THE IMPACT OF INTIMACY AND DISABILITY ON THE PERCEPTION TOWARD REHABILITATION PROCESSES OF A PERSON WITH A TRAUMATIC INJURY

by

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ABSTRACT

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The purpose of this descriptive research study was to investigate any possible interactions between the person with a traumatic injury and their perceptions of rehabilitation processes dependent on their spousal/domestic partner relationship status before and after their injury.

A questionnaire was developed by the researcher and presented to 189 people in Minnesota, Wisconsin, and Florida who have sustained traumatic brain injuries. The surveyed persons were participants in various support or rehabilitation programs. The participation was voluntary and anonymous.

There were 79 questionnaires returned for a return rate of 42%. These self-report surveys were disseminated without the supervision of the investigator. Of the 79 responses returned only 45 indicated they met the criteria of this study. Data was analyzed from these 45 surveys for an adjusted response rate of 24%. Descriptive statistics were used to analyze results from the questionnaire.

Acknowledgements

This research was prompted by the tenacity of a dear friend, who, despite his brain injury and the accompanying physical and psychological effects, has persevered through many battles. He is now the proud recipient of **his** Master's degree.......Way to go *Bob*!!

I would also like to offer my deepest gratitude to my research advisor, *Dr. Susan Eberhard*, for her patience, guidance, support, and the ability to 'nudge' me in this project. We have had quite an experience together....Thanks *Susie*!!

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TABLE OF CONTENTS

CHAPTER

I. INTRODUCTION

II. LITERATURE REVIEW

III. METHODOLOGY

CHAPTER I

Introduction

There is a high incidence rate of brain injury in the United States (CDC, 2000). Recently, more people are surviving brain injuries (CDC, 2000). There is evidence that life is completely different for the person recovering from a brain injury (Voogt, 2001). These changes also affect those close to the person receiving the injury (Kendall & Buys, 1999). The sequalae of brain injury & related behavior disorders can "… have devastating consequences for the individual's family and friends, and social isolation may result" (Gardner, Bird, Maquire, Carreiro & Abenaim, 2003, p.52). Limited resources and services are provided to the families regarding intimate relationships post-injury (The Brain Injury Association, 2001). Very limited information is available regarding injury impacts on the intimate relationships of the person with the injury. There is very little information about what happens with loss of support from those closest to the person with the injury or about how that affects the recovery process for the person with the injury (Brown, Nell, & Phil, 1992). This research project effort was designed to fill these information gaps and to examine the need for further after-brain injury support systems targeted at the significant other (and other support persons) to assist in recovery processes.

Purpose of the Study

The purpose of this research study was to examine the perceptions of the person with brain injury about intimate relationships and the possible impact of spousal/partnership stability on the outlook about future rehabilitation processes. With the advance of theoretical information relating to the connection of mind and body to patient wellness (Flach and Seachrist, 1994; Kieckolt-Glaser & Glaser, 1998) the perception a person has about the quality and stability of their intimate relationships appeared to be an important consideration.

This relationship between brain injury and relationships was evident in recent literature. Dr. Claudia L. Osborn (1998), in her book “Over My Head” told the story of how she went, in one instant, from a busy practicing physician/teacher to a person with a brain injury. In her story she related that while she seemed to “recover” physically, she had numerous alterations in her cognitive abilities. Small tasks like going to the post office became a major expedition. Her roommate, also a physician, later tried to explain to her that she was not the “same person she used to be.” This personality change affected her relationship not only with her roommate but also with her other friends, co-workers, and patients.

This study examined the impact of brain injury related life changes by exploring participant perspectives on the effects of injury on intimate relationships and the effect of those relationship changes on the person with the injury. This was identified as a critical focus of study needed in the field and addressed understanding gaps in the field and in policy.

Scope of the Problem

Numbers of brain injury survivors are increasing due to increased medical interventions. The Centers of Disease Control and Prevention (CDC) in Atlanta, Georgia (2000) reported in 1995-1996 the following impacts from Traumatic Brain Injury:

-- 1 million people were treated and released from hospital emergency departments
-- 230,000 people were hospitalized and survive
-- 50,000 people died

The CDC (2000) also reported an average brain injury incidence rate of 95 persons per 100,000, with twenty-two percent of these injuries resulting in the death of the person involved.

Injury rates for males were about twice that of females and the most likely age for sustaining injuries was 15-24 years old.

Most traumatic brain injuries are the result of an accident or injury that is violent in nature. Brain injury incidence statistics underreport the number of people affected by brain injury. Statistics represent only those with the actual insult to their bodies. There are significantly larger numbers of people who are affected by brain injuries due to their relationships with an injured person (Virtual Hospital, 2000). When one partner sustains a serious accidental disability, 61% of couples become involved in serious marital conflicts (Rosenbaum & Hoge, 1989).

Theoretical Framework

Hallet, Zasler, Maurer and Cash (1994, p. 241) have done research related to “role changes” following a Traumatic Brain Injury (TBI). This research revealed that there are not only physical changes for a person with TBI but other cognitive and social functioning changes as well. Hallet, et al. (1994, p.241) defined “role” as “an expected pattern of behavior associated with the occupancy of a distinctive position in society.” The study revealed that the greatest loss for the person with TBI was the “worker role.”

The Virtual Hospital (an on-line information site), in their Guide for Families and Friends (2000) section explained that it is normal to have varied reactions when someone you love is hospitalized. They specified panic, fear, shock, denial, anger, guilt, isolation, and hope as some of the anticipated reactions. With these anticipated reactions for the non-injured person, there could be a supposition that the injured person would also experience all these emotions along with many more. Rosenbaum and Najenson (1976, p.40) reported that wives experienced “drastic life changes” in relation to a spouse after a Traumatic Brain Injury (TBI). While this research focused on the perceptions of the well spouse, there was scant information on the perceptions of the injured person in the relationship.

Reactions to such drastic changes may affect recovery. The relationship of the mind and its influence on one's health is a newer area of study and research. Flach and Seachrist (1994) termed this new science psychoneuroimmunology. Researchers have found that state of mind can stimulate or suppress the immune system. Drs. Kiecolt-Glaser and Glaser (1998) conducted studies that suggested poor emotional well-being suppressed the body's ability to fight disease. Anxiety and depression were shown to be involved in this suppression. There would seem to be a tie-in to this mind-body interaction when a person with TBI is experiencing major life and role changes.

The long-lasting effects of TBI have a great impact on the processes of rehabilitation and recovery. Brown et al., (1992, p.760) reported that for persons with brain injuries, "psychologic problems and family relationships worsened with time." The severity of the initial injury also seemed to have an impact on outcomes for persons with Traumatic Brain Injury (TBI) in that study.

The Brain Injury Association (2001) has several excellent articles on their website relating to injury and post-injury situations. Carolyn Rocchio, as a parent of a person with a brain injury, wrote for this web page and stated: "the most prevalent impairments subsequent to brain injury are severe cognitive deficits." Brain injury was described as a life-long disability. Services for these clients have been cut back due to restrictions in the health care delivery systems. Rocchio explained that families are not ready to accept these changes in the injured person since they have no training or experience to use as a guideline. The recognition of how brain injury

affects all facets of cognition is a long and tedious process.

Voogt (2001) wrote that the workings of the frontal lobe of the human brain control what is termed executive functioning. This area of the brain is involved in self-determination. In events of great change the person with an injury may experience a “broken spirit” as a result of the losses. There is very little time given to the process of reestablishing the spirit or as he wrote, “No wheelchair exists for a traumatized brain”. He also stated that relationships are compromised following a brain injury.

An Australian research study (Kendall & Buys, 1999) focused on survivors of motor vehicle accidents. The survivors were reported to have a decrease in both quality and quantity of their social relationships as well as increased family breakdowns. In this article, the researchers quoted from a study by Elsass and Kinsella (1987, pp. 67-78) who “...found that people who had sustained serious brain injury tended to be satisfied with a minimal level of social contact since this enabled them to avoid the confusion associated with concentration and memory problems or language impairments.”

The increased incidence of persons surviving traumatic insults with brain injuries, the research showing the relationship of the mind-body health aspects, the information that spouse/family dissonance followed the injury, all contributed to the need for this research project. Little has been told about the needs of the person with the TBI who, after grieving the loss of their “former self” must then find a way to adapt to a new lifestyle. Such adaptation occurs while the person is also placed in a position to decide how, or if, they will continue with any rehabilitation modalities.

Statement of the Problem

The research project used self-report to examine relationship (spouse/partner) stability and how it affected the rehabilitation and recovery for persons with a traumatic injury. Demographic and open ended questions were used to explore and understand the following research problem: How do persons with brain injuries experience effects on intimate relationships after injury and how does this affect rehabilitation and recovery?

Research Questions

The research problem was addressed using the following guiding research questions:

1) What are the impacts of injury on spousal/partner relationships?
2) What are the impacts of injury on the parent/child relationships?
3) What reported factors enhance relationship stability and quality?
4) What reported factors distract from relationship stability?
5) What effects do relationship changes have on rehabilitation?
6) What impact does traumatic injury have on the injured person's future goals?

Definition of Terms

Traumatic Injury in this study was defined as the accident or event that precipitated disability and occurred to those persons with a Traumatic Brain Injury. Traumatic Brain Injury may be referred to as TBI in the remainder of this study paper.

Intimate relationships are defined as spouse/partner or child.

Family included those individuals defined as family by the person with brain injury. Family was listed on the researcher-developed survey as spouse/partner, parent/child, etc. The use of etc. allowed persons with brain injury to identify and define the people they considered members of their family.

Rehabilitation was defined as the range of recovery services identified by the person with the brain injury on the researcher developed questionnaire.

Limitations of Scope

This study explored the experience of those with brain injury. True to the qualitative method, it was a reflection of the experiences of those who participated. Generalizations beyond this sample can be only be made to the extent that other individuals or populations mirror the characteristics of this sample. Effort was made to collect data pertinent to the participants to guide consumers of this study in determining how applicable the information might be in the area and for the population of interest.

The survey was designed with open-ended questions to allow individuals to share their unique experiences. As a result of this qualitative individualized approach, most responses could not be standardized. To the extent possible, commonalities across responses were reported to provide information about the strength of particular themes for the group as a whole.

Qualitative research, because of the richness of data generated, requires the use of small sample sizes. The current study was designed as a survey instrument to allow information from a wider variety of participants. Data was gathered from a cross-section of those with brain injury in order to have access to a large enough sample for comparison purposes. Due to sample size, few efforts were made to delineate groups by injury tenure, rural/urban, or other potentially relevant factors. Thus the study was limited and described only reported experiences and issues as a starting point for understanding injury and relationship effects.

Another potential limitation in scope was the collection of data only from persons with injury. No efforts were made to corroborate what was reported through reports from family or from provider perspectives. Reported results are only the perspectives of persons with injury.

The scope was also limited because the method chosen was a combination of quantitative/qualitative survey. Accuracy of reporting is potentially limited to what can be known as a result of the study. Brain injury by its nature has cognitive effects. Cognitive effects of injury may result in limited understanding of questions or accuracy in perceptions/insight and reporting. Self-reported intimacy experiences were used because there was little available information from this perspective in the literature. The survey was designed so that participants could add comments as desired to ensure that they could communicate as fully as they wished.

This research study was designed to examine intimate relationship (spouse/partner) stability and how it affected the rehabilitation and recovery for persons with traumatic injury. Literature was reviewed that showed brain injury was prevalent and effects widespread. Recovery was often long, difficult and slow. Family members and all other people in relationships with the person with an injury were impacted by the changes with injury. The intent of this study was to better describe, from the injured person’s perspective, how relationships and recovery interacted. The next section describes the literature that formed the base for this study.

CHAPTER II

Literature Review

Traumatic Injury in this study was defined as injuries sustained by those persons with a Traumatic Brain Injury. Traumatic Brain Injury will be referred to as TBI in the remainder of this paper. In order to understand the responses of participants reported in the findings section, it was important to understand the dramatic effects that TBI has on the lives of people affected. Literature was reviewed as a foundation for understanding the impact of injury on survivors. Literature reported in this section includes: (a) TBI primer; (b) recovery, treatment and rehabilitation; (c) physical effects of TBI; (d) cognitive and emotional effects of TBI; (e) personality effects with TBI; (f) the brain/body connection; (g) marital outcomes; (h) family reactions; (i) relationship stability and recovery effects; (j) need for rehabilitation services; (k) outlook on rehabilitation services; (l) a summary of what is known; and (m) summary of what is unknown. The first section, TBI primer will review basic information about brain injury.

TBI Primer

Brain injury has wide-ranging effects on the body and mind. Limitations associated with brain injury depend on the nature of the injury, the area of the brain injured and the extent of those injuries. This section will review: (a) what is brain injury; (b) traumatic brain injury defined; (c) types of injury and (d) statistics - occurrences, ages, and gender differences. The first section, what is brain injury follows.

What is brain injury? Brain injury occurs when there is impact or assault to the brain. Nontraumatic and traumatic injuries are the two major types of brain injury (Man, 2001).

Nontraumatic injury occurs from conditions such as cerebrovascular accidents, illness and infectious agents or toxins. Traumatic injury occurs when there is direct injury to brain tissue such as in a blow to the head or a motor vehicle accident.

Traumatic brain injury defined. The National Brain Injury Association defined Traumatic Brain Injury(TBI) as an insult to the brain, not of degenerative or congenital nature caused by an external physical force that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical functioning. TBI can also result in the disturbance of behavioral or emotional functioning. A gun shot wound to the brain or blow to the head during a vehicle accident, fall or assault is a TBI. In order to understand the effects caused by brain injury it is necessary to understand a little bit more about the types of traumatic injury. Types of traumatic brain injury are defined further below.

Types of traumatic brain injury. One of the classifications of brain injury is whether they are considered closed or open injuries. A closed head injury is the result of some external force which does not fracture the skull. An open head injury results from an object hitting the skull with enough force to fracture the skull. Both types of injuries can result in a TBI. There are varied degrees of insult to the brain in either type of injury (BIA USA, 2003).

Brain injuries can be from a single assault (i.e. auto accident) or from cumulative events (i.e. soccer balls, domestic violence). The physical location of the brain injury has various effects on what after-effects the person sustaining the injury will exhibit. Injuries to the frontal lobe affect, among other things, decision making and social behavior controls. These functions are a dramatic part of maintaining effective social relationships (BIA-Wa.).

Statistics –occurrences, age, and gender differences. Recently more people survived brain injuries due to increased medical interventions. The Centers of Disease Control and Prevention (CDC) in Atlanta, Georgia (2000) reported in 1995-1996 the following impacts from Traumatic Brain Injury:

-- 1 million people- treated and released from hospital emergency departments
-- 230,000 people were hospitalized and survive
-- 50,000 people died

The CDC (2000) also reported an average brain injury incidence rate of 95 persons per 100,000, with twenty-two percent of these injuries resulting in the death of the person involved. Injury rates for males were about twice that of females and the most likely age for sustaining injuries was 15-24 years old.

This brain injury primer section covered background information about brain injury. Effects of injury vary, but more people survived injuries over the last decade. In order to understand how relationships affect rehabilitation it is important to understand something about interventions after injury. The person sustaining a brain injury generally required medical intervention. Information about recovery, treatment and rehabilitation follows.

Recovery, Treatment and Rehabilitation

Treatment occurs immediately at time of brain injury and continues through all phases of rehabilitation. The goal of the intensive or acute care phase of treatment is survival, medical stabilization, locating areas of injury, and prevention of further damage to the brain. Duration depends on severity of injury. Persons with mild traumatic injury may go through this process in a matter of a couple of days or they may just be treated in the emergency room and released. They often go immediately home following this phase of treatment (Kay & Lezak, 1990).

Persons with moderate or severe injuries often require a period of rehabilitation inpatient treatment following acute hospitalization and medical stabilization. The purpose of inpatient rehabilitation services is to enhance activity of daily life function so that the person can return home (BIA USA, 2003; Kay & Lezak, 1990; Kreutzer, Kolakowsky-Hafner, Ripley, Cifu, Rosenthal, Bushnik, Zafonte, Englander & High, 2001).

Inpatient programming has changed. Trends data over the years 1990-1996 were analyzed from 800 survivors served through the National Institute on Disability and Rehabilitation Research (NIDRR) model TBI programs. Results showed that average length of stay in both acute and rehabilitation inpatient settings had fallen precipitously; with rehabilitation stays reduced the most proportionally. Average acute care stays ranged from 22-29 days in 1990-1994 but were down to only 16 days by 1996. Average rehabilitation inpatient stays dropped 12 days during the years 1990-1992 then had steady decreases after 1993. Rehabilitation length of stay began the period at an average of 38 days in 1990 and was down to a low of 20 days in 1996 (Kreutzer, et al, 2001).

The average of 16 days was quite brief for medical stabilization. Of even greater concern, considering pervasive brain injury effects was the 20 day period of inpatient rehabilitation services. No information was provided in this study about how such a dramatic change has affected persons with brain injury.

Sometimes arrangements must be made to coordinate services and supports in the community or in a residential setting if limitations are so severe the person cannot return home. Follow through rehabilitation can be provided at day treatment programs or outpatient facilities once the person returns home. Those who are unable or unwilling to return home may benefit from Community re-entry or independent living facilities. Each person's injury is unique and thus each person experiences a unique recovery (BIA USA, 2003; Kay & Lezak, 1990; Kreutzer, et. al., 2001).

Rehabilitation services do extend into the community, since the overall goal of rehabilitation is functioning consistent with goals in a variety of settings. Often, persons with more pronounced effects from injury require outpatient rehabilitation and outpatient treatment services that last for years. Long-term injury effects may require community based residential or day services even after completion of outpatient rehabilitation (Man, 2001).

The recovery process also affects families and that in turn affects the person with injury and the rehabilitation process. Families encourage the member with TBI during the acute stage and through inpatient rehabilitation. Each new accomplishment is a new milestone. Physical improvements are visible and encouraging. Reality sets in when the person with TBI is told they can go home. They may look the same but the family continues to wait for the before-injury person to return. Return never happens and that reality is difficult to accept. The family must pick up the slack left by the person with TBI who is now unable to participate as before injury. Additionally, the family is burdened with the extra duties involved with medical care and related costs. Support systems during acute phases and early rehabilitation primarily focus on the person with TBI without incorporating the needs of the spouse (Greer & Philbrick, 2001).

Hospitalization and rehabilitation were shown to be processes individually tailored to the needs of the person with TBI. The length of stay for both impatient acute and rehabilitation services has been reduced over the last decade. This was noted as a concern because the effects of TBI are profound. Families were often challenged by the injury and may anticipate even less support options for the survivor in the future. As previously stated, brain injury affects all of functioning. The physical effects of TBI will be discussed in the next section.

Physical Effects of TBI

A closed head brain injury is not necessarily obvious to the general public. There may not be any obvious physical identifiers. Persons who have experienced injury to the brain however may cope with dizziness, headache and fatigue (Borgaro, Prigatano, Kavasnica & Rexer, 2003). Other physical effects may include lack of strength and endurance; recurring pain; paralysis; inability to coordinate motor functions such as walking, talking, or grasping; changes in ability to hear, taste, or see; balance disturbances; hypersensitivity to light and sound; and sleep disturbances (BIA-VA). Gait disorders, ataxia, and tremors; seizure activity; and speech impaired by poor control of the muscles in the lips, tongue, and jaw; plus poor breathing patterns have also been reported (TPN).

Cognitive and Emotional Effects of TBI

Depending on the area of the brain that is injured and the extent of injury many cognitive limitations may result from traumatic injury. Speed of processing, the ability to attend and the ability to remember all may be affected by TBI (Borgaro, Prigatano, Kavasnica & Rexer, 2003). Numerous other cognitive functions can be impacted by injury including: communication, learning, thinking and verbal and abstract problem solving (Cattalani, Tanzi, Lombardi & Mazzucchi, 2002). Cognitive and physical impairments often function reciprocally. Cognitive

deficits are frequently complicated by physical limitations such as problems with fatigue or stamina (Borgaro, Prigatano, Kavasnica & Rexer, 2003).

Injuries to the frontal lobe affect, among other things, decision-making and social behavior controls. These functions are crucial for maintaining effective social relationships. Part of this function is considered executive functioning (BIA-Wa). With impaired executive functions, the individual's ability to maintain a normal social relationship is compromised (Lezak, 1995).

Executive functions are those capacities that enable a person to successfully engage in independent, purposeful, and self-serving behavior. These functions are critical for life management. Executive functions are goal directed behaviors such as planning, organized searches, impulse control, and effective performance. A person with impaired executive functioning will have problems in the areas of independently performing useful work, satisfactory self-cares, or maintaining normal social relationships (Lezak, 1995).

At the same time a person is coping with physical, cognitive and executive function changes as a result of injury, they must deal with the emotional aftermath of the injury. TBI can affect all parts of life so it is understandable that there would be an emotional process that accompanies recovery. The emotional stages of TBI recovery were outlined by Dr. Glen Johnson (1998) to include:

1. Confusion and Agitation- may involve physical or verbal aggression toward family members or nursing staff
2. Denial-"there is nothing wrong with me" even though they may put shoes in the refrigerator or milk in the closet.
3. Anger and Depression-When the injured person realizes they can't do things like they used to. "I am a failure. I can't do this. I'm no good"

1. Testing Phase-"I'm going to see if I just can't be the way I used to be" even if there are consequences after attempting to exceed current abilities.
2. Uneasy Acceptance-learning where they stand and what there limits are.

Cognitive and behavioral impacts of injury also interact. A study of 35 survivors explored previously measured function throughout the recovery course and compared function with ultimate re-employment outcomes. Most physical limitations were found to resolve over time,

especially for the re-employed group. Cognitive effects were diverse, more pronounced and tended to endure especially for those who were not reemployed. These cognitive effects included: speech, communication, learning, memory and attention, thinking, verbal and abstract problem solving. Behavior was also found to endure and be disruptive and included things such as apathy, inertia, depression, childishness, uncertainty, irritability, impulsiveness, perseveration and sexual acting out (Cattalani, Tanzi, Lombardi & Mazzucchi, 2002).

In a study of 45 male survivors and their significant other, neurobehavioral, cognitive and emotional functioning was found to be the greatest barriers to positive outcomes. All of these men had been receiving outpatient services for at least 2 years and had a mean length of time since injury of 10 years. For these men and their significant other it was not physical limitations that were problematic. Instead the pervasive and disruptive behavioral, cognitive and adjustment issues created the greatest challenge (Macmillan, Hart, Martelli, & Zassler, 2002).

Insight is critical to rehabilitation success. The lack of awareness of behavior, cognitive and emotional functioning, often caused problems at home and at work (Port, Willmott & Charlton, 2002). Research has shown that persons with brain injury may have greater difficulty recognizing limitations in executive functioning, one of the higher order cognitive skills. This can impact recognition of the need for rehabilitation services and follow through (Port, et al, 2002). This can also contribute to a sense of changed personality as will be discussed below.

Personality Effects with TBI

Wide ranging changes in behavior such as apathy, inertia, depression, childishness, uncertainty, irritability, impulsiveness, perseveration and sexual acting out may accompany brain injury (Cattalani, Tanzi, Lombardi & Mazzucchi, 2002). The person who was motivated and engaged prior to injury may seem like a different person when brain injury results in apathy and avolition. Similarly, personality is significantly altered when a regularly even-tempered, well reasoned survivor becomes impulsive and irritable following injury. When personality changes are pronounced, the survivor may seem like an entirely different person. Survivor responses that were predictable, based on consistent personality traits, may seem unfathomable after injury.

Loss of control of anger can be a devastating change in the personality of persons with TBI and can have major consequences for how survivors deal with problem situations as well as how others such as family interact with them. Physical changes following injury can create anger problems when the person lacks emotional control. Anger control problems can also arise as a result of frustration when the person experiences difficulty with cognitive changes such as limitations in understanding and communicating (Danark & Gemeinhardt, 2002).

Depression, anxiety and affective distress may also result from brain injury and from frustration with associated limitations (Borgaro, Prigatano, Kavasnica & Rexer, 2003). Such affective changes can contribute to the experience of changed personality after injury. Affective distress was more commonly reported in those who were unable to return to meaningful roles (i.e. work) following injury (Cattalani, Tanzi, Lombardi, Mazzucchi, 2002). Hallet, et. al. (1994)

did research related to “role changes” following a Traumatic Brain Injury (TBI). The study showed physical, cognitive and social role changes for survivors. Hallet, et. al. (1994) defined "role" as "an expected pattern of behavior associated with the occupancy of a distinctive position in society." The greatest loss for the person with TBI was the "worker role." Such role changes may also contribute to a sense of changed personality when the person with injury no longer has structure and reinforcement for the kinds of behaviors and responses that accompany the worker role. All such changes create stress and interact with injury as described in the brain/body connection.

The Brain / Body Connection

The brain controls all functions of the body and is the seat of thought, emotional and behavioral responses. The brain also controls higher order function and the organization of the personality. It is reasonable to expect that changes in brain function might affect all other experiences, including experiences within the family and in rehabilitation or recovery. Meta-analysis showed that persons with TBI experienced cumulative effects that had profound and enduring impact on quality of life. Insufficient research and measurements techniques were available to understand the experience, process or impact on the person (Johnston & Miklos, 2002).

Perceptions about quality of life affect people. The relationship of the mind and health is a new area of research. Flach and Seachrist (1994) termed this new science psychoneuroimmunology. Researchers discovered that the state of mind may bolster the immune system. Drs. Kiecolt-Glaser and Glaser (1998) conducted studies that showed poor emotional

well being suppressed the body's ability to fight disease. Anxiety and depression were shown to be involved in this suppression. Increased anxiety and depression have been demonstrated for some persons with brain injury (Borgaro, Prigatano, Kavasnica & Rexer, 2003).

The long-lasting effects of TBI have a great impact on the processes of rehabilitation and recovery (Gan & Schuller, 2002; Port, Willmott & Charlton, 2002). Brown et al (1992) reported that, “psychologic problems and family relationships worsened with time”(p.760). Often functioning problems only became apparent to the person with injury and family members as the person attempted to function in daily life and experienced frustration or failure (Port, Willmott & Charlton, 2002). Effects were long-lasting with research evidence showing pronounced personal and family impact as much as seven years post injury (Gan & Schuller, 2002).

Steven Hyman (1997), Director of the National Institute of Mental Health, presented current neurobiological mechanism research to the U. S. House of Representatives. He reported that Renee Descartes, a French philosopher who died 347 years prior, had formulated the idea that the mind and body were radically distinct entities. Modern medicine thus relied only on scientific processes to determine an illness. Thought or emotional disorders while they may result in, “…terrible impacts on individuals, families, and national productivity, are often made light of and ignorantly stigmatized”.

Disabilities such as the cognitive effects of brain injury can interfere with coping. Hyman described a process by which the brain receives information to assist the person to cope with both dangerous and painful situations. A person with some distortion to their brain pathways may not have a coordinated response to these messages. This in turn can lead to reduced coping efficacy and more harmful situational and affective/physiological consequences.

The frontal lobe is critical to self-determination. During great change, particularly with compromised executive function, the person with an injury may experience a “broken spirit” as a result of the losses (p. 23). Voogt (2001) noted that TBI treatment afforded very little time or attention to the process of reestablishing the spirit. “No wheelchair exists for a traumatized brain” (p. 23). Relationship complications followed the physical, cognitive and psychic change with injury. Voogt reported that relationships were compromised following a brain injury. Information specific to injury impact on relationships will be reported in greater detail in the next section, marital outcomes.

Marital Outcomes

Brain injury has often affected every part of a person’s life and function. These effects impact the entire family (Cattelani, Tanzi, Lombardi & Mazzucchi, 2002; Gan & Schuller, 2002, Man, 2001). Brain injuries not resulting in a hospital admission are considered mild brain injuries. These persons have a 15% rate of negative consequences even 1 year post-injury (Alexander, 1995). There can also be a significant impact on marriages (Guerrero, Thurman, & Sniezek, 2000). The presence of a severe brain injury almost always adversely affects the sexual/marital relationship (Gosling and Oddy, 1999). Most traumatic brain injuries are the result of an accident or injury that is violent in nature. When one partner sustained a serious accidental disability, 61% of couples became involved in serious marital conflicts. (Rosenbaum & Hoge, 1989). Relatives reported personal problems relating to frustration, depression, and social isolation in relation to family adjustment problems following traumatic injury (Hall, Karzmark, Stevens, Englander, O'Hare, and Wright, 1994).

Relationship breakdowns following brain injury are quite common. Previous studies have shown divorce rates of 30% - 55% (Oddy, Coughlin & Tyerman, 1985; Panting & Merry, 1972 ; Stilwell, Hawley & Stilwell, 1997; Tate, Lulham & Broe, 1989) compared to a divorce rate of 14%-19% for the general population. There appeared to be a relationship between time and breakup. The longer a couple dealt with injury, the more likely the marriage would end. Thomsen (1984) found only two out of 9 couples remained together 15 years after injury. Another study by Wood and Yurdakal (1997) showed that of 131 head-injured adults, 49% had separated after 5-8 years. The more time post-injury, the greater the likelihood of separation. The presence of children in the relationship did not decrease the likelihood of a separation. Longer pre-injury relationships reduced separation risk. There was a benchmark at two years post-injury. This was identified as the time when the person with TBI reached a stabilization plateau and the partner had less hope. The partner then came to the realization that the situation was permanent.

Literature targeted at helping survivors to cope often includes sections designed for the family (Brain Injury Association, 2001; Virtual Hospital, 2000). A variety of changes were discussed in this review that affect the family after injury. Stress and adjustment demands posed by injury are extreme and family responses vary as the entire family system makes efforts to adapt (Gan & Schuller, 2002). Some limited studies have been conducted examining family reactions post TBI. Literature and related studies will be reported below.

Family Reactions

Family members go through their own adjustment process following a loved one's injury.

The Virtual Hospital (an on-line information site), in their Guide for Families and Friends (2000) section explained that it is normal to have varied reactions when someone you love is hospitalized. Among these post-injury reactions were: panic, fear, shock, denial, anger, guilt, isolation, and hope. A tremendous amount of work is involved in grieving losses and reestablishing a sense of predictability so that the entire family can move on toward recovery. There is generally a lack of focus on the family members as the patient receives the main focus. The other family members can be left to deal with their feelings of anxiety, fear, depression, despair, and conflict (Brintnell, Madill, Montgomerie, & Stewin, 1992). Emotional reactions must be resolved and incorporated so that family members can support the person with TBI.

Families provide most of the care for persons with brain injury (Gan & Schuller, 2002; Greer & Philbrick, 2001; Knight, Devereux, Godfrey, 1998). Often the bulk of work and support for the person with injury falls on the shoulders of the surviving spouse. After an injury, the roles of work and home were disrupted. The person with TBI still wanted to contribute. With changed functioning, their ability to implement those contributions realistically became an issue (Thompson, 1985).

A study of spousal reactions after injury (Greer & Philbrick, 2001) showed that family typically became the ultimate caregiver. Rehabilitation services were limited in duration, then the injured person and their family had to begin the process of rebuilding, despite the extent of injury related limitations. Such rebuilding took place in home and community environments with substantially reduced or nonexistent professional support. Often spouses reported being ill prepared for this demanding role. Spouses were quoted as “being stressed out”, or “at my wit’s end”. Spouses made statements such as, “I don’t know how to deal with this anymore” (p.17).

The onset of an injury, coping with change and managing injury effects can precipitate family crisis and feelings of helplessness and inability to effect change (Man, 2001). Often family members experience greater difficulty from injury than the person with the TBI. In a study of 43 persons with injury and 92 of their family members, (Gan & Schuller, 2002) all family members were profoundly affected, not just caretakers. A family rating scale was used to assess seven different areas of family function. Distress was noted by partners and children in all areas. Family distress was more marked than that reported by the person with TBI. This held true throughout the recovery process. Brain injury limitations and family impact did not go away. Distress rates were similar for families at 1-2, 3-5 and longer than 5 years post injury. Overwhelming demands had a profound impact on quality of life and spousal perception of ability to cope (Greer & Philbrick, 2001). Demands occurred at the same time that a couple was becoming reacquainted following return home. Injury demands and effects compromised the couples' experience of the positive rewards needed to maintain a relationship. The effects of injury made it more difficult for the couple to work through changes together. As one spouse reported, "He's not who I married". While brain injuries are unique, so are the families of those sustaining brain injuries. Greer and Philbrick (2001) encouraged that "psychosocial adjustment groups" (p. 18) be used to facilitate the sharing of like situations by members of the family.

Relationships require compromise and negotiation so that problems can be jointly resolved. Relationship building overtures after conflict or struggle help to solidify and re-establish the rewards of the relationship. Such relationship affirming statements and actions require that both partners are able to communicate positively to each other. In a study by Peters, Stambrook, Moore, and Estes, (1990) brain injury often impeded the responses and full participation of the injured spouse. Couples experienced more discord, less cohesiveness and less overt communication. Wives of injured partners reported that there was more disagreement, that the pair had trouble coming to decisions together and had less physical and verbal xpressiveness. Teresa Christiansen (1998) called attention to various family reactions that were of concern in the recovery process. Her article described specific therapeutic considerations when working with families. These included becoming proactive in seeking supports to decrease stress as well as increasing the independence and psychological adjustments within the family systems.

Family members struggled to cope (Knight, Devereux, & Godfrey, 1998). Mood disturbances such as anger, irritability, and aggression caused concern for the caregivers. Some spouses felt the relationships with their husbands had improved and some parents felt they were closer to their children after the injury. Personality changes in the person with TBI caused a consistent degree of distress for relatives through 7 years post-injury. Caregivers had difficult time accessing information about resources and long-term care for the injured person. This problem was exacerbated in rural areas. Caregivers also had to find the narrow path between unrealistic expectations for what the injured person could achieve and over-protective responses that limited independence. Caregivers also had to seek care for themselves to maintain their own quality of life (Knight, Devereux, Godfrey, 1998). This is especially important because there is evidence that what happens with the relationship has implications for recovery and the well being of the injured partner. Relationship stability and recovery effects will be discussed below.

Relationship Stability and Recovery Effects

Brain injury affects relationships as was increasingly evident in recent literature (Gan & Schuller, 2002; Greer & Philbrick, 2001; Knight, Devereux, & Godfrey, 1998; Man, 2001). Dr.

Claudia L. Osborn (1998), in her book “Over My Head” told the story of how she went, in one instant, from a busy practicing physician/teacher to a person with a brain injury. In her story she related that while she seemed to “recover” physically, she had numerous alterations in her cognitive abilities. Small tasks like going to the post office became a major expedition. Her roommate, also a physician, later tried to explain to her that she was not the “same person she used to be.” This personality change affected her relationship not only with her roommate but also with her other friends co-workers, and patients.

The level of intimacy and connection between roommates is less profound than that between committed partners. Research evidence suggested that the effects of injury create major changes for a spouse (Rosenbaum & Najenson, 1976). While this research focused on the perceptions of the well spouse, there was scant information available for review to describe the perceptions of the injured person in the relationship. There was evidence that injured persons experienced profound changes that affected their ability to establish and maintain relationships. Some of that literature is described below.

Sexuality is a fundamental part of intimate relationships and of the human experience. Brain injury complications have often affected the experience and expression of human sexuality. The brain is the most important organ for establishing and maintaining sexual relationships and function, thus problems in sexual function and behavior often follow TBI (Aloni, Keren, Cohen, Rosentul, Romm & Groswasser, 1999). Dr. Balderian (2001) wrote that there was a vast difference in the sexual adaptation ability of persons with TBI, depending on when the injury occurred. Those with an injury that occurred at birth or as a very young child never had experiences with sexuality. Persons who sustained later injuries had to figure out how they fit into this world of relationships and sexuality. The "core desire for an intimate relationship or expression of sexuality" (p.6) was not altered by a person's injury. Attitudes of society and the helping professions were identified as barriers to effective resolution of sexuality issues. This article indicated there was a stereotypical attitude that assumed interest in sexuality was unseemly for the elderly, the clergy, the widowed, and those with disabilities.

Just as there were coping demands for family members post-injury, there were repeated and numerous demands on the person with injury. The effects of injury were consuming, leaving little attention or energy to maintain relationships. Fundamental aspects of relationships such as communication and sexuality were also compromised by injury. Often the effects of injury resulted in social isolation for the person with injury. One study that examined relationship effects for survivors suggested that withdrawal may be a defense and a survival mechanism.

An Australian research study (Kendall & Buys, 1999) studied survivors of motor vehicle accidents. The survivors were reported to have a decrease in both their quality and quantity of social relationships as well as increased family breakdowns. Elsass and Kinsella (1987) reported that people with serious brain injuries tended to be "satisfied with a minimal level of social contact since this enabled them to avoid the confusion associated with concentration and memory problems or language impairments."

Obviously then, there were a variety of relationship challenges reported in the literature experienced by both survivors of brain injury and the families that loved them. Often the challenges proved insurmountable and led to family dissolution. Coping with injury and relationship challenges may affect the recovery process and participation and progress in rehabilitation. The next section will more closely examine need for rehabilitation services.

Need for Rehabilitation Services

Throughout this review, evidence has been presented that a host of challenges are presented by injury and rehabilitation. Such challenges present issues that must be addressed for both persons with injury and their families. Treatments of psychological factors relating to the injured person's physical disability must also include emotional responses, grieving of losses and overall adaptations by the various family members (Britnell, et. al, 1992.). One particular set of studies will be described in this section as a summary of the need for rehabilitation supports.

Empowerment, the capacity to achieve control and mastery in multiple areas of life is critical for coping and was studied for both persons with brain injury and their families (Man,1999; Man, 2001). In the earlier study (Man, 1999) examination of empowerment programming for family members showed that gaining skills and effective problem solving were most important to family members. The follow up study examined factors of empowerment for persons with traumatic brain injury. Results showed that for the injured person, skills and support were most critical. As mentioned elsewhere, families often provide needed support for their injured members. It appears from this set of studies that outcomes would be enhanced for both persons with injury and for their families if rehabilitation services addressed these issues. It seemed that family members and persons with injury recognized the need for such intervention since in both studies long-term morale and knowledge emerged as critical to empowerment.

Outlook on Rehabilitation Services

The Brain Injury Association (2001) has several excellent articles on their website relating to injury and post-injury situations. Carolyn Rocchio writes for this web page and stated:

“the most prevalent impairments subsequent to brain injury are severe cognitive deficits.” Brain injury was described as a life-long disability. Services for these clients have been cut back due to restrictions in the health care delivery systems. Rocchio explained that families are not ready to accept changes in the injured person since they have no training or experience to use as a guideline. Since brain injury occurs inside the person’s body, effects are not readily apparent. The brain affects all other human functions, so impairment after injury can be widespread and diffuse. For the person with injury and their family members, the recognition of how brain injury affects all facets of cognition and life is a long and tedious process.

Often there were inadequate supports to guide and inform persons with injury and their families as they began the process of discovering what injury would mean in their lives. Only after there was a solid base for understanding injury effects could appropriate interventions be designed to address limitations. Unfortunately, often when persons with injuries and their family members reached out for supportive services, they found that those services simply did not exist or there were no resources to purchase services. Surprisingly, there was evidence of reverse triage in the service delivery system. Persons with more severe brain injuries often got access to the fewest services. A survey done in Illinois (Heinemann, Sokol, Garvin & Bode, 2002) reported that those with greater unmet need received fewer services. The research concluded that overall there was a common pattern of unmet needs and services. This was described as a systemic problem that reflected very limited understanding of the needs of persons with injuries. The authors emphasized the importance of comprehensive services and needs in developing policies. Most persons with injuries get the bulk of care from families. As a result of this survey and the other studies previously cited, it was apparent that movement toward more informed policy required additional research to elucidate injury and family relationship effects.

Lack of access to services and supports has profound implications for families and for persons with brain injuries. These effects are enduring. A study of long-term outcomes for persons who sustained TBI ten to 20 years earlier (Hoofien, Vakil, Gilboa, Donovick & Barak, 2002) showed that socio-economic status was a better predictor of family, cognitive, psychiatric, social, and work function than severity of injury or age at injury. In this study of 76 persons who had been injured between the ages of 17-55 and 34 of their family members, age at injury was not found to predict any outcome. Severity of injury was only found to affect the person's level of involvement in activities of daily living (ADLs) since physical capacity greatly affects independent function in such areas. Socio-economic status (SES) on the other hand predicted outcomes for the person with injury in all other areas. Family outcomes were also predicted by SES, although small family sample sizes complicated analysis. Specifically SES was predictive of how well the family functioned, how involved the person with injury was in family life and the level of burden experienced by the family. The authors noted that the robustness of the SES factor in predicting outcomes could have been because those with higher socio-economic status had more resources and supports as well as access to medical and rehabilitation services.

Rehabilitation services should incorporate family. In a metanalysis, MacFarlane (1999) reported that most surviving couples could benefit from therapy. Family therapists could assist with role changes and issues of grief and loss. This therapy could assist both couples as well as families with children as they dealt with the varied role changes following a brain injury.

Summary of What is Known

All of the research and literature described in this review highlighted the challenges experienced by persons with brain injuries and their families. Brain injury survival rates have increased resulting in more persons dealing with life and family issues. Brain injury resulted in physical, cognitive/emotional and personality changes. Those challenges endured over a long period of time and affected every aspect of life. There was evidence of decreasing and insufficient support for treatment or rehabilitation services. Inadequate supports may impact the recovery process and in turn affect quality of life for the person with injury.

There was extensive evidence of family effects from injury. Families provide the bulk of care for injured members. Family reactions to injury were powerful, but often overlooked with the concentration on function and support for the person with injury. Marital disruption was common. Demands on families were great and often resulted in severe distress. Family members demonstrated greater difficulties in dealing with the aftermath of injury than the person with the traumatic brain injury. The review concluded that persons with traumatic brain injury have serious long-enduring problems with quality of life. Additional research was needed to more fully describe issues related to life after injury and the effects of injury on family relationships.

Summary of What is Unknown

Throughout this review of literature, research has shown brain injury had profound effects on the person with injury and on their family members. Methodology created knowledge gaps. Previous studies were formulated with research questions and method generated by professionals, thus less information was known about particular aspects of intimate relationships (e.g. sexuality). This lack was attributed to the biases of professionals (Balderian, 2001).

Broad TBI effects and cognitive limitations also impact measurement. Most reviewed studies used quantitative data to explore both the injury related limitations and outcomes for persons who were injured (Borgaro, Prigatano, Kavasnica & Rexer, 2003; Catalani, Tanzi, Lombardi & Mazzucchi, 2002; Gan & Schuller, 2002; Heinemann, Sokol, Garvin & Bode, 2002; Hoofien, et. al, 2002; Macmillan, Hart, Martelli, & Zassler, 2002; Port, Willmott & Charlton, 2002). Quantitative measures pose challenges because all areas of function can be affected by TBI and it is impossible to sort out what contributes most to observed function (Macmillan, Hart, Martelli & Zassler, 2002). Situational and broad data measures have been used to circumvent this problem, but confidence in results was still questionable.

Researchers have also attempted to enhance results confidence by incorporating data from family members or significant others (Cattelani, Tanzi, Lombardi & Mazzucchi, 2002; Gan & Schuller, 2002; Hoofien, et.al., 2002; Port, Willmott & Charlton, 2002). There was evidence in the research that in many areas family members may not be more accurate than persons with TBI in their assessment of limitation and injury effects (Port, Willmott and Charlton, 2002). Even after review of the family member report literature, the accuracy of brain injury effects and relationship impact was unknown.

Another potential source of information about injury and relationship effects is the perceptions of survivors about life and relationships after injury. There appeared to be a critical gap in the literature when looking for survivor descriptions. Internet information from support organizations and first person accounts do exist, but these sources lacked the scientific rigor found in professional peer-reviewed literature (Virtual Hospital; NIMH; State TBI websites;) Some individual with brain injuries (or their families) post their own websites to share their experiences or request assistance from others who have gone through the same situations. As mentioned, most of the professional literature relied on psychometric measures of function that can be greatly compromised by the effects of injury. Little then was known about perspectives on life and relationships from rigorous examination of data.

Since brain effects are so broad, survivors may be able to provide insight about important questions to ask, how relationships are experienced after injury and how what happens in post-injury relationships affects rehabilitation and recovery. Rehabilitation principles suggest that each person is unique and thus experiences disability in a unique way. Qualitative methods assume that to understand phenomena, the personal meanings, values, and world view must be included (Patterson, DeLaGarza & Schaller, 1998). The qualitative method allows participants to shape emerging understanding of constructs and how those constructs are experienced (Bogden & Biklen, 1992). Open-ended exploration also allows individual variations to emerge, that are lost when group level data are reported in quantitative analysis. Such qualitative exploration and analysis was not available for review. As a result, it was also unknown whether a qualitative exploration of post-injury relationship effects might provide new understanding of life after a brain injury. The method described in the following chapter was designed to address these gaps in the research and literature.

CHAPTER III

Methodology

This was a combination of qualitative and quantitative survey research. A survey was designed by the researcher with demographic questions to describe participants. A series of primarily open-ended questions were used to allow participants to share their perspectives on the research problem. That research problem was: How do persons with brain injuries experience effects on intimate relationships and how does this affect the rehabilitation process. The research problem was answered using the following guiding research questions.

1. What are the impacts of injury on spousal/partner relationships?
2. What are the impacts of injury on the parent/child relationship?
3. What reported factors enhance relationship stability and quality?
4. What reported factors detract from relationship stability?
5. What effects do relationship changes have on rehabilitation?
6. What impact does traumatic injury have on the injured person's future goals?

This section will describe the method used to answer the guiding research questions. Topics covered in this section include: (a) selection and description of subjects, (b) instrument used, (c) data collection procedures, (d) data analysis procedures, (e) strengths, (f) limitations, (d) unknowns, and (e) summary. The first section, selection and description of subjects, follows.

Selection and Description of Subjects

The selection of the participants was done within agencies that serve persons with brain injury in Wisconsin, Minnesota and Florida. Contact was made with well-recognized organizations providing outreach or services to the population including: the Brain Injury

Associations (Wisconsin and Florida), a brain injury treatment program (Minnesota), a community based residential facility (Minnesota), and at a TBI conference in Florida. Each of the TBI organizations was provided with detailed information about the need for the study, protection of human subjects procedures as approved by the University IRB, and sample surveys. Agency help in contacting potential participants was solicited by the researcher. The agencies were requested to recruit participants within the scope of the research. Study inclusion criteria included involvement in an intimate relationship at the time of the person's brain injury.

There were 45 surveys received from persons with brain injuries who were in relationships at the time of injury. These responses were analyzed and make up the bulk of the data reported in the findings section. There were an additional 34 surveys that were completed by persons not in an intimate relationship at the time of injury. True to the qualitative method the process informed the research. The survey was designed with an open-ended format. As a result, many of the items allowed these non-relationship respondents to provide insights very critical to understanding the research problem, and the nature of injury effects on intimacy, and thus on rehabilitation. Review of those non-relationship survey responses showed that a number of responses did shed light on pertinent relationship issues regardless of relationship status at time of injury. A decision was made to include those results as a separate sub-sample of the respondents.

There were 189 surveys mailed and 79 persons with brain injury who returned surveys resulting in a response rate of 41.8%. The bulk of the findings reported were from the 45 individuals in relationships at the time of injury. Results for the 34 non-relationship respondents were analyzed separately and are reported at the end of the findings section. Details about the characteristics of the respondents can be found in the findings sections. More about the instrument used to examine injury relationship effects is described in the following section.

Instrument Used

Data was collected from the self-report information provided on the participant surveys. The survey was designed with the help of an expert who has lived with brain injury for 12 years, and who also provides services to the population. Survey questions were generated that literature and field experience suggested were relevant for understanding the experience of intimacy following brain injury. The expertise of participants was also solicited and incorporated through the use of a comment question that specifically included observations about survey design. Pertinent comments were included in the analysis of data.

Questions were designed for readability and ease of response. Sample items have been included in this discussion of the instrument. Full text of the survey can be reviewed in Appendix C. Items were included to gather demographic information to describe the sample (age, gender, ethnicity, living arrangements and employment status). Injury and relationship experiences were also explored (age at injury, years post-injury, relationship status at time of injury, tenure of relationship prior to injury, number of post-injury years before the relationship was terminated). Each of these background questions was written so that participants could simply endorse a category to respond. Questions were designed as much as possible for response ease and clarity so that the instrument itself would not be a barrier to participation. An example of this design strategy was the living status question, Are you: single/living alone, married/living with spouse, living with a partner of the opposite gender, living with a partner of same gender, other (please describe).

Categorical response options were also provided for questions about relationship pressure and about respondent's children. The pressure question read: Were you pressured to change your relationship (after your injury) by any of the following: (check all that apply) family (parent, children, etc.), medical personnel (doctor, nurse, etc), service personnel (therapists, aides, etc.), social service personnel, and other (s) – describe. Respondents were also asked if they had children at the time of injury (number and ages) and whether those children were in the participant's custody at the time of injury. The final categorical response item read: Are these children still in your custody? Yes (full time, joint custody with spouse/partner, other arrangements – describe) or NO (court declared removal – divorce/other, personal decision, over 18 – own custody).

A series of open-ended items were designed to explore perceptions and relationship experiences. Participants were asked about reasons they felt relationships survived or were terminated as well as about how they felt relationship status affected the rehabilitation process. Two open-ended questions asked about future goals, specifically: What would you consider to be <u>your</u> future goals regarding: FAMILY (spouse/partner, parent/child, etc.) and REHABILITATION (continue it, terminate it, don't care, etc.). A final open-ended item instructed respondents: Please use the space below to add any personal comments you wish to add. (<u>Feel free to continue comments on additional sheets of paper</u>). Do you have any comments about the survey questions? Do you have any comments about how your intimate relationships may have had an impact on your attitude toward your rehabilitation?

Each survey response was reviewed and integrated into the results chapter of this paper. More detailed information about the data collection procedures used follows.

Data Collection Procedures

A questionnaire was developed by the researcher and presented to 189 people in Minnesota, Wisconsin, and Florida from December 2001 through February 2002 who had sustained traumatic brain injury. The surveyed persons were participants in various support or rehabilitation programs. Participation was voluntary and anonymous. A cover letter was sent to the agencies (see appendix) requesting that they distribute the questionnaires to appropriate participants in their programs. Agencies provided each participant with a questionnaire (see appendix) along with a letter (see appendix) explaining the study as well as a stamped and self addressed envelope for returning the survey to this researcher. Upon receipt of completed surveys, survey data were compiled; results were tabulated and then analyzed. More specific information about data analysis procedures is found in the next section.

Data Analysis Procedures

Descriptive statistics were used to analyze the demographic information on the survey. Frequencies and percentages of respondents endorsing each of the demographic categories were calculated. Those results are reported in the findings. The qualitative open-ended questions were reviewed separately and then coded by paragraph. Specific procedures included the generation of response lists for each survey item. Typed lists included the actual responses by all survey respondents from each sub-sample (e.g. in relationship, not in relationship). Two separate reviewers coded the lists, and then emerging themes and categories were compared. Most unique themes or responses that were different from the experience of the group as a whole were noted and reported as appropriate. Thick description was used with ample use of direct citation to capture the meaning within categories and themes. Responses were coded from within as possible.

After all themes and categories were identified, surveys were again reviewed to ensure that the analysis captured the experience of each respondent. Throughout analysis, the expert that assisted with survey development provided insights and perspectives in terms of interpretation of results. The results of all analysis can be found in the findings section. There were strengths to this methodology as well as limitations. Strengths and limitations will be discussed in the next two sections.

Strengths

Some of the strengths of this methodology identified by this researcher were:

1. The instrument was designed with considerable background literature review and experience with persons with brain injury by the researcher. The researcher has 8 years of experience involving the population, so the design of the instrument, the content of the instrument and the structure of the instrument were all tailored to allow the best adequacy and accuracy of information
2. The use of an expert in life with brain injury as well as in understanding issues that emerge through service provision greatly strengthened both design of the instrument as well as veracity and legitimacy in interpreting survey data.
3. The use of two separate reviewers to code results also strengthened confidence in the themes and categories that emerged.
4. The study had a high participation rate of 41.8%. A variety of factors associated with brain injury were anticipated to potentially impede participation. All contact information and recruitment procedures were designed to increase participation.

Specific procedures used to increase participation were: design of instrument, use of agencies that were voluntary and trusted by persons with brain injury to recruit participants, information about the need for the study that resonated with participants as was obvious in the analysis of results.

5. The use of open-ended questions was also a methodological strength. Open questions allowed participants to shape exploration of the topic and to identify material they felt was important to understanding how brain injury and relationships are lived.
6. Another strength was the inclusion of a section that encouraged participants to comment on the topic of injury/relationships and instrument design. This strengthened accuracy in analysis and informed the research process.

Limitations

Some of the limitations recognized by this researcher were:

1. As with all qualitative research, sample sizes must be restricted to allow analysis of the wealth of data that is collected. The size of this sample was very small, with 79 surveys completed. There is the potential, whenever sample sizes are small, that a higher percentage of participants in a certain group could have a greater influence on the total results. Inclusion of data that was unique, or particularly important to understanding the responses of even one participant, was included in analysis and report of findings as a control for this bias.
2. Participation was limited to those recruited based on their participation in a specific program. There may be many other persons not participating in a formal

program with varied views on this subject. Effort was made to include sufficient demographic information and rich description so that others using this research could determine the extent to which findings are applicable.

3. Self-report of this type requires a degree of concentration and honesty. The participants in this study may have had some cognitive limitations due to injury that affected their ability to concentrate or comprehend. Responses may have been distorted by reduced executive function ability following the injury. This limitation was anticipated so methodological measures were put in place to address it. Great care was taken in the design of the instrument so that questions were clear but allowed the person with injury to inform the research.
4. Another limitation was possible disinterest by the solicited agencies or their participants. If an agency did not recruit an unbiased cross section of their members the results may be skewed. Effort was made to control for this potential source of bias through extensive pre-survey contact with agencies. Each agency was contacted and provided detailed information about the study and their role in recruiting participants before surveys were ever sent. Detailed information was also sent with the actual surveys for distribution. Please see a sample in Appendix A.
5. The requested participants may have feared that information would be used to harm them in some way. The anonymous nature of the questionnaire was stated on all forms indicating that there was no intent to harm, but cognitive deficits and dependent status may still have resulted in people electing not to participate

because of fear. It is important to note that the majority of people that were recruited did elect not to participate (110 or 58.2% of the surveys were not returned).

6. The instrument was designed for clarity and ease of understanding. As a result, categories were used for much of the demographic information. For consistency, some questions such as current age, or age at injury followed the same categorical format. This resulted in analysis limitations since sample means could not be computed.

Unknowns

There is considerable information that was not known following the completion of this study. Although efforts were made to prepare the agencies that recruited participants, it was impossible to know for sure whether there was bias in selecting and recruiting participants. It is thus impossible to know for sure how this group may compare to a non-recruited sample. It was also impossible to determine whether participants differed in any meaningful way from non-participants. This study used a self-report format to enhance the quality of information and insights gleaned about the experience of relationships after traumatic brain injury. Due to the tremendous variation in post-injury functional limitations, it was impossible to know what the effects of injury were on reporting about relationships. No effort was made to triangulate by gathering survey information from significant others. It was unknown whether the insights of partners and other family members would differ significantly from perspectives about relationship experiences described by participants with brain injuries. Some information was gathered about pre-injury relationships (length prior to injury). There was no effort to gather additional information about pre-injury relationship quality or lifestyle issues that may have affected the results observed in this study. The method described allowed exploration of intimacy and brain injury from the perspective of persons with brain injury. This section has described the method used to address the research problem. A summary of this methodology description follows.

Summary

This was a combination of qualitative and quantitative survey research. A survey was designed by the researcher with demographic questions to describe participants. A series of primarily open-ended questions were used to allow participants to share their perspectives on the research problem. The research problem studied was: How do persons with brain injury experience effects on intimate relationships after injury and how does this affect rehabilitation and recovery? Guiding questions were used to frame the exploration and were reflected in survey questions. The survey was designed based on literature review and field experience. An expert with brain injury was consulted in survey design and throughout analysis. A sample of the survey sent to participants can be found in appendix C.

Agencies in Wisconsin, Minnesota & Florida that serve persons with brain injuries were asked to distribute the surveys. There were 189 surveys distributed. Of those surveys 79 were returned for a 41.8% response rate. There were both fixed categorical response questions and open-ended items on the surveys. Data was analyzed with frequencies and percentages for the categorical questions. Open ended items were reviewed line by line and coded by paragraph. Two reviewers independently coded and then results were compared. Themes and categories were coded from within to the extent possible. Unique responses that were important to understanding the experience of even a single participant were included. Rich description was used to promote full understanding of each theme and category. The expert who participated in design and development of the instrument provided consultation in analysis of findings. There were a number of strengths and limitations associated with this methodology. Procedures were put in place to restrict the effects of limitations. Just as with any other piece of research, there were also a number of unknowns at the conclusion of this study. Those unknowns are important to note but do not detract from the importance of what was learned about the experience of brain injury and impact on relationships. A detailed description of what was known as a result of this study can be found in the next section results.

Chapter IV

Results

The research project used self-report to examine relationship (spouse/partner) stability and how it affected the rehabilitation and recovery for persons with traumatic injury. Demographic and open ended questions were used to explore and understand the following research problem: How do persons with brain injuries experience effects on intimate relationships after injury and how does this affect rehabilitation and recovery.

A total of 189 questionnaires were sent to agencies in Minnesota, Wisconsin and Florida that provides services to persons with brain injuries. A total of 79 surveys were returned to the investigator for a response rate of 41.8%. These self-report surveys were disseminated without the supervision of the investigator. As a result, there was some misunderstanding of the criteria for participation. Of the 79 response returns, only 45 participants indicated that they met the inclusion criteria: I was in an intimate relationship at the time of my injury. Since this study was designed to examine the effects of injury on intimate relationships, the bulk of analyzed and reported data will be from those 45 useable surveys or 24% of the total surveys sent out to agencies. Thirty four surveys were returned from individuals who were not in relationships at the time of injury. As explained in the methods description, review of those surveys revealed valuable insights. At the conclusion of this analysis section, information will be reported about the experiences of those not in relationships at the time of injury.

Demographics

The participants were nearly equally male (56%) and female (44%). The ethnicity of participants was predominantly Caucasian (76%) with some representation of Latino-American

(4%), Native American (4%), African American (2%) and other/not shown (13%). Both genders were equally represented among the ethnic groups with the exception that the Latino and African American respondents were exclusively male. Current age of respondents was spread across decades. There were equal proportions of respondents who indicated that they were age 19-29 (24%) or that they were age 30-39 (24%), slightly more respondents (29%) indicated that they were age 40-49 and slightly fewer (22%) indicated that they were age 50 or older. Demographic data from the sample at the time the survey was conducted can be seen in the table below.

Table 1: Demographics

Gender	Female N 20 = 44%	Male N 25 = 56%		
Age Today	Age 19-29 N 11 = 24%	Age 30-39 N 11 = 24%	Age 40-49 N 13 = 29%	Age 50 or More N 10 = 22%
Ethnicity	Caucasian N 34 = 76%	Latino N 2 = 4%	Native American N 2 = 4%	African American N 1 = 2%
Ethnicity (cont.)	Other/Not listed N 6 = 13%			

The table above illustrates that this was a predominantly Caucasian sample. There was fairly equal participation by both genders. Participants were also asked questions about their current work and living situations. Results related to present status in employment and living arrangements are summarized in the following section.

Current Work and Living Arrangements

Respondents were asked to indicate their current work and living arrangements. Almost half of the group (21 respondents or 47%) was unemployed. Most employed people worked part-time (16 respondents or 36%) rather than at a full-time job (6 respondents or 13%). Only two female respondents (4%) indicated that they were in school full-time and no respondents were in school part-time.

Living arrangements were varied. The largest group of respondents lived alone (17 respondents or 38%). A total of 18% of the sample lived with a partner, with 4 respondents or 9% of the sample living with a partner of the opposite gender and 9% with a partner of the same gender. Fewer respondents reported that they were married/living with spouse (5 respondents or 11%). A substantial portion of the sample 34% indicated that they had other living arrangements. Other living arrangements included: 4 people or 9% of participants living with parents or children, 5 people or 11% of participants living in a group home and 6 (13%) individuals who did not report. Work and living arrangements are illustrated in the table below.

Table 2: Work and Living Arrangements

Employment	Not Employed N 21 = 47%	Employed - Part-Time N 16 = 36%	Employed - Full-Time N 6 = 13%	Student - Full-Time N 2 = 4%
Living Arrangements	Single - Living Alone N 17 = 38%	With Partner of Opposite Gender N 4 = 9%	With Partner of Same Gender N 4 = 9%	Married - With Spouse N 5 = 11%
--Other Living Arrangements N 15 = 34%	With Parents or Children N 4 = 9%	Group Homes N 5 = 11%	Not Described N 6 = 13%	

The above table demonstrates that most participants were unemployed or employed part-time and living alone. Data related to injury experiences of participants are described in the next section.

Injury Experiences

Respondents were asked to indicate how old they were when their brain injury occurred. There was considerable variation in injury age, since about half of the sample indicated that the injury occurred before age 30 (53%) and there were only slightly fewer people injured after the age of 30 (47%). Specifically 5 respondents (11%) indicated the injury occurred before age 18, 11 respondents (24%) indicated that the injury occurred at the age of 18-23, and 8 respondents (18%) indicated that the injury occurred at the age of 24-29. There were 9 respondents (20%) with brain injury that occurred at age 30-35 and 10 respondents (22%) with brain injury at age 36-50. Only 2 respondents (4%) sustained brain injury at age 51 or over. Age at injury data are illustrated in the following table.

Table 3: Age at Injury

Age at Injury	17 or younger	18-23	24-29	30-35	36-50	51 & over
Male	N 3 = 7%	N 7 = 15%	N 4 = 9%	N 5 = 11%	N 5 = 11%	N 1 = 2%
Female	N 2 = 4%	N 4 = 9%	N 4 = 9%	N 4 = 9%	N 5 = 11%	N 1 = 2%
Total	N 5 = 11%	N 11 = 24%	N 8 = 18%	N 9 = 20%	N 10 = 22%	N 2 = 4%

The above table demonstrates that injuries were greatest in the 18-23 and 36-50 year old age groups. The largest injury group was males injured between the ages of 18-23. In addition to gathering information about age at injury, respondents were asked to indicate how long they had lived with brain injury. Participants had considerable life with injury experience. All participants were beyond the first year of recovery. There were more men (8) than women (3) who reported that it was 1-2 years after their injury (24% of sample). Equal numbers of men (2) and women (2) indicated that the injury occurred 3-4 years previously (9% of sample). Considering those with the most life with brain injury experience (5 years or more) men tended to have lived with injury slightly longer. There were 5 females and 1 male who indicated 5-7 years of life after injury

(13% of sample) and 14 males and 10 females with 8 years or more of living with brain injury (53% of sample). This is illustrated in the following table.

Table 4: Years since Injury

Years Since Injury	1-2 Years	3-4 Years	5-7 Years	8 years or more
Male	N 8 = 18%	N 2 = 4%	N 1 = 2%	N 14 = 31%
Female	N 3 = 7%	N 2 = 4%	N 5 = 11%	N 10 = 22%
Total	N 11 = 24%	N 4 = 9%	N 6 = 13%	N 24 = 53%

The largest group in this sample had 8 or more years post injury, followed by those with 1-2 years post injury. People reported varied effects from injury. The injury and the effects from injury had a dramatic effect on participants' lives and relationships. With the experience of brain injury there were considerable changes in relationship status for participants. Data about intimate relationship experiences are described in the next section: intimate relationship experiences.

Intimate Relationship Experiences

All 45 participants were in intimate relationships at the time of their injuries. The bulk of those relationships were longstanding with almost two thirds (62%) of participants in relationships for 4 years or more prior to injury. There were 10 men and 8 women that reported relationships of 8 or more years (40%) and 4 men and 6 women who were in relationships for 4-7 years prior to injury (22%). There were another 5 men and 4 women who were in relationships for 1-3 years (20%) at the time of injury. Only 6 men and 2 women (18%) had relationships of less than a year at the time of injury.

The effect of injury on intimate relationships was pronounced since 42 of those relationships (93%) had ended when survey data were collected. Only 2 men and 1 woman continued in their pre-injury intimate relationship (7%). Of participants who ended relationships, women had longer post-injury relationships but the majority of all relationship terminations (55%) occurred within the first year post-injury (16 men and 7 women). The second year after injury was also tenuous for relationships since 3 men and 4 women indicated that relationships ended 1-2 years after injury (17%). One man and 3 women (9%) ended relationships 3-4 years post-injury, 2 men (5%) ended relationships 5-7 years post-injury and 1 man and 3 women ended relationships (9%) 8 years or more after the injury. Two respondents (5% of sample) did not report when the relationship ended. Length of relationship and the time that relationships ended are illustrated in the next table, relationship experiences.

Table 5: Relationship Experiences

Pre-Injury Length of Relationship	<1 year N 8 = 18%	1-3 Years N 9 = 20%	4-7 Years N 10 = 22%	8 years or more N 18 = 40%		
Still In Same Relationship	**NO** N 42 = 93%	**YES** N 3 = 7%				
Post-Injury Relationship Ended	<1 year N 23 = 55%	1-2 years N 7 = 17%	3-4 years N 4 = 9%	5-7 years N 2 = 5%	8+ years N 4 = 9%	Not shown N 2 = 5%

The greatest relationship losses occurred before the end of the second year post-injury (72% of sample). This substantial number of relationship disruptions may be influenced by the stress involved with the hospitalization, rehabilitation, financial, and role adjustments immediately following brain injury. Participants were asked about why they felt their relationships endured or ended. Various reasons were given for sustaining and terminating relationships. These will be discussed in the next section.

Sustaining & Terminating Relationships

Participants were asked to explain reasons that relationships were stable or changed after injury. Item number 12 was stated: What do you feel were the reasons the relationship survived OR terminated. The vast majority of respondents (93%) as described above experienced termination of intimate relationships after injury. Various explanations were given about why relationships ended. These termination reasons were clustered into categories that included: *general reasons unconnected to disability* (5 responses), *partner and injury* (6 responses), *change in functioning* (6 responses), *role change* (4 responses), *sex and partnering* (2 responses), *self-decision* (4 responses), *demands* (4 responses), and *abuse* (3 responses). There were also responses from the 3 people still in relationships. Their responses have been grouped into a category of *enduring* (3 responses) and will be described immediately after the termination reason discussion. The first of the termination reasons, general reasons unconnected to disability is described below.

As with the general population, there was evidence that relationships are hard to maintain. The crises of injury did not magically fix relationships. The responses of 5 people attributed breakup to *general reasons unconnected to disability*. Such reasons included: differences, spouse drinking, “grew apart”, and “inability to handle money—incompatibility.” A good summary of this group of experiences was the response by a participant commenting that the relationship ended due to “Many problems not particularly related to TBI.”

Six respondents were vague about relationship difficulties. With brain injury much of the world and life changes are beyond the person's control. Sometimes the person who is injured is able to understand and articulate those changes but for other people causality is less concrete. There were 6 *partner and injury* responses as reasons that relationships ended. Two respondents described the accident or injury as causing the breakup; four mentioned their partner. Partners in this group of responses were described as having "ended the relationship", or were described as "weird", or "unsupportive." Brain injury places tremendous demands on both partners and can complicate the ability to adjust in the relationship. Maintaining the relationship post-injury takes tremendous perseverance as one participant said, "My husband couldn't handle it, my parents did."

Brain injury created changes and 6 respondents mentioned such *change in functioning* as reasons that relationships did not endure. There were 3 responses that mentioned personality, functioning ability, and global post-injury changes in the person. One person mentioned specific behaviors, "My constant walking around made my wife uninterested in me anymore. She got a new boyfriend." Brain injury affected the ability to participate in shared activities and loss of the ease of partnership with both parties reciprocally aiding each other. That particular relationship was severed "Due to the fact that I wasn't able to travel or be the helping hand that [name deleted] needed." Changes also affected the person with the injury and decreased the flexibility needed to maintain relationships. As one respondent explained about breakup, "My decrease in energy and stamina and my change in willingness/ability to put up with things I didn't understand or agree with."

Roles changed with brain injury. This affected both the partner and the person with the injury. There were 4 *role change* responses listed as the reason for relationships ending. One man said that his “wife didn’t want anything to do with me after the accident”, another said, “I wasn’t the man she married.” Another person simply described “differences after TBI - he didn’t understand.” TBI can result in a feeling of disconnection. One response seemed to include such emotional distance but also described difficulty in maintaining a relationship even as roles within the relationship change. “He proposed on April 1. I just looked at him with nothing. He was the caregiver, boyfriend, and it didn’t mesh. Spiritually I changed and he didn’t mesh with that. I wanted more of a spiritual leader.”

Closely related to this change in roles were responses that specifically addressed loss of intimacy in the relationship. The 2 responses described by the theme talked about *sex and partnering*. Intimacy can stabilize a relationship and remind partners about what is good in life and the relationship. Brain injury not only creates changes that affect day-to-day function it can also inhibit intimacy and some of the behaviors that serve as a base for the relationship. One respondent said that the relationship ended because, “[I] lost all interest in intimacy (i.e. sex) after brain injury.” Another respondent described intimacy more broadly. This response highlights the loss of connection and partnering that can come with brain injury, “I was not able to socialize, communicate like I used to. I had no interest in sex anymore.” In addition to changes in functioning, roles, and intimacy the presence of brain injury can create new demands that further compromise the quality and sustainability of relationships. Responses related to demands will be described in the next paragraph.

Brain injury creates *demands* that affect life and relationships. Increased medical costs, dependence or even the separation that accompanies treatment can impact relationships. This is especially true when there is an inadequate support system. One respondent explained the relationship ended because of “Lack of education for spouse, of supports, resources or rehab training.” Despite added costs for medical and rehabilitation care, routine family expenses continue. One person said, “My ex husband couldn’t provide for my daughter and I, especially the medical expenses.” Brain injury can result in partners living in separate worlds, “I was away a long time at the hospital” or the person who commented about “Increased dependence for daily living needs. Spouse needed to move on.” Although a partner may move on, persons with injury must create a life after injury. As shown in this study, this often means creating a life outside of the pre-injury relationship. There were respondents who described termination as an effort to build a new life**.** The theme of self-decision in making a life after injury and relationship termination is described in the next paragraph.

Four respondents described relationships ending because of *self-decision*. One person stated “I decided I didn’t want a relationship”, another responded “I felt the need for closure.” A previously cited response talked about post-injury changes in her spirituality that the pre-injury partner did not mirror, “Spiritually I changed and he didn’t mesh with that. I wanted more of a spiritual leader.” Another respondent talked about ending the relationship because of changed goals. This response had some aspects of the self-decision theme, but also described pervasive injury effects and more global change impact described in other response categories. Brain injury is complicated and complex, the effects of brain injury are so wide-ranging that relationships are difficult to maintain. As was reported, “Change of goals – we were both students. As well, we were both involved in my injury. Seemed to hang over our heads.”

Demands and injury changes were resolved via relationship termination decisions by spouse or by the person with injury. Changes as described in previous paragraphs were pervasive and had substantial life and relationship impact. Such changes affected quality of life for all involved especially with inadequate supports as a previously mentioned response indicated. All of the changes, combined with lack of adequate support, sometimes created vulnerability for the person with a brain injury. A particularly troubling theme emerged in 3 responses; this theme has been described as *abuse*. Such abuse ranged from the apparently mild psychological abuse of "She sometimes commented on people with an underprivileged capacity", to the more blatant "He was abusive to me – for example: He would call me 'moron' because of my traumatic brain injury." Abuse without intervention could degenerate into physical assault, "She noticed all the changes in me after the TBI. She got vicious and would hit me in the head." This type of physical abuse is especially alarming because of the increased vulnerability of the brain after injury.

There were three people who described reasons that their relationships were *enduring* despite the injury. The most positive of these responses described spiritual and emotional anchors that sustained the relationship, "Love, caring, help of God". Two other responses were more pragmatic and echoed the undercurrent of change so prevalent in the reasons given for relationship termination. As one person explained," We have one son. We share custody." Another person remarked on the qualitative changes in a relationship that endured, "No one left physically so 'interaction' continued I would hesitate to call it a relationship--certainly not doing things like before."

As has been obvious throughout this section, there were widely varied reasons for relationship termination. Relationships were compromised by a variety of functional, quality of life and relationship challenges related to a brain injury. Relationships also experienced external pressures. Information about such external pressures will be described in the next section.

External Pressures

An item on the survey asked people to describe external pressures that may have impacted intimate relationships. Specifically this question asked: Were you pressured to change your relationship (after your injury) by any of the following (check all that apply): family, (parent, children, etc.); medical personnel (doctor, nurse, etc.); service personnel (therapists, aides, etc.); social service personnel; others (describe).

Twenty six respondents (58%) did not report pressure to change their relationships from others. Pressure was still a fairly common experience since 19 participants (42%) indicated that they were pressured to change their relationships after injury. The remainder of this paragraph will describe findings specific to the group that experienced pressure to change their relationships. The most common source of pressure was from family and medical personnel. There were 12 people (21%) who noted pressure from family to change their relationship and 7 individuals (12%) who experienced pressure to change from medical personnel. Other professionals in supportive roles also exerted pressure, since 4 people (7%) reported pressure from service personnel (therapists, aides) and 3 people (5%) from social service personnel. There were 6 people (10%) who indicated that they experienced pressure from others but did not specify who those others were.

Injury demands, relationship changes, and external pressures all occur at the same time that an individual is attempting to recover and participate in a rehabilitation process. Stability is an important component for the work and tenacity needed for recovery. Relationships are a valuable component of the base for stability in a person's life. Responses about the impact of the relationship on outlook and feelings toward the rehabilitation process are described in the next section, relationships and rehabilitation.

Relationships and Rehabilitation

Participants were asked to examine and describe how relationships may have affected outlook on rehabilitation. Specifically this question asked "If the relationship is still INTACT, do you feel it has helped you in your outlook toward your rehabilitation process? "Yes—How?" "No—How?" The survey allowed for response from those with severed relationships as well. A second option asked, "If the relationship has ENDED, do you feel that the termination had any impact on your feelings about your rehabilitation process?" "Yes—How?" "No—How?" Those who responded that relationships were intact were a much smaller group and will be discussed in the next paragraph.

Four individuals endorsed the intact relationship question. This was surprising since only three individuals had previously indicated that their relationships endured. Closer examination of these responses illustrated the difficulty in collecting information by survey from those who have experienced brain injury. The additional person not previously identified in an intact relationship said that the relationship had not affected rehabilitation outlook "because the relationship is over." Of the three remaining responses from persons with intact relationships one person said that the relationship had a positive effect on rehabilitation outlook since, "[I] want to go back to it and some way make it work." Two others responded that the relationship had no affect on rehabilitation outlook. One of those people reported, "It hasn't changed a thing." The other person suggested that the kind of pressures noted in the previous discussion had an effect on everything in life. This person wrote, “We fight about having to use personal and financial resources while our auto insurance reneged on its responsibility and the driver who caused the accident was not held accountable for her negligence.”

There were far more responses and thus more varied responses about the effects of terminated relations on rehabilitation, since relationship termination was so common for this sample. Eleven responses indicated no rehabilitation effect and 19 responses indicated that termination had an effect on feelings about the rehabilitation process. The no rehabilitation effect responses were clustered into two themes *no effect* and *getting better.* These will be described at the end of this section. The ways that termination affected feelings about rehabilitation are described below. These responses included themes of p*ositive change* (5), *still friends* (4), *loss* (6), *partner focused* (2) and *other* (2).

Five responses that described relationship effects on rehabilitation process dealt with the theme of *positive change*. Three responses seemed to highlight the positive potential from adversity, “It [relationship termination] was a traumatic experience, one that gave me more reason to try even harder to make progress.” “I was even more determined”, reported another. The third person wrote that the termination “made me a true survivor.” Some people found that the relationship termination and rehabilitation process opened new doors. Both of these, “I was more motivated to help myself be in a healthier relationship during my rehabilitation” and “I got to meet new people and be in a different relationship”, seemed to demonstrate that life change with brain injury can be a time for new direction and action especially when supported through the rehabilitation process.

New directions and actions could enhance and be enhanced by the rehabilitation process when supported, as was evident in 4 *still friends* responses. One person talked about enduring friendship after the intimate relationship was severed, “We are friends - better now (yet not sexually at all). If it weren’t for [rehabilitation center name] and [professional’s name] we would not still be friends.” Maintaining a friendship can be especially important to support parenting after injury. As one respondent reported about the termination of the spousal relationship, “Made me depressed at times even though I knew it had to end for [partner name]’s sake. My ex-husband is still a friend and helped me maintain a relationship with my son.” Another respondent also said that a friendship endured after divorce and that child custody was shared between ex-partners. A fifth respondent was not included in this group although enduring friendship was mentioned because the person wrote that this had no effect on rehabilitation.

There were 10 responses with a more mixed description of relationship termination effects on the rehabilitation process. These responses were from the theme categories of partner focused, loss and other. Two responses were *partner focused*; these included that the partner played games and could not continue to deal with respondent’s deficits. Six responses described loss as affecting rehabilitation. Loneliness, depression, frustration with the system, grief from physical health and injury effects as well as “…the loss of my family in breakdown” all affected rehabilitation outlook. Relationship loss required that people manage their rehabilitation alone. In response to the question did relationship termination have an effect on rehabilitation outlook one person wrote, “yes and no – I don’t like the changes and problems to face alone after 14 years being with the same person.”

People must make rehabilitation progress at the same time they are going it alone managing a host of challenges presented by functional effects of the injury, “I am having great difficulty financially and also have problems with trying to handle business affairs because of short term memory loss." Relationship termination can have a very deep emotional impact that shapes self and rehabilitation outlook. As one respondent wrote, "I felt a temporary lessening of motivation to get better and a lowering of my self-valuation and love-ability." Perhaps most descriptive of this effect was one of the responses from the *'other'* theme, "I am bad. I can't be or do what I used to. It took longer to participate and accept help from rehab without support of spouse."

There were 11 responses that termination did not shape rehabilitation outlook or feelings. In this no effect group there were 2 themes that emerged, *no effect* and *getting better*. There were 4 responses that indicated *no effect*. One of those respondents wrote that the relationship "ended…for both of us", and another who described the partner as using the injury "as a ploy. That's why I don't have my children." A fourth person indicated that there was no effect because, "I didn't know she had a boyfriend until I moved into the foster care home." Many of the responses in this group seemed to have a positive flavor despite reports that there were no rehabilitation impacts. Life focus is different for the person going through the rehabilitation process. There were 7 responses that demonstrated this difference in life focus. These responses have been clustered under the theme of *getting better*. Two of these responses indicated that not having the other around was better, for instance, "I was held back by my ex-wife." Another person noted "I get better for myself' and still another echoed this self-care message, "I am motivated from within. I am doing this for me – no one else." The rehabilitation process was one of "still growing" and relationship termination was "…a refreshing change. I thought I will be just fine—slowly getting better every day." The coping capacity that enables a person to use all experiences for growth and healing was evident in the following person's response. Termination did not shape the rehabilitation experience, "Because I've learned to look at a situation and then flip it over to look at it at a different angle." Termination then affected rehabilitation participation in varied ways. Termination sometimes created greater struggle and sometimes had little effect on rehabilitation. Some of the same strengths and reframing that helped people thrive despite injury effects, minimized potential negative relationship termination effects on recovery. Relationship losses after injury may be more pronounced when unions include children as will be described in the next section, brain injury and children.

Brain Injury and Children

The survey also asked about injury impact on the relationships between parents and children. There were 18 people who wrote that they did not have children (40%), and 24 people (53%) who reported that they did have children at the time of the injury. There were 18 respondents who reported that children were in their custody at the time of the injury. The survey question also gave participants an opportunity to explain the current status of child custody. Responses to this item are discussed below.

The custody of children demonstrated the effects of the relationship terminations and brain injury impact reported elsewhere in these findings. At the time of the survey there were 6 people who indicated that children remained in their custody with 3 fulltime and 3 joint custody arrangements. Most persons lost custody of their children after their injury. There were 12 participants who reported that they did not have custody any longer. Only 10 people endorsed reasons for custody change. Two of these changes/losses of custody were court determined and 2 were described as a personal decision. There were 6 others who indicated other reasons but did not describe those reasons.

Table 6: Children:

Had Children at time of Injury	No N 18=40%	Yes N 24 = 53%	No Response N 3 = 6%
In Your Custody at Time of Injury	No N 6 = 13%	Yes N 18 = 40%	No Response N 3 = 6%
Still in Your Custody	Yes – full-time N 3 = 7%	Yes -joint custody N 3 = 7%	No Response N 22 = 48%
Still in your Custody (con't)	No- Court declared N 2 = 4%	No- Personal decision N 2 = 4%	No- Over 18 N 10 = 22%

*Totals may not equal N 45 since some respondents endorsed more than one question or subcategory.

Considerable change occurred for participants after injury. Those changes often included changes in custody of the injured person's children. The family and intimate relationships that existed prior to injury were often reorganized or eliminated after injury. Such changes could be expected to affect goals for the future. The next section will describe responses to a question designed to explore goals related to relationships and family.

Future Goals for Family

Brain injury creates major changes in daily life and experience. Those changes affect the person with the injury, people who love them and all relationships. Such changes also may affect the way the person anticipates and directs the future. Two questions were asked about future goals. One asked about goals or desires for rehabilitation in the future and will be described later. The second examined future goals related to family and will be discussed here. There were responses to the question, “What would you consider to be your future goals regarding FAMILY (spouse/partner, parent/child, etc). These were clustered into the themes of *partnering* (15), *family or work* (4), *family ring* (6), *relationships with children* (3), *want but* (5), *uncertainty* (1), t*ake it as it comes* (3) and *life is good* (2).

The most common response to this question related to the theme of *partnering*. Partnering, as used by the participants, described as marriage or “long lasting relationship(s)”. There were 15 responses in this category. Nine of those responses exclusively described establishing a partnership, but other people also included having children when discussing a partnering goal. As one respondent said, “I want a spouse and family again. Someone who understands.” Most respondents described wanting children but one man indicated that he “[I] would like a companion but don’t want to father more children.” Two partnering responses resonated with the idea of change and difference in partnering after injury. As one person said, “I would like to return to a more intimate role with my wife. Therapy and drugs have not helped at this time.” Another person remarked, “I would like to get back as close to the same relationship as I had before but a few things I’m sure will be different.”

Work, children and extended family also figured prominently in goals for the future. There were 4 responses that discussed *family or work*. Many of these sounded like the typical American Dream. These responses held images of dreams interrupted. One person wrote, “Get married and have kids, and live in my own house. Start own business with brother.” Another wrote, “To finally be married with my kids, all three of them. Have a house. Having a part time job, going to school part time.”

There were 6 *family ring* responses that described a desire to live and be close to extended family. As one person wrote of the goals for the future, “Grow closer to the family ring and find a spouse for the future if spouse is interested.” Participants commented on a desire to be near and have good relationships with family of origin as well as with their own children. One person hoped to, “Have a good relationship with mother, brother, two children. Hope to see children more often.” The family ring had meaning for participants in the past and present, “My family Pop, Mom, Brother, Sister, Brother-in law, Sister-in-law have been behind me from the beginning”, as well as in the future, “I look forward to becoming a mother-in-law and a grandma.”

Three responses focused exclusively on primary *relationships with children*. Children are an anchoring point for a parent and this was evident whether the parent was simply wishing to see more of their children, dealing with divorce and so wanting to regain a relationship with children or anticipating a future that incorporated children. As one parent said, “I will be involved in my children’s lives through visitation and various school related functions.”

Goals following brain injury must evolve with the life and functioning changes that so many respondents described. There were 5 responses that struck a *want, but* theme, as one respondent said of future goals, “Questionable – who knows- life changed in a second – now it is day to day.” Another person appeared to focus on more than the immediate present but with similar results, “I have meditated on this quite a bit and I do not know if anyone would have or join me.” Such uncertainty can be a barrier in itself as another person wrote, “I don’t know if I will ever have another spouse. I am afraid of the rejection that may come when they find out I have a brain injury.” Sometimes that level of uncertainty goes even deeper, “I would love to have a partner/spouse again but realize that I am not suitable for a partnership. It is a sad and lonely feeling. My children have done a wonderful job of accepting me as I am." Children can be an anchor. Relationships with children may provide continuity and help to ease loneliness, but when injury occurs prior to the conception of children, the injury may be daunting and create a 'want but' experience.

> I want kids more than anything, yet I've been told that my injury will require me to not 'show' my kid's behavior. I will 'talk' behavior. This scares me- I will continue researching self-therapy for the rest of my life. I need a husband that will 'talk' and love the Lord. God is my best friend and I need a spiritual leader in my life and for my kids. I will be a famous advocate for the TBI world.

As has been obvious from the themes that emerged when describing family goals, injury did shape future dreams. Participants had different ways of resolving this as will be apparent in the next paragraph.

Life with injury can make future goals unclear. This was evident in the theme of *take it as it comes* and in the theme that emerged of *uncertainty* reported by a single individual. That single individual wrote that brain injury had not changed the uncertainty about the future he had always felt, "I am unsure as to how intimate and involved I am willing to get in regard to the future with a partner [i.e.: marriage, etc]. This thought of uncertainty was present prior to the accident." There were 3 responses with a *take it as it comes* theme. Those three persons described both the injury and effects as making goal planning related to family low on the priority list. As one person wrote, "I am at an early stage now. I'll just have to take it as it comes." Upheaval from divorce also contributed to the need to take it as it comes, "None (family goals) right now – will not date anyone for at least a year. I need to heal up after this divorce." Sometimes after injury it is easier when people take the approach echoed by one participant "I simply go with the flow."

Life with bran injury is not always so ambiguous or uncertain. There were 2 responses that suggested *life is good*. The first person wrote that goals for the future were to "continue the way it has been." Another offered more insight into the complex experience of recovery and how that shapes the present and future, "We are rebuilding; gradually, painfully, wonderfully, filled with wonder, awe sometimes." The next section will continue with a discussion of goals specific to rehabilitation.

Future Goals for Rehabilitation

The participants were asked to comment on their future goals regarding their rehabilitation process. "What would you consider to be your future goals regarding REHABILITATION (continue it, terminate it, don't care, etc.)? There were 31 comments that clustered into 4 themes. The responses centered around *continue with a specific goal* (9 comments), *just take it as it comes* (3 comments), *continue rehabilitation* (16 comments), and *terminate* (3) responses. Most participants indicated the desire to continue rehabilitation. This reflected on the resilience of the human spirit and the benefit of rehabilitation recovery supports even under such adverse conditions as injury and relationship terminations.

Those who indicated they would prefer to terminate their rehabilitation, stated "terminate it", "getting done", and "Don't participate on a regular basis since my accident was so long ago." The other small group (3 respondents) had a take it as it comes approach to future rehabilitation services. This theme reflected a "Don't care" or "Take it as it comes" attitude. Sometimes this approach to rehabilitation was a painful statement about the depths of change the person experienced after injury. As one person said, "I no longer care because I have lost so much." Frustration, the urge to move on and time all appeared to shape perspectives on rehabilitation service.

Specific personal recovery goals also promoted continued rehabilitation service involvement. A group of 9 individuals planned to continue rehabilitation with a specific goal in mind. Striving to retain and/or regain physical abilities were mentioned as “would like to walk – would like to regain use of my arm -- want to keep working on my rehabilitation”, “Work on improving memory and learn new ways of doing things”, “Continue compensation strategies and independent living assistance to keep my independence and safety with health, meds and money management.” A number of respondents wrote about the use of alternative types of rehabilitation as they continued their quest to return to their pre-injury selves. “Continue it. I am going to a Christian Counselor”, “I continue to care for self and seek those who will help with me. Partner is in health care for health. I do rehab that focuses on mind/body/emotions/spirit connections. Includes voice, movement, puzzles, reading, massage, chiro, dental, medical”, “My formal rehabilitation ended long ago but I continue my own regimen which includes diet, exercise, positive outlook, spiritual rejuvenation, mental stimulation, and adequate rest”. One person reported, “(I) don’t particularly care but, until I have achieved some success at it I believe I would like to continue it.” One person reflected the influence of a systems strategy on their rehabilitation. “I need to continue my rehabilitation mostly due to the fact the company I work for tried to fire me when I disclosed my injury to get the job accommodations. The Rehabilitation Counselor came to my job site and confronted them and they backed away from firing me.” The rehabilitation counselor assisted the respondent with employment retention. This respondent appeared to recognize the importance of continued contact since job retention appeared tenuous. In this situation the employer may have mixed feelings about this forceful move to keep the employee on the job under protest. The stress level for the employee could be increased by this

tension. Continued contact could help the respondent cope with whatever additional job ramifications occurred. Rehabilitation involvement appeared to play varied roles in the lives of persons with injury. This is resonant with the pervasive impact of the injury itself. Appropriate services filled the needs of persons after brain injury and as another person stated elsewhere, "…disabilities change all relationships. Some good, some bad".

As noted earlier, the largest group responded that they would continue their rehabilitation. Five responses just stated "continue" or "continue it" with no other qualifications. One stated, "continue prn". Two others stated, "Continue to get better."" I would like to continue". Three persons indicated "I will continue rehab" "I am completely willing to continue treatment until I feel rehabilitated in all areas," and "I would try to do anything I could that I thought would help me or someone else to return to as 'normal' a life as is possible"

There were only two participants who related a desire to work on their memory. This may reflect the lowered executive functioning that creates the illusion that the person with a brain injury does not realize their memory (along with other brain functions) is altered by this injury. This is also reflected in the responses indicating a desire to work on rehabilitation with alternative therapies such as voice, movement, chiropractic, spiritual rejuvenation, and Christian counseling. While these therapies can serve a purpose, their use may indicate a system problem. If the system is not in place to adequately rehabilitate the client to function in the community and in their relationships, there is a shortcoming somewhere.

Comments on Life, Love, and Rehabilitation

True to the spirit of qualitative research the last item was less structured and more open ended so that participants could better inform the research effort. The last survey item allowed room for participants to *add any personal comments you wish to add. Do you have any comments about the survey questions? Do you have any other comments about how your intimate relationships may have had an impact on your attitude toward your rehabilitation?*”

There were 17 participants who chose to add personal comments. These comments were grouped under the themes of: the *effects of brain injury on my life* (3 comments), *experiences of rehabilitation* (2 comments), *systems change* (4 comments), *relationships* (6 comments) and *support systems* (2 comments).

The first group of comments included perceptions about the experience of rehabilitation. These *experiences of rehabilitation* comments highlighted the variation that people experienced in recovery and rehabilitation supports. Changes in role were also apparent. Brain injury can be isolating when rehabilitation experiences do not include family, relationship or other interventions. One person commented on the way the survey examined brain injury and relationships, “There were no direct intimate questions and there should be. Before my injury my spouse and I lived in a world of sick and not sick. After the injury I was considered ‘sick’ for two years while we waited for me to get ‘well’ or return to my old self. Being ‘sick’ means a spouse won’t touch you because it might be contagious or make you worse. After a couple of years the spouse is frustrated and angry and overburdened by taking over all the responsibilities of the house, job, and kids. Blame must go somewhere if there is no education, support, therapy, or outside resources. Intimacy is lost without education or rehab therapy or outside resources. Intimacy is lost without education or rehab therapy. Thank You.” “I **(**as**)** a consumer feel compelled to share that I’ve come along ways with this experience of REHABILITATION mentally and physically. Mentally I’ve become strong. Physically I’ve gained wait (weight**)** from

medication which has an impact on my self esteem.” The other person commented positively about their rehabilitation experience.

Another group commented on the effects of support systems on their rehabilitation. Family and rehabilitation providers were discussed in these comments. One person used the comment space to describe specific supports that helped make recovery possible, “A lot of things are harder and take more time now but I believe you just have to keep trying and praying. I was fortunate that I had good family support and a wonderful foster care provider. The TBI program at [facility name] was a huge help to me and gave me hope to continue onward.”   Another person was less specific but also used the space to emphasize the role of outside support, “I think a person having a stroke needs a lot of emotional support from family or relatives”.

As has been evident throughout these reported findings, brain injury is a powerful experience that creates pervasive change in the lives of people who experience it. There were 3 people who used the comments space to discuss such effects. These have been grouped under the theme of *brain injury affects my life.* The first two comments suggested that the injury experience was frequently relived**,** was frustrating, and difficult. The third person provided a succinct and rich description of injury effects on self and relationships, “The brain injury affected relationships with my children, parents, siblings, friends, and girlfriend. The changes I could not see in myself, but other people could and it affected communication and understanding highly between myself and other people. Time and therapy helped some but it was like growing up and maturing all over again. The biggest was for other people to accept me as I was after the brain injury, not thinking I would get back to be who I was before the brain injury. Personality changes and disabilities change all relationships. Some good, some bad."

Brain injuries created ambiguity and ambivalence, "…some good, some bad." Four people commented on *systems change* to reduce the more negative impacts of injury. Legal ramifications of the loss of property and family relationships while in recovery (2 comments) and loss of rights after injury (2 comments) were areas for system change. All four comments emphasized the need to improve the rights of a person during the rehabilitation process. The system does not always allow for adequate legal recourse or protection when people are in a state of injury or recovery. As one person commented, "I know that a law should be brought about regarding comatose and incompetent people. One that would protect them from losing money and items like cars, sports equipment, and one's children. This agency would check every hospital and retirement home for people that are incompetent or senile; then collect all said person owns and put it safely away so that no one could steal it." The ability to maintain meaningful life roles such as parenting and career choices also require systems change to better support people after injury. Another comment addressed such roles, "None, except that I would like to be involved in my children's lives. I would also be interested in receiving assistance from the state Department of Rehabilitation to enhance my career and vocation."

Mental, family and financial health are interwoven. One person expressed appreciation that brain injury impact was being studied. Systems change was described as critical to incorporate effects on everyday life, "Thank you for allowing me to participate in this survey. So much work needs to be done to improve the lives of people like me. Poverty, depression, and family breakdowns are a real part of a brain injury. Thank you for taking the time to care."

The last comment in this system change category starkly demonstrated how ineffective current systems are in protecting and promoting the rights of all people including those with brain injury. This person described even broader need for system change, "I am saddened by the apparent condition that even living here in the United States of America, the land of the free and the brave, I have no personal freedom or opportunity." All these comments indicated that there is insufficient support for the person with a brain injury.

There were 34 responses from individuals not in relationships at the time of injury. As described in methods discussion, after review of those responses a decision was made to include data related to those responses in a separate section. The section describing responses from the non-relationship sample follows.

Non-relationship Sample

There were 34 responses from those <u>not</u> in a relationship at the time of injury. In terms of basic demographics they were similar to those in relationships at injury, but differed in age, age at injury, years post injury and living status when surveyed. Of non-relationship surveys there were 15 female and 19 male respondents, the same gender differentiation as found in the primary in intimate relationship at time of injury sample. Non-relationship respondents reported their race/ethnicity as Caucasian/American (7), Hispanic (1), African American (1), and not reported (6). There were more (19 respondents) who did not report this information, by leaving the item blank. This non-relationship sample was older than those in the main relationship sample. The ages represented were 19-29 (5), 30-39 (11), 40-49 (15), and 50 and over (3). Twenty were single living alone (a slightly higher number than for those who were in intimate relationships), one was married living with spouse, two were living with a partner of the opposite gender, and 10 were living in other arrangements (5 in group home, 2 with parents, 2 with other family members, and 1 with a personal care assistant). Non-relationship participants included 13 employed part-time, 2 employed full-time, 16 not employed, 2 who were part-time students, and 1 who did not respond. Not employed respondents represented the same percentages of both groups (47%).

This non-relationship sub-sample was older at time of injury and had been injured less recently. The age at time of injury was reported as: (8) 17 years or younger, (4) ages 18-23, (8) age 24-29, (8) aged 30-35, (5) ages 36-50, and (1) not reported. In response to the length of time since injury, (1) was less than one year, (2) were 3-4 years, (7) were 5-7 years, (23) were eight or more years, with (1) not reported. Again, as reported this group was slightly older at the time of injury and had been post-injury for more years.

All 34 reported they were not in an intimate relationship with a spouse or partner at the time of the injury. As expected most of the relationship questions were left blank. Some of the respondents made comments in response to the question: What do you feel were the reasons the relationship survived. Their responses included “Sex, Drugs, Rock and Roll”, “didn’t have one”, and “he was always there for me and loved me no matter what.” There were also limited remarks for the reasons the relationship terminated. Responses about relationship termination for this group included: “kids”, “poor communications”, and “total opposites”. One person sadly felt pressured to change the relationship because “my family told me not to act disabled”.

It was obvious that some of these respondents had developed relationships after injury. One person indicated that an intact relationship affected outlook toward rehabilitation because, “I feel he has helped me to go on with my life and has been supportive in all my decisions.” Terminating relationships also had positive impact on rehabilitation outlook. One person indicated that termination “helped me stay sober”, another reported, “much happier to pursue the

things I enjoy.” Even when negative impact on rehabilitation outlook was endorsed the person reported that they “kept growing” after the relationship ended. Only one person reportedly felt “less sure about things” after the relationship ended.

Most respondents (19) did not have children at the time of injury although 7 did have children when injured. Most respondent (11) did not have custody at injury, but 3 participants were custodial parents when they were injured. Only one person reported children were still in their custody. Of the remainder 3 had lost custody by some court action, 1 by personal decision and 1 child was over age 18 and in own custody.

These thirty four respondents reported future goals regarding their family in several categories including family inclusion/stability, no goal/doubt, sexuality, or just move on. The family inclusion/stability remarks related to family were: “my family, pop, mom, brothers, sister, brother-in-law, sisters-in-law, have been behind me from the beginning”; “I would like to see my mom”; “I like to see my family”; “my family is very helpful” and “family-continue”. There was also a group of responses relating to spouse/partner/children as family with person who reported that he wanted to, “Be a good father to my 4 year old son, haven’t seen my seven year old daughter since she was one and a half. Tried to contact her mother but was yelled at and hung up on. No further contact.” Two others simply indicated they wanted to see their children more. There were 8 responses that indicated a desire to change current relationship /family status. Most wanted marriage and family; others indicated interest in finding a partner. Three people indicated no goal/doubt about family. As one person said, “doubt it, stay single”.

The area of sexuality was specifically addressed by only one respondent.” I just want to have regular sexual intercourse with my new husband. After the injury and quitting drinking and

drugs I have not been able to have sexual intercourse with my new husband. And I do love him.” There were also 4 responses that demonstrated a desire to just move on. One of those respondents highlighted endurance, “remain divorced-survive empty nest from almost adult child-soon to leave and start own life”.

Just as in the main sample, most comments about rehabilitation goals were to continue with a few caveats. Comments included “continue it” (repeated 8 times), “little step by little step-always forward-I’ve almost got it made. I am taking cognitive induced movement therapy”, “continue it-get help when needed i.e. computer replacement”,” I would like to continue so I can walk”,” I want to continue my rehabilitation until I am on my own”, “I would like to continue it. I feel it makes a difference. Sometimes I don’t feel like doing it, but then I do it and I feel better afterwards. I am a true believer in rehabilitation.” Only 3 people were uncertain or negative about continuing in rehabilitation. Two other remarks were seemingly unrelated: “TBI” and “I hope to get an electric wheelchair”.

The final section of the questionnaire allowed comments about the survey, relationships, or other attitudes toward rehabilitation. A respondent indicted that “I was not in a relationship before, during, or after my brain injury”; and another reported, “I am sick of trying to remember”. One person seemed to sum up how attitudes and intimate relationships can influence rehabilitation processes. “My sister helped greatly. She knew how to motivate me to rehabilitate the best that I could. For awhile I was really down but then my sister had a really serious talk with me. She was very blunt and told me the honest truth. She said it is time to get serious about recovery. I listened to her and it really changed my attitude”. The influence of family members was shown in responses for both the persons who did or did not have intimate relationships at time of injury. Effects were also long-lasting; since often people reported those relationship effects many years post injury. This appeared to further emphasize the need for family support systems to be operational during the rehabilitation processes. The next and final section of findings will summarize the data to respond to the guiding research questions.

Response to Guiding Research Questions

The research project used self-report to examine relationship (spouse/partner) stability and how it affected the rehabilitation and recovery for persons with traumatic injury. Demographic and open ended questions were used to explore and understand the following research problem:

How do persons with brain injuries experience effects on intimate relationships after injury and how does this affect rehabilitation and recovery?

The effects of brain injury on intimate relationships were reflected in the fact that all 45 of the participants had a termination of their relationships following their brain injuries. The relationships were long-standing prior to injury. Those who had been in relationships of 4 or more years prior to their injury represented 62% of the participants, while 40% had been in relationships for 8 or more years before the injury. These relationships did not last long after injury. There was a reported 55% relationship termination within the first year post-injury.

Relationship termination affected rehabilitation. There were 19 out of 45 respondents who indicated that termination of an intimate relationship affected rehabilitation. These responses included positive reactions such as it “made me a true survivor” to the very negative effects of, “I am bad. I can’t be or do what I used to. It took longer to participate and accept help from rehab without the support of spouse”.

The research problem was addressed using the following guiding research questions:

1) What are the impacts of injury on spousal/partner relationships?

The data indicated that there was a very drastic relationship between the injury and relationships. There was a reported loss of spousal/partner relationships as well a disruption of the family unit including children, parents, and siblings. The dissolution of family relationships was marked by the 93% termination rate following the brain injury.

2) What are the impacts of injury on the parent/child relationships?

In this study, there were 24 persons (53%) who had custody of children at the time of their injury. Of these 24, only 3 retained full-time custody of their children, with 3 more sharing some type of joint custody. Several remarks indicated there was a real desire to have the access to a better relationship with their children. There were also a number of responses that indicated a family was something the respondent wanted to pursue again in their future.

3) What reported factors enhance relationship stability and quality?

Results related to enhancement of stability and quality were limited since so few people were able to maintain relationships. The 3 persons who continued in relationship indicated there were emotional and spiritual anchors that sustained the relationship. These included having shared child custody, help of God, and just remaining in the same household, even without intimacy. There were also underlying factors intimated including an ability to maintain a family relationship with economic and vocational goals clearly defined for all partners.

4) What reported factors detract from relationship stability?

There were numerous factors involved in the reported terminations of the relationships in this research. Five persons provided responses that had no direct relation to the brain injury including alcohol, finances, or incompatibility. Three indicated post-injury personality changes affected the relationship. There were also comments on partner’s inability to accept the changes in physical and emotional changes in the injured person. A reported loss of intimacy was also a contributing factor.

5) What effects do relationship changes have on rehabilitation?

Data showed that relationship change effects varied depending on how, or if the relationship changed. Relationships that were enduring for the most part had positive effects. Relationship termination often created difficulties with rehabilitation efforts but sometimes had mixed effects. There was evidence that effects of relationship change on rehabilitation depended on the quality of the relationship prior to injury. Some respondents indicated that termination was positive, for instance in cases where the partner was a negative influence in life or when the partner was abusive. The respondents in this survey tended to predominately be in the age groups of 18-23 (24%) and 36-50 (22%). The experiences of living with the brain injury peaked in the 1-2 years after injury (24%) and 8 or more years after injury (53%).

6) What impact does traumatic injury have on the injured person’s future goals?

Respondents reported a greater interest in continuing rehabilitation (28) than in terminating (3). Fifteen persons specifically mentioned a desire to establish/reestablish a family unit including a partner and/or children. There were indications from participants that goals were complicated by the stresses imposed by the injury and its related life complications.

Unanticipated Findings

The number of persons, who had been in relationships for 8 years or more prior to their injury (40%), was fewer than those in relationships less than 8 years (60%). The shortened duration of these relationships, prior to injury, may have influenced their inability to maintain a long term relationship when the brain injury occurred. Maturity of the persons involved as well as the maturity of the relationship may both be influencing factors here.

The greatest relationship losses occurred before the end of the second year post-injury (72% of sample). This substantial number of relationship disruptions may have been influenced by the stress involved with the hospitalization, rehabilitation, financial, and role adjustments immediately following brain injury.

Summary of Findings

The purpose of this research study was to examine the person with brain injury's perception about intimate relationships and the possible relationship of spousal/partnership stability on the outlook about future rehabilitation processes for a person with a traumatic injury.

There were many reactions to the survey questions. Brain injury definitely affected relationships. All spouse/partner relationships were terminated by the time the survey was conducted. Respondents repeatedly indicated a desire for more intimate connections and contact. There were numerous responses that indicated a need for greater attention in this area. Comments by some of the participants included their requests to receive more education and support for their relationships following injury and immediate institutional care. A more detailed discussion of survey results, conclusions and recommendations will be included in the next chapter.

CHAPTER V

Discussion: Conclusions, Implications and Recommendations

The current study was an examination of brain injury and intimate relationship impact on outlook toward rehabilitation. Findings were reported in the last chapter. This chapter will contain (a) discussion of results, (b) conclusions based on findings, (c) implications of what was learned and (d) recommendations.

Discussion of Results

The research problem studied was: How does brain injury affect intimate relationships and how does what happens to those relationships after injury affect recovery for the person with injury? In this discussion the problem will be addressed through answers to each of the research questions.

1. How did injury affect intimate relationships with partners?
2. How did injury affect relationship with children?
3. How did injury affect goals for future related to relationships?
4. How did relationship affect goals for future related to rehabilitation?
5. What did participants want to tell the world about injury & relationships?

Answer to Research Problem

Brain injury had a major impact on life. Findings showed that brain injury devastated relationships. Change in intimate relationships was the most common post-injury experience reported. For a few participants change was good, but for most participants relationship change meant loss. While five participants described relationship termination as a positive change, most described loneliness, sadness, disorientation and a desire to establish a new relationship. Loss of relationship had an impact on rehabilitation outlook and goals for involvement.

Conclusions Based on Findings

This section will describe conclusions as a result of the research done for this study. Conclusions will be discussed through response to the research questions that formed the basis for this examination of brain injury and relationships. Conclusions to answer the first question are detailed below.

The first research question was: How did injury affect intimate relationships with partners? The answer to the research question was that relationships were affected profoundly and in a variety of ways. As mentioned previously, only 3 of the relationships that existed at the time of injury continued at the time of the survey. Two of those three had signs of disruption. One continued because of the presence of children, a second indicated that they were still living together without physical interactions. Only the third participant in an intact relationship reported a relationship that was, "…still growing and thriving."

The second research question was: How did injury affect relationship with children? The answer to the question about injury impact on parent child relationships was that often injury disrupted those relationships. Custody was only retained by 6 of the 18 participants who had custody at the time of injury. Some of these custody losses were due to divorce or court action, other loss of custody was reported to be voluntary. Only 3 participants indicated they had full-time custody of their children after their injury. Throughout the discussion of goals and wishes for the future, desire for contact with children was expressed. Some participants did report that they were able to retain relationships with their children even after the injury. In those cases the parent/child relationships were described very positively. In descriptions of relationships with children that endured, those relationships appeared to offer a source of stability and constancy as well as support. More commonly parents made remarks that indicated a void was present in relationships with their children. Parents in this group reported a desire to reinstate their pre-injury relationships with their children or to establish new relationships involving children as part of a whole family unit.

The third research question was: How did injury affect goals for future related to relationships? The answer to this question was that injury greatly affected goals for the future related to relationships. Relationships goals were constrained and often described as uncertain after injury. The most common response to what people wanted for the future was the establishment of relationships and increasing contact or maintaining the contact they currently had with loved ones. Some stated a desire to rejoin their pre-injury family unit while others wrote about what they would like to see as a new family unit in their future. In describing future goals participants noted that they were unsure about whether those goals would be attainable as a result of their injuries. As one person said, “I’m not sure if anyone would have or want me.”

The fourth research question was: How did relationship affect goals for future related to rehabilitation? Again the reported effects of the intimate relationship on rehabilitation outlook were profound. Most participants wanted to continue in rehabilitation. Many participants indicated that family members encouraged them and helped them to stick with the rehabilitation effort. The uncertainty typified in the response above also affected rehabilitation goals. Out of the 31 commenting, only 3 responded that they wanted to terminate their rehabilitation. This group included a response “I no longer care because I have lost so much”. It is also important to note that work was mentioned by a number of participants although the questions had not specifically asked about vocational services. When writing about goals for the future, a desire to return to work roles and a concern about income were mentioned. Meaningful work is important to perception of quality of life and a stable income is important to maintain marriage and an intact family. The additional burdens of injury costs make viable work and vocational rehabilitation services an important focus for persons with brain injury.

Finally, the fifth research question was: What did participants want to tell the world about injury & relationships? Respondents had much to say to the world. Relationships and intimacy were vital topics to participants and insufficient professional attention was given to these topics throughout the recovery process. This lack of attention to intimacy was evident in comments thanking the researcher for pursuing this line of inquiry. Powerful and moving testimony was given about the inadequacies of current support structures. The inclusion of an educational component for both the person with the traumatic injury and their families/partners seemed to be an important component requested here. There were also several responses that indicated a lack of funding and community support systems for the family of the person with TBI. The self-frustration of dealing with all the aspects of the injury as well as the spouse/partner relationships seemed to weigh heavily on these respondents.

Since changes in intimate relationships were such a pervasive and disruptive experience, this study has potential for helping the field, families and persons with injury think differently about the support and education needed following injury. Effects of the relationship and of the injury on the relationship were pronounced. As a result there are potential implications for improvements in the rehabilitation processes. These will be discussed below.

Implications

The current study showed that rehabilitation and intimate relationships had a reciprocal relationship after injury. Family was very important in the lives of survivors of traumatic brain injury. Family relationships were affected by injury, and intimate relationships could either help or complicate the rehabilitation and recovery process. Many injury effects that were not resolved through rehabilitation (e.g. behaviors, work) also affected the stability of those intimate relationships. There are implications from study findings for decision-making, for understanding in the field and for future research. These will be discussed below.

For decision-making. A variety of implications were noted that directly affect how services are provided throughout the recovery process. There were 3 implications of study findings that were identified as especially important. These implications for decision-making are detailed below.

1. Current treatment systems do not adequately address family needs. This was evident in the remarkable high rate of relationships that terminated post injury. Relationships were central to participants but access to positive and supportive relationships was reportedly constrained. The study results suggested that in making individual treatment decisions, family needs must be included since whatever affects the family affects the individual. The lack of education about the emotional needs of a person with TBI and their needs for intimate relationships appeared to get lost during the medical focus of “recovery” and rehabilitation. Training and education for family members about changes after injury and how to cope with changes was also evidently lacking since a large proportion of

respondents described those changes as reasons that relationships ended.

2. There were also broader system implications from the results. Financial concerns were cited as reasons for marriages dissolving. There is broad implication here, since the loss of a marriage means fewer resources for the person with injury and thus greater financial burden on the rest of society. Ideally, maintaining a relationship should not interfere with assistance from programs for the costs of disability related expenses.

3. Work is an important source of stable family income. Meaningful work also impacts quality of life and thus might provide buffers for the person with a TBI. Better quality of life and meaningful work roles could ease some of the emotional responses that compromise intimate relationship quality. Better relationships could potentially reduce the formidably high rate of relationship termination and thereby facilitate participation in recovery processes and better long-term outcomes for all who are affected by TBI.

Survivors in this study reported wanting access to vocational services and to work.

For understanding in the field. There were also implications for better awareness and understanding in the field. Two implications for understanding in the field will be discussed on the following below.

1. The CDC indicated that there are about twice as many males as females injured. Males between the ages of 15 and 24 years of age comprised the largest group of persons reported injured by the CDC. In this small sample of 45 participants, there were 25 males and 20 females injured. The largest group in this sample was males injured between age

18 and 23 years old. These results seemed to line up with the CDC figures. Since this is the largest proportion of persons with TBI, these groups are in the greatest need of

assistance programs.

2. Life, relationships and work will affect such individuals over a long period of time as this study showed. It would appear that investing in such services at the time of injury could greatly affect quality of life, participation and success in rehabilitation and recovery, as well as the family and work outcomes people experience throughout all of the years of their lives. The current system is not very effective or efficient since survey data (Heinenmann, Sokol, Garvin, and Bode, 2002) showed that those requiring the most service actually got the least. Better outcomes in early recovery stages could mean less need for services and thus more resources available to those in greatest need.

For future research. Although this study had powerful results to show what life, relationships, and recovery are like for persons with TBI there was much that was not explored. Findings showed that relationships were affected by injury and that injury effects had varied effects on the lives of all survivors. Additional research is needed to fully apply the results of this study.

1. Further research needs to be completed to determine what influences the loss of relationships prior to the second year. A potential explanation of observed relationship termination findings is that this is the time the person with TBI is reintroduced to the family situation following hospital and inpatient rehabilitation programs. While the person with TBI is hospitalized and considered ‘sick’, there may be an anticipation that they will get ‘well’ before they are sent home. This has been suggested by past research (Greer and Philbrick, 2001). When the survivor returns home not ‘well’, there could be

greater stress on the relationship resulting in the high number of relationship terminations observed in this study. What specific needs are present for survivors and their families that could assist family reintegration? What strategies have proven effective in helping families to remain intact following return home?

2. Additional research should be done on successful survivors. Continuation of high quality relationships after injury was rare in this study. What was it that these surviving partnerships had that allowed them to endure and incorporate the injury experience? What strategies were used to negotiate the many hurdles described by other survivors that were no longer in pre-injury relationships? What structural or external differences existed that enabled these couples to thrive after injury? What could be learned from these couples that could be translated into follow-up services for others? Is there more stability in relationships that practice some form of spirituality? How do spouse/partners decide what "well" looks like?

As obvious from even this brief discussion of research implications, study results had substantial potential for the field, practitioners and researchers. A number of recommendations emerged that could enhance the lives of survivors of TBI. Recommendations arising from results are discussed below.

Recommendations

The study had broad implications. The study highlighted particular areas that would enhance outcomes for survivors and their families. Related recommendations for enhanced recovery will be discussed below.

For future change. As was evident throughout the findings there are a number of issues and barriers presented by injury. These issues affect recovery and the intimate relationships of persons with TBI. A number of recommendations for future change were identified. Two future change recommendations will be described below.

1. All services MUST better incorporate intimate relationships. Evidence was presented from the literature (CDC, 2000) that more people with brain injuries survive and related services were not becoming less expensive. Families provide most of the care for the person with brain injury. Results of this study showed that the injury related financial drain on the relationship just compounded any other problems present.

2. Length of stays in inpatient acute care and rehabilitation were falling as discussed in the review of literature (Kreutzer, et al., 2001). The person with TBI is being sent “home” as soon as they are deemed “medically stable”. The physical needs of the injured person can rapidly become an excessive burden to a family trying to emotionally cope with the all the other changes in the person with TBI as was shown in this study. More support and services are required for the person with injury and the entire family system to enhance long-term outcomes.

For changes in knowledge or professional practice. Just as there were study implications and related recommendations for the future, there were very definite implications related to knowledge of brain injury and professional practice. There were 4 recommendations for knowledge and practice that emerged from this study. Recommendations for knowledge and professional practice are described below.

1. One suggestion would be to provide additional support to the significant other of the P/TBI. This support should include an educational component about how intimate

relationships will differ after injury and suggestions to regain pre-injury intimacy. Support must also include education about how intimacy and sexuality can be maintained

in the face of the changed physical capacities of the person with the injury.

2. Provide greater access to service systems for all survivors or members of the family, including financial and emotional counseling. In general more emphasis must be placed on what happens after medical/physical stabilization occurs. Families and persons with TBI need to be prepared for what happens after survival. Current systems focus on saving life not creating a life following injury and this had devastating effects on all.

3. Enhance work services. Issues and barriers to work were evident in this study although work was not the primary research focus. Work can be a stabilizing factor both for the person with injury as well as for the family system. Lack of access to work can reduce the resources that survivors have to cope with injury and recovery.

4. Build on existing expertise by examining successful relationships. This research showed that although rare, such relationships and couples do exist.

For modifications in accepted practices. There have been several mentions of current practices that seem to be working in opposition to the rehabilitation and recovery processes of the person with a traumatic injury and their families. The current practices demonstrated in the literature review seemed to focus the most attention and resources on physical restoration of the person who has been injured. The following recommendations are suggested for the improvements in the area of practices.

1. The information in the literature review indicated there is an inequitable distribution of resources for rehabilitation services. The resources are more readily available to persons

with greater financial resources. Resources could be more equitably disturbed by need rather than ability to pay.

2. The ‘medical model’ does not fully address the emotional and relationship issues of the Person with TBI and their significant other. An integration of the emotional needs into the rehabilitation process would probably address some of the frustration and depression felt by the person with TBI while proceeding through the rehabilitation process.

3. Not all relationship dissolution after injury was bad. Particularly when abuse occurred, when a partner held the other back, or when pre-existing dynamics were destructive, relationship termination was described as a good thing. Practitioners need to be sensitive to relationships issues and theory and professional training must incorporate this. Early on in the recovery process it would be helpful for rehabilitation professionals to test the waters. A frank and open discussion of perceptions about intimate relationships, assessment of factors that could put the relationship at-risk or that could help to sustain the person with brain injury would allow family to be better incorporated in rehabilitation planning.

For changes in systems. There were implications in the literature and surveys that the current treatment methods or theories of rehabilitation are not creating acceptable outcomes. Some of the comments from the survey participants included suggestions for systems changes .Recommendations for change will cover each of the systems that were identified either by participants or by observed results of this study.

1. Treatment systems- Additional financial, psychosocial, and relationship needs require

immediate attention. Attention to such issues must be integrated into all aspects of the recovery process.

2. Career and vocational systems- Some of the participants indicated a desire to have more involvement with their state vocational rehabilitation services. The vocational rehabilitation system has the expertise and trained professionals to address the family dynamics issues while preparing a person to reestablish the “worker role” so vital to their feeling of self worth. It is critical that pre-service and in-service educational training incorporate family dynamics content.

3. Legal systems- One of the participants suggested enacting legislation to protect the rights of persons who are “comatose and incompetent” to prevent losses of their children and personal property. The participant also suggested that personal items should be protected against others taking possession of them. Rights and needs of all must be incorporated, but it was obvious that the person with the traumatic injury may need time and support as they work through losses and choices.

4. Financial/Economic systems-An overall theme in both the literature and the survey data was that there are significant difficulties with finances following a traumatic injury. The socio-economic status of families following the TBI has a significant impact on all aspects of recovery and rehabilitation. One participant stated, “Poverty, depression, and family breakdowns are a real part of brain injury”. Another reported, “My ex husband couldn’t provide for my daughter and I, especially the medical expenses” as a reason their relationship was terminated. Adequate resources and assistance in access to resources may help to keep support systems such as families intact following brain

injury.

5.Personal freedoms- A participant stated, “I am saddened by the apparent condition that even living here in the United States of America, the land of the free and the brave, I have no personal freedom or opportunity”. Traumatic brain injury has impacts on every aspect of the personal lives of both the injured and their family. The personal choices and freedoms of the person with TBI are limited by their physical and financial resources.

6. Other systems- One of the participants listed a response as “I just want to have regular sexual intercourse with my husband. After the injury and quitting drinking and drugs I have not been able to have sexual intercourse with my new husband. And I do love him.” Another stated “I would like to return to a more intimate role with my wife. Therapy and drugs have not helped at this time.” Still another comments “I would like to get back as close to the same relationship as I had before but a few things I’m sure will be different.” These comments draw attention to the fact that the current services being provided are not accomplishing the goals desired by the persons with traumatic injuries or their families.

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APPENDIX

Agency Letter (A)

Participant Cover Letter (B)

Questionnaire (C)

Appendix A

Agency
Address
City

Dear --

I would like to invite you to take part in an exciting project! I am a graduate student at the University of Wisconsin-Stout in the Vocational Rehabilitation program.

My master's thesis project is investigating "***The impact of intimacy and disability on the perception toward rehabilitation processes of a person with a traumatic injury.***" Few services are available to support the family of the person with brain injury. This project is designed to examine the impact of injury on intimate/family relationships. The study also examines how the person with an injury feels that those relationships have affected the recovery/rehabilitation process. Findings from this study may show a need to provide more adequate services and supports to the injured person and their families.

As a provider of services for persons with Traumatic Brain Injuries, I would like to become a partner with you for the purposes of this investigation. I would provide the questionnaires, a cover letter explaining the project, and self-addressed stamped envelopes for the anonymous return of the surveys. I would ask you to distribute the questionnaires to participants in your programs who were in intimate relationships at the time of their brain injury. If you would be willing to do so, we can incorporate my cover letter with a letter from your agency explaining whatever level of involvement / endorsement you care to offer the project.

The questionnaires could be either distributed directly to the participants in your office or could be mailed to them. In order to avoid any possibility that anonymity may be breached, it would be advisable to have the forms mailed/distributed from your office using your client list.

If you are willing to participate in this exciting research for future assistance to your clients and their families, please let me know. If you have any questions regarding your participation, please contact my research advisor or me. I look forward to our future association. Participation in this study will entitle you to a summary, upon request, of all the information gathered during the project.

Thank You.

Sandra Desler
Student Researcher

Susan Eberhard, PhD, CRC
Associate Professor
Thesis Advisor

Sue Foxwell
Human Subjects
Protection Administrative
Coordinator
UW Stout -11 Harvey Hall

Mailing Address

Sandra Desler
University of Wiisconsin   Stout
TBI Study
% Dr. Susan Eberhard
Vocational Rehabilitation - 226
University of Wisconsin-Stout
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ENC: Copy of the proposed questionnaire, cover letter, and University approval of project.

Appendix B

December 20, 2001

Dear Participant;

There is very little information about the impact of intimacy and disability on the recovery and rehabilitation of persons with brain injury. I am asking for your help in a study to learn how intimacy and disability have affected your rehabilitation (and the rehabilitation of others with similar injuries). A research questionnaire is enclosed. This questionnaire should take about 20 minutes or less to complete. I have also enclosed a self-addressed stamped envelope for returning the survey to me.

The information you provide on your survey cannot be connected with you. There is no way for me, the agency sending you this form, or anyone else to know if you have filled out a survey or what your responses were. Your participation is voluntary and will end when you return the form. Your decision to return the survey will not affect your involvement or benefits from the group sending you this letter, or benefits and services from any other program. Survey data will be anonymous and only results about how groups of people responded will be reported. If you have any questions about the research project, you may contact me by electronic mail at deslers@post.uwstout.edu or my thesis advisor, Dr. Susan Eberhard, at eberhards@uwstout.edu. We may both be reached by mail by writing to TBI Research c/o Dr. Eberhard; Dept of Rehabilitation & Counseling; University of Wisconsin-Stout; Menomonie, WI 54751. You may address any questions related to the use of human subjects to Sue Foxwell, 11 Harvey Hall, UW-Stout, Menomonie, WI 54751 (715-232-1126).

There is no direct benefit to you from completing the survey. There is a slight risk that completion of this form may remind you of experiences/feelings that are difficult for you to handle. If this occurs, please contact the staff at the facility where you received this letter for immediate assistance. If I can respond to any of your concerns, you may contact me as indicated in the paragraph above. Thank you again for your willingness to be one of the participants in this research that is very important to me. The dissemination of this information may, in the future, help persons with brain injuries and their families.

Thank you again,

Sandra Desler	Susan Eberhard, Ph.D., CRC	Sue Foxwell
Graduate Student Researcher	Assistant Professor	Human Subjects Protection Administrative Coordinator

NOTE: If you would like a summary of this research, you may submit a self-addressed stamped envelope to Dr. Eberhard with the notation "TBI Study Report" on the outside of the envelope. To ensure your anonymity, please do not submit this request with your questionnaire. You may mail your request and a self-addressed envelope in a separate envelope anytime after you have completed and mailed your questionnaire. The results will be mailed when the research is completed.

PLEASE READ THIS STATEMENT BEFORE YOU COMPLETE THE ATTACHED QUESTIONNAIRE: ***By completing and returning the attached questionnaire you are showing your informed consent as a volunteer in this study. You have been informed of the reason for this study, that potential risks are exceedingly small and that there are no personal benefits to you for participating. The survey contains no name or other identifiers to assure anonymity. You have been informed that you have the right to refuse to participate, and that not participating will not affect you in any way.***

QUESTIONNAIRE (Appendix C)

PLEASE READ BEFORE COMPLETING THIS QUESTIONNAIRE: *By completing and returning this questionnaire you are showing your informed consent as a volunteer in this study. You have been informed of the reason for this study, that potential risks are exceedingly small and that there are no personal benefits to you for participating. The survey contains no name or other identifiers to assure anonymity. You have been informed that you have the right to refuse to participate, and that not participating will not affect you in any way.*

(Feel free to add additional comments for any questions on additional sheets of paper)

Demographics -- Please indicate the most appropriate response

1) Are you:

_____Female _____Male

2) Age today is:

_____18 years or younger
_____19-29
_____30-39
_____40-49 _____50 or older

3) How would you describe your race/ethnicity?(Caucasian; African-American; Asian-American, Latino-American; Native American; etc.)

Majority (list)_________________________
Minority (list)_________________________

4) Are you

_____ living alone
_____married/ living with spouse
_____single
_____living with a partner of opposite gender
_____living with partner of same gender
_____other (please describe)__________

5) Are you currently:

_____employed - full-time
_____employed - part-time
_____not employed
_____a full-time student
_____a part-time student

Experiences - please indicate the most appropriate response

6) How old were you when your brain injury (accident) occurred?

_____17 years or younger

_____**18-23**
_____**24-29** _____**36-50**
_____**30–35** _____**51 or older**

7) How long has it been since your injury?

_____**less than one year**
_____**1-2 years**
_____**3-4 years**
_____**5-7 years**
_____**8 years or more**

Attitudes - Please indicate the most appropriate response

8) Were you in an intimate relationship with a spouse / partner at the time of your injury?

_____**no**
_____**yes**

9) How long had you been in this relationship before your injury?

_____**less than one year**
_____**1-3 years**
_____**4-7 years**
_____**8 years or more**

10) Are you still in this same relationship?

_____**no**
_____**yes - if so, describe relationship**
    _____**male / female**
    _____**same gender**

11) If not in the same relationship, when did it end?

_____**less than one year after injury**
_____**1-2 years after injury**
_____**3-4 years after injury**
_____**5-7 years after injury**
_____**8 years or more after injury**

12) What do YOU feel were the REASONS the relationship:

SURVIVED____
____
____

OR

TERMINATED____

____

____

13) Were you pressured to change your relationship (after your injury) by any of the following: (check all that apply)

_____family (parent, children, etc.)
_____medical personnel (doctor, nurse, etc.)
_____service personnel (therapists, aides, etc.)
_____social service personnel
_____other(s) -describe_______________________________

14) If the relationship is still INTACT, do you feel it has helped you in your outlook toward your rehabilitation process?

_____yes - - HOW?____________________________________

____

____

_____no - - HOW?_____________________________________

____

____

15) If the relationship has ENDED, do you feel that the termination had any impact on your feelings about your rehabilitation process?

_____yes - - HOW?____________________________________

____

____

_____no - - HOW?_____________________________________

____

____

16) Did you have any children at the time of your injury?

_____no - (skip to question number 19)
_____yes - - if so, How Many? _________Ages_________

17) Were the children in your custody at the time of your injury?

_____yes
_____no

18) Are these children still in your custody?

_____yes
  _____full-time
  _____joint custody with a spouse / partner
  _____other arrangements (describe) ______
  ____

_____no
  _____court declared removal (divorce / other?)
  _____personal decision
  _____over 18 (in own custody)

19) What would you consider to be <u>your</u> future goals regarding:

FAMILY (spouse/partner, parent/child, etc.):

REHABILITATION (continue it, terminate it, don‘t care, etc.)

20) Please use the space below to add any personal comments you wish to add. (<u>Feel free to continue comments on an additional sheet(s) of paper</u>) Do you have any comments about the survey questions? Do you have any other comments about how your intimate relationships may have had an impact on your attitude toward your rehabilitation?