CHANGES TO FAMILY DYNAMICS WHEN LIVING WITH INVISIBLE SYMPTOMS OF ACQUIRED BRAIN INJURY

CHANGES TO FAMILY DYNAMICS WHEN LIVING WITH INVISIBLE SYMPTOMS OF ACQUIRED BRAIN INJURY

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A Thesis

Submitted to the School of Graduate Studies

in Partial Fulfillment of the Requirements

for the Degree

Master of Social Work

McMaster University

MASTER OF SOCIAL WORK (2014)	McMaster University Hamilton, Ontario

TITLE: Changes to Family Dynamics When Living With Invisible Symptoms of Acquired Brain Injury

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NUMBER OF PAGES: vii, 138

Abstract

The purpose of this thesis is to explore the changes to family dynamics that result from invisible symptoms of acquired brain injury The perspective put forth is that of individuals living with invisible symptoms of acquired brain injury. This study is based on a thematic analysis of the findings from nine semi-structured interviews with individuals (aged 24-64 yrs.; 6 men, 3 women) who have been formally diagnosed with an acquired brain injury. The data is interpreted and discussed using a critical framework, specifically, Critical Disability Theory.

The findings from this analysis illustrate how invisible symptoms such as cognitive impairments, memory loss, mood changes etc., of acquired brain injury affect family dynamics in relation to emotional roles, domestic roles, financial roles, and perception and treatment of the affected individual. These changes were either exacerbated or minimized by the assumptions, misconceptions and knowledge level of the individual's family in relation to understanding brain injury and the ways in which disability can manifest.

Also important to family relations are the perceptions of participants that they must prove that they do have a disability; the roles healthcare professionals play in the validation of the injuries, both to the individual and the family; and how powerfully dominant constructions of disability – and invisible acquired brain injury in particular – are ingrained in social discourse and impact upon family dynamics for people living with invisible acquired brain injury.

Lastly, an important part of this research is a compilation of recommendations put forth by the participants for healthcare professionals to keep in mind when working with individuals who either are suspected of having or have an acquired brain injury.

Acknowledgements

I would first like to sincerely express my gratitude to the participants who took part in this research. The stories you shared showed your strength, resilience and perseverance. Without all of you, this research would not be possible.

Ann, thank you for your continual support and patience throughout this process. There were many challenges we faced together, and I cannot thank you enough for the encouragement and dedication you have given to me throughout this process.

Brandon, thank you for your unconditional love and support. You were my rock throughout this process and without you, I would not be here today. No words can express how thankful I am.

I would also like to thank my parents, (Alina & Otto) and my Tanti Wanda and Uncle Peter. Without your constant encouragement and support over the years, I would not have realized my full potential. You have guided me through some very difficult times and you have given me courage to accept and recognize my abilities.

Lastly, I would like to thank my closest friends. Your constant support and encouragement has been very much appreciated. There were some days where I just couldn’t see the light at the end of the tunnel, and you were all there cheering me on. Your positivity guided me through the darkest times.

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Introduction

It was a Saturday, late in the afternoon, and I was at a friend's house celebrating a birthday. We had decided to go outside to play a friendly game of basketball - little did I know what would soon ensue. Like all sports, there is some level of physical contact. There was nothing out of the ordinary during this game. While playing, my friend and I ran to grab the basketball. We both bent over at the same time and that's when it happened; our heads collided. I remember the sound I heard as I felt the top of his head smash directly into my left temple. When I got up, I felt immediate pain and was dizzy. We ended the game and went indoors. I remember sitting inside with what I thought was the worst headache I could possibly have. Given that I was just hit on the head, I expected to be in pain and did not give it any additional thought. That evening when I went home, I did not tell anyone what had happened. I did not believe that the headache pain that had transpired as a result of the collision was abnormal. The days following my injury, my symptoms did not go away. I became extremely tired, sensitive to light, easily frustrated, dizzy and physically ill. It was then I disclosed to my mother what had happened and we sought medical advice. I received the diagnosis of concussion with the projected recovery time of a couple of weeks. After the initial two weeks of recovery time, my symptoms actually increased in severity. I began to withdraw from friends and family; experienced intense migraine-like headaches daily; became overly sensitive to light and sound; and noticed an inability to concentrate.

At first, I was confused by the diagnosis of concussion. From my limited knowledge at the time, I believed that in order to have a concussion, one must have lost consciousness. I soon learned that those who do not lose consciousness could experience the same kinds of symptoms as those who have lost consciousness. During my recovery, there was little education provided as to what I could expect in relation to the symptoms of concussion that I might experience, even less information on how to mitigate the concussion effects, and no information pertaining to strategies for coping – either for my family or myself.

The days, weeks, months and years following my concussion have been a constant struggle academically, physically, cognitively and emotionally, not only for myself but also for my family. Many healthcare professionals I was involved with did not fully understand the ways in which post-concussion syndrome could manifest. As a result, I have never been given a clear explanation of my symptoms or recovery trajectory. For quite some time, my symptoms were attributed to other medical diagnoses such as chronic pain, migraines and mental health issues. I became labeled as a “medical mystery” when my symptoms did not respond to standard therapies. When healthcare professionals were consistently unable to provide a precise diagnosis, I was later labeled a “lazy teenager” and a “teenager that wanted attention”. These different labels, conflicting medical opinions and various treatments not only affected me, but also affected the family dynamics within my home.

Living with invisible symptoms of acquired brain injury for the past thirteen years, I constantly find myself having to prove there is something ‘wrong’ with me. I do not fit into the preconceived constructions of what it looks like to be living with a disability, let alone a brain injury. In today’s society, disability is still firmly rooted in the medical discourse where one must have visible abnormalities or deviations from the dominant ‘normal’ standards (Healy, 2005). The medical perspective,

> “emphasizes that the disability is a biological or physiological function within the person. The medical perspective classifies disability entirely within the person with a disability, removed from any external factors. Under this socially conservative perspective, problems due to disability are considered to reside in the individual independently of social context...” (Jaeger & Bowman, 2005; p. 14)

As a result, disability is seen as a “defect or sickness, which must be cured through medical intervention” (Kaplan, 2000, p. 352). Many people develop an understanding of what disability should look like from this dominant construction - an individual living with disability must have visible impairments. This dominant construction is deeply entrenched within our societal fabric, policies, legislation and the media. As a result, individuals with invisible impairments that are not readily apparent to the general population typically are not regarded as having a disability, as their manifestations of impairments are not aligned with the dominant constructions of impairment and disability (Stone, 1995). This results in many individuals living with acquired brain injury to be forgotten and dismissed as many symptoms can manifest as invisible.

Without the inclusion of alternative understandings pertaining to impairment, disability and experience, social workers as well as the general population will continue to perpetuate these faulty constructions. This can result in significant consequences for individuals living with invisible impairments and within the context of this thesis, individuals living with invisible symptoms of acquired brain injury. One of these consequences relates to the validation of disability by healthcare professionals, the self and others – in particular family members. In addition, these dominant constructions can influence how an individual experiences disability as it relates to acquired brain injury thereby shaping what it means to be brain injured.

I believe this dominant construction is engrained within our societal fabric and has shaped the ways in which healthcare professionals responded to me, as well as the ways my family, friends and acquaintances responded to me. My personal experience of living with invisible symptoms of acquired brain injury has led me to an interest in better understanding the role invisibility plays in the lives of other individuals living with acquired brain injury. The focus of my research was to examine the changes that may occur to family dynamics from the perspective of individuals living with invisible symptoms of acquired brain injury. Specifically, I focused on whether and how the invisible manifestations of acquired brain injury play a significant role in contributing to these changes and shaping these experiences.

Within the research literature, the experiences of individuals living with invisible disabilities receive significantly less attention in comparison to those living with visible disabilities. There is even less attention given to individuals who live with invisible symptoms of acquired brain injury (Healy, 2005). This results in limited knowledge of the intimate and personal experiences encountered on a daily basis by individuals within this community. This limited knowledge is then exacerbated by the dominant constructions of how impairment and acquired brain injury should manifest and what it means. As social workers, it is crucial to recognize how these dominant constructions of impairment and acquired brain injury can shape the ways in which we practice. Through using these uninformed constructions, social workers are limited in their knowledge. As a result, the kinds of interventions that may be used have the potential to be harmful and unhelpful. By opening ourselves to the merits of alternative understanding, social workers have the ability to make informed decisions, and identify and implement interventions that may be more beneficial to the individual and their families.

Throughout this thesis, I will be using the term “acquired brain injury”. This term refers to brain damage that occurs after birth, and includes both traumatic and non-traumatic events. It does not include damage that is the result of neurodegenerative disorders (Brain Injury Centre Canada, 2011). The ways in which the symptoms of acquired brain injury can manifest can be both visible and invisible. Given the complex nature of brain injury, no two individuals can expect to experience the same effects (Brain Injury Centre Canada, 2011).

In this thesis, I report upon my research that specifically examined the changes that may occur to family dynamics from the perspective of a small group of people living with invisible symptoms of acquired brain injury. I will also report on the role the invisibility of the symptoms played in each participant’s experience and his/her families’ experiences. It is my hope that this research will provide valuable knowledge that further develops social work’s understanding of the many facets of acquired brain injury and the effects invisible acquired brain injury can have on family dynamics. In addition, this research sought from participants their practice recommendations for social workers and healthcare professionals to incorporate in their daily practice when working with individuals who are suspected of having or have an acquired brain injury, whether it be visible or not.

Literature Review

In order to understand the changes that may occur to family dynamics, and the role invisibility contributes to these changes, it is first important to understand the ways in which the concept of disability has been articulated in the research literature. From there, an exploration of the literature pertaining to acquired brain injury will be examined that will include a focus on the challenges for both the individual and their family.

What is Disability?

It is important to understand the historical and contemporary ways in which Western society understands the notion of impairment and disability. This is crucial to understanding the challenges that one may experience if their symptoms of impairment and disability are invisible. A brief review of the extensive historical literature reveals that human societies have struggled with defining impairment as well as what should be done with those living with impairment and disability (Braddock & Parish, 2001; Iezzoni & Freedman, 2008).

Throughout history, impairment has often been understood to signify sin or, less often, as a blessing. In the Old Testament, there were conflicting views on impairment- one where impairment was met with a charitable obligation and secondly viewed as a punishment by God (Braddock & Parish, 2001). This charitable view is illustrated through the writings found in Leviticus (19:14) “ Thou shalt not curse the deaf nor put a stumbling block before the blind nor maketh the blind to wander out of the path”. In contrast, Deuteronomy (28:15) suggests “if you do not carefully follow His commands and decrees… all these curses will come upon you and overtake you: the Lord will afflict you with madness, blindness and confusion of the mind”. Throughout the Ancient Greek and Roman times, those born with impairments were seen to represent the anger of the gods. To appease the gods, these infants were murdered as a sacrifice (Braddock & Parish, 2001; Stiker, 1997). It should be noted that the infants put to death were most often those with visible physical impairments. “Infants with hearing impairments, vision impairments, and mental retardation were not categorized as deformed and were not put to death” (Braddock & Parish, 2001, p. 15).

Within the middle ages, impairment continued to be viewed as having “demonological origins” (Braddock & Parish, 2001, p. 20). This understanding contributed to the persecution of individuals living with impairment and magic was used in attempts to “cure the disabling condition” (Braddock & Parish, 2001, p. 21). During this time, impairments were also viewed as part of the natural order of society (Braddock & Parish, 2001). As a result, these two understandings of impairment illustrate how there was no universal definition or interpretation of impairment during this time period.

Between the early modern period through to the eighteenth century, there were a number of changes that occurred. In the early modern period, impairment continued to be understood as demonological as individuals were thought to be “possessed or created by Satan” (Braddock & Parish, 2001, p. 21; Colon, 1989; Kanner, 1964). However, within agrarian societies during this time period, as noted by Iezzoni & Freedman (2008), most communities relied on shared resources to survive. Those who were living with impairment were sometimes unable to participate in the production of communal wealth by participating in expected roles, however, in some cases, other roles could be found and expectations were modified. Fortunately, some communities chose to take care of those individuals with impairments for whom alternative roles could not be found to fill the gap. An interesting development during this time period emerged: since both cognitive and physical impairments could be falsified for secondary gain, in some cases individuals within communities became suspicious of one another, not trusting that those claiming impairment really had an impairment (Iezzoni & Freedman, 2008). This suspicion led to the need to prove that one's impairments were true. As a result the focus of understanding impairment shifted again (Iezzoni & Freedman, 2008).

During the Renaissance period, there was a shift towards understanding impairments as stemming from biological etiologies (Braddock & Parish, 2001; Gilman 1982; Winzer 1993). The focus during this time was on curing the individual of their impairments, and was based on "primitive understandings of anatomical functions and to physician's abilities to intervene to address bodily difference as dysfunction" (Braddock & Parish, 2001, p. 21; Gilman 1982, Winzer, 1993). This emerging medicalized understanding of impairment coincided with the rise of science and of classifying and categorizing individuals. Individuals with impairments were classified according to particular impairments, abilities, physical and behavioural features, and as either "dangerous" or "safe" (Braddock & Parish, 2001, p. 21; Fessler 1956; Rushton 1998; Suzuki, 1991). According to Suzuki (1991), those that were considered safe would be cared for by their families and community, and those that were considered dangerous might be looked after by their families or might be sent to a jail.

In the early 18th century, diagnostic tools became more prevalent in order to assist with the diagnosis of impairment (Iezzoni & Freedman, 2008). These diagnostic tools were in part developed to ensure individuals were not falsifying their symptoms to receive charity (Braddock & Parish, 2001; Iezzoni & Freedman, 2008). In addition, with the shift to understanding impairment as a biological factor that could be cured, diagnostic tools and medical interventions were deemed necessary to determine intervention and treatment. Primitive medical interventions used during this time included drilling holes in the affected individual's head to release the impurities, or frying earthworms with goose grease and pouring it into an individual's ear (Braddock & Parish, 2001; Iezzoni & Freedman, 2008; Winzer, 1986).

By the 19th century, the medical model was firmly rooted as the dominant discourse of impairment and of people living with impairment in Western society. During this time, institutions for those living with impairments were being constructed with the (initial) goal of curing those with impairments, although this shifted to a focus on warehousing people with impairment over time (Braddock & Parish, 2001; Iezzoni & Freedman, 2008). This medicalized view that pathologizes impairment has had significant impacts on the lives of people with disabilities and, while alternative understandings have emerged in recent years, it remains strong to this day.

Today, there are many ways in which one can define disability. As a result, there can be conflicting views and values regarding what it means to be disabled (Gronvik, 2006; French Gilson & DePoy, 2002). As we can see from the literature presented earlier, historically, disability and impairment has been viewed as a deficit. Today, the deficit understanding persists within the Western context; however, disability is also beginning to be “understood as an element of human diversity” (Braddock & Parish, 2001; French Gilson & DePoy, 2002, p. 153).

The medicalized approach to impairment and disability – the approach still most frequently utilized by social work – places the impairment within the person separate from their environment (French Gilson & DePoy, 2002; Gronvik, 2006). Within this approach, the individual is considered to be “defective with reference to normative physical, behavioural, psychological, cognitive or sensory being” (French Gilson & DePoy, 2002, p. 154). In contrast, when using a social work “person-in environment lens” (French Gilson & DePoy, 2002, p. 154) our understanding of impairment shifts. This lens requires an examination of the internal and external factors to understand how a disabling condition is made (French Gilson & DePoy, 2002; Gronvik, 2006), meaning that the experience of disability is shifted outside of the individual. The person with the impairment is not disabled as a result of that impairment, but as a result of how society responds to that person – it is societal attitudes, barriers and assumptions that work to disable someone. This more recent but increasingly influential way of understanding disability is that it is a social construction – there is no ‘true’ or single fact of disability: the socially constructed definition of disability is based on the ways in which individual and societal values, beliefs, structures, systems, and culture influence how disability is understood; how it should be expressed and experienced; and how it should be ‘treated’ (Gronvik, 2006). (Note, disability as a social construction and as a medicalized deficit will be further elaborated upon in my theoretical framework section.)

In addition to the above-mentioned understandings of disability, earlier definitions and understandings of disability as either demonization or glorification continue to exist (French Gilson & DePoy, 2000/2002). Contemporary theorists, operating under the influence of pluralism where there are multiple realities, view disability as multi-leveled –a view which adheres to a social construction understanding (DePoy & Gitlin, 1998; French Gilson & DePoy, 2002). As a result, disability is understood not only as socially constructed, but also as a social justice concern that is rooted within economic, socio-political and cultural environments (French Gilson & DePoy, 2000/2002; Linton, 1998; Oliver, 1996). Similarly, legal and administrative definitions of disability use a more exclusionary stance, which also reflects a social constructionist understanding (Barnes & Mercer, 1997; Gronvik, 2006). They are concerned with the ways in which individuals are classified as eligible or non-eligible to receive benefits. It has become clear that there can be more than one definition of disability in use at any given time as different systems (e.g., social welfare, medicine, education, etc.) and programs – which typically have differing purposes, philosophies, and ideologies – then have differing eligibility criteria that reflect their understanding of the kinds of people who should be in receipt of their services (Barnes & Mercer, 1997). Eligibility for services is almost always based on the medicalized understanding of disability, as it requires a diagnosis provided by a licensed healthcare professional. This approach to defining disability is favoured amongst the political sphere as it corresponds with the current dominant neoliberal discourse. Neoliberalism, as defined by McKenzie & Wharf (2010), is "an approach to economics and public policy that strengthens the power of the private business and competitive markets in society and focuses state activity on areas of policy that reinforce the private market" (p.31). In other words, neoliberalism favours minimal government intervention leading to a reduction of spending on social services and an increased reliance of the individual to support themselves, where there is a desire for self-sufficiency in lieu of government reliance. Restrictive eligibility criteria, that relies on and requires professional diagnosis and validation, work to limit the number of people in receipt of (often costly) services.

It is important to note that the contemporary social construction of disability, in Hamilton, Ontario where my research was conducted, is largely influenced by the dominant medical and legal and administrative discourses. These discourses circulate within society through the eligibility criteria for programs and funding, the ways in which we converse with one another, what we consider to be a 'legitimate' impairment, and the overarching government policies and procedures that affect the ways in which we may operate within society. Also important are the ways impairment and disability are visually represented. An example of this visual representation would be the universal sign for a disabled or handicapped person; a person sitting in a wheelchair. This image perpetuates the notion that to be disabled and live with impairment, one must have a visible mobility impairment (Parashar & Devanthan, 2006).

In Western society, the media reinforces and reproduces dominant discourses pertaining to impairment and disability. The face of disability in the media is predominantly a physically apparent impairment, there appears to be little regard for the invisible aspects of disability (Florian, Katz, & Lahav, 1989; Green, Davis, Karshmer, Marsh, & Straight, 2005; Landau & Hissett, 2008). This is, in part, due to the social constructions of impairment and disability, constructions which define impairment and disability according to visible physical differences: those who have an invisible disability are portrayed and understood not as disabled, but as malingering, entitled and fraudulent (Chamberlin, 2006; Landau & Hissett, 2008; Lingsom, 2008). In other words, if we cannot see the disability, it does not exist. These inaccurate representations of impairment and disability can have significant impacts on individuals living with invisible symptoms of acquired brain injury.

Who is Affected by Brain Injury?

Brain injury has the potential to affect any individual in Canada regardless of age, gender, sexual orientation, ethnicity and socio-economic status. The leading causes of brain injury are motor vehicle accidents, falls, bicycle incidents, sports, workplace injuries and medical conditions (Brain Injury Centre Canada, 2011; Brain Injury Association of Durham, 2014). In Canada, it is estimated that over 1.4 million individuals are living with some type or form of disability as the result of brain injury (Brain Injury Association of Nova Scotia, 2014; Brain Injury Centre Canada, 2011). In Canada, one person sustains a brain injury approximately every three minutes, thereby accounting for 465 new cases of brain injury each day (Brain Injury Society of Toronto, 2014; Brain Injury Association of Waterloo-Wellington, 2012). In Ontario alone, there are currently just under half a million individuals living with a diagnosed acquired brain injury. Each year, approximately 18,000 new cases are diagnosed in Ontario, however, it is believed that there are a significant number of individuals living with acquired brain injury that have not been diagnosed or have been misdiagnosed (Ontario Brain Injury Association, 2012). Brain injuries are the leading causes of disability and death for Canadians under the age of 35 with the highest prevalence between the ages of 15-24 years (Ontario Brain Injury Association, 2012; Brain Injury Association of Durham, 2014).

What is Acquired Brain Injury?

As I noted earlier in this thesis, acquired brain injury refers to brain damage that occurs after birth, which includes both traumatic and non-traumatic events and does not include damage that is the result of neurodegenerative disorders (Brain Injury Centre Canada, 2011). Damage may be the result of external force, internal injury or a lack of oxygen where the individual experiences at least one of the following: loss of consciousness, memory loss, altered mental state or focal neurologic deficits. Symptoms of acquired brain injury can include but are not limited to headache, cognitive impairment, prolonged processing time, lethargy, dizziness, tinnitus, fatigue, mood changes, sensory problems, loss of coordination, etc., (Bogan, Livingston, Parry-Jones, Buston, & Wood, 1997; Darragh, Sample, & Krieger, 2001; Arciniegas, Harris, & Brousseau, 2003; Landau & Hissett, 2008; Green, Davis, Karshmer, Marsh, & Straight, 2005). No matter the cause, acquired brain injury can affect many aspects of an individual’s life, including but not limited to “cognitive functioning, to emotional, psychosocial and physical well-being, self-esteem, ability to work and participate in the community, socio-economic status and perception of self” (Lorenz, 2010, pp. 210).

What Does Invisibility Have to do With It?

Symptoms of acquired brain injury are not always visible. When there are no visible impairments, the disability is understood to be an invisible disability. The experiences of those living with an invisible acquired brain injury are unique in the sense that there is a discrepancy in how well one looks physically while simultaneously living with cognitive and emotional abilities that are impaired to varying degrees. In the current literature on invisible acquired brain injury, challenges with diagnosis are frequently discussed as being problematic (Goffman, 1963; Green, Davis, Karshmer, Marsh, & Straight, 2005). The invisibility of acquired brain injury can cause difficulty in diagnosis as often times the changes the affected individual may experience can look like the effects attributed to other conditions with similar symptoms to acquired brain injury (e.g., migraines and depression) (Clements, 1997; Florian, Katz, & Lahav, 1989; Sturge-Jacobs, 2002; Darragh, Sample, & Krieger, 2001; Langloais, Rutland-Brown & Wald, 2006). As a result, consultation with an appropriate healthcare professional is often overlooked and the individual continues on with no accurate explanation for the changes s/he experiences (Clements, 1997; Gordon, et. al, 1999; Landau & Hissett, 2008; Mooney & Speed, 2001; Swift & Wilson, 2001). In addition, these individuals may be inappropriately diagnosed and treated. Due to the misdiagnosis and treatment they may receive, this can cause several consequences for the individual. The most severe consequence is that the impairment is not recognized and the individual is not understood to be a person with a disability.

Research put forth by healthcare professionals suggests that those living with acquired brain injury (and their families) are required to repeatedly explain their invisible impairments in order to prove and legitimize their experiences (Landau & Hissett, 2008; Lingsom, 2008). As a result, others generally do not take those living with invisible impairments seriously as it is often believed that they do not have a legitimate disability (Goffman, 1963; Lingsom, 2008). This is especially important for individuals living with an invisible acquired brain injury as even families can fail to recognize a member is living with impairment and can be classified as disabled. This denial and failure to recognize acquired brain injury within the family is a problem within itself. Tensions within the family dynamic may increase as often the individual with the invisible acquired brain injury may be perceived to be lazy or not pulling their own weight (Lingsom, 2008; Chamberlin, 2006; Goffman, 1963).

How Does this Affect Family Dynamics?

Swift & Wilson (2001) identified four common themes from the perspective of families with a member who has invisible symptoms of acquired brain injury: inaccurate beliefs about recovery time, lack of awareness of how symptoms can manifest, misconceptions of capabilities of those who are brain injured, and misdiagnosis. Those living with acquired brain injury and the families of these individuals may find it increasingly difficult to respond to the changes that are happening to the individual. The individuals living with acquired brain injury may feel isolated within their own families and can become frustrated as often the symptoms they are experiencing are trivialized or chalked up to another issue. Research has shown there is a lack of sensitivity, understanding and legitimization of the individual's experience of acquired brain injury on the individual from both a healthcare and familial perspective. The combination of being misunderstood by both these groups who are very important to people living with acquired brain injury can result in a predictable cascade of problems; tensions and frustrations may elevate within the family leading to the affected individual's further isolation and trivialization. This may lead to animosity amongst members of the family (Chamberlin, 2006). Once a diagnosis is provided that legitimizes the reason for the affected individual's symptoms, a sense of relief and validation can be felt not only by the individual but also by the family (Landau & Hissett, 2008; Lingsom, 2008; Sturge-Jacobs, 2002).

Another prevalent theme within the literature revolves around the notions of disclosure and concealment (Lingsom, 2008; Samuels, 2003). Once a diagnosis is given, many individuals living with an invisible acquired brain injury are faced with the dilemma of whether or not to disclose their disability to others. Disclosure can be viewed in both positive and negative lights. Positive affects of disclosure center around the ability to 'pass" as normal. 'Passing' refers to "the concealment or silencing of the impaired self (Lingsom, 2008, p. 2). In addition, it also "refers to keeping an attribute ascribed from stigma from becoming known to others" (Lingsom, 2008, p. 4). The ability to pass as a 'normal' person is understood to be a privilege in itself as the individual is in control of how they are seen (Darragh, Sample, & Krieger, 2001; Green, Davis, Karshmer, Marsh, & Straight, 2005; Joachim & Acorn, 2000). According to Goffman (1963) "because of the great rewards of being considered normal, almost all persons in a position to pass will do so on some occasion by intent" (p. 95). Passing is also used to direct "stigmatizing gazes" elsewhere (Lingsom, 2008, p. 4). A negative affect of passing may occur if, at some later point, the affected individual decides to identify as impaired or is 'outed' by someone else. As a result of this identification, they could be considered to be fraudulent as they were not forthcoming with their impairments (Goffman, 1963; Lingsom, 2008). Should an individual wish to disclose, they run the risk of becoming devalued, excluded, marginalized and made to feel shame (Lingsom, 2008).

However, concealment of an impairment ("keeping a known attribute as unobtrusive as possible" (Lingsom, 2008, p. 4)) can also cause increased levels of stress and anxiety as the individual is carrying the burden of disability on their shoulders. In this context, 'burden' refers not to the impairment, but to the negative stigma that is associated with impairment and disability as well as the constant fear and worry of exposure. If and when exposure happens, the individual then runs the risk of not being believed as those living with invisible impairments are often thought to be discreditable (Goffman, 1963; Lingsom, 2008). This can result in the potential risk of oppression, discrimination and stigmatization (Green, Davis, Karshmer, Marsh, & Straight, 2005; Darragh, Sample, & Krieger, 2001; Goffman, 1963; Joachim & Acorn, 2000; Lingsom, 2008). The literature suggests concealment of impairment is a phenomenon not only attributed to the individual, but also to the family. Family members may conceal a member's disability from others for fear of being judged, stigmatized and oppressed (Lingsom, 2008; Goffman, 1963).

The potential stigmatization of the individual and the family is often at the root of the decision to conceal impairment; this is a prevalent theme throughout the literature (Goffman, 1963; Green, Davis, Karshmer, Marsh, & Straight, 2005; Lingsom, 2008). Often those who are identified as having a disability are labeled, stereotyped and separated from those who are deemed to be 'normal' (Goffman, 1963). They experience loss of status and are discriminated against. As a result, families and individuals may feel emotional distress, depression, isolation, shame etc. (Green, Davis, Karshmer, Marsh, & Straight, 2005; Joachim & Acorn, 2000).

Frequently, the literature reports on the grieving process that can occur within the individual and the family. Many researchers indicate that the stages of grieving typically thought to occur for the family who have lost a loved one to death have also been identified in those with acquired brain injury as this injury can represent for them the metaphorical death of someone they knew. Researchers have identified this as "ambiguous loss" (Landau & Hissett, 2008, p. 70). This perceived loss of self appears to colour the experiences of the individual living with acquired brain injury as well as those of their family members. Often times the family and the individual are in mourning; grieving the loss of the person the individual was prior to the injury. Accepting this change can, for some, be quite challenging as the person appears 'normal' and there is nothing visibly wrong that would suggest otherwise, however, they are clearly not who they once were. This reluctance to accept this 'new' person, who is now their new identity, can result in denial, anger, guilt and increased stress (Florian, Katz, & Lahav, 1989; Kreutzer, Kolakowsky-Harper, Demm, & Meade, 2002; Landau & Hissett, 2008).

The Importance of Voice

In addition, there are calls in the disability literature for the recognition of the crucial importance of the inclusion of voices of persons living with disability in research – this inclusion is integral to understanding the experiences of others (Hosking, 2008). It is important to reiterate, the voices that currently dominate acquired brain injury literature are predominately those of the family of the affected individual and healthcare providers. As a result, there is limited literature giving voice to individuals living with acquired brain injury, and even less voice to those living with invisible symptoms of acquired brain injury. Most of the research I found was quantitative in nature and the researchers were primarily doctors and other healthcare professionals such as nurses and social workers, none of whom identified as a person with an acquired brain injury. Qualitative studies that represent the perspectives and experiences of the affected individual are few and far between. The majority of qualitative studies on invisible disability and invisible acquired brain injury are researched from the primary caregivers' and other family members' points of view. Consequently, the majority of present research appears to reflect an etic versus an emic perspective. Possible implications of this skew have the potential to affect the ways in which social workers interact with this population, the kinds of services available, funding available and the development of appropriate and relevant care plans. There is a growing belief that insider voices need to be more strongly and actively present in research, not only as research participants, but also in guiding how research is conducted, the kinds of questions asked and the ways in which this data is then analyzed and interpreted (Hosking, 2008). Further research involving the narratives of those most directly affected by acquired brain injury should be conducted to gain a better understanding of the experiences these individuals face.

Although, as noted, a very limited portion of the existing research attends to the experiences of the family and individuals living with acquired brain injury, it must also be noted that there is a lack of literature discussing the kinds of approaches that would be useful in working with these individuals. There is little known about how one may support individuals and their families to mitigate the effects and stigmatization secondary to invisible acquired brain injury. Similarly, there is little information on the effectiveness of the services that are currently available to help these individuals and their families work through a challenging time of grief, newly evolving identities and new beginnings surrounded by multiple obstacles.

Theoretical Framework

Disability Discourse

Throughout the disability literature, there are many ways of understanding disability. Within these understandings, there are two broad definitions that are paramount throughout all definitions of disability (French Gilson & DePoy, 2002). The first is an understanding that disability is located within the individual (medical model) and the second recognizes external factors within the environment that contribute to the experience of disability (social construction) (French Gilson & DePoy, 2002; Jaeger & Bowman). Therefore, for the purpose of this research, I have chosen to focus on the medical and social constructions of disability.

A key premise of the medical discourse is "that diseases and other 'malaises', such as disabilities, are deviations from normal biological functioning. Medical assessment and intervention focuses on addressing deviation and correcting it rather than adapting the environment to accommodate differences" (Healy, 2005, p. 21). As a result, treatments and services are designed to be curative in nature to correct the disability (French Gilson & DePoy, 2002; Mackelprang & Salsgiver, 1997). Individuals that are unable to be cured are then seen as defective - meaning that they are unable to function within socially acceptable norms and therefore seen as deviant and/or noncompliant with socially acceptable behaviours (French Gilson & DePoy, 2002; Longmore, 1997; Mackelprang & Salsgiver, 1997). Here, the notion of disability lies solely in the affected individual without taking into account the roles of social contexts (Healy, 2005; Jaeger & Bowman). Privilege is given to biological understandings of disease in lieu of understanding social contexts and identifying the impact that the environment plays in the experience of disability (Healy, 2005; George & Davis, 1998; Turner, 1995). Impacts of this can be identified in the way society currently responds to disability, for example, buildings may not be constructed in a manner that takes into account the difficulties of those living with impairments. Social, economic, attitudinal and material barriers may also exist but not be recognized as oppressive to people with impairments. As a result, these individuals with impairments must adapt to these limitations in lieu of society adapting to difference (Tregaskis, 2004). As a result, a limitation of the medical discourse is that it fails to acknowledge the impact of historical and cultural prejudice that has the ability to affect how one experiences, understands and responds to impairment (Healy, 2005; Jenkins & Barrett, 2004).

As I noted earlier in this thesis, the social construction of disability has emerged to challenge medical understandings of disability and to take into account the historical and cultural contingency of ‘disability’. Contemporary understandings of disability as a social construction center on the premise that disability and impairment are to some degree independent of each other (Hughes, 1999; Thomas, 2004). According to the medical model, ‘impairment’ can be defined as “any loss or abnormality of psychological, physiological or anatomical structure or function (Barnes & Mercer, 1997, p. 2). In much social model theorizing, impairment is constructed along these same lines – it is the mind/body difference that one identifies or is identified as having. More recently, attention to the social construction of impairment itself has led to shifting understandings: according to these particular social perspectives, impairment can be defined as "continuously constituted and reconstituted in terms of invalidation. To be impaired is to be perceived as invalid, to be seen to be anomalous or contrary to order" (Hughes, 1999, p. 157). For the purposes of this paper, this earlier social model definition is used. The medical definition of 'disability' can be defined as "any restriction or lack (resulting from an impairment of ability to perform an activity in the manner or within the range considered normal for a human being (Barnes & Mercer, 1997, p. 2). In contrast, the social understanding of disability proclaims that disability is the result of human factors, like a building being poorly designed, and oppressive and stigmatizing policies and practices (Tregaskis, 2004). It can be further understood that disability refers to the effects of how society - individuals as well as systems - respond to those who have impairment (Thomas, 2004). Therefore, disability is not the 'fault' or responsibility of the individual, it is the fault and responsibility of society (Hughes & Paterson, 1997; Thomas, 2004). If society were to shift its way of understanding impairment (as difference) and disability, and to organize itself to accommodate difference as opposed to disabling people with impairment, there would be a fundamental shift in the way in which we understand and respond to people with impairment.

Defining the Lens

In research, it is essential for the researcher to present their epistemological positioning so that the reader can understand the theoretical underpinnings of the research (Carter & Little, 2007). The epistemological framework, therefore, guides the way in which the researcher conceptualizes the methods to be used to develop meaningful and relevant research, how s/he determines an analytic strategy, and decision-making regarding how best to convey the information to the audience and participants (Carter & Little, 2007; Mason, 2002).

As mentioned earlier, my motives for researching invisible acquired brain injury have been largely influenced by my personal experience of living with this disability and navigating the changes in my family and in my personal life. As a result of the changes I experienced within my own family, I became fascinated with understanding if and how others might experience change as a direct result of their injury. Through exploration of the existing research literature on disability and acquired brain injury, it has become apparent that in order to examine the changes to family dynamics of individuals living with invisible symptoms of acquired brain injury, social work must understand how disability is constructed, why it has been constructed in this manner and how it affects those living with disability. It is through this understanding of the social construction of disability that we will be able to further explore, analyze, understand and apply the knowledge gained to everyday situations, to social work practice, to our interactions with others and in the context of this research, to our families and healthcare providers.

Until fairly recently, epistemological positivist social science frameworks have dominated disability literature. Those living with disability and their allies felt that such disability research ignored, marginalized and exacerbated their lived experience of disability (Abberley, 1987). Increasingly, disability researchers are turning to critical social science frameworks in response. Critical social science is centered on challenging the dominant discourses that are present within our society and empowering individuals to change that society. This theoretical perspective believes that although people are tied to material conditions, cultural contexts and historical conditions, they are still able to develop new ways of knowing that can enable them to change these relationships, structures and laws (Neuman, 1997). The use of critical theory in research has the ability to develop insight used to guide practical applications while responding to the world that is has set out to change (Hosking, 2008). Examples of this would be altering the language used when working with individuals with impairments, and structuring interventions that account for difference. In my opinion, I feel this framework is best suited to understanding issues related to invisible acquired brain injury as both the concept and the experience with the invisible disability, especially as it relates to acquired brain injury challenges the dominant discourses within society. Therefore, it will provide space for healthcare professionals to expand their knowledge and respond to acquired brain injury in a more inclusive way. This can result in social workers moving away from the implementation of medicalized interventions and treatments and move towards ones that reflect a broader interpretation of 'disability' and are thus more adaptive and inclusive.

Under the overarching theoretical framework of critical social science, is critical disability theory. Expanding upon earlier social constructionist models of disability, critical disability theorists believe that "disability is best characterized as a complex interrelationship between impairment, individual response to impairment and the social environment" (Hosking, 2008, p. 7). As a result, individuals living with disability typically encounter social and material disadvantages that are caused by institutional, social, physical, and attitudinal environments that, in holding firm to a medical perspective, fail to recognize individuals with disability as “normal” as they do not “fit” with the dominant social construction of “normal” (Hosking, 2008). This is very pertinent to understanding the challenges associated with invisible symptoms of acquired brain injury. As with many people with impairment, the ways in which people with acquired brain injury live, behave, interact, communicate etc., may be regarded as different. Further, sometimes those who are living with invisible symptoms of acquired brain injury are unaware of their impairment. While this is, at least in part, due to the dominant medical discourse dictating how disability should manifest and be experienced, the resulting disconnect between such expectations and the actual experiences of a person with an acquired brain injury may affect how the individual sees her/himself and influence how s/he acts and how those around them respond. The relevance of this perspective then leads to an exploration of changing family dynamics as a result of invisible acquired brain injury is apparent.

Locating the Researcher

As mentioned earlier, my experience living with acquired brain injury has been the impetus for my research resulting in my positioning as an ‘insider researcher’. The term ‘insider researcher’ refers to “when researchers conduct research with populations of which they are also members (Corbin Dwyer & Buckle, 2009, p. 58). Here, the researcher shares a common language, identity and experience with the participants (Corbin Dwyer & Buckle, 2009; Asselin, 2003). As a result, my ‘insider’ status has influenced the theoretical lens I have used throughout this thesis. My ‘insider’ status has also influenced the way in which I have approached this research and analyzed the findings.

Conducting research from an ‘insider’ positioning can result in positive outcomes and potential risks. According to Corbin Dwyer & Buckle (2009), insider researchers have the ability to connect and be accepted by their participants more rapidly. This can result in participants becoming more open to disclose their experiences, which contributes to greater, more rich data. At the same time, ‘insider researchers’ may struggle with role conflict (Corbin Dwyer & Buckle, 2009; Brannick & Coghlan, 2007). This dual role can lead to the researcher analyzing data from a perspective other than that of ‘researcher’. Asselin (2003) indicates that this role confusion can happen within any research, however there is an increased risk when researchers belong to the populations they wish to study. This will be discussed further within the methodology section of this thesis.

It is also important to note that other aspects of my social location have also influenced how this research was shaped. My experience living in a middle-class family with the financial means to access resources that are not readily accessible has affected the way in which I understand acquired brain injury. Had I not been able to access resources (such as neuropsychological assessments and an educational specialist), my knowledge and experience of living with this disability would be quite different - I may have never received a proper diagnosis. Given the reality that not all individuals have access to the same kinds of resources, my experiences with healthcare professionals, the information gained from alternative sources, and the ways in which I navigated living with impairments may be much different than those who do not have access.

Methods

Qualitative Methods & Critical Disability Theory

Within the research literature, there has been little space allotted to the voices of individuals living with disability. This is in large part due to the unwillingness of society to accept and validate the experiences of these individuals. Critical disability theory "privileges the voices of disabled people and relies on their voices to challenge the negative attitudes toward disability commonly expressed by able bodied people and so often reiterated in print and visual media" (Hosking, 2008, p. 17). In order to challenge these negative attitudes and give voice to those living with disability, I have chosen to use qualitative research strategies. Qualitative data is used by the researcher to understand and decipher meanings, relationships, values, beliefs and experiences (Mason, 2002). Given that there is limited research pertaining to the experience of individuals living with invisible symptoms of acquired brain injury from their own perspective, I felt that the use of qualitative research methods would allow for the identification and analysis of dominant themes of their lived experience.

Qualitative research can be performed in a variety of ways. According to Gill, Treasure, & Chadwick (2004) and Mason (2002), there are three kinds of qualitative research interviews that can be used in research. These are structured, semi-structured and unstructured. For the purpose of my research, I chose to use a semi-structured approach to interviewing, as this would allow me to explore the lived experiences, perceptions and beliefs of my participants. Semi-structured interviews provide flexibility to explore significant topics that participants may indicate to be of most importance to them. This form of exploration and gathering meaning cannot be done to the same extent if interviews are more rigidly structured. It may also be difficult to achieve this form of relevant exploration in an unstructured environment, as the participant may not feel compelled to discuss the desired topic (Mason, 2002).

Mason, (2002) provides five key guidelines to achieving a meaningful, thought producing, and relevant interview. Keeping these five strategies in mind, open-ended questions such as "is there anything you would like me to know about you before we start", "what has your experience been like living with an invisible acquired brain injury" and "if you could tell your family how you feel, what would you say" were asked. These forms of questions elicited valuable knowledge and generated much discussion.

Given the sensitive nature of this research, this method of data collection allowed for a humanistic approach to data collection and analysis as it is aligned with my ontological positioning; this position being that "peoples knowledge, views, understandings, interpretations, experiences and interactions are meaningful" (Mason, 2002, p. 63). In my research, the qualitative interviews created space for an active and reflexive approach to analyzing the data, thus, resulting in what I believe to have been a well rounded, practical and insightful analysis and lens to understanding changes to family dynamics from the perspective of an individual living with invisible symptoms of acquired brain injury and the role invisibility contributes to these changes.

Participant Recruitment

To recruit participants for this research, a recruitment poster (see Appendix A) was posted throughout the McMaster University Campus. Potential participants were provided with my contact information and encouraged to contact me for more information about the study. A recruitment e-mail (see Appendix B) was also used to recruit participants. This email was sent out to undergraduate and graduate students in the School of Social Work at McMaster University, as well as to students identifying with an acquired brain injury through the McMaster University Student Accessibility Services. Attached to this e-mail was a copy of the letter of information (see Appendix G). The letter of information **(**See Appendix G), provided a detailed outline of the study – what participants could expect during the interview as well as risks and benefits of doing the research. In addition, it informed participants of their right and ability to withdraw from the study at any time with no adverse repercussions. Due to the positive response of participants from my initial recruitment pool of McMaster University, I did not proceed with contacting Brain Injury Association of Peel and Halton, or Medical Associates of Port Credit, as I had originally intended.

As the number of individuals living with acquired brain injury comprises a small percentage of the population in Ontario, and those living with invisible symptoms of acquired brain injury an even smaller percentage, I chose to recruit participants 18 years of age and older. This broad range would ensure that I would be able to meet the minimum number of participants required to continue with my research. Due to the ethical considerations of engaging minors in research, those younger than 18 years of age were not invited to take part in this study.

Resulting from the poster and recruitment email, I had an initial expressed interest from four individuals. One individual did not have an acquired brain injury, however s/he knew of some individuals who might be interested and passed along the study information to them. Several individuals contacted me through this snowball sampling.

Throughout the recruitment process, I was transparent with each potential participant regarding my own diagnosis of acquired brain injury. This allowed me to connect with each participant on a more intimate level and to provide insight and context as to why I had chosen to undertake this area of research. This, I felt, allowed the participant to make an informed decision regarding whether or not they wished to participate in this research.

Of the eight people who contacted me, all eight met the minimum criteria to take part in my study. This was determined through the use of a participant screening form (see Appendix H) to minimize potential research bias and to ensure the anonymity of the participants (Mason, 2002). As I am a member of this community and have worked within various agencies for individuals living with acquired brain injury, it was important to ensure that there were no known pre-existing relationships between the participants and myself. This would allow for a more critical analysis, as I would not hold knowledge of the individual being interviewed. It was also important to ensure participants did not receive services through my places of employment. This would ensure that the motive for participation in this research were not forced and/ or based on the desire for preferential treatment in relation to resource allocations. All eight individuals made the decision to participate. It is important to note that one participant brought their partner to the interview. This individual also lived with invisible symptoms of acquired brain injury and wished to participate in the study as well. In the end, there were a total of nine participants recruited for this research. The age of the participants ranged between 24 and 64 years of age. Six men and 3 women participated.

Semi-structured qualitative interviews were conducted in the manner preferred by each participant. Three interviews were conducted over the telephone, one interview was conducted over Skype, and five interviews were conducted in person at a location of the participant's choosing. It is important to note that one of the face-to-face interviews was a double interview due to the unexpected last minute expression of interest and willingness to participate in this study by the aforementioned partner of one participant. Due to time constraints and logistics for the three of us, we mutually decided that a joint interview would be conducted.

The Interview Process

Before each interview began, I read over the Letter of Information and Consent with each participant. Participants had the opportunity to ask any questions and they were reminded of their right to withdraw from the study ant any time. Each participant who I interviewed face-to-face signed the consent form prior to the start of the interview. The four others with whom I conducted the interview over the telephone and Skype provided verbal consent. The participants who wished to be provided a summary report provided me with the ways in which they would like the information to be sent to them.

Throughout the interview process, I did rely on my interview guide to ensure certain questions were answered. Through the natural course of my conversations with each participant, I found that the majority of my questions were discussed on the participant's own accord without my having to directly ask the questions. Some participants did veer off topic at times. I allowed for this to happen as the content and context of their information was important to creating a rapport and understanding their unique experience.

The semi-structured interviews varied in length (1 hour to 2 ½ hours). Interview lengths were dependent largely on the amount of information the participant was willing to share and their emotional state throughout the interview. In one situation, a double interview occurred which resulted in a longer than normal interview time.

Prior to the start of the interview, I again briefly described my own location and connection to this research. Many participants expressed to me how thankful they were that I was conducting this research and also indicated that they would be able to better articulate themselves as there was a level of mutual understanding present.

To begin the interview, the question "is there anything about you that you would like me to know about you before we start?" was used. This provided participants the opportunity to share any information they deemed necessary for me to understand their positioning and experience. From there, the participants and myself were able to converse about their experience and discuss areas of importance to them. At times, the conversation did veer off topic however I was able to gently guide the conversation back to the original context of the interview.

Over the course of the interview process, there were many similarities and parallels between my personal experience and that of my participants. I found this reality to be difficult to navigate in the interview itself, as I wanted to ensure the information shared with me was not influenced by my own experience. I found it was crucial to be self-reflexive throughout this process, especially throughout the interview, to ensure I asked questions pertaining to their experiences and not my biased understanding of their experiences. After the interviews, I did review what had just transpired and critically reflected on what I had done - did I ask the right questions? Should I have picked up on something that was important? Did I project my experiences onto others? In some instances, I do feel I had missed some important probing questions, however I am not entirely sure if my own insider positioning influenced this.

Throughout the interviews, participants would ask about my experience of living with an acquired brain injury. I initially struggled with the idea of interviewer self-disclosure. According to Reinharz and Chase (2003), “interviewer self disclosure takes place when the interviewer shares ideas, attitudes and/or experiences concerning matters that might relate to the interview topic in order to encourage respondents to be more forthcoming” (p. 79). Researcher self-disclosure also attempts to reduce the power imbalances between researcher and participant and allows for rapport to be built more rapidly, especially when discussing delicate matters (Kvale, 1996; Abell, Locke, Condor, Gibson & Stevenson, 2006). It should be noted that there are constraints to researcher self-disclosure. According to Poindexter (2003), self-disclosure within the context of social work can help position the researcher within the interview. It can also inadvertently draw attention to the researcher. Therefore, it is important for researchers to recognize their motives behind disclosure and ensure they are not being self serving. In addition, researcher self-disclosure may influence the participants' perceptions and explanations of their lived experiences therefore researchers must be aware of what, when and how they disclose (Abell, Locke, Condor, Gibson, & Stevenson, 2006).

In an attempt not to bias the participants' own perceptions of their experience, simple and brief explanations were given, however more detailed experiences were shared towards the end of the interview after they had shared their experience. This was done to ensure that the information provided reflected an accurate representation of their experience. I did find it important to acknowledge and share some of my thoughts should the context allow for it. This, I felt, enabled a deeper level of understanding and rapport to be developed. This was crucial as all participants voiced that it was easier to share their experience with someone who had an intimate knowledge of the challenges.

Upon the completion of the interviews, I believe my choice to conduct semi-structured interviews proved to be of great benefit to the research I wished to accomplish. I felt that I was able to provide a safe space in which participants could share their stories with others with the hope their experiences could provide valuable insight to understanding the experiences and needs of members of this community. This aligned with the main premise of my study - to give voice to individuals living with invisible symptoms of acquired brain injury and to hear their experiences associated with it. In my opinion, I do not feel that I encountered any problems as the result of my self-disclosure throughout the interview process. Given the nature of the research and the challenges that are associated with living with invisible symptoms of acquired brain injury, I was able to connect with my participants on a level that 'outsiders' may not be able to achieve. Throughout the interviews, participants expressed to me that it was nice to talk to someone who understands as it was often articulated that it was difficult to speak to others who had no knowledge of their experiences. Through self-disclosure, I was able to develop rapport quickly with participants and, as a result, I feel I was able to gather more rich data that contributed positively to the research.

Ethical Considerations

Although this study received clearance from the McMaster Research Ethics Board, there were some ethical tensions that did arise throughout this research process. A significant number of the participants had experienced traumatic pasts, which came out over the course of the interview. In recounting their personal stories, many triggered emotions or memories that were painful. To navigate these emotions during these instances, a check-in and a break were offered to each participant and emotional support was given as seemed to be required.

With some participants, suicidal ideation did come up in conversation. Given the nature of acquired brain injury and the prevalence of depression, this is not uncommon. As a registered social worker, I have received training in various risk assessments and suicide interventions. In the instance of expressed suicidal ideation, a risk assessment using the ASIST Suicide Intervention Model was conducted in tandem with the interviews to ensure there was no imminent risk of danger. In one instance, the tone of the conversation turned quite dark. The individual expressed that they wished they had died and that they wished they were dead. A risk assessment was done and the individual assured me that there was no plan in place and that they would not be acting on these feelings. This instance was disclosed to my thesis supervisor and it was suggested that I contact the Ontario College of Social Workers and Social Service Workers. I spoke with a representative at the College and it was determined that my assessment and perception of the incident was acceptable and did not warrant any further action.

Data Analysis

Prior to conducting data analysis, it was necessary that the qualitative interviews be transcribed. Initially, I had decided to find an outside transcriber to help with this process, however through further research I changed my opinion. According to Lapadat & Lindsay (1999), through the act of transcribing interviews, the transcriber is able to develop deeper understandings and analysis of data. This can be attributed to the amount of control the transcriber can exert over the transcription decisions. In addition, the act of transcription is “intertwined with analysis” (Tilley, 2003) and “facilitates interpretive thinking that is needed to make sense of the data” (Lapadat & Lindsay, 1999, p. 82). For these reasons, I made the decision to transcribe the interviews myself.

Once the interviews were transcribed, a critical lens relying on the underpinnings of critical disability theory was used to understand, analyze and interpret the data. While examining the data, I looked to answer questions such as: does invisible manifestation of disability contribute to changes in family dynamics and the perception of the individual living with the acquired brain injury and, if so, how? Does conventional knowledge and understanding of disability affect the experiences of those living with disability and, if so, how? What do participants understand to be legitimate knowledge pertaining to the experience of individuals living with acquired brain injury? Lastly, what changes do participants wish to see in relation to their interactions with healthcare providers and their families?

In order to answer these questions, I relied on open coding. According to Goulding (1999), open coding is used to break down data into individual entities of meaning to conceptualize and label data. These labels and conceptualizations are then attributed to themes that become uncovered as the analysis takes place (Brown, Stevenson, Troiano & Schneider, 2002). Through reading each transcription, I looked at each sentence individually and then at the sentence within the larger context of what the participant had shared. This allowed me to uncover and identify areas of importance throughout each interview. Once this initial analysis was complete, these areas of importance were compared against the ones found in the other interviews and themes were noted. Through using the constant comparison procedure, I was able to compare and contrast the similarities and differences found within the data that belonged to certain themes (Spiggle, 1994).

According to Glaser (2002), the use of open coding and the constant comparative method can reveal the researcher's personal bias, which may influence the data. Keeping this in mind, throughout the data analysis process, I continually needed to be self-reflexive to understand my own perspective on the topic at hand and not allow that to overshadow the meanings, experiences and contexts of what the participants shared with me. Through analyzing the data in a more contextual manner, taking into account the emphasis and meanings voice by the participants, I believe I was able to minimize the level of researcher bias throughout the analysis.

Limitations

Although the sample size for a master's level thesis was respectable for an exploratory qualitative study, it should be noted that the findings put forth by the participants are not indicative of all individuals living with invisible symptoms of acquired brain injury. This is in part due to the variable ways in which their respective brain injuries may have manifested but also due to the variability of their lives prior to injury and after.

A second factor to consider is directly related to the experience of acquired brain injury and the various emotional, perceptual and cognitive changes, which, while not readily or easily detectable, may have influenced participants' responses (Gregory, 1998). It should also be noted, "people with cognitive impairments often cannot effectively recall and articulate experiences, feelings, and perceptions" (Paterson & Scott-Findlay, 2002, p. 399). Despite these possibilities, it is critical to include their voices within research (Hosking, 2008).

Lastly, the inclusion of a joint interview within the research may have impacted the results. It is possible that for each of the two participants involved the presence of the other had some influence over what the respective participants conveyed. Close attention was placed in the analysis of the interview transcript to ensure that, to the best of my ability an understanding of each participant's individual beliefs and interpretations was made.

Findings & Discussion

The analysis of the semi-structured qualitative interviews revealed many important issues relating to the changes to family dynamics that one might experience when living with invisible symptoms of an acquired brain injury. Due to the constraints of this Master's level thesis, I am unable to address all of the themes identified and have chosen to focus on what I felt to be the three most dominant themes present across all interviews**.**

The three dominant over-arching themes that were present throughout the analysis were 1) the importance of understanding disability and acquired brain injury, 2) changes to family dynamics and lastly 3) mitigating the effects of acquired brain injury on the family. Within these general themes, I also identified key subthemes that are pertinent to understanding the challenges and changes one may face when living with invisible symptoms of acquired brain injury.

Within the theme of the importance of understanding disability and acquired brain injury, subthemes emerged around experiences of missed diagnosis, inadequate knowledge of acquired brain injury, and validation by others and the affected individual. Within the theme of changes to family dynamics, subthemes emerged around changing relationships, negotiating the roles, unrealistic expectations, and misconceptions. Within mitigation of the diagnosis, subthemes emerged centering on education, awareness, and inclusion of the family in recovery.

Throughout the analysis of the data, I had to make a conscious effort to ensure my own experiences and understanding of the topic did not overshadow the information imparted to me by the participants. Although challenging, I feel I was able to manage my emotions and biases while being continually self-reflexive throughout this process. As a result, I believe I was able to put forth a critical interpretation of the participants' lived experiences. The data will be presented using quotations from the participants. To protect their identity, gender specific pseudonyms were chosen by the participants (their choice) and pseudonyms were assigned when participants did not provide their own.

The Importance of Understanding Disability and Acquired Brain Injury

The reports from the participants seemed to indicate that the way in which disability is socially constructed plays a significant role in society's attitudes, beliefs and interactions with individuals living with a disability. In addition, due to the complex and individualistic nature of acquired brain injury, there is and continues to be a lack of education and awareness regarding the ways in which one can acquire a brain injury and how it may manifest (Chamberlin, 2006; Clements, 1997; Landau & Hissett, 2008). As with disability more broadly, many individuals already have preconceived beliefs of what it means to be brain injured prior to ever meeting (or becoming) a person with an acquired brain injury. These preconceived constructions of disability and brain injury can affect whether or not an individual is diagnosed, the length of time for diagnosis to occur, and how the individual is perceived by others and by themselves (Clements, 1997; Landau & Hissett, 2008). Nonetheless, being diagnosed is often understood to result in the validation of the disability itself and of the experiences of those who live with the diagnosis.

Out of Sight, Out of Mind: Invisibility and Missed Diagnosis

The findings show that participants expressed challenges when interacting with healthcare professionals. The invisible manifestation of symptoms of acquired brain injury appear to be the underlying factor that affected the ways in which healthcare professionals responded to participants and the ascertainment of a diagnosis. It is important to reiterate, all participants within this study demonstrated high levels of verbal articulation abilities and showed no apparent – or readily visible - forms of impairment. Some demonstrated slight nuances however there was no indication that they were indicative of anything more than just who the person was. The physical representation of the participants, combined with the level of autonomy and articulation thus contradicted the dominant constructions of what it means to be disabled and brain injured. This is consistent with the literature, which reveals how the invisibility of acquired brain injury can impact on interactions with medical professionals and how quickly diagnosis occurs (Landau & Hissett, 2008; Ruff, Iverson, Barth, Bush, & Broshek, 2009).

Participants within this study voiced their frustrations regarding their interactions with their healthcare professionals in their attempts to obtain a diagnosis. Ryan expressed

> "I have been finding that a lot of healthcare professionals forget about head injuries because it's not something that you can easily see, especially when you go in with something like a broken collarbone because that's something that is right in front of them".

Christa also shared that the physicians she came in contact with "focused primarily on the visible physical injuries first" and once the majority of these injuries were dealt with, they then were able to provide a diagnosis of brain injury, which was frustrating to her. Similarly, Paul shared that his physician "knew something was wrong… and it wasn't until a year and nine months later that he [physician] became worried about my memory loss and the fact I was slipping into depression”. It was only then that his family doctor decided to conduct additional assessments to determine the cause of these changes.

All of the participants shared in the belief that the healthcare professionals place the majority of their attention on physical impairments while paying little or no attention to the symptoms that manifested as invisible. As a result, some participants felt that their symptoms were overlooked solely for the reasons of invisibility, thus resulting in missed diagnosis, mis-diagnosis and/or delayed diagnosis. This was frustrating to some participants, as often they did not know their symptoms were attributed to a head injury. Here we can see that “the burden of proof can be very difficult to meet for an invisible injury which is not well understood by science and which is subject to the worst of human prejudices” (Webster, 2000, p. 19). This is in part due to their beliefs of how one can become brain injured and the symptoms that they could experience.

As illustrated above, the complexity of diagnosing brain injury is a problem within itself. This phenomenon can be illustrated when an individual goes to see a physician with a cut on their head resulting from a fall. The physician would tend to the wound first as it is visually the only thing wrong with the individual. During this time, if the individual presents him or herself as articulate and appears to be functioning ‘normally’ then additional assessments may be thought to be unnecessary. In addition, the use of probing questions may not be used as the individual looks and appears to be functioning ‘normally’. During this time, even the injured individual may not recognize the changes that have occurred as a result of the injury, and, if they do, may not attribute the changes to the head trauma that had just occurred. These experiences demonstrate that like the general public, even physicians seem to prioritize the obvious physical signs of injury and impairment and consequently may not be suitably trained or attentive to investigating for invisible impairments of acquired brain injury (Landau & Hissett, 2008; Ruff, Iverson, Barth, Bush, & Broshek, 2009).

Gaps in Knowledge of Acquired Brain Injury Among Healthcare Professionals

Although the incidence rate of acquired brain injury is alarming (Brain Injury Centre Canada, 2011), individuals living with acquired brain injury, their family members and specialists in the brain injury field share a common complaint; the general public and healthcare professionals have an insufficient understanding of the symptoms and issues related to brain injury – particularly to invisible acquired brain injury (Chamberlin, 2006). This was especially noted in the interactions with healthcare professionals that have limited experience with brain injury (Swift & Wilson, 2001). Due to the invisible manifestation of brain injury and absence of any physical evidence of injury, healthcare professionals often overlook the symptoms and attribute it to the belief that the individuals were malingering, thus resulting in the misdiagnosis of individuals (Chamberlin, 2006; Swift & Wilson, 2001).

Clements (1997) suggests that delay in diagnosis can be attributed to the limited knowledge the physician has of the individual (referring to what is normal for said person) and limited knowledge of the injury itself. Once the participants did receive a diagnosis of acquired brain injury, they reported feeling they were still left in the lurch, as there was limited knowledge on the part of healthcare professionals as to what to do next. Participants felt that their healthcare providers were unable to provide relevant information and education pertaining to their diagnosis and recovery trajectory.

Beck indicated that his “GP was helpful but she was kinda like, we can send you to an MRI, but I really don’t know what else to do”. Nina spoke to this frustration as she indicated “every single healthcare provider that I saw said they really don’t know anything about this, like we are making our best guess, we don’t even know how to tell you to treat this”. Nina recalled one specific example when her neurologist said, “I think we are done. I really don’t have anything to offer you and I don’t think you need to see me again”. Further to this idea, Wes shared that “my doctor knows nothing about my brain injury, he doesn’t care”. Here we see that not only family physicians, but also specialists (e.g. neurologists) seem to not have sufficient knowledge pertaining to acquired brain injury. More often than not, these interactions with healthcare professionals contributed to the frustration felt by participants. It also did not allow for the building of trusting relationships to be formed, as the healthcare professionals did not provide appropriate treatment. Similar findings were illustrated in research conducted by Sturge-Jacobs (2002) where participants also became frustrated with their interactions with healthcare professionals. Studies conducted by Falvo, Allen, & Maki (1982), Fitzgerald & Patterson (1995) and Swift & Wilson, (2001) also showed similar findings. As a result, participants felt dismissed by healthcare professionals. Participants interpreted this dismissal and often termination of treatment on the part of the healthcare professionals, as a direct result of their lack of medical knowledge and awareness pertaining to acquired brain injury and how it may manifest. This lack of knowledge is discussed by Chamberlin (2006) and Swift & Wilson, (2001), who reiterate that there is a "lack of a clear and generally accepted understanding" (Chamberlin, 2006, p. 414) of brain injury.

It is interesting to note that even when physicians provided information regarding treatment and recovery, participants reported feeling skeptical of the information being put forth. Ryan shared that "I began to question what he [physician] was saying because I wasn't getting better". As a result, he sought out other healthcare professionals who have more knowledge pertaining to acquired brain injury. As a result, he does not use his family doctor for issues relating to his injury. Other participants have shared in the same sentiment- their family doctors were not knowledgeable and many do not discuss their brain injuries with them. This is problematic as the healthcare professionals are the gatekeepers to care, meaning that, in order to access specialists for individualized care, the initial physician (in most cases the family physician) must initiate the referrals before access can be given (Meekosha & Dowse, 2007). Again, This is troublesome as participants were unable to access or experienced a delay in receiving appropriate care based on the lack of knowledge of their family physicians. This is further illustrated in the study conducted by Landau & Hissett, (2008) where they found that healthcare professionals who neglected to understand or recognize the effects of acquired brain injury could lead to "inadequate treatment and considerable, unnecessary suffering (p. 82) for both the individual and the family members.

Within Canada, there is a two-tiered healthcare system in place for people with acquired brain injury; private and public (Coltantonio et al. 2010). The nature of the individual's injury is the deciding factor of whether or not they will have access to private or public funding. Typically, those who are injured in a motor vehicle accident or a workplace accident received private funding (Coltantonio et al. 2010). An important factor in diagnosis and the receipt of needed services was whether insurance companies (private funding) were involved. Of the nine participants, four had insurance companies involved in their care. The involvement of these insurance companies made a positive difference in how quickly participants received diagnosis and the kinds of care and follow-up they received. Once the insurance companies became involved, participants were more likely to receive a quicker diagnosis. This was in part due to the request for specific tests (e.g. neuropsychological assessments), referrals to specific medical centers and leading specialists in the filed of brain injury. This can be attributed to better and quicker access to an increase of resource pool (Coltantonio et al. 2010). It is important to note here, that some necessary tests are not covered by OHIP (Ontario Health Insurance Plan), and would require most individuals to pay out of pocket. Assessments such as the neuropsychological assessment can range anywhere between $2500.00 - $10,000.00- dependent on the healthcare professional. These fees would be covered by the insurance plans, however if an individual is to become injured in a situation where insurance is not applicable, they are required to pay for these services out of pocket. For some, the sheer expense of these tests is not feasible- especially when most individuals experience instances of unemployment due to their injuries (Webb, Wrigley, Yoels, & Fine, 1995).

According to Webb, Wrigley, Yoels & Fine (1995), the inability for individuals to pay for needed services resulted in minimal improvement and function, and a poorer quality of life.

The four participants in this study with insurance were provided with case managers, neuropsychological assessments, counseling, referrals to clinics, occupational therapists, social workers and other professional healthcare providers. These diagnoses were provided within weeks to months (dependent on the circumstances of their involvement). These forms of resources and access to healthcare professionals are typically provided on a fee for service basis. Participants who were covered under workplace and car insurance expressed that had there not been this additional form of insurance, they would have been unable to access these healthcare professionals and services on their own. This was attributed not only to the financial aspect, but also to the difficulties they were experiencing at the time of diagnosis with coming to an understanding of their diagnosis and their care needs and, consequent to having an acquired brain injury, with cognitively managing their own care. Due to the stress of the injury, individuals may experience diminished cognitive capabilities, which directly affected their coping mechanisms and as a result, affected their ability to manage their care (Wrightson, 1989). It is interesting to note that the participants of this study noted mainly positive experiences and the benefits of the involvement of the insurance company. Coltantonio et al. (2010) found in their study that often insurance companies delayed the allocation of funding and focused mainly on the eligibility process. It is important to note here that despite the potential ineligibility, those who had access to the insurance companies (private funding) received a far quicker diagnosis than those that did not. Coltantonio et al. (2010) also indicate that the delay in eligibility adjudicating may have negative consequences on the individual due to the length of time or ultimate decision that the individual is not eligible for private funding. I would argue here that in the end, these individuals are no worse off than those who were not involved with insurance companies. In fact, I would suggest they may be slightly better off as they were able to access costly and much needed assessments.

Of the remaining five participants, one was provided ongoing care (due to the participant being a young child when the brain injury was acquired). This participant's experience was different from the others as the injury was not associated with insurance. Due to his young age, the nature of the injury and the specialists that were involved, he was provided care until he reached 18 years of age. He did not elaborate as to how his care is different now that he is an adult. The other four participants were provided with limited or no follow-up and were left to navigate the healthcare system and source resources on their own. Nina expressed that she "fell through the cracks". She also made note that due to the nature of her symptoms she would "let the days go by and not take proactive action" not because she didn't want to, but because she was cognitively unable to do so. This is reinforced throughout the literature cited as cognitive symptoms of brain injury pose great challenges.

Healthcare professionals need to have a better understanding of brain injury and how it can affect individuals. The lack of post-diagnosis follow-up and care plans created frustrations for participants. Participants were left to navigate the healthcare system on their own which in many cases proved to be futile as they were struggling through each day. Of the participants who did receive post-diagnosis follow-up and care plans, they were under the direction and care of insurance companies whom had access to the leading healthcare professionals in the field.

Is This Real? Acceptance of Acquired Brain Injury and the Need for Personal Validation

As highlighted above, participants wanted a diagnosis – they wanted to know what was causing them problems. Although all the participants eventually received a diagnosis validating their symptoms, there was yet one more stage of validation they had to endure – acceptance of acquired brain injury and personal validation. Once a diagnosis was provided, all of the participants reported having had a difficult time with accepting the diagnosis. According to Florian, Katz & Lahav (1989), to adapt to the diagnosis of acquired brain injury, the individual must make "internal and external changes" (p. 220). There is a great need for individuals living with acquired brain injury to emotionally accept their brain injury in order to adjust to their new reality (Florian, Katz, & Lahav, 1989). Lynch (1981) puts forth that this can further complicate the individuals' acceptance of their acquired brain injury as there can be a conflict with neurological deficits, past personality and behaviour, existing social demands and responses of the individuals living with the acquired brain injury. As a result, participants felt the need to validate their acquired brain injury for themselves. Ryan expressed "that there was always this denial". He found himself telling everyone about his brain injury as if it was a form of “validation, you know, you are going to tell people so that they can understand and you know yourself you’re not making it up”. Beck voiced his frustration by saying “I don’t even understand it myself, like I all the time think, is this real? Am I really feeling how crappy I’m feeling right now or is this [brain injury] all in my head you know”. This sentiment was influenced by the experiences he had with healthcare professionals “this person has this qualification and this qualification and if you say my symptoms aren’t true and I don’t really understand my symptoms, maybe they aren’t true, so it’s tricky”. Nina shared that receiving a diagnosis “gave me a legitimate, even though it was invisible, I felt like the diagnosis was acceptable and made my symptoms legitimate”.

Participants reported that their physical appearance played a role in their acceptance of their brain injury. Much like their experiences with healthcare providers, by looking physically well, it was more difficult for them to accept that there was something wrong and to accept the diagnosis. Nina expressed that “one of the major challenges is that I can’t see it… if they could do an x-ray or I could see it… because it’s invisible I never know where I’m at”. This phenomena was also reported by Sturge-Jacobs (2002) where the findings also demonstrate that there was a “dilemma of how well they [participants] looked in relation to how unwell they felt” (p. 29) thus causing challenges pertaining to acceptance not only for themselves but also for their family.

Interestingly, a number of participants experienced physical injuries at the time of their injury. Physical injury combined with diagnosis of brain injury provided a cause and effect understanding for these participants, which made space for a marginally easier acceptance of the acquired brain injury. Nonetheless, they still reported having had a difficult time in the acceptance of their diagnosis.

In their search for understanding and validation, participants also took it upon themselves to seek out additional information and resources, as well as other individuals living with acquired brain injury. This was in part due to the limited knowledge healthcare providers relayed to the participants pertaining to recovery trajectories, symptoms and general information. The use of online resources such as sports and brain injury forums were used which allowed for conversations with individuals sharing similar experiences (Darragh, Sample, & Krieger, 2001). Participants also sought out acquaintances and friends with acquired brain injury as well as accessed brain injury support groups within their respective communities (Darragh, Sample, & Krieger, 2001; Schwartzberg, 1994). Although participants received some validation through diagnosis, the limited understanding of acquired brain injuries on the part of their healthcare professionals created uneasiness for the participants. Through contacting other individuals with acquired brain injury, participants felt they were able to validate their diagnoses, symptoms and experiences through hearing similar experiences to their own. These experiences echoed similar findings presented in a study conducted by Schwartzberg (1994). The results from this study showed that the use of peer-support groups enabled individuals living with acquired brain injury to feel legitimized. This allowed for legitimization of symptoms, diagnosis and experiences (Schwartzberg, 1994). In addition, Bogan, Livingston, Parry-Jones, Buston, & Wood (1997) also indicate that interactions with support groups and peers has a positive effect on individuals and their level of understanding and accepting their acquired brain injury.

As we can see above, although participants did express they knew something was wrong with them, they looked to healthcare professionals to both define and legitimize their experiences and symptoms. This in some ways does make sense. We are not all physicians and thus require a physician’s knowledge to help us understand illness and injury, however this goes further. As mentioned earlier, there is a “lack of clear and generally accepted understanding” (Chamberlin, 2006, p. 414) of acquired brain injury. As a result, individuals who are living with acquired brain injury can be without a “legitimating discourse from the authoritative medical profession” (Chamberlin, 2006, p. 414). In the absence of legitimizing discourses, individuals living with acquired brain injury may need to create an alternative identity.

In Foucault’s analysis of truth, “truth ‘does not reside solely in the subject’ but requires an external source of approval or authorization for its completion” (Foucault 1997, p. 66). This speaks to the kinds of knowledge we privilege and who we believe to hold that knowledge. Therefore, the truth and validation of the participants’ experiences could only be established through the relationship between the individual and the physician. Only the physician could legitimize what participant’s recognized as something “not right”, and the symptoms they reported to their doctors. Participants’ knowledge would be rejected unless those who are in a position of power validated their knowing; in this case a physician who is the only person deemed capable of making a diagnosis. In many instances, this validation was hard won as physicians did not always see or believe what participants were telling them. This led not only to a lack of needed care, but also to self-doubt and questioning of one's own knowledge. Despite participants' struggles in achieving a diagnosis, the eventual diagnosis of brain injury was a welcomed event.

You Aren't Brain Injured! In-validation by Others

In disclosing the diagnosis to others, participants were met with disbelief. Within society, we have developed ideas of what it means to be brain injured. These ideas for the most part have been influenced by the dominant discourses that shape the way in which we view and understand disability and acquired brain injury (Linden & Boylan, 2010). These discourses can be found in the way media represents disability and in this case brain injury. Within the media, disability is often portrayed through a limited number of stereotypes, which can have negative consequences for those that experience disability and acquired brain injury. In a study to examine public understandings and misconceptions of acquired brain injury, Linden & Boylan (2010) identified that the media plays a powerful role in shaping the dominant beliefs of what it means to be brain injured. Participants of their study indicated that advertising campaigns were a large influencing factor of their current beliefs of what it means to be brain injured- completely handicapped, in need of 24-hour assistance and unable to recognize their surroundings (Linden & Boylan, 2010). These media images, often "extreme images can provide an unrealistic window" (Linden & Boylan, 2010, p. 647) to others as to what it means to be brain-injured and their lived experiences. As a result, often individuals within society rely on these dominant discourses and representations to shape the way in which they understand acquired brain injury and more broadly, disability. Unless one has had first hand experience with the brain injured population, there is limited knowledge available to challenge and reshape these beliefs (Linden & Boylan, 2010).

Throughout the interviews, all nine participants indicated that when they disclosed to others they were living with an acquired brain injury, they were met with disbelief. Again, it is important to reiterate that these participants had no visible identifying factors that one might readily attribute to conventional understandings of impairment and disability. This invisibility played a key role in the perceptions and reactions not only of healthcare professionals, but also to friends and family whom the diagnosis was disclosed to. Throughout the analysis of each individual participant experience, three main assumptions were identified. In order to be living with brain injury, one must only be able to live and function with assistance, be unable to function at a 'normal' level, and have an additional visible physical impairment. These three issues are illustrated in the following excerpts from the interviews with the participants.

When speaking with Daisy and Thomas, they both shared similar experiences when they disclosed their acquired brain injury to others. Daisy indicated, that "[people] don't know what brain injury really is" and as a result, she has often been told/asked "if you have a brain injury, doesn't that mean that you should be in a coma or something right now?" This further confirms the findings of Linden & Boylan (2010) of the misconceptions of the general public pertaining to acquired brain injury. Thomas also expressed that people have said that he "should be in a home" and "locked up with other people”. Again, Thomas’ experiences were illustrated in the findings of Linden & Boylan (2010) where participants also shared a belief that individuals living with brain injury are dangerous, a menace to society and can be “more violent, unpredictable, aggressive and demanding” (p. 648). These less-positive views were also confirmed by Linden & Crothers (2006). Their research illustrates how the general population shares a common belief that those living with an acquired brain injury must be reliant on others for care, are unable to care for themselves and live independently, and can be considered dangerous themselves and/or others (Linden & Boylan, 2010; Linden & Crothers, 2006).

In a related vein, Beck, Wes and Nina, shared similar experiences. Beck expressed that when he discloses his disability, people often respond with “ I never thought I could have a conversation with someone with a brain injury”. Wes also mentioned that, “I find often though because I cope so well day-to-day and I can be quite articulate, I find that people don’t want to believe me”. Further to this, Nina expressed that “I think some of them were skeptical” in reference to her disclosure of her injury to classmates. What these three participants illustrated was the fact that because the general public appears to understand acquired brain injury as being so significantly debilitating as to require intensive and intrusive supports (Linden & Boylan, 2010), those with invisible acquired brain injury who look ‘normal’ are often not believed to have an acquired brain injury. The cognitive nuances of their brain injuries were ‘minimal’ in the eyes of others; therefore they are understood to appear ‘normal’ and thus not brain-injured. This appearance of functioning at a ‘normal’ cognitive level did not coincide with the common belief of how a brain-injured individual should function.

Ryan, Christa, Jack and Paul support this idea when they discussed how reactions to their disclosure are primarily based on visual perceptions of their physical selves. Ryan indicated, “people don’t believe you. They look at you and there’s nothing wrong”. Christa expressed similar sentiments; she shared “ because of the way I look… I look completely normal… and it’s like they don’t understand”. Jack also says “people with an invisible disability, a lot of the time it can be seen as, well you must be faking it. I’ve gotten that numerous times”. In addition, Paul also shared this belief by saying, “you look okay, you sound okay, you act okay therefore, you are okay”.

As a result, their feedback hinges largely on the dominant construction that disability, in this case acquired brain injury, can only be defined and recognized if it is visible. Interestingly, all participants felt the need to provide varying degrees of education to others regarding their brain injury. Participants noted that even when they provided the education, those they disclosed to, typically conducted their own research to confirm the information that had been imparted to them by the participants.

These common beliefs can be tied to the ever-governing and ever powerful discourses of disability as articulated in the medical model. Within this perspective, disability is seen as “a structural or functional impairment - a negative deviation from “normal” (Gill, 1987, p. 50). Due to the invisible manifestations of the participants’ brain injuries, participants have the unique ability to pass as ‘normal’, thus confounding stereotypic understandings of impairments and disability. Moss and Dyck (2002) explain that individuals with invisible manifestations of their symptoms are “‘in between’ hegemonic discourses – not quite ill but not quite healthy, almost disabled and almost abled, both very nearly normal and very nearly deviant" (p. 33). As we have seen, this has been a challenge for the participants and challenges with 'passing' can occur where the individual is not believed, their concerns are not taken seriously which results in a lack of proper care and supports (Chamberlin, 2006; Landau & Hissett, 2008; Lingsom, 2008; Samuels, 2003).

An important finding of this research is that although participants felt a sense of relief and validation when their symptoms were legitimized, there was this undercurrent that in some instances it would be better to "pass as normal". This "passing" would allow for participants to be treated as 'normal'. Paul shared that "sometimes you want sympathy, sometimes you want to be like everyone else in the classroom type thing and you want to be treated regularly". Paul then went on to explain that having his brain injury manifest as invisible is "like a shield" and you can decided when to use this shield or not. Jack shared similar thoughts and shared that he could "turn it off when I want and… I have the choice of telling people or not". Other participants shared in the same belief that having their brain injuries manifest as invisible offered a level of protection against the stigmatizing beliefs of others. It was recognized by all participants that this was a luxury not all individuals with visible impairments and disability could have. This finding is supported by the literature on passing where being in control of how one is seen by others is a privilege within itself (Darragh, Sample, & Krieger, 2001; Green, Davis, Karshmer, Marsh, & Straight, 2005; Joachim & Acorn, 2000). Participants also spoke to how they sometimes chose to navigate daily life as a 'normal' person; many believed that others did not need to become aware of their injury. This further confirms the findings of

Goffman (1963) who put forth that those who have invisible manifestations would choose to pass at some point or other. However, while passing can be considered as a benefit, passing can also be counterproductive. Those who choose to pass run the risk of becoming ‘outed’ (Goffman, 1963). As a result of not being forthcoming, those around them may feel that the individual has been deceptive and therefore not trustworthy (Goffman 1963; Lingsom 2008). In addition, choosing to pass may impact the kinds of services provided to individuals. Daisy, who could pass, shared that often when she disclosed the services she has accessed, others would question her as to why she is able to access these services thus necessitating she disclose her brain injury. Other participants shared that they were not provided services because they appeared to be ‘normal’ thus having negative consequences on their recovery and daily life.

If we take a step back and reflect on one of the historical reasonings by which the medical model was put forth, we can understand that this model was used to ensure that ‘normal’ people could no longer deceive others into thinking they were disabled; thereby ‘catching’ those who were malingering (Chamberlin, 2006; Iezzoni & Freedman, 2008). The invisible manifestation of brain injury challenges this very belief: while at face value, there may seem to be *nothing wrong* with these individuals (and therefore they should be contributing to society), in truth, acquired brain injury has been found to be a significant injury, resulting in particular challenges for those having experienced it and requiring medical and other interventions.

As my research has shown, dominant perceptions and constructions of what it means to be brain injured and disabled have impacted the lives of the participants. This can be seen through their interactions with healthcare providers, ascertaining a diagnosis, and the processes of self validation and validation by others. As a society, we have been taught to believe “that, by attending to visual and/or auditory cues, it is easy to tell who belongs in which category” (Stone, 2005, p. 294). The hegemony of dualistic thinking tells us that one is either disabled or one is not (Stone, 2005). As a result, we then judge these individuals based on conventional standards. This notion does not take into account that those who may appear ‘normal’ may be struggling with unseen and difficult to articulate symptoms. As a result, this hegemonic and dualistic ideology creates a problem for the participants with invisible symptoms of acquired brain injury. To reiterate the findings of Moss & Dyck (2002) - individuals with invisible disability are “almost disabled and almost abled, both very nearly normal and very nearly deviant” (p. 33). The dualistic thinking of disabled/abled creates a problem. Those with invisible symptoms find that they do not fit within the “neatly pre-defined categories” (Stone, 2005, p. 294). Individuals with invisible manifestations must constantly challenge this dominant dualistic hegemony or they will continue to live within an in-between stage where they are not quite disabled and not quite normal.

Changing the Family Dynamics

Literature reports that acquired brain injury is one of the most difficult injuries for families to come to terms with (Florian, Katz, & Lahav, 1989; Green, Davis, Karshmer, Marsh, & Straight, 2005; Landau & Hissett, 2008). When a family member becomes brain injured, the family is faced with adjustment periods and develops coping strategies to mitigate the effects of the injury (Florian, Katz, & Lahav, 1989). As a result, changes to family dynamics may occur. All participants within this study noted changes within their family dynamics and relationships associated with acquired brain injury. There is nothing that can prepare one for the changes that can result from acquiring a brain injury. This is consistent with the literature, which notes that with the sudden reality of decreased functions, limitations and loss of self, relationships within the family are vulnerable to change (Laroi, 2003; Brooks, 1990). Findings of this research show that participants experienced changes in the following highly interconnected ways: a shift towards caregiver love, strengthening of relationships, and the deterioration of relationships. What is important to note about these changes, is that they are not something that the participants typically wanted or that families had previously discussed: the changes to relationships were forced upon the participant and their families. These shifts, as noted in the disability literature, can lead to many challenges and struggles for the person with the disability (Hughes, McKie, Hopkins, & Watson, 2005).

It should also be said that the definition of “family” varied from one participant to the next. Dependent on the stage in life when the brain injury was acquired and individual circumstances, participants defined and gave weight to family differently. For example, some defined family in relation to whom they were currently living with. For some, family was comprised of a significant other (common-law spouse, boyfriend/ girlfriend), parent(s) and sibling(s) or friend(s). This is not to say the brain injury did not affect relationships the participants had with others who did not live with them (as participants showed it did to some extent), only that this group was not then defined or understood to be family and were thus not the focus of this study. The greatest impacts and changes to the family relationships were associated with who was involved at the time of injury and involved post-injury. Nonetheless, throughout the analysis of interview transcripts for all of the participants, many changes to family dynamics as a function of their acquiring a brain injury were uncovered.

Changes to the Nature of Relationships

For all participants, the diagnosis of brain injury was believed to have played a fundamental role in shifting pre-existing and current relationships. It is important to note that the changes of relationships and possible relationship breakdown are not dependent on the level of trauma the individual experienced (Landau & Hissett, 2008). Participants experienced changes to these relationships in a number of ways. Some participants interviewed readily indicated that there was a definite shift from their previous relationship with one or more family members to a caregiver-cared for type of relationship. Other participants initially denied experiencing any such change, however, this was not reinforced over the course of their interview. In fact, those who did not openly acknowledge a caregiver-cared for type of relationship referenced this form of change multiple times. This change was necessary for participants as their new limitations and symptoms of acquired brain injury affected their capabilities, thus resulting in additional support from their family members. Although this change was reported to be necessary for participants it was also frustrating as these changes reinforced the loss of self that participants were also experiencing as a result of the acquired brain injury. This appeared to be very frustrating to participants. This shift also appears to be implicated in the strengthening and/or deterioration of relationships. These changes could be experienced independently of one another (within different relationships) or experienced at once within the same relationship. It is important when considering these particular findings to remember that all of the participants of this study are adults, ranging in age from 24 to 64 years. This is important because when one is suddenly put in the position of care-receiver as an adult, the experience is different than receipt of care as a child and typically adult relationships had previously not been associated with caregiving. These care giving/ care-receiving relationships are fraught with different meanings, experiences and relations of power (Williams, 2001).

In speaking about his wife, Beck conveyed

> "for a while there, she was more of a caregiver than like a spouse so we kind of took on a different relationship and a different dynamic to it and like the romance and the excitement isn't there as much because it is more like she is doing it almost sort of like a motherly love".

Beck later went on to explain that they "had to consciously try to renew, we have tried to consciously do stuff again to cultivate much more of like what a marriage should be as opposed to her taking care of me". Here, Beck experienced a shift from a marital relationship towards a caregiver-cared for relationship. While initially stressful, with conscious effort on the part of he and his wife, they were able to achieve an eventual strengthening of the marital relationship.

Ryan expressed that his wife, too, had taken on a caregiver role and noted that she would "be a better voice for my health and for me at times", "keep me in check" and advocate on his behalf. Ryan was aware that this shift was, in some ways, useful and necessary – her advocacy on his behalf was helpful. He expressed that he was thankful for her support and willingness to do what was best for him even when he did not realize it at the time. When family members take on caregiving roles, the results can be beneficial to the affected individual (Martire, et al., 2004). This can allow for the reduction of stress and anxiety on the part of the individual (Martire, et al., 2004). Throughout the interview, Ryan also expressed that although there were some initial struggles, their relationship had strengthened over time.

Nina experienced a shift towards her parents and her fiancé taking on more of a caregiving relationship with her following her injury. However, she shared that as a result, her relationships with them were also strengthened as well. “Once I got the diagnosis, my family was really understanding. They wanted me to rest and they were really really worried about my brain”. Her family members all took on the caregiver role, “telling me over and over again that now is not the time to work, now is not the time to worry about school, you need to rest”. Her fiancé also ensured that she took “good care of myself” and he “help[ed her] to make good decisions around my recovery”. Here we can see how family support can be positive. Given & Given (1991) suggest that involvement of family in support of affected individuals can be positive as they typically want what is best for their loved one and will often go to any means possible to ensure they receive adequate support regardless of whether they can provide it or not. Nina also voiced that, “we were forced to really evaluate our relationship… and have a lot of really big conversations”. They also “had to face some pretty big challenges together but in the end it’s brought us closer together”. Nina indicated that her and her partner moved from a common-law relationship and in the end became engaged. Some of the challenges faced were related to their financial situation, as Nina was unable to contribute to the household income. This was a direct result of her injury as she was incapable of working due to the nature of her symptoms.

Strains on relationships are common following an acquired brain injury. This is in part due to the “loss” of the individual as the family knew them (Landau & Hissett, 2008; Laroi, 2003). What this means is that those that are close to the affected individual often have a difficult time realizing their family member has changed. This is largely influenced by the invisibility of their symptoms. This lack of recognition often leads to the “breakdown of couples, parental and family relationships” (Landau & Hissett, 2008, p. 71). In a study by Wood & Yurdakul, (1997), they noted relationship changes in almost half of their participants. Changes included divorce, calling off an engagement and the termination of common-law relationships. Although most literature highlights the breakdown of relationships, we can see here that Nina’s situation is different. Nina and her partner experienced a strengthening of relationship and experienced a positive relationship progression and the shift to caregiver-cared for relationships that followed Nina’s acquired brain injury worked only to strengthen existing family relationships.

Daisy indicated she was “the baby of the family” prior to her accident. She indicated that her family took care of her prior to her injury however after the incident, she noticed an increase in her family becoming more “protective and everything”. She went on to say that after some time she felt “they returned to normal”, to the same level of care she experienced prior to her injury. At the time of the injury, she understood why her family took on more of a caregiver role, however she indicated that they would often forget that she could do certain tasks, and would not expect her to be capable of performing the same kinds of tasks as before her injury. Consistent with the literature, this caused some frustration for her (Kelly, 2012). Now, Daisy says her family "has a strong relationship" and they "continue to get stronger". For Daisy, this strengthening of her relationship is, in part, attributed to her brain injury and also attributed to the strength of her relationships prior to her injury.

Having a family member take on a caregiving role was not always wanted, nor did it always result in a stronger relationship. Christa expressed that prior to her injury, she had a rocky relationship with her mother, was estranged from her father, and had a difficult relationship with her brothers. She expressed that she believes her family is "out to destroy her". After her accident, her mother stepped in as a caregiver, however, after only nine months, her mother "abandoned" her to live with her new boyfriend. Christa believes that the reason behind her mother initially taking on this caregiver role was not about love, but due to her belief "that my mom has Munchausen's by proxy". Pointing to the complexity of human relationships, and in some ways challenging disability literature that understands 'care' as an unwanted and negative experience for people with disabilities, Christa's experience of her mother's caregiving was ambivalent. Christa expressed that she was both angry and saddened by the end of this relationship. It appears that, on some level, she was desiring of the caregiving, however she was not surprised as she had always had a rocky relationship with her mother. Although Christa experienced a temporary shift with her mother assuming a caregiver relationship, her familial relationships in the end remained unchanged and largely unaffected by her injury.

Like Christa, Wes also had a rocky relationship with his mother. Once his mother found out about his injury, his mother stepped into a caregiver role, which was not readily accepted by Wes, and she was turned away. This lack of acceptance was in part due to a tumultuous and fractured relationship that had not been addressed or repaired. This was not his only relationship that was impacted by the acquired brain injury. At the time of Wes' injury, he was in a long-term relationship. Shortly after his return home, the relationship fell apart. Wes reported that "[the relationship] already had a lot of tension in it. After my brain injury, for awhile things were okay and then those tensions resurfaced and I didn't have the ability to deal with them and neither did [my partner]". Further complicating the situation, he could "no longer have an intimate relationship". Here, Wes illustrates that having an acquired brain injury exacerbated existing tensions within his relationship that ultimately led to its breakdown. The experiences of Wes and Christa are aligned with the findings of Wood & Yurdakul (1997). Although there was a breakdown on an intimate relationship level, Wes and his partner continue to be close friends. After the breakdown of this relationship, however, Wes was able to experience a positive relationship with a family member who assumed the caregiving function in a helpful and welcome way. Wes spent time with his aunt, who provided him with a "very strong family environment, very supportive, very understanding and let me progress at my own rate". At this time, his aunt "took on a caregiver role and gave me that time to heal".

These changes to relationships with family members, however, are not always simply ‘good’ or ‘bad’. Thomas experienced an initial strengthening of family relationships and, on the part of his mother, an eventual shift towards a caregiver relationship. Like Christa and Wes, Thomas did not have contact with his family prior to his accident.

> “After my accident, I talked with my family a lot and then I didn’t talk to my brother again at all and then I spoke with my dad briefly for short period of time and then I stopped talking to him and then I spoke with my mother constantly”.

While his relationships with his brother and father deteriorated, related to pre-existing issues, that with his mother has changed for the better. Currently, Thomas’ mother is “very much part of my life since the day of my accident”. She is also involved in all aspects of his care and has taken on the role of caregiver despite Thomas being able to live independently. Thomas indicated that he is thankful for the involvement of his mother within his life and he appreciates all the help and support she provides. Nonetheless, he did also indicate that she needed to learn to take a step back and allow him to manage his life more freely. Consistent with the literature, for some of the other participants, the receipt of care was often both welcome and needed, it was not something to be resisted (Fudge Schormans, in press).

Paul reported an interesting experience of this shift by a family member to a caregiving role, one that appears markedly different from that of the other participants. At the time of Paul’s injury, he was divorced with three grown children. He reported that prior to his injury, he had a close relationship with his children whom often referred to him as the “world’s greatest dad” to their friends. Due to an insurance payout, Paul has seen the relationship between him and his children change: “they [my children] are coming to me for money instead of for me…for the relationship.” This has caused some deterioration in the kind of relationship they share as the children are currently not valuing the emotional relationship have with their father. Paul expressed that this was disappointing to him, as he would like to have a relationship that was not based on money.

Currently, Paul’s youngest daughter has stepped in as the caregiver and is living with him. Paul shares that “she is relishing the role of looking after her dad for the moment, but I actually clean the dishes in the morning, fold the clothes and clean the floor so I don’t know who is looking after who”. Paul indicated that his daughter does do some cooking, however, this is typically at one in the morning when he is sleeping. In some ways, Paul does feel that she has taken on this ‘caregiver’ role for the wrong reasons and is taking advantage of his generosity. Although there appears to be a caregiver role assumed by his daughter, there still continues to be a caregiver role associated with Paul – with that of still parenting the daughter living with him. It is not clear if in actual reality his daughter has taken on a caregiver role in the true sense, or in the sense that Paul might be hoping for, and the motives behind her decision to act as a ‘caregiver’ are unknown at this time.

The changes Jack experienced within his family are slightly different in comparison to the other participants. Jack was diagnosed with his brain injury at the age of seven. Jack indicated that “we’re all very close” in relation to his family. Jack did note that

> “it was like a shift between, you know, there was me, my mom, my dad and my sister. My dad and my sister stayed together and my mom and I stayed together… [my sister] was banded with dad, and my mom and I, my mom was there for me when I needed her and she was the one supporting me”.

Jack has noted that after his injury his “parents became more hyper vigilant and were trying to fight my battles for me” they also “coddled” and “pampered me a lot”. He also indicated “they were there to support me, maybe too much sometimes”. Jack’s experience reflects the concerns highlighted in the disability literature about the negative impacts of ‘care’ for people with disabilities, rooted in dominant discourses about the vulnerability of people with disabilities (Hughes, et al., 2005). He expressed that if he has not had an acquired brain injury, his parents would have not acted in this way. This belief was based upon the stark difference between how his parents act with his younger sister. As Jack has grown, there have been changes to the relationship that he understand to be are purely related to his age and maturity. Despite this growth, he believes that his mom still has this image “stuck at the back of her mind thinking about how you know, what if he doesn’t make it”. This has affected their relationship where she has taken an increased worrying role and may be more protective of him than she would otherwise have been. His father has “supported me on everything that I wanted to do even if he was worried, he knew logically that he could connect with me”. Here, this appears to show that his father has stepped away from the caregiver role and is allowing space for autonomy and personal growth. It should be noted that Jack does not feel his relationship with his sister has changed in any way as they are very close to one another. Throughout the interview, Jack expressed that although there may be differing opinions, he is very close with his family and this experience of acquired brain injury continues to strengthen their relationship.

Negotiating the Roles

As been previously discussed, acquired brain injury can affect the kinds of relationships one may experience. These changes feed into reshaping the pre-existing roles that were found within families. According to Lefebvre, et al., (2005), families have a difficult time adapting to new situations. When brain injury occurs, it does not only disrupt the life of the affected individual, it affects all members. “The organization of the family, the roles of each member, activities and habits are shaken up and questioned (Lefebvre, et al., 2005, p. 594). As a result, the family equilibrium is placed in a volatile state and new roles must be identified and negotiated. Sometimes involved in this process is a grieving stage for the family members and the affected individual, as in order to make these changes, they must accept these new limitations (Kreutzer, Kolakowsky-Hayner, Demm, & Meade, 2002; Landau & Hissett, 2008; Lefebvre, Pelchat, Swaine, Gelinas, & Levert, 2005; Laroi, 2003).

Within the family unit, one can identify hierarchies and structures that influence the ways in which roles are assigned to family members. A role can be defined as “an integrated and socially determined set of beliefs, values and expectations that define how one ought to behave” (Laroi, 2003, p. 179). Within families, there are often expectations that are placed on one another concerning roles and responsibilities relating to domestic duties such as household maintenance, financial responsibilities (including generation of income), and parenting (Kreutzer, Kolakowsky-Hayner, Demm, & Meade, 2002; Laroi, 2003). Often, when one member of the family becomes brain injured, a renegotiation of the familial roles soon ensues. Having particular family members assume a caretaking role was not the only role that necessitated renegotiation. It is important to note that the reaction and role change of the family members is dependent on the relationship established with the individual prior to the injury (Kreutzer, Kolakowsky-Hayner, Demm, & Meade, 2002; Perlez, Kinsella, & Croww, 2000). Evidence also shows that the changes are harder for spouses to accept in comparison to parents, especially pertaining to caregiver-care type roles (Kreutzer, Gervasio, & Camplair, 1994a; Kreutzer, Gervasio, & Camplair,1994b; Kreutzer, Kolakowsky-Hayner, Demm, & Meade, 2002). In addition, Banks (2003) found that typically the woman would assume the caregiver type role over the male.

A challenge that was experienced by all participants was the changing and negotiating of roles within their family. Roles were constantly changing and being adapted to new limitations or new gains in the participant's ability. Within the study, participants spoke to role changes pertaining to domestic roles, financial roles and emotional roles. Although the role changes within the family were necessary at the time of injury, participants shared that these role changes should not be fixed in stone. Roles continued to adapt over the course of recovery, and as participants saw gains in their abilities, they indicated that they readily took on more responsibility.

Domestic Roles

Ryan shared that "I was spending the day at home and I was essentially doing nothing at the beginning, she was doing all of that and then I, I start doing more of the household chores". He also explained that "I would do what I could" and that "I could still do bits of things at a time and then as I got better, I would do more of the household stuff". This created a significant change in his wife's role, as initially she took on more and these expectations were new to her. At the same time, this initial lack of responsibilities and then shifting to new responsibilities were new for Ryan as well. Ryan expressed that his wife found these new responsibilities hard for her as well as frustrating. This is similar to the findings of Kreutzer, Kolakowsky-Hayner, Demm, & Meade, 2002 where they found spouces experienced increased frustration pertaining to their new roles. Ryan also felt frustrated resulting from his inability to contribute to the family. Due to the nature of his symptoms, often he would start something to help in the home, but then his symptoms would become aggravated resulting in incomplete tasks and setbacks. Here we can see evidence of the willingness to take on more roles within the home and contribute more to the family. Due to the nature of the symptoms, often this is not possible for the individual to always complete and therefore impacts the kinds of roles the individual can take on.

Beck also experienced similar changes within his family as there was a fundamental shift in what he could do prior to and after his injury. As a result, his wife does things "she doesn't really like to do" and he is unable to mitigate these effects. Beck expressed that he wished that he could do more however due to the nature of his injury, he is unable to do so. Beck reported that he too feels frustrated and guilty for not helping his wife. He reported that it is difficult to live the life of a "75 year old retired guy" at the age of 33. This is an interesting finding as one could speculate that here there are feelings of being less able and an increase in dependency on others. This is also interesting that Beck compares the symptoms to aging, and attributes more negative stereotypical roles to changes associated with it.

Emotional Roles

As a result of Wes' acquired brain injury, he indicated that he has difficulty with maintaining personal relationships. He indicated that this is the result of his inability to "develop this greater knowledge of my partner". As a result, he indicated that

> "she [his partner] deserves better and I know that's a relationship reflex too when people want out, and I don't really fucking mean it because I really don't want out but I love her more and I want to give her what she wants, I just don't have that, I no longer possess the ability to anticipate my partners needs".

Here, Wes seems to express emotional tension and conflict about whether to stay in the relationship or not. It appears that he wants out, when in fact he does not. His inability to develop a greater knowledge of his partner and to anticipate her needs, has hindered his ability to maintain the kind relationship he desires and the one that he believes his partner deserves. To help the reader understand, in the interview Wes compared his life to the popular movie "50 First Dates" (Segal, 2004), where the main character is unable to make new memories. As a result, he finds that he is unable to remember important things like how his partner is feeling, if she is sick, and if they have plans together. Here we can see how the brain injury has affected his emotional role with his partner and played into his feelings of inadequacy. These kinds of symptoms are consistent with the symptoms of acquired brain injury. This experience speaks to the difficulty to effectively manage one's own symptoms and the negative consequences it may have on others. Similar findings were found in the study by Wood & Yurdakul (1997), where the impact of acquired brain injury on relationships proved to be too difficult for relationships to weather; ultimately resulting in the relationship break down.

Jack experienced an emotional role shift with his mother but not with his father. Jack feels that he has had to “step-up” and become the more logical voice in his relationship with his mother and, as a result, he has taken on a parental role with his mother – attending to her emotional needs. Jack explained this by saying that often times his mother “can’t see past that emotion aspect”. This change is in part due to what he perceives to be the belief in the back of his mom’s mind of “what if he doesn’t make it”. As a result, Jack “shares more openly with my mom… I know she will struggle with knowing that I am doing certain things… it’s good for her”. Some examples provided centered around independence such as driving or playing sports. Here he demonstrated how a parent often does things that their children struggle to understand to teach them and provide emotional growth; he feels compelled to do the same for his mother. Here, we can see how this connects back to the difficulties of needing care and protection by being seen as vulnerable. What is interesting is that his mother seems to regard him this way, and while this may work to reinforce negative ideas about ‘care’ for people with disabilities, it is also interesting that he does not seem to really see this as limiting. Jack still does the things she doesn’t want him to do, but he has now added the task of taking care of her.

In some cases, roles may change, however this change is not necessarily influenced by the acquired brain injury. In Jack’s case, as he has aged, his role within the family has changed. These changes can be attributed more to his emotional growth and increasing autonomy than to the acquired brain injury itself. He shared that his relationship with his father is a "friendship first and a parental component second" – he requires less and less care from his father thus allowing them to find a space for a different kind of relationship than they previously had.

Negotiating shifting emotional roles were the hardest for participants to accept because the chance of regaining of post injury self was minimal (Florian, Katz, & Lahav, 1989; Laroi, 2003). Regulation of emotion, reading emotional and social cues, and providing emotional support are tasks that participants found very difficult. Often they could no longer attend to the emotional needs of their family members, read situations accurately and manage their own emotions. This contributed to the breakdown of some relationships as well as caused increased tensions and frustrations (Wood & Yurdakul, 1997).

Financial Roles

Both Paul and Nina provided examples of how financial roles have changed within their families. Nina indicated that her partner had to take on more of the financial responsibilities in their relationship. Due to her injury, Nina has been unable to go back to full-time work. Her partner "has had to step up and be the breadwinner in the family and it is really stressful for him, like he's not really comfortable with being the sole breadwinner". This is supported in the literature as often disability results in negative changes to one's financial security (Laroi, 2003). Due to their financial situation and the stress of this new role on her partner, it has “put a pressure on me to go back [to work], pressure to move out of this position financially”. Here, Nina is speaking to her resistance of the pressing desires and beliefs of others (that she is ready and capable) to return to work. Due to the nature of her symptoms, she does not feel she is able to return at this time knowing the current negative financial impacts her acquired brain injury has on her family. Pressure to return back to work is a consistent finding within the literature. Often the affected individual contributes financially to the family unit and with the reduction in financial resources some families may face hardships. As a result, families often put pressure on the individual to return to work sooner than they are able to (Hibbard, et al., 2002; Kreutzer, Kolakowsky-Hayner, Demm, & Meade, 2002; Landau & Hissett, 2008).

In speaking to how his relationship with his children has changed, Paul expressed that “I don’t like my role anymore because they were coming to me for money instead of coming to me for me”. Prior to his accident his children came to him “for a bit of money but they were coming for the relationship”. This change in roles has led him to experience “a sort of strange relationship and a strain on the relationship”. This is an unusual shift- how, like in Nina’s case, acquiring a brain injury is more often associated with a negative change in one’s financial situation, and often creates multiple challenges for people (Laroi, 2003). Paul’s situation seems less common. While he is in some ways in a better financial position, he still experiences significant stress in his relationships as a function of a change to his financial situation attributed to the acquired brain injury.

Most participants of this study voiced that they found it difficult to accept the new role changes that occurred in their families. They spoke to the frustrations and guilt they feel over not being able to regain the family roles they held prior to their injury and most participants voiced strong desires to "return to normal". Similar findings were identified by Landau & Hissett (2008) where their participants also reported "feeling very guilty about their new "diminished" role within the family or partnership (p. 74). Although some (but not all) participants have regained the ability to assume more responsibility for certain aspects of these roles, the changes that have stemmed from their injury are still bothersome. Participants expressed the desire to take on more and to do the same things they were able to before. They reported feeling guilty about doing much less than previously and, in a roundabout way, forcing family members to take on more than their fair share. Some participants expressed that on the days that they felt good; they would take on more responsibility. Unfortunately, many times when this was done, they would regress as either the cognitive or physical effort was too much for them to handle.

Challenges Resulting from Unrealistic Expectations and Misconceptions

As discussed earlier, typically members of the participants' families shared in the dominant understanding of what it means to be living with a disability and living with an acquired brain injury. This resulted in family members having misconceptions and unrealistic expectations of the individuals (Swift & Wilson, 2001). These misconceptions and expectations can cause friction within the family and increase tensions and frustrations. This is consistent in the literature as it indicates that family members might feel that the individual is intentionally malingering, deliberate in their actions or lazy (Landau & Hissett, 2008; Laroi, 2003). This is more evident in instances where the acquired brain injury is invisible and the family does not have an adequate understanding of the nature of the injury (Landau & Hissett, 2008).

All participants of this study expressed their frustration regarding the expectations family members had of them. They attributed this to the invisibility of their symptoms and the limited knowledge family members had pertaining to acquired brain injury. Similar findings were found within Stone's (2005) research with survivors of stroke. Stone's (2005) research highlighted that the invisibility of the brain injury influenced the ways in which others perceived survivors, including family members. This resulted in unrealistic expectations being placed on the individual. In addition, the study found that those who are close to them often forget that the individual has any disability at all (Stone, 2005). From the participants' interviews, it appears that this limited knowledge – when combined with the inability to see brain injury – contributes to the challenges and changes that may take place within the family.

Within Paul's family, prior to his injury he was seen as the "rock" of the family – he provided emotional support to his children and was constantly available to them. Paul shared that "so you know I'm the rock that they'll lean on so they can't accept the rock maybe has a fracture in it, you know". This spoke to his inability to maintain the same kind of relationship with his children. When speaking of his symptoms, Paul shared that "my kids seem to think it's a game and an act. I wish that it was, and it has been pretty tough that way because they have a very low tolerance for my mistakes". He then goes on to say

> “sometimes you get the least benefit from your family because they think they know you. Well, they think they know you well but they don’t know the new you so they assume that it’s the old you pretending to be the new you which is very hard”.

Paul’s experience seems to match that cited in the literature, as it would appear that from Paul’s perspective, his children’s lack of understanding of his acquired brain injury has important effects on how they respond to him and, consequently, on their relationship. There seems to be a lack of acceptance of the real impacts of his acquired brain injury on his day-to day life and as a result, his children are unfairly expecting him to be as he was. This is also evident when it was earlier noted that his family could not accept that maybe “the rock had a few fractures”. Here, we can see how the children’s beliefs of brain injury play into their acceptance and understanding of the changes. This lack of acceptance and understanding contributes to how they respond to their father.

Participants of this study were very much aware that they were unable to meet the expectations of others. This caused frustration for both parties. Participants voiced they became frustrated with the unwillingness of others to accept their newfound limitations resulting from their injuries. Family members became frustrated because the individual looked “*exactly the same”* and “*normal,”* so there appeared to be no reason for the participants not to meet these expectations. Many participants suggested that had their disability involved some form of physical impairment, others would not place such unrealistic expectations on them.

Nina expressed concern regarding the length of time she may need support. She has been told by members of her family that, “she needs to rest so that she can get better”. This seems to reflect her family’s expectation that she will recover fully from her brain injury.

This expectation can be attributed to the lack of knowledge the affected individual and their family has pertaining to acquired brain injury. In addition, information relayed to the individual and the family pertaining to recovery is equally important. Landau & Hissett (2008) highlight the importance of receiving an accurate diagnosis and valid information pertaining to the brain injury itself. Participants of their study reported that they were often told that they "will recover soon" (Landau & Hissett, 2008, p. 77) thus providing the individual and the families with false hope that the brain injury is "fixable" (Kreutzer, Kolakowsky-Hayner, Demm, & Meade, 2002; Swift & Wilson, 2001). Families should also be educated on the recovery process where recovery is variable and not everyone will recover to a point of being as they were prior to the injury (Landau & Hissett, 2008). Families should also be guided towards forming new realities, inclusive and accepting of this "new" person. Given her recovery to date Nina voiced that, "I'm just really scared that I'll never get better, I'll never be free of it". This expectation and her consequent worry about it adds to the pressure on her to actively work to "get better". Given that physicians have not given her a set recovery time for her injury, she voiced that she is

> "afraid that I might need more support later. I'm afraid that they think it might be time sensitive and that there might be an end when really it could be I need support for lots of years in different ways".

Here, we can see that there has been a fundamental change in her familial relationship- one where she is reliant on others to get by day-to-day and requires additional support from them. However, while she is cognizant that this might be a long-term (perhaps permanent) situation for her, it is her belief that the pressure on her from her family to "get better" may actually be detrimental to the process of getting better. Nina's fears are not uncommon and as studies have found, families do have a preconceived timeline of when their family members should get better (Landau & Hissett, 2008; Laroi, 2003; Swift & Wilson, 2001). Should the affected individual not recover within the family's idealistic timeline, there is the potential for the family to become impatient, intolerant and relationships may breakdown (Landau & Hissett, 2008).

Daisy experienced a very similar experience related to misconceptions about invisible acquired brain injury. Initially, Daisy's family believed that she would recover from her brain injury. She shared "because I was such a brainy person before, they thought, oh, I will get over this injury quickly". From Daisy's perspective, their limited and faulty knowledge did not allow them to realize "that it was a brain injury and it takes years and you don't get over it, you learn to live in a new way with it". Like Nina, this misconception was a challenge for Daisy as she indicated her family wanted "the old me back". This sentiment was only heightened as "it [brain injury] is the invisible disability and they're like "nothing is wrong with you, you are fine". What helped to change their understanding of her diagnosis was when her father had a stroke. This allowed her father to "relate to having a brain injury, he, he understands that I could only do so much". After her father's diagnosis of brain injury, her family's expectations for Daisy to return to her "normal", "old self" diminished.

Prior to Beck's injury, there was discussion of starting a family with his wife. Since his injury, this has been placed on hold. He voiced that since his brain injury he "can't really take care of myself" and will often have "brain injury moments in a week – leaving my underwear in the middle of the kitchen…turning the furnace off in the middle of winter… locking my keys in the car”. He goes on to state, “that’s been a huge stress because she really wants to have kids, its something that we discussed but then it becomes hard too because it’s kind of like brain injury is the trump card”. Here the expectation – held by both of them – is that he will return to a version of his “old” self where he will be capable of continuing on with their life plans. This has changed the familial relationship as the focus has been shifted from the family unit (he and his wife) and their joint desires (to start a family) to a focus on his needs and limitations resulting form the acquired brain injury. Currently, Beck sees this as an unrealistic expectation resulting from where he is at in terms of his recovery. Beck indicated that he and his wife have discussed that this may be unrealistic for them, however there is still a strong desire to start a family on both their parts. Here, the unrealistic expectation is stemming from both, as this is something they both want and would like to work towards and appears to be a stressor and pressure within their relationship.

It is frustrating when ‘normal’ physical bodies lead others to have unrealistic expectations of our capabilities and misconceptions of our health: this notion was echoed by the participants in Stone’s (2005) study. Another finding of Stone’ study was that “Participants pointed out that others who are close to them commonly forget that they have disabilities, or deny that they have any disabilities” (2005, p. 300). The same finding was found within this research. An explanation I can put forth is that family members so often want to believe that nothing is wrong with their family members. This could be in part an emotional response or concern that our loved ones haven’t been hurt to the degree they know they have. Even if that is the case, there are other possible factors involved.

There is an associated level of stigma that is connected to disability and – by proxy – to the family members of people with disabilities (Goffman, 1963; Green, Davis, Karshmer, Marsh, & Straight, 2005). By denying or 'pretending' their family members are fine, they can reduce the amount of stigma they may experience and, subconsciously, these individuals may feel that they also then reduce the stigma felt by the affected family member (Goffman, 1963; Green, et al., 2005). Although participants did not explicitly use the word "stigma", participants spoke to it in many different ways. Some participants indicated that their family members felt stigmatized especially in public situations where the person's behaviours differed from accepted norms and thus required managing or explaining resulting in challenging situations for not only themselves, but for their family members.

Some participants discussed the challenges they faced in social situations, which directly affected their family members. Due to the invisible nature of their injuries and how physically well participants appeared to be, participants found that they would have to constantly explain why they were unable to stay at an event for prolonged periods of time (if they could attend at all), be in crowded areas, or need the lights to be dimmed. Ryan expressed that "your whole lifestyle changes" after you have a brain injury. "The biggest thing is that you are not obviously injured, you can, only the people who know you really well can see the effects, understand what's going on". Even those who did understand what was happening often forgot. This caused the participants to have to constantly remind those around them of the diagnosis or to manage this in other ways (such as cutting people off or leaving social situations when the reason for their discomfort was not obvious to others). In addition, participants also voiced that their significant others or family members often withdrew from social circles and outings as they felt compelled to stay at home with the participant. There was this unwritten misconception on the part of the family member that the participant needed them at home or would be upset if they went out without them (Florian, Katz, & Lahav, 1989). This again reinforced that caregiver role as mentioned earlier. In addition, this resulted in a shift in behavioural patterns on the part of the participant and on the family members – participants needing to withdraw from activities/ events and family members feeling compelled to miss out on activities/ events as well to ensure the participants' well being. Participants did not speak to any tensions or resentments due to this.

An alternative to this is that often times families limit the amount of interactions they have with society to avoid confrontations (Florian, Katz, & Lahav, 1989). This can be in part due to the negative stigmatizing understandings society hold of individuals with acquired brain injury. Involvement in said society has the potential to force family members to acknowledge these stigmatizing beliefs and confront their denial that something may actually be wrong with their loved one (Florian, Katz, & Lahav, 1989; Green, Davis, Karshmer, Marsh, & Straight, 2005).

Mitigating the effects of acquired brain injury on the family

An important finding from this research highlighted that participants of this research engage in strategies to mitigate the effects of their brain injuries felt by their families. The main sources of mitigation put forth by the participants centered around education and awareness, and the inclusion of family in recovery.

Education & Awareness

Education and awareness is important for a number of reasons. More often than not, healthcare providers are the ones providing education to families and communities (Linden & Boylan, 2010). Healthcare professionals generate studies and as a result, their findings influence the ways in which society takes up the notion of brain injury and disability. Within disability literature, there has been little attention given to invisible disabilities and the experience of individuals who live with them (Chamberlin, 2006; Landau & Hissett, 2008; Stone, 2005; Swift & Wilson, 2001).

As it has been discussed at length throughout this research, healthcare professionals and members of society have unrealistic and inaccurate conceptions of what it means to be impaired and disabled, and as a result, what it means to be living with disability. This results in a skewed representation of disability throughout society, which further influences the ways in which society at large internalizes and externalizes the information. Those who are living with invisible symptoms of acquired brain injury and their families are not immune to the effects of these beliefs and discourses.

Within this research, participants took on an active role of educators. This role of educator was not solely within the family unit, but spread to friends and members within their respective communities. Participants in this study engaged in acts of awareness and education through varying means. The ultimate goal of these acts of awareness and education was to challenge the dominant discourses and beliefs by providing an alternative understanding and representation of disability and acquired brain injury.

Wes shared of his involvement within an educational institution where he contributed to ‘Brain Injury Awareness Week’. He also spoke to being involved with many spoken word pieces and other art pieces to create awareness of brain injury within the community. He felt this was important as there needs to be a better understanding of brain injury within society.

Paul spoke to providing others with information. He indicated that sometimes people can sense something is there but they don’t know what. He said that he often provides information relating to brain injury as “ giving information to people is really good because now they have a choice to understand or not and most people decide to understand”. Rosie also spoke to ways in which she provides education and awareness to others by “giving speeches at large universities on my experiences of living with a brain injury”. She feels that this is helpful as the more knowledge that is put forth, a better level of understanding can be developed of the brain injury community.

Participants could not stress enough the need for greater education pertaining to acquired brain injury, not only for healthcare professionals, but for themselves, their families, and society at large. Participants believe that education would allow for a better understanding of what they could experience in relation to recovery and interpersonal relationships. Thus resulting in a better understanding of the nature of acquired brain injury and help to dispel dominant – and inaccurate –portrayals of what it means to be living with brain injury. Participants indicated that they constantly have to provide education to their families pertaining to their diagnosis. This education would also extend beyond the family unit to friends and others within their respective communities to provide explanation for the changes that were occurring to them, and to lessen the stigma associated with their injury. As part of the recovery process, all participants engaged in forms of creating awareness within their communities. The methods included, but were not limited to, spoken word pieces, plays, writings and memoirs, guest speaking (within agencies and educational institutions), and fundraising.

The findings in this section are aligned with the findings of Linden & Boylan (2010). Within the general population, there is a great misunderstanding pertaining to acquired brain injury. Participants of their study voiced that there is no adequate truthful information that is readily available to the general public (Linden & Boylan, 2010). As a result, harmful constructions of acquired brain injury continue to be perpetuated through the dominant discourses that circulate within society. When participants of their study were asked what the role of individuals living with acquired brain injury should be, participants voiced that affected individuals should engage in acts of education and awareness (Linden & Boylan, 2010). Through the findings of this study, we can note that participants do engage in acts of awareness and education in the communities in which they belong. Their involvement can have a direct impact on their families as they can present valuable knowledge and alternative lenses to understanding the impact of their experiences on the self, others and society.

Inclusion of Family in Recovery

Another form of mitigation participants engaged in was the inclusion of family members within their recovery. As the diagnosis affects the whole family unit and not just the individual, participants would often try to bring family members to appointments so that they could have the opportunity to ask questions, learn more about the diagnosis and potentially gain strategies to use within the home. Ryan expressed that the involvement of his wife in appointments to ask questions and learn strategies has been very helpful. It has allowed for a holistic approach to care to which he indicated he is thankful for. This is consistent with the literature; Laroi (2003) highlights the importance of involving the family in recovery. Involving the family in appointments allows for the opportunity for family members to discuss their concerns in a safe place. In addition, family members may gain greater insight and education to comprehend what is happening to their family member (Laroi, 2003; Lefebvre, Pelchat, Swaine, Gelinas, & Levert, 2005). This is useful as it can help to dispel any misconceptions of the family member and can provide an explanation for behaviour they may not understand.

In some cases, although participants made the effort to include their family in medical appointments, some members of the family were not receptive to this. Paul shared that he brought his family to his doctor's appointment so that his doctor could explain to them what had happened. His family was not receptive of this. Paul stated that this was in part due to there being "a portion of denial" and unwillingness to accept this injury. Christa experienced similar instances however she indicated that her family "didn't care about her" thus, would not attend appointments with her. In some of these instances, participants could only attribute this resistance to an ongoing denial that there was something wrong with the participant. This is unfortunate as literature shows that the involvement of family is beneficial and can have profound positive impacts (Laroi, 2003; Lefebvre, Pelchat, Swaine, Gelinas, & Levert, 2005).

Participants discussed the benefits of including family members in activities to enhance recovery. Participants indicated that in working with some healthcare professionals, life strategies and coping mechanisms provided reflected the interests and hobbies of the individual. Provided the participant could still engage in these activities, it was suggested that family members also engage in these activities, not only to provide support but also to be able to connect with family members. Beck indicated that his neuropsychologist encouraged him to do tai chi, yoga and meditate and encouraged his wife to participate. Beck indicated that his wife was not receptive to this idea- however he did not provide a reason as to why. He indicated that he felt this joint activity would be beneficial to them as it was often difficult to find things they could both enjoy. Again, although some family members were resistant, participants felt it was beneficial to their recovery and to maintaining a positive relationship in lieu of only focusing on the injury.

Within the literature, healthcare professionals have recognized the importance of a holistic approach to care and the significance of including family members (Kreutzer, Kolakowsky-Hayner, Demm, & Meade, 2002). Participants found that although this may be true, it did not account for the readiness and willingness of these family members to engage in the recovery process. Possibilities put forth by the participants centered on their denial to accept the diagnosis. Nevertheless, despite family members lack of willingness to accept the diagnosis and the changes associated with it, they still actively pressed and encouraged family members to engage in this process. Often times, participants would try to include family members in what appeared to be leisure activities but were really activities of recovery put forth by their respective healthcare professionals. In some instances, participants went to their social groups to ensure that their significant others had access to a safe and supportive environment to disclose frustrations. Participants shared that they believed their family members were unaware of these strategies used on a daily basis.

Summary

Participants of this research shared valuable knowledge and information that can be useful to not only social workers, but also other healthcare professionals. From the analysis of the qualitative interviews, the key findings and messages put forth include the following: existing literature focuses primarily on the caregiver and family experience with limited attention to the experiences of the affected individual. As a result, there is limited research available to expand the knowledge base of healthcare professionals and the general public as it pertains to the affected individual's experience.

The medical model plays a significant role in shaping the experiences of those living with invisible symptoms of acquired brain injury. Under this model, medical constructions of what it means to be impaired, disabled and brain injured can result in harmful consequences for not only the individual, but also the family. Consequences of this that were uncovered throughout this research centered on the inadequate knowledge pertaining to acquired brain injury held by medical professionals which led to delayed and/or misdiagnosis and the invalidation by self and others. The literature would suggest that the role the medical profession plays in perpetuating these often-misinformed constructions further contributes to the harmful medicalized stereotypes of what it means to be living with an acquired brain injury. As a result, this dominant construction then contributed to the changes in family dynamics that participants experienced.

Participants of this research spoke to changes occurring within the family dynamics pertaining to changing relationships, role changes and the unrealistic expectations and misconceptions held by family members. Given the nature and complexity of acquired brain injury, as highlighted within the findings and discussion, the changes one may encounter are not uniform across all members. This is indicative of the complex nature of brain injury itself, the individual's relationship with their respective families, and their past and present life experiences. The findings of this section highlighted some of the challenges – and positives – that can be associated with acquired brain injury, and the importance of recognizing that although one may assume the impacts can be devastating, there are many layers and aspects that would indicate otherwise.

Lastly, the research highlights the importance of education and awareness, not only for healthcare professionals and for family members, but also for the society at large. Participants of this research could not stress enough the importance of having the availability of accurate information pertaining to acquired brain injury readily accessible. With so many inaccurate beliefs circulating within society pertaining to invisible acquired brain injury, participants took it upon themselves to find ways to provide alternative understandings that dispel these harmful assumptions and beliefs. With the continuation of efforts at increasing awareness and providing education, there is hope that future experiences (of people living with acquired brain injury, their families, and the professionals and members of society they engage with) will be shaped more positively and, at the very least, a greater understanding and appreciation of the individual's lived experiences might be achieved.

Implications

Why Does This Matter?

This research has identified the need to redefine the current dominant constructions held by society pertaining to the manifestation of impairment; specifically invisible acquired brain injury. Participants within this study expressed how current preconceived notions as to what acquired brain injury looked like, coupled with the medical discourses around acquired brain injury, impairment and disability more broadly, shaped the ways in which healthcare professionals, families members, the general public, and they themselves responded to acquired brain injury.

Today, individuals living with disability, as compared to their non-disabled counterparts, continue to be excluded from the public domain despite their willingness and abilities to participate within "the public sphere, as workers, citizens and consumers" (Meekosha & Dowse, 2007, p. 169). Social workers can play an essential role in the lives of individuals living with disability. To ensure this role is one that is useful to people living with disabilities, social workers need to acknowledge and be mindful of their own assumptions and perceptions of disability and impairment, and recognize that they may be involuntary agents of this exclusion and prejudice.

As both a social worker and an individual living with an acquired brain injury, I believe it is necessary to give voice to individuals living with disability so that we may begin to change what professionals and the general public value as knowledge. By working with them to legitimize their voices and knowledge in the eyes of the wider world, we are able to shed light on the lived experiences of disability in lieu of imposing outsider beliefs on their experiences. In addition, I call on the support and commitment of individuals with and without acquired brain injury to create greater awareness of acquired brain injury as a means of dispelling pervasive generalizations that have proven harmful. Through this, we can work towards developing a more inclusive and truthful understanding of what it means to be living with invisible symptoms of acquired brain injury and recognize how many individuals have been inappropriately supported as a consequence.

Possibilities for Social Work Research

Within current research, there are limited studies addressing the experiences of those with acquired brain injury – particularly from their own perspectives. Given the unique nature, complexity and prevalence of brain injury, there is a need for more research to explore the experiences of these individuals. Further attention should be placed on the unique challenges associated with living with the invisible symptoms associated with brain injury. What could not be explored in my research was whether the ways that this invisibility mattered for participants with acquired brain injury would be the same or different for people living with other invisible impairments. Further research could explore this.

Using critical disability theory, I call on future researchers to give voice to this community of individuals. Legitimizing their knowledge and valuing their lived experiences will create space for more meaningful social inclusion and will facilitate stigma reduction. This can allow for change to take place across social structures as opposed to solely directed at the site of the individual (Hosking, 2008). To accomplish this, I would suggest qualitative research methodologies be used. Knowledge generated through qualitative methods has the potential to influence policy makers, healthcare professionals and society at large (Mason, 2002).

Implications for Social Work Education

The task of dispelling harmful dominant constructions of disability rests in the kinds of education that are available to us as social work students. Within social work education and the broader profession, our understandings of disability have been located almost exclusively within the medical model (French Gilson & DePoy, 2002; Hiranandani, 2005; Meekosha & Dowse, 2007). This is, in part, a consequence of the lack of research into the experiences of individuals living with invisible disability that is conducted from a critical lens that highlights the perspectives of people who are living with the invisible disability. The medical model of disability views disability "as a functional limitation, as an individual 'problem', 'pathology', 'dysfunction', or 'deviance'" (Hiranandani, 2005). This results in the 'problem' of disability being located solely within the individual – it does not account for the role that social structures and policies play in shaping the way in which disability is experienced. Meekosha & Dowse (2007) and French Gilson & DePoy, (2002) suggest that within undergraduate programs of social work, many students have adopted this medical model approach to disability resulting in the assumption of demeaning and patriarchal roles when working with individuals who are disabled. Although budding social workers are typically exposed to and taught to critique notions of gender, race and class within society, this same level of critique has not been consistently or sufficiently applied to issues pertaining to disability (French Gilson & DePoy, 2002).

In speaking from my own experience, within my undergraduate degree, a course studying disability was not offered, as there were no professors available to teach it. As a result, I feel there were significant gaps in my knowledge and education pertaining to the social construction of disability and how society responds to it. This was especially concerning to me, not only as an individual living with disability, but also as the majority of my professional practice has been working with individuals who experience disability and I have witnessed first hand the negative consequences that can result from the medicalized approach. Although this has only been my experience, I cannot help but wonder how the lack of availability of a course on understanding disability has impacted my graduating cohort. Have my fellow classmates sought out additional information to form a critical understanding of disability? How have they come about their own understandings of disability and the role of social workers in the lives of people with disabilities? What kinds of knowledge and what theoretical perspectives inform their practice with disabled people? Even had a course on disability from a critical perspective been offered, I wonder how many of my classmates would willingly take this course?

In my opinion, students of social work faculties need to be exposed to alternative ways of understanding disability; the same ways in which they are taught to critically analyze gender, race and class. I would suggest that the schools of social work include a critical disability lens within first year introductory courses and emphasize the need to not only challenge dominant constructions of disability, but to support students to challenge their own values and assumptions. Should this be implemented and accomplished, social workers will be better prepared, with the tools needed to go out into the workforce and contribute to a shift that moves away from an exclusive focus on the medical model of disability. By so doing, they would be contributing to a new perspective of disability, one which shifts the focus away from requiring people with disabilities to change towards attending to how society responds to people with disabilities.

Implications for Social Work Practice

The ways one professionally practices social work is largely influenced by social work education and training. The inclusion or exclusion of disability perspectives in social work education therefore influences the approaches social workers use in practical settings.

Currently, in Western society, traditional roles for social workers employed within the disability sectors are “associated with the assessment of the individual, along biological, educational and psychosocial dimensions” (Meekosha & Dowse, 2007, p 171). As a result, social workers adopt – or are required to execute – “the gate-keeping role” (Meekosha & Dowse, 2007, p 171) through the determination of who is and is not eligible for services and resources within a bare-boned system (Davidson & Davidson, 1996; Meekosha & Dowse, 2007). Eligibility is based on assessments that are largely rooted in biomedical understandings.

In adopting a critical disability approach, social workers can recognize that disability is not solely experienced at the level of the individual, but also at multiple sites within society. The interactions between these sites influence how individuals are socially excluded or included, their status and power, and the legitimization of their contributions (Hosking, 2008; Meekosha & Dowse, 2007; Swain, French , Barnes, & Thomas , 2013). Thus, social workers operating from this perspective can take into account how dominant constructions, policies, media representations etc., shape the ways in which these individuals can function daily, and incorporate this into more broadly based assessments of the person's situation. It will also expand the 'targets' of social work intervention – not just the individual but also their families, networks, communities and the larger societies in which they live.

Taking into consideration the notion of privileging voice and placing value in the experiences of those living with disability, participants shared their experiences of what it was like to work with healthcare professionals involved in their care. I then asked participants to tell me what they felt social workers and other health professionals could do differently in their practice and interactions with people living with acquired brain injury. The participants of this research expressed their desire to share what they felt is needed for all professionals to keep in mind when they work with individuals living with acquired brain injury, regardless of whether symptoms are visible or invisible. Below is a point form summary of their thoughts. It is my hope that as professionals read this research, they place weight in these strategies and incorporate them into daily practice.

- Adapt to the level of the person and not have the person adapt to you.
- Educate yourself regarding brain injury - no one expects you to be an expert, but they do rely on your knowledge.
- Create awareness through educating the individual, family and general public about what brain injury is.
- Validate their experiences- it doesn't always seem real to the individual.
- Be mindful of language (for example do not say "let's brainstorm").
- Don't say I look fine; looking fine has nothing to do with how I feel.
- Talk to *me.* No one understands my experiences better than I do. Go to outside sources for clarification - not for the whole story.
- Systems are in place that don't account for the individual- there is not a one size fits all approach.
- Respect - respect my knowledge, respect me as an equal, respect who I am and respect that I have a disability that you may not have initially been aware existed.
- Don't expect the individual to change - this is their new reality. Society needs to accept who we are and not force us to be who they want us to be.

If social workers keep the above recommendations in mind throughout practice, social workers will have the ability to legitimize the lived experiences of those living with acquired brain injury, and privilege the knowledge put forth. In addition, social workers can challenge the dominant constructions by providing alternative ways of understanding and education to those around them and society at large. Social workers can also incorporate acts of resistance within daily practice by challenging the medicalized system in which they work, and practice from a position where impairment does not equal disability but equals inclusivity.

Using an Insider Perspective in Social Work Research

To conclude, I want to return to the question of my own insider status in this work. The literature tells us that the use of an insider perspective in social work research has the potential to result in positive outcomes or create potential risks (Corbin Dwyer & Buckle, 2009). Within the context of this research, I believe my positioning as an insider researcher allowed me to be positioned as a 'legitimate' listener in the eyes of the participants, someone who was entitled to hear their stories. This is in part due to the common language, identity and experience I share with the participants (Corbin Dwyer & Buckle, 2009). As a result, I believe (and participants reported) I was able to make participants feel more comfortable in sharing their stories and establishing rapport with them. This is important as it appeared that my intimate and personal knowledge of living with invisible symptoms of acquired brain injury allowed me to be positioned as a researcher that would more likely believe and understand the experiences shared with me.

Much strength can be found within research conducted through the lens of an insider researcher. Within this research, my own position as an insider enabled me to contribute to an area of research that is limited in scope and breadth, and provide alternative understandings to the dominant understandings that circulate within society. My insider positioning, knowledge and experience also appeared to influence the ways in which I was able to pick up on the more subtle nuances of the conversations I had with participants. As a result, I feel my positioning allowed me to recognize the importance of some of the seemingly “little things” participants shared. To situate the reader, an example of this can be seen in the overprotectiveness of Jack’s parents. At face value, overprotectiveness is not uncommon in parent-child interactions. What is important here is that when coupled with an injury such as acquired brain injury, this overprotectiveness may extend into adulthood and can take on a new meaning that is not always readily apparent or fully understood by others who have not experienced this. As a result, by being able to pick up on these seemingly innocuous comments, the research might make important contributions to social work.

In addition, it is important to recognize that the critically self-reflexive insider researcher is likely able to separate their lived experiences and understandings from that of their participants’ lived experiences and understandings. As an insider, although I have particular understandings of what it means to be brain injured and what changes can occur – understandings rooted in my own experience – I feel I was able to approach this research without any preconceived notions of what I might hear from participants. I was careful to try not to let my own experience determine what I saw/heard or to influence the analysis of the interviews too greatly. Within my research, this I feel can be best illustrated in the section on the effects of invisible acquired brain injury on the family. My analysis reflects the variability and complexity of individual and family experiences – countering critiques that an insider researcher cannot see other than her/his own experience, it does not present a singular account. It neither seeks to idealize or demonize families, instead recognizing and reporting on how family experiences of invisible acquired brain injury are both complicated and messy. This further illustrates how I (and other insider researchers) are able to move beyond our own experiences and contribute important knowledge to social work's understanding of acquired brain injury and the effects invisible symptoms have on family dynamics.

Another example emerging from this research is how the research highlighted that for all of the participants, many different individuals involved in their lives did not believe that they were brain injured, and the repercussions of this disbelief included harmful consequences for their lives. If an outsider researcher were to share in the same feelings of disbelief, then our understanding of acquired brain injury is compromised and will likely serve to perpetuate these harmful constructions of what it means to be brain injured. This sense of disbelief and suspicion around 'invisible' impairment might then also have potential harmful consequences for future research both on invisible acquired brain injury, but also to other invisible disabilities.

In relation to this research insider positioning then broadens and complicates a social work understanding of invisible acquired brain injury. This then allows for social work research to offer a critique that makes visible the experiences of invisible acquired brain injury that a medical model serves to hide. The importance and strength of this insider positioning can thus have positive outcomes in the generation of knowledge.

APPENDIX A: Recruitment Poster

PARTICIPANTS NEEDED FOR RESEARCH ON…

ACQUIRED BRAIN INJURY

Are you…

18+?
Been diagnosed with an invisible acquired brain injury?
Want to tell your story?

If so, you are invited to participate in a 60-minute semi-structured interview on your experience of living with an invisible acquired brain injury.

For more information about this study, or to volunteer for this study, please contact:
Kristine Zogala
School of Social Work
647-339-1417
Email: *zogalak@mcmaster.ca*

This study runs between April May 1, 2014 - May 31, 2014

This study has been reviewed by, and received ethics clearance by the McMaster Research Ethics Board.

Call Kristine Zogala
647-339-1417
Or
Email:
zogalak@gmail.com

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647-339-1417
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zogalak@gmail.com

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APPENDIX B: Email Recruitment Script

Kristine Zogala, BA, BSW, RSW

Masters Candidate in Social Work

A Study of Changes to family dynamics when living with invisible Acquired Brain Injury

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E-mail Subject line: McMaster Study – Changes to family dynamics when living with Invisible Acquired Brain Injury or Participants Needed

April 28, 2014

Hello,

I am inviting you to take part in a 60-minute semi-structured interview as part of my Social Work Master's thesis at McMaster University. I am carrying out a study to learn more about the changes one my experience to the family dynamic when living with "invisible" symptoms resulting from an acquired brain injury.

I am looking to recruit participants who have been diagnosed with an acquired brain injury. This will enable me to study any changes from the affected individual's perspective.

It is expected that there will be no risks to you in taking part in this study. You can stop at any time. I have attached a copy of a letter of information about the study that gives you full details. This study has been reviewed and cleared by the McMaster Research Ethics Board. If you any have concerns or questions about your rights as a participant or about the way the study is being conducted you can contact:

The McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Research Office for Administration, Development and Support (ROADS)
E-mail: ethicsoffice@mcmaster.ca

Thank you in advance for your time and consideration.

Kristine Zogala, BA, BSW, RSW
Masters Candidate in Social Work
Department of Social Work
McMaster University, Hamilton, Ontario
Tel: 647-339-1417
zogalak@mcmaster.ca

APPENDIX C: Advertisement Letter
Provided by Medical Associates of Port Credit
Kristine Zogala, BA, BSW, RSW
Masters Candidate in Social Work
A Study of Changes to family dynamics when living with invisible Acquired Brain Injury

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May 1, 2014

Hello,

Kristine Zogala, a McMaster University student, has contacted Medical Associates of Port Credit asking us to tell our patients about a study she is doing on the changes to the family dynamics when living with an invisible brain injury. This research is part of her Masters thesis in the Social Work Program at McMaster University.

The following is a brief description of her study. She has asked us to attach a copy of her information letter to this email. That letter gives you full details about her study.

If you are interested in getting more information about taking part in Kristine's study, please read the brief description below and or **CONTACT KRISTINE ZOGALA DIRECTLY** by using her telephone number or McMaster email address. **Tel: 647-339-1417** or **zogalak@mcmaster.ca**. The researcher will not tell me or anyone at Medical Associates of Port Credit who participated or not. Taking part or not taking part in this study will not affect your status or any services you receive.

Kristine Zogala is inviting you to take part in a 60 minute semi-structured interview that will take place on convenient date, time and location of your choice. Interviews may be conducted via email, telephone or in person. Interviews will not take place at Medical Associates of Port Credit to ensure your privacy and confidentiality. Kristine will work out those details with you. Kristine hopes to gain an insider's knowledge on your experience living with an invisible acquired brain injury and if there have been any changes to your family dynamics. Kristine has explained that you can stop being in the study at any time.

In addition, this study has been reviewed and cleared by the McMaster Research Ethics Board. If you have questions or concerns about your rights as a participant or about the way the study is being conducted you may contact:

McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142
Gilmour Hall – Room 305 (ROADS)
E-mail: ethicsoffice@mcmaster.ca

Sincerely,

Medical Associates of Port Credit

APPENDIX D: Email Recruitment Script
Sent by holder of participant's contact information
Kristine Zogala, BA, BSW, RSW
Masters Candidate in Social Work
A Study of Changes to family dynamics when living with invisible Acquired Brain Injury

---

Sample E-mail Subject line: McMaster study about invisible acquired brain injury and changes to family dynamics or Participants Needed

May 1, 2014

Hello,

Kristine Zogala, a McMaster University student, has contacted Medical Associates of Port Credit asking us to tell our patients about a study she is doing on the changes to the family dynamics when living with an invisible brain injury. This research is part of her Masters thesis in the Social Work Program at McMaster University.

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In addition, this study has been reviewed and cleared by the McMaster Research Ethics Board. If you have questions or concerns about your rights as a participant or about the way the study is being conducted you may contact:

McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142
Gilmour Hall – Room 305 (ROADS)
E-mail: ethicsoffice@mcmaster.ca

Sincerely,

Medical Associates of Port Credit

APPENDIX E: Advertisement Letter
Provided by Brain Injury Association of Peel and Halton
Kristine Zogala, BA, BSW, RSW
Masters Candidate in Social Work
A Study of Changes to family dynamics when living with invisible Acquired Brain Injury

Sample E-mail Subject line: McMaster study about invisible acquired brain injury and changes to family dynamics

Hello,

Kristine Zogala, a McMaster University student, has contacted Brain Injury Association of Peel and Halton (BIAPH), asking us to tell our service users about a study she is doing on the changes to the family dynamics when living with an invisible brain injury. This research is part of her Masters thesis in the Social Work Program at McMaster University.

The following is a brief description of her study. She has asked us to attach a copy of her information letter to this email. That letter gives you full details about her study.

If you are interested in getting more information about taking part in Kristine's study, please read the brief description below and or **CONTACT KRISTINE ZOGALA DIRECTLY** by using her telephone number or McMaster email address. **Tel: 647-339-1417** or **zogalak@mcmaster.ca**. The researcher will not tell me or anyone at Brain Injury Association of Peel and Halton (BIAPH) who participated or not. Taking part or not taking part in this study will not affect your status or any services you receive at BIAPH.

Kristine Zogala is inviting you to take part in a 60 minute semi-structured interview that will take place on convenient date, time and location of your choice. Interviews may be conducted via email, telephone or in person. Interviews will not take place at BIAPH to ensure your privacy and confidentiality. Kristine will work out those details with you. Kristine hopes to gain an insider's knowledge on your experience living with an invisible acquired brain injury and if there have been any changes to your family dynamics. Kristine has explained that you can stop being in the study at any time.

In addition, this study has been reviewed and cleared by the McMaster Research Ethics Board. If you have questions or concerns about your rights as a participant or about the way the study is being conducted you may contact:

McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142
Gilmour Hall – Room 305 (ROADS)
E-mail: ethicsoffice@mcmaster.ca

Sincerely,

Brain Injury Association of Peel and Halton

APPENDIX F: Email Recruitment Script
Sent by holder of participant's contact information
Kristine Zogala, BA, BSW, RSW
Masters Candidate in Social Work
A Study of Changes to family dynamics when living with invisible Acquired Brain Injury

Sample E-mail Subject line: McMaster study about invisible acquired brain injury and changes to family dynamics

Hello,

Kristine Zogala, a McMaster University student, has contacted Brain Injury Association of Peel and Halton (BIAPH), asking us to tell our service users about a study she is doing on the changes to the family dynamics when living with an invisible brain injury. This research is part of her Masters thesis in the Social Work Program at McMaster University.

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In addition, this study has been reviewed and cleared by the McMaster Research Ethics Board. If you have questions or concerns about your rights as a participant or about the way the study is being conducted you may contact:

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Gilmour Hall – Room 305 (ROADS)
E-mail: ethicsoffice@mcmaster.ca

Sincerely,

Brain Injury Association of Peel and Halton

APPENDIX G: Letter of Information

Kristine Zogala, BA, BSW, RSW
Masters Candidate in Social Work

A Study of Changes to family dynamics when living with invisible Acquired Brain Injury

Faculty Supervisor:	Student Investigator:
Dr. Ann Fudge-Schormans	Kristine Zogala
Department of Social Work	Department of Social Work
McMaster University	McMaster University
Hamilton, Ontario, Canada	Hamilton, Ontario, Canada
905-525-9140 x 23790	647-339-1417
fschorm@mcmaster.ca	zogalak@mcmaster.ca

May 1, 2014

Purpose of the Study:
This study aims to investigate the changes to family dynamics from the perspective of an individual living with an invisible acquired brain injury. This research is for a McMaster University thesis in social work.

What will happen during the study?
I will ask you to participate in an interview that may last up to 60 minutes. The questions that will be asked will consist mainly of open-ended questions. These questions will focus on your experience living with an invisible acquire brain injury. Emphasis will be placed on any changes to your family dynamic that you may have experienced. With your permission, I will record the interview to make sure that I accurately represent your answers. This recording will be erased once your interview has been transcribed. Handwritten notes may also be taken during the interview and will be kept in a locked filing cabinet. Upon study completion, these handwritten notes will be shredded.

Are there any risks to doing this study?
Although the risks involved in participating in this study are minimal, some of the questions may raise issues that are difficult for you. You are free to skip any question you would prefer not to answer and can stop the interview at any time. You may also worry about how others will react to what you say. Your privacy is of the utmost importance to me. I describe below the steps I am taking to maintain the confidentiality of what you tell me.

Are there any benefits to doing this study?

The research will not benefit you directly. I hope to learn more about how invisible acquired brain injury can affect family dynamics. I hope that what is learned as a result of this study will help to better understand the many complexities that are associated with invisible acquired brain injury from the perspective of the affected individual. In addition, I hope this research will give voice to those who may feel their voice has been lost as a result of their injury. These findings can inform service providers about the unique challenges you may face which can lead to better services available to you and your family.

Who will know what I said or did in the study?

Every effort will be made to protect your confidentiality and privacy. Your name will not appear on any reports or in the final publication. I will not use your name or any information that would allow you to be identified. However, we are often identifiable through the stories we tell. Since your community is small, others may be able to identify you on the basis of references you make. Please keep this in mind in deciding what to tell me. The information you provide will be kept in a locked desk/cabinet where only I will have access to it. Information kept on a computer will be protected by a password. All handwritten notes and transcriptions will have your name replaced with a pseudonym (fake name) of your choice or one will be assigned to you. Once the study has been completed an archive of the data, without identifying information will be maintained for 5 years.

Legally Required Disclosure

Although I will protect your privacy as outlined above, if the law requires it, I will have to reveal certain personal information if you are a risk to yourself or others. Risk would include imminent danger to yourself (such as suicide). Risks to others would include child abuse, or actions causing harm towards others. Disclosure of any illegal activity would also need to be disclosed.

What if I change my mind about being in the study?

Your participation in this study is voluntary. If you decide to be part of the study, you can stop (withdraw), from the interview for whatever reason, even after signing the consent form or part-way through the study or up until approximately ***May 31, 2014*** at which point I will have started writing up my findings. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

How do I find out what was learned in this study?

I expect to have this study completed by approximately *August 2014.* If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study
If you have questions or need more information about the study itself, please contact me at:
647-339-1417 or at zogalak@mcmaster.ca. If you wish to speak with my academic supervisor Dr. Ann Fudge-Schormans, she can be reached at 905-525-9140 x 23790 or fschorm@mcmaster.ca.

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.
If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Research Office for Administrative Development and Support
E-mail: ethicsoffice@mcmaster.ca

APPENDIX H: Participant Screening Form

Kristine Zogala, BA, BSW, RSW

Masters Candidate in Social Work

A Study of Changes to family dynamics when living with invisible Acquired Brain Injury

1. **Are you 18 years of age or older? ☐ Yes ☐ No**
   If no, individual is unable to participate.

2. **Have you been formally diagnosed with an Acquired Brain Injury? ☐ Yes ☐ No**
   If no, individual is unable to participate.

3. **Is your Acquired Brain Injury Invisible? ☐ Yes ☐ No**
   If no, individual is unable to participate.

4. **Do you receive services through Peel Halton Dufferin Acquired Brain Injury Services? ☐ Yes ☐ No**
   If yes, individual is unable to participate.

5. **Do you receive services through the Neurologic Rehabilitation Institute of Ontario? ☐ Yes ☐ No**
   If yes, individual is unable to participate.

6. **Do you receive services through Central West Specialized Developmental Services? ☐ Yes ☐ No**
   If yes, individual is unable to participate.

7. **Are you a friend, acquaintance or family member of the researcher Kristine Zogala? ☐ Yes ☐ No**
   If yes, individual is unable to participate.

APPENDIX I: Letter of Consent

Kristine Zogala, BA, BSW, RSW

Masters Candidate in Social Work

A Study of Changes to family dynamics when living with Invisible Acquired Brain Injury

Consent

- I have read the information presented in the information letter about a study being conducted by Kristine Zogala of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time or up until approximately May 31, 2014
- I have been given a copy of this form.
- I agree to participate in the study.

1. I agree that the interview can be audio recorded.
   ☐ Yes
   ☐ No

2. ☐ Yes, I would like to receive a summary of the study's results.
   Please send it to this email address:
   ____
   Or to this mailing address:
   ____
   ____
   ____

☐ No, I do not want to receive a summary of the study's results.

4. Pseudonym (If you would like to choose a fake name for the assignment, please write it here.
   Otherwise one will be assigned to you:
   ____

Signature: ____

Name of Participant (Printed) ___________________________________

Date: ______________________________________

APPENDIX J: Interview Guide

Kristine Zogala, BA, BSW, RSW

Masters Candidate in Social Work

A Study of Changes to family dynamics when living with invisible Acquired Brain Injury

Information about these interview questions: This gives you an idea what I would like to learn about invisible acquired brain injury. Interviews will be one-to-one and will be open-ended (not just "yes or no" answers). Because of this, the exact wording may change a little. Sometimes I will use other short questions to make sure I understand what you told me or if I need more information when we are talking such as: "*So, you are saying that …?*), to get more information ("*Please tell me more?"),* or to learn what you think or feel about something ("*Why do you think that is…?").*

1. **Is there anything you would like me to know about you before we start?**
2. **Information about you: Your age now? Are you married? Do you have children and how old are they? Who do you live with? What do you like to do?**
3. **Tell me about your brain injury. When did it happen? How did it happen? Where did it happen?**
4. **What has your experience been like living with an acquired brain injury? Are there any positives? Challenges?**
5. **Did you have to wait long for a diagnosis? How long? Was this frustrating?**
6. **Can you describe your interactions with healthcare professionals? Were they positive/ negative? Does anything stand out most?**
7. **Are you involved with any services? Are these helpful? Why or why not?**
8. **How has your family reacted to your ABI?**
9. **Have there been challenges within your family since your diagnosis? Why or why not?**
10. **How have your family reacted to your ABI?**
11. **Has your role within the family changed? How? How does this make you feel?**
12. **Have family members roles changed? How?**
13. **Is your family involved in any services with you?**
14. **If you could tell your family how you feel what would you say? Do they know this already?**
15. **What is challenging about having an invisible disability?**
16. **Are there positives to having an invisible disability?**
17. **Do you feel the need to disclose to others?**
18. **If there is one thing you could change about your experience, what would it be?**
19. **Is there something important we forgot? Is there anything else you think I need to know about your experience?**

END

APPENDIX K: Counselling Services Information Sheet McMaster

Kristine Zogala, BA, BSW, RSW

Masters Candidate in Social Work

A Study of Changes to family dynamics when living with invisible Acquired Brain Injury

Counselling Services Information Sheet

- ***Here is a list of services where you can find someone to talk to, if you have something on your mind.***
- ***If, at this time, you aren't ready to use one of these services, you might want to talk to a trusted family member or friend that you would normally go to when you have something on your mind.***

Services in Hamilton:

Brain Injury Services

Offers community and residential programs to individuals living with acquired brain injury.
(905) 523-8852
225 King William St #508, Hamilton, ON L8R 1B1
http://www.braininjuryservices.com

Hamilton Brain Injury Association

Offers support groups to individuals and families living with acquired brain injury.
822 Main St E, Hamilton, ON L8M 1L6
http://www.hbia.ca

Distress Centre Hamilton

The Distress Centre Hamilton, offers 24 hour telephone support, crisis intervention, and referral to other agencies where appropriate, for people in distress. This Centre is staffed by trained volunteers.

24 Hour Crisis Line: You will speak to a trained volunteer. The line may be busy at times but this number is in service. 905-522-8611

Salvation Army 24 Hour Suicide Hotline:

Tel. 905-522-1477
Web: www.hopesalive.ca

Services at McMaster University:

Student Accessibility Services
MUSC B107 ext. 28652
Offers support to students with disabilities to assist with academic and disability related needs.

Student Wellness Centre
MUSC B101 ext. 27700
offers personal counselling and other psychological services.
http://wellness.mcmaster.ca/personal/personal-counselling/about-personal.html

Other Sources:
For more information and resources offered by McMaster University and throughout Hamilton visit http://wellness.mcmaster.ca/personal.html or "Inform Hamilton" http://www.inform.hamilton.ca/

APPENDIX L: Counselling Services Information Peel Halton

Kristine Zogala, BA, BSW, RSW

Masters Candidate in Social Work

A Study of Changes to family dynamics when living with invisible Acquired Brain Injury

Counselling Services Information Sheet

- ***Here is a list of services where you can find someone to talk to, if you have something on your mind.***
- ***If, at this time, you aren't ready to use one of these services, you might want to talk to a trusted family member or friend that you would normally go to when you have something on your mind.***

Services in Peel & Halton

Peel Halton Dufferin Acquired Brain Injury Services

Offers clinical, community and residential programs to individuals and families living with acquired brain injury.

905-949-4411

176 Robert Speck Parkway, Mississauga, ON, L4Z 3G1

http://www.phabis.com

Brain Injury Association of Peel and Halton

Offers support groups to individuals and families living with acquired brain injury.

(905) 823-2221

2155 Leanne Blvd., Suite 204 Mississauga, on L5K 2K8

http://www.biaph.com

Distress Centre Peel

The Distress Centre Hamilton, offers 24 hour telephone support, crisis intervention, and referral to other agencies where appropriate, for people in distress. This Centre is staffed by trained volunteers.

24 Hour Crisis Line: You will speak to a trained volunteer. The line may be busy at times but this number is in service. 905-278-7208

Distress Centre Halton

The Distress Centre Hamilton, offers 24 hour telephone support, crisis intervention, and referral to other agencies where appropriate, for people in distress. This center is staffed by trained volunteers.

24 Hour Crisis Line: You will speak to a trained volunteer. The line may be busy at times but this number is in service. 905-846-4541

Other Sources:

For more information and resources offered throughout Peel and Halton, visit http://www.211ontario.ca

APPENDIX M: Oral Consent Script

Kristine Zogala, BA, BSW, RSW

Masters Candidate in Social Work

A Study of Changes to family dynamics when living with invisible Acquired Brain Injury

Introduction:

Hello. I'm Kristine Zogala. I am conducting interviews about invisible acquired brain injury and how it can affect family dynamics. I'm conducting this as part of my research at McMaster University's School of Social Work in Hamilton, Ontario. I'm working under the direction Dr. Ann Fudge-Schormans of McMaster University's Department of Social Work.

I would like to thank you for contacting me to become part of my study. Before we begin, I would like to go over a few frequently asked questions about my study. This will hopefully answer any questions you may have. If you still have any questions after I have explained my study, please feel free to ask and I will make sure everything is clear for you.

What will happen during the study?

I will ask you to participate in an interview that may last up to 90 minutes. The questions that will be asked will consist mainly of open-ended questions. These questions will focus on your experience living with an invisible acquire brain injury. Emphasis will be placed on any changes to your family dynamic that you may have experienced. With your permission, I will record the interview to make sure that I accurately represent your answers. This recording will be erased once your interview has been transcribed. Handwritten notes may also be taken during the interview and will be kept in a locked filing cabinet. Upon study completion, these handwritten notes will be shredded.

Are there any risks to doing this study?

Although the risks involved in participating in this study are minimal, you may feel uncomfortable with some of the questions asked. If you find that some questions are too personal and/or intrusive, you may choose not to answer these questions. You can also withdraw your participation at any time. If you experience any distress after participating in this study, it may be beneficial to confide in a trusted friend, family member or contact one of the agencies found on the Counselling Services Information Sheet that will be provided to you. Your privacy is of the utmost important to me. I describe below the steps I am taking to protect your privacy.

Who will know what I said or did in the study?

Every effort will be made to protect your confidentiality and privacy. Your name will not appear on any reports or in the final publication. I will not use your name or any information that would allow you to be identified. However, we are often identifiable through the stories we tell. Since your community is small, others may be able to identify you on the basis of references you make. Please keep this in mind in deciding what to tell me. The information you provide will be kept in a locked desk/cabinet where only I will have access to it. Information kept on a computer will be protected by a password. All handwritten notes and transcriptions will have your name replaced with a pseudonym (fake name) of your choice or one will be assigned to you. Once the study has been completed an archive of the data, without identifying information will be maintained for 5 years.

Are there any benefits to doing this study?

The research will not benefit you directly. I hope to learn more about how invisible acquired brain injury can affect family dynamics. I hope that what is learned as a result of this study will help to better understand the many complexities that are associated with invisible acquired brain injury from the perspective of the affected individual. In addition, I hope this research will give voice to those who may feel their voice has been lost as a result of their injury. These findings can inform service providers about the unique challenges you may face which can lead to better services available to you and your family.

Voluntary participation:

- Your participation in this study is voluntary.
- You can decide to stop at any time, even part-way through the interview for whatever reason, or up until approximately May 31, 2014.
- If you decide to stop participating, there will be no consequences to you.
- If you decide to stop I will ask you how you would like me to handle the data collected up to that point.
- This could include returning it to you, destroying it or using the data collected up to that point.
- If you do not want to answer some of the questions you do not have to, but you can still be in the study.
- If you have questions or need more information about the study itself, please contact me at: 647-339-1417 or at zogalak@mcmaster.ca

- If you wish to speak with my academic supervisor Dr. Ann Fudge-Schormans, she can be reached at 905-525-9140 x 23790 or fschorm@mcmaster.ca.

This study has been reviewed and cleared by the McMaster Research Ethics Board. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Research Office for Administration, Development & Support (ROADS)
E-mail: ethicsoffice@mcmaster.ca

I would be pleased to send you a short summary of the study results when I finish going over our results. Please let me know if you would like a summary and what would be the best way to get this to you.

Consent questions:

- Do you have any questions or would like any additional details?
- Do you agree to participate in this study knowing that you can withdraw at any point with no consequences to you?
- Do you agree to have your interview audio recorded?

APPENDIX N: Oral Consent Log

Kristine Zogala, BA, BSW, RSW

Masters Candidate in Social Work

A Study of Changes to family dynamics when living with invisible Acquired Brain Injury

RESEARCHER'S LOG FOR RECORDING VERBAL CONSENT

Participant's Name	Participant's Pseudonym	Agree to follow-up interview: Yes or No	Interview can be audio recorded: Yes or No	Date:

APPENDIX O: Teach Back Questions for Participants who may have problems with study information

Kristine Zogala, BA, BSW, RSW

Masters Candidate in Social Work

A Study of Changes to family dynamics when living with invisible Acquired Brain Injury

Teach Back Questions

Researcher Instructions: Guidelines:

- Carefully go through the plain language Letter of information and consent questions or your oral consent script.
- Explain: *"It's my job to explain things clearly and to make sure I did this right"*
- Ask the teach back questions below:

1. **Goal of the Research and Protocol**
   "Tell me in your own words about the goal of this research and what will happen to you if you agree to
   in this study."

2. **Benefit and Compensation**
   "What do you expect to gain by taking part in this research?"

3. **Risks**
   "What risks would you be taking if you joined this study?"

4. **Voluntariness**
   "Will anything happen to you if you refuse to be in this study?"

5. **Discontinuing Participation**
   "What should you do if you agree to be in the study but later change your mind?"
   "What will happen to information already gathered if you change your mind?"

6. **Privacy**
   "Who will be able to see the information you give us?"

7. **Contact Information**
   "What should you do if you have any questions or concerns about this study?"

Researcher's next steps:

a. If the participant understands questions 1 – 7 move on to the completion of the consent process and obtain either written or verbal consent as appropriate for this participant.
b. If the participant doesn't have a clear understanding of the study, ask them if the participant would like to anything to be explained again.

c. If the participant is still unclear, thank the participant for their time and end the exchange.

APPENDIX P: Oath of Confidentiality
Kristine Zogala, BA, BSW, RSW
Masters Candidate in Social Work
A Study of Changes to family dynamics when living with invisible Acquired Brain Injury

Oath of Confidentiality

(*Check the following that apply*)
I understand that as:
[ ] an interpreter
[ ] transcriber
[ ] audio assistant
[ ] video assistant
[ ] research assistant
[ ] other (*Please specify*) ____

for a study being conducted by Kristine Zogala of the Department of Social Work, McMaster University, under the supervision of Dr. Ann Fudge-Schormans, confidential information will be made known to me.

I agree to keep all information collected during this study confidential and will not reveal by speaking, communicating or transmitting this information in written, electronic (disks, tapes, transcripts, email) or in any other way to anyone outside the research team.

Name: ______________________________________
Signature: ______________________________________

Date: _______________________

Witness Name: _______________________________
Witness Signature: ________________________________

Date: _____________________

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