activities. Sadness and regret were the prevailing emotions accompanying these stories.

For two participants, the brain injury affected their ability to play sports, which had been a significant part of their pre-injury life. For example, Matt experienced his inability to play sports due to physical effects of his injury as his most significant injury-related loss. To compensate for it, he devotedly follows a large number of sporting events both on TV and live. This story repeatedly surfaced throughout his narrative, and at one point he called watching sports his ‘top priority’. This seems to be an important part of his identity, as he even started the interview by presenting himself as a sports fan:

I: Can you start by just telling me about yourself?

M: Ok, I'm (1) just I- I'm a very sports minded person, [I: Mm-hmm] I like sports, before the accident I used to play all kinds of sports, like baseball, with my friends, [I: Mm-hmm] football, and (1) hockey and everything, sponge hockey, I was really big into sponge hockey and everything. [I: Mm-hmm] But after my accident I- I stopped, I played baseball a little bit after my accident, (.) [I: Mm-hmm] but that's... I played it with my brother, he plays it all the time too, so (.) we both really big into sports. [I: Mm-hmm] but ...

To counteract the sense of loss, Matt tries to participate in sports vicariously, which seems to contribute to his sense of self by providing him continuity in terms of being a sports person as well as help alleviate his feelings of sadness.

Another participant, Claire, regrets not being able to play the piano as well as she could before. She told a story of being a gifted piano player as a child, and how after her injury, she lost the ability to develop this skill past a certain point due to a hand tremor:

I: But you still continue playing the piano, don't you?

C: Not much any more.

I: No? Why not?

C: No, it's kind of disheartening. I do like to play, and I do like the music [I: Uh-huh] that I make, but it's disheartening (.) to know that I can't go any higher, you know. [I: OK] (2) When I was very young, (.) taking lessons and all that, like I could play (1) fairly well [I: Uh-huh] but again, that's when my hand didn't shake, [I: Uh-huh] you know. (4) It's just that I don't have time for it any more.

This is a story about lost potential, and it is interesting to note how it evolves within the same narrative. First, Claire explains that she does not play any more because of her hand

tremor, but after a long pause, perhaps giving her time to consider her words carefully, she suddenly comes up with a new, external reason for not playing – lack of time.

Perhaps, the sadness related to her inability to play well was so intense that by changing the cause from internal (her physical limitation) to external (lack of time) she protected herself from getting more upset.

Externalizing as a strategy to deal with unpleasant emotions was used by another participant as well, when he told a story of being unable to work. For Brandon, the combination of financial difficulties, his perception that he ‘should’ be working, and his desire to work on the one hand but being unemployed on the other hand, created significant emotional distress. As he developed this story, he introduced additional causal explanations for his unemployment. He started off by saying that he was unable to do the work he used to do before the injury due to post-injury weight gain and poor balance. Then he added that ‘employers won’t let me’ work, as well as that the kind of work he liked was not available on the job market any more. Finally, when asked whether he tried to look for a job, Brandon explained his difficulties by not having transportation to get to work:

I: Did you try to find a job?

B: Oh, I c- I could probably get a job in a (2) ten minutes.

I: OK.

B: Um, (1) there a fellow up the road here, he has a (:) uh landscaping, uh, business.

I: Mm-hmm.

B: But it's a very s- successful [I: Mm-hmm] landscaping business. And (.) I could go work for *him*, if I had, if I had transportation to get there, [I: OK] and (2) I could go work for him.

I: Mm-hmm.

B: Um, and there is lot of, lots of things that I, I could do if I had, had (1) different means.

I: Like transportation?

B: Like transportation.

It seems that when he was asked directly about whether he actually tried to look for a job, Brandon felt most vulnerable and needed to use the strongest defense he could come up with to protect himself from facing his limitations or feeling judged – an external cause that he had no control over. Having mobility difficulties was part of Brandon's overall narrative. However, another prominent story he told was about having a scooter, and the freedom it gave him to travel where he wanted. In fact, the scooter was in Brandon's apartment at the time of the interview. These two stories seem to contradict one another, as Brandon first talks about being able to go on enjoyable scooter rides, and later about lacking the transportation to go to work. This may seem confusing to the listener, but perhaps, there is a combination of factors that prevented Brandon from getting employment, which he tried to tie together in his story, with lack of mobility being only one of them.

Another strong negative emotion frequently emerged in the participants' narratives: They told many stories about frustration, both with themselves and the world and people around them. Finding ways to cope with frustration was not easy for them,

and the participants told stories about different strategies they developed to manage their emotional reactions. The majority of participants acknowledged that they experienced certain physical and cognitive limitations caused by their injury. These limitations created significant feelings of frustration with themselves, when they could not accomplish their goals because of these injury-related difficulties, such as having pain, not being able to work, or forgetting things. A few participants mentioned their use of humor to deal with those emotions. Humor seems to help counteract negativity and allows the person to laugh at themselves, as in a story told by Shelly. She has a difficulty with spelling, as she cannot spell short simple words, yet she has no problem spelling long words:

S: And it's like, (.) why can't I spell the easy ones rather than the, the longer ones.

That gets frustrating.

I: Ok.

S: At times it can get really (.) annoying.

I: Okay. So, what do you say to yourself when you get frustrated?

S: I just say, oh well. I just laugh it off. ((laughs)) [I: Oh yeah?] I just say, just say, oh well, that's me.

I: Okay. So kind of using humour?

S: Yeah, I find humour is helpful.

I: Yeah?

S: 'Cause if, if you don't have humour in life, then (.) you know, you're gonna be depressed.

Later in the interview she shared that depression ran in her family. So, her narrative shows that approaching emotional difficulties with a smile is protective against getting

depressed. A story about focusing on the positives, as opposed to negatives, was also very prominent in her narrative. Finding good in the situation was a deliberate emotional strategy that helped her and five other participants deal with feeling frustrated. For example, the participants included positive and reassuring self-statements in their stories of injury-related limitations, as if to help counteract the negative emotions that invariably arise in those stories. James, who had the most recent injury in the sample, and whose story about the aftereffects of his brain injury was more raw compared to most other participants, also told a story of being proud of himself for exceeding his doctor's expectations for recovery:

I: Sounds good. So you mentioned that there are some days when you are happy.

J: Mm-hmm, yes.

I: Is there a reason that makes you happy on those days?

J: It's just the way I feel happy, [I: Mm-hmm] for some reason I just feel happy, uh, very proud of myself. [I: Ok] Yeah, proud, (.) very proud. Because the doctor gave me fifteen percent chance to live, [I: Mm-hmm] and here I am walking, talking, carrying a conversation, [I: Yeah] understanding things. I've never seen a doctor so happy, for he shook, literally shook, he could not write a note, [I: Mm-hmm] because of what he expected out of me, I surpassed that [I: Wow] d- dramatically. [I: Mm-hmm] Which I am very proud to say, I became myself like this.

Creating a story that emphasizes his seemingly exceptional recovery appears to counteract the story of frustration with memory struggles, migraines, and having to relearn his relationship with his body.

Another way to deal with self-directed frustration and sometimes pity caused by realizing their limitations is a downward comparison, where the participants compared themselves to other people who were worse off after their brain injuries. For example, the participants emphasized that they came out of their coma while others didn't, had fewer physical limitations and better mobility than some, and were better off financially than people who received smaller compensations. Putting their struggles in perspective in this way allowed them to appreciate the relative nature of their difficulties and arguably helped alleviate their frustration with their own situation.

### **Misunderstood and Insignificant**

Many participants told stories about a lack of understanding and support from other people and society in general. For a significant number of them, brain injury did not produce visible physical impairments, and so they struggled with what has been termed in the literature as an "invisible" disability. Being misunderstood or not heard was a prominent theme woven throughout many of their stories. This was a source of significant frustration and resentment for them.

Two participants told stories of how they shared their experiences of living with a brain injury with people who had little knowledge about this type of injury. They saw this sharing as a way to make themselves understood and in a broad sense, to spread the awareness about what living after a brain injury means. This may be a way for them to reclaim their right to be understood by and thus more included into society. For example, James told a story of people thinking he was faking his injury because he had no visible physical deficits, and how hard it was to get people to understand what he was dealing with:

J: Most people out on the street don't see that. They don't (.) understand what I- or what we're going through in the group. [I: Mm-hmm] It's very hard to explain it to people.

I: Have you tried?

J: Yes, I have.

I: Can you give an example? Like, who would you try to explain it to?

J: Anybody, someone on the street. It's like being drunk [I: Mm-hmm] and that part of your life is (.) you pass out, it's blank, [I: Mm-hmm] you cannot remember, that's how I tell them to imagine [I: Mm-hmm] and then they start understanding.

I: Ok.

J: Because if they do it that way then it's like a light bulb going on [I: Mm-hmm] inside, they understand what I'm going through. [I: Mm-hmm] But when- if you don't (.) explain things to them [I: Mm-hmm] they're very, um, (4) short-minded, or close-minded. [I: Close-minded.] Close-minded, yes.

I: And how does this make you feel?

J: Like I am (1) a two-year-old [I: Mm-hmm] trying to express my feelings to them [I: Mm-hmm] that's how it makes me feel. On certain days it does make me feel that way, [I: Mm-hmm] on certain days it doesn't. [I: Mm-hmm] It makes me feel proud (.) to explain things (.) the way my situation is.

James deals with his frustration of being misunderstood by enlightening others, which he underscores with the use of the metaphor of a light bulb going off in a person's head the moment they understand his difficulties. Bringing this change in people's perceptions of

the life with a brain injury makes James proud, and seems to give him some sense of empowerment.

All participants but one told stories about turning to their social supports to deal with the frustration of being misunderstood. They tried to find the understanding they needed from family members, friends, as well as other people who sustained a brain injury. They mentioned the important role the local support group for brain injury survivors played in their social support network. It allowed them to meet others who are dealing with similar struggles, and feel a sense of belonging. For example, Shelly tells a story of appreciation when describing how the support group allowed her to connect with others and not feel lonely among people who don't understand the brain injury:

I: Yeah. So if you were to talk to somebody who just had a brain injury, recently, as a person who has had it for, you know, a while, what kind of advice would you give them? What could you tell them?

S: That it gets better as time goes by. Just, you know, takes time. It's a struggle, [I: Mm-hmm] you know. You will get frustrated. You will look at- wish that you were the way you were before you had your head injury. [I: Mm-hmm] And, uh, (2) just keep coming back to the survivor's group and you will meet nice people and understand [I: Mm-hmm] (1) people because (1) ((the local support group)), I told my mom, has saved me in a lot of ways.

I: Oh, how so?

S: Because if I didn't have ((the local support group)) (1) and I w- I didn't know other survivors [I: Mm-hmm] (.) that ha- that are struggling, like I said, the same way I struggle, (.) I would be, I would be lonely.

I: Mm-hmm.

S: So *coming* here, I'm meeting other people that are in the same boat as I am. [I: Mm-hmm] You know, some of them are in wheelchairs, like I said. Some, (.) you know, have their disability through drinking. Some (1) had a stroke. Some (1) uh, childhood drugs, whatever, [I: Mm-hmm] you know. So I try, just say, you know, keep coming back to the- Get the support that you need [I: Mm-hmm] and you will get it.

However, a few participants who presented themselves as being minimally affected by their brain injury, told a competing story of being dissatisfied with the notion of disability associated with participation in the survivors' support group. Claire, for example, is ambivalent about the group. On the one hand, she needs the sense of belonging it provides to her, yet she rejects being associated with the idea of having a disability:

I: Tell me about the brain injury support group, where we met. Do you like going there, how does it make you feel? [C: Uh-huh] Why do you keep coming?

C: Half I feel like (1) you know, part of me feels, like, you know, they do provide support and activities and a sense of camaraderie [I: Uh-huh] but, um, half of me feels like (2) um (1) very needy when I go there. [I: Oh, how so?] Um, (1) you know, it's (2) interacting with the people there is knowing that you have (.) a disability, and (1) you know, you're all there for that reason. [I: Uh-huh] (2) [...]

I: So, a part of you likes being there, but part of you doesn't.

C: Yeah, (.) yeah.

I: 'Cause it just reminds you that you have a brain injury.

C: Exactly.

I: That's why you're there. Is there something that you like about the group?

C: Yeah, I mean, (1) it's a good support system, I guess. [I: Uh-huh] (2) But again, I mean, (3) it just focuses on disability. Um, half the people there (1) don't even form friendships, [I: Uh-huh] you know.

Claire regrets that real friendships are not made there, because people only come to the group because they have a disability. She likes the sense of 'camaraderie' but feels that it is forced on to the participants by their disability, and that takes away the enjoyment of these meetings for her.

For some participants, the frustration with others and society in general was rooted deeper than just a lack of understanding. They felt "insignificant" and "useless" because of their injury. The way they used the language when constructing their stories provides a passageway to better understanding their emotional struggles. One participant, Nancy, told a story about how her father wanted to protect her from premarital sexual activity. He advised her not to take a job in another city for fears that she would be assaulted. She sounded frustrated with the way her father handles this, as well as her family's attitude towards her cognitive abilities after the injury, and described it in decreasingly negative terms, going from 'stupid' to 'vulnerable':

N: But that was, before that my dad was (1) well, he was even, after my car accident my dad (1) They perceived me as (.) as (: ) stupid. ((chuckles)) [I: Ok] As (: ) (2) gullible.

I: Mm-hmm.

N: As (: ) easily persuadable or whatever. As (: ) vulnerable, I guess. And so, they, ohm then my dad told me all kinds of things to try to protect me, but he told me all the BAD things. [I: Oh] He didn't tell me, he didn't, he, he didn't (1) th- they don't take courses on how to parent [I: Yeah] ((chuckles)) There is no such thing as a parenting course, right? And so, (1) he, ok, I got a job interview in ((names a different province)). So, first, mm, my first job really since I, after I left home. [... ] And my dad tells me he didn't think I should do it because (.) he figured I was gonna get raped while I was out there.

Nancy reduces the harshness and negativity of self-directed adjectives, going from an offensive 'stupid' to a milder 'gullible' to an almost neutral 'easily persuadable' to calling herself 'vulnerable', more a victim than someone to be blamed for her difficulties. Arguably, controlling her word choice this way allowed Nancy to feel better about and have more compassion towards herself.

On a structural level, a pattern of how different stories follow each other in a narrative can also provide an example of how participants manage their unpleasant emotions related to feeling insignificant. Andrew repeatedly mentioned throughout his interview that, as he is living with the consequences of his brain injury, he feels insignificant and "pathetic", that he "has nothing, and is worth nothing". One of the stories he tells is about helping people and stopping crime, and overall being a good person before his injury. It seemed that telling stories about his past deeds allowed him to increase his self-worth in his and conceivably in my eyes as well. Another prominent story was about a conspiracy against him on the part of the Justice Department. This story was invariably accompanied by expressions of anger. There was a repeated pattern in his

narrative that when he would talk about something emotionally difficult or upsetting, he would change the subject to reiterate the conspiracy story, and then follow that with a self-asserting story in which he would talk about his achievements or some other positive thing about himself. In this example, he spoke about his disability claim being denied for the fifth or sixth time:

A: She handled my appeal with them [I: Mm-hmm] and even though she handled the appeal and she's a professional aid and everything, they got back in touch with and (.) said (1) that I'm, I'm not worth anything, they are not gonna do anything for me. I mean, these are, pff, (.) if half the time I tell you if you don't know, if you wanna cry or jump off fucking ((names a high-rise building in downtown)) building, you know, 'cause (.) you're *lost*, you got NOTHING! When my mom dies or goes into a hospital, whatever, and my dad's already in one, (1) what am I gonna do? They certainly not gonna leave me in the house and (1) I'll be out on the street. (.) It's like, should I be picking out my bus shack right now? I (1) [I: Mm-hmm] it's really fucking pathetic what's happening to me. And it's the justice system (1) doing this to me, it's really, really pathetic. I don't know if anyway that you could actually *help* me with this, and it's not why I did this, I did this to get, so that people could have a greater understanding about brain injuries [I: Mm-hmm] but the way my brain injury has occurred (.) was (.) it's total corruption within the system that did that to me.

I: Mm-hmm.

A: There is no way for me to prove it, and I (.) there's, there probably *is* a way. I don't know [I: Mm-hmm] my way around courtrooms or anything, I don't know

anything about that. Like, I've always been on the side of justice and truth, I don't know what it's like to go to court.

In Andrew's story, financial difficulties are linked to uncertainty about his future and his feelings of worthlessness. Perhaps falling back to the familiar story about conspiracy as an external cause of his difficulties helps Andrew deal with anxiety and frustration from feeling alone and vulnerable. And then, as a way to soothe himself, he finishes with a self-affirming statement.

Another participant, Carl, talked about feeling like "a useless piece of medical shit (.) and or some kind of medical deformity" after he had been given an unfavourable medical prognosis after his brain injury. Tapping into the same feeling of worthlessness, he later told a story of how some of his friends wrote him off as 'useless' after his injury. His narrative was dominated by derogatory language and frequent use of profanity. For example, he referred to the police as 'bastards in blue', his daughter as a 'juvenile delinquent', doctors as 'hypocrites', the French quarters of Winnipeg as 'the frog area', a shopping center as a 'shoplifting center', and a priest's clothes as a 'monkey suit'. In addition, his performative stance was characterized by projecting himself as very important, whereby he proudly spoke about how dangerous he could be to other people, including the police, if they crossed him. For example, here he is talking about trying to control his anger by not caring about what people say or do:

C: In a lot of ways, it keeps a lot of people healthy. (.) Sorry for putting it that way, but.

I: What do you mean, keeps a lot of people healthy? You wouldn't get angry at them?

C: I just don't bother getting angry at them, 'cause I don't give a shit. I don't have *time* for it.

I: Oh?

C: I just listen to it, ignore it, and walk away.

I: Ok.

C: As if to say, almost, sorry for putting it this way, but 'Fuck you, we can handle it next time'.

I: Ok. And is it easier for you this way?

C: Yes, it is.

I: Mm-hmm.

C: Because it keeps the (.) boys in blue 90 percent of the time off my back.

I: Ok, and you mean the police?

C: Yeah, uh-huh.

I: Ok.

C: Keeps 'em off my back, and they don't bother me, I don't bother them.

I: Ok, that works for you.

C: It works (.) for them.

I: For them, too?

C: For them, for their health and well-being.

Throughout his narrative, Carl presented himself as a strong and maybe even dangerous person, who was not to be discounted or mistreated. He denigrated others through the words he used to talk about them, possibly in an attempt to reassure himself of his worthiness in the face of an environment that seemed to constantly tell him he was

not. However, the struggle with anger was a difficult one for Carl, seen in his history of violent behaviour. In his narrative, there was an obvious mismatch between the paralinguistic expression of anger and his verbally presented attitude of not caring about anything (“not basically giving a shit (.) in the long run”). One would expect calmness to the point of indifference from a person who genuinely does not care, but Carl’s narrative was replete with instances of frustration, anger, and notably, the desire to connect with others.

He also found a creative way of dealing with his emotions. He told a story about letting his emotions manifest through his writing:

I: Ok. ‘Cause you write stories, right?

C: Uh-huh, and I’ve got 903 of them right as of now.

I: Wow! And what does it do for you?

C: It just lets me express (3) in writing what I am thinking and or what I wish to do, to who, and or why, and or whatever at all. [...]

I: What makes you write the stories?

C: Whatever comes to mind. [I: Mm-hmm] It can be vulgar, it can be pleasant as hell, it can be naïve, hypocritical...

I: Mm-hmm. So, whatever you feel like.

C: Whatever comes to mind. [I: Mm-hmm] If I don’t wanna say it, I put it into words and or sentences.

I: Ok. And how do you feel after you complete a story?

C: In a lot of ways good. (2) [I: Because-] Because I’m using my head. [I: Mm-hmm]

For Carl, releasing his strong emotions through writing seems like a viable alternative to directly expressing them towards other people because it could potentially lead to altercations and violence. In addition, saying ‘I’m using my head’ is a counter-narrative to the story he tells of being discarded by others as useless. He is proud of being able to use his “damaged brain,” and so, even with a brain injury, he is not useless after all. Throughout the interview, Carl expressed having many strong negative emotions related to feeling insignificant, and the different ways he deals with them come through in his stories. Interestingly, he was friendly towards the interviewer, and did not express any negative attitude about the interview situation.

### **Memory Deficits**

The most common cognitive limitation the participants talked about was poor memory, both in terms of having lost memories about their past and struggling with remembering things in the present. Seven out of nine participants told stories about their efforts to cope with their memory difficulties. This theme was prominent in their narratives, in part because memory struggles created in the participants feelings of anger, frustration, embarrassment, being inadequate, and being lost. The lack of control most of them felt over their memory was summed up in a metaphor of memory as a rolodex by Andrew:

I: Does it happen to you often that you don’t remember things that just happened recently, like not-

A: Oh yeah, very. There is, mm, I don’t know if I even have like a short term memory any more.

I: Ok.

A: Though (.) everything is there, it's on a rolodex, it's just happens to n-, it's what, what the matter is like, you know, where the rolodex stops spinning, and then [I: Mm-hmm] you, by the rolodex I mean your brain, right.

I: Yeah.

A: And (.) yeah, sometimes I remember things that I had no idea that I would ever [I: Mm] remember. (.) And sometimes I remember things that they should, I should have no idea of.

Just as a rolodex, his memory seemed to contain all the necessary information, but Andrew felt he had no control over what information would become available to him, that is, at what point the rolodex would stop spinning.

The participants described a number of various strategies for addressing their memory difficulties. A few participants relied on other people in their lives, usually family members, to help them fill the gaps about past events. Shelly engaged in different cognitive tasks to train her brain, which she thought might help with her memory as well, such as doing crossword puzzles and playing games on the Internet. She also told a story of how she struggles with remembering sequences of steps, in particular, to dress herself in the morning. Remembering a large number of small bits of information feels overwhelming to her, and she developed a system where she prepares her clothes the night before so that she does not have to struggle with remembering how to dress in the morning.

Another strategy most of the participants talked about was writing things down and keeping calendars of things they needed to remember. Externalizing memory in this way was very helpful, and allowed the participants to create environmental supports to

help themselves manage their memory difficulties. For example, Matt told a story about a daily planner he keeps where he writes down things he needs to remember. The importance of this self-help tool for him is manifested in his multiple use of absolutes, such as ‘everything’ and ‘all’:

M: I need the book, it’s- I look, I look at it all the time to see what’s, what I got in there. (1) Everything. ((looking through the planner))

I: How many books have you gone through, probably a lot, hey?

M: Well, yeah, a few, well, it’s once a year, anyways.

I: Oh, yes, ok.

M: Probably, couple a year, probably. I write everything, you see, how mangled up it gets, [I: Mm-hmm] because I, I take it all the time.

Having other people to rely on for reminders and using external cues to support memory seem to be the two most commonly used strategies for the participants when it comes to memory. These strategies are what people without brain injury also seem to use; however, for the participants in the study, memory impairment is a serious handicap in everyday living, and therefore their reliance on these strategies is prominent in their narratives.

### **Physical Consequences**

The common physical difficulties experienced by the study participants included poor balance, migraines, and epilepsy. Although a few of them also struggled with mobility issues, all of them were able to walk on their own. Overall, throughout the interview there was significantly less of a focus on physical difficulties and, correspondingly, physical, as compared to cognitive and emotional, self-care. Possibly,

this is due to a relatively mild level of physical impairment in this sample. In addition, for eight out of nine participants, the brain injury happened at least 5 years prior to the interview. Over time, the physical consequences of their brain injury probably somewhat subsided or were not that severe to begin with. The participants might have gotten used to dealing with the existing physical difficulties without devoting as much attention to them as they might have before. Alternatively, it is conceivable that it is more difficult to deal with cognitive, as opposed to physical, limitations, and therefore the former receive more prominence in the participants' narratives than the latter.

A few stories about managing physical health, however, emerged from the interviews. Four participants talked about listening to and knowing their bodies as a way to anticipate and take care of their physical needs. For example, Shelly described how she managed her fatigue, so that she could have enough energy:

S: Like you know, sometimes when I come home from work, I have to (.) lay down (.) [I: Mm-hmm] at 4 o'clock. I lay down for a (.) hour or two, and I'm fine. Then I get up and (.) have supper or whatever, and (.) I'm okay.

I: So kind of go by how you feel?

S: Yeah. (1) Yeah, and I HAVE to do that because (.) as I've gotten older, I have to realize I'm not the same person as I was (.) fi- fi- when I was in my 20's or 30's, you know.

The participants also talked about taking care of their bodies through staying active, avoiding harmful substances and things that could exacerbate their physical symptoms. Four out of nine participants emphasized the importance of physical exercise in their lives, and they named things like riding a bike, walking, swimming, weight

training, tai chi, playing badminton, and bowling as ways to stay physically active.

George, who used to smoke, drink alcohol, and take illegal drugs before his injury, had been abstaining from the substances since his injury to not cause further problems:

G: I haven't t- I haven't (.) touched anything. I haven't, and I never will. I don't *need* to.

I: And why haven't you touched them?

G: Why?

I: Yeah.

G: Because! Like, (1) sss, I just don't really need anything like that, uh, it's not good for my health or anything else.

I: Mm-hmm.

G: And I don't need to do anything else to (.) cause anything (.) to my health or anything *like* that, because I was, (.) [I: Mm-hmm] seizures and everything else, and I'm not causing anything to (.) have a seizure or anything like that, I'm just (.) living the, the way I'm living now, and (1) I'm doing a good job, so. I just wanna do, you know, stay away from that kinda stuff.

I: Ok. So, you are trying to take care of your health.

G: I am.

Relying on medication and health care professionals was another important part of their stories. Sometimes arranging one's physical environment in ways that make remembering to take one's medication was a useful strategy, especially when the person had memory difficulties. For example, James had to rely on this strategy to make sure he took his medications:

J: Yeah, but my blister pack tells me ‘morning’, uh, ‘breakfast’, ‘lunch’, ‘supper time’.

I: Ok, I see.

J: All the pills are there, I just take one and put it on the front of the (.) end table

[I: Mm-hmm] where I sit in the mornings to have my coffee, it’s right there beside my coffee cup. [I: Mm-hmm] So when I see that I remember taking that in the morning.

I: Ok. And is that how your doctor told you to do it?

J: No, he hasn’t really said too much to me.

I: Mm-hmm. So how did you figure out this system?

J: Because I couldn’t remember if I took my medications or not, [I: Mm-hmm] that’s why they’re in a little, um, bubble pack now, [I: Ok] because it’ll tell me whether I taken my pills or not [I: Mm-hmm] and which is a lot helpful to me [I: Mm-hmm] cause I don’t have to worry about it any more.

Stories about interactions with health care professionals, such as physicians and physiotherapists, were frequently included into the participants’ narratives. The participants viewed these people as an important resource in managing their physical health. However, those relationships could also be a source of frustration if such care was not reliable. For example, Brandon has to rely on home care workers to help him with his everyday routines, because he has difficulty walking. He expressed frustration and hopelessness at dealing with home care workers when he could not count on them:

B: Yeah, it is, [I: Mm-hmm] it is (.) nice, like (2) [sighs] sometimes I, I find uh home care sometimes very, very aggravating [I: Ok] and I get very aggravated. (2) [...]

I: How come your home care is aggravating?

B: Oh, because sometimes they (1) they (.) they come in and they don't do what they're supposed to do, and [I: Mm-hmm] um, (.) or (.) my regular girls don't show up and they don't- nobody calls me to let me know if somebody else is coming.

I: Mm-hmm.

B: And what time they're coming, 'cause [I: Mm-hmm] the schedule is always changing. [I: Mm-hmm] So, (.) can be very aggravating.

I: So, what do you do when that happens?

B: Well, n- nothing you can do. Absolutely nothing.

I: Mm-hmm.

B: I, I mean, you can call, you can call and (1) try and see if they'll send somebody else.

I: Mm-hmm.

B: Most times they can't, or don't, (.) or won't.

Feelings of pride for their efforts to take care of physical health were part of the participants' stories. They emphasized improvements in their health due to exercising, not smoking or taking other substances, and overall attention to their physical health. For some participants, this was in contrast with the way they treated their physical health

before the brain injury. For example, George sounded quite proud when he told a story of his weight loss:

G: 'Cause I went to see my doctor today. [I: Mm-hmm] Uh ((clears throat)) I was two thirty seven, and I weighed myself today, and I'm two oh seven.

I: Mm-hmm, so you lost some weight.

G: Thirty pounds!

I: Wow.

G: Yeah. And it's, I ain't doing it just because uh (1) not eating or anything like that, it's just because I'm just taking really good care of myself, and I'm going swimming every week, and (1) ride my bike, and pretty much do everything that I'm supposed to do.

The participants also described barriers to taking effective care of their physical health. They mentioned lack of financial resources, lack of energy, and poor memory as major obstacles. For one participant, James, living with his physical limitations presented a double challenge. He told a heart-wrenching story of trying to get used to the changes in his body after the injury. For example, he does not have the senses of taste and smell any more, and he does not feel hungry. In addition, he struggles with poor memory, so that he may forget to take his medication, to go to a doctor's appointment, and even to eat:

J: Sometimes I just go days without eating (.) until I get told to eat, "When was the last time you ate?"...

I: So, you don't remember and you don't feel hungry?

J: No.

I: That's why, Ok.

J: No, I don't remember and (.) like I said I'm having to learn, like, my body all over again. [I: Mm-hmm] It's like (1) learning a body over, and over, and over, and every time you learn something (2) someone else says 'Oh, you already knew that!' and that's [I: Mm-hmm] a big let down for me, [I: Oh...] because it feels like it's the first time, [I: Ok] but it's not, it could be a hundredth time or something like that. [...] Um, (1) my memory (.) is very hard- I'm very hard on myself because of my memory shortness. I should know better.

I: So you are hard on yourself, can you explain that?

J: Because of my memory. I should know how my body wants and feels [I: Mm-hmm] because I'm forty-six year old, I should know my body [I: Mm-hmm] but I don't. [I: Mm-hmm] It's a whole new learning for me.

Living with physical consequences of his injury is a daily struggle for him, as one can see from his description of learning about his body, when he repeats the word 'over' three times, emphasizing his continuous but not very successful effort. This struggle is often frustrating and seems far from over.

Many participants did not tell stories about their physical deficits. Perhaps, they saw it as routine and undeserving attention, or maybe attention to physical health did not have a lot of importance for them. Those who did incorporate it into their stories mostly felt proud for making an effort to look after their physical health, although they also mentioned difficulties and obstacles.

## **Discussion**

In this study brain injury survivors talked about struggling with as well as dealing with, and sometimes even overcoming difficulties in different areas of their lives. Most of the difficulties or challenges were related to psychological and social functioning, and a few had to do with physical limitations due to the injury. The ways in which the participants tried to deal with the existing issues and maintain their physical and psychological wellbeing were interpreted through the lens of self-care. Their narratives reflect a broad range of self-care strategies, suggesting that there is a significant variability in how individuals with TBI respond to difficulties and distress.

### **Coming Up with an Explanation**

Brain injury survivors' attempts to come up with an explanation for their brain injury in a way that allows them to accept it is one strategy to restore their psychological well-being, and as such, can be understood as an example of self-care behaviour. As the participants presented their ideas for making sense of the injury, they simultaneously used different strategies to deal with emotional distress related to the injury itself or its consequences. From listening to participants' narratives, it became clear that cognitive and emotional processes are intertwined and affect each other during construction of their injury explanations.

Constructing an explanation of why the brain injury happened to them was a prominent feature of all the participants' narratives in this study. Those who came up with a satisfying explanation for their injury seemed to be able to move towards acceptance of the injury. This finding is similar to what Fraas and Calvert (2009) found in their investigation of narratives by survivors of acquired brain injury. Over 80% of their

participants described the importance of accepting their injury, and the period of emotional struggle that they had to go through before they were able to accept what happened to them. For the participants in this study, as well, developing an acceptable explanation for the brain injury allowed them to accept the injury and incorporate it into their larger life narrative, often after a period of anger and inability to make sense of the injury.

Alternatively, those participants who were struggling with trying to understand why the injury happened to them, or whose explanation for the injury implied deliberate injustice, experienced visibly stronger psychological distress. Research by Nochi (2000) suggests that the lack of a coherent or acceptance-promoting injury narrative is closely linked to difficulties reconstructing one's sense of self after the injury. From this point of view, it is clear that coming up with an explanation for the injury goes further than simply answering the 'why' question; it is linked to reconstructing one's sense of self, which is closely tied to psychological well-being. It seems that TBI survivors had a strong need to find an explanation for their injury, to integrate it into their life story.

Answering the 'why' question is connected to reconstructing one's identity after a life-changing event such as a TBI, and allows the individual to move towards acceptance of this traumatic event and one's changed self. As the participants' stories suggest, this is a long and difficult process, which may take years and requires the individuals to draw on different resources for support. Such resources can be both internal (e.g., cognitive strategies) and external (e.g., social support).

As a cognitive process, developing an explanation for the injury seemed to include a few different elements. For example, the participants included positive aspects

of life after a TBI, such as feeling lucky to have survived, into their injury narratives. Focusing on the positives has been demonstrated to relieve psychological distress and promote ‘adaptive adjustment’ after a brain injury (Shotton, Simpson, & Smith, 2007). One of the ways to reframe the brain injury in a more positive light was the idea expressed by some participants about becoming a better person through overcoming difficulties brought on by their TBI. They felt that dealing with the challenges that resulted from their brain injury allowed them to grow as a person, to let go of unhealthy behaviours, and learn new ways of relating to people. Finding the ‘silver lining’ in this way helped the survivors to come to terms with the injury, and allowed for a balanced view of the injury as something that has not only negative but also positive consequences, which in turn contributes to better adjustment to living after the brain injury.

It is worth noting that brain injury survivors might face unique challenges with regards to cognitive self-care, as the injury itself often affects the very abilities required for self-care. This may make it harder for the person to process what happened to him or her by undermining the resources necessary for self-care efforts. This may also help explain why for many brain injury survivors it takes years to construct a meaningful story about their injury. For example, in my investigation, some participants struggled with creating an understanding for why their injury happened to them, several years after the injury, while their physical healing, by contrast, was well under way.

A few studies on self-care found that turning to religion was a useful strategy for overcoming psychological distress for some individuals living with chronic health conditions (e.g., Harvey & Silverman, 2007; Leach & Schoenberg, 2008). In this study, the participants were asked about the role of religion and spirituality in their lives. Some

participants included the idea of a higher power into their narrative, which seemed to have facilitated their ability to accept the injury. However, other participants either did not rely on this as a way to help create the story about the injury, or expressed anger at the notion that their injury could be perceived as god's plan. This example illustrates how self-care strategies are not one-size-fits-all, and can lead to different emotional effects in different people.

The participants were at different stages in developing the stories explaining their injury. The meaning of the injury was also different for each participant. To understand where the person is in the process of constructing their story and what the injury means to them, Frank's (1995) framework of illness narratives can be useful. Frank suggests that an individual's journey in constructing a story about their illness results in one of the three types of illness narrative: the restitution narrative, the chaos narrative, and the quest narrative. Through the restitution narrative, individuals present themselves as having returned to the pre-injury state of health, that is, they have experienced complete recovery. While research strongly suggests that even mild brain injury is likely to have life-long consequences (e.g., Crowe, 2008), the severity of measurable impairment does not necessarily determine the type of the illness narrative the individual will construct. In fact, it is questionable whether there is a straightforward correlation between objective measures of someone's injury-related impairments and the extent of their recovery suggested by their illness narratives.

In the present study, two participants presented restitution narratives, as they emphasized that they had recovered and did not show any visible signs of a brain injury. To an outside observer, such as the interviewer, their stories may seem inconsistent with

the “reality” that both women struggle to find employment, keep attending a brain injury survivors’ support group, and have slight but functionally significant physical effects of their brain injuries. Another type of the illness narrative, the chaos narrative, is poignantly illustrated the participant whose story revolves around trying to understand why his brain injury happened to him, yet he is unable to come up with a satisfying explanation. His distress is compounded by the daily struggle with physical consequences of the injury. The chaos narrative is difficult to tell as it has little structure, and it is marked by loss of control and feelings of being overwhelmed by difficulties. Finally, the quest narrative, according to Frank, is the most conducive to one’s acceptance of the illness. In the context of the present study, participants presenting such narratives believed that they could gain something valuable through the experience of living with the consequences of the brain injury. Thus one participant discussed how accepting her brain injury allowed her to learn important life lessons and become a better person.

Presumably, it is natural for a person experiencing health problems to want to feel better. What ‘feeling better’ means, however, may be different depending on the particular disease or condition. Jumisko, Lexell, and Söderberg (2009) investigated this in a sample of participants who sustained moderate or severe brain injury. Their findings suggest that feeling well in this population is contingent on understanding and accepting their injury and constructing a post-injury self that includes the aftereffects of their injury.

The results of the current study and previous research demonstrate that creating a story about the brain injury is a common element of TBI survivors’ narratives. It is also clear that there are numerous frameworks in which they can be understood and interpreted. It seems that the stories that provide the injury survivor with a satisfying

explanation facilitate acceptance of the injury and are related to better psychological functioning. Alternatively, struggling to construct such stories is related to significant distress. What seems to be important is the subjective perception of the story as reasonable by the individual; it does not have to be ‘coherent’ or believable to other people, as long as it makes sense to the TBI survivor and facilitates his or her acceptance of the injury.

Two significant motives come through in the participants’ narratives. On the one hand, as already mentioned, they were constructing an explanation for why the brain injury happened. It seemed important for participants to develop some sort of understanding of this life event, given its significant impact of the participants’ lives. On the other hand, participants told stories about adapting to their limitations and changed roles. They tried to make the best of their situation, and to learn how to live with the consequences of the injury. Some individuals seemed to have been more successful in adapting to their condition than others, as judged by injury-related psychological distress they expressed during their interviews. These two motives are intertwined, as the experience of developing an understanding of the injury appears to facilitate the process of adaptation and adjustment.

### **Dealing with Losses and Limitations**

A number of participants discussed the losses that they had to suffer as a result of their brain injury. These included losing the ability to work as well as to participate in their favourite leisure activities due to injury-related physical or cognitive limitations. The participants described different ways in which they tried to compensate for these losses. For example, one participant who used to play a lot of sports before the injury,

compensated for not being able to play by closely following a large number of sporting events. Another participant, who could not find employment, spoke of how he was doing a lot of work around the house and in the garden. Thus, both participants put deliberate effort into finding ways to engage in valued activities to the best of their current abilities, and they seemed proud to share these stories.

Unfortunately, even if it was possible for TBI survivors to recapture some of their lost functions, the realization of their functional limitations and the associated struggles created feelings of sadness and frustration in many participants. The participants included a number of self-care strategies in their narratives when discussing how they were managing these feelings. For example, some participants externalized the causes of their difficulties to be grounded in their environment or a larger current social and economic situation. Another useful strategy for the participants to overcome frustration and regret was to use downward comparisons, when they compared themselves with other people who were worse off after their TBI or succumbed to their injuries. These cognitive self-care efforts are similar to the ‘cognitive structuring’ strategies reported by Leach and Schoenberg (2008) in their investigation of perceived control and self-care in older adults with multiple chronic conditions.

Finally, another important manifestation of self-care mentioned by a number of participants was using humor and trying to think positively. These participants deliberately tried to counteract their negative emotions, especially when they were related to situations over which the participants perceived no control. It is worth noting that a sense of humor and positive thinking are related to the psychological concept of optimism, which in turn has been linked to better health outcomes and quality of life. For

example, the results of a study of optimism in adults with physical chronic diseases suggests that optimistic beliefs and expectancies are linked to better mental health independent of the controllability of the disease (Leach & Schoenberg, 2008).

Overcoming losses and limitations caused by a TBI was a common theme in the participants' narratives. Each participant had a unique pattern of deficits, so the strategies they used differed accordingly depending on their particular situation. Yet their narratives point to the overarching idea that most of them made efforts to compensate for these losses or alleviate the distress caused by them.

### **Misunderstood and Insignificant**

TBI survivors are often marginalized in the society as they struggle with the stigma of an invisible disability and are often unable to find employment, which puts them into precarious financial and housing conditions. This struggle is reflected in a few participants' narratives, as they talked about being misunderstood by other people because most people are unfamiliar with potential consequences of a brain injury. More generally, the participants felt misunderstood by society, which may reflect their often-marginalized status.

Beard and Fox (2008) call this process of being pushed to the margins of society and not being given enough consideration due to a medical diagnosis *social disenfranchisement*. They conducted a qualitative investigation looking at experiences of people who have been diagnosed with Alzheimer's disease. They focused on how the participants incorporated the diagnosis and its limitations (specifically, memory deficits) into their identity, and how they negotiated their relationships with health care professionals and other people in their lives. The authors found that their participants felt

“socially demoted” after being diagnosed, and they used a number of strategies to normalize their deficits, incorporate the diagnosis into their identity, and manage their social interactions in a way that would minimize disenfranchisement. For example, they tried to focus on the positive, be proactive, attain serenity, accept help, and use humour. Their support group seemed to play an important role in these processes, as it awarded the participants the opportunity to share their experiences, feel a sense of camaraderie, feel useful, and ultimately, facilitate the acceptance of the diagnosis (Beard & Fox, 2008).

Many individuals living with the diagnosis of TBI seem to experience similar social disenfranchising, as they also need to reconstruct their identity to include changes to their physical and mental functioning, and struggle to have their voice heard. Understandably, this may create the feelings of frustration and resentment. In my study, one way for the participants to deal with those feelings was to promote the understanding of brain injury through sharing their stories. Being able to explain to others how living with a brain injury felt not only helped them to manage their frustration, but also contributed to their sense of empowerment. This allowed the participants to take the role of an expert, an ‘educator’, as they had the first-hand knowledge and experience that most other people don’t have.

Another way in which many participants dealt with unpleasant emotions was to reach out to their social support system, which included family members, friends, and the local brain injury survivors’ support group. It is important to note that in this case self-care depends on the availability of other people in the survivor’s life and the quality of his or her relationships with these people. Previous research indicates that it is common

for brain injury survivors to experience the shrinking of their social support networks (e.g., Morton & Wehman, 1995). In this study several participants talked about having fewer friends than before the injury. Some of the reasons included not being able to participate in the same activities as before, lack of understanding of the brain injury from their friends, and strained relationships with their family members. It is not difficult to imagine how a brain injury survivor's cognitive and emotional difficulties, along with potential personality changes, might put a strain on his or her relationships with others. Due to these consequences of the brain injury people may find it more difficult to deal with the survivor after the injury than before. Yet it has been repeatedly demonstrated that social support is a crucial resource for individuals dealing with brain injury as well as other chronic health conditions (Fraas & Calvert, 2009). It seems that having a brain injury puts an individual at risk for having limited social support systems, all the while this may be a crucial resource for the person in this situation.

A few participants talked about feeling insignificant and useless after their injury. Not being able to find employment, struggling financially, being dependent on their elderly parents, and the already mentioned lack of understanding from the larger society are all likely contributors to this feeling. To overcome these deeply distressing emotions the participants included self-affirming stories into their narratives, speaking about the times and situations when they were proud of themselves, both before and after their injury happened.

### **Memory Deficits**

Struggling with memory difficulties was a common theme for many participants. They included both not being able to remember parts of their past, and problems with

forming new memories. Understandably, this sometimes created significant distress for the participants, as well as made them feel lost and frustrated by lack of control over their memory. They described several strategies to help their memory: relying on family members for reminders as well as filling the gaps about their past, keeping the brain active by crossword puzzles and other tasks, keeping detailed calendars and writing things down. Figuring out and implementing these behavioural strategies consistently was an important challenge for the participants.

### **Physical Consequences**

Most participants experienced some physical limitations due to their brain injury, yet the stories about managing these limitations were not given much emphasis in their narratives. The following ways to maintain their physical health were described by the participants: listening to their body to anticipate problems, exercising and staying active, avoiding substances that can exacerbate their symptoms, relying on medication, and relying on health care professionals. The participants' stories about taking care of their bodies were sometimes accompanied by them feeling proud of themselves, especially when they paid more attention to physical self-care after the injury than before the injury. The strategies used by the participants in this study are consistent with previous research findings on self-care as management of physical symptoms.

There were also a few stories about barriers to taking care of one's physical symptoms. For example, lack of financial resources, lack of energy, and poor memory all made this more difficult, such as when the individual forgets to take his or her medication on time. In addition, if the services provided by health care professionals were unsatisfactory, this created difficulties for self-care as well as led to emotional distress in

the participants. These results are similar to the barriers to self-care found by Bayliss et al. (2003) in their study of self-care in adults with comorbid chronic physical conditions. Their participants also reported that their physiological difficulties and financial concerns interfered with their self-care efforts.

### **Self-Care**

The World Health Organization defines self-care as a deliberate action that individuals, family members, and the community should engage in to maintain good health (WHO, 2009). Presently there is no one accepted definition of self-care; different disciplines define the scope of self-care differently depending on their perspective and approach to health care. Godfrey et al. (2011) conducted an investigation of the evolution of the concept of self-care over the past several decades. They found that it had been expanding to include more elements and different areas of functioning:

By the 2000s the definition's reference to healthcare professionals now includes the option of collaborative care and the supportive role of healthcare professionals, the care by others and of others is definitive, and notions of adaptation to illness or disability, and achieving one's personal potential and independence are part of the process. Self-care is described as including social support and addressing psychological and emotional needs as well as dealing with health, illness or disability (Godfrey et al., 2011, p. 10).

According to this study, there is a trend towards a broader understanding of self-care, although there is still no agreement on the definition of self-care between researchers and practitioners working in different disciplines. However it is clear that the scope of self-care includes a variety of activities, in physical, social, and psychological areas of

functioning, and therefore it needs to be understood as a complex psychological phenomenon.

First, our understanding of self-care should encompass both physical and mental health. It is likely the case that right after the injury, the physical aspect of self-care is at the forefront, as the survivors learn about their changed body and establish routines for management of physical consequences of the injury. As the time goes by, though, management of physical symptoms demands less attention. Taking care of physical issues takes up relatively little space in the participants' narratives. Instead, psychological difficulties become primary targets of self-care efforts, which can be understood as both helping to alleviate distress and to promote better quality of life. In their narratives the TBI survivors talked about being misunderstood, dealing with losses and limitations and other issues that created emotional distress for them. Self-care manifested both in the ways they tried to manage their psychological difficulties, and the way they talked about them. The suggested distinction among emotional, cognitive, and spiritual self-care is arbitrary and served as a tool to understand the multifaceted nature of this phenomenon. It is difficult to tease apart these categories in the participants' stories, as they are intertwined and work simultaneously. What is important is that self-care is a complex psychological phenomenon that is not limited to management of physical symptoms caused by the trauma, but also includes dealing with psychological difficulties.

Second, self-care is manifested in more than just deliberately chosen behaviors; people can engage in self-care without necessarily being aware that their behaviours help them deal with their difficulties. In the present study, while some self-care strategies were deliberately used by the participants (e.g., using daily planners, seeking social support),

others were simply part of their daily functioning and came through in the narratives, without the participants making a conscious decision to apply them (e.g., word choice, externalizing). It is the researcher's interpretation that the latter type of self care behaviours allowed the participants to minimize distress; however, it is unclear whether the participants would agree with this interpretation.

Barriers to self-care efforts included financial difficulties, physical issues like fatigue, and psychological factors, such as poor memory. After listening to the TBI survivors' stories, it is clear that for many of them life after the brain injury is a daily struggle, which makes taking care of themselves more difficult due to the consequences of the injury. This difficulty is often compounded by the misunderstanding by others that their difficulties are due to lack of trying or motivation. The misunderstanding experienced by the survivors may be part of the general societal attitude towards disability, which, according to the social model of disability, is oppressive and stigmatizing towards individuals with physical and mental impairments (Taylor, 2005). From this perspective, a significant part of the disadvantages experienced by people with disabilities stems from society's lack of supports and accommodation for their unique circumstances (Siminski, 2010). For the participants in my study, this may mean lack of available transportation, insufficient disability payments, and lack of knowledge about the brain injury in the general population.

Overall, the participants' narratives in my study strongly suggest that the concept of self-care is broader than defined by the medical model, as it includes strategies to improve and maintain psychological wellbeing as well, at least for those who had lived

with their limitations for a few years, and have been able to establish a satisfactory system of physical symptom management.

### **Implications**

Narrative investigations such as the present study allow TBI survivors to share their stories and express their lived experiences in a way that can be understood by the larger society. This is important from the vantage point of giving voice to a marginalized population group, as TBI is often associated with stigma and these individuals feel misunderstood and devalued.

In practical terms, better understanding of self-care in TBI survivors will contribute to a more comprehensive rehabilitation process for them, especially in the long term, when the management of physical symptoms might have become routine, while psychological difficulties persist. Health care professionals may offer cognitive rehabilitation which has been shown effective in reducing anxiety, and improving memory, interpersonal relationships, and self-image in brain injury survivors (Carney et al., 1999). In addition, training in more effective social skills maybe helpful for TBI survivors as these skills are essential for maintaining and developing a social support network.

Some of the strategies for maintaining psychological wellbeing and dealing with emotional distress are not specifically related with brain injury, and can be relevant for individuals living with other chronic health conditions. For example, keeping a daily planner for medical and other appointments, having a regular exercise program, and emphasizing the importance of having social support networks.

Finally, listening to TBI survivors' stories promotes understanding and greater acceptance by the larger society of this condition and people affected by it. Marginalization experienced by many TBI survivors is at least in part due to societal attitudes towards disability, as argued by the social disability model (Taylor, 2005). Notwithstanding their potential cognitive and emotional deficits, individuals who sustained brain injury have the same intrinsic value as a person as any other member of society. Therefore, they are entitled to be viewed as equal members of the society, and not discounted or taken less seriously because of their limitations. When examined through this citizenship lens, the experiences shared by TBI survivors in their narratives provide a foundation for arguments in favour of improving their status and treatment (Bartlett & O'Connor, 2007).

Future research would benefit from broadening the definition of self-care, if the goal were to capture the complexity of this phenomenon. It should not be limited to management of physical symptoms in research with people who live with chronic health conditions. Investigators would achieve a deeper understanding of self-care activities and processes, as well as barriers, if they pay attention to efforts that the individuals make towards taking care of their emotional, cognitive, and spiritual needs. Self-care is affected by numerous factors, both within (e.g., available cognitive resources) and outside the individual (e.g., the number or people in his or her social support network). Including these factors into an investigation would allow to paint a richer picture of self-care and its interaction with other psychological and social processes. If we are to move towards a holistic understanding of health, research focus should define self-care as including multiple domains.

**Reflexivity**

Reflecting on the researcher's part in the investigation is important for a fuller understanding of how narratives are constructed, presented, and received, and is strongly recommended by some authors in the field (e.g., Shaw, 2010). As a graduate student in psychology, conducting a narrative research study with brain injury survivors was a unique and interesting experience for me. Before starting data collection, I attended several meetings of the survivors' support group as an observer, with the permission of the group facilitator and the participants themselves. This allowed me an opportunity to get acquainted with the group, to observe the group dynamic, to get a sense of the things survivors tend to talk about, and to establish friendly communication with the group members. Just as I was interested in them, they were interested in me, and asked me about what I do and what my research is about. I felt that I was welcome to come to these meetings. In analyzing the results of the study, I focused on individual interviews, and did not treat my observations as data because I did not obtain agreement to participate in research from every member of the support group. However, my attendance of these meetings and familiarity with the group processes helped me better connect with my participants during individual interviews. I talked to them during group discussions, and arguably the participants felt more comfortable being interviewed by someone they already knew.

Each interview was unique, as the participants shared their life stories with me, which often included distressing and sensitive topics. I felt appreciative that they agreed to open up to a person they have only known for a couple of months. Interviewing the participants presented a few challenges, however, and it required good communication

and problem solving skills, as well as patience and a non-judgmental attitude. For example, it was difficult for some participants to stay on one topic, and they tended to go on tangents. Other times they would forget about the interview appointment, or would be easily distracted during the interview. Conducting the interview with one participant was a bit frustrating to me because the participant brought their dog to the interview, and the dog created a lot of distraction as it would not sit still and would bark frequently. Sometimes the interview would go longer than planned, and because they were normally conducted before the survivors' support group meetings, the participant would miss the beginning of the meeting.

Analyzing each interview felt like an adventure, because I would need to think about multiple layers of stories, and their interconnection, and try to tease apart different self-care processes, all the while paying attention to performative elements and their meaning, for example, how the participants chose to present themselves to me. Some stories provided richer data than others; the challenge was to try to represent all narratives in the results of the study, as each story is unique, even if it is less developed than others. Some interviews were more difficult to analyze because the participant was tangential or gave overwhelmingly detailed descriptions of some past events, sometimes repeating them several times throughout the interview. During the interviews, it was important to find a balance between allowing the participants to express themselves freely and choose what they were going to talk about, and address the interview guide questions I had prepared in advance. Therefore, for the participants who tended to go on tangents more often, I sometimes had to re-direct their attention to the questions that I had planned to ask.

### **Limitations and Future Research**

The participants' narratives reflect their unique experiences of living after a brain injury, and the goal of a qualitative investigation is not necessarily to achieve generalizability of results but to elucidate individual lived experience. The participants' stories reflected their understanding of injury and making sense of the challenges and limitations they have to face. However, conducting narrative research with brain injury survivors presents unique challenges. A brain injury sometimes results in limited cognitive abilities, which might affect the ease of communication with the survivor but does not diminish the importance of hearing their story. It is difficult to estimate the impact of these factors on the participants' narratives.

In addition, the stigma of brain injury may have affected the participants' willingness to discuss the difficulties associated with it. To try to counteract this limitation the researcher made an effort to establish good rapport with the participants both before and during the interviews. Because narratives are potentially constructed differently depending on the audience to which they are presented, researcher characteristics, such as being female, not having a brain injury, and being a graduate student in psychology, might have influenced the narratives as well. Perhaps, it affected the events that the participants chose to talk about. However, it is difficult to estimate the impact of these characteristics on the participants' narratives.

The present study used a convenience sample of TBI survivors from the local brain injury survivors' support group. The content of their stories might have been affected by the shared experiences as members of that group. Therefore, potentially, there were commonalities in the participants' stories stemming from shared environmental

factors, such as being treated in the same hospital or being seen by the same health care professionals, and so forth. However, the survivors' support group came out as an important element of the social support network for many participants, thus contributing to the richness of their stories as well.

Only those individuals who could communicate reasonably clearly were included in the sample, therefore limiting the sample to the survivors who either had a mild TBI or made a relatively good recovery of their language abilities. In addition, the sample was culturally homogeneous, as all participants were White or of European origin. The sample included three women and six men, with the age range from 35 to 55 years old. The results of the study should not be assumed to generalize to a more diverse population of brain injury survivors.

More research is needed to better understand the concept of self-care in the psychological domain in general, and in this population in particular. The existing research strongly suggests that self-care in its multiple manifestations is linked to rehabilitation after an injury, coping with illness, and overall quality of life. One may hope that over time, as results of studies in different fields accumulate, there will emerge a common definition of self-care that can be more easily shared by different disciplines.

Additionally, future qualitative studies with brain injured populations would help better understand self-care in application to this type of trauma. It would be interesting to compare results of studies with people who suffered different types of brain damage, as well as to explore gender, age, and cultural differences in how self-care manifests in the survivor's daily living and narratives. For example, would women's stories of self-care differ from males'? Would older people experience it differently than younger people,

independent of the time since injury? Another factor that might potentially influence experiences of self-care is one's socio-economic status, as it is related to self-care barriers, and so, it appears beneficial to include individuals that differ on this dimension into future studies of self-care. Since social support was an important resource for many participants, differences in self-care among injury survivors who are single and those who have a partner may be worth exploring. It also might be interesting to compare White and Aboriginal populations in terms of what self-care means to them, as it might be understood differently in different cultures.

### **Final Remarks**

This research examined self-care narratives of TBI survivors. The results indicate that self-care is a complex psychological phenomenon, and it affects both physical and psychological well-being. There is no one accepted definition of self-care to date in the research literature. However, the trend has been to expand the definition from focusing purely on physical self-care, suggested by the medical model, to the definition with a broader scope, which includes psychological and social variables. Although the narrow focus on management of physical symptoms may be useful for some investigations, illness management and health maintenance include so much more than that. As the participants' stories show, complex emotional and cognitive processes are working simultaneously to facilitate adjustment to living with the brain injury, in addition to a number of interpersonal and societal influences. Disseminating TBI survivors' experiences is necessary for a better understanding of this condition and the struggles these individuals face, by health care professionals and the larger society. Developing such

understanding will facilitate more effective health and community services, and help reduce the stigma that is still associated with living with a brain injury.

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## Appendix A

## Study Advertisement Flyer

**LOOKING FOR: Traumatic Brain Injury Survivors for a Research Study**

**The study:** An interview about your everyday life after the brain injury (about 1 hour).

**Who can participate:** Anyone who's had a brain injury caused by a trauma for at least 2 years.

**Place:** The Brain Injury Association or at your home, whichever is more convenient for you.

**Compensation:** A Tim Horton's gift card and transportation costs (taxi or parking).

**For more information:** Please contact Uliana at (204) 230-9103 or [umnevzor@cc.umanitoba.ca](mailto:umnevzor@cc.umanitoba.ca)

**Principal investigator:** Uliana Nevzorova, Master's student, Department of Psychology, University of Manitoba

**Supervisor:** Dr. Maria Medved, Associate Professor, Department of Psychology, University of Manitoba

The study has been approved by the Bannatyne Health Research Ethics Review Board of the University of Manitoba.

**THANK YOU FOR SHARING YOUR STORY!**

Please take this flyer with you if you are interested

Appendix B

Interview Guide

Can you tell me what a typical day is like for you, perhaps, yesterday?

What do you do in your free time?

Do you have people to hang out with?

Except for the support group, what other places in the community do you go to?

Tell me about something that has upset you recently.

What is the most difficult in your life right now? How do you deal with it?

How do you deal with the physical difficulties cause by the injury (if the participant has any)?

What do you do for pleasure?

How is your life different from what it was before?

What do you do when you feel down?

What does going to church do for you (if the participant mentions going to church)?

Appendix C

Demographic Information

Participant:

Age:

Gender:

Cultural Background:

Education:

Work History:

Relationship Status:

Date of Injury:

Cause of Injury:

Duration of Hospital Stay:

Notes:

## Appendix D

## Transcription Conventions (Medved &amp; Brockmeier, 2004)

< >	Speed up talk
> <	Slow down talk
[ ]	Start and end of overlapping speech
(2)	Pauses in seconds (here: 2 seconds)
(.)	Micropause
(:)	Prolongation of preceding vowel
((Text))	Transcriber's comment
<u>Underlining</u>	Emphasis
<b>CAPITALS</b>	Speech that is louder than surrounding speech
-	Utterance interrupted
<i>Italics</i>	Increase of pitch