# QUALITY OF LIFE AFTER A TRAUMATIC BRAIN INJURY: THE ROLE OF SPIRITUALITY

# By

### JEFFREY C. WERTHEIMER

Bachelor of Arts Miami University Oxford, Ohio May, 1997

Master of Arts West Virginia University Morgantown, West Virginia May, 1999

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INJURY: THE ROLE OF SPIRITUALITY

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## CHAPTER I

#### Introduction

The Centers for Disease Control and Prevention (CDC) estimated that 5.3 million American children and adults, 2% of the population, currently live with disabilities resulting from traumatic brain injuries (Brain Injury Association, 2001). It affects over 2 million people each year in the United States of America. Statistics indicate that a brain injury occurs approximately every 20 seconds. Medical professionals, therapeutic services, and technology have made great strides in the treatment of devastating diseases, but still, little is known about the treatment of individuals with traumatic brain injury (National Brain Injury Association, 2001). It is time to explore the depths of this silent epidemic.

The relationship between the brain and behavior is exceedingly intricate and frequently puzzling. The myriad of neuropsychological and biochemical interactions involving the brain are complex, and our understanding of the fundamental relationship between the brain and behavior is still very limited. Individuals who have traumatic brain injuries may experience physical impairment, but the more problematic consequences involve cognitive, emotional, and behavioral changes. Due to the paucity of knowledge and understanding of these changes, there is great desire to understand how individuals perceive their quality of life after such an injury. Furthermore, given that one's perception, behavior, and personality may be potentially effected after a brain injury (Williamson, Scott, & Adams, 1996), it is of interest to explore the lives of people with traumatic brain injuries.

Traumatic brain injury is a broad term that encompasses any injury to the head that engenders a change in consciousness (Lezak, 1995). Traumatic Brain Injury (TBI) has been an area of interest to researchers because of the profound changes that can occur in people's quality of living including functional status, personality, level of dependence, and health issues. For decades, research has emerged regarding the relationship between quality of life and health (Fitchett, Rybarczyk, DeMarco, & Nicholas, 1999). The ideological thrust of quality of life research is to promote means for people to live in ways that are best for them (Kim, Heinemann, Bode, Sliwa, & Kling, 2000).

Quality of life refers to the degree of excellence in life (or living) relative to some expressed or implied standard of comparison, such as most people in a particular society (Frisch, 1999). Quality of life has been associated with other terms, such as life satisfaction and subjective well-being. Although much of the literature uses these terms interchangeably, they have different nuances. Life satisfaction and subjective well-being are general constructs describing one's overall life (Fabian, 1991). Quality of life, on the other hand, has a holistic emphasis and describes perceptions of social, emotional, psychological, and physical well-being (Carr, Gibson, & Robinson, 2001; Hoffmann, Rouse, & Brin, 1995).

The search for predictors of quality of life is a very popular research area in professional psychology (Kane, 2001). A number of researchers have explored the relationship between quality of life and demographic variables in different

participant/patient samples. Quality of life has been significantly related to material assets, employment status, physical comfort, marital status (e.g., divorced or widowed participants reported lower quality of life than participants who were married), functional ability, longer time since injury, and spirituality/religion (Boschen, 1996; Boswell, Dawson, & Heininger, 1998; Carr et al., 2001; Cotton, Levine, Fitzpatrick, & Dold, 1998; Kane, 2001; Olson & Kane, 2000). Research has found a variety of factors that were not related to quality of life, including material wealth, social status, severity of disability, age at onset of disability, and diagnosis (e.g., type of physical disability; Diener, 1984; Duggan and Dijkers, 2001; Kunzmann, Little, & Smith, 2000; Viemero and Krause, 1980). The importance of exploring variables that are related to quality of life still remains for survivors of a traumatic brain injury.

Recently, psychologists are recognizing that clients' spirituality is an important aspect of clients' quality of life and cannot be ignored in therapy and rehabilitation. Even neuropsychologists are realizing that taking into consideration brain-behavior relationships means not only understanding the functional basis to localized deficits, but elucidating underlying personal mechanisms of recovery – looking at a patient holistically (Christensen, Pinner, Moller, Pedersen, Teasdale, & Trexler, 1992). Psychologists help patients deal with core identity issues. When they are recovering in rehabilitation, psychologists may ask their patients questions about spirituality. Spirituality plays an essential role in human psychology and it exists across cultures. It is one of the webs of life that provides a deeper connection to the community and the world. "It informs the creation of a sense of personal identity and provides a 'sacred canopy' under which spheres of relevancy are created that orient human values and ultimately

determine human behavior" (Shafranske, 1996, p. 2). Spirituality can be viewed as being connected to a higher power to nature and our surroundings. It can be viewed as the experience when life flourishes not only to satisfy the everyday, material wants, but fulfillment of the capacities to understand, reflect, and appreciate (Shafranske, 1996). Spiritual beliefs, unlike scientific and commonsense understanding, allow the inexplicable to be comprehended and the challenges and tragic discontinuities of life to be accepted (Shafranske, 1996).

Research findings have provided a greater understanding of the relationship between spirituality and demographic variables. Several studies have found that some demographic and health variables are related to spirituality, including age, gender, race, education, health status, and functional ability (Anderson, Anderson, & Felsenthal, 1993; Benner, 1988; Carter, 1974; Fowler, 1981; Kim, et al., 2000; Mahalik & Lagan's, 2001). In a study examining individuals undergoing inpatient rehabilitation, marital status and impairment course (acute-onset vs. exacerbation of chronic condition) were not significantly related to spirituality (Kim, et al., 2000). Since spirituality is considered the core of an individual and part of everyday experiences (Cook & Kelley, 1998), it is conceivable that more demographic variables are related rather than unrelated to spirituality.

Many have argued that it is important to understand spirituality and the various dimensions to it (Bergin, 1988; Fukuyama & Sevig, 1999). Hatch, Burg, Naberhaus, and Helmich (1998) identified four important aspects of spirituality. They created a model that includes the following four spiritual dimensions: External/Ritual (the rituals in which they engage to be spiritual beings and to connect to a higher power), Internal/Fluid (the

beliefs they hold about their life and the experience of inner/personal growth), Existential/Meditative (the existential issues about which they may ponder or meditate including purpose and meaning in life), and Humility/Personal Application (the ability to be humble and modest and to apply spiritual principles in one's daily life). This appears to be a good working model that goes beyond a broad concept of spirituality and adds different dimensions to this prolific belief.

The relationship between spirituality and quality of life has been evident in a variety of populations, including patients with cancer, people with disabilities (e.g. mental retardation, amputation, or neuromuscular weakness), and people in rehabilitation (e.g. individuals with a spinal cord injury, a hip replacement, or a substance abuse problem; Belavich, 1998; Fitchett, et al., 1999; Koenig, 1997; Mathews & Larson, 1995; Olson & Kane, 2000; Pargament, 1997; Salisbury, Ciulla, & McSherry, 1989). Seventy-five percent of medical patients report using religion/spirituality to help them cope when they are ill (Koenig, 1997). In another study, former rehabilitation inpatients rated their religious beliefs to be important to them and thought of them regularly during treatment (Anderson, Anderson, & Felsenthal, 1993). While spirituality has been significantly related to well-being to some rehabilitation patients, research has not explored the relationship between spirituality and individuals who have a traumatic brain injury.

It is important to consider the relationship between spirituality and its role in the recovery of a person after he or she survives a traumatic brain injury. Spirituality plays an essential role in the lives of individuals throughout society. Moreover, spirituality and religion have had a long-standing association with people who are ill or disabled (Selway & Ashman, 1998). Historically, the religious community had the primary responsibility

of providing care for individuals with severe disabilities. In modern times, an invitation to medical professionals, including those who practice within the realms of physical and/or psychological treatment, has evolved to inquire about and utilize the role that religion and spirituality play in the lives of their patients/clients. With the severity of a traumatic brain injury and the knowledge today that people are surviving such injuries, it is important to explore the role of one's spirituality and how it affects his or her life after surviving a brain injury.

A short vignette may help to illustrate the emphasis that an individual may place on the role of spirituality in his or her rehabilitation after a traumatic brain injury.

Sullivan (2000) provided the following story subsequent to her traumatic brain injury:

I was devastated after a horrible accident of being hit by a car going 50 mph, more than a year ago. It left me with a hip replacement and a brain injury. The first six weeks I was comatose and then had to learn all over again. I do not remember my surgery, pain, or the airplane ride to the hospital.

One morning I woke up about 6:30 a.m. and a voice was saying to me: "Helen, you must get up and walk or you'll never get out of this hospital. I want you to go back to Brainerd and tell the church members: 'I am coming soon.' " I could not see anyone around my bed, but only noticed that I was in the hospital. This was my first memory after the accident.

My daughters from Brainerd, Seattle, and Saudi Arabia had been there with me in the first six weeks. And my two brothers from Nebraska and Colorado were there, but I do not remember seeing any of them. I've been told they encouraged me and prayed for me. I received more than 300 cards and many phone calls.

When I woke up, I had to learn to walk, talk, and think all over again. I even went through the "terrible twos" and my teenage years. Yes, I have come a long way in the last 13 months. After all the 24-hour care, surgery, and therapy, I learned how to walk, feed and care for myself. I am now independent. God has been good! My doctors and therapists call me the "miracle lady."

My neighbor said yesterday, "Even though you lost your hip and had brain injuries you can still be a gardener, a people gardener, since you worked as a nurse for 30 years you know how to garden people. And you must now tell people how God saved your life and encourage others." I have gone through many stages: comatose, surgery, dizziness, depression, and all the stages of brain injury recovery. I even had to find out who I was. I asked the questions, "Who am I? Am I the person who was in a coma? Am I that person who can't communicate as well as before? Am I that person who is the shadow of me?" All I can say is, "I like who I am, keep active and trust in Jesus for his help. And my family had a lot to do with my rehabilitation. Thanks to all!" (p. 1)

It is important to consider the commonalties between spirituality and rehabilitation. Both are journeys of discovery: both are paths toward defining oneself, how one relates to the universe, and where one is headed (Nosek & Hughes, 2001). Further, "this process of definition is punctuated by points of change, a convergence of readiness for a new awareness and an event that provides the momentum" (Nosek & Hughes, 2001, p. 24). The occurrence of a traumatic brain injury is an event that can lead to the importance of understanding one's self and the changes that have occurred. Spirituality can be more than a strong motivator in all the psychological and physical domains of rehabilitation. It can be a means of finding hope, optimism, meaning, and ultimately the self.

Spiritual and religious beliefs are prominent throughout the United States. The Gallup Poll (1995) found that 96% of Americans believe in God or a universal spirit and 60% indicate that religion is "important" or "very important" in their lives (Elliot, Kilpatrick, & McCullough, 1999). Spirituality continues to be acknowledged as "very important" in the American society. Furthermore, it was reported that society believes that religious and spiritual practice will steadily expand over the next 100 years (Gallup Poll, 2000).

People are standing on a pinnacle of centuries still asking the deep questions that life presents. People desire to understand their own lives, the meaning of situations, events, and experiences. They ask, "Who am I? What is our ultimate purpose? Why did this happen to me?" This is no different for individuals who have a traumatic brain injury. Some suggest that going beyond explanation to acceptance is to experience our spirituality (Nosek & Hughes, 2001; Shafranske, 1996). Out of that acceptance, one may experience a sense of meaning, understanding, and at times, the courage to face confusion, disappointment, loss, and suffering.

Publications abound argue that spirituality is a key to wellness (Aponte, 1996; Bergin, 1991; Fowler, 1981; Frankl, 1963; Jung, 1954; Shafranske & Malony, 1996). Experts agree that the spiritual core of an individual is central to a person's well-being (Cook & Kelley, 1998). Individuals in our world are struggling with a variety of issues, including mild to severe psychopathology, disability, confusion, lack of meaning, isolation and/or acceptance, as well as forms of cognitive dissonance. According to Aponte (1996), people are seeking therapy not only to cope with disability or mental illness, but for guidance, direction, and example. They are asking for values, purpose, and meaning – to explore their spirituality. Many of the problems involving life after a brain injury concern fundamental issues of life and meaning (Baumeister, 1991). Therefore, discussing spiritual issues could be an integral and beneficial component of treatment for individuals who have a traumatic brain injury (Richards & Potts, 1995; Tan, 1993).

#### Statement of the Problem

There is a revolution going on in psychology and rehabilitation that can be euphemistically described as "addressing the forgotten factor" (Josephson, et al., 2000).

Throughout the previous decade, a plethora of research has revealed the importance of addressing spirituality within the therapeutic context (Bergin, 1991; Fukuyama & Sevig 1999; Kemp, 1996; Mahoney & Graci, 1999; Shafranske, 1990, 1996). Studies have shown that adherence to religious tenets and/or spiritual practices will foster physical and mental health (Larson, Swyers, & McCullough, 1998; Levin, 1996; Pargament, 1996, 1997). Although research has demonstrated progress in the treatment of individuals who have received a traumatic brain injury (Lezak, 1995; Miller, 1993; Smith & Godfrey, 1995), research has not directly addressed the role of spirituality in the recovery of individuals with traumatic brain injury. Moreover, a few researchers have explored the important role spirituality plays in the quality of life in other medical populations, including oncology patients, older patients, patients with multiple sclerosis, and other patients with chronic illnesses (Kim et al., 2000). Little is known, however, about the relationship of spirituality with the quality of life among individuals with traumatic brain injury.

### Purpose of the Study

This study explored the relationship of spirituality with quality of life among individuals who have experienced a traumatic brain injury. The relationships of demographic characteristics with spirituality and quality of life were examined. The participants in this study were individuals who had experienced an injury to the head resulting in a change in consciousness, otherwise, known as a traumatic brain injury. The aspects of spirituality that were explored among these individuals included: the rituals in

which they engage to be spiritual beings and to connect to a higher power (External/Ritual), the beliefs they hold about their life and the experience of inner/personal growth (Internal/Fluid), the existential issues about which they may ponder or meditate including purpose and meaning in life (Existential/Meditative), and the ability to be humble and modest and to apply spiritual principles in one's daily life (Humility/Personal Application; Hatch et al., 1998). These spiritual aspects were measured by the Spiritual Involvement and Beliefs Scale (Hatch et al., 1998).

Quality of life refers to the importance of and satisfaction with a variety of life roles. Quality of life centers upon excellence or goodness in aspects of life that go beyond mere subsistence, survival, and longevity; quality of life focuses on aspects that make life particularly enjoyable, happy, and worthwhile (Frisch, 1999). Quality of life was measured by the Quality of Life Inventory (Frisch, 1994).

#### Significance of the Study

More research is needed to address the role of spirituality and religion for persons with disabilities and rehabilitation patients (Underwood-Gordon, Peters, Bijur, & Fuhrer, 1997). Despite increased attention that is being focused on spirituality and health, research reveals that physicians are often reluctant to explore spiritual issues with their patients (King & Bushwick, 1994; Maugans & Wadland, 1991). Practitioners continue to focus on concrete and/or substantive information and claim that they will not consider using non-empirical findings even when the people voice their needs and desires (Maugans & Wadland, 1991). The sincerity of incorporating spiritual interventions into modern treatment approaches is in its infancy, as many practitioners continue to be skeptical. However, the number of empirical studies that include spirituality has grown over the past decade, particularly those pertaining to oncology, gerontology, and various general medical populations, including individuals with an amputation, spinal cord injury, or neurodegenerative diseases (Kim et al., 2000). In these populations, spiritual beliefs and well-being are related to many dimensions of well-being and quality of life (Kim et al., 2000). This study is designed to further the understanding of the role of and importance of spirituality in relation to quality of life in individuals who have suffered a traumatic brain injury. No researchers to date have explored spirituality in people with traumatic brain injuries, or the relationship between spirituality and quality of life in this group of individuals. Thought pieces have been written about the ways in which spirituality helps people who have suffered a traumatic brain injury cope with and find meaning in their "new life" (Prigatano, 1992; Miller, 1993). The current research was designed to provide evidence that spirituality is a prodigious part of their recovery, and that it would be beneficial to understand and to utilize the role that spirituality plays in the survivors' lives.

#### **Research Questions**

The following research questions will be addressed in this study:

1. What is the relationship of spiritual involvement and beliefs (External/Ritual, Internal/Fluid, Existential/Meditation, and Humility/Personal Application)

with quality of life among individuals who have experienced a traumatic brain injury?

- 2. What is the relationship of participants' demographics with their quality of life?
- 3. What is the relationship of participants' demographics with their spiritual involvement and beliefs?

#### Research Hypotheses

The following hypotheses were addressed in this study:

- 1. Spiritual involvement and spiritual beliefs (External/Ritual, Internal/Fluid, Existential/Meditation, and Humility/Personal Application) will be significant predictors of quality of life among individuals who have experienced a traumatic brain injury. More specifically, it is hypothesized that believing in a higher power and participating in spiritual rituals, acknowledging and experiencing personal growth, finding meaning and purpose in life, and having congruency between beliefs/values and actions in daily activities will be significant predictors for quality of life. The subscales of the Spiritual Involvement and Beliefs Scale will be positively related to quality of life.
- 2. Some demographic variables will be positively related to quality of life. In particular, it is anticipated that the quality of life will be positively related to time since injury (longer), site of injury (frontal lobe regions), number of people living in the home (more people), ability to take care of oneself

(greater independence), and income level (higher income level). It is hypothesized that the longer the period of time since the injury, the greater one's recovery may be, which may result in a higher quality of life. Since the damage to the frontal lobe has high probability of negatively affecting personality, judgment, and awareness of deficits, it is hypothesized that individuals with frontal lobe damage will perceive themselves as having a higher quality of life, as they may not be aware of their deficits or limitations. It is hypothesized that the more people living in the home the greater the potential for more support for a survivor, which in turn, will increase one's quality of life. It is also hypothesized that the greater the independence and the greater one's income, the greater the quality of life.

3. Some demographic variables will be positively related to the participants' spiritual involvement and beliefs. In particular, it is anticipated that spiritual involvement and beliefs will be positively related to time since injury (longer), site of injury (non-frontal lobe), number of people living in the home (more people), and ability to take care of oneself (greater independence). It is hypothesized that the longer the period of time since the injury, the more likely it is for a person to find meaning and purpose in the accident and their life. Since frontal lobe damage has a high probability of affecting awareness, judgment, and personality, it is hypothesized that persons with non-frontal lobe injuries will be more spiritual, as they will have more awareness of their deficits. Notably, the majority of people with disabilities or medical conditions utilize spiritual practices as a method of coping (Belavich, 1998;

Pargament; 1997). It is hypothesized that more people living in the home will foster an environment that is strong in support and community, which will strengthen humility, personal growth, and the ability to find meaning in adversity. It is also hypothesized that the more independent one is the more he or she can practice their spiritual beliefs, the more personal growth they may experience, and the more they will find meaning in the challenges that they have experienced.

#### Definition of Terms

<u>Anger</u> - a threatening, arousal-generating response that either signals physical aggression or is in itself a verbal attack on another (Prigatano, 1992)

<u>Agitation</u> - a state when individuals exhibit constantly uninhibited movement (Prigatano, 1992).

Anosmia: is the absence of the sense of smell.

Ataxia: a lack of coordination

<u>Closed Head Injury (CHI)</u>: is an injury where the skull makes contact with a relatively immovable surface at a high rate of speed. As a skull comes to an abrupt stop, the velocity of movement is then imparted to the brain, along with whatever rotational forces were present. The impact of the brain in the skull and/or the shear strain on the brain can cause momentary distortion on the brains shape and density (Levin, Benton, & Grossman, 1982; as cited in Williamson, Scott, & Adams, 1996).

<u>Demographic Characteristics</u>: An indication of a special feature of a person or population; especially with reference to age, gender, race, education, employment, social status, annual income, religion, and aspects related to a person's traumatic brain injury.

<u>Dharma:</u> carries a deeper meaning of mission in life, those predispositions, such as genes and past life experiences that equip a person for the path he or she follows in this life.

Existential/Meditative: a subscale of the Spirituality Involvement and Beliefs Scale which addresses existential issues such as finding meaning and purpose.

External Ritual: a subscale of the Spirituality Involvement and Beliefs Scale which addresses spiritual activities/rituals and includes a belief in an external power.

<u>Faith</u>: an essential and less variable personal quality, which encompasses the way one views themselves, other people, and the universe as they are experienced in the light of the transcendent dimension (Wulff, 1996).

Hemiparesis: weakness on one side of the body.

<u>Humility/Personal Application:</u> a subscale of the Spirituality Involvement and Beliefs Scale, which addresses one's ability to be humble and modest and the application of spiritual principles (one's spiritual values are consistent with one's actions) in daily activities.

Internal/Fluid: a subscale of the Spirituality Involvement and Beliefs Scale, which addresses evolving internal beliefs and personal growth. Internal beliefs refer to believing in the qualities that reside within the self (e.g. trusting oneself, believing in oneself, understanding oneself and one's identity, and understanding how one relates to other people). Personal growth refers to developing the self, reaching or moving toward maturity, cultivating one's beliefs.

<u>Irritability</u> - a tendency to be easily annoyed or upset (Prigatano, 1992).

<u>Penetrating Head Injury (PHI):</u> "The essential feature of PHIs is a focal lesion penetrating the skull and dura that is frequently caused by gunshot wounds or severe depressed skull fractures. Because of the impact-absorbent nature of the penetration of the skull, the morphological changes produced in these injuries are restricted more narrowly to the path of the projectile or the area directly under the depressed fracture" (Williams, Scott, & Adams, 1996, p. 12).

<u>Pseudodepression:</u> a potential result of left frontal lobe damage wherein patients exhibit such symptoms as outward apathy and indifference, loss of initiative, reduced sexual interest, little overt emotion, or little or no verbal output (Kolb & Whishaw, 1996).

<u>Pseudopsychopathy:</u> a potential result of right frontal lobe damage wherein patients exhibit immature behavior, lack of tact and restraint, coarse language, promiscuous sexual behavior, increased motor activity, and a general lack of social graces (Kolb & Whishaw, 1996).

Quality of Life: refers to the degree of excellence in life (or living) relative to some expressed or implied standard of comparison, such as most people in a particular society (Frisch, 1999). Quality of life, according to the Quality of Life Inventory, refers to the relative importance of and satisfaction with a variety of life roles. Quality of life centers upon excellence or goodness in aspects of life that go beyond mere subsistence, survival, and longevity; quality of life focuses on aspects that make life particularly enjoyable, happy, and worthwhile (Frisch, 1999).

Quality of Life Total Score: After creating an overall weighted rating ranging from -6 to 6 (multiplying the importance and satisfaction ratings of a particular domain), the quality of life total score can be computed. The quality of life total score is computed by averaging all 16-satisfaction ratings with nonzero importance ratings. Moreover, the total score reflects one's satisfaction in only those areas of life one considers "important" or very "important."

<u>Religion:</u> Religion is considered the standardized framework through which spirituality may be expressed, and that the particular framework is heavily influenced by the culture in which it originates (Ingersoll, 1994). Religion can be considered the "form", while spirituality is the "essence" - distinct from any specific cultural expressions.

<u>Sensorimotor deficits:</u> The inability to respond to basic sensations and perceptions, including touch, taste, smell, sight, and/or hearing.

Spirituality: A definition of spirituality developed by leaders of the Association for Spiritual, Ethical, and Religious Values in Counseling (ASERVIC) refers to spirituality as

the animating force in life, represented by such images as breath, wind, vigor, and courage. Spirituality is the infusion and drawing out of spirit in one's life. It is experienced as an active and passive process. It is an innate capacity and tendency to move towards knowledge, love, meaning, hope, transcendence, connectedness, and compassion. It includes one's capacity for creativity, growth, and the development of a values system. ("Summit Results", 1995).

Fukuyama and Sevig (1999) state that this definition is useful because it is inclusive, attentive to psychological growth, and fairly compatible with counseling values.

<u>Traumatic Brain Injury (TBI)</u>: is a broad term that encompasses any injury to the head that engenders a change in consciousness.

Weighted Scores of Quality of Life: The score that results from the multiplication the degree of importance (0 = not important, 1 = important, 2 = extremely important) and the degree of satisfaction (-3 = very dissatisfied, -2 = somewhat dissatisfied, -1 = a little dissatisfied, 1 = a little satisfied, 2 = somewhat satisfied, 3 = very satisfied) within a particular quality of life domain. Negative scores indicate clear dissatisfaction with an area of life while positive scores denote satisfaction with or fulfillment in this area.

## CHAPTER II

## Review of the Literature

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The present study examined the relationship of spirituality with quality of life among individuals who had traumatic brain injuries. The review of the literature will be divided into three primary sections. The first section will examine the topic of traumatic brain injury, including the understanding of TBI, the psychosocial effects of TBI and psychological approaches to rehabilitation following the trauma. The second section will examine the topic of quality of life in our society. The third section will examine the role of spirituality in the lives of our global society, including a description of spirituality, the history of spirituality and its role in psychology, the relationship of spirituality and quality of life, and the inseparable concepts of spirituality and rehabilitation.

#### Understanding Traumatic Brain Injury

The importance of acknowledging that a traumatic brain injury is not a description of a person or a group of people, but rather, a way of describing a severe injury that could potentially change a person's entire life is paramount. Therapists, physicians, and society alike should know that individuals who are

survivors of a brain injury might experience changes in personality, cognitive ability, and physical ability. They may experience the process of human development all over again - the stages from infancy to adulthood. Moreover, traumatic brain injuries may require survivors to learn how to walk, talk, and relate to others all over again. In addition, they may experience deep-seeded feelings of confusion, isolation, meaninglessness, hopelessness, dependency, and angst.

The brain is the most complicated organ of the body, and researchers and clinicians are only beginning to understand its functionality. Each person's brain injury is different. Even if ten people had a brain injury in the same location, due to the unique make-up of each person's brain, the deficits or changes that follow are most certainly different. Although one can make some broad generalizations that provide a basic framework for exploring the organization of the brain, each person is different and each person's brain consists of a continual interaction of the different areas (Kolb & Whishaw, 1996). In addition, people with traumatic brain injuries have their own unique reactions, both physically and emotionally, to the inevitable change that follows, regardless of how small the change may be (Lezak, 1995; Miller, 1993).

At the present time, most discussions of intervention after brain injury are framed in terms of cognitive rehabilitation – retraining language, memory, attention, and other functions – with less focus on the emotional, personal, psychodynamic, and existential aspects of recovery from brain damage (Leber & Jenkins, 1996). Research is finding that individuals who have a brain injury need psychotherapy and/or rehabilitation at least as much as, if not more than, the traditional clients in psychotherapy. In order for psychotherapy to have a truly positive and enduring effect, therapy should go beyond the passive hand-holding type of counseling that is usually prescribed or given to this particular population (Miller, 1993). Moreover, one treatment modality is not sufficient for this population. A holistic approach to treatment will help these patients deal with the physical, emotional, cognitive, social, and the existential/spiritual aspects of having a traumatic brain injury. An understanding of the journey these individuals experience is needed. Later in this chapter, spirituality will be discussed as a protective factor in helping people with traumatic brain injuries cope better with their life in general.

The size of the population affected by TBI is alarming when one considers that the number of brain injuries increases cumulatively over time (Volpe & McDowell, 1990) and that survival rates are also increasing due to medical advances (Christensen et al., 1992). Because of medical advances and the increased number of survivors, it is incumbent upon our rehabilitation services, both psychologically and physically, to attend to the greater needs of such individuals. Furthermore, because psychological training with people who have traumatic brain injuries is not a part of most training programs, therapists may not be as familiar with the special needs and issues of these patients (Leber & Jenkins, 1996).

Traumatic Brain Injuries have been described as closed head injuries (CHI), penetrating head injuries (PHI), and traumatic brain injuries (TBI;

Williams, Scott, & Adams, 1996). A CHI occurs when the skull makes contact with a relatively immovable object at a high rate of speed. Williams et al. (1996) described a CHI as an event when the skull comes to an abrupt stop, and the velocity of the movement is then imparted to the brain, along with the rotational forces that were present. Moreover, these forces may stretch and rotate the brain within the skull. Thus, both the strain and the direct contact that the brain experiences can cause damage. Even the momentary distortion of the brain's shape and density can cause the axons to be pulled apart and the cell bodies to be disrupted (Williams et al., 1996).

It may be helpful to address the three crucial processes that determine the neurological impact of TBI secondary to CHI. These processes are called diffuse axonal injury, focal cortical contusion, and hypoxic-ischemic injury (Alexander, 1987; as cited in Williams et al., 1996). Williams et al. (1996) clearly explain these phenomena.

Diffuse axonal injury results from the shear strain induced by CHI... The relationship between amount of damage and eventual outcome in some psychosocial and cognitive measures is more predictable in patients that have suffered diffuse axonal injury than those whose injuries are limited to focal cortical contusion or hypoxic-ischemic injury (Gale et al., 1995). Focal cortical contusions are local abrasions on the brain's surface resulting directly from the impact of the brain against the interior of the skull... This impact may occur as a result of either the linear force of the impact, the rotational force of the impact, or both. Changes resulting from hypoxic-ischemic injury include frank infarction in the distribution of one cerebral vessel, patchy small areas of infarction in the distribution of one or more arterial border zones and erratic neuronal dropout." (p. 11)

Although CHI is the most common among TBIs, it is important to address PHI and differentiate it from CHI. PHI is known to be a focal lesion penetrating the skull and dura (a tough fibrous matter that lines the skull) that is frequently caused by gunshot wounds or severe depressed skull fractures (Williams et al., 1996). The impact of the penetration of the skull results in an injury that is restricted more narrowly to the path of the object that caused the penetration or the area under the depressed fracture (Grafman & Salazar, 1987). Although PHI produce focal lesions, a resulting edema and bleeding could cause diffuse damage and produce multiple behavioral deficits (Berg, Franzen, & Wedding, 1987). However, individuals with PHI typically make rapid gains, and the majority of those who survive their injuries return to work (Berg et al., 1987).

The terms traumatic brain injury (TBI) will be used to broadly encompass the vast amount of head injuries that engender a change in consciousness. "Traumatic brain injury" is preferable because it emphasizes that the brain has been damaged secondary to external forces (Prigatano, 1992). The depth and duration of a coma were the most useful indicators of brain injury. Since clinical judgment of the depth of a coma was largely subjective and unreliable, the Glascow Coma Scale (GCS; See Table 1, p.132) was designed to provide an objective indicator of the degree of unconsciousness. By giving the GCS serially, it has proved possible to identify the recovery from unconsciousness objectively. A score of 8 or less is often used as a criterion for severe closed-head injury, a score of 9 to 12 is the criterion for moderate injury, and a score of 13 to 15 is criterion for mild injury (See Table 2, p. 134 for comparison of GCS scores and duration of unconsciousness). "Of those requiring hospitalization for more than 24 hr, approximately 75% are classified as mild, 15% as moderate, and 10% as severe" (Williams et al., 1996, p. 10). Furthermore, traumatic brain injuries can result from a variety of sources. A few of the most notable causes of TBI are

motor vehicle accidents, falls, physical abuse, and violence (including firearms and physical attacks; Lezak, 1995).

As a result of the TBI, psychological functioning will inevitably be effected. Discrete psychological activities such as processing everyday situations, perceiving the color of an object, talking with a friend, as well as moving a finger, arms and/or legs can be disrupted by a focal injury, or by an injury that effects more diffuse parts of the brain (Lezak, 1996). This injury or damage to part(s) of the brain may affect many functions, and as a result, a cluster of deficits tends to occur together with some regularity (Lezak, 1995). Moreover, the outcome of a TBI will affect one's physical self, and it will also, ultimately, affect a person's psychological nature, and thus, will have a rippling effect and influence an injured person's entire world. The duration of the effects is life long. It is important to note that recovery after a TBI may vary from one person to another, but brain injury potentially affects, in some way, shape, or form, a person's cognitive and/or physical abilities or at a minimum one's perception throughout life.

### A Brief Overview of Brain Functionality

#### The Frontal Lobes

The frontal lobes are considered our emotional control center and home to our personality. There is no other part of the brain where lesions can cause such a wide variety of symptoms (Kolb & Whishaw, 1996). The frontal lobes are involved in motor function, problem solving, spontaneity, memory, language, initiation, judgment, awareness, impulse control, and social and sexual behavior. Lezak (1995) identified 5 behavioral problems associated with frontal damage. The five behavioral problems are (1) problems starting mental or physical activities, for example, decreased spontaneity, decreased productivity, decreased rate at which behavior is emitted, or decreased or lost initiative, (2) difficulties in making mental or behavioral shifts, whether they are shifts in attention, changes in movement, or flexibility in attitude, or perseveration or rigidity, (3) problems stopping, for example, impulsivity, over-reactivity, disinhibition, and difficulties in holding back a wrong or unwanted response, (4) deficiencies self awareness, including inabilities to perceive performance errors, to appreciate the impact one makes on others, or to size up a social situation appropriately (also found in Prigatano 1991; Schachter, 1990; Stuss, Gow, & Hetherington, 1992), and (5) a concrete attitude (loss of abstract thinking abilities), for example, viewing objects, experiences, and behavior at their most obvious face value. As patients lose their abstract thinking abilities, they may be incapable of planning, lack foresight, have difficulty sustaining goal-directed behavior, and may be non-compliant with rules (Lezak, 1995; Miller, 1985).

One of the most common effects of frontal lobe damage can be a dramatic change in social behavior. An individual's personality can undergo significant changes after an injury to the frontal lobes, especially when right and left frontal lobes are involved. Left frontal damage usually manifests as pseudodepression and right frontal damage as pseudopsychopathology (Blumer & Benson, 1975). Pseudodepression is a potential result of left frontal lobe damage wherein patients exhibit such symptoms as outward apathy and indifference, loss of initiative, reduced sexual interest, little overt emotion, or little or no verbal output (Kolb & Whishaw, 1996). Pseudopsychopathy is a potential result of right frontal lobe damage wherein patients exhibit immature behavior, lack of tact and restraint, coarse language, promiscuous sexual behavior, increased motor activity, and a general lack of social graces (Kolb & Whishaw, 1996). Frontal lesions can also affect sexual behavior. Orbital frontal damage can introduce abnormal sexual behavior, while dorsolateral lesions may reduce sexual interest (Walker & Blummer, 1975).

#### Occipital Lobes

The occipital lobes are the center of our visual perception system. There is probably more known about the occipital lobes than about any other region of the cortex, because of the dominance of the sense of vision in humans and the great interest of researchers in how the brain processes visual information (Kolb & Whishaw, 1996). The occipital lobes are not particularly vulnerable to injury because of their location at the back of the brain, although any significant trauma to the brain could produce subtle changes to our visual-perceptual system, such as visual field defects and scotomas (Kolb & Whishaw). The occipital lobe is involved in visuospatial processing, discrimination of movement, and color discrimination (Lezak, 1995). Damage to one side of the occipital lobe causes loss of vision with exactly the same "field cut" in both eyes. Disorders of the occipital lobe can cause visual hallucinations and illusions (Miller, 1993). Miller stated that visual hallucinations (visual images with no external stimuli) can be caused by lesions to the occipital region or by temporal lobe seizures. Visual illusions (distorted perceptions) can take the form of objects appearing larger or smaller than they actually are, objects lacking color or objects having abnormal coloring. Lesions in the parietaltemporal-occipital association area can cause word blindness with writing impairments (alexia and agraphia, respectively; Kandel, Schwartz & Jessell, 1991).

### Parietal Lobe Functioning

The parietal lobes can be divided into two functional regions, the anterior zone and the posterior zone (Kolb & Whishaw, 1996). The anterior zone involves sensation and perception and the posterior zone involves integrating sensory input, primarily with the visual system. The first function of the parietal lobe is to integrate sensory information to form a single perception (cognition). The second function of the parietal lobe is to construct a spatial coordinate system to represent the world around us. Individuals with damage to the parietal lobes often show striking deficits, such as abnormalities in body image and spatial relations (Kandel, et al., 1991).

Damage to the left parietal lobe can result in right-left confusion, difficulty with writing (agraphia), difficulty with mathematics (acalculia), disorders of language (aphasia), and the inability to perceive objects normally (agnosia; Kolb & Whishaw, 1996). Damage to the right parietal lobe can result in neglecting part of the body or space (contralateral neglect), which can impair many self-care skills such as dressing and washing (Kolb & Whishaw). Right side damage can also cause difficulties in making things (constructional apraxia) and drawing ability. Patients who have right side damage may also deny their deficits (anosagnosia). Bi-lateral damage (large lesions to both sides) can cause a visual attention and motor syndrome. This is characterized by the inability to voluntarily control the gaze (ocular apraxia), inability to integrate components of a visual scene (simultanagnosia), and the inability to accurately reach for an object with visual guidance (optic ataxia) (Lezak, 1995).

#### Temporal Lobes

There are two temporal lobes, one on each side of the brain located at about the level of the ears. Kolb and Whishaw (1996) identified eight principal symptoms that are associated with damage to the temporal lobe. These symptoms include: (1) disturbance of auditory sensation and perception, (2) disturbance of selective attention of auditory and visual input, (3) disorders of visual perception, (4) impaired organization and categorization of verbal material, (5) disturbance of language comprehension, (6) impaired long-term memory, (7) altered personality and affective behavior, and (8) altered sexual behavior.

The temporal lobes help in sorting new information and are believed to be responsible for short-term memory (Kolb & Whishaw, 1996). The right temporal lobe is mainly involved in visual memory (e.g., memory for pictures and faces), but is also involved in the recognition of drawings, tonal sequences, and many musical abilities (Lezak, 1995). The left temporal lobe is mainly involved in verbal memory (e.g., memory for words and names).

The temporal lobes are also involved in the primary organization of sensory input (Read, 1981). Individuals with temporal lobe lesions have difficulty placing words or pictures into categories. Lezak (1995) indicated that language could be affected by

temporal lobe damage. Left temporal lesions disturb recognition of words, whereas, right temporal damage can cause a loss of inhibition of talking.

Seizures of the temporal lobe can have dramatic effects on an individual's personality. Temporal lobe epilepsy can cause perseverative speech, paranoia and aggressive rages (Blumer & Benson, 1975). Severe damage to the temporal lobes can also alter sexual behavior (e.g. increase in activity; Blumer & Walker, 1975).

## Cerebellum

The cerebellum is the portion of the brain that is located at the back below the occipital lobe and is attached to the brain stem. The function of the cerebellum varies from one part of the structure to another, depending on the connections with the rest of the nervous system (Kolb & Whishaw, 1996). Kolb and Whishaw indicated that damage to the cerebellum might result in impairment of the equilibrium, postural defects, and impairments of skilled motor activity. Ataxia, a problem of muscle coordination, is common when the cerebellum is damaged. This can interfere with a person's ability to walk, talk, eat, and to perform other self-care tasks.

## Psychosocial Effects of TBI

## **Physical Impairments**

The physical changes have a prodigious impact on the individual and his or her psychosocial functioning. A wide range of neurophysical disabilities may result from TBI, including language impairment, sensorimotor deficits, hemiparesis (Zahara & Cuvo, 1984), ataxia, anosmia, posttraumatic epilepsy (Jennett & Teasdale, 1981), and visual difficulties (as cited in Smith and Godfrey, 1995). "It is estimated that about 40% of TBI patients suffer some form of clinically significant neurophysical disability (Perry, 1983), which will tend to resolve during the first few months after injury (Jennett & Teasdale, 1981)" (Smith & Godfrey, 1995, p. 3). However, it is important for psychologists and other rehabilitation specialists to be aware that neurophysical difficulties may be permanent for a minority of TBI patients (Thomsen, 1984).

Chronic pain is a physical problem (and often a psychological problem) that exists for some of the individuals who have experienced a traumatic brain injury (Williams, Scott, & Adams, 1996). Although it is not known exactly how many people with a brain injury suffer additionally from chronic pain, the experience of clinicians in treatment settings suggests that these conditions overlap quite frequently (Miller, 1993), which is not surprising considering that the main causes of both pain and postconcussion syndromes are automobile accidents and other external blows to the head. Pain can become a major influence in how one perceives his or her quality of life. Yates, Chalmer, St. James, Follansbee, and McKegney (1981) found that among patients with advanced cancer, less pain leads to greater happiness and greater quality of life. Miller (1993) indicated that chronic pain could lead to the abandonment of external attachments and interests, which can result in the patient's withdrawal from family, friends, and social activities. Chronic pain can also lead to increased emotional distress, such as frustration, anger, tension, agitation, and sadness (Benjamin, Barnes, Berger, Clarke, & Jeacock, 1988). Turk and Okifuji (2002) posited that people who attribute their symptoms to an injury appear more likely to view any physical sensation as harmful and noxious, thereby increasing anxiety. This increase in anxiety, consequently, may increase activity avoidance and functional limitations, which in turn will negatively affect quality of life. Turk and Okifuji also indicated that beliefs about the meaning of symptoms, the patient's ability to control pain and the impact of pain on his or her life, and worry about the future have been shown to play a central role in chronic pain.

## Cognitive Impairments

"Cognitive impairment is thought to encompass perception, processing of abstract information, executive functioning (i.e. planning, self-monitoring, goal setting), learning, attention, speed of information processing, language, and memory" (Mollowy, 1983; Szekeres, Ylvisaker, & Cohen, 1987; Zahara & Cuvo, 1984; as cited in Smith & Godfrey 1995, p. 3). Cognitive impairment is one of the most common effects of a TBI (Prigatano, 1996). Seventy percent of 100 TBI patients had cognitive impairments as long as 6 years after injury (Tate, Fenelon, Manning, & Hunter, 1991). Miller (1993) reported that cognitive deficits subsequent to a TBI may reflect actual organic brain injury; it may signal "psychological factors;" or it may reflect both simultaneously. Thus, when cognitive deficits exist, it will be important to the therapeutic process to know the etiology and extent of the cognitive deficits.

## Personality Change

Family members often state that one of the most notable changes after a TBI is personality change (Prigatano, 1992). Neurological factors are a large contributor to personality change; however, psychological reactions (Wood & Burgess, 1988), premorbid characteristics (characteristics before injury; Cicerone, 1989), level of adaptive coping responses, and extrinsic environmental factors (O'Shanick, 1989) are likely to play a part (as cited in Smith & Godfrey, 1995). Behavioral and emotional difficulties among people with brain injuries have been well documented in the literature (Baker, Schmidt, Heinemann, Langley, & Miranti, 1998; Cripe, 1989; Kaplan, 1991; Prigatano, 1991; Stambrook, Moore, & Peters, 1990). Baker et al. (1998) stated that the behavioral and emotional changes may be due to neuropsychological consequences, increased vulnerability to psychological distress (Linn, Allen, & Willer, 1994) or both. Moreover, Baker et al. found that, despite etiology, people with TBI report higher levels of distress and more psychiatric symptoms than the normative sample. The personality changes that may occur can be either subtle or more obvious. In a milder form, changes may affect a survivor's interpersonal competency. "This impairment may be characterized by a range of pathological features, including the following: impoverished verbal fluency

(Brooks & Aughton, 1979), inability to utilize environmental cues (Giles & Clark-Wilson, 1988), use of inappropriate speech forms and gestures, expansive talk (Giles, Fussey, & Burgess, 1988), impaired social perceptiveness (Lezak, 1978), tangentiality (Prigatano, Rouche, & Fordyce, 1986), failure to initiate and maintain conversation, poor eye contact, negative affective content in speech (Brotherton, Thomas, Wisotzek, & Milan, 1988), difficulty paying attention to what is said, and inability to express thoughts accurately" (Richardson, 1990, as cited in Smith & Godfrey, 1995, p. 7). Lezak (1987) found that 90% of a group of individuals with a TBI reported difficulties with social interaction.

The more obvious personality changes can present themselves through the ostensible change in behavior and/or lack of emotional control. Behavioral change and change in emotional functioning have long been recognized as one of the primary results of many types of brain impairment (Leber & Jenkins, 1995). Behavioral deficits that are often seen include impulsiveness, apathy, lack of drive, loss of motivation, and lack of self-care skills (Miller, 1993; Smith & Godfrey, 1995). These behavioral changes can create a formidable barrier for individuals who have a TBI who wish to resume their pre-injury social and vocational roles.

Several emotions are common as a result of TBI. Prigatano (1992) stated that irritability is the most common personality and behavioral complaint identified by both the TBI survivor and the spouse. Irritability and agitation may be a neuropsychological problem, or they may be a reaction to a behavioral disturbance (Miller, 1993; Prigatano, 1992). Further, anger can be a presented emotion on several accounts. For example, TBI survivors may have a lowered tolerance for frustration and possibly heightened emotional lability. As with non-brain-injured people, anger results in response to frustration (Dollard & Miller, 1950; Prigatano, 1992). Depression, anxiety, and low self-esteem also follow a TBI (Leber & Jenkins, 1995; Lezak, 1987; Miller, 1993). When the mental functioning of previously introspective, self-aware, and autonomously behaving persons have been impaired by a brain injury, their experience of themselves and the world changes (Miller, 1993). As a result, tremendous anxiety and depression with decreased self-confidence are likely to follow. In one study, 70 % of the individuals with TBI reported elevations of depression and 50% displayed evidence of anxiety (Perlesz, Kinsella, & Crowe, 1999).

Although many emotions are experienced along this journey, they vary according to time as well as among individuals. As a variety of emotions inevitably arise, denial may influence their course. Denial is the primary emotional reaction in the first 6 months following an injury (Cicerone, 1989; as cited in Smith & Godfrey, 1995). Several types of denial appear to exist after an illness or injury, such as denial of the injury, denial of the impact, and suppression of thoughts about the injury (Havik & Maeland, 1988; Jacobsen & Lowery, 1992; Livneh, 1999; Rosen, 1986). Furthermore, Leber and Jenkins (1995) noted that denial may result in failure to appreciate or acknowledge cognitive deficits such as memory, judgment, and attention-concentration (Caplan & Shechter, 1987), personality changes, and other psychological symptomatology (Butler & Satz, 1988).

As can be imagined, life after a TBI does not only affect one person, it affects those who share their lives with the survivor. Manifestations and sequelae of TBI, such as cognitive and behavioral changes, significant personality alterations, and disruptions of role and relationships, affect the brain-injured person's social interactions, and in turn, affect the family (Florian & Katz, 1991). The roles of the parents, the spouse, and even the children will be altered due to a traumatic brain injury of a person (for review see Florian & Katz, 1991; Perlesz et al., 1999). Family relationship issues tend to be rated as a substantial problem in the recovery process after a TBI (Long, Glueckauf, & Rasmussen, 1998). For example, marital functioning appears to deteriorate within the first 12 months after trauma (Livingston, Brooks, & Bond, 1985) and family friction between parents, siblings, and/or children may also increase within the first 12 months after injury (Oddy & Humphrey, 1980). Even after five years post-injury, relatives reported experiencing an increase in challenging behaviors (i.e. violence, verbal aggression, dependency) and a reduced ability to cope with the brain-injured family member compared with their experience at one year post-injury (Stebbins & Leung, 1998).

Reviews have revealed a number of consistent family emotional responses to the sequelae of TBI (Brown & McCormick, 1988; Florian et al., 1989; Graffi & Minnes, 1989; Lezak, 1988; Livingstone & Brooks, 1988; as cited in Florian & Katz, 1991). The most frequent responses were depression, denial, anger and grief, psychosomatic manifestations, and disturbances in social and family functioning (Florian & Katz, 1991).

For example, "On the Symptoms Checklist-90 (SCL-90; Derogatis, 1983), spouses 'demonstrated significantly elevated affective symptom scales, with 73% acknowledging symptoms of depression and 55% demonstrating symptoms of anxiety' (p.135)" (Perlesz et al., 1999, p. 7). To exacerbate the tumultuous period of stress and sadness within the family, family caregivers have stated that they lack the confidence and the edification to take care of the family member with TBI (Grant, Elliot, Newman-Giger, & Bartolucci, 2001). Therefore, it is important to recognize that psychologists and rehabilitation specialists would be valuable in presenting and conceptualizing not only a framework for helping the survivor, but also working with the system surrounding the patient who survived a TBI. The findings addressed in this section confirm that TBI can have a negative impact on family members. However, it is pertinent to note that not all families and family members are necessarily affected in this way (for review see Perlesz et al., 1999).

### The Support System

Although families that share the lives with individuals who have a TBI may go through tumultuous and strenuous times in the months or years following the injury, they are a critical part of the coping process for the survivors. It is well known that social support (i.e. friends and family) is of paramount importance to the recovery process of individuals who have a TBI. Therefore, there is great need to briefly highlight the importance of addressing the influential role of the support system.

Related to the present study, researchers have found that the support system for individuals with TBI is one of the best predictors of adjustment and quality of life (Long, et al. 1998; Miller, 1993; O'Hara & Harrell, 1991; Perlesz et al., 1999; Smith & Godfrey, 1995). Other quality of life predictors in these studies included cognitive factors (e.g. lower education and frontal lobe damage) and psychological factors (happiness, fairness, and freedom). Family relationship issues are a predominant influence on the daily function of adults with TBI (Long, et al., 1998). Long et al. (1998) found that psychosocial and vocational issues were the second most frequently reported concerns, which suggests that the family's quality of life may have been reduced as a result of . functional losses associated with the disability or the stigma of the disability. Moreover, the TBI circularly affects the lives surrounding the survivor. The life style of the survivor is altered, which in turn affects/disrupts the lifestyle of the family, which in turn affects the adjustment and recovery of the survivor. More specifically, the family members may find it difficult to balance their typical daily lifestyles and the newfound caregiving activities, as mentioned in the previous section.

In summary, both the family's and the survivor's quality of life may be affected subsequent to the traumatic brain injury. Support for both the family and the survivor has been found to be of paramount importance to the recovery process of individuals who have a TBI. Because the survivor's condition may need constant care and the family may have difficulty balancing daily activities and caregiving responsibilities, however, he or she may not have the constant support that is desired. Although this has yet to be studied, it is argued that survivors may turn to extra support above and beyond the family, such as a stable force (e.g., God, a higher power of being) within his or her spiritual beliefs.

### Psychological Approaches to Rehabilitation

Besides vocational and occupational rehabilitation, speech therapy, and psychopharmacological approaches to treating individuals with TBI, it is of paramount importance to address the psychological components of rehabilitation. Psychological considerations are crucial to a good recovery from a brain injury. Hymann (1999) stated that true restoration of the person means not just walking, talking, and returning to work if possible, but it means restoration of hope, purpose, self-love, and self-esteem. Brain injury is psychologically shattering because it robs the injured person of his or her accustomed level of control over his or her mind, body, moods, and environment (Hymann, 1999). In doing so, it challenges the survivor's core identity and forces him or her to ultimately give up or go through a processing of denial, anger, grieving, acceptance, mourning and rebirth to a new life shaped around what he or she has not lost.

Historically, "survivors of traumatic brain injury have been excluded from traditional insight-oriented or relationship psychotherapies and more structured cognitivebehavioral treatment" (Leber & Jenkins, 1995, p. 490). Misconceived notions that permanent cognitive, linguistic, and affective disturbances were the outcome of TBIs inhibited many from receiving or even seeking therapy (Prigatano, 1991). Recently, the psychological aspects of rehabilitation have become accepted as a part of holistic treatment, with a focus on helping survivors face, accept, and optimally live with the newfound transition.

There has been a plethora of literature addressing the benefits of cognitivebehavioral therapy with individuals who have a TBI (Leber & Jenkins, 1995; Miller,

1993; Prigatano, O'Hara & Harrell, 1991; Wilson, 1991). Cognitive-behavioral techniques are thought of as readily applicable and highly effective when working with individuals with such an injury (Cicerone, 1989). Relaxation training can help assist TBI individuals with situationally related stress, problem solving training can help with daily challenges, stress-inoculation training can help manage aggression, rational emotive therapy can help with cognitive restructuring, psychosexual interventions have been found to successfully reduce exhibitionism, and interpersonal-skills training have helped with interpersonal functioning (see Smith & Godfrey, 1995 for further discussion).

Behavioral approaches have been found to be useful. Behavioral interviewing scales, checklists, and direct observation can all be used to identify and monitor the everyday implications of neuropsychological impairment (Wilson, 1991). Wilson (1991) highlighted the point that behavioral approaches provide a wealth of concrete techniques. For instance, the SORKC (stimulus, organism, response, contingency, and consequence; Kanfer & Saslow; 1969) can take into account the past, motivation, insight, differences in reinforcement schedules, and the physical and neurological condition of each patient (Wilson, 1991; See Wilson, 1987, 1989 for further review).

Although there is a paucity of literature that addresses the use of psychodynamic therapy with individuals who have a brain injury, some notations are meritorious. Cameron (1963) found that traditional approaches emphasizing object relations when working with individuals who have a brain injury did not prove useful. However, more recent literature has stated that a dynamic approach can be useful. Smith and Godfrey (1995) reported that psychodynamic therapy tends to involve attempts to reconcile preinjury and present self-image. Also, related constructs from ego-analytic theory, such as insight theory, are now found to be valuable, but have needed a different psychological and theoretical context to be useful (Drubach, McAlaster, & Harman, 1994; Godfrey, Knight, & Patridge, 1996; as cited in Nelson & Adams, 1997). Stern and colleagues (Geva & Stern, 1985; J.M. Stern; 1985; B. Stern & J.M. Stern, 1985; Tadir & Stern, 1985) use dream therapy as a means of circumventing denial, grief therapy to address loss issues, and Freudian therapy for the reconciliation of aggressive and libidinal drives (Smith & Godfrey, 1995). Helping individuals with TBI with insight orientation can be very valuable. Prigatano (1999) stated that impaired self-awareness is a problem after brain injury and it can be beneficial to address this issue. A lack of self-awareness may very well be a psychological defense (Prigatano & Weinstein, 1996; as cited in Prigatano, 1999). Prigatano (1999) highlighted the importance to differentiate impaired selfawareness as a neuropsychological disturbance from denial of disability as a method of coping.

Empowerment theory has been used favorably as an approach to psychotherapy with this population. Nosek and Hughes (2001) stated that working with one's selfefficacy is empowerment and should be understood as a powerful source in therapy. Furthermore, they posited that "self-efficacy is the power to manage the 'burden' of disability, to accept limitations while engaging in behaviors to promote wellness, to encounter the barriers and discrimination that are still rampant in our society while not succumbing to the anger and frustration that they provoke, to move disability from the foreground to the background of life in service of higher goals of dharma" (Nosek & Hughes, 2001, p. 27). O'Hara and Harrell (1991) created an empowerment model that has the components of structure, motivation, information, acceptance, and skills. This model is designed for the patients to regain power and independence. Furthermore, it provides the patient with the opportunity to obtain information, to work toward self-acceptance, to experience acceptance by another, to learn new skills and coping behaviors, and to work toward goals at his or her own pace and in his or her own style.

The existential quandaries that may arise after a brain injury are as thick as the ocean is deep. Searching for meaning and purpose may be a confronting force soon after a TBI. Prigatano (1991) referred to the loss of sense of meaning as a "wounded soul." Typically we are able to confront and integrate the existential realities of mortality and vulnerability through the deaths of elderly loved ones and through less dramatic life changes and illnesses encountered in the normal aging process, with the comfort of spiritual, philosophical, and religious belief systems (Nardell, 1991; as cited in Miller, 1993). With a sudden, self-altering event such as a TBI, it may be difficult to recognize the meaning that once existed. "Therapy can address the matter by helping the patient get in touch with the precarious grasp we all have on life and the precious nature of the gift of life" (Miller, 1993, p. 67). Moreover, given that clinicians have found that spirituality is a significant part of the lives of patients with traumatic brain injury (e.g., Miller, 1993; Nardell, 1991; Prigatano, 1986), more empirical research exploring the function (and correlates) of spirituality for TBI patients could enhance the treatment for such patients.

There are numerous articles that address the importance of the existential approach in psychotherapy. Schneider (1999) stated that the unique advantages of existential approaches are that they address not just symptom profiles, such as angst, depression, or cognitive difficulty, but life concerns, such as finding meaning in life, confronting one's culture, connection in relationships, and discovering one's self or one's

calling. The existential approach can look at the presenting problems and address the greater meanings that go along with the adversity and the auspicious aspect of the client's life. It is more than a treatment; it is an approach that allows for deep exploration and understanding (Park & Folkman, 1997). Moreover, existential approaches provide an opportunity to include the relationships within the client's life, including the therapist and client's relationship. Schneider (1999) posited that these relationships are a condition, atmosphere, and/or forum within which not just symptoms but complex life issues—such as meaning, purpose, and values – can be explored and addressed.

Park and Folkman (1997) stated that theoretical concepts and empirical research on topics related to meaning and meaning-making are fruitful. They posited that many studies have found that the role of meaning-making is paramount in the coping process. Further, existential approaches among individuals who have experienced loss and/or trauma are tremendously beneficial (Davis, Nolen-Helsema, & Larson, 1998). Exploring the meaning within the lives' of clients could validate their existence and provide a source of strength, motivation, and support (Nardell, 1991). Furthermore, through such existential explorations, psychotherapy is able to approximate its most noble aspirations, maximizing the patient's quality of life (Miller, 1993).

Prigatano (1986) provided profound contemplative statements when he stated that God can represent a coming to grips with reality, a connecting of one's self to something beyond a limited biological existence. Moreover, when the connection takes place, the patient has a sense of integration and individuation that is necessary for acceptance of the tragedy of his or her life (Miller, 1993). The concept of God has extraordinary psychological significance for many individuals who have a traumatic brain injury. Hymann (1999) posited that getting in touch with faith, spirituality, and/or one's own core self can improve recovery to a remarkable degree. Therefore, one can get past the focus on the deficits and the focus on the future, and look more toward the urgency of the moment. When one can live the moment and, for example, embrace things that stimulate the senses (i.e. smell of flowers, the taste of food, the sounds of nature, the texture of soft blanket, or even the companionship of friends or family); he or she can enhance quality of life (Miller, 1993).

## Quality of Life

Frisch (1999) reported that quality of life is based on "excellence" or "goodness" in aspects of life that go beyond mere subsistence, survival, and longevity. Quality of life refers to the degree of excellence in life (or living) relative to some expressed or implied standard of comparison, such as most people in a particular society (Frisch, 1999). Moreover, quality of life focuses on aspects that make life particularly enjoyable, happy, and worthwhile, such as meaningful work, self-realization, and a good standard of living. Cotton, et al. (1998) noted that some influences in how people perceive their quality of life are social support, coping, and psychological adjustment. Viemero and Krause (1998) used both quantitative and qualitative procedures to examine the life satisfaction of 45 adults with physical disabilities from Finland and Sweden. Their findings indicated that life satisfaction is associated with occupational status or participation in meaningful activities, social integration, and psychological resources to cope with disability-related stressors. Severity of disability, age at onset of disability, and diagnosis were found to have no relationship with life satisfaction.

Quality of life has been associated with other variables, such as life satisfaction and subjective well-being. Although much of the literature uses these concepts interchangeably, they have different nuances. Life satisfaction and subjective well-being are more synonymous than life satisfaction and quality of life, and they appear to be general constructs describing one's overall life (Fabian, 1991). Quality of life, on the other hand, looks at three primary areas: physiological well-being, characteristics that describe a person's functional ability, and perceptions of psychological health (Hoffmann, Rouse, & Brin, 1995). Moreover, quality of life has a holistic emphasis on social, emotional, psychological, and physical well-being (Carr, Gibson, & Robinson, 2001).

Quality of life has been explored in two primary domains: objective characteristics (e.g. financial stability, economic resources, functional ability) and subjective characteristics (e.g. happiness, meaningfulness, purposefulness, personal . growth, and autonomy). Many people may perceive the objective characteristics as having great importance on their perception of whether quality of life is high or low. However, more and more individuals are considering the subjective characteristics as more important (Diener, 1984). Duggan and Dijkers (2001) stated that

An individual may envision his or her quality of life as high despite the presence of adverse factors, such as economic hardship, declining health, and social losses. Conversely, an individual who enjoys good health, an abundance of economic resources, and high social status can perceive their life to be empty, lonely, and meaningless – therefore, without quality. Objective characteristics of people do not necessarily correspond to subjective experiences. (p. 3)

Objective living conditions or circumstances such as the quality of housing or material wealth have not reliably been related to quality of life (Myers & Diener, 1995). Duggan and Dijkers (2001) found a combination of factors (both subjective and objective) that lead to higher levels of quality of life in patients who have had a spinal cord injury (SCI). In particular, they found that financial security, material assets, meaningful social roles, and a longer time since injury appear to be prerequisites for high-level quality of life. In addition, they found that financial stability, material resources, and emotional and spiritual "capital" were in short supply for many persons who reported lower levels of quality of life. Furthermore, personal growth and positive value changes following SCI offset the economic and social disadvantage of persons who had higher economic and social status.

Mehnert, Kraus, Nadler, and Boyd (1990) looked at quality of life and overall life satisfaction in 675 individuals diagnosed with Multiple Sclerosis. The majority reported that they were at least somewhat satisfied with their quality of life. Specifically, Mehnert et al. (1990) discovered that the older one is when he or she becomes disabled, the lower the life satisfaction; the greater participants' self-perceived degree of limitation, the lower their level of reported life satisfaction; divorced or widowed participants reported lower life satisfaction than participants who were married, currently cohabiting, or single; the highest life satisfaction was reported by participants who were working or attending school or training programs; and individuals who believed that close acquaintances did not view them as disabled reported higher life satisfaction than participants who perceived the opposite to be true.

There are several other studies that reveal the relationship between variables and quality of life and life satisfaction. Boschen (1996) examined life satisfaction in 82 people with spinal cord injuries (SCIs). He found that life satisfaction was correlated with self-concept, health status, income level, residential satisfaction, locus of control, residential choice, and activities choice congruence. It was interesting that life satisfaction was not significantly correlated with level of spinal cord injury (paraplegia vs. quadriplegia) or time since onset of disability. Viemero and Krause (1980) used both quantitative and qualitative procedures to examine the life satisfaction of 45 adults with physical disabilities from Finland and Sweden. Their findings indicated that life satisfaction is associated with occupational status, participation in meaningful activities, social integration, and psychological resources to cope with disability-related stressors. Severity of disability, age at onset of disability, and diagnosis were found to have no relationship with life satisfaction. Coyle, Lesnik-Emas, Emas, and Kinney (1994) found that leisure satisfaction was the most significant predictor of life satisfaction among a sample of 91 adults with SCIs. Leisure satisfaction explained 43% of the variance in the life satisfaction scores. However, it should be noted that the vast majority of participants in this study were unemployed. In a qualitative investigation, Boswell, Dawson, and Heininger (1998) interviewed 12 individuals with SCIs regarding their QOL and found that it was strongly influenced by attitude toward life, work opportunities, and level of resources.

Fitchett et al. (1996) found that faith and a sense of purpose and meaning in life were strongly associated with higher quality of life for individuals with cancer and HIV. Similarly, a study including college students out of McGill University found that

existential domain of spiritual well-being was an important predictor of overall quality of life (Cohen, 1996; as cited in Cotton et al., 1998).

Thus, several variables can be taken into account when considering an individual's quality of life. Zautra, Burleson, Smith, Blalock, Walston, DeVellis, DeVellis, and Smith (1995) stated that not only can the objective aspects of quality of life (behavioral measures and social statistics) be considered, but also it should be incumbent upon researchers to address the subjective appraisals of life quality.

# Spirituality and Quality of Life

Religion is considered the standardized framework through which spirituality may be expressed, and that the particular framework is heavily influenced by the culture in which it originates (Ingersoll, 1994). Religion can be considered the form, while spirituality is the essence - distinct from any specific cultural expressions. Clinebell (1995) provided an all-encompassing statement that embraces the concept of spirituality. He posited that spirituality describes the human need for meaning, personal growth, and value in life and the desire for the relationship with a transcendent power. Furthermore, Shafranske (1996) stated that "It informs the creation of a sense of personal identity and provides a 'sacred canopy' under which spheres of relevancy are created that orient human values and ultimately determine human behavior" (p. 2).

Participating in spiritual practices consistently emerges as a significant contributor of quality of life indications such as life satisfaction, happiness, and meaning in life (Diener, 1984; Levin & Tobin, 1995). A recent study found that 77% of patients said that doctors should consider spiritual needs of their patients, and another 48% of the hospitalized patients actually wanted their doctors to pray with them (King, 1994). Dijkers (1997) believed that subjective quality of life can be defined as the fit between a person's expectations and his or her achievements, as experienced by the person, within a time perspective (as cited in Duggan & Dijkers, 2001; see Figure 1, p. 133). More extensively, the quality of life encompasses more than just the expectations and achievements of an individual. The Wheel of Wellness highlights that spirituality is at the core of human growth, human perception, and human behavior (Myers, Sweeney, & Witmer, 2000; see Figure 2, p. 134). Spirituality is thought of as the core characteristic of healthy people and source of all other dimensions of wellness. Riley, Perna, Tate, Forchheimer, Anderson, and Luera (1998) highlighted the importance of spirituality in a study; they reported that among persons with chronic illness, the non-spiritual group evidenced lower levels of quality of life and life satisfaction. Through a comprehensive critique of the research literature on religiosity and domains of general well-being, Poloma and Pendleton (1990) found that religiosity was an important predictor of quality of life, including general life satisfaction, existential well-being, and overall happiness (Emmons, 1999). Specifically among persons living with disabilities, spirituality appears to be related to both quality of life and life satisfaction (Kim et al., 2000). How patients with a TBI perceive their quality of life and find meaning during recovery, for example, has sometimes been shown to predict cognitive outcomes better than traditional objective predictors, like Glasgow Coma Scale scores (Teasdale & Jennett, 1974) or length of posttraumatic amnesia (Russell, 1971; as cited in Nelson & Adams, 1997).

Reiley et al. (1998) exemplified the relationship between spirituality and quality of life in their research among persons with chronic illness. They conducted an in-depth study on the quality of life and different types of spiritual well being in 216 cancer and medical rehabilitation inpatients. Three groups were found: patients whose religious beliefs provided meaning, patients with an existential sense of meaning, and a third group of patients who had no sense of meaning, either religious or existential. They found that the third group had lower quality of life and life satisfaction than those in the other two groups (Fitchett et al., 1999). In another study, Nosek & Hughes (2001) found that spirituality was an important tool used by women with disabilities (e.g., arthritis, neuromuscular disorders, cerebral palsy, postpolio, and spinal cord injury) in creating more optimism, hope, and greater satisfaction with their quality of life by strengthening relationships and creating opportunities for personal development. The women in their study stated that spirituality was a key ingredient in their happiness.

Human beings have an instinctual drive for happiness and optimism, trying to eliminate uncomfortable experiences and to shy away from a cloudy life. Buss (2000) stated that happiness is a common goal toward which human beings strive, but for many reasons it remains frustratingly out of reach. Theorists have stated that striving for happiness is an essential feature of the human experience that complements development throughout the life span. Happiness and spirituality have been linked together in a variety of studies (Bergin, 1985; Bergin, 1991; Fitchett, 1996; 1988; Kim, 2000; Nosek and Hughes, 2001; Shafranske, 1996). For instance, Maslow (1964) discussed "peak experiences" - moments of self-actualization during which an individual feels more integrated, more at one with the world, more perceptive, and more creative (Gagan,

1998). He stated that these experiences embody the realization of spirituality in one's life. Moreover, when one has a peak experience, he or she is encountering an element in life that is of a spiritual nature. Sirch-Stasko (1996) elaborated on this, "The essence of a peak experience is its transcendental quality, which enables individuals to feel connected with the universe" (p. 3).

In a comprehensive review of the literature, religion has been found to play a major role in many people's lives (Gartner, 1996). In fact, religious involvement correlated both positively and negatively to mental health variables. The positive correlates of religion were physical health, mortality, suicide, drug use, alcohol abuse, delinquency, divorce and marital satisfaction, well-being, and depression; the negative correlates of religion were authoritarianism, dogmatism, suggestibility, and dependence (Gartner, 1996). Pargament (1990) demonstrated empirically that religion could be a potent source of support and coping as well as a way to construct a personal philosophy of significance (i.e. beliefs and social affiliations).

## Spirituality

Currently, there is resurgence of interest in spirituality in the Western culture. It is important to recognize the movement that is occurring. Bergin (1986) contended that it is a widespread cultural phenomenon, a return to the study of spiritual values, but it is happening with new sophistication and more systematic and empirical analysis. Spirituality is often an integral component of culture and needs to be addressed by the therapist (Fukuyama & Sevig, 1999). In many cultures, spiritual or religious concerns are not separated from physical, mental, or health concerns. Spiritual forces are believed to be related to illness or psychosocial distress, and thus, addressing spirituality in psychotherapy may be an integral resource for fostering a higher quality of life. In a meta-analysis of over 200 published studies, the relationship between spirituality and health was highly positive (Thoresen, 1998). Further, those with higher levels of spirituality coped better with adversities in life and reported lower disease risk, fewer physical health problems, and higher levels of psychological functioning than those with lower levels of spirituality (Sue & Sue, 1999).

Research has found demographic variables to be related to spirituality. Spirituality and age are related, particularly when addressing psychological maturity and spiritual maturity. Fowler's (1981) theoretical model clearly illustrates the relationship between spirituality and age. He created a developmental model that focuses on the processes of religious affiliation and self-in-relation to God or transcendent power. Fowler presented a linear, stage model that progresses from "undifferentiated faith" of infants through "universalizing faith" of elders and wise ones. The final stage is owned faith, the culmination of searching, when one can claim a faith system that works for one. He indicated that as one's spirituality develops, he or she becomes more open to different perspectives, resulting in a greater understanding the complexity and simplicity of life. Fowler also stated that as people age and reach the final stages of spiritual development, they begin to accept themselves as a whole being. They become more aware of their own well being and the well being of the community around them. Moving away from theoretical conceptualization, empirical evidence has also confirmed that there is a relationship between age and spirituality. Research has found that there is increased

salience of spirituality among older adults and the role that spirituality may play in coping with change and loss associated with advanced age (Belavich, 1998; Pargament; 1997; Pargament, Van Haitsma, & Ensing, 1995).

Kim et al. (2000) found that race was related to spirituality in a group of patients (e.g., spinal cord injury, amputation, multiple sclerosis, organ transplant, chronic obstructive pulmonary disease) who were undergoing rehabilitation. Specifically, they found that African Americans reported greater spirituality than other racial-ethnic groups. In Matheson's (1996) research, he indicated that it is of paramount importance to integrate spirituality into counseling when working with individuals who are Native Americans. In Fukuyama and Sevig's (1998) book, "Integrating Spirituality into Multicultural Counseling," there was an emphasis on the importance of addressing spirituality across race and across cultures.

The relationship between spirituality and gender has been examined. Research findings indicated that women were more spiritual than men (Poloma & Gallup, 1991) and were more likely to express the need for a religious/spiritual dimension within their daily lives (Batson & Ventis, 1982; Lindsey, 1990). Mahalik and Lagan (2001) found that social constructs led women to be more spiritual and religious than men. Men in the United States do not attend to their spiritual lives to the same degree as women. Because men are socialized to avoid all things feminine (Levant & Pollack, 1995), and because the feminine mode is the basis of internalized religious experience and expression (Zock, 1997), men may not internalize religiosity or experience spiritual well-being to the extent that women do because they constrain themselves from actions that may be considered feminine (Mahalik and Lagan, 2001).

There has been research on the relationship between functional ability and spirituality. Anderson, Anderson, and Felsenthal, (1993) found that individuals who were dependent found it difficult to find meaning and purpose in life. Specifically, they found that among a sample of 142 former rehabilitation inpatients with spinal cord injuries, 80% rated their spiritual beliefs as important to them, but expressed concerns that ranged from believing that God was punishing them to the sense that they were losing purpose in life. Conversely, Pargament and Park (1995) indicated that religion's involvement was also used as a resource (e.g., prayer) and as a means of coping (e.g., seeking spiritual support) to adverse situations such as being more dependent after a serious injury.

Kim et al. (2000) found that marital status and chronic versus acute impairment were not related to spirituality. While working with individuals who were on an inpatient rehabilitation facility (e.g., spinal cord injury, amputation, multiple sclerosis, organ transplant, chronic obstructive pulmonary disease), they expected that individuals with chronic conditions who presumably had more time to adjust to living with the disability, would report higher levels in spiritual well being (with less fluctuation over time) compared to individuals with acute-onset conditions. They found, however, that an exacerbation of a chronic condition severe enough to warrant impatient rehabilitation admission had a spiritual, emotional, and psychological impact equivalent to that of an acute-onset condition. In addition, they found that marital status was not related to spiritual well being. They speculated that whether someone was divorced, single, married, or widowed, it is plausible that they all may maintain equivalent levels of spiritual beliefs.

A further glimpse into spirituality is justified due to the depth of its meaning. There has been much discussion and debate on what spirituality really is. Spirituality could be considered a huge umbrella that encompasses many rich components. Under this umbrella are three primary factors: religion, faith, and the spiritual experience in and of itself. "Spirituality, which comes from the Latin, *spiritus*, meaning 'breath of life,' is a way of being and experiencing that comes about through awareness of a transcendent dimension and that is characterized by certain identifiable values in regard to self, others, nature, life, and whatever one considers to be the Ultimate" (Elkins, Hedstrom, Hughes, Leaf, & Saunders 1988, p 10).

According to the review of the literature, the spiritual experience has a few crucial components (Shafranske, 1996). First, the spiritual experience involves an awareness of the transcendent dimension. The transcendent dimension may, but does not necessarily, incorporate a deity or higher power. It is a state found in all human beings that allows people to move toward inner peace, connection or unity, and a capacity to feel. It is a personal experience in which the individual gets to experience the heartbeat of the Universe, which pulsates within each of us (Trieschmann, 2001). Second, the spiritual experience is a presently felt phenomenon. This feeling may be vague or precise, but it is a feeling that carries meaning and understanding of some nature. And third, the spiritual experience brings new meaning, which in turn leads to growth. It allows a person to reach a form of clarity, creating more life energy and allowing more awareness to self and others.

Spirituality is thought of in most accounts as having some transcendent element and implying an awareness of something beyond human existence than that of which we are typically aware. A deep sense of belonging, connectedness, and openness to the infinite (Shafranske & Gorsuch, 1984, p. 233), and ultimate meanings and values by which humans live their lives (Kundtz, 1998, p. 114) are essential elements of spirituality. Apponte (1996) suggests that spirituality is an active dynamic force that springs from within the core of a person, as well as from family and community. Further, he views spirituality "as a complex dynamic in people's lives that develops, matures, and evolves through triumphs and hurts, changes and growth; think of it as so much a part of life that no emotional pain, psychological distress, or relationship struggle can be understood in depth without accounting for people's spirituality" (p. 495).

In sum, spirituality generally refers to something that is transcendent, ultimate, and meaningful. It can be thought of as the depth dimension of human existence (Meyers, 1997). Religion, on the other hand, can be thought of as an organized system of faith, worship, and rituals. It is important to note that for some, the religious experience is associated to the traditions of religion and expressed within a community, and for others, it is a private experience of spiritual ideas and practices. Thus, it is the purpose of this study to focus on spiritual and religious experiences as they are tied to mental health – psychology for those who have survived a traumatic brain injury. To appreciate the nature of the prominence of this topic, one must understand the magnitude of the origins of spirituality. "Psychologists trained in the dominant historical tradition of the 20<sup>th</sup> century may be startled to learn that psychology and religion have historically been inextricably intertwined (Kemp, 1996 p. 72)." Questions concerning human behavior and thoughts have been asked throughout history. The writing of philosophers, poets, and religious leaders record many insights into human nature. More than 2000 years ago, two of the most notable philosophers, Plato followed by Aristotle, speculated at great length about the nature of human beings, the origin of their knowledge and behavior. Aristotle believed in the existence of the soul, asserting that the "active reason" part of the soul propels humanity toward the highest purpose – the acquisition of knowledge (Bowie, Michaels, & Solomon, 2000). Indeed, his theory of the human being's inner potential is considered a forerunner of self-actualization theory, later addressed by Carl Jung and Abraham Maslow.

Religion and spiritual issues have been at the forefront of the intellectual and pragmatic experience. It has dominated psychological thought with great fervor since its birth. The term psychology came about in the sixteenth century from the Greek terms *psyche*, meaning "soul", and *logos*, meaning the "study of"; hence, psychology meant "the study of the soul". Later, psyche, became translated as "mind" creating the new definition of psychology "the study of the mind." The Renaissance marked an end to the dominance of rationalism and brought about with it beliefs that knowledge should be acquired through observation and experimentation, the beginning of the scientific method

(Bowie et al., 2000). Rene Descartes, the predominant thinker of the time, introduced the concept of dualism and the interaction of the body and the mind (Sdorow, 1990). He believed that the mind consisted of innate ideas, derived ideas, and a self-God, and that individuals should prove things through their own reasoning. Joining Descartes, were the empiricists, Locke, Berkely, Hartley, Mills, who believed that only through ideas does one come to understand self, thus resurrecting Aristotle's *tabula rasa* – a blank slate on which are written the life experiences we acquire through our senses (Sdorow, 1990).

The field of psychology continued to progress, evolving into the birth of modern psychology (late 19<sup>th</sup> century to the present). William James (late 19<sup>th</sup> century and early 20<sup>th</sup> century) delved into why people think and act in particular ways. James noted that consciousness is always active and selective: our mind focuses on things that are important to us, that help us accomplish our goals (Sdorow, 1990). James also found that by pragmatically thinking about religion in such a way that allowed one to get to the truth, one might be able to utilize religious or spiritual experiences and assess its impact on the intensity of human action and on the shaping of human welfare (James, 1985). James suggested that religion was a cure for philosophical melancholy; religion being in the supernatural sense or having "faith in the existence of an unseen order of some kind in which the riddles of the natural order may be found explained" (Levinson, 1981, p. 30). He also discussed the innate desire of individuals to indulge in what he referred to as spiritual self-seeking (Cook and Kelly, 1998).

Furthermore, James stated that a connectedness between religion and mental health exists and that experiencing religion can produce inner paths to a supernatural kind of happiness (Horton, 1998). James viewed religion as one's commitment to a specific set

of thoughts and ideas and/or maintaining an attitude of healthy mindedness. "James also refutes any importance to the social behaviors of religion such as church attendance, and emphasizes the importance of internalizing one's religion in order to become spiritual, creating inner change" (p. 17).

The industrial revolution along with scientific advances further shaped psychology into a separate discipline from religion/spirituality. Empiricism, which contends that all knowledge is based on objective facts discovered through observation and experimentation, had cast its spell (Bowie et al., 2000). Thus, by the turn of the twentieth century, the spiritual influences that were illuminated in psychology and philosophy were on the decline because of empiricism.

While there were still theorists who utilized and subscribed to the importance of spirituality, other schools conceptualized emotional concerns within the context of mind/body/soul split (Cook and Kelly, 1998). Freud, for example, in the 1920's viewed problems as biological in nature, moving away from spirituality. Freud asserted that religion and spiritual tendencies were "a universal obsessional neurosis" (Mack, 1994, p. 28). Freud and other psychoanalysts believed psychoanalysis explained both normal and abnormal behavior, the concept of unconscious motivation, the influence of childhood experience on adult functioning, and the role of defense mechanisms. Moreover, it was emphasized that psychoanalysis does not address the notion of a spiritually endowed psyche. Like the spiritual aspect of psychology, this approach has been criticized because it is difficult to "measure" the unconscious and consequently suffers as a scientific model (Bettelhiem, 1982).

And more recently, other theorists moved toward more behaviorist approaches (i.e. John Watson, Skinner, and Lazarus). Behaviorists' explanations of human behavior rarely took into account what was going on in the mind (Sdorow, 1990). Researchers focused instead on measuring environmental conditions and subjects' responses to them. It should be noted that both psychoanalytic and behavioral approaches were established upon a mechanistic and naturalistic conceptual foundation that deliberately excluded spiritual perspectives (Bergin, 1988).

The cognitive movement has added strength to the shift away from mechanism and naturalism by combining an agentive perspective with rigorous research (Bergin, 1988; Robbins & Hayes, 1993). The cognitive movement emphasized the importance of exploring the mind – how thoughts affect feelings and behavior – the nature of the mind and how we learn. Further, Bergin (1988) stated that "social, cognitive, and affective variables have become important explanatory tools, and theorists are dealing with a level of complexity and internal nuance that is far beyond the hydraulic mechanisms of psychodynamics and the elementary notions of control via stimulus-response connections" (p. 22). As a profession then, we have become divided on the matter of addressing the spiritual needs of individuals with whom we work.

In the latter half of the twentieth century, new philosophies were developed – existentialism and humanism. Both existential psychology and humanistic psychology uphold the importance of free will; authenticity; accepting responsibility for one's actions; acknowledging the uniqueness of human beings; studying the human being as a whole; exploring subjective experience; and seeking a meaningful life through personal growth (Hergenhahn, 1992). There were several individuals who believed in utilizing

spirituality and religion in the realm of clinical practice. Carl Rogers viewed religion as extremely important in his life and utilized techniques to help individuals find congruency between their actual self and ideal self. The common theme throughout Rogers approach was that human life was a spiritual journey toward health and wholeness (Sdorow, 1990).

Abraham Maslow originated humanistic psychology and stepped away from behaviorism and analytic approaches (Sdorow, 1990). He is thought of as a prodigious contributor to transpersonal psychology. He presented the hierarchy of needs, which addresses the spiritual component of life. Specifically, Maslow discusses physiological needs, safety and security, belongingness and love, esteem, self-actualization, and transcendence (spiritual fulfillment). Gagan (1998) eloquently elaborated on one of Maslow's greatest contributions:

Maslow and his colleagues viewed their clients through a lens of possibility framed by self-knowledge and self-responsibility. Movement toward wholeness encompassed the role played by spiritual influences and experiences, and Maslow's hierarchy of needs embodied mystical, peak experiences – moments of self-actualization during which an individual feels more integrated, more at one with the world, more perceptive, and more creative. In his words, 'The emotional reaction in the peak experience has a special flavor of wonder, of awe, of reverence, of humility and surrender before the experience as before something great.' (p. 34)

In addition, Hawks (1994) highlighted the connection between spirituality and Maslow's theoretical model of the hierarchy of needs. He stated that spiritual health and Maslow's concept of self-esteem are interconnected. Maslow argues that love and acceptance are prerequisites to self-esteem. Hawks suggests that spiritual health is based on faith in a world view that leads to fulfillment based on values, beliefs, and behaviors. Self-esteem

occurs when an individual maintains harmony with his or her value system that follows from a strong sense of faith and spirituality.

It is important to note a key player in the realm of spirituality and religion in psychology. Carl Jung established himself as an internationally eminent psychiatrist. He is thought of as paragon who embraced religious and moral concerns in psychotherapy. Although Carl Jung was sought after by Freud (Leahey, 2000), Jung's thinking departed markedly from Freud's. Carl Jung broke away from the psychoanalysis approach and redefined many of Freud's concepts and presented a more optimistic, creative view of human kind. Jung emphasized the importance of giving attention to the soul and spiritual development within the healing process.

For many years, Jung's school of thought was rejected by mainstream psychologists because of its emphasis on clinical examples and its historical and mythical learnings. "Jung has far less appeal than Freud, because there is so much discussion of occultism, mysticism, and religion in Jung's writings that it apparently repels many psychologists" (Calvin & Lindzey, 1978, p. 148). These thoughts changed, however, over the last twenty years. Jungian analysts began to garner respect while Jung's concepts (e.g., use of symbols, dream interpretation, and active imagination) were adopted by countless psychotherapists. Today, Jungian psychology is credited with being the primary impetus behind integrating psychological thought and the realm of the soul.

In the late 1980's and the 1990's, the importance of spirituality was reestablished within the field of psychology. For example, spirituality is addressed in the national accreditation standards of the psychology profession. "The American Psychological Association (1992, p. 1601) mandates that psychologists take an informed view of

religion as a dimension of human difference and diversity" (Shafranske, 1996, p. 3). In the APA Monitor, Clay (1996) reported that although traditional psychologists have disregarded the importance of religion in mental health, their faith in religion is growing. In the past, religious beliefs have been associated with signs of weakness and even pathology. Clay contended that current research suggests that religious faith may enhance mental health, regardless of affiliation, be it Muslim, Christian, Jewish, Buddhist, Hinduism, or others. Bergin (1986) stated that a movement is occurring. Specifically, since spirituality and religion are widespread cultural phenomena, social scientists are using new sophistication and more systematic and empirical analyses to demonstrate their importance (Bergin, 1986; Spilka, Hood, & Gorsuch, 1985).

The path of spirituality and psychology went from being thought of as intertwined, to an evolutionary split, to recent interest in spirituality in training and clinical practice. "It is timely to add a spiritual keystone to the building blocks already provided by the behavioral, psychodynamic, humanistic, life-span developmental, and cognitive approaches" (Bergin, 1988, p. 22). The question is not, "Should we utilize spirituality?" It is now, "How do we address spirituality?" and "What interventions can be used?" Psychology remains a collection of approaches, each struggling to find a comfortable niche somewhere between empiricism and humanism.

### Spirituality in Psychotherapy and Rehabilitation

Mental health professionals and other rehabilitation specialists are neglecting an important cultural issue across all ethnic backgrounds, spirituality and religion

(Fukuyama & Sevig, 1999). It is the very issue of cultural encapsulation or cultural neglect and its effects on the client's growth that has generated prodigious cerebration within the realm of our clinical practice and our training programs. Students in applied psychology programs lack training in spiritual and religiosity (Bergin, 1985; Pargament, 1997; Sue & Sue, 1999; Virginia, Taylor, Nelson, & Wertheimer, 1999).

Exploring clients' spirituality is highly needed (Bergin, 1991; Cook & Kelly, 1998; Gartner, 1996; Kemp, 1996; Shafranske & Malony, 1990). Psychologists and rehabilitation specialists need to gain an appreciation of the significance of religion and spirituality in mental health interventions. Given that the majority of society includes religiosity and/or spirituality in their lives, it is likely that people seeking rehabilitation and/or counseling services use their spirituality in different ways to cope with their problems. Therefore, it is very appropriate to explore how clients' spirituality positively and/or negatively influences the issues that bring them to therapy.

## Coping with Adversity

In recent years there has been a growing body of research that has addressed the role of various religious strategies for coping with stress and their implications for adjustment. People "employ religion in coping with a wide variety of events and adversities, such as raising a handicapped child (Barsh, 1968; Friedrich, Cohen, & Wilturner, 1988), cancer (Yates, Chlamer, St. James, Follansbee, & McKegney, 1981; Gibbs & Achterburg-Lawlis, 1978), and daily hassles (Hathaway, 1992; Belavich, 1994; Belavich, 1998, p. 2)."

People use their religiosity to cope in different ways. Individuals may choose to pray in a variety of ways, ask clergy or congregation members for assistance, look to religion for an understanding of the reasons for the event's occurrence, attend services, do good deeds for others, or beg for a miracle in response to a negative event. These religious coping strategies have different implications for adjustment (Pargament et al., 1994; Park & Cohen, 1993). For example, Pargament et al. (1990) found that the performing of good deeds and religious rituals was related to more positive adjustment on measures of psychological status and beliefs about event outcome in a sample of church members coping with a negative life event. Park and Cohen (1993) found that religious pleading, which involves asking for a miracle and bargaining with God, was related to increased level of depressive symptoms in their sample of college students coping with the recent death of a close friend.

## Religion and Coping

In a comprehensive review, Levin and Vanderpool (1987) found that "twenty-two out of twenty-seven studies found the frequency of religious attendance to be significantly associated with health in a positive direction" (Gartner, 1996 p. 188). Religion is a common practice in life, both for specific events and for general personal growth. It appears that religion is frequently employed by many people in response to negative life events. The reasons that a person may choose to involve religion in response to a stressful event can vary. Pargament (1990) identified several specific functions of coping with respect to religion: religion, he said, may offer a response to the desire for greater self-esteem, a sense of power and control in life, a personal growth, a sense of hope, feelings of intimacy, expression of feelings, a sense of personal identity, restraints on undesirable impulses and feelings, and comfort.

Pargament and Park (1995) noted that religion has often been conceptualized unidimensionally as a set of beliefs and practices. It has also often been viewed negatively by individuals in the field of psychology as an immature defense strategy or an inappropriate coping mechanism that has negative consequences for mental health (Ellis, 1962; Freud, 1927/1961; as cited in Leahey, 2000). However, religion can play a role in numerous and positive ways in the coping process. Religion can be a part of every element of the coping process (Pargament, 1990). Pargament and Park (1995) cite religion's involvement in events (e.g., marriages and funerals), appraisals (God's will, God's punishment), resources (e.g., general religious practices), coping activities (e.g., doing good deeds, seeking spiritual support), and goals or objects of significance (e.g., closeness with God) as examples of its multi-faceted role.

In a similar perspective, Hathaway and Pargament (1992) have noted that religion can provide a range of coping strategies by allowing people to draw on social, cognitive, spiritual, and behavioral aspects of their faith in the face of difficulties. Thus, religion can play a variety of roles in coping, a view that contrasts with the uni-dimensional descriptions of religion.

#### Conclusion

Traumatic brain injuries may be more prevalent than people are aware. Most people know someone who has experienced some form of brain injury whether he or she is cognizant of it or not (Brain Injury Association, Inc., 2001). The Center for Disease and Prevention estimated that 5.3 million (2% of the population) American children and adults currently live with disabilities resulting from traumatic brain injuries (Brain Injury Association, Inc., 2001). Moreover, one million people are treated and released in hospital emergency rooms for brain injury each year. Lives can be changed dramatically, in an instant, after a single major automobile accident, or slowly over time, after repeated concussions sustained during friendly sporting events, as each injury may result in chronic dizziness, headaches, and fatigue.

Many models and methods of psychotherapy and other forms of rehabilitation for individuals who have a traumatic brain injury have been noted in the literature (For review, see Miller, 1993). Recognizing the presence of generalized organic personality changes is important, and respecting the individual variations of cognitive processing and emotional quandaries is poignant in a person's life after a traumatic brain injury. Furthermore, the treatment of the person who has experienced a brain injury requires a multimodal approach (Smith & Godfrey, 1995). O'Hara (1988) suggested that the patient can best be served by psychotherapeutic and rehabilitation efforts that address cognition, emotion (including attention to adjustment reactions to trauma, posttraumatic changes in personality, and preexisting long-term personality traits), and behavior (including the management of such physical changes as diminished energy, seizures, and the setting of goals and the development of opportunities for successful progress by the patient). A holistic approach will invaluably affect the quality of life of the survivor of a traumatic brain injury.

Quality of life can be thought of as a form of "excellence" or "goodness" in aspects of life that transcend mere subsistence, survival, and longevity (Frisch, 1999). In quality of life research, one often distinguishes between subjective and objective quality of life. Subjective quality of life is associated with feeling good, finding meaning and purpose, personal growth, and being satisfied with things in general, and objective quality of life is about fulfilling the societal and cultural demands for material wealth, social status, and physical well-being (Duggan & Dijkers, 2001). Quality of life in this dichotomous fashion deals with life's surface as well as life's depth; between these two poles of existence can be found an existential core of experienced life meaning. A deeper connection to and understanding of self may lead to higher levels of quality of life. In addition, more information about the factors that affect quality of life among individuals with TBI is warranted.

Spirituality is considered fundamental in the human condition, but it may not necessarily be experienced through the physical senses and/or expressed through everyday language. It has to do with relationships with other people, ourselves, our environment, and with something that transcends human beings. It has to do with the universal search for individual and collective identity as people respond to challenging experiences, encounter positive and negative events, and search for meaning and purpose in life and for values by which to live. Spirituality relates to that aspect of inner life through which people acquire insights into their personal existence, which are of

enduring worth. It is characterized by reflection, the attribution of meaning of experience, valuing a non-material dimension to life and intimations of an enduring reality (Chandler, Holdem, & Kolander, 1992). It is important to know that spirituality is a very individual matter. Many find meaning and explanations in the teachings of a particular religion, while others find meaning in the course of everyday experiences. Yet the notions that people develop spirituality suggest that it is an aspect of an individual's life in which progress and changes can be made, and thus, it is an integral and important element to address in therapy.

## CHAPTER III

### Methodology

This chapter provides an overview of the methods used in this study. The methodology of this study consisted of the following sections: (1) Participants, (2) Instruments, and (3) Procedure.

### **Participants**

The final participants in this study included 119 individuals who have suffered a traumatic brain injury and are members of the Brain Injury Association in two states in the Midwest and one state in the Southeast. Five hundred packets were sent out, and 131 packets were returned, a 26% return rate. Of the 131 packets that were collected, eight of the packets were missing a significant amount of data, and 4 of the packets were completed by individuals under the age of 18. These eight packets were not included in the analyses of this study. Of the 119 remaining participants, 42 % were female (n=50) and 58 % were male (n=69). The mean age of the 119 participants was 42.38 years (sd=14.14), with a range of 19 to 84 years. The majority of the participants were Caucasian (90.8%, n=108), with the remaining participants identifying themselves as African American (8.4%, n=10), Native American (2.5%, n=3), and "Other" (.8%, n=1).

In terms of marital status, 40.3% were single (n=48), 29.4% were married (n=35), 22.7% were divorced (n=27), 5% were widowed (n=6), and 2.5% were partnered/common law (n=3). Half of the participants had children (50.4%, n=60). Approximately 32% of the sample lived alone (31.9%).

With regard to education, 5% did not complete high school (n=6), 10.1% obtained a GED (n=12), 31.1 % completed high school (n=37), 28.6% completed some college (n=34), 17.6% obtained a Bachelor's degree (n=21), 6.7 % obtained a Master's degree (n=8), and .8% obtained a Doctoral degree (n=1). In terms of employment status, onethird of the participants indicated that they were employed (33.6%, n=40); whereas, twothirds were unemployed (66.4%, n=79). On average, the participants in the study reported a yearly income range of \$20,001 to \$25, 000 (SD = 3.2: Categories).

With regard to religion, 91.6% were Christian (n=109), 4.2% were Non-Christian (n=5), and 4.2% were nonreligious (n=5). Most participants indicated that their spiritual beliefs did change after their traumatic brain injuries (84.9%; n=101), with 15.1% reporting no change in their spiritual beliefs (n=18). Most participants (75.6%; n = 90) became more spiritual after their traumatic brain injuries, while 19.3% reported that their spirituality has stayed the same (n=23), and 4.9% reported being less spiritual following their traumatic brain injuries (n=6).

In terms of the site of the brain injury, 34.5% indicated damage to the frontal lobe (n=41), with 64.7% reporting damage to areas of the brain not affiliated to the frontal lobe region (n=77). The mean length of time since the injury was 167.2 months (sd=106.3), with a range from 16 to 433 months. Over half of the participants (53.8%; n = 64) reported having chronic pain, with 46.2% reporting no chronic pain (n=55). In

terms of caring for themselves, 20.1% of the participants view themselves as dependent (n=24), with 79.8% indicating that they were independent (n=95). A summary of the demographics of this sample is presented in Table 3 (See Appendix A).

#### Instruments

# Quality of Life Inventory (QOLI)

The QOLI (Frisch, 1994) was developed to provide a universal measure of positive mental health or life satisfaction which could augment existing measures of negative affect and symptoms of disease or psychological disturbance and which would be useful in screening, progress/outcome assessment, and treatment planning (for a review see Frisch, 2000; and Ogles, Lambert, & Masters, 1996). Specifically, the QOLI was designed to comprehensively screen for problems-in-living as well as for strengths in everyday functioning, and address life satisfaction. The instrument consists of sixteen items selected in all domains of life that have been empirically associated with overall life satisfaction: Health, Self-Esteem, Goals-and Values or Philosophy of Life, Money or Standard of Living, Work, Play or Recreation, Learning, Creativity, Helping or Social Service/Civic Action, Love or Love Relationship, Friends or Friendships, Relationships with Children, Relationships with Relatives, Home, Neighborhood, and Community. Respondents rate how important each of the 16 domains is to their overall happiness and satisfaction (0 = "not at all important", 1 = "important", 2 = "very important") followed by a rating of how satisfied they are in each area (-3 = "very dissatisfied") to 3 = "very dissatisfied"

satisfied"). Some examples of the questions include, "How important is your community to your happiness?" and "How satisfied are you with your community?"; "How important is self-esteem to your happiness?" and "How satisfied are you with your self-esteem?"; "How important is money to your happiness?" and "How satisfied are you with the money you have?"; and "How important is work to your happiness?" and "How satisfied are you with your work (If you are not working, say how satisfied you are about not working)?" Respondents have the opportunity to write down what problems interfere with their satisfaction in each area on a supplementary section of the QOLI answer sheet.

The importance and satisfaction ratings for each domain are multiplied to form an overall weighted rating ranging from -6 to 6. Specifically, the overall weighted score results from the multiplication the degree of importance (0 = not important, 1 = important, 2 = extremely important) and the degree of satisfaction (-3 = very dissatisfied, -2 = somewhat dissatisfied, -1 = a little dissatisfied, 1 = a little satisfied, 2 = somewhat satisfied, 3 = very satisfied) within a particular quality of life domain. Negative scores indicate clear dissatisfaction with an area of life while positive scores denote satisfaction with or fulfillment in this area.

The overall quality of life score is then computed by averaging all 16 satisfaction ratings with nonzero importance ratings (add all the numbers that are nonzero, and divide by the number of nonzero importance ratings). Moreover, the quality of life total score can be considered the numerical number that results from adding together the weighted scores from the sixteen domains and dividing by the amount of domains that are nonzero. For example, if 15 out of the 16 weighted scores were nonzero, one would divide by 15.

The total score reflects one's satisfaction in only those areas of life one considers "important" or "very important".

Frisch (1994) administered the QOLI to individuals drawn from a non-clinical population from 12 states from the four major United States geographical regions. A total of 798 individuals participated in the study. Temporal stability of the QOLI T scores was examined with test-retest reliability coefficients from a subsample of 55 participants in the normative study. The 2-week test-retest reliability was 0.73 (p < .001). Internal consistency reliability (coefficient alpha) of the sum of the QOLI Weighted Satisfaction ratings was 0.79. The use of the sum of Weighted Satisfaction ratings for computing coefficient alpha was believed to provide a good substitute for the use of the QOLI raw score (Frisch, 2000). The sum of the Weighted Satisfaction ratings is computed over all 16 areas of life whereas the QOLI raw score is computed over only the Important and Extremely Important areas of life. The correlation between the sum of the Weighted Satisfaction ratings and the QOLI raw score was 0.99.

Data from two other measures of life satisfaction were collected in order to assess the convergent validity of the QOLI. The QOLI was significantly and positively correlated with the Satisfaction With Life Scale,  $\underline{r} = .56$ , p < .001 (Pavot & Diener, 1993), and the Quality of Life Index,  $\underline{r} = .75$ , p < .001 (Ferrens & Powers, 1992). The correlation between QOLI T-scores and scores on the Marlow-Crowne Social Desirability Scale was .25. While statistically significant (p < .001), the small size of the correlation suggests that the impact of the social desirability response set on QOLI scores was minimal since it accounted for only about 6 % of the variance in QOLI scores. The means and standard deviations of the QOL total score and of the 16 domains within the QOLI for this sample are provided in Table 8, Appendix A. The majority of the domains within the QOLI were highly correlated (See Table 9). The internal consistency reliability estimate of the sum of the QOLI Weighted Satisfaction ratings (the QOLI total score) for this sample was .88.

### Spiritual Involvement and Belief Scale (SIBS)

The SIBS (Hatch, Bury, Neberhaus, & Hellmich, 1998) was developed to be a comprehensive and widely applicable instrument for the assessment of spiritual status. The authors developed a list of underlying principles of spirituality that are shared by multiple aspects of spirituality, including a relationship with/belief in a power greater than oneself, purpose in life, fulfillment from nonmaterial things, faith, trust, identity, prayer, meditation, spiritual activities with others, appreciation for mystery of life, ability to forgive, ability to apologize, ability to find meaning from suffering, gratitude for life experiences, and spiritual belief involvement.

The instrument consists of 26 items. Responses on the first twenty-three items can range from "Always" to "Never" on a five-point Likert scale. Some examples of these items include, 1) I can find meaning in times of hardship, 2) Prayers do not really change what happens, 3) I believe there is a power greater than myself, 4) My life has a purpose, and 5) I examine my actions to see if they reflect my values. The twenty-fourth and twenty-fifth items have a five-point Likert scale that included, "0 times," "1-3 times," "4-6 times," "7-9 times," and "10 or more times." These items assessed participants'

frequency in praying and meditating respectively. The twenty-sixth item assessed participation in spiritual activities with others and included a five-point Likert scale that included: "0 times," "1-5 times," "6-10 times," "11-15 times," and "more than 15 times."

A factor analysis of the SIBS was conducted by using both orthogonal (Varimax) and oblique (Promax) factor rotations on data (Hatch, et al., 1998). First, the orthogonal rotation (Varimax rotation) was used and it yielded a clear four-factor structure. The factors are: (1) External/Ritual, which typically addresses participation or level of involvement in spiritual activities/rituals (e.g. "Participating in spiritual activities helps me forgive other people"); (2) Internal/Fluid, which includes items that refer to evolving spiritual beliefs and internal spiritual beliefs (e.g. "Spiritual activities have not helped me develop my identity"); (3) Existential/Meditative, which addresses the existential issues of meaning and purpose (e.g. "I can find meaning in times of hardship"); and (4) Humility/Personal Application, which deals with humility and application of spiritual principles in daily activities (e.g. "I examine my actions to see if they reflect my values"). Eigenvalues for the four factors were 9.52, 6.95, 3.55, and 3.98, respectively. Because of the large number of items loading on two or more factors, an oblique factor rotation (Promax rotations) was run. Designed to assess the degree of association between factors, this analysis revealed a four-factor structure nearly identical to that found in the orthogonal rotation.

The internal consistency reliability of the total SIBS score for the original sample was assessed using Cronbach's alpha and yielded an overall coefficient alpha of .92 (Hatch et al., 1998). Test-retest reliability (mailed 7 to 9 months after the initial administration) was .92. Convergent construct validity was assessed by correlating the total SIBS with total Spiritual Well Being Scale (SWBS) scores, yielding a Pearson correlation of .80. The item content suggests good face validity. The strong relationship between the SIBS and the SWBS confirms that it is a valid measure of spirituality.

For the current study's sample, the internal consistency reliability estimates for the External/Ritual, Internal/Fluid, Existential/Meditative, and Humility/Personal Application subscales of the SIBS were .39, -.13, .22, and .16, respectively, which suggests that these subscales were not reliable for the participants in this study. Due to the low reliability estimates for these subscales, an exploratory principle components analysis of the SIBS was conducted for this sample. This analysis will be described in detail in the Results section.

# Demographic Questionnaire

The demographic questionnaire was used to collect information regarding age, sex, race, annual household income, highest level of education, occupation, current religious/spiritual belief orientation, religious affiliation, marital status, if the participant had children and how many, number of individuals living in the home, type/site of the brain injury, the time since injury, level of independence, level of chronic pain, if and to what degree spirituality changed after the traumatic brain injury, and to what degree the traumatic brain injury affected physical functioning, ability to work, relationships with others, ability to learn, moods, and feelings about one's self.

#### Procedures

The executive director and the president of the Brain Injury Association in three states were contacted by the primary researcher to discuss this research project and its implications for individuals who have traumatic brain injuries, and to request permission to conduct this study with its members. Further, this study was discussed at a Quarterly Board Meeting. Permission was granted by each state organization. The executive directors of the three state organizations randomly selected members (every third member from their lists) from their organization and sent the names to the primary investigator. Two hundred and twenty-five members of the Brain Injury Association were randomly selected from the Southeastern State (out of 1500 members), 200 were randomly selected from the other Midwestern State (out of 100 members). Research packets were collated, labels were placed on the packets, and then the packets were mailed to the members. The questionnaires in the packets were put in a random order by the primary investigator to control for order effects.

The members of the Brain Injury Association in the two Midwestern states and one Southeastern state were mailed a survey packet containing 1) a cover letter indicating the purpose of the study, a request for their participation, a statement regarding nonparticipation and confidentiality, voluntary withdrawal options, and an "800" number that participants can call to get a resource list, including counseling services and Brain Injury Association support groups, in case they experience psychological distress following their participation in the study, 2) the Spiritual Involvement and Belief Scale, 3) the Quality of Life Inventory, 4) a demographic sheet, and 5) a self-addressed, stamped return envelope. The questionnaires in the packets were put in a random order to control for order effects. A cover letter was included in each packet informing the participants that this research was conducted by one of the board members of the Brain Injury Association, and that the research was supported by the president and the executive director of their state along with the other board members. A postcard was sent 3 weeks after the distribution of the packets.

Those who agreed to participate indicated their agreement by signing and returning the informed consent form with their completed packets. When the packets were returned, the informed consent form was separated from the rest of the materials and stored in a locked cabinet to ensure the confidentiality of the participants' responses.

#### CHAPTER IV

#### Results

The purpose of this study was to explore the relationship of spirituality with quality of life among individuals who have experienced a traumatic brain injury. In addition, the relationships of participants' demographic characteristics with spirituality and quality of life were examined. The results of the findings will be presented in this chapter. Please note that the tables are listed in Appendix A.

# New Research Question: What is the structure of the SIBS for this sample of people with traumatic brain injuries?

Due to the low internal consistency reliability estimates for the four SIBS subscales, an exploratory principle components analysis with oblimin was conducted. The oblimin rotation was selected because it was assumed that if multiple factors existed within the SIBS, they would be related. Based on the Kaiser rule (retain factors with eigenvalues greater than one) and the examination of a scree plot (Stevens, 1996), a onefactor structure emerged (See Table 5, p. 145 for the eigenvalues; See Figure 3, p. 156 for the scree plot). The internal consistency reliability estimate for this factor was .77. Based on review of the item-total correlations, items 3 and 9 were deleted to increase the reliability of this factor scale. The final Cronbach alpha coefficient for this factor was .91.

This one factor ("Spirituality") accounted for 54.8% of the total variance in spirituality scores and represented a theoretically important construct. Items loading at or above .40 were used to interpret the factor. Eleven items loaded on this factor above .40. See Table 4 for the significant items loading on this factor. These items represent an integration of the External/Ritual, Internal/Fluid, and Existential/Meditative dimensions of the SIBS. This factor was named Spirituality. A visual representation of differences in the original SIBS factors (Hatch et al. (1998) and the one-factor solution found in this study can be examined in Table 6.

Research Question 1: What is the relationship of spiritual involvement and beliefs with quality of life among individuals who have experienced a traumatic brain injury?

A forward multiple regression analysis was originally planned to answer this first research question, with the four subscales of the SIBS (External/Ritual, Internal/Fluid, Existential/Meditative, and Humility/Personal Application) as the predictor variables and the total QOL score as the criterion variable. It was hypothesized that spiritual involvement and spiritual beliefs (External/Ritual, Internal/Fluid, Existential/Meditation, and Humility/Personal Application) would be significantly related (in a positive direction) to the level of quality of life among individuals who have experienced a traumatic brain injury. Given that the subscales of the SIBS were not reliable for this sample and the subsequent principle component analysis resulted in only one factor for spirituality, a multiple regression analysis could not be conducted as originally proposed. Instead, a Pearson moment correlational analysis was conducted. There was a significant positive correlation between Quality of Life and Spirituality ( $\mathbf{r} = .37, \mathbf{p} < .001$ ).

# Research Question 2: What is the relationship of participants' demographics with their quality of life?

To answer research question 2, correlational analyses (for continuous data) and ttest analyses (for categorical data) were conducted on the demographic variables with the overall score on the Quality of Life Inventory. The demographic variables that were explored included: sex (male, female), age, number of people living in the home, employment status (employed, unemployed), years of education completed, income level, site of brain injury (frontal lobe, non-frontal lobes), time since brain injury, level of independence (0-10), and chronic pain (yes, no). Due to the lack of ethnic and religious diversity in this sample, t-tests could not be conducted to explore racial and religious affiliation differences in quality of life scores. Only 11 people of color participated in this study. The majority of participants were Christian (109) and only 10 people identified with other religions or no religion.

It was hypothesized that some demographic variables will be significantly related to quality of life. In particular, it was anticipated that the quality of life would be positively related to time since injury (longer), site of injury (non-frontal lobe regions), number of people living in the home (more people), ability to take care of oneself (greater independence), and income level (higher income level).

The results of the Pearson correlational analyses indicated that there were no significant relationships between quality of life and the following demographic variables: age, number of people living in the home, education completed, annual income, date of injury, and ability to take care of oneself. See Table 7 for the correlation matrix.

The results of the t-test analyses indicated one significant finding. The results of the t-test for the quality of life by site of injury indicated significant differences, t (115) = -2.16, p=.03. Individuals who suffered a brain injury in the frontal lobe region reported a higher quality of life (M=2.63, SD=1.95) than those who had non-frontal lobe injuries (M = 1.81, SD = 1.92).

# Research Question 3: What is the relationship of participants' demographics with their spiritual involvement and beliefs?

To answer research question 3, Pearson correlational analyses (for continuous data) and t-test analyses (for categorical data) were conducted for the demographic variables with the Spirituality factor score. The demographic variables that were explored included: sex (male, female), age, number of people living in the home, employment status (employed, unemployed), years of education completed, income level, site of brain injury (frontal lobe, non-frontal lobes), time since brain injury, level of independence (0-10), and chronic pain (yes, no). Due to the lack of ethnic and religious diversity in this

sample, t-tests could not be conducted to explore racial and religious affiliation differences in quality of life scores.

It was hypothesized that some demographic variables will be related (in a positive direction) to the participants' spiritual involvement and beliefs. In particular, it is anticipated that spirituality will be positively related to time since injury (longer), site of injury (non-frontal lobe), number of people living in the home (more people), and ability to take care of oneself (greater independence).

A significant negative correlation was found between spirituality and annual income (r = -.20, p < .05). Participants who reported lower annual incomes were more spiritual than participants who reported higher annual incomes.

There were no significant findings for the series of t-tests that were conducted for the categorical demographics and spirituality.

# CHAPTER V

#### Discussion

Spirituality is so central and important to many people that mental health professionals need to address its impact on clients' quality of life. More and more empirical evidence is confirming the importance of exploring spirituality in treatment. Fukuyama and Sevig (1999) indicated that 75% of individuals participating in psychotherapy find it important to discuss spiritual/religious issues. Koenig (1997) found that 75% percent of medical patients report using religion/spirituality to a large extent to help them cope when they are ill. Therapists cannot conventionally ignore the existence of spirituality, nor assume that its recognition would be resented by clients as impertinent or indecorous. Moreover, knowledge confined to psychopathology or general neuroanatomy is now inadequate to address the needs of clients in counseling and rehabilitation. Treatment for individuals who have experienced a traumatic brain injury cannot remain narrowly focused or limited in its scope. It would behoove therapists to provide services to individuals in a fashion that not only address the cognitive and physical domains, but also the existential and spiritual domains, when it is appropriate to do so.

Many researchers have proposed that spirituality is a major contribution to one's quality of life (Koenig, 1997, Fitchett, et al., 1999; Pargament, 1997; Mathews & Larson,

1995; Olson & Kane, 2000). Over 200 studies have documented relationships between religious commitment and reduced psychopathology, greater emotional well-being, improved coping, and strengthening of social support (Matthews, 1997). These theories explain various factors that may influence the individual's perception of his or her quality of life. Spirituality specifically, has been thought to be a "key to wellness". (Frankl, 1963; Aponte, 1996; Fowler, 1981; Bergin, 1991; Shafranske & Malony, 1996; & Jung, 1954). Spirituality is thought of as the core characteristic of healthy people and source of all other dimensions of wellness. Overall, studies show that religious/spiritual beliefs usually play a positive role in adjustment (Fitchett, Min, Peterman, & Cella, 1996). Until this study, however, the relationship between quality of life and spirituality for people with a traumatic brain injury had not been explored.

It is well understood that living with a traumatic brain injury can create great stress and distress on survivors' different states of well-being. Medical advances have paved the way for surviving the injury and also extended the lives of the survivors; and thus, fruitful opportunities have developed for health care practitioners to enhance the survivors' quality of life. With recent renewal of the spiritual realm and its relationship to healing, practitioners, researchers, and clients alike may wonder what role spirituality plays in the life of people who have had traumatic brain injuries.

# The Structure of the SIBS for the Population within this Study and its Findings

Spirituality was originally conceptualized using the four dimensions proposed by Hatch et al. (1998): External/Ritual, Internal/Fluid, Existential/Meditative, and Humility/Personal Application. Of interest, the original factor structure of the SIBS was not reliable for this sample of people with traumatic brain injuries. Instead, a different factor structure of their spirituality emerged. Based on the responses of this sample, spirituality was identified by a unidimensional factor structure. Rather than finding separate dimensions of spirituality in terms of external, internal, or existential aspects, many of the items in these subscales grouped under one factor. This factor called Spirituality accounted for 54.8 % of the total variance in the SIBS scores.

Studies have found that some patient groups view spirituality as having multidimensional aspects while other studies have found that spirituality is unidimensional in nature. Individuals battling life-threatening illnesses use spirituality in complex and variable ways (Simoni, Martone, & Kerwin, 2002). Research on coping has highlighted the role of spirituality in social cognition, including attributions of the nature and controllability of an aversive event and its reframing or reinterpretation in a more positive light (Pargament, Ensing, Falgout, Olsen, Reilly, Van Haitsma, & Warren, 1990). Pargament et al. (1990) used factor analysis to place 31 different strategies within six categories of religious coping: spiritually based coping, good deeds, religious support, discontent, pleading, and religious avoidance. They found the best predictors of outcome to be belief in a just, loving God; the experience of God as a supportive partner; involvement in religious rituals; and the search for spiritual and personal support through religion. Hall's (1998) qualitative analyses of the spiritual responses of 10 individuals with advanced HIV suggested spirituality could influence interpretation of body and mind states. Three themes were revealed: a purpose in life emerges from stigmatization, an opportunity for meaning arises from an incurable disease, and spirituality frames life

after suffering. Sevensky (1981) suggested that prayer allows expression of the anger, disappointment, and fear that often accompany the illness experience; engenders a closer relationship with God; and provides the opportunity for contemplation and meditation. Additionally, it assists one in repairing damaged relationships, letting go of the past, achieving a sense of closure while also providing hope of an ultimate victory, despite death, by joining God (Sevensky, 1981).

The current study, however, revealed that people who survive a traumatic brain injury tend to see spirituality in a different way. Rather than finding separate dimensions of spirituality in terms of external, internal, or existential/meditation aspects, the sample's pattern of responses indicated one dimension of spirituality. Theoretical support for the unidimensional aspect of spirituality can be found in the research literature. According to Clinebell (1995), spirituality in and of itself encompasses the human need for meaning, personal growth, and value in life and the desire for the relationship with a transcendent power. Spirituality describes universal qualities that should be considered as a whole force, rather than in its various parts (Fukuyama & Sevig, 1998). One could liken this idea to Plato's famous statement, "The whole is greater than the sum of its parts." He believed that people are not isolated discrete entities in a mechanical universe, but are instead part of a larger whole which constitutes them, and therefore the goal of their lives is learning to understand the nature of that "whole" in order to bring themselves in line with its evolutionary unfolding or development (Bowie et al., 2000). In this study, people with traumatic brain injuries appear to view spirituality as a whole entity.

This could be a very valuable concept to consider when discussing spiritual issues with individuals who have experienced a traumatic brain injury. In line with a theoretical

conceptualization based on Lazarus and Folkman's (1984) theory that beliefs influence cognitive appraisals, viewing spirituality as a whole entity may have helped them to reappraise their situation, to find support, and to gain a greater sense of control, thereby aiding in psychological adaptation.

It is possible that this population did not respond to these items in the same way as the original sample because the distinctions in spiritual dimensions may not be important to them. As mentioned above, they may see that the whole concept of spirituality is important, not all of the subcomponents. Moreover, they may see spirituality as a collective concept. They may want to embrace this profound concept in its simplicity rather than its complex nature (the multidimensional aspects presented by others). Rather than trying to break the concept of spirituality into subcomponents, it will be better received by the survivor of a brain injury to address spirituality as a whole, not in its parts.

Another possible explanation for this finding can be noted via a medical perspective - by conceptualizing brain functionality after a brain injury. This sample may not be able to segment the components of spirituality, and in turn, incorporated them into one understandable perspective. Many individuals with brain damage, particularly frontal lobe damage, lose cognitive flexibility and the ability to think abstractly (Lezak, 1995; Kolb & Whishaw, 1996). Therefore, it is possible that, due to potential cognitive deficits, survivors of brain injuries may respond to these items in a way that a single domain of spirituality emerges rather than a multi-dimensional model.

# Relationship of Spirituality and Quality of Life

There was a significant, positive relationship between spirituality (factor score) and quality of life. Spirituality, as a whole, encompassed beliefs (Internal/Fluid), activities (External/Ritual), and meaning-making (Existential/Meditative) for this sample.

Yalom (1980) identified four central spiritual concerns of the psychoexistential orientation: death, isolation, meaninglessness, and freedom. These concerns can be found in an individual's journey as he or she is recovering from a brain injury. Moreover, a survivor of a brain injury likely cogitates, at some time in his or her recovery, about the near death experience, isolation from family and friends (e.g. feeling alone, self-alienation), meaninglessness/hopelessness in his or her existence, and lack of freedom (e.g. feeling dependent on others). Therefore, a possible explanation for the relationship between spirituality and quality of life may be that people with a traumatic brain injury appear to utilize the ability of finding meaning and purpose to help optimize their quality of life during their recovery process. Subsequently, the degree to which one subscribes meaning and purpose affects the perceived level of quality of life.

This finding supports Ingersoll's (1994) and Hinterkopf's (1994) statements that finding meaningfulness in experiences will help foster a greater quality of life, which will in turn lead to positive growth. This finding also confirms Baumeister's (1991) discovery that many of the problems involving life after a brain injury concern fundamental issues of life and meaning. Similarly, a study out of McGill University found that the existential domain of spiritual well-being was an important predictor of overall quality of life in persons with cancer and HIV (Cohen, 1996; as cited in Cotton et al., 1998). Participating in rituals that involve spiritual experiences as well as identifying personal growth and evolving internal beliefs seem to be related to quality of life for individuals who have survived a traumatic brain injury. Believing in a higher power and involvement in spiritual rituals (e.g. church, prayer) and their positive relationship to quality of life may be explained in a couple of ways. First of all, it is important to note that researchers have found that the support system for individuals with TBI is one of the best predictors of adjustment and quality of life (Miller, 1993; O'Hara & Harrell, 1991; Long, et al. 1998; Perlesz et al., 1999; Smith & Godfrey, 1995). It is well known that attending a church, a temple, a mosque, or other designated spiritual environments provides a strong support system for many. Pargament (1990) demonstrated empirically that religion could be a potent source of support and coping.

By having external spiritual beliefs and participating in rituals, people may experience a strong connection to something greater than themselves, a higher power. Several publications have stated that a belief in a higher power or a transcendent being positively affects one's quality of life in medical populations, including individuals with cancer, HIV, and amputations (Belavich, 1998, Gartner, 1996, Koenig, 1997, Fitchett, et al., 1999; Olson & Kane, 2000). Further, Shafranske (1996) stated that spiritual rituals and traditions accentuate the threads of religious sentiment that are woven within its cohesive fabric of meaning and social affiliation. The relationship between spirituality and quality of life confirms other researchers' findings and supports philosophies in that those who believe in a higher power and participate in spiritual rituals have a higher perception of their quality of life than those who do not believe in a higher power. The concepts of identifying personal growth and having evolving internal beliefs are important when looking at one's quality of life. Pargament (1990) demonstrated empirically that strong internal beliefs through religiosity could be a way to construct a personal philosophy of significance (i.e. beliefs and social affiliations). Spirituality can help foster a sense of personal identity (internal beliefs) and can help potentiate a person in everyday life (personal growth). It can help to orient human values and human behavior. Csikszentmihalyi (1990) completed a profound book on "Flow: The Psychology of Optimal Experience." He emphasized that the ultimate experience of joy and happiness is an individual creation, an individual journey. Furthermore, he stated that nurturing one's personal beliefs and identifying personal growth and goals are prodigious components to improving one's quality of life.

The relationship between spirituality and quality of life in people with traumatic brain injuries can also be understood through Abraham Maslow's work. As an individual with a brain injury pursues rehabilitation, finding him or herself through his or her journey of the hierarchy of needs, he or she may identify personal growth and personal beliefs. These survivors are achieving goals as they regain abilities lost following injury, and they are in the process of becoming, finding out who they are post-injury. Moreover, movement towards wholeness of the self highly involves the role played by spiritual influences (Gagan, 1998), and subsequently, an individual feels more integrated, more at one with the world, and more perceptive as he or she strives to live optimally. Hawks (1994) identifies the concept of "movement toward wholeness" as a way of building selfesteem, which in his thoughts is positively connected to spiritual health. Hawks suggests that spiritual health is based on faith in a worldview that leads to fulfillment based on

values, beliefs, and behaviors, and that self-esteem occurs when an individual maintains harmony with his or her value system that results from a strong sense of faith and spirituality. Thus, as one recovers from a brain injury, he or she likely seeks fulfillment, which occurs through identifying personal growth and having evolving internal beliefs.

In this study, the participants' change in spiritual beliefs since their TBI is noteworthy. More than 75% of the participants became more spiritual after their injuries, while a little more than 19% reported that their spirituality stayed the same, and almost 5% reported being less spiritual following their brain injuries. Furthermore, 63% of the participants said that their spirituality "changed significantly" or "a great deal" after their injury. This finding could be explained within the context of coping with adversity. A traumatic brain injury challenges an individual physically, socially, and psychologically. Furthermore, it may threaten one's sense of meaning, purpose, and significance in life. Research on other life-threatening illnesses (e.g., cancer, HIV) has indicated that individuals often turn to religion and spirituality to cope (Dunbar, Mueller, Medina, & Wolf, 1998; Pargament, 1997; Simoni, Martone, & Kerwin, 2002). Furthermore, Pargament (1997) stated that, under duress, people may embrace spiritually as a coping resource, especially in cases in which the usual human coping resources are ineffective or are threatened, as in the face of potentially debilitating brain injuries. It could also be explained in other ways. Maybe they find "God" later in life. However, for some people, spirituality may not be important to them. They may use other coping mechanisms to deal with their brain injuries. Moreover, spirituality is not a coping mechanism for everyone.

#### Relationships Between Demographics and Quality of Life

There was a significant relationship between the site of the brain injury and the perceived quality of life. Individuals who suffered a brain injury in the frontal lobe region reported a higher quality of life than those who had non-frontal lobe injuries. Notably, those who sustained injuries to both non-frontal lobes and frontal lobes are categorized as having a brain injury in the frontal lobe region. An individual who sustains a brain injury in the frontal lobe may present with deficits in planning, judgment, insight, selfawareness, organizing, problem solving, and attention (Lezak, 1995; Kolb & Whishaw, 1996). Personality changes and a variety of higher cognitive functions including abstract thinking, good judgment, appropriate behavior, and self-awareness are some of the most notable changes after an injury occurs to the frontal lobe region (Kolb and Whishaw, 1996). An individual who sustains an injury in the non-frontal lobe region may present with visual reception and visual recognition deficits (occipital lobe), visuo-spatial deficits (right parietal lobe), disruption in the ability to understand spoken and/or written language (left parietal lobe), disruption in the ability to tell one smell from another and one sound from another (temporal lobes), deficits with visual memory and verbal memory (right temporal lobe and left temporal lobe, respectively), and deficits with balance and muscle coordination (cerebellum; Lezak, 1995).

Given the differentiation between frontal and non-frontal lob injuries, a possible explanation for this finding is that individuals who have damage to the frontal lobe region may not have the insight, awareness, and/or judgment to recognize the severity of the deficits, if they are aware of any deficits at all. This condition is called anosognosia, the

unawareness or denial of illness. Conversely, one may conclude that individuals having deficits that relate to non-frontal lobe areas may be more aware of their limitations. Thus, individuals who have frontal lobe damage may not consider his or her deficits as severely or as negatively impacting their daily functioning as a person who has non-frontal lobe damage. Subsequently, individuals who have frontal lobe damage may perceive their quality of life to be better than those individuals who have damage in non-frontal lobe areas.

This supports Lezak's (1995) statement that a common result of frontal lobe damage is a deficit in self-awareness. Ownsworth, McFarland, and Young (2001) found that patients whose executive functioning was impaired demonstrated greater deficits in self-awareness and self-regulation. Furthermore, a deficiency in self-awareness results in an inability to perceive performance errors, to appreciate the impact one makes on others, or to interpret a social situation appropriately (Prigatano, 1991; Schachter, 1990; Stuss, Gow, & Hetherington, 1992).

This result substantiates the results of a study that was conducted by Shallice and Burgess (1991). They gave patients a list of six errands (e.g. by a brown loaf of bread) and an instruction to be at a particular place 15 minutes after starting to retrieve items on the list. Additionally, the patients were to get answers to four questions (e.g. What is the price of a pound of tomatoes?). They were not to enter shops except to buy something and complete the tasks as quickly as possible, without rushing. The patients who had frontal lobe damage found this task to be very difficult. They were insufficient, broke rules, and failed several of the tasks. Yet, when quizzed, all of the patients understood the task and attempted to comply. It is important to note that after the completion of the exercise, several of the patients were not aware of the degree of their poor performance. Therefore, one may speculate that a person who has frontal lobe damage may also lack the awareness of some of the deficits that would negatively influence one's perception of his or her quality of life.

Individuals with non-frontal lobe injuries, on the other hand, reported lower levels of quality of life when compared to individuals with frontal lobe damage. People who suffer non-frontal lobe damage do not tend to have deficits with self-awareness (Lezak, 1995). In this sense, they may be more aware of their deficits and/or limitations, which in turn, can lead to their perception of a low quality of life. For example, a poet who injures his left parietal lobe may have difficulties with writing, with mathematics, and with language. Since he has difficulty with writing and with language, he may find it difficult or impossible to construct poetry, his passion; subsequently, he may perceive his quality of life as low. It is possible and likely that because people with non-frontal lobe damage are more aware, they might realize the limitations of their abilities in daily life more accurately than people with frontal lobe damage.

It is possible that people with non-frontal lobe damage are aware of their deficits, and they might exaggerate the nature of their quality of life in a negative way. For example, an architect who wants to receive compensation for a work-related brain injury that affected her visuospatial ability (right parietal lobe) might want to exaggerate her symptoms to increase her compensation. Although unfortunate, as in any population, a person who has incentive to exaggerate his or her symptoms may do so to be wellcompensated. It is noteworthy to mention that others may exaggerate their symptoms for the sole purpose of receiving attention.

There were no significant relationships between quality of life and the following demographic variables for this sample of individuals with TBIs: age, number of people living in the home, education completed, annual income, date of injury, and ability to take care of oneself. There have been mixed results in the literature regarding the relationship between quality of life and these demographic variables in various patient samples. For example, research has found that financial security, material assets, meaningful social roles, and a longer time since a physical injury appear to be prerequisites for high-level quality of life (Myers & Diener, 1995). On the other hand, research has indicated that people may envision their quality of life as high despite adverse objective factors, including economic hardship, declining health, and social losses, and others may perceive the quality of life as low even when they have excellent health, an abundance of economic resources, and high social status (Duggan & Dijkers, 2001). In other words, objective factors such as annual income (materialistic items), social status, and longer time since injury do not predict high levels of quality of life. Other research has found that the subjective factors (e.g., perceived experiences) lead to the perception of having a high or low quality of life (Mehnert et al., 1990).

In this study, demographic characteristics of this sample (i.e., number of people living in the home, education completed, annual income, date of injury, and ability to take care of oneself) were not related to quality of life. One explanation is that personal characteristics are not as important as other variables such as physical (lobe damage location) or psychological characteristics of the individuals. Moreover, it is likely that quality of life is based more on subjective aspects/qualities (e.g. happiness, meaningfulness, purposefulness, attitude toward life) than objective aspects/qualities of the individual (e.g., age, gender, annual income, social status). This finding contradicts other research that supports the importance of objective characteristics (Boschen, 1996; Boswell, et al., 1998; Gall & Evans, 2000; Myers & Diener, 1995), and it supports Diener's (1984) findings that more and more individuals are considering the subjective characteristics to be more important than objective characteristics. A possible explanation for the lack of a relationship between demographics and quality of life is that some people realize that wealth, economic resources, physical appearance, and functional ability (among other objective factors) may only make an individual happy, elated, or joyful temporarily. Multiple investigations have revealed that what makes life genuinely satisfying and meaningful, in turn, creating longer and greater levels of happiness, is the state of mind, the state of consciousness, and the connection between self and values (Csikszentmihalyi, 1990).

No significant relationships were identified between time since injury and quality of life. This finding was unexpected, as it was hypothesized that the longer the period of time since the injury, the greater one's recovery may be, which would result in a higher quality of life. Since the average years since injury was 14, with a range of 1 year to 36 years, the majority of this sample have possibly received extensive rehabilitation and adapted to their injury. This finding is similar to another study that found that life satisfaction was not significantly correlated to time since onset of disability (in spinal cord patients; Boschen, 1996). According to Mehnert et al. (1990), quality of life may be related to how one perceives his or her situation, regardless of the time since injury.

There was no significant relationship between the ability to care for self and quality of life. This finding was unexpected. It was hypothesized that the greater the

independence, the higher the quality of life. However, the majority of this sample (78.1%) rated themselves as "almost independent" or "independent" (therefore restricting the range on this variable of interest). Since the average years since injury was 14, with a range of 1 year to 36 years, the majority of this sample has possibly received extensive rehabilitation and adapted to their injury, thus being able to care for oneself. This finding contradicts Kim et al.'s (2000) finding that that the greater the participants' degree of limitation, the lower their level of reported life satisfaction. It might, however, fit with Brickman and Campbell's (1971) views that people are unhappy when they first encounter misfortune or adversity, but they adapt and it no longer makes them unhappy.

The number of people in the home was not related to quality of life. This was inconsistent with expected findings. It was postulated that more people living in the home would foster an environment that is strong in support and community, and in turn increases quality of life. Researchers have found that the support system for individuals with TBI is one of the best predictors of adjustment and quality of life (Long, et al. 1998; Miller, 1993; O'Hara & Harrell, 1991; Perlesz et al., 1999; Smith & Godfrey, 1995). Such results might reflect the fact that the amount of people in the home is not as important as the quality of support in and out of the home. Moreover, individuals with a TBI may base their evaluation of life quality on the quality of care and support rather than on the quantity or amount of people providing it.

No significant relationships were identified between annual income and quality of life and employment status and quality of life. It was hypothesized that the greater one's household income, the greater the access to medical and psychological treatment, which in turn would lead to greater quality of life. Time since injury, the average years since

injury being 14, may be a major influence on how these individuals perceive the importance of annual income and employment status. Over time, those who experience a traumatic brain injury may realize that a reduction in income and ceased employment tend to be the norm. Sixty-six percent of this sample was unemployed and 63.9% experienced significant changes in their ability to work, which means that they are probably receiving disability and/or living with others who are earning money. The fact that employment status was not related to quality of life was unexpected.

Csikszentmihalyi (1990) indicated that many people find identity and great satisfaction from their work; some even find optimal experiences within the work environment. This finding contradicts Viemero and Krause's (1998) study on quality of life with adults who have physical disabilities. They used both quantitative and qualitative procedures to examine the life satisfaction of 45 adults with physical disabilities from Finland and Sweden. Their findings indicated that life satisfaction is associated with occupational status or participation in meaningful activities, social integration, and psychological resources to cope with disability-related stressors. This sample may, however, base their evaluation of life quality on other life domains such as relationships with others (family, community) and ability to learn rather than on their annual income and employment status. Moreover, a readjustment of life priorities may account for the finding that annual income and employment status were not related to quality of life. Ostensibly, a person's perspective, mindset, or the connection between self and values may play important roles in quality of life (Csikszentmihalyi, 1990; Mehnert et al., 1990).

Having chronic pain or not having chronic pain did not affect quality of life for people in this study. This was an unexpected finding. This contradicts previous research

that has found that among patients with advanced cancer, less pain leads to greater happiness and greater quality of life (Yates et al., 1981). This does, however, support Duggan & Dijkers' (2001) finding that health or illness does not predict high or low levels of quality of life. Since the current sample has been coping/adapting to their traumatic brain injury, on average, for a number of years, they may have learned how to manage their chronic pain, if they had any, so that it does not affect their quality of life.

Due to the lack of ethnic and religious diversity in this sample, racial and religious affiliation differences in quality of life could not be explored.

#### Relationships Between Demographics and Spirituality Involvement and Beliefs

Annual income was significantly related to spirituality in this sample of people with traumatic brain injuries. This indicates that individuals who have more money are less spiritual than those who have less money.

A possible explanation can be derived from a sociological perspective. The more affluent a person is, the more the person may be exposed to and distracted by materialism or tangible things (Csikszentmihalyi, 1999). Metaphorically speaking, like a fish immersed in the water in which it swims, people take for granted a certain amount of hope and trust in the medical system and in the technology that surrounds them. As the fruits of technology have ripened and survival rates have increased, hope has increased and the expectancy of medical help ensued due to materialistic devices that would potentially bring about a better life. Furthermore, since the affluent population may be able to easily access medical treatment, temporary caregivers (for respite), and mental health professionals, they may not extend themselves to the spiritual realm for help as much as a person who does not have the same amount of access to such resources. Moreover, it can be posited that many people seek a higher power when the clouds are dark and heavy, but not as much as when the sun is shining. For example, when students await the scores of a difficult exam or prepare for a dissertation defense, they may attend church and/or pray more regularly than they would if they did not have these stressors. Or, a farmer may rely on technology to help her water her crops, but when the irrigation system is broken, she may pray to God for rain. This finding supports Worthington's (1989) statement that people who are in crisis often spontaneously consider spiritual matters during periods of intense emotions or psychosocial disruption. When considering this population, it is possible that individuals who have financial resources may not use their spiritual beliefs until their tangible resources have been exhausted (or they may use them to a lesser degree than those who have fewer financial resources).

Another possible explanation has to do with the concept of control. Affluent people tend to perceive themselves as having a major influence in their fate (Csikszentmihalyi, 1999). Moreover, they may perceive themselves as having a great deal of control over what happens to them. In turn, this group may take more responsibility for their actions, rather than believing that a higher power (or an external force) is largely influential in their lives. Conversely, individuals who do not have as much money may tend to believe in fate or defer to a higher power for guidance and help. This group may believe that a higher power has control over what happens, and subsequently, they use their spiritual resources to help them through life more than individuals who are able to use materialistic resources.

Other demographic characteristics of this sample (i.e., age, number of people living in the home, years of education completed, time since brain injury, and level of independence) were not significantly related to spirituality. The lack of a relationship between age and spirituality was unexpected, given the increased salience of spirituality among older adults and the role that spirituality may play in coping with change and loss associated with advanced age (Pargament, Van Haitsma, & Ensing, 1995). However, the individuals in this study were not older adults. Their age ranged from 19 to 50 years of age. It may be at the more advanced stages of aging that quality of life is significantly affected by spirituality. It is also possible that changes in spirituality often attributed to age may be more accurately attributable to the experience of coping with the changes in health status and social role that typically occur with aging in later life. Or, perhaps age differences did not emerge in this sample because most of the participants had a substantial period of time (average of 14 years with a range of 1 to 36) to cope with the changes and losses associated with the life-altering, traumatic brain injury.

No significant relationships were identified between education and spirituality. This contradicts the findings by Kim et al. (2000). While studying individuals undergoing rehabilitation (e.g., spinal cord injury, amputation, stroke, multiple sclerosis), they found that as individuals acquire more education, it becomes difficult for them to maintain a "simple" faith that provides them with comfort and assurance wherein a benevolent higher power is concerned about their lives. Moreover, education tends to explain several aspects of life, including science, human nature, and the nature of their surroundings. The implication is that when human beings come to know and understand their universe, they do not rely on religion and spirituality to support them. Kim and colleagues indicated that

the more educated people are the more they are prone to question their spiritual beliefs and rely on what they know and understand when confronted with adversity or "disease." The lack of a relationship between education and spirituality may be due to the geographical region where the data was collected-the Bible Belt. Individuals who reside in the Bible Belt may be religious and spiritual, regardless of educational background. Thus, the fact that this sample of people with TBIs resided in the Bible Belt could explain. why over 95% of this population identified themselves as religious and over 75% of the participants of this study identified themselves as more spiritual after their traumatic brain injuries. Also, research has indicated that individuals often turn to religion and spirituality to cope with illness, duress, and physical disabilities (Dunbar, Mueller, Medina, & Wolf, 1998; Kim et al., 2000; Pargament, 1997; Simoni, Martone, & Kerwin, 2002). It is possible that this sample represents other groups of patients with physical disabilities who turn to spirituality for coping. Given the fact that these participants had at least a high school diploma or higher, this restriction of range regarding educational level may have affected the lack of significance found between education and spirituality.

There was no significant relationship between time since injury and spirituality. On average, the participants in this study were far along in their recovery and coping related to their TBI (14 years since injury on average). Spirituality may have a greater relationship to demographic variables when survivors of a traumatic brain injury are trying to recover in their first few years after injury. However, more research is needed to explore this.

This finding may support the notion that spirituality and recovery from a traumatic brain injury are individual journeys. As Nosek & Hughes (2001) stated, both

are journeys of discovery: both are paths toward defining oneself, how one relates to the universe, and where one is headed. Since each person's recovery is unique, unpredictable, and independent of a timeline, it can be understood that a survivor's spiritual involvement and beliefs are independent of the date of injury. Moreover, this finding could imply that regardless of time since injury, spiritual involvement and beliefs are utilized in the lives of individuals who have experienced a traumatic brain injury.

### Implications for Practice

This study provides further evidence that spirituality is related to quality of life, but for a different group of rehabilitation patients. The research findings of this study empirically validate what several practitioners have indicated. Prigatano (1991) contended that no matter what a patient's religious affiliation, the concept of God has a prodigious psychological significance for many brain-injured patients. Miller (1993) posited that God can represent many things for the person who has a brain injury, such as, a coming to grips with reality, a connecting of one's self to something beyond a limited biological existence, and an awakening to the appreciation or greater appreciation to life. Shafranske and Gorsuch (1984) indicated that spirituality and finding meaning and purpose could provide a deep sense of belonging, connectedness, and openness to the experiences that the world presents. This is where the mental health professional may want to focus in therapy--finding meaning and purpose in clients' lives and identifying and fostering personal growth. Providing clients who have a TBI with the space to meditate and contemplate on purpose and meaning of their current situation could be very

rewarding for them. While recognizing both loss and change and the ensuing painful process, a therapist can emphasize the qualities that are still, in part or in whole, defining features of who he or she was, still is, and is becoming. Through this exploration process, the gap between the patient's premorbid and post-injury self can be partially closed, reducing the sense of self-alienation, isolation from objectification of self, and the accompanying ego-dystonic states. The therapist can focus on the survivors' strengths and ability to find meaning and purpose during times of adversity. For example, when adversity threatens to paralyze someone, metaphorically or literally, it would be beneficial to reassert control by finding a direction in which to invest meaning and purpose, a direction that lies outside the reach of external forces. When every aspiration is frustrated, a person still must seek a meaningful purpose or goal around which to organize the self. Then, even though that person may objectively be at the demand to this new state (possibly a temporary state), subjectively he or she is free. This frame of thought is consistent with the concepts introduced by Duggan and Dijkers (2001). It would behoove an individual to focus on the subjective state rather than an objective state, which in turn will enhance quality of life. Quality of life is not as influenced by what someone can or cannot do, but how he or she perceives himself or herself doing something.

Understanding the relationship between spirituality and subjective well-being could also be beneficial for therapists treating individuals with a traumatic brain injury. Subjective well-being in the context of quality of life is comprised of a wide range of distinct dimensions such as life satisfaction, positive affect, happiness, personal growth, satisfying social relationships, and autonomy (Diener, 1984; Kunzmann, Little, & Smith,

2000). Research has found that subjective well-being is a prodigious contribution in people's perception of quality of life. Further, research has proven that spirituality consistently emerges as a significant contributor of quality of life indications such as life satisfaction, happiness, and meaning in life – subjective well-being (Diener, 1984; Kim, et al., 2000; Levin & Tobin, 1995). Given these findings, addressing spirituality in therapy could help improve patients' quality of life and well-being.

Individuals who have survived a traumatic brain injury may benefit from a therapy that addresses their subjective well being - working with the patients' perception of themselves, their life roles, their spirituality, and their world. After all, the subjective aspects of life are very important, as it is desirable for people themselves to think that they are living good lives. Diener (2000) said it best; "Quality of life is democratic in that it grants to each individual the right to decide whether his or her life is worthwhile" (p. 34).

This approach could be helpful in changing negative affect and negative thinking by highlighting the importance of subjective well-being. Therapists could facilitate more efficient information processing by having them look at subjective rather than objective aspects of their quality of life. Furthermore, therapists could help patients explore their needs, goals, and wishes and whether or not these ideals are being fulfilled; the smaller the discrepancy between one's aspirations and achievements, the greater the level of quality of life (Diener, Emmons, Larsen, & Griffen, 1985). In addition, therapists could focus on positive human experiences rather than negative affect and "pathology." Multiple investigations have revealed that what makes life genuinely satisfying and meaningful, in turn, creates longer and greater levels of happiness and a better quality of

life, is the state of mind and the connection between self and values (Csikszentmihalyi, 1990).

Bennett (1987) noted that brain injury might be an opportunity for personal growth; thus, therapists may want to consider addressing this concept in their approach. Over time, persons who have experienced a brain injury may believe that some good things, if not many, have resulted from their injury. The spiritual concept of internal growth and evolving internal beliefs may be present in many individuals after a brain injury. For example, some survivors have even stated that it has helped them in life, and that they would not change what happened. In a TBI group facilitated by the primary researcher, one client stated that, although he cannot work and it takes him longer to accomplish tasks that were previously easy to him, he believes that he has a greater connection to the world. This same client added that he has become closer to his higher power, his family, and himself.

As there are many advantages to discussing spirituality in therapy, any undue existential pressure or pressure to explore spirituality should not be placed on the person receiving counseling or psychotherapy services. Helping someone find meaning and purpose in adversity and in positive aspects of life can be extraordinarily therapeutic. It is important to note, however, that in helping the patient formulate a sense of meaning in life and of meaning in adversity, it is important for the therapist to avoid imbuing his or her own values and goals on the patient, serving instead as a sounding board for, and facilitator of, the patient's creative self (Miller, 1993). The extraction of existential meaning from adversity is something that should be ultimately discovered by the patient, not imposed upon him by the therapist. Such actions or discussions are usually unconsciously motivated by a need to reinforce the therapist's own meaning system, not the patient's. Miller (1993) stated that helping individuals seek existential meaning could be part of a therapeutic rescue fantasy in which the patient is helped by being given the magical gift of supreme positive outlooks on life. Some may argue that this concept of spirituality is all right as long as it does not do harm to the patient. Once again, it is the therapists' duty to abstain, to the best of their ability, from imposing values or beliefs onto the individuals seeking services. But, human beings do crave meaning and purpose, and if a spiritual or religious orientation can nourish the patient in his or her journey back to optimal functioning, then the therapeutic role must stretch to include some measure of guidance in the affairs of the numinous. Helping clients to connect to a spiritual part of themselves, or to a community of persons who share a spiritual tradition, may provide additional resources for coping and a reconnection to other people if they are feeling isolated, alone, or disconnected.

A major part of the human experience may be neglected by ignoring the spiritual frame of reference of the person recovering from a traumatic brain injury. "Ignorance of spiritual constructs and experience predispose a therapist to misjudge, misinterpret, mismanage, or neglect important segments of a client's life which may impact significantly on adjustment and growth" (Bergin & Payne, 1991, p. 201). Therefore, psychotherapists and rehabilitation specialists could meet the needs of clients by being open and sensitive to spiritual issues.

There is another important matter to mention when addressing the importance of exploring the concept of spirituality in therapy. While most people embrace spirituality (Gallup Poll, 1995; Shafranske, 1996), some people may not view it as important.

Therefore, therapists should be careful not to confront or push spiritual issues in therapy if spirituality is not valued by the client. In cases where clients are ambivalent about their spirituality, therapists need to be careful not to impose their values on their clients. While spirituality was related to quality of life, this does not imply that spirituality is the only way to a better life for TBI clients. Exploring a variety of ways to enhance clients' lives will be meaningful.

### Limitations of the Study

The limitations of this study should be taken into consideration. First, the factor structure of the SIBS leaves a relatively large portion of the variance unexplained. The factor that emerged from the SIBS accounted for 54.8% of the variance in the scores, leaving 45.2% unaccounted. At the same time, factor structures that account for much variance have been viewed as statistically and clinically significant. This means that the SIBS is meaningful, just in a different way for this sample of people who have survived traumatic brain injuries. Clinicians may choose to use this factor structure to score spirituality for patients with TBIs. However, more research is needed to confirm this factor structure with other samples of people who have survived a traumatic brain injury. Second, there are limitations in the measures of this study. The present study relied on self-report data, which can be affected by influences such as social desirability of the respondent and the mood or cognitive focus of the respondent. Individuals who want to fake bad, or rather, emphasize the negative aspects of their situation can also affect the data. Given that participants completed these forms at home, there may be factors that

differentially influenced their responses (e.g., how quiet the environment was when completing the forms, the time of day they were completed, etc.).

Third, while an adequate sample size was obtained in this study, it is unclear how generalizable these findings are to other people with TBIs. Given that all of the participants had been in recovery for at least one year since their injury, it is possible that the findings might not be the same for people in the early stages of recovery (days, weeks, and/or months after the injury).

Fourth, the individuals who completed the survey may not represent the vast array of current severely injured individuals – those who were physically and/or cognitively. unable to complete the survey. Fifth, this homogeneous sample does not reflect the greater variance in the population with regard to the demographic variables ethnicity and religiosity. The majority of participants were Caucasian Christians. Thus, generalizability of the results may be limited. Sixth, the return rate for this sample was 26%. Considering that 74% did not return the surveys, there may be something unique about the 26% that did participate. It is possible that they were more spiritual, or interested in spirituality, and/or had higher qualities of living compared to those who did not to participate in this study. Therefore, generalizability of the results may be limited. Finally, it is important to keep in mind that the individuals in this sample were members of the Brain Injury Association (BIA). This association is well known for its support groups. The support system for individuals with TBI is one of the best predictors of adjustment and quality of life (Long, et al. 1998; Perlesz et al., 1999; Smith & Godfrey, 1995). Thus, the participants in this study may have higher quality of life than those who have a traumatic brain injury and are not members of the BIA.

#### Future Directions

The relationship between spirituality and quality of life for individuals with a traumatic brain injury provides an important perspective to consider when treating individuals medically and psychologically. The further study of spirituality in this population and others will provide new energy and insight into the scientific study of human beings and individual differences and similarities. Clinical research on spirituality will advance with the use of reliable measures of religious/spiritual commitments. Preliminary studies suggest that a healthy relationship to a higher power of being can orient an individual positively in the world in which he or she lives, and serve as a stable force in both challenging and tranquil times (Pargament, 1997; Belavich, 1998). Longitudinal studies are needed to better clarify issues of the role and function of spirituality in relation to quality of life over time. In addition, research is needed to explore the impact of discussing spiritual issues with patients in the rehabilitative/psychotherapy context. Further, studies should be conducted to show what impact the inclusion of spirituality in practice has on both the clients and the therapists involved.

While the findings of this study indicate that spirituality is related to quality of life for individuals who have survived a traumatic brain injury, further research is recommended to explore quality of life and spiritual issues for this patient population. For example, future research should continue to explore whether or not spiritual domains (e.g. External/Ritual, Internal/Fluid, Existential/Meditative, Humility/Personal Application), rather than spirituality as a whole, are useful in assessing the spirituality of people with traumatic brain injuries. Gender and racial differences in spirituality and quality of life could also be explored. Future studies might also consider including an additional method of data collection (e.g., interviewing, behavioral observations) to add more substance to and confirm the findings. Qualitative research could describe the participants' stories, giving the researchers rich information that could not be retrieved by using quantitative approaches.

Since the average years since injury for the participants was 14, with a range of 1 year to 36 years, the majority of this sample has possibly received extensive rehabilitation and adapted to their injury, thus being more independent and able to handle the cognitive and adaptive challenges in everyday life than those who have been injured in recent days, weeks, or months. It would be beneficial for future research to explore aspects of subjective well-being with this population to gain a greater understanding into what contributes to quality of life for them. Furthermore, it would be beneficial and interesting for research to explore quality of life and spirituality within the first few weeks, months, and years after the injury.

In sum, the study of spirituality and quality of life offers a bridge to the examination of new pathways to deepen our understanding of an individual's journey through life, particularly the complexity of a journey after a traumatic brain injury. The study of spirituality points to new and potentially fruitful directions of research. It will be important for researchers and practitioners who work with people who have survived a traumatic brain injury to explore the role that spirituality plays in their lives as well as other factors that may promote their quality of life. The exploration of spirituality and quality of life can lead to a better understanding of the patient, a greater understanding of

the patient's recovery, and an opportunity to highlight and utilize strengths within the patient that would otherwise go unnoticed.

#### Conclusions

Spirituality was related to quality of life in this sample of individuals with traumatic brain injuries. These participants viewed spirituality as a unidimensional construct/entity, which may help them reappraise their situation, find support, and gain a greater sense of control, thereby aiding in psychological adaptation. Individuals who suffered brain injuries in the frontal lobe region reported a higher quality of life than those who had non-frontal lobe injuries. In addition, people who reported less annual income were more spiritual than people who reported a higher annual income. Implications for practice include exploring clients' level of spirituality as a possible coping mechanism in their lives as well as exploring other factors that may promote their quality of life. Therapists must be aware of their own prejudices or biases with regard to spiritual issues and avoid imposing their values on their clients.

### Afterward

This study explored the relationship of spirituality with quality of life among individuals who have experienced a traumatic brain injury. It is of great importance to acknowledge and to pay tribute to the feedback of several of the participants. Although this study provided confidentiality and only requested the return of the self-report surveys, many participants contacted the primary investigator to discuss their reaction to the research project and to discuss how important the role of spirituality was in their recovery.

Of note, 32 phone calls and six letters followed participation in this study. The phone calls consisted of individuals either telling their story about the role that spirituality plays in their quality of life or a thank you for exploring such a topic. The letters were similar. Notably, two of the letters were also accompanied with books that were written by the survivors.

These actions that were made by several of the participants were not only noteworthy; they were also inspiring. The participants expressed their captivating history. They went in depth with respect to their journey, including a description of their injury and how their spiritual beliefs played a vital role in their recovery. Eminently touching, the phone calls, letters, and books were an excellent and unexpected supplement to the remarkable experience that ensued from completing a dissertation on such a fascinating topic.

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# Appendix A

# Tables 1-9

# Table 1

The Glascow Coma Scale (Teasdale & Jennet, 1974)					
Response	Points	Index of Wakefullness			
Eye Opening (E)					
None	1	Not attributable to ocular swelling			
To Pain	2	Pain stimulus is applied to chest or limbs			
To speech	3	Nonspecific response to speech or shout; does not			
		imply the patient obeys command to open eyes			
Spontaneous	4	Eyes are open, but this does not imply intact			
		awareness			
Motor Response (M)					
No response	1	Flaccid			
Extension	2	"Decerebrate;" adduction, internal rotation of			
		shoulder, and probation of the forearm			
Abnormal Flexion	3	"Decorticate," abnormal flexion, adduction of the			
		shoulder			
Withdrawal	4	Normal flexor response; withdraws from pain			
		stimulus with abduction of the shoulder			
Localized Pain	5	Pain stimulus applied to supraocular region or			
		fingertip causes limb to move to attempt to avoid it			
Obeys commands	6	Follows simple commands			

Table 1 (continued)

Response	Points	Index of Wakefullness	
Verbal Response (V	<b>(</b> )		
No response	1	(Self-explanatory)	
Incomprehensible	2	Moaning and groaning, but no recognizable words	
Inappropriate	3	Intelligible speech (e.g., shouting or swearing), but	
		no sustained or coherent conversation	
Confused	4	Patient responds to questions in a conversational	
		manner, but the responses indicate varying degrees	
		of disorientation and confusion	
Oriented	5	Normal orientation to time, place, and person	

Note: The summed Glascow Scale is equal to E + M + V (3 - 15 points)

### Table 2

Classification of Severity of Traumatic Brain Injury (Lezak, 1995, p. 755)

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## Traumatic Brain Injury

Measure	Mild	Moderate	Severe
Glasgow Coma Scale	13-15	9-12	3-8
Loss of consciousness	< 20 min.	20 min –36 hr.	> 36 hr.

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Demographics of the Participants (n = 119)

Variable	Response	N	Percent	M	SD
Age	Overall Age			42.38	14.14
Age	-	21	26.1	72.30	17.17
	19 years to 30 years	31			
	31 years to 40 years	26	21.9		
	41 years to 50 years	29	24.3		
	51 years to 60 years	16	13.4		
	61 years to 70 years	15	12.5		
	71 years to 80 years	0.0	0.0	•	
	81 years to 90 years	2	1.6		
Sex	Female	50	42.0		
	Male	69	58.0		
Marital Status	Single	48	40.3		
	Partnered/Common Law	3	2.5		
	Married	35	29.4		
	Divorced	27	22.7		
	Widowed	6	5.0		
Race	African American	10	8.4		
	Native American	3	2.5		
	Asian	0	0.0		

4

Table 3 (continued)

Variable	Response	Ν	Percent	М	SD
Race (Continued)	Hispanic	0	0.0		
	Caucasian	108	90.8		
	Other	1	.8		
Children	No	59	49.6		
	Yes	60	50.4		
People in Home	Overall People in Home			2.31	1.30
	1 person	38	31.9		•
	2 people	39	32.8		
	3 people	21	17.6		
	4 people	10	8.4		
	5 people	7	5.9		
	6 people	3	2.5		
	Omitted by participant	1	.8		
Employed	No	79	66.4		
	Yes	40	33.6		
Level of Education	Years of Education	13.70	2.82		
	Did not complete High School	6	5		
	Completed GED	12	10.1	·	

Table 3 (continued)

Variable	Response	N	Percent	M	SD
Level of Education	High School	37	31.1		
(Continued)	Some College	34	28.6		
	Bachelor's Degree	21	17.6		
	Masters Degree	8	6.7		
	Doctoral Degree	1	.8		
Annual Income	Less than \$10,000	29	24.4		
	\$10,001 to \$15,000	18	15.1		
	\$15,001 to \$20,000	11	9.2		
	\$20,001 to \$25,001	7	5.9		
	\$25,001 to \$30,000	4	3.4		
	\$30,001 to \$40,000	14	11.8		
	\$40,001 to \$50,000	8	6.7		
	\$50,001 to \$60,000	10	8.4		
	\$70,001 to \$80,000	5	4.2		
	\$90,001 or more	5	4.2		
Religion	Overall Christian	109	91.6		
	Overall Non-Christian	10	8.4		
	None	5	4.2		

# Table 3 (continued)

Variable	Response	N	Percent M SD
Religion (Continued)	Agnostic	0	0
	Atheist	0	0
	Baptist	34	28.6
	Buddhist	0	0
	Catholic	25	21.0
	Episcopalian	0	0
	Hindu	0	0
	Jehovah's Witness	0	0
	Jewish	5	4.2
	Lutheran	3	2.5
	Methodist	12	10.1
	Mormon	0	0
	Muslim	0	0
	Nondenominational	11	9.2
	Presbyterian	5	4.2
	Unitarian	4	3.4
	None	5	4.2
	Other	15	12.6

# Table 3 (continued)

Variable	Response	N	Percent	М	SD
Spirituality Change	Overall Change			6.60	3.78
	Did not change at all (0)	18	15.1		
	Changed very little (1-3)	11	9.2		
	Changed somewhat (4-6)	15	12.6		
	Changed significantly (7-9)	30	25.2		
	Changed a great deal (10)	45	37.8		
Spirituality Affected	Overall Affected			7.84	2.51
	Less Spiritual (0-4)	6	4.9		
	Stayed about the same (5)	23	19.3		
	More spiritual (6-10)	90	75.6		
TBI Effect Physical Functioning	Overall Functioning	119	100	6.58	2.94
runctioning	Did not change at all (0)	5	4.2		
	Changed very little (1-3)	17	14.3		
	Changed somewhat (4-6)	30	25.2		
	Changed significantly (7-9)	39	32.8		
	Changed a great deal (10)	28	23.5		
TBI Effect Ability To Work	Overall Ability to Work			7.08	3.46
	Did not change at all (0)	8	6.7		

Table 3 (continued)

Variable	Response	N	Percent	M	SD
TBI Effect Ability To Work	Changed very little (1-3)	14	11.8		
(continued)	Changed somewhat (4-6)	21	17.6		
	Changed significantly (7-9)	25	21		
	Changed a great deal (10)	51	42.9		
TBI Effect	Overall Effect on Relations			5.69	3.56
Relationships	Did not change at all (0)	16	13.4		
	Changed very little (1-3)	17	14.3		
	Changed somewhat (4-6)	33	27.8		
	Changed significantly (7-9)	23	19.3		
	Changed a great deal (10)	30	25.2		
TBI Effect Ability	Overall Effect on Learning			6.10	3.44
To Learn	Did not change at all (0)	16	13.4		
	Changed very little (1-3)	17	14.2		
	Changed somewhat (4-6)	23	19.4		
	Changed significantly (7-9)	37	31		·
	Changed a great deal (10)	26	21.8		
TBI Effect Mood	Overall Effect on Mood			6.18	3.49
	Did not change at all (0)	14	11.8		
	Changed very little (1-3)	20	16.8		

# Table 3 (continued)

Variable	Response	N	Percent	M	SD
TBI Effect Moods	Changed somewhat (4-6)	19	16		
(continued)	Changed significantly (7-9)	33	27.7		
	Changed a great deal (10)	33	27.7		
TBI Effect How You feel about	Overall Feelings Toward Sel	f		6.37	3.55
Yourself	Did not change at all (0)	14	11.8		
	Changed very little (1-3)	12	10.1		
	Changed somewhat (4-6)	29	24.4		
	Changed significantly (7-9)	24	20.2		
	Changed a great deal (10)	40	33.6		
Site of Injury	Frontal Lobe	41	34.5		
	Non-Frontal Lobe	77	64.7		
	Occipital Lobe	30	25.2		
	Right Parietal Lobe	26	21.8		
	Left Parietal Lobe	31	26.1		
	Right Temporal Lobe	16	13.4		
	Left Temporal Lobe	21	17.6		
	Other	29	24.4		
	Omitted by participant	1	.8	·····	

# Table 3 (continued)

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.

Variable	Response	N	Percent	<u>M</u>	SD
Months Since Injury	Overall Months Since Injury			167.3	18 106.32
	12 months to 36 months	7	6.4		
	37 months to 72 months	24	19.8		
	73 months to 108 months	18	15.1		
	109 months to 144 months	8	6.6		
	145 months to 180 months	12	10		
	181 months to 216 months	10	8.3		
·	217 months to 252 months	13	10.9		
	253 months to 288 months	10	8.3		
	289 months to 324 months	5	4.2		
	324 months to 433 months	12	10.1		
Ability to Care	Overall Ability to Care4Self			7.50	3.20
For Self	Dependent (0)	10	8.4		
	Almost dependent (1-3)	10	8.4		
	Somewhat independent (4-6)	) 6	5		
	Almost independent (7-9)	45	37.8		
	Independent (10)	48	40.3		
Chronic Pain	No	55	46.2		
	Yes	64	53.8		

4

Items	Loadings on Factor 1
11. My spiritual beliefs continue to evolve.	.887
7. A spiritual force influences the events in my life.	.824
14. My spiritual life fulfills me in ways that material	.805
possessions do not.	
17. I have a personal relationship with a power greater	.793
than myself.	
19. Spiritual activities help me draw closer to a power	.748
greater than myself.	
10. Participating in spiritual activities helps me forgive	.740
other people.	
8. My life has a purpose.	.726
24. During the last WEEK, I prayed (check one)	.657
10 or more times.         7-9 times.         4-6 times.         1-3 times.         0 times.	
12. I believe there is a power greater than myself.	.648
6. Some experiences can be understood only through	.638
one's spiritual beliefs.	
2. I can find meaning in times of hardship.	.625

Factor 1 = Spirituality

Total Variance Explained by Each Component for the Spiritual Involvement and Beliefs

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Scale Scores
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	<u>Initial Ei</u>	genvalues			
Component	Total %	of Variance	<u> </u>	<u> </u>	 
1	6.027	54.792			
2	1.167	10.610			
3	.810	7.366			
4	.721	6.550			
5	.543	4.938			
6	.453	4.118			
7	.371	3.377			
8	.322	2.929			
9	.261	2.370			
10	.166	1.513			
<u>11</u>	.158	1.438	<u> </u>	—	 <u> </u>

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# Visual Representation of Differences in the SIBS Factors Between the Hatch et al. (1998)

Study and the Current Study

Fac	ctors		
Hatch et al. (1998)	Wertheimer (2002)		
(F1) External/Ritual	(F1) Spirituality		
items: 3, 5, 6, 7, 9, 10, 12, 14,	items: 2, 6, 7, 8, 10, 11, 12, 14,		
17, 19, 22, 24, and 26	17, 19, and 24		
(F2) Internal/Fluid			
items: 1, 2, 5, 6, 8, 11, 13, 14,	· · ·		
15, 16, and 19			
(F3) Existential Meditative			
items: 2, 8, 9, 16, 24, 25, and 26			
(F4) Humility/ Personal Application			
items: 20, 21, 22, and 23	•		

See Appendix B, p. 163 for the SIBS instrument.

Table 7

<u>Contenation in</u>	Tatrix of Den	lographic	s, rotar	Quality of	Life Score,	and Spin	iuanty r	actor
Variable	QOLscore	Spirit	Age	Pnhome	Educom	Income	Tbida	Care
QOLscore	1.00							
Spirit	.37***	1.00						
Age	.13	06	1.00					
Pnhome	12	08	31**	1.00				
Educom	.12	15	.10	08	1.00			
Income	.11	20*	04	.31**	.30**	1.00		
Tbida	.08	.04	.42**	42**	.01	23**	1.00	
Care	13	11	.01	18*	.01	.13	.12	1.00
* p < .05	<b>**</b> p < .01	*** p	<.001					

Key for the Quality of Life score, subscale of the SIBS, and Demographic Variables:

QOLscore = Quality of Life score	Pnhome = People living in home
Spirit = Spirituality	Educom = education completed
Income = Annual Income	Tbida = Traumatic Brain Injury

DateCare4self = Ability to Care for oneself

A Summary of Means, Standard Deviations, and Ranges of the Total Quality of Life

Score and of the Total Score for Each Domain (Importance x Satisfaction)

SD Variable Μ Score Range QOLTOT 32.56 30.09 -96 - 96 Domain 1: Health -6 - 6 .81 3.76 Domain 2: Self-Esteem -6 - 6 2.35 3.36 Domain 3: Goals and Values 2.57 2.60 -6 - 6 -6 - 6 2.93 Domain 4: Money .30 Domain 5: Work -6 - 6 .53 3.64 -6 - 6 Domain 6: Play 1.57 3.18 -6 - 6 Domain 7: Learning 1.29 3.02 Domain 8: Creativity 1.85 2.92 -6 - 6 -6 - 6 Domain 9: Helping 2.11 2.82 -6 - 6 Domain 10: Love 1.69 4.14 -6 - 6 Domain 11: Friends 2.76 3.09 -6 - 6 Domain 12: Children 3.04 2.48 Domain 13: Relatives 3.62 2.90 -6 - 6 -6 - 6 2.77 Domain 14: Home 3.22 -6 - 6 Domain 15: Neighborhood 2.79 2.90 2.71 2.52 -6 - 6 Domain 16: Community

Table 9

Correlation Matrix for	or the Domains	s within the Quality	y of Life Inventory	
Variable	D1Health	D2Self-Esteem	D3Goals/Values	D4Money
D1Health	1.00			
D2Self-Esteem	.68**	1.00		
D3Goals/Values	.41**	.52**	1.00	
D4Money	.44**	.32**	.36**	1.00
D5Work	.34**	.43**	.37**	.40**
D6Play	.47**	.48**	.51**	.43**
D7Learning	.54**	.46**	.40**	.49**
D8Creativity	.35**	.35**	.27**	.14
D9Helping	.50**	.41**	.33**	.26**
D10 Love	.34**	.18	.18	.37**
D11Friends	.24**	.12	.24**	.17
D12Children	.05	.03	03	.20**
D13Relatives	.18	.18*	.32**	.29**
D14Home	.19*	.22*	.29**	.53**
D15Neighborhood	.21*	.38**	.42**	.30**
D16Community	.26**	.24**	.33**	.34**

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Table 9 (continued)

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Variable	D5Work	D6Play	D7Learning	D8Creativity
D5Work	1.00			
D6Play	.37**	1.00		
D7Learning	.41**	.49**	1.00	
D8Creativity	.04	.39**	.39**	1.00
D9Helping	.37**	.44**	.51**	.47**
D10 Love	.44**	.42**	.35**	.09
D11Friends	.30**	.53**	.32**	.30**
D12Children	.17	.20*	.25**	.17
D13Relatives	.38**	.39**	.41**	.21*
D14Home	.32**	.38**	.18	.12
D15Neighborhood	.34**	.37**	.16	.20*
D16Community	.17	.38**	.23*	.14
Variable	D9Helping	D10Love	D11Friends	D12Children
D9Helping	1.00			
D10 Love	.40**	1.00		
D11Friends	.37**	.48**	1.00	
D12Children	.27**	.43**	.32**	1.00
D13Relatives	.35**	.31**	.36**	.27**
D14Home	.11	.38**	.36**	.34**
D15Neighborhood	.19*	.31**	.45**	.20*
D16Community	.16	.24**	.40**	.26**

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Table 9 (continued)

Variable	D13Relatives	D14Home	D15Neighborhood	D16Community
D13Relatives	1.00			
D14Home	.20*	1.00		
D15Neighborhood	.22*	.43**	1.00	
<u>D16Community</u> * p < .05 ** p <	.21*	.52**	.64**	1.00

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Appendix B

Figures 1-3

TI	ME
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EXPECTATIONS <----> ACHIEVEMENTS

Goals Values Standards Desires Aspirations Wants/needs, etc.

Performances Possessions Relationships Accomplishments Characteristics, etc.

### **EVALUATIONS**

Life satisfaction Happiness Morale, zest for life Well-being Depression Self-esteem Positive/negative affect

Figure 1. General Quality of Life Model: Used in the "Subjective Approach" (Dijkers,

1997; as cited in Duggan, & Dijkers, 2001)

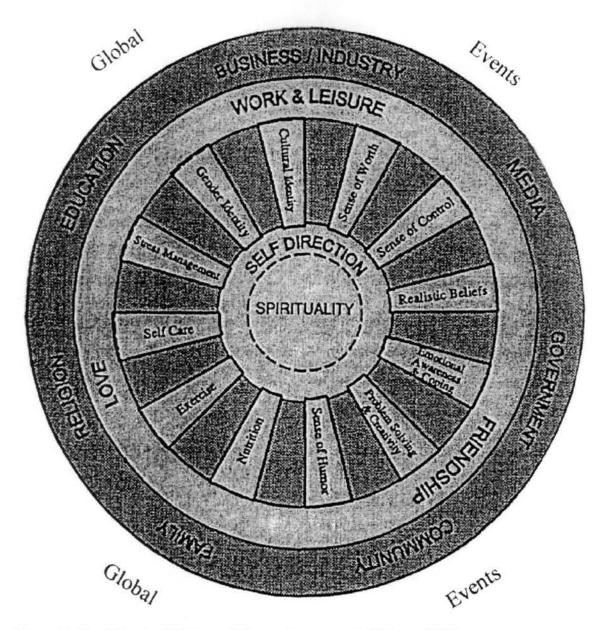


Figure 2. The Wheel of Wellness (Myers, Sweeney, & Witmer, 2000)

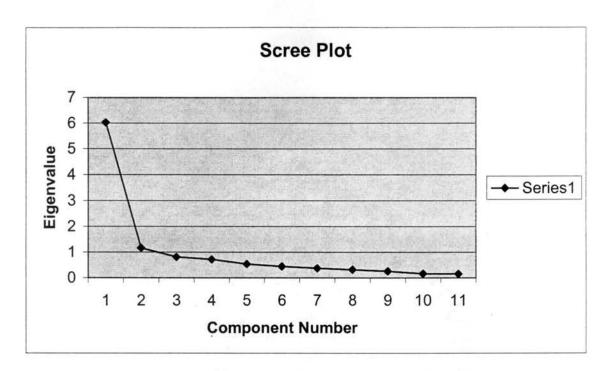


Figure 3. Scree Plot for the SIBS Principle Component Analysis

# Appendix C

# Demographic Form

Directions: Please answer each question by filling in the blank, checking the blank, or circling the number that best describes you.

1) How old are you?	Age	2) Sex: _	Female	Male
c) d) e)	Partnered/Common Law	-	<ul> <li>c) Asian/Asian/Asiand) Hispanic/2</li> <li>e) White, not</li> </ul>	merican/Black Indian/Native American an American Latino(a)
5) Do you have any childr	en? Yes How ma No	any?		
6) How many people live	in your home, including	yourself? _67	89	_1011 12+
sister(s)	fatherstepn grandmothergrand other familyfrien	nother dfather	stepfather aunt(s)	uncle(s)
· · · · ·	No			
<ul> <li>9) What is your present or</li> <li>10a) What is the highest le did not com GED, or eq high school</li> </ul>	evel of education complet plete high school uivalent	ted? some bach mast	university educat elor's degree er's degree oral degree	ion; number of years
10 = 2 years of high 11 = 3 years of high 12 = 4 years of high	school $14 = 2$ school $15 = 3$	years of col years of col years of col year of a M	lege or vo-tech lege or vo-tech aster's degree	19=1yr Doctoral 20=2yr Doctoral 21=3yr Doctoral 22=4yr Doctoral Other:
11) Your annual househol a) Less than 10,000 b) 10,001 to 15,000 c) 15,001 to 20,000	d) 20,001 to 25,00	$\frac{100}{100} = \frac{g}{h}$	40,001 to 50,000 50,001 to 60,000 61,001 to 70,000	j) 70,001 to 80,000 k) 80,001 to 90,000 l) 90,001 or more
12) Religious Affiliation: Agnostic Atheist Baptist Buddhist Catholic	Episcopalian Hindu Jehovah's Witness Jewish Lutheran	Mo: Mu: Nor	thodist rmon slim n-Denominational sbyterian	Unitarian None Other:

#### Demographic Sheet

13) To what extent have your spiritual beliefs changed since your brain injury? 0 . . . . 1 . . . . 2 . . . . 3 . . . . 4 . . . . 5 . . . . 6 . . . . 7 . . . . 8 . . . . 9 . . . . 10 not at a great all deal 14) In what way was your spirituality affected by your traumatic brain injury? 0 . . . . 1 . . . . 2 . . . . 3 . . . . 4 . . . . 5 . . . . 6 . . . . 7 . . . . 8 . . . . 9 . . . . 10 Less More Stayed Spiritual the Same Spiritual 15) To what extent does your traumatic brain injury effect your physical functioning? 0 . . . . 1. . . . 2. . . . 3. . . . 4. . . . 5. . . . 6. . . . 7. . . . 8. . . . 9. . . . 10 not at a great all deal 16) To what extent does your traumatic brain injury effect your ability to work? 0 . . . . 1 . . . . 2 . . . . 3 . . . . 4 . . . . 5 . . . . 6 . . . . 7 . . . . 8 . . . . 9 . . . . 10 not at a great all deal 17) To what extent does your traumatic brain injury effect your relationships with others? 0 . . . . 1 . . . . 2 . . . . 3 . . . . 4 . . . . 5 . . . . 6 . . . . 7 . . . . 8 . . . . 9 . . . . 10 not at a great all deal 18) To what extent does your traumatic brain injury effect your ability to learn new information, knowledge, or skills? 0.....1.....2.....3.....4.....5.....6.....7.....8.....9.....10 not at a great deal all 19) To what extent does your traumatic brain injury effect your moods? 0.....1.....2.....3.....4.....5.....6.....7.....8.....9.....10 a great not at deal all 20) To what extent does your traumatic brain injury effect how you feel about yourself? 0.....1.....2.....3.....4.....5.....6.....7.....8.....9.....10 a great not at deal all

#### **Demographic Sheet**

21) Where was the site of the traumatic brain injury? (Check all that apply)

- \_\_\_\_\_ Front of head (Frontal Lobe)
- \_\_\_\_\_ Back of head (Occipital Lobe)
- Upper Right side of head (Right Parietal Lobe)
- Upper Left side of head (Left Parietal Lobe)
- Lower Right side of head (Right Temporal Lobe)
- Lower Left side of head (Left Temporal Lobe)
- \_\_\_\_\_ Other: \_\_\_\_\_\_

22) When did your brain injury occur (month/year)?

23) To what degree are you able to take care of yourself? (Circle the number that best describes you.)

 $0 \dots 1 \dots 2 \dots 3 \dots 4 \dots 5 \dots 6 \dots 7 \dots 8 \dots 9 \dots 10$  dependent independent

24) Do you have chronic pain? \_\_\_\_ Yes (if yes check all that apply) \_\_\_\_ No

head	neck	shoulder(s)	upper arm(s)	elbow(s)
lower arm(s	s)wrist(s)	hand(s)	knuckle(s)	finger(s)
upper back	mid back	lower back	chest	stomach
hip(s)	groin	upper leg(s)	knee(s)	lower leg(s)
ankle(s)	foot (feet)	toes	other:	<u></u>

25) For each of these locations of pain, please rate the intensity of your pain on a scale from 0 to 10, "O" being no pain and "10" being severe, excruciating pain.

0.....1....2.....3.....4.....5.....6.....7.....8.....9.....10 no pain severe pain

head	neck	shoulder(s)	upper arm(s)	elbow(s)
lower arm(s	)wrist(s)	hand(s)	knuckle(s)	finger(s)
upper back	mid back	lower back	chest	stomach
hip(s)	groin	upper leg(s)	knee(s)	lower leg(s)
ankle(s)	foot (feet)	toes	other:	

## Appendix D

### Instruments

## **Quality of Life Inventory**

### Michael Frisch, Ph.D.

A copy of the instrument, Quality of Life Inventory, can be retrieved from "NCS Assessments." The company is located at P.O. Box 1416, Minneapolis, MN 55440. The company can also be contacted by the phone or the internet (1-800-627-7271, <u>http://assessments.ncspearson.com</u>, respectively).

## The Spiritual Involvement and Beliefs Scale

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Robert Hatch, MD, MPH; Mary Ann Burg, MSW, Ph.D.; Debra Naberhaus; and Linda Hellmich, Ph.D.

# Please answer the following questions by checking your response.

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1.	In the future, science will be able to explain everything.					
2.	I can find meaning in times of hardship.	<u> </u>		<u></u>		
3.	A person can be fulfilled without pursuing an active spiritual life.		<u> </u>			
4.	I am thankful for all that has happened to me.				<u> </u>	
5.	Spiritual activities have not helped me become closer to other people.					
6.	Some experiences can be understood only through one's spiritual beliefs.					·
7.	A spiritual force influences the events in my life.		<u></u>			
8.	My life has a purpose.	<b>_</b>		<del></del>		
9.	Prayers do not really change what happens.					
10.	Participating in spiritual activities helps me forgive other people.					
11.	My spiritual beliefs continue to evolve.	<u></u>				
12.	I believe there is a power greater than myself.				<del>-</del>	
13.	I probably will not reexamine my spiritual beliefs.					
14.	My spiritual life fulfills me in ways that material possessions do not.					<u></u>
15.	Spiritual activities have not helped me develop my identity.					
16.	Meditation does not help me feel more in touch with my inner spirit.					

Spiritual Involvement and Belief Scale

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
17.	I have a personal relationship with a power greater than myself.					
18.	I have felt pressured to accept spiritual beliefs that I do not agree with.					
19.	Spiritual activities help me draw closer to a power greater than myself.					
Ple	ase indicate how often you do the follo	wing.				
		Always	Usually	Sometime	s Rarely	y Never
20.	When I wrong someone, I make an effort to apologize.					
21.	When I am ashamed of something I have done, I tell someone about it.				• 	
22.	I solve my problems without using spiritual resources.					· ·
<b></b>	Levamine my actions to see if they					

- 23. I examine my actions to see if they reflect my values.
- 24. During the last WEEK, I prayed ...(check one)

 10 or more times.
 7-9 times.
4-6 times.
 1-3 times.
0 times.

25. During the last WEEK, I meditated ... (check one)

 10 or more times.
7-9 times.
 4-6 times.
 1-3 times.
 0 times

26. Last MONTH, I participated in spiritual activities with at least one other person...(check one)

 more than 15 times.

 11-15 times.

 6-10 times.

 1-5 times.

 0 times

### Appendix E

#### Cover Letter

#### Dear BIA Member,

I am a member on the Board of Directors of the Brain Injury Association of Oklahoma. I would like to invite you to participate in a study exploring quality of life after a brain injury and to what extent spirituality plays a role. Participation would involve completing three questionnaires which typically takes about 30 - 45 minutes to complete. All of the information you share is confidential. We feel that this information could provide therapists and other rehabilitation specialists valuable insight into how to improve the treatment of individuals who have experienced a brain injury.

The Board of Directors of the Brain Injury Association of Oklahoma as well as the Internal Review Board at Oklahoma State University have approved this research. We would like to encourage your participation, but I want to emphasize that participation is clearly voluntary. Thank you so much for your help.

Sincerely,

Jeffrey Wertheimer, M.A. Board of Directors of BIAOK

### Appendix F

### Informed Consent Form

You have been invited to participate in a research study which looks at the quality of life after a traumatic brain injury and to what extent spirituality plays a role. This research study has been approved by the Board of Directors of the Brain Injury Association of Oklahoma, Missouri, and Alabama. Participation in this study would involve completing an information sheet and two questionnaires. You will not write your name anywhere on any of the forms. This consent form will be separated from the other questionnaires, so there is no way to connect your identity to your responses on the questionnaires.

Completing these questionnaires will typically take about 30 - 45 minutes of your time.

Possible benefits of participating in this study include an increased awareness and understanding of how you perceive your quality of life after a TBI and how spirituality plays a part in it. We hope the results of this study will provide important information on this topic, help heighten awareness about the lives of individuals with a TBI, and improve treatments for individuals with TBI. There are no foreseeable risks of participating in this study. However, some individuals may view certain questions as personal and sensitive in nature.

Your participation is completely voluntary. There is no penalty for refusal to participate, and you are free to withdraw your consent and participation in the project at any time without penalty.

All of the information you provide is strictly confidential. This consent form and the questionnaires will be mailed back to the researcher to ensure the privacy of your responses. Since you are not writing your name anywhere on any of the forms in the research packet, there is no way to connect your identity to responses on the questionnaire.

# If you choose to participate in this study, please sign your name and date at the bottom of the page.

If you have any questions about this study, you can contact the researcher of this study, Jeff Wertheimer, M.A., Carrie Winterowd, Ph.D., School of Applied Health and Educational Psychology, 434 Willard Hall, Oklahoma State University, at (405) 744 – 6980; Charlotte Bowen, the executive director of the Brain Injury Association of Oklahoma at 1-800-765-6809; or Sharon Bacher, IRB Executive Secretary, 202 Whitehurst Oklahoma State University at (405) 744-5700. Thank you for your interest and help with this project. We genuinely appreciate your participation in this study.

# I hereby consent to participate in this study. I have read and fully understand the consent form. I sign freely and voluntarily.

Signed:

Date: \_\_\_\_\_

#### Appendix G

Institutional Review Board Approval

### Oklahoma State University Institutional Review Board

Protocol Expires: 2/24/03

Date: Monday, February 25, 2002

IRB Application No ED0275

Proposal Title: QUALITY OF LIFE AFTER A TRAUMATIC BRAIN INJURY: THE ROLE OF SPIRITUALITY

Principal Investigator(s):

Jeffrey Wertheimer 1705 N. Manning Stillwater, OK 74075 Carrie Winterowd 434 Willard Stillwater, OK 74078

Reviewed and Processed as: Expedited

Approval Status Recommended by Reviewer(s): Approved

Dear PI :

Your IRB application referenced above has been approved for one calendar year. Please make note of the expiration date indicated above. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46.

As Principal Investigator, it is your responsibility to do the following:

- 1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be submitted with the appropriate signatures for IRB approval.
- 2. Submit a request for continuation if the study extends beyond the approval period of one calendar year. This continuation must receive IRB review and approval before the research can continue.
- 3. Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of this research; and
- 4. Notify the IRB office in writing when your research project is complete.

Please note that approved projects are subject to monitoring by the IRB. If you have questions about the IRB procedures or need any assistance from the Board, please contact Sharon Bacher, the Executive Secretary to the IRB, in 203 Whitehurst (phone: 405-744-5700, sbacher@okstate.edu).

Sincerely,

Carol Olson, Chair Institutional Review Board

# VITA2

### Jeffrey C. Wertheimer

#### Candidate for the Degree of

#### Doctor of Philosophy

# Dissertation: QUALITY OF LIFE AFTER A TRAUMATIC BRAIN INJURY: THE ROLE OF SPIRITUALITY

### Major Field: Educational Psychology

#### Biographical:

- Personal Data: Born in Boston, Massachusetts, on January 20, 1975, the son of Charles and Nancy Wertheimer.
- Education: Graduated from Houston High School, Germantown, Tennessee in May 1993; received Bachelor of Arts degree from Miami University, Oxford, Ohio in 1997; received Master of Arts from West Virginia University, Morgantown, West Virginia in 1999; Completed the requirements for the Doctor of Philosophy Degree with a major in Educational Psychology: Counseling Psychology in August, 2003.
- Experience: Currently completing my internship at Ann Arbor's VA Health System with an emphasis in neuropsychology and psychotherapy. Worked in various hospitals conducting neuropsychological evaluations and providing psychotherapy for individuals, couples, families, and groups. I have also provided counseling services in a variety of other settings, including community agencies, medical clinics, crisis centers, homes, a juvenile detention facility, and a federal correctional institute. I have been an assistant director of a counseling psychology clinic and a learning center, and I have supervised several masters' level counseling students, have participated in teaching a few courses, have participated in research pertaining to spirituality, attachment and anger, the comorbidity of schizophrenia and obsessive-compulsive disorder, and traumatic brain injury. In addition, I have presented outreach programs to the community.

- Professional Memberships: International Neuropsychology Society; Brain Injury Association; American Psychological Association (Division 36 Psychology of Religion; Division 17 – Counseling Psychology; Division 40 – Neuropsychology); American Counseling Association.
- Awards: Research Comprehensive Exams for the Doctoral Degree Passed with Honors, Oklahoma State University, Stillwater, Oklahoma, 2001; Outstanding Leadership in Counseling Psychology, West Virginia University, Morgantown, West Virginia 1999. Outstanding Leadership in Gerontology Miami University, Oxford, Ohio, 1997; Outstanding Senior Award, Miami University, Oxford, Ohio, 1996. Scholarship and Leadership Award: Miami University, Oxford, Ohio, 1996.