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**Acquired Brain Injury: Journeys from pre-injury to return to work**

**by**

**Catherine Boyce**

**A Thesis**

**Submitted to the Faculty of Graduate Studies and Research  
Through Social Work  
in Partial Fulfillment of the Requirements for  
the Degree of Master of Social Work at the  
University of Windsor**

**Windsor, Ontario, Canada**

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## ABSTRACT

This qualitative research study explored pre-injury to return to work journeys of nine individuals who sustained a mild or moderate acquired brain injury. An exploratory phenomenology method identified phases, themes, and sub themes.

Five phases of their journey were identified as: 1) ABI event, 2) acute hospitalization, 3) recovery, 4) return to work, and 5) post recovery. Common themes were: 1) gaps in memory, 2) fear, 3) need to be normal, 4) striving to be normal, and 5) achieving a new normal.

Within the memory gap theme, sub themes were identified as: 1) loss of time, and 2) bits of memory. Within the fear theme, sub themes were: 1) family vigilance, 2) fear of unknown, and 3) loss of control. The need to be normal theme found sub themes as: 1) following the treatment map, 2) reliance on others, and 3) living in a cloud. The striving to be normal theme identified sub themes as: 1) workplace obstacles, 2) work hardened, and 3) coping with limitations. Sub themes within the achieving a new normal are: 1) coping with challenges, and 2) thankful.

This study identified a conceptual map of phases, themes, and sub themes, as the journey the nine participants encountered after sustaining a mild or moderate acquired brain injury. This journey described a process that the participants went through to achieve a new normal. Implications for social work practice are recommendations for individual supportive and adjustment counselling, family intervention, advocating for adequate financial assistance while not able to work, and advocating for social justice for the person who has suffered an acquired brain injury. This study may provide service

providers with information about prevention, increased the awareness of the impact of an acquired brain injury, and its relation to work.

## DEDICATION

I dedicate this thesis to my family

To my husband Paul,

our daughters Sandra, Paula, and Courteney

Thank you for your unconditional love, support, and patience while we travelled this journey together.

## ACKNOWLEDGEMENTS

Completion of this thesis has provided me with a wealth of knowledge about the field of research. I would like to thank my thesis supervisor, Dr. Brent Angell, for providing me with guidance through the art and science of research. Through his expertise in academic writing, and knowledge of social work research, I was able to gain knowledge that has assisted me in my everyday practice as a professional social worker.

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## CHAPTER 1

### INTRODUCTION

#### Acquired Brain Injury: Journeys from pre-injury to return to work

This qualitative research study explored the pre-injury to return to work journeys of nine individuals who experienced a mild or moderate acquired brain injury. Literature from social work, psychology, sociology, and nursing was examined to gain a better understanding of the complex nature of an acquired brain injury. Data from nine face-to-face interviews were analyzed and themes were identified. Information for service providers has been identified to understand a person's recovery, increase awareness of the impact of an acquired brain injury, and its relation to return to work.

#### *Rationale and Importance of this Study*

The rationale, for choosing to study return to work for the person who has sustained an acquired brain injury, is multifaceted. The process of return to work may affect the individual's physical and psychological well-being, the family structure, social issues, and financial concerns, therefore, the experience may alter a family's lifestyle. A person that is not working for an extended amount of time, or unable to return to employment, may experience altered family function, financial challenges, and social isolation. Return to work has been identified as an indicator of successful recovery (Depalma, 2001; Kowalske, Plenger, Lushby and Hayden, 2000; Vandiver, Johnson and Christofero, 2003; Wantanabe, Miller and Elligott, 2003; Webb, Wrigley, Yoels and Fine, 1995).

Researching the stories of brain injury survivors, who have returned to work, may identify positive outcomes that may be helpful for others to become successful in

returning to a pre-injury lifestyle, which includes working. Understanding what was most important, for a survivor of an acquired brain injury, when recovering from an injury, and returning to work has identified ways for service providers to assist individuals and family members. The results of this study may potentially inform policy, and increase the awareness of the impact of acquired brain injury, and its relation with return to work.

*Benefits of the Study and Implications for Social Work Practice, Research and Education*

The nine participants of this study have benefited by knowing that they have provided the researcher with their insights and experiences, and that this knowledge may be used to increase awareness of the consequences of an acquired brain injury, and its relation to return to work. Their stories may contribute to social work interventions, and those of other helping professions, to assist others who have sustained an acquired brain injury. Benefits to the scientific community will be to increase the awareness of the impact of acquired brain injury, to increase awareness of prevention, and to provide information on return to work for service providers.

Implication for social work practice is to increase awareness to service providers, of the challenges a survivor of an acquired brain injury, and their family member encounters. This research study may contribute to the qualitative literature on return to work of the survivor of brain injury. Many research studies have been quantitative studies on return to work for the survivor of brain injury (Dikmen, Machamer, Powell and Temkin, 2003; Gamble and Moore, 2003; Tennant, Macdermott and Nearly, 1995). Several qualitative studies have been done that have used the narratives of brain injury

survivors to identify the impact of an acquired brain injury, the recovery, and the return to work (Gething et al., 2002; McColl et al., 2000; Nochi, 1998; Rowlands, 2001).

### *Pathophysiology of Acquired Brain Injury*

#### *Classifications*

An acquired brain injury is classified into three categories: 1) mild, 2) moderate, and 3) severe (Black and Matassarini-Jacobs, 1993; Whitman, 1994). At the scene of an injury, or on admission to the emergency room, the Glasgow Coma Scale 9 (GCS) is a screening tool used to assess neurological functioning using three parameters; 1) eye opening, 2) best motor response, and 3) best verbal response. The GCS Scores range from three to 15, with a score of three representing no response, and 15 representing complete alertness and the ability to follow commands (MacKay, Chapman and Morgan, 1997). Persons who have sustained a mild brain injury has a GCS score of 13-15, and those with a moderate brain injury score 9-12; a GCS score of 8 or less indicates a severe injury (Wong and Hockenberry, 2003). The GCS is used to assess the level of consciousness during the first few days after injury (Smeltzer and Bare, 2000). Since a coma is largely dependent on location of injury, another measure of severity is Post Traumatic Amnesia Time, or the time it takes from the moment of the accident until there is continuous memory of events of the day (Whitman, 1994). A scale used to assess cognitive functioning and evaluate ongoing recovery is the Ranch Los Amigos Level of Cognitive Functioning (Smeltzer, et al., 2000).

This research study has focused on the person who had sustained a mild or moderate acquired brain injury and had returned to work. To understand the complicated nature of a person returning to work one must understand the different processes involved

with the acute, and recovery phase of the brain injury. Whether the person is classified with a mild or moderate acquired brain injury during the acute phase of intervention, the recovery process may vary according to the area of the brain injured and the severity of the injury.

The brain is the thinking, sensing, and controlling system of the human body and damage to any part of the human brain can affect the individual physically and emotionally (Mackay et al., 1997). It is believed that once destroyed, brain cells cannot regenerate, therefore brain cell death is thought to be permanent (Whitman, 1994). An acquired brain injury is an injury to the brain tissue, that is a result of external forces rather than degenerative, or a brain injury present at birth. The term head injury is a term used to refer to any craniocerebral trauma, which includes an altering of consciousness; no matter how brief the experience is (Lewis, Heitkemper and Dirksen, 2004).

### *Head injuries*

Head injuries are caused by sudden force, or rapid movement to the head resulting in sudden impact with brain tissue in one of three ways: 1) acceleration, 2) deceleration, and 3) deformation (Black et al., 1993). When an immobile head is struck by a moving object, an acceleration injury occurs (a ball striking a head). A deceleration injury occurs if a head is moving and strikes a stationary object. An example of a deceleration injury is when moving vehicles collide and a person suddenly decelerates and impacts the stationary object (the windshield). An example of an acceleration/deceleration injury is when a ball hits a persons head and that person falls to the ground hitting their head on a hard surface. A skull fracture is a deformation injury because it results from the



disruption of the integrity of the cranial bones of the skull which protect brain tissue, and in some cases intrusion into the cranial cavity (1993, p.741).

Head injuries can be classified by descriptions such as blunt, penetrating trauma, coup or contrecoup injury (Black et al., 1993). Blunt injuries are often a consequence of acceleration/deceleration injuries. Injuries can result at different locations in the brain due to the brain's ability to move within the skull. A coup injury occurs at the point of contact, and the contrecoup injury, because of the brain's movement inside the skull, occurs as brain tissue bounces against the skull on the opposite side of the impact (1993, p. 742). Damage to the brain can be categorized as focal or diffuse depending upon how the injury occurred (Hoeman, 2002). Focal damage is localized on either hemisphere and is generally a result of a gunshot wound, falls, intracranial hemorrhage, cerebral vascular accidents, or brain tumors. Diffuse brain damage can result with a closed head injury from the tearing and bruising of brain tissue because of the movement of the brain against the skull at the time of injury (2002, p.601). Whether or not the person has suffered a brain injury is the most important aspect of a head injury (Smeltzer et al., 2000). Although a head injury may initially appear minor, irreversible brain damage and cell death occurs when the resulting cerebral edema causes increased pressure inside the skull. As intracranial pressure increases, brain tissue is interrupted causing cellular damage. Brain tissue requires a constant flow of oxygen in order for the brain cells to remain viable (2000, p.1676).

Primary head injury is damage from the impact, and secondary injury may include complications of recovery that may include cerebral edema, hemorrhage, or infection (Black et al., 1993). These complications negatively impact recovery or even cause cell

death, even in an injury that had originally appeared to be minor (1993, p.742). All medical interventions are intended toward the preservation of brain homeostasis, and the prevention of secondary injury (Smeltzer et al., 2000). Infection is a risk to open fractures, and edema from the injury can be associated with brain tissue damage (Wong et al., 2003). One of the most common complications of a head injury is a subdural hematoma (O'Toole, 1992).

### *Increased age*

Increased age is a factor that predicts a poorer outcome for the person that has sustained a brain injury (Lewis, Collier and Heitkemper, 1996). Other health problems may mimic symptoms of a brain injury, and often the diagnosis of brain injury in the elderly is often delayed due to atrophy, and additional space in the cranium; which results in the delay of the onset of symptoms (1996, p.1704). A misdiagnosed episode of confusion in the elderly may result in a long-term disability, because of brain damage (Smeltzer et al., 2000). The majority of brain injuries do not occur in the elderly; however the older adult may experience more complications, and be less able to tolerate the respiratory or cardiac problems associated with recovery (Black et al., 1993). The presence of pre-existing medical conditions, and poor tolerance level during the rehabilitation phase may make recovery to full independence difficult (1993, p. 752).

### *Statistics and Incidence of Acquired Brain Injury*

#### *United States*

According to Whitman (1994), The National Head Injury Foundation reported 750,000 head injuries occurred each year in the United States. In the United States 1.4 million people sustain a traumatic brain injury each year, and 230,000 people are

hospitalized which is 20 times the amount of persons hospitalized for spinal cord injury (Centers for Disease Control [CDC], 2004). It was estimated that 50,000 people die yearly from brain injury, and 80,000 to 90,000 people experience the onset of long-term disability associated with brain injury (CDC, 2004).

### *Canada*

Acquired brain injuries occurring, each year in Canada, have been estimated at 50,000 (Whitman, 1994; Hamilton Brain Injury Association (HBIA), 2004). This type of injury accounted for 24,265 injuries which is 11% of all injuries reported by the National Trauma Report (Canadian Institute for Health Information (CIHI), 1998). The National Trauma Registry reported hospital admissions for head injuries were a result of: unintentional falls at (43%), motor vehicle collisions at (33%), other accidents (10%), and all other causes at (15%) (CIHI, 1998). The National Trauma Registry 2003 reported 51.4% of injuries, 15,492 of these injuries were classified as head injuries (CIHI, 2003). According to the *HBIA* (2004) it is estimated that the direct and indirect costs of brain injury in Canada is over three billion dollars annually.

### *Ontario*

The Ontario Trauma Registry Bulletin reported fractures and dislocations were the leading diagnosis among trauma hospitalizations followed by cranial injuries (CIHI, 1998). The Ontario Brain Injury Association compiles an *Estimate Incidence of Traumatic Injury in Ontario Report* (Ontario Brain Injury Association (OBIA), 2001). This report projects estimates based on Statistics Canada. The projection for the number of head injuries in Ontario in 2001 was 18,518 out of a population of 11,816,100 Ontarians. However, only 14,973 injured were estimated to seek medical attention. Mild

brain injuries were estimated at 12,046 individuals, moderate injuries were estimated at 1,317 individuals, and severe injuries were estimated at 676 individuals (p.2). Each day in Ontario, it is estimated that 44 people will sustain a brain injury, 16,000 persons a year (HBIA, 2004). HBIA (2004) reported that 84% of Ontario residents with traumatic brain injury have multiple disabilities. According to a study completed by the Ontario Brain Injury Association (2003) the causes of brain injury among 630 adult participants examined include: 51.9% motor vehicle collisions, 8.9% anoxia, 8.9% work related, 8.6% illness, 6.6% falls, 4.3% sports and recreation, 4.0% other, 3.8% bicycle and 3.2% assaults.

#### *Windsor-Essex County*

From January to December 2004, 2,419 emergency room visits at Hotel Dieu-Grace Hospital in Windsor, Ontario were identified as persons who had suffered from an acquired brain injury (ABI Planning Report, 2005). Traumatic brain injuries were identified as 77% and non traumatic were identified as 33%. Injuries were identified as injuries to persons 16 years of age and older. A traumatic injury was recorded as a motor vehicle accident, fall or assault, and a non traumatic injury was recorded as a hemorrhagic stroke, tumor, anoxia, or an infection such as meningitis (2005, p.4).

#### *Injury Prevention*

Motor vehicle crashes are the most common cause of head injuries (Lewis et al., 1996). Falls, assaults, sports related injuries, and recreational accidents account for other causes of head injuries (1996, p.1700). One of the best ways to prevent head injuries is to prevent motor vehicle accidents (Lewis et al., 2004). The consumption of alcohol is a major factor contributing to the incidence of head injuries (Black et al., 1993). Reflexes

are slowed. Changes to perception and cognitive processes, such as decision making, result from alcohol consumption, which leads to accidental injuries. These changes increase the chances of being involved in a motor vehicle accident or a dispute (1993, p.743).

### *Education*

Education of the impact and consequences, associated with a head injury, is the primary prevention for persons of all ages (Black et al., 1993). Educating adults and children about the importance of the use of bicycle and motorcycle helmets is an important part of prevention. Education about the importance of seatbelts and airbags is essential. Informing the public about the dangers of alcohol or drug use while driving a motor vehicle is one of the key prevention strategies associated with head injury (1993, p.743).

### *Legislation*

The incidence of acquired brain injury raises concern and the need for prevention has been addressed in the media in recent years. The media and the Government of Ontario have addressed air bags, bicycle helmets and seat belts. According to the Ministry of Transportation (Government of Ontario, 2003), wearing a seat belt properly is the single most effective way to increase chance of survival in a motor vehicle crash. Airbags do not take the place of seatbelts but reduce the forward movement on impact, and minimize the chance of the driver or front seat passenger colliding with the dashboard or the windshield (2003, p.1). One third of fatally injured drivers in Ontario were not wearing a seat belt at the time of the crash (2003, p.2). Mouzakes et. al., (2001) explored the impact of airbags and seatbelts, on the incidence of severe facial injuries, in

automobile accidents in the State of New York. This study found that individuals who used a seatbelt in a vehicle with an airbag sustained facial injuries at a rate of 1 in 449, and persons with no airbag or seatbelt sustained injuries 1 in 40 (2001, p.1191). The New York State Department of Motor Vehicle (2003) reports non-restrained fatalities are highest among people 16- 44 years of age. Two thirds of brain injury survivors that had been involved in a motor vehicle accident are under the age of 30, and males outnumber females three to one (Smeltzer et al., 2000).

The use of helmets for recreational and organized sports has been addressed recently in the media. Cheng et al., (2000) concluded that many sports are associated with head injuries, suggesting the need for improved head injury prevention. The Government of Ontario (2004) passed the first reading of Bill 109 on June 22, 2004, An Act to Amend the Highway Traffic Act, to legislate that all persons riding on or operating a bicycle, scooter, skateboard, and in-line or roller skates must wear a helmet. The only exception to this law is; a person who uses a wheelchair is not required to use a helmet. According to Leblanc, Beattie and Culligan (2002), about 50 Canadian children and adolescents die from bicycle-related injuries annually, and 75% of all these fatalities are due to acquired brain injuries. A study by Leblanc et al. (2002) in Halifax examined helmet use in 1995 through 1999 and found helmet use increased following legislation mandating helmet use while bicycling. This study concluded that cycling fatalities, due to acquired brain injuries were preventable at a small cost with little inconvenience (2002, p.587). At this time, the University of Toronto/ Toronto Rehab Varsity Athlete Concussion Program is conducting tests on university athletes involved in contact sports.

This study will establish guidelines on how soon an athlete with a mild acquired brain injury can return to playing their sport after an injury (Toronto Rehab, 2005).

## CHAPTER 2

### REVIEW OF LITERATURE

A person who lives with the effects of an acquired brain injury may encounter many challenges to their daily life. Return to work for the survivor of an acquired brain injury has been identified as being important for reintegration into society (Depalma, 2001; Kowalske et al., 2000; Vandiver et al., 2003; Wantanabe et al., 2003; Webb et al., 1995). Physical and psychological limitations may cause the survivor of an acquired brain injury to experience difficulty with return to work. This literature review will begin with a general overview of acquired brain injury, and conclude with a more specific review of barriers to return to work. This review will address: 1) impact of an acquired brain injury, 2) predictors for return to work, and 3) barriers to return to work.

#### *Impact of an Acquired Brain Injury*

The outcome of an acquired brain injury and its sequelae may affect many areas of a person's life. Physical, cognitive, social, and family changes may impact the survivor of the brain injury. Living with the effects of this long-term disability creates many challenges and adjustments for all affected by this unexpected life experience.

#### *Physical changes*

Physical changes for the survivor of an acquired brain injury may include small changes to physical functioning that may not be noticeable to others, or may include physical limitations that may limit independent functioning. Statistics concerning the incidence of brain injury are incomplete. A person may die at the scene of the accident and the cause of death may not be recorded as an acquired brain injury. In addition an acquired brain injury may be regarded as too minor of an injury to treat, or health care is



not sought by the injured person (Lewis et al., 2004). A concussion is a minor brain injury, and can be described as a sudden transient mechanical injury with an interruption of neural activity with no apparent structural damage (Smeltzer et al., 2000; Lewis et al., 2004). The incident involves a period of unconsciousness lasting a few seconds to less than five minutes (Smeltzer et al., 2004). Exhibiting irrational behavior may be the result of damage to the brain tissue in the frontal lobe. Damage to the brain tissue in the temporal lobe may produce temporary amnesia or disorientation. Although a concussion was often thought of as having no significant sequelae, studies have identified that often headaches, lethargy, personality and behavior changes, attention deficits, memory problems, and difficulties with work are often residual effects of the injury (2004, p.1676). Behavioral changes such as irritability, disinhibition, and emotional lability may be present with mild brain injury (Hoeman, 2002).

Post concussive syndrome refers to symptoms of concussion that continue to persist from two weeks to months after the injury (Lewis et al., 2004). According to Hoboubi, Long, Koshy and Ward (2001), post concussive symptoms may persist long after a mild brain injury. The most common post concussive complaints include: 1) fatigue, 2) headache, 3) dizziness, 4) irritability, 5) sleep disturbances, 6) poor concentration, and 7) poor memory (2001, p. 637).

The following section will address research studies and will be categorized as 1) mild, and 2) moderate and severe brain injuries, as most studies discuss moderate and severe in the same study. A study of 157 hospital subjects, identified as having a Glasgow Coma Score of 13- 15 and 109 trauma controls, examined the criteria used to define mild brain injury and how pre-injury characteristics of survivors affect their

neuropsychological outcome after a head injury. This study concluded that the severity of the participant's symptoms decreased with time therefore, their neuropsychological difficulties may not be caused by the mild brain injury, but attributed to pre-morbid traits (Dikmen, Machamer and Temkin, 2001). Individuals with a mild brain injury may not display physical signs of impairment but may experience difficulties coping with the demand of everyday life (Lewis et al., 2004). The injured person may experience symptoms of headache, lethargy, personality and behavioural changes, decreased attention, decreased short term memory, and changes to intellectual ability (p. 1507).

The impact of moderate brain injury might become problematic as physical and psychological symptoms may result in a disability for three months or more (Black et al., 1993). Rehabilitation for the person who has sustained a moderate acquired brain injury may include physical, occupational, speech, and cognitive therapies to return the person to a functional level (p. 752). Reintegration into mainstream society, for a brain injury survivor, may be the most difficult phase of the healing process. A study, in the United States, examined functional limitations in all areas of life of 210 moderate to severe brain injury participants, three to five years after injury. (Dikmen et al., 2003). Results indicated that the severity of the injury was related to the degree of limitation, and found disabilities for the participants were permanent after three to five years, therefore impacting on their personal and societal perspectives (2003, p. 1454).

According to Sbordone, Litter and Pettler-Jennings (1995), the assumption has been that the recovery phase for a person who has survived an acquired brain injury happens within the first six months, and a survivor's full recovery potential is reached within the first two years after injury. In this study, data was collected at one, two, three,

five, and 10.5 years after injury, of 20 male and female subjects classified as having a severe brain injury. Findings indicated improvements may be identified 10 years after injury in seven of the 14 categories that were studied. Significant improvements were identified in 1) work-leisure, 2) cognitive functioning, 3) motor functioning 4) behavioral response to the environment, 5) initiative-independence, 6) social-interpersonal, and 7) language communication (1995, p.291). Research infers reintegration and recovery for a survivor of brain injury may be long term and ongoing long after formal rehabilitation is completed (Dickmen et al., 2003; Sbordone et al., 1995).

### *Quality of life*

Quality of life issues may be as important as the physical outcome of acquired brain injury. A study examining 22, two year post injury, and 136 life long survivors of mild to severe acquired brain injury revealed that the impact of injury was not confined to only physical changes (Gething et al., 2002). Physiological consequences are compounded by social, environmental, the educational system, and the economic system, therefore having a profound effect on quality of life for persons with an acquired brain injury. Ten key issues identified by this study were: 1) poorer quality of life than members of the general population, 2) diversity between participants (people are individuals and failure to take this in account can impact negatively, 3) health (persons with brain injury reported twice as many health conditions as the general population), 4) community and professional attitudes (attitudes and ignorance resulted in major barriers to education and employment), 5) caregivers and families (caring had a great emotional, physical and psychological costs), 6) provision and use of information (difficulties with obtaining and making optimal use of the information),

7) community reintegration (confronting person with the realities of injury and need for emotional support throughout life), 8) compensation (stressful time for individual), 9) service need (“constant battle” to obtaining services associated with income, employment, education and training), and 10) and barriers to opportunities (poor memory, difficulty with concentration and fatigue) (2002, p.9).

### *Cognitive changes*

Cognitive changes, due to mild acquired brain injury, may impact on a person’s quality of life, family functioning, and return to work. Modern medical technology such as magnetic resonance imaging (MRI) and positron emission tomography (PET) identifies, and confirms a mild injury whereas in the past underlying pathologies would have gone undetected using computed tomography (CT) scans (Kay, Newman, Cavin, Ezrachi and Resnick, 1992). Patients diagnosed with transient brain abnormalities in the past would have been seen as non- brain damaged (1992, p.377). CT scan is the best diagnostic instrument to determine craniocerebral trauma, as it allows for rapid diagnosis (Lewis et al., 2004). Mild brain injuries may be identified as neurological disabilities, and symptoms are often displayed as difficulties with cognition. Decreases in cognitive functioning include: poor attention, concentration, memory and impaired perception, processing speed, conceptual and executive functioning (Fabiano and Daugherty, 1998). With accurate diagnosis and intervention the majority of individuals diagnosed with a mild acquired brain injury are able to return to their previous lifestyle including employment (1998, p.6).

Cognitive difficulties such as decreased attention span, poor concentration, memory loss, and impaired perception also impact the lives of persons living with the

effects of moderate or severe brain injury (Dickmen et al., 2003). Exploring the deficits of 210 moderate to severe brain injured participants identified that 60 % reported cognitive difficulties. Due to cognitive problems daily assistance was required to perform activities of daily living (2003, p. 1454).

Teadsdale, Hansen, Gade and Christensen (1997) studied 55 moderate to severe brain injury subjects who had participated in a neuropsychological rehabilitation program. Their study examined neuropsychological test scores to assess the effectiveness of cognitive rehabilitation before and after an intensive rehabilitation program. Results indicated significant and small improvements in cognitive test scores after rehabilitation. However, no evidence that improvement in test scores from pre to post program was associated with subsequent positive outcome. Positive outcome was identified as return to education or return to work (1997, p.38). Ponsford, Olver and Curran (1995) examined 175 brain injury participants (89% were identified as severe brain injury) from an intensive hospital rehabilitation program in Victoria, Australia. Their results indicated that two-thirds of the sample reported cognitive, behavioral, and emotional change two years post injury. Word finding difficulties, reduced processing speed, poor concentration, problems with planning, poor organizational skills, impulsiveness, and initiative were common cognitive complaints. Behavioral changes were identified as irritability, increased short temper and increased aggression. Emotional changes were identified as increased anxiety and increased feelings of depression (1995, p.7). Results of this study identified that 35% of the persons employed, and 48% attending school prior to injury were able to return to work or school. Also, only 15% were able to return to their previous recreational activities and interests (1995, p.6).

A study examining neurological assessment of 152 outpatients with brain injury found positive home, school or work outcomes were related to processing speed of information, memory, and simultaneous processing abilities (Girard, Brown, Buenett-Stolnack and Hashimoto, 1996). Difficulties with memory were identified by 56% of 186 participants of a study conducted with survivors of moderate to severe injury on an average of seven years post injury (Tennent et al., 1995). Results indicated that, in the long term, that over one-third of the participants were experiencing difficulties that preclude them from living a normal life (1995, p.602).

### *Social changes*

Social reintegration after a person experiences an acquired brain injury may have an impact on a person's quality of life. In a three to five year follow-up study of 210 moderate to severe brain injury survivors with respect to social integration, 55% reported no difficulties in this area (Dickmen et al., 2003). However, 10% found it more difficult to relate to others, 25% stated they had fewer friends, and 10% stated they were isolated and dependent on parents, families, or an institution (2003, p. 1455). Similar results were found from 186 moderate to severe brain injury survivors and their caregivers, seven years after injury (Tennent et al., 1995). Reported were socially problematic behaviors such as 1) making mistakes when talking (33%), 2) being rude (27%), 3) making silly jokes (17%), 4) embarrassing behavior (15%) and, 5) hogging conversations (3%). In addition, loneliness was identified by 22% and 36% of the survivors experienced difficulties occupying their time. Quality of life was reduced for both survivors and their caregivers, and the study recommended appropriate counseling, vocational counseling, and family support in the years immediately following a brain injury (1995, p. 600).

Social skills may be compromised by the injury and further reduced by consistent low self-esteem and isolation. A qualitative evaluation of a strengths-based approach, *Circles of Support*, demonstrated a capacity for making a difference for all five men and five women participants diagnosed with having a moderate to severe brain injury (Rowlands, 2001). This study identified participants as being socially isolated, lonely, having no community involvement, and lacking an intimate relationship. *Circles of Support* acknowledged the strengths of the individual, their family members, and the community. The individual shared his or her dreams with circle of members. As a result of development of friendships and empowerment of the individual, the focus is directed for the individual to have the power to take control of their life. The study completed in-depth interviews with brain injury survivors, family members, and circle members. Findings of this study indicated participants demonstrated a capacity to engage in social relationships once initiated by the *Circles of Support* (2001, p. 283).

The issues of social isolation and reintegration of the person who has sustained an acquired brain injury is being examined by The Rehabilitation Research Center for Traumatic Brain Injury and Spinal Cord Injury in California (The Rehabilitation Research Center, 2005). The research center is currently enrolling participants in a community based mentoring program to assist with social issues for persons who have an acquired brain injury. This study is recruiting interested participants between 16 to 26 years of age, interested in returning to school or work, have an acquired disability, and interested to be mentors for a participant with a disability (2005, p.1).

In a study examining 73 moderate to severe brain injury survivors at Craig Hospital in the State of Colorado, one year after injury, social integration was

significantly correlated with perceived attitudinal barriers, indicating negative attitudes of others may be related to decreased participation (Whiteneck, Gerbart and Cusack, 2004). This study used a 25 item instrument scale to measure the frequency, magnitude, and overall impact of perceived environmental barriers. The scale contained questions regarding physical, environmental, family and community attitudes, access to technology, government policy, and employment issues. The goal of the study was to quantify a range of barriers that keep people with disabilities from functioning within their communities (2004, p. 194).

Psychosocial functioning may be one of the most important issues for the survivor of acquired brain injury. Results of a study of 74 mild to severe brain injury participants and 46 non-neurological matched controls in the United Kingdom, showed less use of emotion focused, avoidance, and wishful thinking strategies predicted better psychosocial performance (Malia, Powell and Stewart, 1995). Coping was defined as a dynamic process, changing as the problem changes. This study found that despite brain damage and impaired cognition, participants made use of a similar pattern of coping skills as did the non-neurologically injured participants. The study suggests it was advantageous for participants to face their problems and not avoid them in order to obtain psychosocial independence. This study indicated the importance of the service provider to assist the person with the acquired brain injury to perceive their problems clearly, and to develop a positive problem solving approach to coping (1995, p.615).

#### *Family changes*

Family members and the health and welfare system may bear the costs associated with acquired brain injury. Family structures and roles within the family system may



change after a family member has sustained an acquired brain injury. A spouse's role may have to change to accommodate the care giving needs of their partner. One-third of moderate to severe brain injury survivors in a study of 210 participants were unable to be left alone three to five years after injury (Dikmen et al., 2003). A study by Tennant et al. (1995) of 186 moderate to severe brain injury survivors, despite reports of two thirds of the participants having good recovery, the study identified that one third of the survivors continued to experience effects preventing them from living a so-called normal life. Their results indicated that quality of life particularly the ability to occupy one's time was problematic. Furthermore, the survivor's inability to occupy time affected quality of life of the caregiver as well. Sixteen percent of the participants required regular personal support with activities of daily living. The study indicated that the participants often fall between the separate responsibilities of health, social and employment agencies, therefore may experience difficulties with accessing assistance for retraining or maintaining employment (1995, p. 603). The consequences of the injury may affect and change roles of all members of a family.

Some family members may be able to cope with the physical disabilities of severe brain injury however; changes to relationships may become problematic due to emotional and behavioral changes to their loved ones (Depalma, 2001). Some caregivers have identified a consequence of the injury as a loss of the survivor, since the injured person has changed emotionally when compared to their psychological status prior to their injury. This study identified that family members were often angry, with the survivors, because of what life changes had happened to them. The narratives of the participants identified losses as including physical and cognitive functioning, however, the most

frequent identified losses were; 1) changes to family relationships and friends, 2) former lifestyle, and 3) employment (2001, p. 44).

Depression and aggression are identified as two frequently diagnosed psychiatric disorders that may cause stress for family members (Miller, Burnett and McElligott, 2003). This research indicated that counseling and support groups should be the foundation of therapy (p.12). In a study in St. Catherines, Ontario, 72 pairs of brain injury survivors and family members were identified as having positive care feelings more than negative ones, however higher levels of impairment were generally predictive of mood disturbance and an increase in negative feelings about providing care (Wells, Dywan and Dumas, 2004). Research examining quality of life issues for persons with an acquired brain injury and their caregivers found significantly more psychosocial problems reported by the individual and their care giver than the general population (Gething et al., 2002).

#### *Predictors for Return to Work*

Return to work for the survivor of mild, moderate or severe acquired brain injury may be a way of identifying a successful recovery. Employment, community integration, positive self-worth, independence, and returning to previous lifestyles are important goals after one has experienced a brain injury (Depalma, 2001; Kowalske et al., 2000, Vandiver et al., 2003; Wantanabe et al., 2003). According to Webb et al., (1995) employment had the strongest direct effect on a moderate to severe brain injury survivor's quality of life.

#### *Rehabilitation and supportive employment*

The literature is mixed when identifying the percent of brain injury survivors and

their return to work. Johnstone, Vessel, Bounds, Hoskins and Sherman (2003) examined predictors of success for 78 moderate to severe brain injury participants of a vocational rehabilitation services program in the State of Missouri. The average time of unemployment prior to vocational services was 2.7 years. The three best predictors of success were identified, in this study, as: 1) counseling, 2) guidance, and 3) on the job training (2003, p.164). Findings in this study indicated 17% were rated as being successfully employed. The vocational rehabilitation services program found new employment for most participants to working in service, clerical and industry, as well as two people were found employment in a sheltered workshop, and one person held a professional position. The professional was the only participant that had held a position as a professional prior to injury (2003, p.165).

Ponsford et al., (1995) examined a group of 175 moderate to severe brain injury survivors, who had participated in an intensive hospital rehabilitation program, in Australia. Only 61% of the participants were employed prior to injury and 15 % were students. This study found that 2 years post acquired brain injury; 33 % were employed full time, and 9 % were employed part time (1995, p.6). This study did not specify if any individuals were able to return to their previous employment. Johnson (1998) studied work status of 64 moderate to severe brain injury survivors, studied in the United Kingdom, 10 years after injury. This study indicated 42 % were employed, 20 % showed an irregular pattern of work, and the remainder had made little or no attempt to work. The study found those who were working at the time of the injury and returned to previous employment identified support in the work environment an important factor in determining outcome. Rehabilitation interventions within the work environment were

instrumental in enabling return to work and re-establishment in the work force (1998, p.73). Gamble et al., (2003) identified 48% of 1,073 moderate to severe brain injury survivors, as being competitively employed, in a study that examined disparities in vocational rehabilitation outcome of survivors residing in southeastern United States. Supportive employment was identified as a significant positive predictor of competitive employment. (2003, p. 55).

Return to work for 120 moderate to severe brain injury survivors in Washington, D.C., examined outcomes one year after rehabilitation (Salazar et al., 2000). Participants were randomly assigned to either an institutionalized cognitive rehabilitation program or a limited home rehabilitation program. The research questioned if traditional institutionalized rehabilitation programs were effective and cost efficient method of returning brain injury survivors to their maximum potential. This study found that rehabilitation was a predictor of positive outcome of return to work, however no difference was found with outcome between participants of an inpatient rehabilitation program and a limited home rehabilitation program (2000, p.3080). Coetzer, Hayes and Toit, 2002 studied employment outcomes for 65 moderate to severe brain injury participants, who had participated in a rehabilitation program, and concluded that rehabilitation should address employment issues earlier in the rehabilitation process. It was identified that the majority of persons that had returned to work had returned within the first year after their injury (2002, p.231).

According to Vandiver et al., (2003) supportive employment, by utilizing the Brain Injury Assessment Model, is a successful approach for return to work. This article describes a multidisciplinary team approach that includes medical, vocational,

neuropsychological, team meetings, situational assessments, job search and placement, and follow-up components. In a three year period, the agency provided services to 63 individuals diagnosed with a mild brain injury and 53 individuals were placed into competitive employment. Follow-up statistics indicate that 84% had identified a successful return to work (2003, p. 459). A study that examined supportive employment indicated that it is a significant positive predictor of competitive employment outcomes (Gamble et al., 2003). However, lower wages, decreased hours of work, monetary costs to maintain supportive employment, and service time costs were issues identified as needing to be addressed further (2003, p.55).

Kowalske et al., (2000) described successful outcome using an enablement model in a qualitative study of three participants with varying degrees of acquired brain injury disabilities. This outpatient rehabilitation program in Dallas, Texas described employment from re-entry to support within the work environment. The enablement model in this study was described as enabling vocational environments which were structured for a participant's individualized job environments. The outcomes of these three case studies identified successful return to work for the participants (2000, p.998). Johnstone et al. (2003) examined outcomes of 78 moderate to severe brain injury participants in Missouri. This study indicated that 14 times higher employment success was identified if the client was provided with counseling and guidance (2003, p.164).

### *Cognitive factors*

Cognitive factors have been studied as predictors for return to work for the person with an acquired brain injury. In a study examining 90 moderate to severe acquired brain injury survivors in Australia, results showed lower levels of perceived stress significantly

predicted higher self reported vocational success (Kendall, 2003). Participants in this study were interviewed at discharge from the hospital; two months post discharge, and six months later. The nature and severity of the injury appeared to be unrelated to vocational adjustment in the initial periods following brain injury. However, the data identified that consistent employment disruptions may be associated with frontal lobe lesions in the brain and may indicate serious cognitive impairment. In addition, emotional distress was highly correlated with poor return to work outcomes.

(2003, p. 42). Performance IQ score on the Wechler Adult Intelligence Scale-Revised was found to be the most significant predictor for return to work in a study investigating success of 45 brain injury survivors one year after rehabilitation in Toronto, Ontario (Ip, Dorman and Schentag, 1995). Cognitive factors may be a factor when predicting return to work for the survivor of brain injury.

#### *Pre morbid factors*

Research implies many variables can be identified when addressing return to work for the person with a brain injury. Johnstone et. al., (2003) in a study examining predictors of success for state vocational rehabilitation in the United States, found that the majority of the participants of this study were young and male, and some were identified with having limited education, multiple injuries, substance abuse history, and learning disabilities. This study suggests pre morbid factors may have a role in predicting outcome (2003, p.164).

Teasdale et al. (1997) in examining return to work for 55 survivors of moderate to severe brain injury, in Denmark, found it was difficult for an older patient to find employment as educational programs were not available to them. This study found it was

often assumed the older patient would settle for early retirement or a disability pension (1997, p.37).

In a study examining 90 participants with mild, moderate, and severe acquired brain injuries found that perceptions of oneself prior to the injury were important in determining the extent to which reactions to disability influenced outcomes. The meaning of disability, and the participant's reaction to it were important factors with return to work. Participants who had strong personal motives to work and a sense of meaning with their work were more likely to return to their previous employment (Kendall, 2003).

The Mayo Clinic Traumatic Brain Injury Model System is currently doing a research study to examine long term outcome in people diagnosed with significant traumatic brain injury from 1935 to 2000. Specific goals of the project are: 1) identify a population based sample stratified by severity, 2) identify factors associated with positive outcomes such as employment, relationships, aging, independent living, and satisfaction and, 3) examine relationship of outcomes of age, gender, and severity (Mayo Clinic College of Medicine, 2005). This study may identify predictors for return for work for the person with an acquired brain injury and may provide service providers with information to assist with an individual's return to work.

Predictors for return to work for the survivor of an acquired brain injury have been studied and many predictors have been identified. Major predictors of return to work, in the research studies, identified in this paper are 1) rehabilitation and supportive employment, 2) cognitive factors, and 3) pre morbid factors.

### *Barriers to return to work*

Return to work for the survivor of a mild, moderate, or severe brain injury may be considered a good indicator of adaptation. However, successful return to work may be problematic due to barriers. Barriers may be environmental, perceptions of the survivor, or perceptions of employers and the public. After a person survives an acquired brain injury, return to work is a goal that may often equate to successful recovery.

#### *Environmental barriers*

Environmental barriers may be problematic for the survivor of a brain injury. A study by Whiteneck, et al., (2004), involved 73 participants of a Traumatic Brain Injury Model Systems program in the State of Colorado. This study examined 25 barriers for mild, moderate, and severe brain injury survivors. Results of this study identified participants diagnosed with a mild brain injury reported more environmental barriers than participants diagnosed as having a moderate or severe brain injury reported.

Environmental barriers were described as transportation, design and layout of home and office, natural environment such as terrain, and climate and other aspects of the surroundings such as lighting, noise and crowds. These researchers proposed, that the person with the mild injury might have a better insight into their needs, than the person identified as having more injury. In addition, people needing physical assistance reported more work or school barriers, where as, people needing cognitive assistance reported increased difficulties overall and policy barriers (2004, p.202).

#### *Perceptions of survivors of acquired brain injury*

A four- year project in Australia, explored quality of life issues for mild to severe brain injury survivors, spinal cord injury survivors, and their caregivers (Gething et al.,



2002). This study found that brain injury survivors were concerned first with cognitive consequences of their injury. Second in importance, concerns with psychological adjustment issues such as: community, educator and employer attitudes, and ignorance of brain injury. This study identified that the impact of injury is not restricted to direct medical and physical cost, but is compounded by social, societal and personal factors. This study found that both brain injury survivors and caregivers demonstrated a more external locus of control than the general population. This study had a comparison group of 57 individuals from the general population (2002, p.4).

Brain injury survivors may experience difficulties with their own attitudinal issues when exploring return to work issues. According to Rotter & Hochreich (1975), internal locus-of-control of reinforcement proposes that people believe what happens to them are a result of their own behaviors and attitudes. In contrast, a person with an external locus-of-control believes what happens to them are a result of luck, chance, fate or powerful outside factors or forces. Coping strategies and locus-of-control following traumatic brain injury were examined with 53 male subjects in a study completed in the Province of Manitoba (Moore and Stambrooke, 1992). This study found that lower external-locus-of-control was associated with significantly lower mood disturbance, physical difficulties and less depression. This study indicated that the age of the person with a brain injury may play a role in coping strategy used and their locus-of-control beliefs. In addition, lower locus-of-control belief was associated with higher self-esteem (1992, p.91).

#### *Perceptions of employers and the public about acquired brain injury*

A study by Bricout and Bentley (2002) found that job applicants that were not identified as having a disability were rated as more employable, than applicants identified

as having a severe disability. The severe disability in this study was identified as an acquired brain injury. This quantitative study examined perceptions of a random sample of 1000 employers belonging to a national association of human resource managers. An unanticipated finding of this study was that physical and psychiatric disabilities were rated the same, contrary to the researcher thoughts that an anticipated higher employability rating would be found for physical disabilities (acquired brain injury) than psychiatric disabilities (2002, p. 92). This study indicates the employers perceptions may be a barrier to employment.

Because of the lobbying efforts of the Brain Injury Association of Chatham-Kent, Bill 125, the Ontarians with Disabilities Act, has included the words “brain injury” in the definition of disability (BLACK, 2004). According to Perrin (1999), the major barrier for persons with disabilities is the attitudes of others, including employers, the public, and administrators of government programs including Human Resource Development Canada employment programs. Perrin contends the lack of understanding and negative attitudes excludes people from society and the workplace. Lack of interaction and lack of opportunity is the result of constant rejection, which takes its toll on the self confidence of people. Despite a demonstrated return on investment, that can enable people with disabilities to work, attitudes are often responsible for the lack of understanding of the costs of disability (1999, p.48). Rehabilitation approaches are most likely to be effective when they are focused on the workplace and practically oriented. A coordinated approach with the individual involved with disability management and supported employment is important. Contrary to common perceptions, workplace accommodations are not costly, some at no cost, and with half costing less than \$250.00 (1999, p.50).

The social model of disability can be identified as persons considered disabled by society's failure to accommodate their needs and societal responses to the impairments (Barnes, 2002). Drake identified four factors that contribute to the exclusion of persons with disabilities as: problems of power, levels of participation, impact of environmental barriers, and majority mandate, the majority being persons without disability. The research indicates society's attitudinal barriers may play a role in the exclusion of the persons with disabilities (2002, p. 382).

#### *Summary of review of literature*

A person who lives with the effects of an acquired brain injury and its sequelae may encounter many challenges to daily life. Physical and psychological limitations may cause the survivor of a brain injury to experience difficulties with return to work. This literature review has addressed; 1) impact of an acquired brain injury, 2) predictors for return to work, and 3) barriers to return to work for the person who may have to live with the long-term consequences of an acquired brain injury. Impact of acquired brain injury identified in the research studies in this paper identified physical, cognitive, social, and family issues as problematic. Predictors for return to work were identified as rehabilitation and supportive employment, cognitive factors, and pre morbid factors. Barriers to return to work, identified in the research studies in this paper, were identified as environmental barriers, perceptions of acquired brain injury survivors, and perceptions of employers and the public about acquired brain injury.

Changes in many areas of the person's daily life for the person who has suffered from the acquired brain can become frustrating and problematic. The changes not only affect the person but may affect all areas, including family life and their employment.

After a person sustains an acquired brain injury, they may experience a recovery period that is extensive. This person may appear physically to be the same person as before the injury, but may not be able to perform everyday tasks as they had in the past.

## CHAPTER 3

### DESIGN AND METHODOLOGY

#### *Constructivist Research*

Constructivist research emphasizes cognitive structures or schemas, such as organizing philosophy, arrangement, and interactive feedback from the environment (Rodwell, 1998). Reality and meaning is constructed in a way that is reflective of all participants. Constructivist research is subjective, and is set in an interpretive framework in which reality is relative and perspective. In constructivist research the researcher shares the process with the participants. The researcher does not give up power, or gives the power to the participants; however, constructivists recognize that participants have power and attempt to facilitate its discovery among those participating in the research study. Assumptions about important aspects of the knowledge building process include reactivity, indeterminacy, and interaction (1998, p.21). Qualitative research develops as the study progresses.

Quantitative research in social work is positivistic. In social work, positivistic research works from the problem question to a generalizable conclusion. Results of positivist research are quantitative-descriptive in numerical or statistical form. The researcher's role in positivist research is passive and detached from the subjects of the study (Rodwell, 1998; Holosko, 2001).

Qualitative research studies use methods that attempt to find the nature of the social and psychological phenomenon (Epstein, 1988). Qualitative methods can collect detailed descriptions of social reality and these descriptions can serve as ends-in-themselves or in generating useful hypotheses that may contribute to a quantitative study.

This method describes the reality of the social construct from the point of view of the participants within the system being studied. Therefore the active participants can tell the researcher how, why, and what they are doing in the social situation. One type of inductive approach for theory development has been referred to as grounded theory (1988, p.188). Grounded theory is a description or explanation of the phenomenon that results as findings or themes emerge from the data during analysis (Glasser, 1995; Rodwell, 1998). Instead of a theory that is tested, grounded theory is grounded in the unique experience of the content of the inquiry in order to generate theoretical concepts (Rodwell, 1998). Concepts are developed from the data disclosed by the participants involved in the study.

This researcher has completed a literature review, has had social work experience intervening with brain injury survivors, however, the focus of this study began as the inquiry process began with the participants. In other words, the researcher has allowed each participant to tell their story and the researcher respected their story because it is their reality. The final form and the real question of the study will be determined by the context and the interaction with the participants (Rodwell, 1998).

Several qualitative research studies have been conducted with persons who have sustained an acquired brain injury (Gething, et al.; McColl et al., 2000; Nochi, 1998; Rowlands, 2001). A qualitative research study, using the grounded theory method, was used by Nochi (1998). A study of 10 mild to severe brain injury survivors from the United States identified three themes through the use of narratives (Nochi, 1998). The grounded theory method was used to identify the themes as: 1) loss of clear self-knowledge, 2) loss of self by comparison, and 3) loss of self in the eyes of others. This

study, through the use of face-to-face interviews developed a deeper understanding of the sense of self that people with acquired brain injury experience (1998, p.870).

### *Goal of study*

The goal of this research study; Acquired Brain Injury: Journeys from pre-injury to return to work, was to: use the participants' narratives to gain insight into the participants' journey from before they sustained an acquired brain injury, until their return to work. This study used the phenomenology method to describe phenomenon in context, identify themes, and to develop a deeper understanding of the return to work issues a person encountered after recovering from an acquired brain injury. This study was interested in understanding the person's journey and human experience from the individual's own frame of reference.

The participants' narratives have become the basis of this study. Narratives or hearing the participants' stories, as they view it themselves, is a common tool for the social worker during all stages of intervention. The researcher of this study was comfortable using this investigative method because it is used in every day practice, when gathering information to assist clients. However, it was difficult, at first, to put oneself in the researcher's role when the counselor role is a more comfortable position. The researcher role became more comfortable the more interviews completed. During the first interview, the researcher realized that the experience of having an acquired brain injury had impacted the participant's life in many ways; since the person had returned to work, the participant was not looking for assistance but was willing to participate in the study so that others may be helped. This realization on the researcher's part made the researcher's position of counselor easily abandoned for the new role of researcher.

This research study's goal was to explore the participants personal experiences and insights, and examine what was important to the individual, at all stages, from before pre-injury to return to work. Structured interviews do not allow the participant to provide the interviewer with what may be most important to the participants; therefore questions in this study were open-ended and tentative in order to allow the inquiry process to emerge. The face-to-face interview was an appropriate tool to use with a person with an acquired brain injury, because the person may experience difficulties understanding questions asked and may be more comfortable with telling their story.

The skill of observing, listening, speaking, and reading are important elements of the data collection (Rodwell, 1998). These skills were utilized before, during, and after the interview process. The researcher observed the environment where the participant was being interviewed. Field notes were kept in a journal that became part of the data. Information from the participant's ABI client file was reviewed after each interview was completed. Information retrieved from the client file included medical data from the acute care hospital or referral source, client's level of education, psychological testing results, and symptoms the client identified as problematic at the intake process.

#### *Participation of Acquired Brain Injury Consultation Team members*

This research study began with the participation of the outpatient Acquired Brain Injury Consultation Team (ABI) members of Windsor Regional Hospital. The ABI Consultation Team provides help to persons who have been affected by an acquired brain injury who require assistance with community reintegration, and psychosocial functioning. The professional staff includes a program manager, psychologists, a social worker, and an occupational therapist. Individualized client assessments are completed



by the team professionals, and through collaboration with other health professionals, the team members promote optimal care for the person who has survived an acquired brain injury. Short term intervention and education is provided to individuals, family members, and other professionals to assist with the management of altered lifestyles of the person who has been affected by an acquired brain injury.

#### *Criteria for choosing participants*

A meeting was held with the ABI Consultation Team members on October 4, 2005, at the Western Campus of Windsor Regional Hospital. All team members were present. The purpose of the meeting was to explain the research study, and provide the team members with criteria for choosing participants for the study. The researcher was not able to choose the participants because access to client and client files were not available until the team members obtained permission from the participant.

The researcher outlined the research study and the criteria for choosing participants for the study. Inclusion criteria were: 1) person who suffered a mild or moderate acquired brain injury, 2) employed one year prior to injury, 3) 19 to 60 years of age, 4) Acquired Brain Injury Consultation Team referral and service provided, 5) return to work after injury, and 6) a family member willing to participate. Letters of Information, for the study, were provided to all members of the team.

The ABI Consultation Team members agreed to participate in the study, and all members of the team signed Consents to Participate in the study. Team members agreed to identify participants for the study. It was explained their role would be to contact clients who had been provided service from their program, and briefly explain the study. They were requested to obtain verbal permission for the client's telephone number, and

home address to be given to the researcher. After permission was obtained, the team member would explain that a Letter of Information outlining the study would be mailed to their home for them and their family member to review. In addition, their role was to inform the potential participant that a telephone contact would be made by the researcher to schedule an interview. The ABI Team members were requested to document, in the client record, that the person had been contacted for the study, and had provided verbal permission for their name to be provided to the researcher. By having the ABI Team members identify participants, this procedure maintained confidentiality for their clients that were contacted but did not wish to participate in the study.

#### *Recruitment of participants*

The Acquired Brain Injury Consultation Team members recruited the participants for this research study. Twelve names were provided to the researcher. One female potential participant was eliminated because the researcher had provided counseling services to her in the past. One male potential participant was eliminated because his wife refused to participate. One male participant was contacted several times, after the third contact he stated he would contact the researcher with a date for an interview. He did not contact researcher, therefore was eliminated from the study.

Members of the ABI Consultation Team reported they experienced difficulty obtaining participants for this study. They reported many of their clients had relocated and were not able to be contacted. They stated many of their clients did not return to work. Several clients were contacted to query if they would like to participate, however, an ABI Team member reported some clients did not want to participate because it was too difficult or painful to discuss their injury.

### *Transparency of researcher and locating self*

This researcher has been employed in the health care field for over 30 years. A variety of experiences have been encountered as a result of being employed in the nursing profession for 16 years, and being a social worker for the past 15 years. Numerous exposures to persons that had sustained an acquired brain injury have been experienced. Counseling survivors of acquired brain injury was provided at the Rehabilitation Day Hospital and Homecare clients of Community Care Access Centre when the researcher was the social worker for these programs. In the past, the researcher was the social worker at the Acquired Brain Injury Consultation Team at Windsor Regional Hospital, for one and a half years. For two years the researcher worked, as a social worker, on the Rehabilitation Unit at Western Campus of Windsor Regional Hospital, and provided services to survivors of acquired brain injury. Presently, the researcher works on an acute care medical unit at the Metropolitan Campus of Windsor Regional Hospital. Job title on this unit is Case Manager, Social Worker and Discharge Planner. With these past and present experiences it would be difficult to not have any biases.

### *Biases*

Biases may be identified as assumptions prior to the interview. Biases of the researcher include: 1) pre morbid work history (if the person experienced difficulties with employment prior to injury, the difficulties will prevail and exacerbate after injury), 2) the greater the family support, the return to work will be a success, 3) survivors of severe injury do not return to work, 4) vocational counseling should be initiated while the person is hospitalized. These biases have impacted the findings of this study. Although all attempts were made to not think as a social worker and a health care provider biases

can be identified as attempting to draw conclusions of the study before the data was analyzed.

When the researcher was the social worker on the Rehabilitation Unit, the typical rehabilitation patient, that had survived an acquired brain injury, often had multiple physical disabilities which took priority over a psychosocial need, or return to work issues. The patient often was more interested in physiotherapy sessions because ambulating independently was more important to them, at that time. The patient often voiced that once they returned home, after discharge from the hospital; they will no longer have difficulties. Family members seemed to experience difficulties dealing with the reality of the situation because, often, the person's appearance was the same as before the injury, therefore they thought that once the person returned home everything was going to become normal again. No follow-up was completed after the discharge from the hospital, therefore, the researcher was not able to identify if the person had returned to work or had experienced difficulties adjusting to the realities of their new situation.

When the researcher was the social worker at the Day Hospital, as well as an in-home counselor for a home care program, the experience was that clients did not voice their concerns for several months after they had returned from the hospital. They began to disclose their concerns when behaviors became problematic at home because the person did not return to their former self. In other words, the person began to realize that their life was not going to be like it was before the injury occurred.

## *Data Collection*

### *Profile of participants*

After reviewing a Letter of Information, nine persons who had suffered an acquired brain injury and nine participating family members agreed to be interviewed for this research study. The participants consisted of six males and three females. Five participants were married and had their spouse present during the interview. Two participants, who were single, were interviewed along with their mothers. One single participant was interviewed with her ex live in boyfriend, and one divorced participant was interviewed with his brother-in law. All participants were asked, prior to the interview, if they were comfortable being interviewed with their significant other being present. All participants were interviewed with their family member present during the interview. Interviews were conducted from October 2005 to January 2006.

### *Telephone contact*

The first contact the researcher had with the participant was a telephone contact to the client's home. The Letter of Information was discussed and each participant and family member was asked if they were willing to participate in the study. After a brief telephone conversation outlining the research study, an appointment was scheduled for an interview in their home. At that point, the researcher did not have any knowledge about the participant other than their name, address, telephone number, and that they had service provided by the ABI Consultation Team.

### *Interview question*

At each interview the researcher began with the statement: I understand you experienced an acquired brain injury. 1) Would you be willing to explain how you

sustained your acquired brain injury?, 2) What experiences did you have during your recovery?, and 3) What was the process for you to return to work?

### *Interview*

All interviews were completed in the participant's home with a family member present. A detailed explanation of the study was provided prior to the interview. The Consent to Participate in Research form and the Consent to be Audio-taped form were explained to the participants and family member, and signed, prior to beginning the interview. Limits to confidentiality were discussed and the participant's ability to withdraw from the study at any time was explained. Each participant was asked prior to the interview, if they would be comfortable being interviewed with their family member present. All participants, at their request, were interviewed with their participating family member.

Interviews were audio-taped to allow the researcher to focus full attention on the participant's story and provide less distraction for the participant. Each audio-tape was transcribed verbatim by the researcher. Names of the participants were changed, and any identifying information was removed from the record of the researcher. Audio-tapes were kept in a locked cabinet to ensure confidentiality. The researcher explained to the participant and the family member that the only information obtained prior to the interview was 1) their telephone number and address, 2) they had experienced an acquired brain injury, and 3) they had services provided by the ABI Consultation Team.

After each interview was completed, the researcher went to the ABI Consultation Team to review the participant's outpatient client file. The majority of information

obtained in the client file was self-report; therefore much of the same information that the participant had provided during the interview was in the client file.

### *Confidentiality*

The first contact with participants they were informed, by the Letter of Information, that confidentiality would be maintained. Limits of confidentiality were outlined in the letter, and addressed with each participant and participating family member before the interview began. In addition, in the participant's home, the Consent to Participate, and the Consent to Audio-tape the interview was explained. Each participant and participating family member was informed that their name and any identifying factors would be changed so they would remain anonymous. They were informed that the interview tape would be kept in a locked cabinet. It was discussed with each participant that the interview could be terminated, by them, at any time without consequences. In addition, the researcher assured them, that the ABI Consultation Team members did not provide any details about them, or their injury before the interview. These procedures assured that the participant had full informed consent prior to participation in the study.

### *Rigor of the study*

Constructivist rigor is considered in two dimensions; 1) trustworthiness, and 2) authenticity (Rodwell, 1998). Trustworthiness shows elements necessary to ensure there can be confidence in the research findings. The features of trustworthiness are: 1) credibility, 2) dependability, 3) confirmability, and 4) transferability. The system of trustworthiness is documented in the form of an audit trail that includes all raw data. Trustworthiness is entirely dependent on quality data collection and analysis (1998,

p.102). Elements of Authenticity are: 1) fairness, 2) ontological authenticity, 3) educative authenticity, 4) catalytic authenticity, and 5) tactical authenticity. According to Rodwell 1998, because of the association between the quality of the research product and the quality of the research process, demonstration of fundamentals of trustworthiness can serve the purpose of authenticity.

This researcher's audit trail is in the form of documentation that is a running account of all progress from start to finish of the study. A system of tracking all raw data was used by the researcher before, during, and after each interview. Field notes were kept on all participants. These field notes contained a description of the participant's environment, any information relevant in telephone conversations prior to the interview, and the researcher's thoughts after the interview.

During the interview, the researcher jotted down important thoughts and feelings of the participant, as well audio taping the interview. Each interview was transcribed by the researcher as soon as possible after the interview. Notes were kept during the data analysis process to assist the researcher with formulating categories. This audit trail tracked the development of the research. The researcher used all relevant data in the final paper. All stages of the process were overseen by the researcher's academic supervisor. This process allows outside researchers to replicate this study.

Credibility and truthfulness of this study can be identified by the chains of evidence and sets of narrative accounts that are plausible and credible. The chain of evidence is also linked with the data retrieved from the client file at the ABI Consultation Team. According to Franklin and Ballan (2001), it is recommended that 8-15 cases are



needed to establish consistency in findings. This study of nine participants has established consistency in the results.

Each interview was approximately one to one half hours in the client's home with participant and a participating family member. The time allowed the participant and participating family member to become comfortable with the researcher. This time frame provided the participant with rich descriptive data. The interview was conducted in the participant's home so the participant and family member would be comfortable with the environment. Each participant and family member was interviewed one time.

#### *Method of Data Analysis*

This study has explored, through face-to-face interviews, the journeys of the nine participants who have recovered from a mild or moderate acquired brain injury. Analysis of the data begins with the first contact and continues until the final report is completed (Rodwell, 1998). Analysis of this research study began with the first interview of the participant. Interviews and the emerging themes that each interview had shaped were part of the analysis process. Formal data analysis was completed when all of the interviews were completed, and transcribed. Interviews were transcribed by the researcher.

Organizing the data began by eliminating all of the researcher's conversations, and numbering each line of each interview. Each data unit was recorded on an index card with a: 1) coding for the participant, 2) the numbered line that the unit was taken from, and 3) a color-coding to identify the category. An example an index card identifying a participant, a category, what line of conversation, and the unit of data are:

P3MFR ---purple line---3-254

In a fog, yah, I would say in the recovery stage

Explanation of data card:

P3MFR- refers to: participant 3, married, female, recovery

purple line- refers to the category "recovery"

3-254 – 3<sup>rd</sup> participant, line number 254

In a fog, yah, I would say in the recovery stage --- a data unit that can stand alone

Interviews were analyzed identifying data units that were able to stand alone.

Data units consisted of a word, a sentence, or several sentences that had meaning on its own. Each data unit was put into categories. Analysis occurred through three types of coding: 1) open, 2) axial, and 3) selective. Open coding labeled chunks of data according to categories. Placing categories in a relationship within a framework of conditions, consequences, and contexts is axial coding. Determining the core categories completed selective coding. These categories were mutually exclusive. Comparing the data units completed sorting of the data units. The next process was the lumping, which brought together the categories or relative themes. The reconstruction phase compared units and identified common themes or categories that seemed to be related. According to Rodwell (1998) in most cases no more than nine categories capture the whole data set. After analyzing the data from the nine interviews, phases, themes, and sub themes were identified.

## CHAPTER 4

### RESULTS

#### *Profile of the participants*

Nine individuals participated in this research study. The mean age of the participants was 36.22 years. The mean return to work was 10 months after the acquired brain injury occurred. The mean full scale IQ was 100.17, although 3 participants did not have a psychological test conducted by the ABI Consultation Team psychologist. Education levels varied with: 1) one participant completing grade 11, 2) three participants graduated from high school completing grade 12, 3) three participants had completed community college, and 4) two participants had university education. The participants with a college education graduated with diplomas in: nursing, landscape design, and law and security. One participant had two years university education and one participant had a master level. Acquired brain injuries had occurred from 1 to 5 years prior to the interview. Three participants were classified as having a mild acquired brain injury. Six participants were classified as having a moderate acquired brain injury. Five participants were married, three participants were single, and one participant was divorced. In addition, five participants experienced a traumatic brain injury and four participants experienced a non traumatic brain injury. Summary of this data is listed in Table 4.1

Table 4.1

PROFILE OF PARTICIPANTS					
Classification of ABI & type of injury	Injury Age & date of injury	Marital Status & Gender	Return to work after acquired brain injury	Full scale IQ tested by ABI Team psychologist	Education at time of injury
Mild ABI closed head injury-MVC-no seat belt	December 2000 38 years	Married Male	8months	115	Community College
Moderate ABI- acute subdural hematoma-(altercation)	December 2002 21 years	Single Male	10months	Not tested	Community College
Moderate ABI Aneurysm	December 2002 43 years	Married Female	12months	77	Grade 11
Moderate ABI Subarachnoid bleed	December 2001 46 years	Married Male	12months	128	University Masters level
Moderate ABI closed head injury-MVC-helmet on	March 2003 32 years	Married Male	8months	Not tested	Grade 12
mild ABI closed head injury MVC	October 2004 23 years	Single Female	1month	Not tested	2 years university
mild ABI closed head injury-fall	July 2003 52 years	Divorced Male	14months	90	Community College
Moderate ABI-occipital hematoma (anoxic)	December 2004 21 years	Single Female	10months	81	Grade 12
Moderate ABI- ruptured aneurysm	April 2004 50 years	Married Male	12months	110	Grade 12

## *Phases*

Analyzing data from nine interviews identified five phases, which took place during the journeys of the participants of this study. The five phases of their journey identified by this study are: 1) ABI event, 2) acute hospitalization, 3) recovery, 4) return to work, and 5) post recovery. This journey of the nine participants can be described as a process that the person experiences in order to obtain the goal of achieving a new normal in the final post recovery phase. The person who has suffered an acquired brain injury has to experience one phase of their journey before they can succeed to the next phase, or they may not be successful with obtaining their goal of achieving a new normal. In other words, the person needs to experience a recovery phase prior to their return to work phase, or their return to work may not be successful. This conceptual map of phases of the journey, for the person who has suffered an acquired brain injury, describes the process the person experienced from the time of injury to approximately two years post recovery.

Family members also went through a journey that followed the course of their loved one that had suffered an acquired brain injury. They experienced all phases of the journey, however, their experiences were identified as different. They identified fear in the acute hospitalization phase by being vigilant, while their loved one was medically unstable. During the recovery phase family members identified they were willing to be caregivers because their loved one became reliant on their assistance. During the return to work phase they were supportive of their loved ones' return to work process. The post recovery phase identified family members as being thankful for their loved ones' recovery.

The nine participants of this study can be categorized into two types of acquired brain injury: 1) traumatic brain injury, and 2) non traumatic brain injury. Four participants can be described as experiencing a non traumatic brain injury. The non traumatic brain injuries can be described as: 1) an aneurysm, 2) a subarachnoid bleed, 3) an occipital hematoma, anoxic, and 4) a ruptured aneurysm. The traumatic brain injuries can be described as: 1) three closed head injuries – motor vehicle crashes, 2) an acute subdural hematoma – altercation, and 3) a closed head injury –fall. All participants suffered an acquired brain injury; however, the identification of the acquired brain injury was different for two of the participants that had experienced a motor vehicle crash.

Two of the participants that experienced a motor vehicle crash had several other physical injuries that required acute hospitalization. Their acquired brain injury was not identified until after they returned home from their acute hospitalization phase. Physical injuries took priority over the identification of an acquired brain injury. However, in spite of the identification of an acquired brain injury at a later date, their ABI event phase, acute hospitalization phase, recovery phase, return to work phase, and post recovery phase identified the same common themes and sub themes as the other participants. The three participants that experienced a traumatic brain injury with no other physical injuries experienced the same journey as all of the participants.

#### *Phase: ABI Event*

The acquired brain injury event phase began with an injury to the brain of the participant. Injuries to the nine participants of this study were identified as three mild injuries and six moderate brain injuries. Two participants suffered aneurysms, one had a subarachnoid bleed, and one participant experienced an anoxic brain injury. Five

participants experienced a closed head injury; three participants were involved in a motor vehicle crash, one was assaulted, and one had a fall. Although all injuries were unique, acquired brain injuries occurred as a result of each event.

*Phase: acute hospitalization*

The acute hospitalization phase was identified as: when the participant was admitted to hospital until discharge from the acute care hospital. The average length of stay in an acute care hospital was 22.1 days. Eight participants were hospitalized in a Windsor hospital and one participant was hospitalized in a Detroit hospital.

*Phase: recovery*

The recovery phase was identified as: after the participant was discharged from an acute care hospital until the day they returned to work. During this phase the participant was medically stable. This phase included taking part in inpatient, outpatient, and in home rehabilitation. The average recovery phase was identified as 9.2 months.

*Phase: return to work*

The return to work phase was identified as: when the participant returned to work. The average return to work for the nine participants was 10 months. All participants had returned to their previous employment.

*Phase: post recovery*

The post recovery phase was identified as: the amount of time since the participant's injury and the time the participant was interviewed for this study. The average post recovery time was identified as 2.2 years.

### *Themes and sub themes*

Each phase of the participants' journey identified a theme. The five themes corresponding to the phases are: 1) gaps in memory 2) fear, 3) need to be normal, 4) striving to be normal, and 5) achieving a new normal. This conceptual map was developed after identifying that all participants had a common journey from the acquired brain injury event to post recovery. Working within these concepts sub themes were identified within each theme.

Sub themes identified in the gaps of memory were identified as: 1) bits of memory, and 2) loss of time. The fear theme identified sub themes as: 1) family vigilance, 2) fear or unknown, and 3) loss of control. The need to be normal theme found the sub themes: 1) following the treatment map, 2) reliance on others, and 3) living in a cloud. The sub themes of the striving to be normal theme found: 1) workplace obstacles 2) work hardened, and 3) coping with limitations. The theme achieving a new normal found: 1) coping with challenges, and 2) thankful as sub themes.

### *Phase: ABI event*

#### *Theme: gaps in memory*

Although all injuries were different and unique to themselves all participants experienced gaps in their memory. Gaps in memory during the time of the ABI event phase were a common experience for all participants. Sub themes for gaps in memory were identified as: 1) loss of time, and 2) bits of memory.



*loss of time.*

All participants were able to describe what they were doing moments prior to their injury, however, at some time they experienced a loss of time where they were not able to recall what had happened. One participant described his experience as:

I would like to comment on this loss of consciousness thing. I swore up and down that I did not have any loss of consciousness. But it's the not true. Now when I think about it, I don't remember breaking my arm. My arm was broken in two. There's some gap there. I've just come to realize that in last year or so.

This participant had been injured five years prior to being interviewed for this study. He stated he had just realized, in the last year, that there had been "a gap."

Another participant described his experience as: "I had no idea where I was or what happened." This person had a fall and had no recall of the event prior to or during his fall.

*bits of memory.*

All participants reported they are able to remember "bits and pieces" around the time of their acquired brain injury event. One participant described her experience as "When they put me in the ambulance I came to, and I remember them saying it was just a migraine." One participant described his injury as: "I had all kinds of injuries. I don't know how the injury happened to my head. I don't know if it happened during the accident, there was no blood or anything. There were a lot of mysteries." Another participant described his experience as: "I had no idea where I was, or what happened."

One participant stated: "All of this is hazy. So this is just recall from what others have told me." Another participant reported: "I had the helmet on when I was on the

snowmobile. I flew through the air and when they found me the helmet was off. The guy didn't know if it was off or not".

The ABI event phase began with an injury to the brain of the participant. Injuries were classified as three mild brain injuries and six moderate brain injuries. All participants' injuries were different and unique to themselves; however, all participants experienced a common theme of gaps in their memory of the acquired brain injury event. Sub themes for gaps in memory are identified as: 1) loss of time and 2) bits of memory. Memory was identified as problematic throughout the ABI event phase by the participants. It is interesting to note that memory may have played a role throughout their entire journey, however, participants did not identify their ongoing difficulties as having an association with their memory deficits.

#### *Phase: acute hospitalization*

##### *Theme: fear*

A common theme found during the acute hospitalization phase was fear. Family members, as well as, the participant identified fear. Fear was described in many different ways at this phase. Sub themes are identified as: 1) family vigilance, 2) fear of unknown, and 3) loss of control.

##### *family vigilance.*

Support from family members was identified as important to all participants during the acute hospitalization phase. Many family members reported that they had stayed with their loved one "around the clock" because of their fears. One mother, who is a nurse, described her experience with her son's hospitalization as:

After a few days in the intensive care unit they moved him to the floor (medical unit). I thought it was too soon, but, I was staying with him. So it didn't matter. They gave me a cot and I slept between his bed and the older gentleman. I was worried about his head and the area where the bone flap was removed. When they are children they give them helmets, but as adults they don't, so, I was worried.

A wife of a participant, (who is a nurse) became worried about her husband's care because he was not investigated for a head injury, and she felt he had experienced one as a result of the motor vehicle crash. She described her experience as:

In the hospital he was acting very bizarre. I was telling the nurses that this was not normal (his behavior). They kept saying that he was fine; that it was just the pain meds. It's just the pain meds. So everything got missed. He wasn't checked for a brain injury.

A similar experience with a participant was described by his wife, who was also a nurse. She stated that the hospital staff was not concerned with his head injury because his CT scan, which had been done in the emergency room, had normal results. She stated he had life threatening injuries to his lungs, liver, spleen, and fractured ribs, and that they were more concerned with those injuries than concerned with the head injury. She stated she was at his bedside at all times because of worry. When he began to arouse from the coma he began to pull out tubes. One participant stated that everyone (his family and friends) were so "scared" because he had spent eight days in a drug induced coma. He reported "everything was very hazy around that time."

*fear of the unknown.*

Most participants identified fear of the unknown during the acute hospitalization phase. Fear was described by a female participant after suffering an aneurysm as:

When I felt the pain I knew what it was. The doctor said the blood vessels in the brain were weakened, smoking didn't help, it increased the blood pressure. These are the things that made the aneurysm burst. I had a fear that after my operation it would happen again.

Fear for this participant was that she would experience a reoccurrence of her aneurysm. One participant described an incident while being hospitalized as: "I think the worst incident happened when I started having spasms. They said they were small strokes. I had a CT scan and it showed where the blockage was and that blood clots were in my lungs. I spent the next few weeks in the intensive care unit." Another participant's family member identified that the participant had problems with his vision while in the hospital. He described the participant as being "more scared of not having his eyesight" as the most important issue during hospitalization. Another participant described waking up from surgery as: "I woke up from surgery and was paralyzed on my right side."

In the acute hospitalization phase, the participants that suffered a non traumatic brain injury described their fear of reoccurrence or a worsening of their brain injury. The participants of the traumatic brain injury described their fear as concerns about their physical well being describing eyesight or paralysis as problematic. Fear of the unknown was a common sub theme for all participants because none of them had experienced an acquired brain injury before.

*loss of control.*

A participant's mother, who was supportive of her son during the acute hospitalization phase, described her son's fears when she described his behavior as odd:

He became acting strange, and became fearful of the older gentleman saying this guy had all the power and was going to get him. He kept asking me to bring him a sword so he could fight him off.

Another participant described a time during his hospitalization that he required restraints to control his behavior:

At the time I thought I was being kidnapped by foreign terrorists. I actually injured myself further by escaping from my restraints and my cage. Once I stood up my equilibrium was off and I fell again. I injured my head a second time while I was in the hospital. It was a very difficult time. A very scary time. Let's say for about a year I almost couldn't think about it because it hurt.

During the acute hospitalization phase participants described their physical injuries. Support of family members was identified an important part of the hospitalization. Family members were described as being at the bedside throughout the acute phase. Fear was identified as a theme for both participants and the family members during the acute hospitalization phase. Sub themes were identified as: 1) family vigilance, 2) fear of unknown, and 3) loss of control.

#### *Phase: Recovery*

##### *Theme: need to be normal*

The theme; need to be normal, was identified during the recovery phase of the nine participants of this study. This theme was a time when the participant convalesced

and rehabilitated in hopes of returning to their pre-injury lifestyle. This theme was categorized into three sub themes: 1) following the treatment map, 2) reliance on others, and 3) living in a cloud.

*following the treatment map.*

During the recovery stage all participants had a need to be normal and the way to accomplish this was: to be compliant and follow the treatment map as recommended by health care professionals. Seven participants had some type of rehabilitation to return to a functioning level after hospitalization. Two participants were transferred, after an acute hospitalization period, to an inpatient rehabilitation unit. One participant's length stay on the rehabilitation unit was two weeks, and one length of stay was one month. Two participants were provided in home rehabilitation. One participant participated in an outpatient rehabilitation program. Three participants participated in both in home therapies and outpatient services. Rehabilitation was described as physiotherapy, occupational therapy, social work, psychological services, nursing, and speech therapy.

One participant who had been injured in a motor vehicle crash described his rehabilitation process as:

I had out patient physiotherapy after discharge from the hospital. There was a delay in the healing of the radial nerve palsy. It didn't resolve for several months.

At this point I was pretty cooperative with the therapists.

This participant had stopped physiotherapy after about three months and had attempted to return to work. However his surgeon discussed his non compliance and convinced him to return to therapy. He described this time as:

He said I can't work and do physiotherapy at the same time. In so many words he said he would not be my physician any longer if I did not want to be compliant and follow a treatment plan. He wanted me to be compliant so I said I'll be compliant and go to physiotherapy three times a week.

One participant, when describing his therapies stated the "hardest thing was doing everything over again." This same participant said "with therapy everyday I didn't feel normal." He was compliant with his therapy and stated "I followed the map."

One participant described his motivation to get better as: "The physiotherapist couldn't believe it. May be it was me, I had to get better." Another participant's spouse stated "He never refused anything. He took all the help he could get."

Several participants discussed their memory deficits after they returned home from the hospital. Memory, although identified at this phase, was not seen by the participants as troublesome as it had been in the ABI event phase, where they felt they only had bits of their memory and had loss of time. At this phase, although memory remained problematic, several participants described ways they learned to compensate for their memory deficits. Occupational therapy was provided to assist with memory problems and many participants were taught to utilize a memory book as a way of coping. One participant described her memory as poor during the recovery phase. "I couldn't remember what I made for supper, so I would make the same thing every night." This participant, after learning how to use the memory book, stated this strategy was helpful with assisting with her memory problems. She would write in the memory book what she had made for supper, therefore she stopped duplicating meals. Many participants used strategies to assist with memory problems. Most participants used a

memory book, daily journals, or calendars. One participant used a palm pilot as a strategy to cope with his memory problems.

*reliance on others.*

All participants described supportive family and friends. Several participants described family members as, not only being supportive, but assisting them to cope with their memory problems. One participant described his wife's assistance as:

For months, I was leaving the house without my shoes on. I would get halfway up the stairs and realize. Its winter time and I don't have my shoes on.

My wife would have to remind me. You know you have to put your shoes on.

One participant's wife assists her husband to cope better with his memory problems by "jogging his memory." He describes this coping strategy as:

Because I forget a lot, my wife does not tell me I have forgotten things, she gives me little cues. The cues will jog my memory, then, I'll come up with it. It's bad enough that you can't remember, but you don't want your wife telling what you forgot. It's nice to get a little cue so I can remember.

One participant found his parents very supportive. His mother stated he was bothered by a bare spot on the back of his head due to all of the bed rest in the hospital. She reported after hospitalization he always wore a baseball cap to cover the spot. He stated he did not wear a baseball cap prior to his injury. His mother contacted a hair replacement clinic and had a hair transplant done for him to conceal the bald spot.

Two participants found support from people that had experienced a similar injury as they had. Both participants stated that it was easy to talk to a person who had



experienced the same and it made them feel like they were understood. One participant described this experience as:

It's so hard to explain. Ted's brother's wife had been in an accident with life threatening injuries. We were talking and she was able to understand. Someone that didn't have the same experience couldn't understand. It's hard some people you can talk to and others don't care.

This participant found peer support helpful in his recovery phase.

All participants described a desire to return to work when they thought they were feeling stronger and able to work. Participants described this time, as a time where their physical strength was returning and they were beginning to plan for returning to their previous employment. However the decision to return to work was not one's own decision but required medical approval. Reliance on medical approval was required for the work place as well as disability benefits to continue throughout the recovery phase. One participant needed to return to work for financial reasons to receive regular wages. He described his disability wages as not adequate to support his financial needs. His brother-in-law reported:

He went through a whole lot of financial stuff because of it all. There was no insurance like if he had been hit by a truck. We're not too covered for illness. After six months he went to 2/3 of his wage to 1/2. Long term disability paid 1/3 of his regular wage. He had just bought a condo. He had divorce payments. A lot was going out, and nothing going in. It's not like he could do a little overtime or do an odd job on the side.

Several participants had requested their doctors to sign papers so they could

return to work. Their physicians refused to sign their return to work forms because the physician stated that it was too early in the recovery process to return to work. Monetary factors were a common reason for their return to work.

One participant had gone to his work office a month prior to returning work to become acclimatized to the environment. He relied on his colleagues to assist him emotionally with his return to work. He described his desire to return to work as: “That was probably the worst time. I was really obsessed with work. That’s all I thought about was work. I had it in my mind that I was going back to work. I worried a lot about work.”

Most participants were unable to drive a motor vehicle during their recovery period. Several participants relied on others for their transportation needs. One participant stated: “My daughter was driving me everywhere. She drove me around for about three or four months.” Another participant said: “My friends would come and pick me up and take me places.

*living in a cloud.*

All participants reported some type of atypical behavioral during the recovery phase. Most participants reported they had difficulties with controlling their temper. A participant’s wife described her husband’s change in behavior:

He started doing bizarre things after he came home from the hospital. One day we pull up to a convenience store. He goes in. He comes out with the owner yelling at him. You know he’s picking fights. Her husband responds with: Now at this time I realize I was picking fights. At that time I didn’t. I was intolerant of that guy being rude to me. So I entered into an altercation with him. It really was

unusual behavior for me, but at that time I was really doing goofy stuff. This is not normal. I'm typically very easy going.

One participant described her recovery as "up and down emotionally." One spouse described her husband as being "unreasonable" in situations where he would have been able to handle the problem prior to the injury." One participant laughed a great deal after her injury. If she had forgotten something, she laughed and would say "oh well, it's my brain injury."

Several participants described their recovery phase of the acquired brain injury as being in a fog or in a dream. One participant described his recovery as: "I would say it was six or seven months after the injury, I realized everything had been foggy for a long time. It was like living in a cloud." Another participant described his recovery as: "the whole time I was off it was like a dream." One participant described the time as "feeling doopey, it's like I was watching myself."

The average length of a recovery phase was 9.2 months for the nine participants. The theme; need to be normal, was identified at this phase. This theme was categorized into three sub themes: 1) following the map, 2) reliance on others, and 3) living in a cloud.

#### *Phase: return to work*

##### *Theme: striving to be normal*

All participants went through a return to work phase. Participants returned to work on an average of 10 months after sustaining an acquired brain injury. All participants returned to their previous employment after the recovery phase. The common theme at the return to work phase was identified as: striving to be normal. Three sub

themes during the return to work phase was identified as: 1) workplace obstacles, 2) work hardened, and 3) coping with limitations.

*workplace obstacles.*

Workplace obstacles can be identified as restrictions imposed on the participant returning to work. In other words, the participant was not able to return to work with out any preparation for their return. Workplace obstacles for participants were identified during the return to work phase time because restrictions were imposed on them to return to their pre-injury job. All participants had a planning phase before they returned to their previous employment. Participants were assisted by many different professionals depending on their situation. One participant had their insurance company provide a work coordinator to assist with the return to work process. This person worked with the management of the company to set up an appropriate work schedule and attend meetings with the client to discuss issues pertaining to adjustment back to work.

Several participants worked together with management to determine an appropriate back to work plan. One participant's labor union was involved with the return to work plan. The majority of the participants followed the work plan recommended by their physician. Most participants' doctor recommended a slow return to work and the recommendations were presented and accepted by the work place. One participant had a return to work plan recommended by his neuropsychologist. His mother described this intervention as: "the neuropsychologist recommended the work plan. He did neuro- psych testing and recommended the gradual return to work since he stated it takes two years for a person to have full return"

One participant was required to have hearing and eye tests before he could return to work. This same participant had to have medical and psychological testing before his return. In addition, he had to complete annual safety testing within the work environment. Management would not consider his return to work until he was off work one year. He described that time as: “Since I had this injury and this seizure thing, they put me on dilantin. I had to prove to them I was seizure free or without dilantin, before I could return to work.”

*work hardened.*

All nine participants returned to their job that they had prior to their acquired brain injury. Despite all participants returning to their previous employment they found the work different then they had prior to their injury. All participants had work schedules that were individualized for their needs.

One participant, who owned a construction company, returned to work in a supervisory capacity for three months, in contrast to, before the injury he physically did the work. One participant, who worked at a fast food restaurant, went back part time hours and worked the day shift, where more people were available to assist her if needed. One participant called his modified return to work a “work hardened.” He explained:

Work hardened. You ease yourself back into the job where you work ½ days for about a week. That was about it. It didn’t last long. Someone was there if I needed assistance. I really didn’t need to call on anyone, but someone was available.

On participant described her return to her management job at a big box store:

I went back four hours a day, three days a week. They gradually increased my hours according to what I wanted. I found that ideal. They also provided a person called a support pole. I worked along side this person for approximately six months until I was able to resume full time duties.

All participants described the return to work process as a slow process with requiring some type of support within the work environment. Memory was not described as problematic at this phase of their journey, however, most workplaces had support in their environment to assist with memory deficits that may occur.

*coping with limitations.*

Physical changes and behavioral changes were identified as problematic for all individuals during their return to work phase. Tiredness was described as problematic for the majority of participants. A wife of a participant who had returned and work ½ days described this time as: “He was so tired when he came home from work; he went to bed to sleep.” Several participants complained of dizziness after their return to work. Two participants had to use a ladder in their work environment and found this task difficult. However, they have learned to cope with this disturbance by not going up the ladder but having someone else do the task for them. One participant discussed having a headache, however, she stated “I want to work, headache or not.”

Behavioral changes were identified by the majority of participants after that had returned to work. One participant described his return to work as experiencing some difficulties with “not seeing eye to eye with others.” One participant described his back to work process as:

I think I was trying to get back to normal. The need to become normal again. I knew I was normal, but, I had gone through some craziness you know, getting back to full time and having a regular life. I really liked going to work, but some days I didn't want to be there. There was a lot of flipping off, I was able to control it better at work.

One participant described his back to work as "brutal." He stated it was a struggle to do his job. He described his work as:

I don't feel part of the picture, mechanical things I do are okay, but when I have to concentrate and read, it was frustrating. Recommendations or solutions did not come as well. In some situations I would become confrontational.

This participant's wife comments were; It was embarrassing for him, having people see him like that. He struggled to stay till noon so he could lunch with the guys, to make it normal.

Many participants made changes to their type work in order to accommodate their changes in their life. One participant made several work place changes after experiencing difficulties with performing his daily tasks and interacting with others in the work environment. He described his change as:

I started my own home care company. I had much more difficulties with being an administrator than a Chief Executive Officer. It's (administrator) a much more demanding job. I think I fit this job into the new me. I'm not saying I'm cognitively delayed or anything, but I'm not as sharp as I used to be. This is suited to my new personality.

One participant returned to school on a full time basis. He stated he wanted

to improve himself for better employment in the future. Two participants started school on a part time basis: one to change jobs in the future, and one to continue with an apprentice program provided by his work place. Three participants returned to their pre injury jobs with the hopes of maintaining that employment until retirement. One participant quit her return to work job to accept a job that paid more money. She also added two part time jobs to her work schedule.

One participant opted for a disability pension through his insurance plan. He described his experience as:

All the doctors said I was able to work again, but, not make the money like I had in the past. They said that's not going to happen, as you are getting older your capacity diminishes, and then add the brain injury and it sort of complicated things. I did not qualify for the CPP-disability plan but opted for the disability insurance through my work place.

All participants went through a return to work phase. Participants returned to work on an average of 10 months after sustaining an acquired brain injury. All participants returned to their previous employment after the recovering phase. Although all participants' jobs were different, a common theme was identified as: striving to be normal. Three sub themes during the return to work phase was identified as: 1) obstacles, 2) different work, 3) coping with limitations.

*Phase: post recovery*

*Theme: achieving a new normal*

All participants, at some point, after they had returned to work, had learned to cope with the limitations imposed on them by their injury. A common theme identified,



at this phase, for all participants was: achieving a new normal. Two sub themes were found within this theme: 1) coping with challenges, and 2) truly blessed.

*coping with challenges.*

All participants identified changes to their lifestyle that were imposed on them by their acquired brain injury. However all participants found ways to cope with the many challenges that face them daily. One participant reported he “gets lost while driving.” He finds this disturbing and explained:

The biggest puzzling part for me is getting lost. Getting out there and not knowing where I’m at. That’s the strange thing about directions; I was really good at it. Last week I got lost going to a friend’s house. It’s really embarrassing because they may find out I get lost.”

He reports he has learned to compensate for this change in his life and memory loss by saying: “I always get there. It just takes a lot longer and more gas.”

One participant stated her “brain was a blank”. She experienced memory problems and would compensate at work and at home by saying it was not her; it was her brain injury. She explained how she copes with the situation at work

I’m pretty easy going. Customers will come up to me and say don’t you remember, and I’ll say nope. They will say they were in last month and I’ll say it’s called an aneurysm. I don’t remember. Sorry about that. They look at me and say Oh my god. I say oh well that’s the way it is.

All participants described changes to their lifestyle since their injury and ways of adapting and coping to those changes that affect to their current lifestyle. Several participants’ spouses assist them with lifestyle changes. One participant stated he was

unable to return to his job as a financial investor however, his wife was doing all of his financial planning and investments. One participant's husband has taken over paying all the bills. He stated the doctor said his wife should avoid stress, and this is one way he could assist her. He reported: "I write all the bills now. She doesn't even see them when they come in. I put them right away." He explained that this was a role reversal because it was his wife's job to do the bills for the first 25 years of marriage. In their situation, they learned and accepted their role and responsibility changes.

Several participants discussed continued physical concerns and how they managed their physical symptoms. Two participants continued with going to the gym to keep up their strength. One participant continues to have chiropractic intervention to deal with the constant neck pain. Several participants discussed frequent headaches, however found ways to cope with the situation. The majority of participants stated that their behaviors, like displaying their anger, had subsided and they were able to deal with controlling the anger at this time.

*thankful.*

The majority of the participants expressed how thankful they were for their recovery. One participant described his thankfulness as:

We can joke about a lot of things, but we consider ourselves very lucky, truly blessed. After the accident no one is pushing any one in a wheelchair, nobody's dead, and there are no permanent injuries that interfered with our life. We are able to create a life for our children and have procreated, because we have more children now than before the accident.

Several participants had reported God had played a role in their healing process. One participant stated that their Christian faith and all the prayers helped her. She called herself “a miracle” because the doctor had given her a 30% chance of survival.

Several participants stated they were very “lucky” that they had survived with little ongoing problems. A wife of a participant stated “he beat the odds, he wasn’t supposed to make it.” One participant considered himself very fortunate that that he loved his job and stated “it’s more of a thing I love doing.”

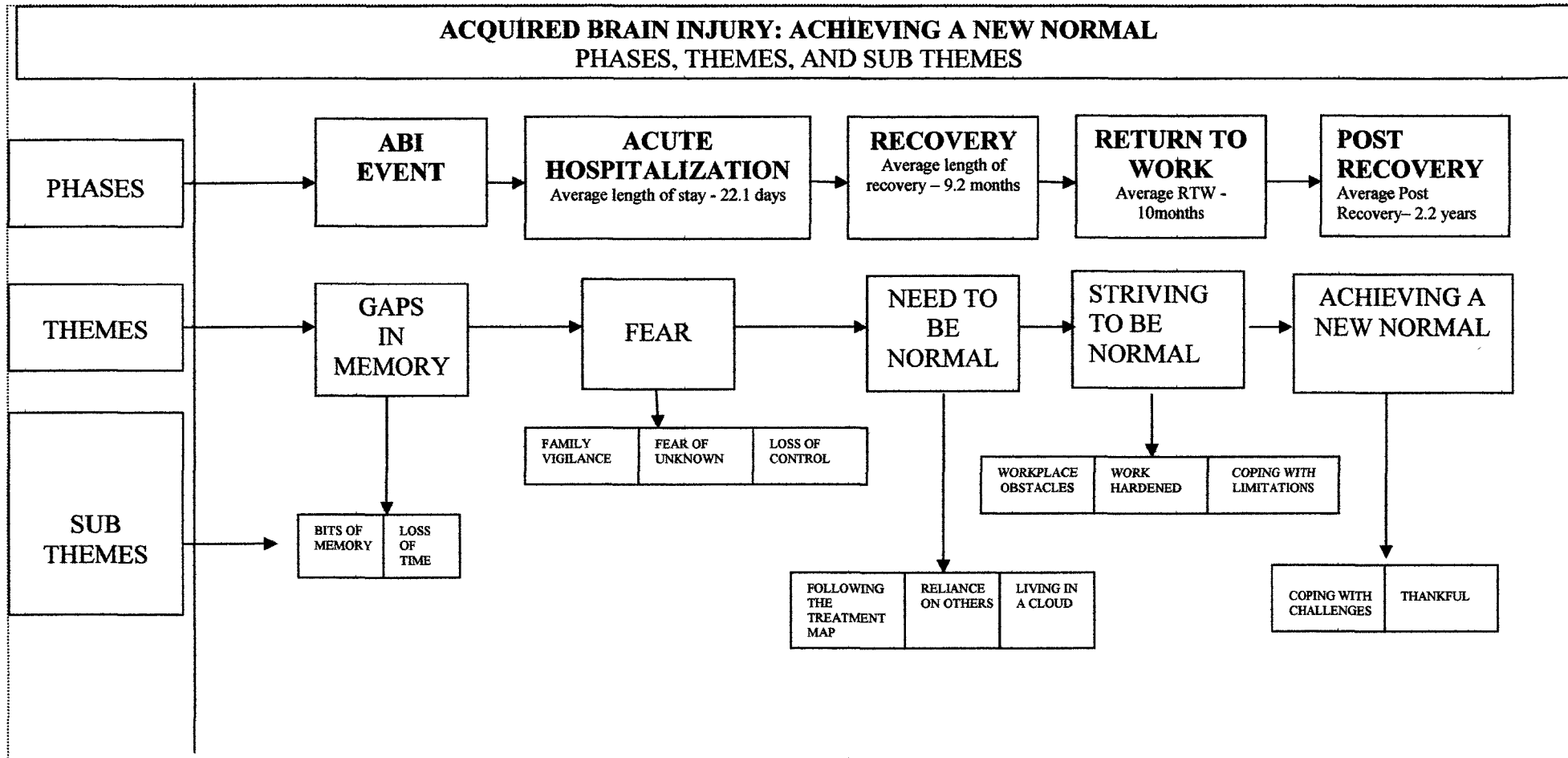
All participants, at some point, during the post recovery phase, had discussed being thankful for their recovery and appeared to have achieved a new normal. They appeared to have made changes to their new lifestyle imposed on them by the injury. A common theme identified, at this phase, for all participants was: achieving a new normal. Two sub themes were found within the achieving a new normal theme: 1) coping with challenges, and 2) thankful.

#### *Summary of phases, themes and sub themes*

Analyzing data from nine face-to-face interviews has identified five phases which took place during the journey of the nine participants of this study. This journey can be described as a process that each participant went through in order to achieve their new normal as described in the post recovery phase. The five phases of recovery identified by this study are: 1) ABI event, 2) acute hospitalization, 3) recovery, 4) return to work, and 5) post recovery. Each phase identified a theme. The five themes corresponding to the phases are: 1) gaps in memory 2) fear, 3) need to be normal, 4) striving to be normal, and 5) achieving a new normal. This conceptual map was developed after identifying that all participants had a common journey from the ABI

event to their post recovery. Working within this conceptual map; sub themes were identified within each theme. See Table 4.2 for the conceptual map of phases, themes, and sub themes.

Table 4.2



Boyce, 2006

## CHAPTER 5

### DISCUSSION AND RECOMMENDATIONS

#### *Introduction*

This study, *Acquired Brain Injury: Journeys from pre-injury to return to work*, used an exploratory phenomenology method to complete this constructivist research. Analysis of the data from the nine face-to-face interviews identified five phases of the journey a person who had sustained an acquired brain injury from the acquired brain injury event to post recovery. Five phases were identified as: 1) ABI event, 2) acute hospitalization, 3) recovery, 4) return to work, and 5) post recovery. The phases of the journey for the individual who has suffered an acquired brain injury can be described as a process. During this process the individual needs to journey through each phase before moving to the next phase to be successful with their journey to achieving their new normal in the post recovery phase. Within the five phases common themes emerged. Five themes were identified as: 1) gaps in memory, 2) fear, 3) need to be normal, 4) striving to be normal, and 5) achieving a new normal.

Sub themes emerged within each theme. The sub themes identified in the theme gaps of memory were identified as: 1) bits of memory, and 2) loss of time. Emerging sub themes identified within the theme of fear was identified as: 1) family vigilance, 2) fear of unknown, and 3) loss of control. The sub themes identified within the need to be normal theme identified sub themes as: 1) following the treatment map, 2) reliance on others, and 3) living in a cloud. The striving to be normal theme found sub themes as: 1) workplace obstacles, 2) work hardened, and 3) coping with limitations. Sub themes that emerged within the theme achieving a new normal were: 1) coping with challenges,

and 2) thankful. This study identified these phases, themes, and sub themes within the journey a person who experiences an acquired brain injury.

This chapter will discuss the findings of this study and compare results with the findings of other published research studies. Literature will be addressed according to phases of the journey that this study has identified.

These stages of recovery are somewhat like the stages of grief as identified by Kubler-Ross (1969). The five stages of grief are 1) denial, 2) anger, 3) bargaining, 4) depression, and 5) acceptance. In the Kubler-Ross model all stages need to be experienced before acceptance can begin. The participants of this study appeared to go through similar stages of grief as they worked through their process of loss of a previous lifestyle.

The journey of the participants of this study can be described as being similar to the emotional stages of recovery, of a person who has suffered a head injury, described by G. Johnson (1998). In Johnson's emotional stages of recovery, five stages are identified as: 1) confusion and agitation, 2) denial, 3) anger and depression, 4) testing phase, and 5) uneasy acceptance. These findings are based upon Johnson's experience as a clinical neuropsychologist working with individuals that have experienced an acquired brain injury. The stages are described as common stages that the person goes through to the final stage of uneasy acceptance. At the uneasy acceptance stage they learn to accept their limitations but may not be happy with the changes to their life.

Memory appeared to be problematic at all phases of recovery, although participants did not describe it as troublesome because they appeared to find ways to compensate for their difficulties. Participants that had experienced a traumatic brain

injury, that included other physical injuries, appeared to be at first different from the rest of the participants. However, their narratives described the same process of an acquired brain injury journey as the rest of the participants had experienced. They described their ABI event and acute hospitalization phase the same as the participants that had an identified acquired brain injury from the beginning of their journey.

*Phase: ABI event*

The ABI event phase of a participant's journey was identified as the acquired brain injury incident. Gaps in memory were identified, by all nine participants of this study, during the ABI event phase. This is consistent with the findings "loss of clear self knowledge" as identified by Nochi (1998), in a qualitative study, which examined the narratives of 10 persons who had sustained an acquired brain injury. Nochi's theme identified participants, who suffered an acquired brain injury, as experiencing memory blanks. In addition, loss of time and participants experiencing bits of memory were identified in Nochi's findings. Likewise, participants in this study reported memory blanks as momentary losses, while others reported longer periods. Some of the participants reported they are still not able to recall the events of their acquired brain injury incident, years following the event. Others participants described their hospitalization as being not having a clear mind. These memory blanks identified in this study, would suggest these nine participants might have struggled sometime throughout the ABI event phase and may have experienced a "loss of clear self" as described by Nochi.



### *Phase: acute hospitalization*

This study identified in the acute hospitalization phase fear as a theme for the patient, as well as the family members. Family support was an important part in the acute hospitalization phase. Many studies identified family support as an important aspect of the recovery process of the person who has sustained an acquired brain injury (Nimgade and Costello, 2003; Rowlands, 2001; Gething, 2002; Kendall, 2003) however, these studies did not identify fear as a common theme.

A case study by Nimgade and Costello (2003) identified the 64 year old participant as spending his first week in the intensive care unit of a hospital and requiring four point restraints. This is consistent with the acute hospitalization phase of this study when loss of control is identified as a sub theme. Several participants of this study identified some form of physical or chemical restraint during the acute hospitalization phase.

### *Phase: recovery*

The recovery phase of this research study identified an average length of recovery as 9.2 months.

#### *following the treatment map.*

Rehabilitation or following the treatment map was identified, in several studies, as an important factor in the recovery process (Coetzer et al., 2002; Fabiano et al., 1998; Kowalske et al., 2000, Ponsford, 1995). This is consistent with the findings of this present study during the theme need to be normal. The sub theme, following the treatment map, was identified by participants as rehabilitation throughout their recovery

phase. Participating in rehabilitation made the participant feel they were doing all they could to return to their pre-injury self.

*reliance on others.*

This present study identified reliance on others as a sub theme of the need to be normal theme. Personal support was identified as important and meant different things for the nine participants of this research study. This finding is consistent with a longitudinal study that examined 90 participants from an inpatient rehabilitation unit identified with having a traumatic brain injury (Kendell, 2003). The purpose, of the study, was to investigate the utility of psychosocial factors in the prediction of vocational adjustment following a traumatic brain injury. Results of Kendell's study indicated persons with high levels of social support tend to perceive themselves as more able to manage their difficulties successfully and, therefore, reported higher levels of vocational adjustment (2003, p.42). It concluded the importance of social support needs of individuals, and stressed the importance of vocational rehabilitation to address the needs of returning individuals to the workplace, as soon as possible, in some capacity, or by linking them to others that have returned to work successfully (2003, p.42). The findings, of this research study, are consistent with Kendell's research because social support and reliance on others was an important part of all nine participants of this study.

*living in a cloud.*

In this study, living in a cloud was identified as a sub theme of the need to be normal theme. During the recovery phase several participants displayed episodes of anger that affected their ability to cope with situations. Several family members discussed behavior changes that were inconsistent with their pre-injury behavior. This

study was consistent with the findings of Vanderploeg et al, 2003. A general conclusion of a study examining 4,322 males, 626 with a mild head injury and 3,896 with no injury, suggested that even a mild head injury can adversely affect an individual's ability to cope or adapt, especially when one's cognitive reserves, before injury, were less than optimal, thus increasing the chance of unfavorable social outcomes. Adverse social outcomes can be identified with participants displaying anger toward others at work or at home (p.159).

*Phase: return to work*

The average return to work, for the nine participants of this research study, was 10 months. According to Coetzer, et al., 2002, the majority of people who have suffered an acquired brain injury returns to work within the first year. This research study is consistent with the findings of Coetzer's study. Eight participants, of this research study, returned to work within the first year of their acquired brain injury, and one participant returned to work 14 months after his injury.

*workplace obstacles.*

A sub theme of the return to work phase was identified as workplace obstacles. These obstacles were identified as requirements for return to work and the planning process that took place prior to their return. Several participants of this study identified many different professionals assisting them with their return to work process. The Brain Injury Assessment Model, (BIAM), was used in Oregon to assist with supporting employment for adults with acquired brain injury (Vandiver et al., 2003). This model was identified as vocational assessments, completed by a multidisciplinary team, to assist with return to work for the person with an acquired brain injury. Although the nine participants of this study had different assistance with their return to work, similar

strategies were utilized during the return to recovery and return to work phase and consistent with the BIAM model by Vandiver. The BIAM model identified nine steps with return to work as: 1) medical rehabilitation, 2) vocational assessment, 3) neuropsychological assessment, 4) team meetings, 5) situational assessment, 6) follow-up team meeting, 7) job search, 8) job placement, and 9) follow-up. The therapeutic strategies involved in the BIAM model have been derived from two theoretical approaches: Cognitive Rehabilitation and Social Learning Theory (p.459). Comparing strategies used by the participants of this research study to the BIAM model is linked with caution since none of the nine participants of this research study had been involved in a structured vocational program. It is interesting to note, that several strategies are comparable. All participants, except one, had medical rehabilitation either in acute care, in-patient rehabilitation, or in-home therapy. All participants were assessed by the Acquired Brain Injury Consultation Team and information had been discussed with the multidisciplinary team members. Five of the nine participants had psychological testing consistent with the BIAM model. Similarly, professionals, in this research study, included insurance companies that assisted with planning the return to work, as well as, members of the Acquired Brain Injury Consultation Team. Four of the nine participants had some type of job coaching, and all nine participants had a gradual return to work. All participants did not have the same services offered to them; however, some strategies were consistent with Vandiver's model. This is consistent with this study's sub themes of workplace obstacles and work hardened.

This study's findings are consistent with the findings of the Johnstone, 2003, study that identified counseling and guidance as important factors with return to work.

All participants of this study had some counseling and guidance prior to their return to work.

*work hardened.*

Johnson (1998) suggested that the severity of injury may not be a predictor for return to work, however, other variables may need to be considered. Johnson suggests for the person to return to previous employment, to familiar routines and supported work, there was only a weak relationship noted with severity of injury. These findings suggest that the opportunity for support from a previous employer is very important in determining long-term outcome (p.74). This research study concurs with the findings of Johnson's study. Likewise, all nine participants returned to their pre injury employment. Several participants found return to their previous employment difficult, and resulted with changing jobs, employment status, returning to school. One participant had returned to his previous employment but did not obtain support in that environment. One participant had found his employer supportive, but his position was within an independent working environment, therefore the employer support was not as needed.

Findings of this study were consistent with an enablement model described by Kowalske et al., 2000. Similar to several participants of this study, Kowalske identified a return to work plan that consisted of a rehabilitation team in conjunction with the employer to outline a formal return to work plan.

*coping with limitations.*

This research study concurs with the results of a study examining life issues for people with an acquired brain injury, spinal cord injuries, and their caregivers

(Gething, 2002). Gething's study found that many other variables influences return to work, not physical factors alone. It identified that physical barriers impeded participants return to work only within the first year after injury. After one year of recovery, participants of this research study were able to compensate for their physical deficits and return to working. This finding was consistent when comparing the nine participants of this study. During the recovery phase, the sub theme following the treatment map identified physical barriers such as speech deficits, paralysis and poor eyesight. At the return to work phase all participants physical ailments were resolved, or the participant was able to find ways to cope with the limitations. Tiredness, headaches, loss of temper, irritability was identified as problematic at return to work phase; however, participants were able to find strategies to cope and manage their changes. These findings are consistent with a study by Tennant et al., 1995.

Several participants stated they were short tempered when they had returned to work. One participant stated that he was always able to handle the "quick pace" of his job, however, after the brain injury they experienced difficulties with behavioral changes, and not being able to understand why they were behaving differently than before. Most participants stated they are better now with dealing with a stressful situation than when they were initially recovering from the injury. One participant stated "it's still in the back of my mind." "Loss of self" by comparison was identified by Nochi, 1998, as the person comparing how life was before the injury, compared to present. This researcher suggests all participants were comparing themselves to the way they were before the injury. Several participants were attempting to improve their status in order to get back to their pre injury level. Most participants were hopeful that they will return to his pre injury

level instead of needing to compare himself to the way he was. This experience of the participants of this study is consistent with “Loss of Self” by comparison, as identified by Nochi.

*Phase: post recovery*

The post recovery phase identified achieving a new normal as the theme. The average length of post recovery for the nine participants of this study is 2.2 years. In this phase all participants appeared to be trying to achieve a new normal for themselves and their families.

*coping with challenges.*

One participant reports he continues to “get lost” in the car but doesn’t want anyone to find out because he finds himself very embarrassing. His experience is similar to the findings of a qualitative study examining the ten narratives of persons who sustained a brain injury and identified “loss of self in the eyes of others” as a theme (Nochi, 1998). This theme is consistent with the findings of this research study when comparing a participant of this study and his behavior. He was concerned others would see a change in him, and label him as a person with a brain injury if he disclosed he was getting lost, or his inability to fulfill his job as an administrator effectively. As a result, he continues to drive to places and “gets lost”, and subsequently doesn’t disclose it to the person at his destination. This same participant attempted twice to do jobs as an administrator and experienced difficulties getting along with his co-workers. He did not admit to the employer that he felt the tasks of his job were too difficult; instead he opened his own home care company, and hired someone to be an administrator. He did admit that for himself, being a Chief Executive Officer was much easier than being an

administrator. He had not disclosed these difficulties to anyone but his wife and this researcher, at the time of the interview. This finding emerged in the sub theme identified coping with challenges. This participant, although realizes he has some difficulties with directions, has found ways to cope with them. This finding concurs with Nochi's findings because this participant does not want to be labeled by others as having a "loss of self."

Results of a study examining 90 persons, with a traumatic brain injury, from an inpatient rehabilitation unit, indicated that persons that had strong personal motives and meaning in their work were more likely to return to work (Kendall, 2003). These persons indicated they would be able to achieve important goals in their life by working (2003, p. 43). Consistent with the results of this finding, one participant of this study identified that his work did not feel like a job because he loved to work with wood. He was a finish carpenter and enjoyed working with wood and creating things. This participant has identified work as being more difficult after his injury, however, has learned to cope with the challenges because he loves his work.

*thankful.*

Results of a qualitative study conducted in Kinston, Ontario indicated that changes in spirituality were identified in 16 participants described as having an acquired brain injury or a spinal cord injury (McColl, et al., 2000). Specific changes in spirituality were described as: 1) a greater awareness of self, 2) a change in their view of their own independence, 3) a sense of purpose for them self that was not present prior to the onset of the disability, 4) greater awareness of their own mortality and vulnerability, 5) a new understanding of trust, 6) loss of some significant relationships, greater appreciation of



others and the world, and 7) a greater understanding of other disadvantaged groups (2000, p.817).

Research findings of McColl, et al., 2000) were similar to the results of this research study. Similarly, several participants stated God was part of their recovery process. They described God as being present in their lives, and their belief that their faith had guided themselves, and their family through that time in their lives.

Unlike the study by McColl et al., none of the participants indicated their faith had changed after their injury. A participant had stated his attitude for life had been changed, that for about a year and a half he felt he was invincible. He felt that because he had made it through a life threatening accident that he was immortal. Another participant stated he felt an “awakening” and a chance to live again. One participant stated she was more aware of others who had been injured and stated how more fortunate she was than them. These findings emerged from the sub theme thankful.

This research study was consistent with the findings of Gething et al., 2002, when identifying external locus of control for caregivers of persons who have sustained an acquired brain injury. Luck was identified by most of the nine participants. They reported they felt lucky that they had survived the initial injury. One participant felt very lucky that her daughter was home to assist her when she experienced the aneurysm. A family member stated the participant was lucky he survived the initial crash, and did not have any repercussions because of his risky behavior during the recovery period. These findings emerged in the sub theme “thankful.”

### *Summary of research findings*

This study has identified five phases of recovery, after analyzing the data from the interviews of nine participants that had experienced a mild or moderate acquired brain injury. The journey of the nine participants can be described as a process as they journey through the phases. Each phase of the journey needs to be experienced before they can move to the next phase or they may not obtain their goal of achieving a new normal in the post recovery phase. The five phases of the conceptual map are: 1) ABI event, 2) acute hospitalization, 3) recovery, 4) return to work, and 5) post recovery. Five common themes that emerged from these five phases were: 1) gaps in memory, 2) fear, 3) need to be normal, 4) striving to be normal, and 5) achieving a new normal. In addition sub themes were identified that emerged from each theme. Some findings with this research study were consistent with other research that had examined individuals that had recovered from acquired brain injury.

### *Limitations*

The researcher's goal was to explore the journeys of nine participants who returned to work after experiencing a mild or moderate acquired brain injury. Data from nine face-to-face interviews were analyzed and themes were identified. However, limitations to this study can be identified.

### *Biases*

Biases can be identified as assumptions by all participants of this study, Acquired Brain Injury Consultation Team members, and the researcher. The ABI Team members may have had biases when selecting participants for this study. The team members may have chosen participants, they felt, would provide the researcher with results that would

reflect in a positive manner toward this study, as well, as presenting the ABI Team in a positive way.

Researcher biases may have interfered with the interview, data collection, and analysis of this study. The researcher had previous social work experience with persons who had suffered an acquired brain injury, therefore had assumptions prior to the interview process. These biases, although the researcher was aware of them, may have influenced this research study.

Similarly, the participants may have had biased opinions about the researcher being identified as a professional social worker. Their opinions may have been positive or negative. The participants may have had biases in a negative or positive way towards the ABI Team members, depending how they experienced their program.

Interpretation of the data of this research study should be viewed with caution because of several factors: 1) all participants were obtained from one out-patient program that provides intervention to persons with an acquired brain injury, 2) all participants experienced different types of acquired brain injuries and at different times, 3) all participants had different educational and employment history, 4) 3 participants were female and 6 participants were male, and 5) all participants were different ages.

All participants were provided by the Acquired Brain Injury Consultation Team at Windsor Regional Hospital. Researching participants from other out patient programs and in patient rehabilitation units may have provided different results. Using participants that were not hospitalized may have resulted in different findings.

All nine participants had different acquired brain injury experiences. Three participants experienced a motor vehicle crash, 3 participants had an aneurysm, 1

participant experienced anoxia as a result of a seizure, and 2 participants had a fall resulting in an acquired brain injury. Three participants were classified as having a mild acquired brain injury and 6 participants were classified as having a moderate acquired brain injury.

All nine participants had different education and employment history. Two participants were university educated, one obtaining a master level degree. Three participants were college educated, all graduating with diplomas. Two participants had completed high school and one participated completed grade 11. Three participants were female and six participants were male. Ages of the participants ranged from 21 years to 52 years of age at the time of the injury.

### *Recommendations*

#### *Implications for Social Work practice*

This research study; Acquired Brain Injury: Journeys from pre-injury to return to work has identified a conceptual map that recognized the journeys of nine participants that had suffered an acquired brain injury. This conceptual map may be useful to social workers and other service providers to assist a person that has sustained an acquired brain injury. This section will address micro and macro level of social work practice and how one can assist a person in all phases of their journey. Individual supportive and adjustment counseling, family intervention, financial issues, and research related to an individual who has sustained an acquired brain injury will be addressed.

One of the most important findings of this study is that the participants went through a process to achieve their goal of obtaining a new normal. Their journey took approximately two years from the time of the acquired brain injury event until they

achieved a new normal. Memory was identified as problematic beginning with the ABI event and continued throughout all phases. Programs and services, for the person that has suffered an acquired brain injury, should address memory deficits. Often, throughout all phases, the acquired brain injury survivor, may appear to be non compliant. This research suggests that memory may be problematic, however, service providers may identify a person as non compliant without probing further to find that memory deficits are the problem. Therefore, this research suggests a system of professional support throughout the individual's journey starting from the ABI event phase to the post recovery phase as paramount for the individual who has sustained an acquired brain injury.

The health care system focuses on illness and once a person is medically stable fewer services are provided. The person who has suffered from an acquired brain injury may not have the ability to maneuver throughout the health care system without assistance. This research suggests professional support is required at all phases of the ABI journey.

A tracking system of all individuals that have suffered an acquired brain injury should be recorded in the emergency department. This initial recording will start the person on an ABI pathway that will follow them from injury to post recovery. Once a person is hospitalized or sent home from the emergency department a team of professionals will follow their care. If admitted to the hospital, the multidisciplinary team will assess the individual and provide care as needed. When the person is discharged from the hospital, an automatic referral to the local Acquired Brain Injury Consultation Team will be activated. At that time, the ABI Team will provide ongoing

intervention by their multidisciplinary team. The ABI Team will assist and provide intervention throughout the recovery, return to work, and the post recovery phase. With one team of professionals, that specialize in working with persons that have suffered an acquired brain injury, the somewhat piece meal services that are now provided by the health care system will be eliminated.

### *Individual and supportive counseling*

#### *Micro level of practice*

The advanced generalist social worker can assist the survivor of acquired brain injury at the micro level by providing individual supportive counseling. To eliminate theoretical narrowness a broad based approach to assessment and intervention should be utilized so the clinician does not limit oneself to one method. A broad based approach assists the social worker to be innovative and responsive to the client's needs. The survivor of an acquired brain injury may require many different approaches to assist with the many challenges they may encounter. Individual strengths of the client should be the focus of intervention.

#### *Phase: acute hospitalization*

During the acute hospitalization phase the social worker's role is to provide individual counseling and educate the patient on what a brain injury is. Networking with other health care professionals such as physiotherapy, occupational therapy, and speech language pathologists to assist with educating the client is important during the acute hospitalization phase. Educating the patient on how the acquired brain injury may affect their behavior and ways to cope with their behavior changes is useful at this time.

At the acute hospitalization phase the sub theme fear of the unknown was identified in this study. At this phase, the social worker's role is to allow the individual to discuss their fears and educate them on how they can avoid another acquired brain injury in the future. Discussing helmet use, no alcohol use, and ways to lead a healthier lifestyle is important at this phase of their journey. Education may assist with alleviating many fears at the time of the acute hospitalization phase.

The advanced generalist social worker can assist the individual with their feelings by allowing the person to grieve their losses. The survivor may experience difficulties because they may not be able to remember what they were like prior to injury because of cognitive deficits. The memory deficits at the acute phase of hospitalization may be long lasting depending on extent of brain damage. Long-term memory loss may be problematic if the survivor has difficulty identifying family members and life prior to injury. In addition, the survivor may experience difficulties with understanding the reasons for their condition. The social worker can assist the survivor with piecing together their life prior to injury with assistance from family members. Pictures of past experiences and family members can be helpful to fill in the memory blanks that the survivor may experience. Individual and adjustment counseling can assist with the client's fear of the unknown.

Making community referrals to support groups or an acquired brain injury consultation team is appropriate intervention at time of discharge from the acute care hospital. A referral to the local Community Care Access Center for personal support, rehabilitation, and respite services are important if the patient returns to their home

environment. Advocating for services through the community services or the patient's insurance adjuster is appropriate intervention at this time.

*Phase: recovery*

The person at the recovery phase may require assistance with grieving their functional losses because of a physical disability that may impede their full recovery. An example of this type of loss is the person is not ambulatory and requires a wheelchair to be mobile. The social worker can assist with supporting the survivor through grieving their loss of independence because of their change in lifestyle.

*following the treatment map.*

At the recovery stage the social worker can encourage the individual to continue with their rehabilitation plan. At this phase, the rehabilitation often appears to be slow for the individual, often the person feeling that they will never accomplish their goals. Providing emotional support and this time is an important intervention. The individual should be encouraged to acknowledge their accomplishments they have made since their injury and not dwell on how they were prior to their injury. The person should be encouraged to follow the treatment map in order to achieve their goals.

At the recovery phase, because of the acquired brain injury, it is common that the individual may not be able to operate a motor vehicle. It is the social worker's role to provide the individual with information regarding transportation for the person with disabilities if the person requires out patient therapies. If the individual is not able to arrange their own transportation the social worker can assist. If the individual had insurance it is the social workers role to discuss the transportation issue with the insurance case manager to arrange to provide the cost.



*reliance on others.*

Reliance on others was identified as a sub theme of the need to be normal theme.

At this phase, the social worker can encourage the person to use a memory book to write down daily what they have done and how they can become more independent.

Encouraging an individual to participate in a peer support group is important at this phase. This study identified two participants that found a great deal of support from a person that had a similar acquired brain injury experience as they had.

*living in a cloud.*

The sub theme living in a cloud identified problematic behaviors during the recovery phase. Many, participants of this study, identified that their world felt like in was in disarray or living in a cloud. The social worker's role is to affirm that this feeling is normal for a person who has experienced an acquired brain injury, and reassure the client that these feelings will subside with time. Well being and coping after an acquired brain injury, concerns not only the person's physical ability or inability, but the whole of the individual in their new situation. Social skills training may be useful if inappropriate behavior is displayed.

*Phase: return to work*

The social worker role is to liaise with the individual's employer to assist with the return to work process. This research study identified the importance of professional support in the striving to be normal theme during the return to work phase.

*work place obstacles.*

The social worker can assist with the implementation of the strategies required to return to gainful employment. The intervention should continue after the person returns

to work to identify ongoing concerns. Encouraging the person to continue to utilize their memory book is important at this phase. Advocating for the client is important at the return to work phase. The social worker's role is to schedule work place assessments with the occupational therapist for equipment needs to accommodate the client's changes to the work environment. Scheduling meetings with the individual's employer to set up a proper scheduling is important at this time. Educating the employer regarding acquired brain injury and how the injury has affected their employee is important at this phase.

*work hardened.*

This study identified support within the work environment and reduced working hours as important. The social worker's role at this phase is to advocate for the individual that the return to work be individualized to the client's needs. Educating the employer on the importance of a gradual return to work is appropriate at the work hardened sub theme.

*coping with limitations.*

The sub theme coping with limitations in this study identified the individual realizing that their physical and behavioral concerns may be interfering with their work environment. Individual counseling to assist the individual to identify what their limitations imposed on them are and strategies to assist with coping is a social worker's role. In addition, if the person is unable to maintain their return to work employment; discussing alternatives and community programs to assist with change is appropriate at this time.

### *Phase: post recovery*

The social worker can assist the survivor with self-esteem issues so the person can be accepting of their new lifestyle. At the post recovery phase, the theme of achieving a new normal was identified in this study. At this phase, the participant had learned to cope with the many new challenges that they had encountered. The social worker's role, at this phase, is to assist the client to see more realities that may allow them to realize alternate choices, therefore starting where the client is at and assisting with the emotional needs of the survivor.

### *Macro level of practice*

At the macro level of practice the advanced generalist social worker can assist the individual with community integration. The individual should be encouraged to participate in a peer support group. If there is not a peer support group in the community, a peer support group should be initiated by the social worker. Securing a location to develop a support group in a hospital or community center is the role of the social worker.

In the hospital environment the social worker can initiate a peer visitation program. This program would be initiated with the assistance of the hospital volunteer program. All peer support visitors would be volunteers that would make a friendly visit to the individual who had sustained an acquired brain injury. Permission from the patient would have to be obtained prior to the visit. This program would not only provide support, but would alleviate the fears associated with the unknown. This program would also assist with community integration by providing a contact person in the community.

Continuing education for the social worker is important to keep updated on the current research on acquired brain injury. Joining a social work network consisting of other social workers with an interest in acquired brain injury is important. Discussing new research and keeping abreast of new research will benefit clients by being able to provide updated education.

At the macro level, the social worker can be involved in the local Brain Injury Association at the board of director's level. Being part of the administrative, decision making, and policy process will assist persons who have sustained an acquired brain injury at the community level. Advocating, for the person who has sustained an acquired brain injury, to be part of their community is important at the macro level of social work practice.

### *Family Intervention*

#### *Micro level of practice*

All nine participants of this research study identified personal support as an important part of the recovery process. The social worker can provide supportive counseling and education to all family members. Each individual is unique, as is each family situation. Educating regarding lifestyle changes and ways to cope with problematic behaviors, and memory deficits is a role for the social worker to assist with family members to gain mastery of their lives.

#### *Phase: acute hospitalization*

During the acute hospitalization phase the social worker's role is to provide supportive counseling to the family members. Assisting family members to cope with the patient's "loss of time" and educating them on the many changes to their loved one's

behavior throughout their hospitalization is the role of the hospital social worker.

Providing emotional support for family members from admission to discharge is important. Networking with the medical and nursing staff to keep family updated and scheduling family conferences are important at the acute hospitalization phase.

Educating the family members about acquired brain injuries may alleviate many of the fear associated with hospitalization. Making community referrals to a Community Care Assess Center at discharge is important so the family member will have a professional and supportive contact in the community.

*Phase: recovery*

The advanced generalist social worker can assist individual family members to cope with lifestyle changes. At the recovery phase this study identified reliance on others as a sub theme. The recovering individual becomes dependent on their family members for many daily tasks. The primary care giver may find daily care giving stressful. The family member may not want to disclose all their personal and care giving issues in front of the survivor; therefore may require counseling on an individual basis. The primary caregiver may require emotional support to be able function in his or her new role. The caregiver in a counseling session is allowed, in a supportive environment, to ventilate frustrations in regards to care giving. This experience gives the caregiver an opportunity to speak to an objective person who may be able to provide recommendations to ease some stress in the home. The social worker can educate the caregiver regarding relaxation techniques and respite care so they may be better equipped to cope with their lifestyle changes. Providing information for community respite services is important at the recovery phase of the person's journey.

Educating all family members is an important role of the social worker at the recovery phase. The social worker can assist the survivors and their families by educating the public about acquired brain injuries. Support groups for the family member may provide the opportunity to educate and find ways for the survivor of an acquired brain injury to become reintegrated into the community. Caregiver stress support groups are important at the recovery phase of the client's journey. All family members and primary care givers should be encouraged to attend the care giver stress support groups.

#### *Macro level of practice*

At the macro level the social worker can initiate and develop family support groups in the community. Providing education at the support groups is appropriate. Peer support and caregiver stress groups should be initiated and developed if not available in the community. Respite care programs should also be developed if not available in the community.

#### *Financial Concerns*

##### *Micro level of practice*

At the acute hospitalization phase, the social worker's role is to discuss financial concerns with the patient and the family. If the person is employed, providing the person with the Employment Insurance information is important. If the person was not employed prior to hospitalization, providing information for Social Services is important for the person to have some income and drug benefits. The social worker's role is to discuss with the case worker at Social Services the need to initiate the Ontario Disability Support Program because of the individual's medical needs. Assisting the individual to complete the application form is essential if they are not capable of completing it.

If the individual or family does not qualify for Social Service benefits because their monthly income is too high; yet their income is not adequate to purchase prescription medications, the Trillium drug benefit program should be initiated. This is provided by the Ontario Government according to an income scale. Another recommendation of the social worker should be to have the individual request drug samples from their physician until drug benefits are initiated. Discussing financial concerns with the patient's physician and advocating for waiving the cost for completing medical forms at this time is important if the person can not afford to pay the cost of physician's letters. The researcher's experience is that the cost of physician's notes is often a barrier to the patient's securing the proper benefits.

At the recovery phase, the social worker's role is to assist the individual with short term, long term benefits, or CPP-disability benefits. Encouraging the individual to secure proper benefits is important because the individual can become discouraged and often overwhelmed with all the forms required at this time. Fears of the individual will be lessened if they do not need to be concerned with finances. The social worker's role is to assist with completing application forms for disability benefits, and advocating for the individual at the administrative level of these programs.

#### *Macro level of practice*

Social policy to promote the well being of the person who has sustained an acquired brain injury is paramount. The participants of this study returned to work within the year except one participant that returned after 14 months. One participant identified financial difficulties because of his injury and not being able to work. Government Employment Insurance sickness benefits only provide 15 weeks of coverage for a person

who qualifies with medical documentation of injury (Government of Canada, 2005). The Canada Pension Plan- Disability (CPP-d) benefits are for a person who because of a severe or prolonged disability and are unable to regularly pursue any substantially gainful employment (Government of Canada, 2005). The person who is recovering from a mild or moderate acquired brain injury may not qualify for CPP-d benefits because their doctor does not believe they will be permanently disabled. Therefore, the person will be provided Employment Insurance sickness benefits for 15 weeks but will not have an income after that time unless they are fortunate enough to have private insurance coverage. The person without personal income or other family income will suffer financially due to the injury.

A person, who does not have private insurance benefits during their recovery, may not have an income. The person who has private insurance benefits may find that the benefits are not adequate to support their household until they return to work. The social worker's role is to advocate, to the government, that the Employment Insurance be increased in duration, for the person who is recovering from an acquired brain injury. In addition, the length of time to receive sickness benefits should be increased to one year after injury. If a person has not recovered after a year, then Canada Pension P-disability should be initiated. In addition, the social worker should advocate that medical notes from physicians should be paid by Employment Insurance because the costs of medical notes can be a barrier for the injured person.

Lack of finances and inability to return to gainful employment may marginalize the person who has suffered an acquired brain injury. Marginalization may be the most dangerous form of oppression (Mullaly, 2002). The person who has suffered an acquired



brain injury, because of the sudden onset of their illness, may not have the financial resources to carry them throughout their recovery in the way they were accustomed to while they were working. The lack of resources may lead to many problems with their home, family, and social environment. The person who has a disability should be provided with the same rights and opportunities as the person that does not have a disability. However, because of the problems identified with memory for the person who has sustained an acquired brain injury, the person may not be able to negotiate and exercise their rights in the government system that provides financial compensation. The social worker's role is to advocate for social justice for all persons that have a disability so they will not be marginalized by society.

#### *Research*

This research study may contribute to the qualitative literature on persons who have an acquired brain injury and have returned to work. Several studies have used the narratives of persons who have survived an acquired brain injury to address the return to work issues (Gething,2002; Nochi, 1998; Rollands,2001). Information for service providers have been identified to provide information about a person's recovery, increase the awareness of the impact of an acquired brain injury, and it's relation to return to work. This study has addressed five phases that were identified by obtaining data from nine participants that had an acquired brain injury. Future studies could research these five phases individually. The family member could be researched individually to identify what phases they found problematic for themselves and their loved one. This qualitative study could be the stepping stone for a larger quantitative study researching the phases, themes and their sub themes.

Factors such as gender, post recovery cognitive functioning, rehabilitative intervention, compensation seeking status are avenues for further study. A study researching persons who have not returned to work compared with the nine participants of this study, who were identified as being motivated, would be an interesting study to pursue.

An unanticipated finding of this study was that most participants felt that God had been part of their recovery. Future research could focus on the spiritual aspect of recovery for the person that suffered an acquired brain injury. Changes in spirituality for individuals and family members could be researched.

#### *Summary of social work implications*

The advanced generalist social worker can assist the person who has sustained an acquired brain injury through all phases of recovery. The social worker can provide supportive and adjustment counseling to the person with the injury and family members to assist with returning the person to a functional level. Assisting with community reintegration and providing education is an important role of the social worker. Initiating peer support groups, friendly visiting programs, caregiver stress groups and family educational groups are the role of the social worker. Advocating for changes to policy of the financial benefit programs provided by Human Resource Canada is an important role of the social worker so that the person who has sustained an acquired brain injury may be able to recover with adequate funding. Advocating for social justice for the person that has suffered an acquired brain injury is an important role of the social worker.

### *Conclusion*

This qualitative research study has explored, through face-to-face interviews, the journeys of nine participants who have recovered from a mild or moderate acquired brain injury. This study examined barriers and challenges the nine participants who had sustained an acquired brain injury and their family member encountered on their journey to return to gainful employment. The nine participants and their family member, provided by the Acquired Brain Injury Consultation Team, were interviewed and data from the narratives were analyzed. A conceptual map, of the journey of the participants of this study, was identified as a process that persons who have suffered an acquired brain injury travel through to obtain a goal of achieving a new normal.

Implications for social work practice are providing education, ongoing supportive intervention to individuals and families, interacting with the survivor's employer for return to work issues, advocating for changes to the financial policies of Human Resource Canada, and promoting social justice. Information for service providers has been identified to provide information about a person's journey of recovery, increase the awareness of the impact of injury and its relation to return to work. The journeys of the nine participants of this research study have provided the researcher with a greater understanding of the issues involved with acquired brain injury and its relation to return to work.

UNIVERSITY OF WINDSOR

LETTER OF INFORMATION

Title of Study: Acquired Brain Injury: Journeys from pre-injury to return to work

You are asked to participate in a research study conducted by Catherine Boyce BSW, RSW a graduate student from the School of Social Work, under the supervision of Dr. Brent Angell at the University of Windsor. The results of this study will be contributed to a Master of Social Work Thesis and submitted to the University of Windsor as part of the requirements for a Master of Social Work Degree.

If you have any questions or concerns about the research, please feel free to contact Catherine Boyce at 257-5111 extension 76824 or Dr. Brent Angell at 253-3000 extension 5057.

PURPOSE OF THE STUDY

The purpose of the study is to explore the return to work experiences of persons after sustaining an acquired brain injury. A family member will be included in the interview to provide his or her experiences. The results of this study may provide Social Workers with information to enhance social work practice when working with individuals with an acquired brain injury. Information may be valuable for Social Workers and other health care professionals in areas of prevention, hospitalization, rehabilitation, and return to work.

PROCEDURES

If you volunteer to participate in this study, we ask you to do the following things:

Participate along with a family member in an in-depth interview to explore your life experiences before and after you sustained an acquired brain injury. The interview will also focus on issues surrounding your return to work and maintaining employment. The interview will be audio taped and later transcribed by the writer or an assigned typist. This information will be kept confidential. Total amount of time will be approximately two hours.

Use of your personal and medical information from your client file from the Acquired Brain Injury Consultation Team at Windsor Regional Hospital will be used in a confidential and general way. Your case may be discussed with the Acquired Brain Injury Consultation Team.

Interviews will be conducted in your home.

## POTENTIAL RISKS AND DISCOMFORTS

There are no known risks to you participating in this study. Your service with the Acquired Brain Injury Consultation Team will not be affected. Your employer will not be contacted. Should you find the interview questions upsetting in anyway you are free to not answer the question or stop the interview.

## POTENTIAL BENEFITS TO SUBJECTS AND/ OR SOCIETY

This study will provide you with an opportunity to educate service providers and employers about any barriers you encountered when you returned to work after an acquired brain injury. Your answers will contribute toward social work interventions to assist individuals who have returned to work and/or maintain employment. The community at large stands to benefit from education for employers and employees about potential barriers for return to work for a person who has sustained an acquired brain injury.

## PAYMENT FOR PARTICIPATION

You will not receive any compensation for participating in this study.

## CONFIDENTIALITY

Any information that is obtained in connection with this study that can be identified with you will remain confidential and will be disclosed only with your permission. Your name or family member's name will not be mentioned at any time in this study and your identity will not be associated with any comments. The interview tapes will be kept in a locked cabinet. The tapes will not be used for any other purpose but to assist the interviewer with the data collection. No identifying data will appear in the results.

Conditions in which confidentiality cannot be guaranteed are: 1) if you express a desire to hurt yourself or someone else; or 2) if a child is at risk

## PARTICIPATION AND WITHDRAWAL

You can choose to decide whether or not to participate in this study. If you and a family member volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

## FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS

Research results will be available on the University of Windsor Research Ethics Website at [www.uwindsor.ca/reb](http://www.uwindsor.ca/reb)

## SUBSEQUENT USE OF DATA

This data may be used in subsequent research for issues relating to return to work after an acquired brain injury. The data will be confidential and will not disclose in any way any identifying factors of participants.

## LIABILITY

If you sign this consent form, it does not mean that you waive any legal rights you may have under the law

## RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. This study has been reviewed and received ethics approval clearance through the University of Windsor Ethics Board and the Windsor Regional Hospital Research Ethics Board. If you have any questions regarding your rights as a research subject, contact:

Research Ethics Coordinator  
University Of Windsor  
Windsor, Ontario  
N9B 3P4

Telephone: 519-253-3000, ext. 3916  
E-mail: [lbunn@uwindsor.ca](mailto:lbunn@uwindsor.ca)

And / Or

Research Ethics Office  
Room 4248  
Windsor Regional Hospital  
1995 Lens Ave.,  
Windsor, Ontario N8W 1L9

Telephone: 519- 254-5577 ext. 52278

## SIGNATURE OF THE INVESTIGATOR

These are the terms under which I conduct research

\_\_\_\_\_  
Signature of investigator

\_\_\_\_\_  
Date

UNIVERSITY OF WINDSOR

CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: Acquired Brain Injury: Journeys from pre-injury to return to work

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Participant's Initials\_\_\_\_\_

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Conditions in which confidentiality cannot be guaranteed are: 1) if you express a desire to hurt yourself or someone else; or 2) if a child is at risk

#### PARTICIPATION AND WITHDRAWAL

You can choose to decide whether or not to participate in this study. If you and a family member volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

Participant's initials\_\_\_\_\_



## **FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS**

Research results will be available on the University of Windsor Research Ethics Website at [www.uwindsor.ca/reb](http://www.uwindsor.ca/reb)

## **SUBSEQUENT USE OF DATA**

This data may be used in subsequent research for issues relating to return to work after an acquired brain injury. The data will be confidential and will not disclose in any way any identifying factors of participants.

## **LIABILITY**

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## **RIGHTS OF RESEARCH SUBJECTS**

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And / Or

Research Ethics Office  
Room 4248  
Windsor Regional Hospital  
1995 Lens Ave.,  
Windsor, Ontario N8W 1L9

Telephone: 519- 254-5577 ext. 52278

Participant's initials \_\_\_\_\_

**SIGNATURE OF RESEARCH PARTICIPANT/ LEGAL REPRESENTATIVE**

I understand the information provided for the study- Acquired Brain Injury:  
Journeys of pre-injury to return to work- as described herein. My questions have  
been answered to my satisfaction, and I agree to participate in this study. I have  
been given a copy of this form. I agree that this data can be used in subsequent  
research studies.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Participating Family Member

\_\_\_\_\_  
Signature of Participating Family Member

\_\_\_\_\_  
Date

**SIGNATURE OF WITNESS TO CONSENT INTERVIEW**

My signature as witness certifies that I witnessed the participant voluntarily sign  
the consent form in my presence

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Print Name

\_\_\_\_\_  
Participant's Initials

**SIGNATURE OF INVESTIGATOR**

In my judgment, the participant is voluntarily and knowingly giving informed consent and possesses the legal capacity to give informed consent to participate in this research study.

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Date

\_\_\_\_\_  
Print Name

\_\_\_\_\_  
Participant's Initials

CONSENT FOR AUDIO TAPING

Participant's Name:

Title of the Project: Acquired Brain injury: Journeys from pre-injury to return to work

ID Number:

Birth Date:

I consent to the audio taping of interviews

I understand these are voluntary procedures and I am free to withdraw at any time by requesting that the taping be stopped. I also understand that my name will not be revealed to anyone and that taping will be kept confidential. Tapes are filed by number only and stored in a locked cabinet.

I understand that confidentiality will be respected and the viewing of the materials will be for professional use only.

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

#### APPENDIX A.4

### UNIVERSITY OF WINDSOR CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: Acquired Brain Injury: Journeys from pre-injury to return to work

You are asked to participate in a research study conducted by Catherine Boyce BSW, RSW a graduate student from the School of Social Work, under the supervision of Dr. Brent Angell at the University of Windsor. The results of this study will be contributed to a Master of Social Work thesis and submitted to the University of Windsor as part of the requirements of a Master of Social Work Degree.

If you have any questions or concerns about the research, please feel free to contact Catherine Boyce at 257-5111 extension 76824 or Dr. Brent Angell at 253-3000 extension 5057.

#### PURPOSE OF THE STUDY

The purpose of the study is to explore the return to work experiences of persons after sustaining an acquired brain injury. A family member will be included in the interview to provide his or her experiences. The results of this study may provide Social Workers with information to enhance social work practice when working with individuals with an acquired brain injury. Information may be valuable for Social Workers and other health care professionals in areas of prevention, hospitalization, rehabilitation, and return to work.

#### PROCEDURES

If you volunteer to participate in this study you will be asked to do the following;

As a member of the Acquired Brain Injury Consultation Team you will be asked to provide your comments and opinions on potential outcomes of this study and potential responses by the participants and their family members. These comments will be included in a written section of this study. Any information that is obtained in connection with this study will remain confidential and will be disclosed only with your permission.

#### POTENTIAL RISKS AND DISCOMFORTS

There are no known risks to participating in this study

#### POTENTIAL BENEFITS TO SUBJECTS AND / OR SOCIETY

This study will provide you with the opportunity to voice your opinion on a population of people that you have had the experience of providing intervention to as health care professional.

Participant's initials\_\_\_\_\_

## PAYMENT FOR PARTICIPATION

You will not receive any compensation for participating in this study.

## CONFIDENTIALITY

Your name will not be printed in this study unless you wish it to be.

## PARTICIPATION AND WITHDRAWAL

You may choose to decide whether or not to participate in providing your opinion for the written section in this study.

## FEEDBACK OF THE RESULTS OF THIS STUDY

Research results will be available at the University of Windsor Research Ethics Website at [www.uwindsor.ca/reb](http://www.uwindsor.ca/reb)

## SUBSEQUENT USE OF THE DATA

This data may be used in subsequent research for issues relating to return to work after an acquired brain injury. The data will be confidential and will not disclose any names.

## LIABILITY

If you sign this consent form, it does not mean that you waive any legal right you may have under the law.

## RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. This study has been reviewed and has received ethics approval through the University of Windsor Ethics Board and the Windsor Regional Hospital Research Ethics Board. If you have any questions regarding your rights as a research subject, contact:

Research Ethics Coordinator  
University of Windsor  
Windsor, Ontario

Telephone: 519-253-3000, ext 3916  
E-mail: [lbunn@uwindsor.ca](mailto:lbunn@uwindsor.ca)

And/ Or

Research Ethics Office  
Room 4248  
Windsor Regional Hospital  
1995 Lens Ave.,  
Windsor, Ontario  
N8W 1L9

Telephone: 519-254-5577  
ext. 52278

Participant's initials \_\_\_\_\_

#### SIGNATURE OF RESEARCH PARTICIPANT

I understand the information provided for the study- Acquired Brain Injury: Journeys of pre-injury to return to work- as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form. I agree that this data can be used in subsequent research studies.

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Signature of participant

\_\_\_\_\_  
Date

#### SIGNATURE OF WITNESS TO CONSENT

My signature as witness certifies that I witnessed the participant voluntarily sign the consent form in my presence

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Print Name

\_\_\_\_\_  
Date

#### SIGNATURE OF INVESTIGATOR

In my judgment, the participant is voluntarily and knowingly giving informed consent and possesses the legal capacity to give informed consent to participate in this research study.

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Print Name

\_\_\_\_\_  
Date

Participant's initials \_\_\_\_\_

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