ADJUSTMENT OF ADULTS WITH TRAUMATIC BRAIN INJURY: A QUALITATIVE INQUIRY

By

ALICE DIANE SCHARF-LOCASCIO

A DISSERTATION PRESENTED TO THE GRADUATE SCHOOL IN THE COLLEGE OF EDUCATION OF THE UNIVERSITY OF FLORIDA IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

UNIVERSITY OF FLORIDA

2001
ACKNOWLEDGMENTS

I would like to acknowledge all survivors of traumatic brain injury who courageously embrace the challenges of adjustment and survival. I thank in particular the participants in this study—Teresa Lynn, Bernie, Taz, Lex, and Shelley—who provided much valuable information and inspiration for me to continue this study.

I am indebted to many friends and family members who provided encouragement and faith to help me persevere through this process. To my husband, Paul, gratitude in return for being so giving and supportive is not enough. To Shannon, my daughter-to-be, someday I will thank you for giving me the incentive and drive to complete this project.

I am also indebted to those who have taught me so much and served on my committee. I appreciate the guidance and support of Mary Howard-Hamilton, Rob Sherman, and Ron Spitznagel in conceptualizing and developing; and I thank them for supporting me through this project. I also appreciate Harry Daniels for agreeing to be a part of this project late in the process and Peter Sherrard for helping me to keep my focus.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgments</td>
<td>ii</td>
<td></td>
</tr>
<tr>
<td>Abstract</td>
<td>vi</td>
<td></td>
</tr>
<tr>
<td><strong>Chapters</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 INTRODUCTION</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Purpose of the Study</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Summary</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>2 REVIEW OF LITERATURE</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Disability</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Psychosocial Adjustment to Disability</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>40</td>
<td></td>
</tr>
<tr>
<td>Policies and Legislation</td>
<td>44</td>
<td></td>
</tr>
<tr>
<td>Traumatic Brain Injury</td>
<td>53</td>
<td></td>
</tr>
<tr>
<td>Summary</td>
<td>71</td>
<td></td>
</tr>
<tr>
<td>3 METHODOLOGY</td>
<td>73</td>
<td></td>
</tr>
<tr>
<td>Research Questions</td>
<td>75</td>
<td></td>
</tr>
<tr>
<td>Purpose</td>
<td>77</td>
<td></td>
</tr>
<tr>
<td>Problem</td>
<td>80</td>
<td></td>
</tr>
<tr>
<td>Research Design</td>
<td>82</td>
<td></td>
</tr>
<tr>
<td>Participants</td>
<td>83</td>
<td></td>
</tr>
<tr>
<td>Data Collection and Analysis</td>
<td>85</td>
<td></td>
</tr>
<tr>
<td>Summary</td>
<td>87</td>
<td></td>
</tr>
<tr>
<td>4 CASE STUDIES AND CONTRACTS</td>
<td>89</td>
<td></td>
</tr>
<tr>
<td>Case Study 1: Teresa Lynn</td>
<td>90</td>
<td></td>
</tr>
<tr>
<td>Case Study 2: Bernie</td>
<td>97</td>
<td></td>
</tr>
<tr>
<td>Case Study 3: Taz</td>
<td>102</td>
<td></td>
</tr>
</tbody>
</table>
Abstract of Dissertation Presented to the Graduate School
Of the University of Florida in Partial Fulfillment of the
Requirements of the Degree of Doctor of Philosophy

ADJUSTMENT OF ADULTS WITH TRAUMATIC BRAIN INJURY:
A QUALITATIVE INQUIRY

By

Alice Diane Scharf-Locascio

August 2001

Chairperson: Mary Howard-Hamilton, Ed.D.
Major Department: Counselor Education

The literature in traumatic brain injury rehabilitation has grown
substantially over the past 25 years as survival rates have dramatically increased
due to advancements in neuro-surgical medicine. The bulk of this literature
addresses various psychosocial problems from the perspectives of those who
treat and support the survivors of traumatic brain injury. In addition, extensive
literature exists attempting to present relationships and predict rehabilitation
outcomes for survivors of traumatic brain injury. In recent years, conceptualizing
the meaning of disability has shifted from viewing deficits as being intrinsic within
the individual to viewing the deficits as being environmental. Further,
rehabilitation ethics mandate a consumerism approach, one that includes the
client goals in treatment planning exercises. Achieving compliance with these
shifts in rehabilitation necessitates that rehabilitation professionals understand
adjustment of survivors of traumatic brain injury phenomenologically.
This study examined adjustment and rehabilitation from the perspectives of adult survivors of traumatic brain injury. Qualitative case study techniques were used to ascertain the viewpoints of three males and two females about their adjustment to traumatic brain injury. Participation criteria for this study included that the individuals had to be between 20 and 50 years old; they must have incurred a traumatic brain injury; they must have participated in rehabilitation; and they must have been aware of their adjustment issues for participation in this study. The data were collected by interviewing and audio-recording the five participants and then the information was transcribed. From the transcriptions, case studies were constructed and then analyzed using the constant comparative method to determine themes and constructs to satisfy the first purpose of this study. The derived constructs were compared and contrasted with three theories of adjustment to disability and traumatic brain injury to satisfy the second purpose of this study. Finally, the implications from this study and recommendations for future research were presented.
CHAPTER 1
INTRODUCTION

Possibilities are more important than what already exists, and knowledge of the latter counts only in its bearing upon possibilities.

(Dewey, 1959, p. 119)

Though the above quote was meant for applications in education philosophy, it also applies to rehabilitation philosophy. The quote by Dewey is introduced as a means to encourage readers to accept the possibility that individuals who become brain injured might achieve far more than expected of them and more than was predicted for them after becoming injured. The reality of this happening may challenge traditional paradigms that serve to guide rehabilitation and medical personnel in providing optimum care for patients and clients. These paradigms may unintentionally preclude client potential by imposing confining and limiting parameters.

Rehabilitation personnel are charged with facilitating attainment of treatment goals of individuals with an acquired disability. Ideally, clients give their input and proceed through a rehabilitation program with targeted goals outlined by the rehabilitation team to completion and satisfaction. In reality, treatment goals are most often pre-established and aligned with existing philosophies and paradigms that are then adjusted and implemented in compliance with funding sources. Rehabilitation staff and personnel are
trained accordingly, providing guidelines and expectations for patients and families. Should clients decide upon goals that do not “fit” the philosophies and theories endorsed by the treatment paradigm, the patient is viewed as noncompliant, unaware, or in denial (Hill, 1999). As such, competing realities exist. One reality is that of the survivors who are recipients of and experts on the transpired trauma, as they experienced everything first-hand. The polar reality is that of the observers (Crisp, 1993; Wright, 1983; Yuker, 1994). The observers are all others including family and rehabilitation treatment providers as they experienced second-hand the sequella of the imposed tragedy or accident (Crisp, 1993; Wright, 1983).

The shock of trauma, sudden illness, or accident affects survivors in such a way that they need the help of observers such as rescue and medical professionals in order to survive the acute stages (Livneh & Antonak, 1997). At this point, survivors or observers of the accident communicate their version of events. As helping professionals acquire this information, they begin forming a reality of what happened to the victims in order to assess, diagnose, and deliver services deemed appropriate for the survivor (Rubin & Roessler, 1995).

Millions of individuals acquire various illnesses and disabilities every year according to Social Security Administration (19998) statistics. These millions of individuals have their personal developments disrupted by the acquired illness and disability. They are forced to incorporate into their inevitably continuing development the impact of their new disabilities in accordance with financial constraints imposed by funding sources such as
insurance plans, government assistance, or client resources (Prigatano, 1999). Individuals with acquired disabilities are presented with consequential choices of avenues to pursue in efforts to adjust to the new disability. Committing to these choices and life goals inadvertently defines different aspects of a developing identity (Erikson, 1963, 1982; McAdams, 1993). Likewise, the rehabilitation philosophy adopted and implemented by rehabilitation specialists influences the decisions made by survivors and their families (Olkin, 1999; Prigatano, 1999).

Shaping identity is significant enough without incorporating the variable of an incurred disability. Self-concept is no longer appropriate without including the new parameters introduced by a disability (Deloach, 1981, 1994). This is because the individual with an incurred moderate to severe disability is unable to function day-to-day without acknowledging limitations and changes (Livneh & Antonak, 1997; Olkin, 1999). Thus, the process of rehabilitation begins in order to assist survivors with adapting to the changes caused by the incurred handicap or disability (Olkin, 1999).

**Statement of the Problem**

Current rehabilitation counseling trends claim to use an active consumer/survivor approach to developing treatment plans and goals, with the rationale being that treatment objectives are better achieved with maximum consumer/survivor involvement. Maximizing client involvement in treatment planning leads to increased satisfaction for the client/consumer (McAlees & Menz, 1992). This seems to be little more than an ideal as a recent study by
Chan, Shaw, McMahon, Koch, and Strauser (1997) showed that practitioners discount the consumers' opinions for several reasons. The survivor of incurred disability is viewed by the helping professional as naive about prognosis, incapable of understanding the diagnosis, or is unable to use clear judgment in goal planning post-injury (Chan et al., 1997). If this is true, then practitioners merely espouse the principles of maximum consumer involvement but do not practice it, thereby reaching an ethical dilemma.

Recent philosophies regarding people with disabilities and society endorse the premise that the environment and nondisabled people impose the handicaps encountered in interactions between person and environment (Gilson & Depoy, 2000). People with disabilities are viewed as capable of achieving goals and activities daily and as intrinsically capable though they may achieve their goals in nontraditional or unorthodox manners (Gilson & Depoy, 2000; Oliver, 1996). Ironically, many rehabilitation programs, as stated previously, espouse this philosophy while in reality perpetuating oppressive measures (Olkin, 1999).

At high risk for viewing clients as incapable of fully grasping the scope of their disabilities are rehabilitation programs for traumatic brain injury treatment. Traumatic brain injury is acquired damage to the brain due to blunt insult to the head caused by acceleration or deceleration impact (Krauss & McArthur, 1999). The effects of the damage range from mild to severe for survivors causing complications and deficits across the span of foundational domains such as cognition, personality, behaviors, and physical capabilities (Krauss & McArthur,
Because the extent and combination of affected domains is different for each survivor, the rehabilitation team faces unique challenges. Because this disability group has far-reaching neurobehavioral and cognitive implications, interpreting differences between client and treatment goals is easily dismissed as lacking insight, awareness, or clutching to denial (Hill, 1999; Prigatano, 1999).

Measures such as the Glasgow Coma Scale (1974) implemented to categorize and predict outcomes for survivors with traumatic brain injury as mild, moderate, or severe seem to take into account physical variables in acute phases of injury. Positive correlations have been found between predictions and outcomes for survivors that indicate that such instruments are reliable (Krauss & McArthur, 1999). Other studies suggest little or no relationship between predictions and outcomes that should raise serious questions of validity to rehabilitation providers (Krauss & McArthur, 1999).

Several researchers suggest that problems exist when predictions and prognoses take place out of context (Hill, 1999; Livneh & Antonak, 1997; Prigatano, 1999). To explore or even predict behavior out of context runs the risk of limiting the individual to the parameters of the outside observers. Only the survivor is expert on fully understanding the challenge(s) of adapting to an imposed disability. Endeavoring to learn these challenges phenomenologically is critical in rehabilitation planning (Prigatano, 1999). Understanding the client perspectives is paramount as it is the only way to maximize consumer/survivor involvement and to best facilitate restoration to
optimal functioning (Prigatano, 1999). Learning what adaptation means within the context of individual situations and then to try to understand the complexities of human behavior must occur phenomenologically. Practitioners must incorporate a whole, qualitative understanding of client problems in the client environment or context in order to optimally facilitate clients toward reasonable goals.

Therefore, the problem is that current positivist, medicine, and rehabilitation philosophies fail to explain how and why people with traumatic brain injury exceed prognoses and predictions made with nominal measures and scales. Also unexplained adequately are the numbers of patients deemed unaware or naïve because they do not comply with recommended treatments. This presents the possibility that said rehabilitation philosophies are not adapted to allow for these variances to fall within normal realms. Rather, such individuals are labeled as anomalies, unaware, or in denial of their circumstances. To explore this phenomenon quantitatively would explain matters only in terms of quantity and would not answer the questions of how and why individuals with severe traumatic brain injuries at times exceed expectations and prognoses or do not comply. Such questions can be answered only by exploring the constructs offered by the actual survivor of traumatic brain injury. In doing so, problems imposed by rehabilitation programs implementing prescriptive goals upon clients in addition to the problems of client awareness, denial, and naïveté are likely to be addressed.
Purpose of the Study

The purpose of this study was to obtain descriptions from survivors of traumatic brain injury about their perceptions of adjusting to disability and then to compare the perspectives with existing disability theories and practices. Because research in brain injury rehabilitation is newer than other disability groups, there is not an abundance of literature that presents relevant issues from the client perspective. In addition, there is scarce literature in brain injury research that examines neurobehavioral and psychosocial constructs thereby revealing the youth of brain injury research (Olkin, 1999; Prigatano, 1999).

Trauma to the brain potentially affects foundational domains of an individual including cognition, personality, intelligence, and physical functioning. The term rehabilitation for this disability group may be a misnomer because an injury affecting these facets of identity concurrently may require the individual to habilitate (Hill, 1999). Traditional rehabilitation therapy that endeavors to return individuals to optimal functioning may be inappropriate when the survivor may need to start all over again, not merely return to a previous state. It is difficult to argue that a person who suffers from personality changes can return to being the same person (Hill, 1999). The only way to determine the needs of the client and the course of disability treatment planning is to endeavor to understand what the client currently perceives as the rehabilitation treatment course to follow (Prigatano, 1999). This means examining the current context of the client and de-emphasizing the process of restoring patients to a state of functioning that may be impossible due to the imposed deficits of traumatic brain injury.
Therefore, the first purpose was to examine through inquiries of actual survivors what it means to inquire and adjust to traumatic brain injury. Second, the constructs uncovered through qualitative, semi-structured interviews were compared and contrasted with three existing models of disability and brain injury rehabilitation.

**Definition of Terms**

**Rehabilitation.** Rehabilitation is a restorative process that strives to return an injured individual to optimum functioning and maximize the potential for independent living (Rubin & Roessler, 1995). Attempts are made to restore an individual to independent functioning after acquisition of an injury or illness in an effort to achieve independent living. A person who has become disabled or handicapped builds upon premorbid, preexisting information while incorporating the imposed disability into this knowledge base. This process comprises the rehabilitation that ideally develops strategies to overcome societal and self-imposed obstacles (Maki & Riggar, 1997).

**Habilitation.** Individuals, whether disabled or not, spend their initial years building a repertoire of knowledge, attitudes, behaviors, and experiences. The individual participates in a learning process and foundation-building process known as habilitation (Maki & Riggar, 1997; Wright, 1983). This foundational knowledge is used as a reference point during rehabilitation treatment planning (Wright, 1983).

**Traumatic Brain Injury.** For the purposes of this study, traumatic brain injury was viewed purely as blunt trauma to the head causing damage to the
brain tissue. Closed head injury was used synonymously while head injuries were delineated as any injury to the head or face not having neurological consequence, necessarily (Krauss & McArthur, 1999).

**Morbid.** For the purposes of this research, *morbidity* connotes the incidence of disability or traumatic brain injury. *Premorbid* connotes conditions that existed for individuals before acquisition of disability and *postmorbid* refers to conditions existing after the acquisition of disability.

**Adjustment.** Some authors maintain that adjustment and adaptation are separate. Livneh and Antonak (1997) view adjustment as a subset of adaptation in that *adjustment* is the final phase of the adaptation process connoting acceptance and acclimation to disability. This author adopted this definition and used the model presented by Livneh and Antonak titled "Adaptation to Disability" but focused on the constructs presented in the adjustment phase of the model during the comparison analysis of this research.

**Self-Concept and Identity.** For the purpose of this study, *identity* is defined as a combination or cluster of experiences which one incorporates within oneself to form a conceptual whole or complete self image (Rangell, 1994).

**Awareness.** *Awareness* means to have insight and knowledge of one's conditions and surroundings and to be conscious. To have deficits in these areas so that one is not conscious, alert, or knowledgeable of one's conditions
and surroundings connotes a condition known as anosognosia (McKinlay & Watkiss, 1999).

Summary

This study explored problems that arise in adjusting to traumatic brain injury for the individuals who incur them. A traumatic brain injury results in acute and permanent neurological damage to the central nervous system affecting foundational domains such as personality, cognition, and emotion (Krauss & McArthur, 1999). Medical and rehabilitation efforts collaborate in order to assist individuals who acquire traumatic brain injury to recover and compensate for deficits in order to return to an optimal state of independent functioning. As Hill (1999) pointed out, however, it is unreasonable to expect someone whose personality or emotions have changed to return to a previous state. Further, patients with traumatic brain injury can be easily dismissed as being unaware, in denial, or noncompliant should they choose goals aside from those recommended by rehabilitation professionals. This study examined these problems by inquiring how actual survivors of traumatic brain injury perceive and pursue adjustment. Interviews were conducted with survivors from which case studies were developed along with an analysis of derived themes and constructs. The uncovered themes and constructs then were compared with existing brain injury rehabilitation paradigms.

In doing so, several assumptions were made. One assumption was that individuals who acquire traumatic brain injury adopt an adjustment process. Second, participants in this study were survivors of traumatic brain
injury who had undergone formal rehabilitation of some type. Third, the participants answered researcher questions in an honest manner. Fourth, the data obtained on each participant were independent of data obtained on other participants. Finally, all participants were aware and cognizant of their participation in this study, each having consented to participating independent of coercion or persuasion by the author or family members regardless of whether the traumatic brain injury was categorized as mild, moderate, or severe.

Chapter 2 reviews the literature in several categories including disability, adjustment, history and legislation regarding disabilities, rehabilitation, traumatic brain injury, and traumatic brain injury rehabilitation. Chapter 3 outlines the methodology used to collect and analyze the data while the following chapters present the findings and discuss the results and implications of this study. Chapters 4 and 5 present the results, and Chapter 6 discusses the findings and recommendations.
CHAPTER 2
REVIEW OF LITERATURE

In order to explore adjustment to traumatic brain injury from the survivor’s perspective, it is important to have an understanding of the pertinent literature. A review of the literature is presented, describing adjustment issues relevant to disability, rehabilitation, and traumatic brain injury as follows: (1) disability, (2) theories of psychosocial adjustment to disability, (3) rehabilitation, (4) policies and legislation regarding people with disabilities, (5) traumatic brain injury, and (6) models of adjustment to traumatic brain injury.

Disability

Disability Defined

A disability is a congenital or acquired physical, mental, or emotional condition that detours the achievement of daily objectives (Rubin & Roessler, 1995). Congenital disabilities are those conditions that are present at birth such as mental retardation or physical deformities. Acquired disabilities are those that are incurred through illness or accident, sometime throughout the lifespan. Since disabilities and handicaps are not synonymous, disability is distinguished from a handicap. A disability is a limitation of functioning on some level of organ or body system but does not obstruct task accomplishments such as activities of daily living. With a disability, the manner
in which the task is normally accomplished may change, but the task is still achieved (Rubin & Roessler, 1995; Wright, 1983). Conversely, a handicap is an environmental obstruction that prevents normal accomplishment of vocational, social, educational, or recreational objectives (Gilson & Depoy, 2000; Rubin & Roessler, 1995; Wright, 1983).

Olkin (1999) stated that a wide variety of different types of disabilities exists and can be viewed in terms of severity on a scale from least severe to most severe. For example, nearsightedness may fall on the least severe, left side of the scale while traumatic brain injury falls toward the more severe right side of the scale. Separately, disability can be observed in terms of a health continuum according to Olkin (1999). On the left end, less severe illnesses occur such as colds and other minor ailments. Toward the right end of the scale are those illnesses that are life threatening such as Duchenne muscular dystrophy because this disease affects involuntary muscles such as the lungs or heart (Livneh & Antonak, 1997). It is possible to have a serious disability and yet be extremely healthy. For instance, people with mental retardation, cerebral palsy, or amputees may exhibit excellent health, while others with serious disabilities may exhibit debilitating secondary symptoms (Olkin, 1999).

Secondary symptoms or illnesses are conditions caused not by the disability itself but rather by the results of the disability. For instance, muscular dystrophy, comas, and spinal chord injuries, among others, cause limited mobility that leads to a variety of potential death-causing illnesses such as debulcutis ulcers, pneumonia, and urinary track infections. Generally, however,
disabilities are regarded in terms of function, or the degree that one is able to achieve the day-to-day activities known as activities of daily living (ADL) (Livneh & Antonak, 1997; Olkin, 1999).

Inconsistencies exist across contexts and professions when defining disability. The degree of function, stigma, and illness are interchangeably pitted against each other, often spurring countless legal battles across the country (Olkin, 1999; Rubin & Roessler, 1995). For example, obesity, height, and learning disabilities entail legal ambiguity that yields inconsistent disability decisions (Olkin, 1999). The Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 have been credited with prompting the continuous “fine-tuning” of the definition of disability. The Americans with Disabilities Act of 1990 defines disability as follows:

The term “disability” means, with respect to an individual any physical or mental impairment that substantially limits one or more of the major life activities of such individual such as caring for oneself and performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, or working. The individual must have a record of such impairment and must be regarded as having such impairment. (ADA, 1990, p. 12111)

This definition focuses on the degree of function that qualifies or disqualifies an individual with a disability. A more poignant perspective is to ask when people with disabilities consider themselves to be disabled (Livneh & Antonak, 1997; Maki & Riggar; 1997; Olkin, 1999). Olkin (1999) identified three disability identity groups that people with disabilities gravitate toward. The first of these, called the “functional limitations group,” may accept benefits such as handicapped parking, but reject seeing themselves as disabled
Olkin, 1999). These individuals interact with the non-disabled community and are accepted and treated as "normal," especially if their disabilities are not too severe or carry little stigma (Olkin, 1999). Because of being treated as normal, there is little motivation to examine identity as anything other than normal, yet these individuals admit a "kinship" to those who are disabled (Olkin, 1999; Wright, 1983).

A second disability group that people with disabilities tend to identify with is the "Disability Identity Group" (Olkin, 1999). These individuals have integrated their disability with their self-concepts. Such individuals try to function in society as normally as possible but may recognize that they need assistance from those who are "able-bodied" (AB) (Deloach, 1981; Olkin, 1999). A third disability identity, a group called the "Civil Rights Group," is a subset of the second, "Disability Identity Group." This group takes a proactive approach, having already incorporated their disability into identity. They see disability as a social construct. These individuals view the disabled community as a minority group that has been suppressed and actively advocates for them (Olkin, 1999).

Along with severity of disability and severity of residual effects of the disability, two other factors determine how people with disabilities identify themselves, including etiology of disability and degree of financial and social dependence (Rubin & Roessler, 1995; Wright, 1983). The acquisition of a disabling condition disrupts what would have been a normal development process. The impact of incurring disability can have overwhelming effects on the psychological, social, vocational, economic, and physical facets of daily
functioning. Congenital disability necessitates that caregivers teach a normative process so that the individual with a handicap at birth may one day achieve independent living. Children with congenital disabilities learn to incorporate the effects of their disabilities or handicaps during formative years by their experiences with caregivers. These guardians tend either to coddle too much, thereby fostering a dependent personality; or the guardians teach their children to ignore the disability (Olkin, 1999). Other parents take steps to educate and provide support for the ongoing socialization process for their children with special conditions.

Disability and Identity

The precise meaning of identity has no consensus among theorists and scholars. Numerous theories exist that endeavor to explain identity, each presenting the elements of identity through different paradigms. The term has appeared to be an enigma to the scientific world, as only certain aspects are quantifiable (Kegan, 1982). The recent trend in psychology is positivist and attempts to quantify data in order to disprove a hypothesis according to Kegan (1982). This, however, may be the cause of other aspects of identity to be overlooked and be left undefined. Defining identity may be a qualitative process (Kegan, 1982; McAdams, 1993). Identity is shaped by context(s) and experiences with certain components remaining unchanged as one encounters changes and transformations (Rangell, 1994).

Many times people see themselves relevant to the people and things in their lives, thereby defining themselves in a context (Kegan, 1982). It is
important to understand that a single definition of identity that is applicable to all contexts is nonexistent (Kegan, 1982). However, the present study partially focused upon individual self-concepts and differences perceived before a disability versus after a disability as influenced by their rehabilitation processes. For the purpose of this study, identity is defined as a combination or cluster of experiences which one incorporates within oneself to form a conceptual whole or complete self image within one's current context (Rangell, 1994).

**Disability and Stigmatization**

Adventitious disability necessitates that clients learn or relearn to accomplish goals and daily tasks using residual capabilities (Rubin & Roessler, 1995; Wright, 1983). After acquiring a disability or handicap due to accident or illness, normal developmental processes are disrupted. As this happens, the individual with the incurred disability begins an interchange with the environment that shapes subsequent psychosocial development. How people see themselves with their respective disabilities is affected by self-appraisal and societal stigma. A stigma refers to the appraisal that society gives to phenomena such as race, religion, sexual preference, disease, and disability (DeLoach, 1994; Livneh & Antonak, 1997; Olkin, 1999). Should the individual belong to the same groups that most of the population belong to, then the individual is generally accepted as being "normal" and nonstigmatized (DeLoach, 1994; Olkin, 1999). However, should the individual possess traits that deviate from what is considered and accepted as normal, the "normal"
population regards such individuals as different. Consequently, people with disabilities elicit a variety of anxieties from the nondisabled population from pity and apathy to avoidance and disdain (DeLoach, 1994; Olkin, 1999; Shontz, 1984).

The degree of stigmatization appears to be related to both the context in which the disabled and nondisabled interact and the nature of the disabling condition (DeLoach, 1994; Olkin, 1990). A study conducted by Sigelman, Howell, Cornell, and Cutright (1991) produced findings that people without disabilities are less likely to consider intimate relationships with people with any sort of disability or difference. The public seems to be more willing to consider friendships or work relationships with people with disabilities and differences (Sigelman et al., 1991). Olkin (1999) found that the public tends to be more accepting of certain disabilities such as cancer, blindness, or paraplegia than it is of other disabilities such as drug addiction or AIDS. The latter disabilities were viewed as controllable and evoked feelings of anger and blame, whereas the former disabilities evoked sentiments of low responsibility (Olkin, 1999). The impact of the polar values of independence and humanity is great on those with disabilities and handicaps. Our culture places a high value on being independent financially and socially (Rubin & Roessler, 1995). Although this past century did witness the introduction of policies and legislature that attempted to create equal access and opportunity for minority groups, the sentiment of being self-supportive overshadowed efforts that fostered human interests. In a society such as the United States where
personal responsibility and independence are valued, negative public opinion and perception toward those with abnormalities carries a price. People with disabilities are left to interpret and incorporate their environment’s opinions about them as the process of adjustment.

**Current Disability Models**

One model of disability conceptualization is the medical model of disability. The medical model views disability as a “permanent biological impediment” causing those with disabilities to be less capable than those without disabilities (Gilson & Depoy, 2000). This paradigm sees the problem to be addressed by rehabilitation services as within the individual (Gilson & Depoy, 2000). The medical model encompasses the premises of rehabilitation. As such, rehabilitation professionals endeavor to restore individuals with disabilities and foster recovery to a state of desirable functionality (Gilson & Depoy, 2000).

The social model of disability sees individuals with disabilities not as in need of restoration or repair but as individuals who add to the diversity of the human condition (Gilson & Depoy, 2000). This philosophy sets goals of removing environmental and social barriers, as the problem exists within the social context and not within the individual with disability. While the shift toward this paradigm exists, it still competes with the medical model in rehabilitation contexts (Hill, 1999; Oliver, 1996).

The political model of disability indicates that it is a barrier preventing people from working. As such, the focus is on people with disabilities and their
ability to make economic contributions to society, thereby setting up an interesting paradox. People with disabilities hold power as a group because of legislation that defines them, but because value is placed upon economic contribution, the societal stigma of people with disabilities being less capable of contributing is perpetuated (Crisp, 2000; Gilson & Depoy, 2000).

Finally, the multicultural model sees individuals with disabilities as a group that is not bound by the lists of symptoms within their diagnoses but as a group inclusive within itself because of the societal and political circumstances forced upon them (Crisp, 2000; Gilson & Depoy, 2000). One underlying theme that can be derived from all of these models is that people with disabilities are "under-positioned" socially and politically. In the endeavor to facilitate adjustment to a disability, the presentation and awareness of these models lends to a better understanding as to why acceptance of a disability can be a difficult undertaking (Crisp, 2000; Gilson & Depoy, 2000).

**Psychosocial Adjustment to Disability**

Adjustment to a disability in American society is often erroneously perceived as the individual achieving normalization, functioning independently with the majority of society (Perrin & Nirje, 1985; Rubin & Roessler, 1995). One common misconception in our society is that of success and normalization equated with independence. Dependence of any type is viewed negatively, perpetuated by media and entertainment icons. Self-made individuals are upheld and praised for being independent from familial and governmental support (Rubin & Roessler, 1995). In our society, the word "disability" connotes
neediness and incompetence, and those with disabilities are seen as needing support and services. Therefore, it becomes easy for those with disabilities to be perceived negatively (Fine & Asch, 1988). The message is evident that dependency is not valued in our society; hence, public perception devalues those with disabilities. Paradoxically, those who are independent and self-made are supported at one time with either or both family and government support. Further, even those who are perceived as successful may have trouble in areas such as housekeeping, shopping, and managing finances and therefore may seek assistance (Rubin & Roessler, 1995).

For people with disability, survival becomes a process of assimilating information from the environment, including devaluation and residual capabilities into psychosocial adjustment and eventually adaptation. As the nondisabled public perceives people with disabilities as less valuable, those who are afflicted with disability absorb and either reject or accept the devaluation into self-concept (Rubin & Roessler, 1995; Wright, 1983). Residual capabilities are those abilities that are unaffected within the individual with incurred disability, whereas the affected domains are those that are disabled (Livneh & Antonak, 1997). While the focus was upon incorporating disability into self-concept, past models of adjustment to disability used the terms "adjustment" and "adaptation" to disability interchangeably such as the conceptual models proposed by Wright (1983), Vash (1981), and Shontz (1975, 1984).
A traumatic disability is usually the result of an accident or sudden illness causing changes in the ability to function in one or several domains and/or appearance (Livneh & Antonak, 1997). While many theories exist speculating the psychosocial recovery of the individual, it is agreed that the impact of a traumatic disability has psychological implications for the individual (Livneh & Antonak, 1997). One of the earlier attempts to conceptualize adjustment to disability was presented by Dembo, Leviton, and Wright (1956) as a coping framework. The coping framework listed characteristics that foster adjustment of an individual with disability. These characteristics included emphasis on residual capabilities, being proactive with shaping one's life, acknowledging personal accomplishments, managing negative experiences, minimizing environmental limitations, and participating in avocational or vocational activities (Dembo, Leviton, & Wright, 1956, 1975; Livneh & Antonak, 1997). This coping framework was opposite of a succumbing framework or mindset. Those who succumbed to the effects of a disability rather than trying to minimize the effects were viewed as succumbing.

Earlier Adjustment Paradigms

Wright (1983) expanded these writings and suggested that acceptance or adjustment is the ability to minimize perceived or actual loss while retaining value of residual capabilities (Livneh & Antonak, 1997). The difference between perceived and actual loss is the same as the disabled individual's interpretation of the lost functions versus what is actually lost (Livneh & Antonak, 1997; Wright, 1983). Because the acceptance of a disability involves
the victim's interpretation, Wright equates psychosocial adjustment with acceptance versus denial of the incurred disability (Wright, 1983). She proposed four changes that the individual must make in order to limit self-depreciation and maximize adjustment. These changes include identifying values unaffected by disability, minimizing the importance of physical appearance, confining the effects of disability to only the affected areas, and transitioning values from being externally based to internally based (Livneh & Antonak, 1997; Wright, 1983).

Shontz (1989) supported a form of qualitative inquiry that allowed the researcher to examine experiences from the perspectives of survivor. Shontz's "personology" approach used representative case studies to observe the perceptions of people pertaining to their choices, experiences, motivation, conflicts, and possibilities rather than environmental causalities (Shontz, 1989). The goals of personological research sought to enhance the ability of researchers to gather data about contextual considerations, facilitate understanding the human perspective, and develop effective ways of applying theories to the individual rather than the masses (Shontz, 1989). In addition to his philosophy of research with people with disabilities, Shontz offered his view of adjustment.

Similar to Wright, he stated that adjustment was a dual process that encompassed, first, the abilities of people to maximize environmental opportunities and, second, the environment providing accommodations. Shontz (1975) stated that adjustment was the last stage of a reaction process
to incurring a disability that is congruent with the subjective perception of the external environment. He suggested that adjustment is optimized when the environment and the subjective realities of people or compatible. As the environment and individual accommodate and acclimate to one another, then adaptation is achieved (Shontz, 1975, 1989). Last, Shontz maintained that the best consultants when researching rehabilitation issues are those who actually have experienced the targeted malady first hand, dubbed the “insiders” by Beatrice Wright in 1983 (Gordon & Shontz, 1990; Wright, 1983). All individuals who observe the victim of acquired disability, whether they are a part of the treatment team, the family support system, or virtual strangers, are “outsiders.” These individuals are all a part of the environment providing feedback and impressions, intentionally or unintentionally, to insiders, thereby affecting adjustment (Dembo, Leviton, & Wright, 1975; Wright, 1983).

Vash (1981) conceptualized the process of adjusting to a disability as normal reactions to abnormal stimuli. Vash (1981) stated that the normal reaction is the psychological process of acclimating to an injury, while the accident or illness itself is the abnormal stimuli. She seemed to readily accept the reaction of the individual as unconditionally normal, while the environment is not always accepting of those reactions. While Vash, Shontz, and Wright differed in how they conceptualized adjustment to disability, they all agreed that a variety of factors affect adjusting to illness or injury. Existing before the disability was acquired, these identified factors influence adjustment processes after illness or disability is incurred. According to Vash, these
determinants fall into three categories: external factors such as the environment, the type and severity of disability, and internal factors such as personality and self-concept (Livneh & Antonak, 1997; Schlossberg, 1981; Vash, 1981; Wright, 1983).

As an individual acquires a disabling illness or condition and reacts to it, the environment provides feedback to the reactions in two ways. First, sentiment toward handicaps and disabilities is reflected by the construction and implementation of concrete, physical objects (Vash, 1981). For instance, adjustments are made to the physical environment by inserting elevators and ramps when stairs are impassable or by developing a relay hearing service when telephone use is impeded. These environmental adjustments are concrete and static, representing the paradoxical attitudes of normalized society. Hence, culture and environment have a large role and responsibility in defining disabilities and attitudes toward them (Vash, 1981; Wright, 1983). Those physical objects designed to enhance accessibility were designed and implemented by engineers and architects who shaped and therefore defined an environment (Vash, 1981; Wright, 1983).

A second type of environmental feedback comes from people and their attitudes. These attitudes are influenced by societal values and customs interwoven with attempts to reverse the underlying tone of rejection or nonacceptance toward those who are different (Olkin, 1999; Vash, 1981). Vash attributed these attitudinal barriers to several factors including over-evaluation of physique, under-evaluation of spirituality, societal tendency of blaming the
victim, and assuming that mourning the loss of function has to take place (Vash, 1981).

Another determinant affecting psychosocial functioning is the nature of the injury or disability. The type of disability seems to influence the perceptions of the survivor and the public. For instance, auto-immune deficiency syndrome (AIDS) carries a more negative stigma than pancreatitis, both of which involve immune system malfunction (Olkin, 1999). Severity and age of occurrence and visibility of the disability affect rehabilitation treatment planning, as well as public perception (Livneh & Antonak, 1997; Olkin, 1999; Vash, 1981). Those who look different or abnormal generally are believed to be more handicapped than those with invisible disabilities (Livneh & Antonak, 1997; Shontz, 1985; Wright, 1983).

For those facing terminal illness, rehabilitation objectives include getting affairs in order, grief and bereavement counseling for family members, lessening the demands of vocational activities, and focusing on avocational activities (Livneh & Antonak, 1997). Those who incur non-life-threatening disease or injury experience shifts in psychosocial functioning such as changing jobs or physical activities. As the ramifications of the incurred maladies are drastically different, so are the intrapsychological variables of the individual. The previously mentioned variables are constant for both groups; however, the utilization may be different. For instance, cancer patients who are in denial about the lethality of cancer may hasten their deaths if ignored or refused. Similarly, brain-injured patients who are in denial about their injuries
may need additional attention from rehabilitation staff and family to insure individual safety.

Personal characteristics such as self-concept, gender, and values inherently affect perceptions and adjustment to incurred disability (Livenh & Antonak, 1997). Self-concept refers to how one sees oneself (Livneh, 1997; Schlossberg, 1981; Wright, 1983; Vash, 1981). Self-concept formation begins early in life and forms by integrating self-knowledge gained by assimilating feedback from the environment with sensory experience and cognition. Influenced by developmental and social learning theories, Wright (1983) described the formation of self-concept and self-esteem as an integrative process that continually evolves, influenced by the individual perceptions of self and feedback from the environment. These characteristics comprise what Wright (1983) described as the inside perspective. The effect of having been traumatized is then affected greatly by the insider perspectives or perceived control over the situation (Wright, 1983). Locus of control refers to how individuals perceive their sense of control of and in the world (Rotter, 1971). An individual with a high external locus of control believes that fate and the environment control circumstances, which connotes that the individual is a victim of the environment. An individual with a high internal locus of control believes that the ability to control circumstances lies within the self (Livneh & Antonak, 1997). The personal philosophy that the individual adopts tends to affect adaptation to disability significantly, according to research (Livneh & Antonak, 1997; Wright, 1983).
Many studies assess the relationship between locus of control and level of adjustment to disability. For example, Roberta Trieschmann (1989) investigated numerous personality traits and their relationship to positive adjustment to spinal chord injury. She found that those individuals with a higher internal locus of control had more positive adjustment. Levenson (1975) expanded upon Rotter's locus of control concept and determined that three categories exist, including internality, influence of powerful other, and chance occurrences. The additional category accounted for those catastrophic events that are caused by chance, such as weather catastrophes or other accidents (Levenson, 1975).

Krause, Stanwick, and Maides (1998) conducted further research with spinal chord injury patients to determine, among other things, the relationship between internality or internal locus of control and adjustment, short and long term, to the disability. The results showed that those with higher locus of control had a favorable emotional outcome. Likewise, the results also showed that those influenced by powerful others with higher external locus of control had more difficulties emotionally (Krause et al., 1998). Other researchers have examined and determined that those with higher internal locus of control tend to take more responsibility in all aspects of having incurred a disability. These individuals tend to self-blame or own the occurrence of disability. Likewise, they also actively set goals and expectations of themselves in order to succeed in achieving life goals and/or treatment goals. This is similar to a phenomenon known as "efficacy," referring to the potential expectations and goals that a
person has for oneself (Bandura, 1977). Other adjustment theories maintain that individuals who experience trauma and subsequent disability must experience or do experience emotional phenomena such as depression, anger, or denial in order to achieve adjustment and adaptation that are typically seen in phase models (Livneh & Antonak, 1997).

The Phase Models

The phase models find roots in earlier adjustment models such as the model for adjustment and adaptation to grief and dying introduced by Kubler-Ross (1969). In this model, characteristics that were common in the adjustment processes of dying patients and their families were introduced as phases including shock, denial, anger, depression, and acceptance (Kubler-Ross, 1969).

The phase models maintain that humans experience certain emotional reactions to trauma and illness when adventitious disabilities occur. These reactions include shock, anxiety, denial, depression, internalized anger, externalized hostility, acknowledgement, and adjustment (Livneh & Antonak, 1997) (Appendix F). Studies reveal all or a combination of these phases may be present and that the phases do not occur sequentially, necessarily (Livneh & Antonak, 1997). For instance, Livneh and Antonak (1991) found that reactions to disability were nonlinear, multidimensional, and hierarchical. The results of the study showed the ordering of phases including maladaptive reactions that blended in with the hypothesized order of adaptive reactions. This study found relationships among the variables that varied with time. For
instance, anxiety and depression had different intensities after time passed (Livneh & Antonak, 1991). The phase model also makes several assumptions. For instance, permanent, significant changes and psychological dissonance must be experienced, and the phases do not occur in sequence or in isolation of other phases (Livneh & Antonak, 1997).

Shock is a common initial response to overwhelming physical and psychological trauma and may be experienced physically or psychologically as a numbing, confusing, depersonalized, or retarded state of being (Livneh & Antonak, 1997). Anxiety is another response to trauma and is experienced as irritability or heightened emotion after initially learning of the incurred trauma or illness. Physiological reactions may coincide with this phase, such as rapid pulse, breathing difficulties, or non-productive hyperactivity, for instance, that may heighten the individual’s state of shock (Livneh & Antonak, 1997).

Denial as a reaction to disability is usually seen as a coping phase or stage experienced by an individual during the rehabilitation process. Billings and Moos (1981) outlined a two-faceted conceptual model of coping with denial. In facet one, the process of coping has three components. The first component focuses on appraisal of situation and is affected by logical analysis, cognitive redefinition, avoidance, and denial of the crisis life event incurred. The second component focuses on problems and how to solve them in the external sense, such as through support systems or resource availability. The third component focuses upon the emotionality of the individual, such as affective regulation or acceptance level. The second facet is comprised of three
components including active-cognitive, active-behavioral, and avoidance (Billings & Moos, 1981).

Denial is controversial according to some researchers and practitioners who view it as a phase of the recovery process after an individual has experienced crisis. Others view denial as a distortion of reality in an effort to alleviate anxiety. Freud (1936) believed that it operates unconsciously and therefore is inaccessible with insight. Wright (1983) discussed denial in her model of rehabilitation, stating that denial could be viewed or renamed as "as if" behavior. "As if" behavior is when the individual with illness or disability acts as if it did not exist or attempts to minimize the effects of such (Wright, 1983). She believed that doing so is valuable because the individual is allowed to slowly acclimate to the reality of adventitious injury or disease. Some researchers believe that denial may be an important survival mechanism when faced with extreme distress or anxiety elicited by crisis (Langer, 1994). While denial may initially aid in assimilating the occurrence of disability into belief and reality, its continuance leads to dysfunction and potential danger (Langer, 1994). The denial of a disability or illness may create danger for the individual or others if the individual attempts to do tasks that are no longer possible due to limitations and handicaps (Langer, 1994).

Feelings of hopelessness, despair, and grief have been observed as common reactions to acquired disability. Other common depressive symptoms that comprise the depression phase are self-devaluation, isolation, despair, and helplessness that may be experienced after realizing that
permanent loss or change has taken place (Livneh & Antonak, 1997; Rodin, Craven, & Littlefield, 1991).

Internalized anger is listed as a phase that involves self-blame and resentment. Typically, individuals who experience this phase are in some way responsible for the occurrence that caused disability. Suicidal ideation and self-injurious behavior may occur during this phase as a result. For example, Heinemann and Shontz (1984) described a case study of a male who acquired paraplegia due to a hang-gliding accident. The young man was viewed as extremely compliant through rehabilitation as he wished to appear to take responsibility for the accident with no regrets but also minimized his disability. A year later, he was re-hospitalized for a failed suicide attempt, having experienced intense feelings of depression, hopelessness, and self-blame (Heinemann & Shontz, 1984). Externalized anger is hostility that is directed toward aspects of the environment, people, or objects believed to be related to or caused the disabling condition. Examples of externalized anger are passive-aggressive acts, abusive accusations, feelings of antagonism, and blame directed at others (Livneh & Antonak, 1997).

In the acknowledgment phase, individuals recognize that the conditions imposed by disability are permanent. Individuals begin to re-orient themselves with the environment as a process of integrating old and new self-concepts ensues (Livneh & Antonak, 1997; Olkin, 1999). Finally, adjustment refers to the emotional and cognitive reconciliation that the acquired disabling condition is permanent, triggering a process of re-acclimation with the environment. In this
phase, the individual who has adjusted has established a renewed sense of self-value, carries out new vocational and social goals, recognizes new and old potentials and talents, and overcomes obstacles in pursuit of new goals (Livneh & Antonak, 1997).

Livneh and Antonak (1997) maintained that these phases overlap and even occur concurrently to the extent that they suggest that the process of adjustment and adaptation occur simultaneously (Livneh, 1986; Livneh & Antonak, 1997). After incurring a disability, adjustments begin occurring immediately, both consciously and unconsciously, for the patient. As this process begins, so does a reciprocal relationship between the individual with the environment. The individual may try through trial and error to attain daily functioning goals while the environment gives feedback (Wright, 1983). Livneh and Antonak's Model of Adaptation to Disability (1997) attempted to portray a model of adaptation that is more integrative than the phase models (Livneh & Antonak, 1997) (Appendix F).

In understanding the internal and external factors affecting psychosocial adjustment, the age of onset of disability, the individual's internal or external locus of control, and interactions with the surrounding environment before the accident affect how the individual adjusts after disability has incurred. To gain a better understanding of how individuals go through the adjustment process, psychological theories including social learning theory and developmental theories can be viewed in conjunction with phase models of adjustment.
The groundwork had been broken in the field of psychology during the 20th century leading to further exploration down different paths including rehabilitation and adjustment. Theories of psychology attempted to explain and understand personality, cognitive and emotional domains, and the experiences affecting the perceptions and decisions of individuals. As adjustment is acknowledged as a part of various life situations, rehabilitation could not ignore the psychosocial ramifications of acquiring disability. In order to understand foundational elements brain injury rehabilitation, it is worthwhile to examine theories that help to explain elements that constitute behavior such as cognition, emotion, and personality traits in conjunction with adjustment models.

There are many theories that have been generated as an attempt to explain and understand human behavior and personality. Several have been chosen to discuss to exemplify frameworks of understanding behavior through qualitative inquiry and adjustment to disability. The theories focused upon in this study are Albert Bandura’s Social Learning Theory, Erik Erikson’s developmental models, and Marcia’s middle adulthood developmental model.

Social Learning Theory

Albert Bandura (1986) developed a theory of learning and behavior derived from behavioral theories such as classical conditioning and operant conditioning. Whereas classical conditioning was concerned with responses to conditional stimuli, operant conditioning was concerned with antecedents
and consequences of behavior. What is important to notice is that the purposes of these approaches were concerned with stimuli external to the individual, thereby ignoring the internal processes of the individual.

Bandura maintained that human cognition and vicarious experiences also affect behavior and that it is the result of a triad of the environment, behavior, and covert individual processes interacting simultaneously (Bandura, 1997). Bandura maintained that in this triad one factor is always affected by the other two and that cognition, comprised of motivations, thought, and emotion, act together to determine behavior, thereby outlining Social Learning Theory (Bandura, 1997).

From Bandura's social learning theory came the term "efficacy," referring to the perceived ability and competency to carry out desired tasks. This means that the ability of an individual to accomplish a task is affected by the level of belief one has in oneself to accomplish it (Bandura, 1986). This relates to incurring a disability in that the individual sets goals based on the belief of one's abilities or residual capacities. Residual capabilities are those capabilities one retains or discovers following adventitious illness or disability (Wright, 1983). For instance, after traumatic brain injury is acquired, changes occur cognitively, emotionally, and behaviorally, caused by the unpredictable progression of edema and hemorrhaging from the impact (Chadwick, 1985; Cook, 1992). After the brain-injured patient becomes aware of the transpired changes, new efficacy goals evolve.
The social stigma caused by a disability affects identity resolution (Susman, 1994; Wright, 1983; Vash, 1981). The response by the environment to the disability is many times negative or deviant (Strauser, 1995; Susman, 1994). Barring denial that would hamper achieving recovery goals, the expectations of efficacy may be altered and changed by four things according to Bandura (1986). These include performance accomplishment, vicarious experiences, verbal persuasion, and emotional arousal (Bandura, 1977).

Performance accomplishment is simply the mastering of tasks set before the individual. The achievement of such fosters positive expectations for further achievement to ensue (Bandura, 1977). Vicarious experiences are the observations of role models with similar conditions as the individual (Bandura, 1977). Once individuals observe other similar individuals accomplishing tasks, safety and the expectancy of positive outcome become possible (Bandura, 1977). Verbal persuasions are the suggestions and empowerment of individuals to succeed, thereby increasing efficacy expectation (Strauser, 1995). Finally, emotional arousal, if negative, adversely affects positive efficacy expectations and visa versa (Bandura, 1977).

Therefore, rehabilitation interventions should focus on fostering high efficacy expectations and providing compatible interventions (Strauser, 1995). Further, should lowered self-evaluation and lowered efficacy expectations exist, then interventions such as group counseling and empowerment techniques should be employed by the rehabilitation professionals involved (Strauser, 1995).
Ego Identity Developmental Theories

Erikson. Adjustment may be viewed through the developmental theories of Erikson and Marcia upon acquiring a disability or chronic illness. Individuals are forced to incorporate the changes brought on by the disability cognitively, emotionally, and socially, thereby affecting the developmental process. Erik Erikson (1963) first developed the concept of ego identity development, believing that individuals pass through a series of stages with developmental tasks to be accomplished in each stage. His conceptualization of how identity forms includes a tripartite relationship among biological, psychological, and societal processes that he developed in response to Freud's psychosexual, developmental stages (Kroger, 1993, pp. 1-20). Erikson saw Freud's psychosexual stages of development as limiting in that Freud focused more on processes that happened within the individual with little emphasis upon the reciprocal relationship between the person and environment.

Therefore, Erikson proposed a developmental model of identity purporting that individuals are given a set of tasks to achieve in eight developmental stages that encompass the life span (Kroger, 1993, pp. 1-20). If individuals accomplish the tasks within each developmental stage, then positive attitudes toward the self and environment develop. If individuals fail to accomplish the tasks in each stage, then potentially debilitating beliefs toward the self and environment develop (Kroger, 1993, pp. 1-20). Last, in each stage, the potential exists for achieving certain values by striving for positive resolution between polar attitudes. For instance, the first stage is "basic mistrust versus
trust," occurring the first year of life during which the infant and caregiver establish whether the world is trustworthy as the infant’s needs are met (Erikson, 1982, 1997). The value to be attained in this stage is hope (Erikson, 1982, 1997).

The second stage, ages 1 to 3 years old, is “shame and doubt versus autonomy,” during which the child attempts to master tasks and assert will. The value to be attained at the second stage is “will” (Erikson, 1982, 1997).

The third stage is called “guilt versus initiative,” where toddlers attempt to master their bodies and the world around them. The value to be attained in the third stage is “purpose” (Erikson, 1982, 1997). The value to be attained in the fourth stage is “competence.” During the fourth stage, “industry versus inferiority,” children learn about themselves as workers, especially related to schoolwork and tasks. The fifth stage, “identity confusion versus identity,” encompasses adolescent-aged youth who are trying to explore the boundaries of themselves in relation to society. Individuals in this stage are concerned with defining the possible and potential parameters of identity. The value to be attained in the fifth stage is “fidelity” (Erikson, 1982, 1997).

The sixth stage is “isolation versus intimacy” during which young adults have made commitments to identity and now seek relationships characterized by reciprocal love and devotion. The value to be attained in this sixth stage is to find love (Erikson, 1982, 1997). The seventh stage encompasses the middle adult years and is characterized by a want to give or teach others for the greater societal good. In this stage of “generativity versus stagnation,” individuals carry
out their generative needs by raising children or being civically involved for example. The value to be attained in the seventh stage is to demonstrate caring for others. The eighth stage, "despair and disgust versus integrity," includes the senior years and is when individuals reflect over their lives and decide whether their lives have been productive and worthwhile. The last value to be obtained is wisdom (Erikson, 1982, 1997).

Marcia. James Marcia initiated research in college settings in order to identify how young and middle adults resolve conflicts and commit to identities. He proposed that four identity statuses exist to represent how individuals cope with the conflicts that arise in resolving identity. These statuses, or types of commitment, include foreclosed identity status, the identity diffuse individual, the identity in moratorium, and individual with achieved identity. According to Marcia (1999), individuals with foreclosed identity have not explored oneself or relational conflicts but have made commitment to identity. Such individuals tend to be less mature, preferring involvement stereotypical and superficial relationships and endeavors (Marcia, 1993, 1999).

Individuals who are identity diffuse are those who have not encountered crises and have made no commitments to identity. Such individuals have considered different possibilities but have not engaged any particular conflict or crisis (Marcia, 1999). Individuals with moratorium identity status have encountered conflicts but have not made commitments to identity. Achieved identity is the fourth ego identity status at which point individuals have encountered crises and made commitments to identity (Marcia, 1993, 1999).
Individuals in moratorium and achieved identity status tend to be more mature in behavior and decision making processes (Marcia, 1993, 1999). These four statuses represent ways that adults reconcile different life crises, such as incurring a disability and then committing to decisions. As mentioned previously, making decisions affects and shapes development and adjustment accordingly (Livneh & Antonak, 1997; McAdams, 1993; Wright, 1983).

The purpose of understanding and facilitating adjustment is to help individuals achieve optimal functioning after disability is acquired. This is the concept that encompasses rehabilitation. The issues, models, and theories that explain the processes of adjustment to disability set forth parameters with which to understand and plan for adjustment to occur (Maki & Riggar, 1997).

Rehabilitation

Rehabilitation Defined

Individuals, whether disabled or not, spend their initial years building a repertoire of knowledge, attitudes, behaviors, and experiences. The individual is participating in a learning and foundation-building process known as "habilitation" (Maki & Riggar, 1997; Wright, 1983). This foundational knowledge is used as a reference point during rehabilitation treatment planning for both the individuals with incurred disability, who remember how they were before, and the rehabilitation team (Wright, 1983). Rehabilitation focuses upon maximizing client's levels of functional independence in order to re-assimilate into societal roles as independently as possible (Maki & Riggar, 1997; Olkin, 1999). Therefore, rehabilitation endeavors to return individuals with
adventitious injury or illness to optimal states of functioning. Idealistically, a team of rehabilitation professionals such as medical doctors, nurses, occupational therapists, physical therapists, speech pathologists, psychologists, and rehabilitation counselors works with the rehabilitation candidates to achieve goals set by the patients in specific areas of functioning including psychological, vocational, sociological, and physical spheres (Purtilo, 1991; Olkin, 1999). Rehabilitation team members form a collaborative, cohesive bond to work toward client goals; however, issues may arise that work against the morals and ethics of the team concept (Maki & Riggar, 1997; Naji, 1975).

Rehabilitation Goals and Confounding Variables

The goal of the team is to foster patient autonomy by honoring the desired outcomes goals of patients. By giving the client this autonomous role, the team empowers and acknowledges that patients are the rightful and rational owners of their destinies. The team, therefore, acts to respect patient autonomy, upholding the beneficience morality (Purtilo, 1991). The team holds discussions that consider patient welfare, focusing upon the individuals' abilities to set reasonable, achievable goals. Upon finding that the individual is making harmful or irrational decisions, the team may decide to impose opinions, a concept known as paternalism (Purtilo, 1991). The paternalistic dynamic of the rehabilitation team is controversial because, when employing paternalism, the team endeavors to maintain a standard that allows client autonomy, known as “beneficience.” However, the team may, at times, exclude
the client or guide the client along traditional or "well-traveled" treatment plans, thereby limiting client input and possible potential (Purtilo, 1991). Having a rehabilitation team supposedly allows a system of checks and balances that function to prevent diversions from the standards of "benefiance" (Purtilo, 1991). Unforeseen dynamics may influence the group such as reliance upon a set of prescribed treatments, instead of individualizing the treatment plan. In other words, rehabilitation professionals are prone to fall into a treatment rut and are uncomfortable with deviations despite the fact that every client is different. For instance, with traumatic brain injuries, assumptions that the client lacks understanding or awareness may occur, prompting a professional to make recommendations accordingly. Though the client may have experienced deficits, awareness and judgment may be intact. In such instances, the professionals believed to be acting in the best welfare of patients may be inadvertently limiting client potentials (Purtilo, 1991).

Another negative phenomenon known to occur is for the team to "cover for" or go along with" the weakness of a member or members of the team (Purtilo, 1991). At this point, agendas other than facilitating clients toward their goals are being served. Second, team members may become biased as a consequence of either liking or disliking a patient (Purtilo, 1991). A premise of paternalism maintains that paternalism is justifiable when it fosters patient dignity and potential (Morrison, 1991; Purtilo, 1991). Such objectives assist rehabilitation professionals in adhering to values existing in the autonomy-beneficience team approach (Purtilo, 1991).
Inclusion and Consumerism

In practicing consumerism inclusion, it is vital to include the client in treatment goal planning and in collecting data about perceptions, attitudes, and experiences encountered during the rehabilitation process. Rehabilitation programs regularly boast including the insider in the planning and implementation goals and even agree that maximum involvement by the consumer fosters optimal recovery (Chan et al., 1997). However, because of previously mentioned cultural, attitudinal, political, and financial barriers, true client/consumer involvement is, at times, an idealistic sentiment (McAlees & Menz, 1992). In addition, previous studies that indicated high levels of client satisfaction with rehabilitation treatment measured variables in a skewed fashion (Bativity & Dejong, 1990; Heppner & Claiborn, 1989; Richard, 2000).

Bativity and Dejong (1990) conducted evaluative studies of past quantitative studies that reported high levels of consumer satisfaction and found that the large majority of such studies measured satisfaction as a single construct on issues that were important to clinicians and providers rather than the clients. Research that defined satisfaction as multi-dimensional had higher rates of consumer dissatisfaction with rehabilitation services as constructs were explored that mattered to the clients (Richard, 2000; Singh, 1990). Other research conducted by Crisp (2000) that found that perception toward social stigma played a role in client satisfaction with rehabilitation. Those that believed they were oppressed by society due to having a disability
were less satisfied with rehabilitation treatment than those who de-emphasized their disabilities (Crisp, 2000).

In determining whether clients are satisfied with rehabilitation goals and treatment plans, an obvious source to turn to is the client (Richard, 2000). Rehabilitation alleges to rely heavily upon the concepts of client efficacy derived from the teachings of Bandura (1977) who purported that individuals, given the right conditions, strive toward their expected optimal selves and functioning (Caeser, 1997; Richard, 2000). In remaining true to the premises and purposes of rehabilitation to return individuals to optimal states of functioning, expectations of the client must be observed and included (Chan et al., 1997; Richard, 2000; Wright, 1983). In summary, the concept of inclusion begins during implementation of rehabilitation or habilitation treatment goals.

Policies and Legislation

Ancient Policies

Historically, attitudes toward those with disabilities were unforgiving, uncharitable, and inhumane as religions and philosophies of many early societies prevented positive attitudes toward inhabitants with disabilities. The disabled were those people whose functioning deviated significantly from the majority population in the areas of intellectual functioning, physical functioning, physical appearance, and behaviors (Covey, 1998; Rubin & Roessler, 1995). Such individuals were shunned, ostracized, and considered liabilities by many early societies. In some earlier and present societies, those with disabilities
were and are believed disdained by God, hence earning His wrath and damnation (Covey, 1998; Olkin, 1999; Rubin & Roessler, 1995).

The early Greeks placed importance upon body-soul unity, connoting a damaged soul if the body is damaged or abnormal in some manner. Eugenics was practiced, leaving children and adults with abnormalities to be eliminated by the elements propagating stronger, more normal individuals (Covey, 1998; Mackelprang & Salsgiver, 1996). The Romans tolerated those with mental disabilities in only the elite upper classes while all others were considered burdens and were discarded, though treatment receptacles did exist (Covey, 1998; Rubin & Roessler, 1995). Perceptions of those with mental disability in ancient and medieval were that the individual is inhabited by demons or the devil. During the 16th century, attitudes shifted from that of the individual being possessed by demons to the individual being sick (Covey, 1998). Through the rise of Christianity and Catholicism to the present, the church as socially affected public perception of people with disabilities (Covey, 1998).

Renaissance Policies

Housing for those with abnormalities began to arise as asylums in Europe. The public was charged admission for a glance of an individual with the disability in these asylums, ancestor to the circus (Rubin & Roessler, 1995). Conditions of the asylums were often unsanitary and treatment of the inhabitants was less than humane (Covey, 1998; Rubin & Roessler, 1995). Training for those with mental retardation existed in the 17th century and documentation of teaching the deaf can also be found, marking evidence of
early forms of rehabilitation post-renaissance (Covey, 1998; Rubin & Roessler, 1995). In the 17th and 18th centuries, schools for the deaf and blind arose indicating further efforts to create productive environments for those with certain disabilities. This trend was a reaction to the rise of Christianity in earlier centuries. As benevolent as such efforts were, society and Christian beliefs still shunned those with mental and severe abnormalities. Families that had members who were disabled tried to hide them so as not to ruin chances of marriage for normal family members (Covey, 1998).

19th Century to Present Policies

As a result of the Social Darwinism movement in the 19th century, the concept that self-worth correlates to the level of monetary income earned was an engraved belief in American society (Covey, 1998; Rubin & Roessler, 1995). The underlying philosophy was that in order to have worth in society, people must contribute to society through work and productivity (Covey, 1998; Rubin & Roessler, 1995). Culture in the United States placed lesser value on contributions to society that do not earn paychecks such as childcare, home maintenance, and home financial management, thus devaluing activities as such. Though these were necessary and valuable services, they were viewed as of lesser importance than contributions involving financial productivity (Buchanan, 1990). Evidence of this sentiment was seen in public laws such as the Smith-Fess Act of 1920 that provided rehabilitation services for those individuals for whom there existed some vocational potential, thus eliminating aid for those deemed unemployable (Hahn, 1987).
The perspectives represented by this sentiment presented a dilemma for the individual with incurred disability. Either the individual adopted the attitude of helplessness and devaluation or the opposite attitude of minimizing the incurred deficits and maximizing goal attainment (Rubin & Roessler, 1995; Wright, 1983). Crisp (2000) found four profiles of people with disabilities after conducting qualitative inquiry of perceptions of rehabilitation by those with disabilities. These profile included “battlers” who saw themselves as unhelpable and victims of their predicaments. “Strugglers” were those who saw their disabilities as major disruptions to life whereas “contenders” de-emphasized or redefined their disabilities. Finally, “optimizers” acknowledged their disabilities while de-emphasizing its impact and accommodating with the environment (Crisp, 2000).

The purpose of having rehabilitation public policies and delivery systems in place was to create equal access to opportunities which could maximize the potential to achieve goals (Gilson & Depoy, 2000; Perrin & Nirje, 1985). Though such policies reflected sentiments that sympathize with those with disabilities, adherence to policies fostered the notion that those with disabilities must be “normalized” into society (Crisp, 2000). This notion suggested the more archaic thinking that individuals with disabilities are weak, of lesser ability, or crippled that is reflected in the medical model’s definition of people with disabilities outlined by Gilson and Depoy (2000). Such thinking was the trend at the turn of the 20th century, however.
Current laws and attitudes reflect modern beliefs and trends toward humanism and inclusion that occurred early in the 20th century (Covey, 1998). Rehabilitation became a recognized profession in the 20th century as a result of concurrent changes and events such as advances in medical technologies in institutions, industrialization, and the World Wars. During the early 20th century war efforts, people with disabilities were hired into the work force. It was noticed that such individuals were capable of making production rates despite their handicaps. After World War II, mortality rates decreased as a result of medical advances making re-assimilation into the work force for disabled veterans necessary (Covey, 1998; Mackelprang & Salsgiver, 1996; Zunker, 1998).

Earlier public policies such as the Smith-Hughes Act of 1917, the Soldier’s Rehabilitation Act of 1918, and the Smith-Fess Act of 1920 were impetuses for evolving public laws and policies. The Smith-Hughes Act of 1917 provided federal dollars to match state dollars spent on vocational education as a result of the nation’s trend from ruralization toward industrialization. The Soldier’s Rehabilitation Act of 1918 was the first federal program designated for the purpose of vocationally rehabilitating disabled veterans. Pensions were paid to veterans disabled in any activity while in the service dating as far back as the Revolutionary War. Vocational rehabilitation was provided only to those deemed to be employable after receiving services (Rubin & Roessler, 1995). The Smith-Fess Act of 1920 was the first civilian
program launched for persons with disabilities providing vocational rehabilitation for those deemed to be employable (Rubin & Roessler, 1995).

The Vocational Rehabilitation Act Amendments of 1954 enacted by President Eisenhower significantly increased funding for the vocational rehabilitation movement for those with mental and physical handicaps by creating funding for the training of rehabilitation professionals (Rubin & Roessler, 1995, p. 33). Later, Social Security amendments and vocational rehabilitation amendments created income for those unable to work and assistance for those able to return to work in some capacity (Rubin & Roessler, 1995, p. 37). Other disability legislation contributed toward inclusion and socio-political equality, including the Architectural Barriers Act of 1968 that stated that all federally financed and constructed transportation facilities or buildings must be accessible and useable by people with mobile, visual, and auditory disabilities (Fleischer & Zames, 1998).

Section 504 of the Rehabilitation Act of 1973 prohibited businesses and employers who received federal funds from discriminating on the basis of physical or mental disabilities. This bill utilized the concepts developed in Title IV of the 1964 Civil Rights Act that prohibited discrimination based on race, ethnicity and religion (Fleischer & Zames, 1998; Rubin & Roessler, 1995). The Individuals with Disabilities Education Act (IDEA) of 1975 provided that children with disabilities receive a free, public education with the least restrictive environment (Fleischer & Zames, 1998). The Fair Housing Act Amendments 1988 stated that discrimination against people with disabilities was prohibited
in housing sales, rentals, or financing such housing. Further, landlords were required to make reasonable accommodations of existing premises and new buildings must be accessible (Fleischer & Zames, 1998; West, 1991).

These laws paved the way for more recent antidiscrimination laws such as the Americans with Disabilities Act 1990 signed by President George Bush. The Americans With Disabilities Act (ADA) of 1990 was important legislation created after information was gathered from three Senate hearings, 63 public hearings, and surveys issued by Louis Harris and Associates in 1986 that indicted multiple injustices occurring to peoples with disabilities (Rubin & Roessler, 1995, p. 85). The ADA of 1990 opened the door wider for the disabled to access mainstream society and ensured that enforceable standards exist (Rubin & Roessler, 1995, p. 85). The Americans With Disabilities Act (ADA) of 1990 addressed discrimination concerns congruent with section 504 of the Rehabilitation Act of 1973. Section 504 of the Rehabilitation Act of 1973 was criterion based in that it required that an individual possess an impairment, physical or mental, causing substantial limitations for daily life; that the impairment be documented; and that the individual be regarded as having an impairment (Adams, 1991). From a condensed legal perspective, the Americans with Disabilities Act of 1990 utilized the language of Section 504 of the Rehabilitation Act of 1973 defining a disability as follows:

(1) A mental or physical impairment which substantially limits one or more of the major life activities of that person, (2) a record of the impairment(s), and (3) is regarded as having such an impairment. (p. 12111)
The Americans with Disabilities Act (ADA) of 1990 prohibited discrimination and disqualification of an individual from hire who with reasonable accommodations could perform the tasks of the job in both the public and private hiring sectors. It also provided for equal access to public services and facilities causing physical barriers to be modified to enhance accessibility. Last, it mandated that accommodations be made to enhance access to telecommunications (Adams, 1991; Fleischer & Zames, 1998; Rubin & Roessler, 1995; Zunker, 1998).

These more recent laws reflect changes in attitudes by people with disabilities and the public that are reflected in the social and political models of viewing people with disabilities. This more modern epistemology states that disabilities are caused by the failure to remove environmental barriers, thereby imposing obstacles and social restrictions (Crisp, 2000; Gilson & Depoy, 2000). Advocacy groups for those with disabilities strive for inclusion by increasing awareness among businesses that making their businesses accessible will increase revenues. However, this sentiment is opposed as studies show that employers fear that having people with disabilities and abnormalities in their businesses will drive consumers away (Condeluci, 1995).

Nevertheless, employers are given incentives such as tax breaks to hire those with disabilities and are also encouraged to retrain injured employees in order to keep their workman's compensation insurance from rising. Employers express concerns regarding costs of special accommodations,
effect of accommodations on work schedules and fellow employees' attitudes and concern regarding productivity levels being adversely affected (Roessler & Sumner, 1997). The latter concerns of employers and entrepreneurs reflect the pervasive avoidance of inclusion of people with disabilities. A more recent study by Hernandez, Keys, and Balcazar (2000) that examined the impact of the Americans with Disabilities Act of 1990 on employer attitudes found that overall employers were more willing to hire people with disabilities. The study did show that increases in employment of those with disabilities has occurred over the last 10 years, but a significant gap exists between positive attitudes toward hiring people with disabilities and actual hiring rates suggesting that the positive attitudes are superficial (Hernandez et al., 2000).

While inclusion of minority populations into functional society is the goal of policies and legislation, the attitudes of the general population still perpetuate exclusion (Condeluci & Williams, 1997). Likewise, rehabilitation professionals are prone to absorb, perpetuate, and impose onto clients the paternalistic, prescriptive values brought on by exclusionist attitudes (Crisp, 2000). Achieving goals such as returning an individual to work in a modified capacity is plausible because it relieves financial strain for insurance companies and the government; however, it fosters the notion of admonishing those who are unemployable (Kuehn, 1991). As people with disabilities assume positions that contribute to society and not only taking from society, the more likely the public will be able to change negative attitudes (Rubin & Roessler, 1995). Rehabilitation professionals have the chance to foster
changes in both the attitude of the representative public as well as disabled individuals aiming to assimilate with society after a disability is inflicted.

**Traumatic Brain Injury**

**Statistics**

Adults with traumatic brain injury are the chosen focus for this research. In 1985, the projected cost of lifetime care for a person with incurred traumatic brain injury was only $85,000 per person across all levels of severity. By 1999, advances in medical technology have improved survival rates for individuals with severe traumatic brain injury that drove up the cost of lifetime care by as much as four times the original projection to approximately $300,000 per instance of severe head trauma (Kraus & McArthur, 1999). In 1995 Miller et al. collected data from the late 1980s from worker's compensation data banks and found that medical costs for all severe head injuries approached $300,000 per instance as cited in Kraus and McArthur (1999). It was also found that acute medical costs for the more severe injuries approached $2.4 million based on the 1994 research of Miller et al., as reported by Kraus and McArthur (1999). The total cost per new instance in head injury in the United States is $6.5 billion with the cost of the subsequent year's medical cost projected at $13.5 billion (Kraus & McArthur, 1999).

Because of the increased survival rates of individuals with traumatic brain injury, the rehabilitation needs also had increased dramatically, emphasizing the need for a better understanding of traumatic brain injury and its effects. Traumatic brain injury is acquired damage to the brain as a result of
impact from acceleration injuries such as being hit by a moving object or deceleration injuries such as striking a stationary object while in motion (Noble, Cobley, Laski, & Noble, 1990; Krauss & McArthur, 1999). Genetic abnormalities occurring prenatally and perinatally, degenerative diseases such as Alzheimer’s disease, infectious diseases, tumors, and strokes are excluded from this definition (Livneh & Antonak, 1997). The definition of traumatic brain injury is inconsistent in the literature. Some authors use the terms “head injury” and “traumatic brain injury” synonymously, while others use the terms separately. Used separately, the term traumatic brain injury refers to acute damage to the central nervous system. Head injury refers to both damage to the central nervous system as well as other injuries lacking any neurological sequella, such as soft tissue injuries to the face, scalp, or skull fractures (Kraus & McArthur, 1999; Woo & Thoidis, 2000). Other terms used synonymously in the literature include closed head injury, nonpenetrating head injury, and blunt head trauma, but are more descriptive than the all inclusive term, head injury, previously described (Livneh & Antonak, 1997).

Statistics show that there are certain populations that are at higher risk for sustaining such injuries. For instance, the highest incidences of closed head trauma are reported to be between the ages 15 and 24. Mortality rates are highest in this age group as well. Males outnumber females at a ratio of 3.4 to 1 (Woo & Thoidis, 2000). Woo and Thoidis (2000) cited that nonwhite minorities are at higher risk for incurring head injury. Krauss and McArthur (1999), however, stated that measures taken by hospitals to record race or
The ethic incidence of head injury vary too greatly to validly claim that any one group sustains injuries more than another. Studies show that there are higher numbers of head injury among lower socio-economic populations (Krauss & McArthur, 1999; Woo & Thoidis, 2000). Motor vehicular collisions account for 50% of the incidences of head injury with falls accounting for 21% of new cases (Woo & Thoidis, 2000). Firearm injuries account for 12% of head trauma, and males between the ages of 25 and 34 incur such injuries at 6 times the rate of females the same age. Sports injuries account for 10% of new cases of head injury, and the remaining percentage falls into the category of "other" as causes for head injury new cases (Woo & Thoidis, 2000). Finally, records show that 56% of the incidences of new head injuries show a blood alcohol level that is positive, a factor that compounds acute medical treatment phases as respiratory complications tend to increase (Krauss & McArthur, 1999).

The amount of literature has grown tremendously since the 1980s regarding traumatic brain injuries relevant to mortality and morbidity. One study noted that in the Journal of Neurosurgery between 1944 and 1974 there was a total of two articles that related mortality and morbidity to traumatic brain injury (Hill, 1999; Langfitt, 1978).

Strauss and Savitsky in 1934 compiled physical symptoms of closed head injury and called the malady "post concussion syndrome" (Fabiano & Daugherty, 1998). One of the earliest documented accounts of brain injury was of an individual named Phineas Gage who in 1868 received a frontal lobe brain injury. Significant in this account is that the impact of his injury was that not only
were the physical repercussions recorded but also the psychosocial sequella. His family and friends described his personality and behaviors as being so different that he did not seem like the same person (Hill, 1999; Stuss, Gow & Ross Hetherington, 1992).

**Primary injuries**

Gage’s injury was localized in that a railroad spike became lodged in his frontal lobe. His injury was also considered to be a penetrating injury in that a foreign object penetrated his brain matter. Examples of other penetrating injuries are bullet wounds, along with any other foreign object that penetrates the skull and brain tissues. These are also examples of primary injuries, those injuries that occur immediately upon impact. Primary injuries can be focal, such as Gage’s injury, or diffuse affecting brain tissue widespread, also known as diffuse axonal injury (Burke & Ordia, 2000; Wehman & Kreutzer, 1990). Axons are the connecting cells in the brain that are believed to be the transmitters of neurochemicals that ultimately result in autonomic actions, non-autonomic actions, and behavior (Graham, 1999). Other types of focal injuries include skull fractures, intracranial hematomas, cortical contusions, lacerations, and penetrating wounds.

Skull fractures are associated with increased risk for brain injury, hematoma, or cranial nerve damage but can occur without neurological consequence. A hematoma is intracranial hemorrhaging, bleeding in the brain, that can cause further damage due to the pressure build-up within the enclosed casing of the skull (Burke & Ordia, 2000). This is the leading cause
of complications, coma, and death; patients may seem fine initially but later
decline due to the increasing pressure within the brain due to hemorrhaging
(Graham, 1999). Cortical contusions, bruising of the brain, are most commonly
associated with traumatic brain injuries. These contusions are more
predictable because, upon impact, the brain is thrust upon the bony
protrusions of the inside wall of the skull. Upon doing so, the brain
experiences coup and contrecoup ricochet effect inside of the skull case. Coup
injuries to the brain occur as the brain is thrust forward in the direction of the
impact. Contrecoup injuries occur to the opposite side of the brain after the
coup impact has bounced in the opposite direction (Burke & Ordia, 2000).

**Secondary injuries**

Secondary injuries are injuries that occur as a result of the biochemical
and physiological changes occurring within hours or days after initial impact.
Neuro-chemical and cellular changes can take place as a result of failing
autonomic systems. Keeping patients properly oxygenated is critical; too much
oxygen to the brain could result in increased blood flow and increased
hemorrhaging; however, too little oxygen could suffocate brain cells (Graham,
1999). In addition, neuro-chemical agents are released that can lead to other
secondary complications such as swelling, cell toxicity, and lesions (Burke &
Ordia, 2000). Other secondary complications include intracranial pressure
(ICP), cerebral edema (swelling of the brain), and hydrocephalus, also know as
water build up in the brain, and co-morbid injuries occurring elsewhere in the
body (Burke & Ordia, 2000).
Other factors thought to impact medical and rehabilitation outcomes for individuals incurring traumatic brain injury are duration and level of unconsciousness or coma, duration of amnesia before and after injury, hypoxia, and blood alcohol level (Moore & Stambrook, 1995; Prigatano, 1999). The initial assessment includes assessment techniques to determine the condition of the injury victim such as level of consciousness gauged by Glasgow Coma Scale, pupil size and response, blood pressure, and heart rate. Additionally, a mental status examination, reflex, muscle strength, and sensation are performed to assess neurological abnormalities, but patient response is required and may not be available if unconscious (Ordia, 2000). Indicators for admission to the hospital for observation include altered level of consciousness, prolonged loss of consciousness, nausea and vomiting, seizures, severe headaches, focal neurological signs, skull fracture, cerebral contusion, hematoma, edema, or cerebrospinal fluid presence (Ordia, 2000).

Surgical management of intracranial hemorrhages, penetrating injuries, and intracranial pressure may become necessary for the moderate to severe injuries, though mild injuries are not excluded. Initial treatments include osmotic diuretic treatment which is the administration of agents to dehydrate the brain, blood pressure management, elevation of the head to foster proper fluid drainage, controlled hyperventilation to keep oxygen in the brain regulated, temperature control, sedation to foster proper vascularization, and anti-seizure medication. If intracranial pressure is unmanageable, then inducing a
barbituate coma is considered until ICP has been at optimal levels for over 24 hours (Ordia, 2000).

Scales Used to Categorize Brain Injury Severity

The Glasgow Coma Scale (1974) is widely used to measure levels of unconsciousness or coma that indicate the severity of brain injury. This scale assesses patient response to verbal commands, motor movement commands, and responses with eyes (Table 1).

Another measurement used to categorize, then predict neurological and neurobehavioral outcomes after incurring traumatic brain injury is the Ranchos Los Amigos Scale of Cognitive Functioning. The Rancho Los Amigos Scale of Cognitive Functioning categorizes behavioral responses used in the Glasgow Coma Scale on a total of eight levels (Table 2).

Another scale commonly used to anticipate severity of injury measures the duration of amnesia following injury, known as post-traumatic amnesia. Another type of amnesia is the loss of memory of events prior to an accident known as retrograde amnesia (McKinlay & Watkiss, 1999). The following criteria are use to categorize the severity of injury (Table 3).

The impact of traumatic brain injury (TBI) can range from mild deficits to severe deficits causing symptomatic problems cognitively, behaviorally, or physically. Some deficits may remain permanent while others may go through a spontaneous recovery (Prigatano, 1999). The above-mentioned scales are common tools used to categorize the severity of injury and positive correlations have been documented between the levels of coma, duration of amnesia with
Table 1

Glasgow Coma Scale

<table>
<thead>
<tr>
<th>Patient's Response</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Eye opening</strong></td>
<td></td>
</tr>
<tr>
<td>Eyes open spontaneously</td>
<td>4</td>
</tr>
<tr>
<td>Eyes open when spoken to</td>
<td>3</td>
</tr>
<tr>
<td>Eyes open to painful stimulation</td>
<td>2</td>
</tr>
<tr>
<td>Eyes do not open</td>
<td>1</td>
</tr>
<tr>
<td><strong>Motor</strong></td>
<td></td>
</tr>
<tr>
<td>Follows commands</td>
<td>6</td>
</tr>
<tr>
<td>Makes localizing movements to pain</td>
<td>5</td>
</tr>
<tr>
<td>Makes withdrawal movements to pain</td>
<td>4</td>
</tr>
<tr>
<td>Flexor (decorticate) posturing to pain</td>
<td>3</td>
</tr>
<tr>
<td>Extensor (decerebrate) posturing to pain</td>
<td>2</td>
</tr>
<tr>
<td>No motor response to pain</td>
<td>1</td>
</tr>
<tr>
<td><strong>Verbal</strong></td>
<td></td>
</tr>
<tr>
<td>Oriented to place and date</td>
<td>5</td>
</tr>
<tr>
<td>Converses but is disoriented</td>
<td>4</td>
</tr>
<tr>
<td>Utters inappropriate words, not conversing</td>
<td>3</td>
</tr>
<tr>
<td>Makes incomprehensible nonverbal sounds</td>
<td>2</td>
</tr>
<tr>
<td>Not vocalizing</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td></td>
</tr>
</tbody>
</table>

Severe Traumatic Brain Injury                   less than 9
Moderate Traumatic Brain Injury                 9 to 12
Mild Traumatic Brain Injury                     greater than 12

(Teasdale & Jennett, 1974)
Table 2

**Ranchos Amigos Scale of Cognitive Functioning**

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level I</td>
<td>No response</td>
<td>Patient in a deep sleep and unresponsive</td>
</tr>
<tr>
<td>Level II</td>
<td>Generalized response</td>
<td>Patient reacts to stimuli non-purposefully</td>
</tr>
<tr>
<td>Level III</td>
<td>Localized response</td>
<td>Patient reacts purposefully, but inconsistently</td>
</tr>
<tr>
<td>Level IV</td>
<td>Confused-Agitated</td>
<td>Patient is hyperactive, cannot process information</td>
</tr>
<tr>
<td>Level V</td>
<td>Confused-Inappropriate</td>
<td>Patient reacts to simple external structure, not independently</td>
</tr>
<tr>
<td>Level VI</td>
<td>Confused Appropriate</td>
<td>Patient is goal directed, but needs external direction</td>
</tr>
<tr>
<td>Level VII</td>
<td>Automatic Appropriate</td>
<td>Patient behaves appropriately, but seems robot-like with poor short term recall</td>
</tr>
<tr>
<td>Level VIII</td>
<td>Purposeful Appropriate</td>
<td>Patient alert, oriented, able to integrate past and recent events and is aware</td>
</tr>
</tbody>
</table>

(Nalkmus, Booth, & Kodimer, 1980)

Table 3

**Measures of Duration of Amnesia**

<table>
<thead>
<tr>
<th>Duration</th>
<th>Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 5 minutes</td>
<td>very mild</td>
</tr>
<tr>
<td>5 to 60 minutes</td>
<td>mild</td>
</tr>
<tr>
<td>1 to 24 hours</td>
<td>moderate</td>
</tr>
<tr>
<td>1 to 7 days</td>
<td>severe</td>
</tr>
<tr>
<td>1 to 4 weeks</td>
<td>very severe</td>
</tr>
<tr>
<td>More than 4 weeks</td>
<td>extremely severe</td>
</tr>
</tbody>
</table>

(McKinlay & Watkiss, 1999).
cognitive, and neurobehavioral outcomes (Krauss & McArthur, 1999; McKinlay & Watkiss, 1999). However, as cited in Kraus and McArthur (1999), Povlishock in 1992 and Maxwell in 1993 conducted studies that showed weak or no relationship between level of coma and duration of amnesia with outcomes. Use of the Glasgow Coma Scale (1974) as useful as it has been is controversial in terms of validity as a predictive instrument (Antonak, Livneh, & Antonak, 1993; Krauss & McArthur, 1999). Other researchers question the use of such instruments, arguing that they are relevant only to the acute physical symptoms. Abstract constructs that make up personality cannot be anticipated or predicted accurately at the time of injury (Crisp, 1994; Hill, 1996). Further, recalling that 56% of neurological injuries involve victims with positive levels of blood alcohol consumption, inebriation confounds accurate categorization of the Glasgow Coma Scale (Krauss & McArthur, 1999; Pentland & Whittle, 1999). In addition, complications with oxygenation causing a condition known as hypoxia also distort accurate measurements of the severity of injury (Pentland & Whittle, 1999). Therefore, categorization of mild, moderate, and severe seem only relevant within the context of acute medical phases and cannot be wholeheartedly relied upon as accurate predictors of at least neurobehavioral and psychosocial complications.

Changes After Traumatic Brain Injury

From the period of time immediately after injury through the first year of recovery, complications in foundational domains such as personality, cognitive, physical, and psychosocial aspects of individual with traumatic brain injury can
be affected (Livneh & Antonak, 1997; Antonak et al., 1993). Because this particular disability has the propensity to impact each survivor in so many ways, determining and predicting rehabilitation needs has proved to be challenging. Assessment techniques used to determine deficits and residual capabilities include neurological examinations, psychiatric examinations, neuropsychological examinations, as well as assessments administered by a variety of specialized therapists such as speech pathologist, occupational therapists, physical therapists, and vocational rehabilitation counselors. After appropriate assessments have been administered, the team of treatment professionals together with the survivor and family members construct short-term and long-term goals. Examples of common cognitive deficits include short-term memory loss, long-term memory loss, attention deficits, slowed executive function, and lowered intellectual functioning (McKinlay & Watkiss, 1999).

The treatment team works concordantly to improve deficits with cognitive retraining techniques known as cognitive remediation that has consisted of standard exercises designated by test scores, seldom tailored to the client context (McKinlay & Watkiss, 1999). Physical, functional, recreational, emotional, and vocational difficulties are also addressed through an array of services provided by the rehabilitation team including orthopedic doctors, neurologists, physical therapists, occupational therapists, speech pathologists, psychologists, counselors, and vocational counselors (Prigatano, 1999).
Brain Injury Rehabilitation Challenges and Limitations

Because of the unpredictable nature of traumatic brain injury and its overlapping sequella, it has been difficult to measure the breadth of issues for each individual through positivist inquiry (Livneh & Antonak, 1997). To do so imposes serious limitations to growth and recovery potential. The most useful manner of attempting to understand the victims' perceptions of acquiring brain injury is adherence to understanding survivors' reality of events phenomenologically (Prigatano, 1999). Factors recognized as significant in determining psychosocial outcome for TBI survivors include pre- and post-injury education, personality, social network, cultural, financial, TBI sequella, resources, medical care, and treatment team. Antonak et al. (1993) noted that emphasis needs to be placed upon psychosocial sequella subsequent to brain injury as this has more significant impact upon social relationships and therefore is a better predictor than the physical sequella. Hill (1999) noted that literature documenting traumatic brain injury from a psychosocial perspective is scarce, especially from the perspective of survivors. Longevity studies tend to focus upon a span of 3 to 5 years post-injury, and Hill (1999) contended that this is not long enough to make accurate predictions.

Significant deficits exist in the knowledge base of psychosocial adaptation to traumatic brain injury because of problems with using appropriate research methodologies. Selecting the most appropriate research design is problematic because defining variables has been difficult. Variables become defined from data collections of which the majority are retrospective
interviews and symptom checklists from family members, rehabilitation providers, and sometimes consumers (Livneh & Antonak, 1997; Antonak, Livneh, & Antonak, 1993; Bergland & Thomas, 1991). Prigatano and associates conducted a search from 1985 through 1995 of research that looked for research titles that reflected brain dysfunction concurrently with the constructs of frustration and confusion. Out of 7,600 articles found involving traumatic brain injury, only 14 reflected these or similar emotions (Prigatano, 1999). One ethnographic study of 21 moderately injured survivors of closed head injury notes the loss of identity and sense of self that were determined through semi-structured interviews and observations and the coping mechanisms the survivors used to redefine their new identities (Krefting, 1989). Another qualitative study examined and interpreted the themes that emerged in terms of personality types that represent different levels of having coped with and adjusted to the changes incurred after traumatic brain injury (Crisp, 2000). Examining these changes qualitatively is, perhaps, the most valid method for facilitating the process of discovering a new self (Hill, 1999; Prigatano, 1999).

One of the most challenging aspects for helping professionals in working with brain-injured populations is to determine whether or not their client's judgment is clear. In working with populations with disabilities and brain-injured populations, sometimes clients set unrealistic goals for themselves after a disability is incurred. Clients either experience a lack of understanding of the extent of acquired disabilities or they are experiencing
denial. The rehabilitation professional is faced with the task of ascertaining the client's decision-making capabilities. This has serious implications as the professional also has to ascertain the client's potential to improve decision-making skills if the patient does seem to exhibit unrealistic expectations. Should the professional determine that the client cannot set realistic goals because of the cognitive damage, then goals must be set for that person (Prigatano, 1999). However, should clients demonstrate potential to do so, then rehabilitation professionals must empower and allow clients to pursue desired goals (O'Hara & Harrell, 1990).

The problem is that this is not always easily determined. Should rehabilitation professionals determine goals for individuals that possessed the capacity to do so, then such counselors have not served their clients. Instead, the basic rights of the client have been ignored and devalued. This has serious ethical implications. Therefore, it is imperative that the client's subjective reality be understood, respected, and upheld. To do this, assessments and testing are available to ascertain levels of cognitive and emotional functioning and potential. It is also vital to see through the client's eyes and endeavor to understand phenomenologically from the insider's perspective (Prigano, 1999; Wright, 1983).

Models of Brain Injury Rehabilitation

In examining the philosophies of current traumatic brain injury rehabilitation theory, two trends that appear to be dominant throughout the
literature are one that is "community-based" and one that is "systems-based" (Dahmer et al., 1993; Ragnarsson, Thomas, & Zasler, 1993).

The systems-based treatment modality is predominantly inpatient and medically based as it is designed to treat acute stages of moderate to severe injuries. This model usually takes place at a facility where a combination of services is implemented including medical care, psychiatric services, counseling, occupational therapy, physical therapy, speech pathology, vocational counseling, and recreational therapy. Once the patient achieves criteria set by the rehabilitation team for a reasonable level of functional independence, the patient begins a transition to the home environment with the family. From here patients participate in day treatment until discharge is determined appropriate by the team. Financial resources as well as the patient support system usually impact determination of patient discharge to the home. With some facilities, case managers follow the case and "check in" on the client and aid in facilitating transition. Ultimately, it is up to the client to transfer the skills acquired at the facility to home (Brain Injury Association, 2000).

Community-based programs implement treatment in settings other than medical facilities. Once patients are deemed medically stable, they can participate in specialized therapies within their homes working in occupational therapy, physical therapy, speech pathology, counseling, and vocational counseling. Such services are designed to facilitate the survivors in transitioning from dependence to independence within their communities. Another example of a community-based program is that of a supported
community program that provides a place of residence to assist with transitioning toward community re-entry (Brain Injury Association, 2000).

While there are numerous traumatic brain injury rehabilitation treatment programs, this literature review focused upon models in the literature that foster survivor efficacy and empowerment with an attempted understanding of the perspective of the survivor. Three such models were examined including Livneh and Antonak’s (1997) Psychosocial Adaptation to Disability phase model, O’Hara and Harrell’s (1990) Empowerment Model, and Prigatano’s (1999) “Principles for treating individuals with traumatic brain injury” cognitive-based model.

**Psychosocial Adaptation to Disability**

Livneh and Antonak (1997) developed a conceptual model of adaptation to disability (Appendix F). Adjustment is viewed as a subset of and last stage of adaptation, whereas adaptation is the continuous evolvement through which an individual with acquired illness or disability achieves maximal independence within the environment. Adjustment is differentiated from adaptation in that it is the final phase in the adaptation process enveloping acceptance of disability and assimilation of pre-injury psychological components and post-injury psychological components.

There are four classes of adjustment and adaptation according to Livneh and Antonak (1997). In Class I variables deal with the disability characteristics such as age, extent of injury, type of injury, degree of neurological impairment, and lethality. Class II variables contain socio-demographic information
including gender, ethnicity, developmental stage, education, marital status, and job title. Personality attributes make up Class III variables and include values, self-image, premorbid psychosocial adaptation, attitudes, locus of control, and defense mechanisms. Class IV variables include socio-environmental factors such as home environment, social groups, friends, and attitudinal barriers imposed upon the client (Livneh & Antonak, 1997).

These four classes of variables impact each stage of progression while adjusting and adapting to disability. These stages of progression include an early stage that involves shock, anxiety, and denial of the trauma. Intermediate states focus upon steps toward acceptance of the incurred trauma and include anger and depression. The later stages move the survivor acceptance and adjustment. A circular sequence accounts for different reactions and decisions regarding the trauma at any given point during the process eliminating the model from being a linear stage model entirely (Livneh & Antonak, 1997).

**Empowerment Model**

The Empowerment Rehabilitation Model (Appendix G) (O'Hara & Harrell, 1991) is unique in that a brain-injured individual may enter treatment at any point after becoming injured. Psychotherapeutic intervention is emphasized in order to enhance emotional adjustment, mastery of cognitive skills, and social skills. The Empowerment Model's guiding principle maintains that all of the foundational domains--cognitive, emotional, physical, and interpersonal--must reintegrate at a rate chosen by the client in order to move victims to survivors (O'Hara & Harrell, 1991).
This model embraces goals for the rehabilitation team and survivors of traumatic brain injury in order to achieve empowerment, instilling belief in another individual’s ability to succeed. These goals include enhancing motivation, enabling clients with information about their injury, providing structure until the clients are able to do so on their own, teaching skills and strategies to compensate for losses, and facilitating acceptance of differences before injury and after injury (O’Hara & Harrell, 1991). The underlying premise of this model is that facilitation of the above-mentioned goals leads to an enhanced internal structure and motivation equated with empowerment for individuals with incurred traumatic brain injury. The model is presented nonhierarchically as EXTERNAL STRUCTURE + MOTIVATION + INFORMATION + ACCEPTANCE + SKILLS = EMPOWERMENT (O’Hara & Harrell, 1991). No component can be eliminated or dismissed, or the goal of empowerment is unlikely to be achieved.

Holistic Neuropsychological Rehabilitation Program

George Prigatano, a practitioner and researcher in brain injury rehabilitation, stated that in order to facilitate clients from post-acute stages of traumatic brain injury through adjustment and reintegration with oneself and society, awareness and judgment need to be restored or compensated (Prigatano, 1995, 1999). He emphasized that cognitive remediation and restructuring, along with psychotherapy be implemented in order to enhance adjustment to traumatic brain injury. He proposed several components for a “Holistic Neuropsychological Rehabilitation Program” as development of a
therapeutic atmosphere and bond between treating therapist teams and client. These included cognitive retraining, small-group cognitive retraining hour, cognitive group therapy, individualized cognitive retraining, psychotherapy, family involvement and education, and the protected work trial.

In pursuit of developing a therapeutic atmosphere and understanding the perspectives of clients, Prigatano (1999) maintained that clients could optimize therapeutic goals if confusion and frustration were reduced and trust was established between the rehabilitation staff and client. Group therapy and individual treatment modalities were endorsed as mechanisms to restore and restructure cognitive functioning or to introduce strategies to compensate for deficits (Prigatano, 1999). He introduced small-group cognitive therapy hour as another means of implementing this concept, yet in a short, concise time frame that holds the clients' interest (Prigatano, 1999). Family education was meant to inform and support the immediate support systems of the clients so that loved ones had a better understanding of how they and their loved one were impacted. Last, supported return-to-work programs were introduced to enhance the transition in returning to and maintaining work (Prigatano, 1999).

Summary

Adjusting to and living with traumatic brain injury is a complex journey for the survivor as well as for those who are treating and supporting the individual. The survivors of traumatic brain injury experience intrinsic and extrinsic variables during the process from cognitive and emotional to sequella to social stigma and isolation. Shifts in disability legislation have led to subsequent
shifts in disability philosophies; the environment, the outsiders, rather than the individual with disability imposes handicaps and disabilities. Rehabilitation philosophies have experienced similar shifts in theory, but inquiry is needed in order to determine whether the shifts are occurring yet in practice. Quantitative methods of ascertaining rehabilitation treatment methods have provided limited information that is skewed by the parameters of the questionnaires and assessments that gauge satisfaction and adjustment. Qualitative methods of ascertaining this information provide valuable data but are scant; therefore, this study endeavors to provide additional data for the research base in a qualitative fashion. The following chapter discusses the qualitative methods chosen for answering the research problem presented in this study. In this endeavor of learning how survivors of traumatic brain injury view their adjustment and rehabilitation interventions, two purposes are accomplished. One is that the perceptions of survivors of traumatic brain injury is learned phenomenologically and that accounts of the survivors may be properly constructed from the inside view to the outside view. Second, the derived constructs from these survivors may be compared and contrasted with existing theories of adjustment to disability and traumatic brain injury.
CHAPTER 3
METHODOLOGY

The review of relevant literature lends a better understanding into what is already known about adjustment issues in disability and brain injury rehabilitation. The earlier writings of Beatrice Wright (1983), Carolyn Vash (1981), and Franklin Shontz (1975) present psychosocial issues that result from incurring a disability that lead to the more recent paradigms of understanding the psychosocial issues of disability from social, multicultural, and needs-based perspectives discussed by Oliver (1996), Wendell (1996), and Brown et al. (2000). From these writings, the progression of understanding these issues has gone from viewing disability as being an intrinsic phenomenon within the individual that must be minimized and reframed to viewing obstacles presented by disabilities as being strictly environmental (Crisp, 2000). As such, one of the questions raised by this research is how has rehabilitation fostered or impeded individuals with traumatic brain injury in aspiring to their rehabilitation and life goals. The literature recognized that survivors of traumatic brain injury endure neurological sequella causing permanent changes in foundational domains such as emotion, personality, cognition, and other physio-neurological changes. Questions were also raised in the literature regarding the appropriateness of
imposing rehabilitation agendas upon individuals with traumatic brain injury that expected individuals to return to a previous state of functioning.

The literature also observed and challenged the validity of using the Glasgow Coma Scale by Teasdale and Jennett (1974) as a predictor of outcome for rehabilitation potential because it fails to accurately address anything but the acute physical and neurological effects of a traumatic brain injury. It does not take into account pre-accident and post-accident emotional, cognitive, and personality variables such as values, determination, motivation, and preferences that play significant roles in achieving goals and efficacy. Questions remain unanswered about outcome.

The literature contains scarce information that constructs the accounts and perceptions of survivors of traumatic brain injury relevant to their adjustment and rehabilitation journeys. This chapter introduces the qualitative methods that purport to answer the questions posed in this study that positivist, quantitative methods cannot. The reader will encounter discussions of purpose, problems that lead to conducting this study, the research design, the participants, the sampling process, data collection and data analysis.

Positivism, the epistemological basis for quantitative inquiry, maintains that the external world is an objective reality that never changes and that phenomena can be examined entirely separate from other phenomena. The many interactions among people, the environment, and cognition are discounted. Empirical information collected from a representative sample can be quantified and statistically measured to provide information that is then
applied to the larger majority. The problem with this epistemology is that phenomenon observed in static environments may not be relevant to the individual contexts of human behavior and experience (Bogden & Biklen, 1992; Gall, Borg, & Gall, 1996; Stake, 1995). Further, quantitative methodologies are more concerned with the relationships among phenomenon and less concerned with its specific details. Positivism or quantitative inquiry is like casting a net and then studying the relationships and differences among the specimen caught. Post-positivist inquiry, the theoretical basis for qualitative inquiry, takes into account the nuances, relationships, and particulars of an individual's natural environment. Qualitative case study endeavors to examine intensively a defined, bounded instance of an individual experience (Stake, 1995). Analogously, case study is the examination of just one of the specimen caught among the haul rather than examination of relationships among the entire haul (Runkel, 1990). The research questions posed below are answered best by using a methodology such as case study research that examines details in depth and within context.

**Research Questions**

1. What perceptions do individuals with traumatic brain injury have of their injury and rehabilitation?

2. How do the survivors of traumatic brain injury view their adjustment?

3. How does the survivor of traumatic brain injury evaluate rehabilitation progress and adjustment?

4. How do the perceptions of the survivors of traumatic brain injury compare with theories of disability and traumatic brain injury adjustment?
This study targeted the perspectives of people with traumatic brain injury. The aim was to gain an understanding of the experiences of survivors during the rehabilitation and adjustment processes. Another goal was to compare the experiences of survivors of traumatic brain injury with existing disability and traumatic brain injury theory. In order to meet the goals of this study, it was necessary to include the context and its details rather than objectifying the goals with a null hypothesis (Campbell, 1995; Gall, Borg, & Gall, 1996).

The individual milieus, consequential interactions, and the perceptions of the participants provide germane and rich information for the researcher. The process of collecting data from a qualitative viewpoint draws from a post-positivist philosophy called phenomenology (Gall, Borg, & Gall, 1996). Phenomenology is the study of understanding the participant’s experiences within context; accordingly, the researcher must interact with participants' in the environment of the latter in order to collect data (Gall, Borg, & Gall, 1996; Stake, 1995). The post-positivist movement arose as social and behavioral researchers realized that nullifying the context also nullifies contextual validity and reliability.

In the 19th century Comte introduced the study of humans through objective, scientific methods, fostering positivist thought in the study of human behavior (Gall, Borg, & Gall, 1996). As the positivist trend developed, a few of the students opposed its dehumanizing effects including Dilthey, Kant, and Buber (Gall, Borg, & Gall, 1996). Under Dilthey’s tutelage, Buber offered that the research of people and human behavior must not be reduced to studying “I-
it” relationships (Campbell, 1995). Rather, the focus must be upon the “I-thou”
relationships and interactions (Campbell, 1995). Buber was saying that it is
inappropriate to objectify people and relationships as it negates the context
(Campbell, 1995; Gall & Borg, 1996). In presenting information about
qualitative inquiry, a rationale exists for the research methodology most
appropriate for this study.

**Purpose**

This study examined two goals; one was to gain an understanding of
what it is like to incur and adjust to a traumatic brain injury. Extensive literature
describes the behaviors of clients with traumatic brain injury provided by
medical and rehabilitation staff and the family support systems. Treatment
plans and prognoses are developed based on these observations and
opinions that influence the potential rehabilitation outcomes for clients (Crisp,
1993; Prigatano, 1999). Though medical and rehabilitation teams espouse
client inclusion in rehabilitation planning, clients in this particular population
are often assumed to be lacking awareness and sustaining levels of denial.
While many victims of traumatic brain injury do suffer from awareness deficits,
not all of them do (Crisp, 1994; Livneh & Antonak, 1997; Prigatano, 1999). This
study was concerned with examining the experiences of traumatic brain injury
from the survivor’s perspective because the juxtaposition of the referenced
psychosocial dynamics, awareness and denial, is often in opposition to
treatment modalities. Perhaps it is appropriate to view awareness and denial
not merely as functions of or in opposition of an overall adjustment process but
as facilitators of the process (Liveneh & Antonak, 1997).

A second purpose of this study was to compare the experiences of the participants with existing models in brain injury and disability adjustment. In doing so, any differences that arise between the constructs derived by the participants and the constructs of the existing theories may address the appropriateness of such treatment modalities. The three models that were chosen to compare with the results of the case studies conceptualized components of empowerment and understanding client contexts. The first model applies to any disability population, while the last two are specific to traumatic brain injury.

Livneh and Antonak (1997) developed a conceptual model of adaptation to disability. They viewed adjustment to be a subset of adaptation, whereas adaptation is the continuous evolvement and dynamic overall process through which an individual with acquired illness or disability reaches an optimal state of congruence with the environment. Adjustment delineates from adaptation, according to Livneh and Antonak, in that it is the final phase in the adaptation process encompassing acceptance and reintegration of pre-injury psychological components and post-injury psychological components (Livneh & Antonak, 1997). For the purpose of examining the rehabilitation processes that embrace these components, this model is included (Appendix F). This model depicts four classes of variables that overlap and progress circularly so
as to incorporate pre-injury and post-injury variables acclimating together to achieve adjustment.

A second theory, the Empowerment Rehabilitation Model (O'Hara & Harrell, 1991), maintains that all of the foundational domains--cognitive, emotional, physical, and interpersonal--must reintegrate at the pace desired by the client. In doing so, the rehabilitation professional facilitates movement from victim to survivor and fosters empowerment (O'Hara & Harrell, 1991) (Appendix G).

The model is presented nonhierarchically as EXTERNAL STRUCTURE + MOTIVATION + INFORMATION + ACCEPTANCE + SKILLS = EMPOWERMENT (O'Hara & Harrell, 1991) (Appendix G). The theory maintains that, should a component be eliminated or dismissed, the goal of empowerment is less likely to be achieved.

George Prigatano (1995, 1999) offered components for a "Holistic Neuropsychological Rehabilitation Program" as development of a therapeutic atmosphere and bond between treating therapist teams and client, cognitive retraining, small-group cognitive retraining hour, cognitive group therapy, individualized cognitive retraining, psychotherapy, family involvement and education, and the protected work trial. He maintained that awareness and judgment need to be restored with cognitive remediation and treatment (Prigatano (1999).
Problem

Extensive literature in traumatic brain injury rehabilitation examined the perceptions of rehabilitation professionals and family members of survivors of traumatic brain injury (Crisp, 1993). Beatrice Wright (1983) called these above-named support individuals "outsiders" because they were not the actual victims of injury or illness, but rather the observers and helpers of individuals who survive such tragedies (Wright, 1983). The survivors of injury or illness are the "insiders" because they possess the expertise of what it is like to incur these disabilities (Wright, 1983). Numerous quantitative studies addressed the effectiveness of rehabilitation strategies for this population, relying upon methodologies that answer null hypotheses with deductive statistical measures, generalizing the results to a larger sample of the population (Crisp, 1994; Gall, Borg, & Gall, 1996). The bulk of such studies report variables given from the perspectives of "outsiders," rather than from the experts or "insiders" (Hill, 1999).

Several problems exist when applying quantitative statistical measures to determine effectiveness of rehabilitation treatment modalities. The effects of having incurred a traumatic brain injury (TBI) are not the same for each individual with TBI. Traumatic brain injury is defined as nonpenetrating trauma inflicted to the cranium by being hit, shaken, or acceleration and deceleration impact (Noble et al., 1990). Because the brain is surrounded by fluid encased in the skull, blunt trauma causes a ricochet effect against the inside of the skull known as coup-contra coup (Krauss & McArthur, 1999; Prigatano, 1999).
Trauma results in the brain being injured, not only at the point of impact, but also where the brain is thrust against the inside wall of the cranium (Prigatano, 1999). Further, head position, age of onset, body position, and the force of impact are all variables determining how the brain ricochets inside the cranium (Krefting, 1990; Prigatano, 1999). Therefore, individuals with TBI may share the same diagnosis but may have very different symptoms with different cognitive domains affected (Prigatano, 1999). Generalizing results of a quantitative study to members of the traumatic brain-injured population imposes suppositions that may not apply to all members.

A second problem with the "blanket diagnosis" of traumatic brain injury (TBI) is that incongruent perceptions of the symptoms may exist between survivors and their caregivers. Caregivers are able to depict what it is like to live with TBI survivors, and rehabilitation professionals can describe what it is like to treat a person with TBI. Only those with TBI are able to portray accurately what it is like to incur and adjust to life with TBI and its symptoms. Gaps between perceptions may lead to erroneous assumptions. For instance, because foundational domains such as cognition and personality can be affected, rehabilitation professionals run the risk of evaluating a client with TBI to be lacking judgment (Crisp, 1994; Prigatano, 1999). Consequently, this assumption makes the goals of the client prone to dismissal by the rehabilitation treatment team, resulting in an ethical conflict (Crisp, 1994; Krefting, 1990; Prigatano, 1999).
Another problem is that adjustment is contextual, while quantitative research is noncontextual for populations with traumatic brain injury (TBI) (Crisp, 1993; Prigatano, 1999). The adjustment that takes place in an inpatient rehabilitation setting may be very different from that of the client’s environment. Testing that predicts adjustment outcomes takes place in a sterile, clinical environment and may hold little validity, once the clients return to their own surroundings. Similarly, the levels of adjustment for individuals with TBI in the home environment and the work environment may have great differences. Understanding adjustment deductively leaves many unanswered contextual questions, while inductive methods such as case study research best answers inquiries about perceptions (Stake, 1995).

**Research Design**

Of the qualitative methodologies, case study research permits the researcher to collect data in a defined instance within the client’s natural setting. Case study research is the thorough examination of the particular(s) of a bounded instance (Stake, 1995). Its goal is to learn about the phenomena occurring within the instance defined and to assemble the phenomena into an accurate understanding (Bogden & Biklen, 1992; Crisp, 1993; Stake; 1995). The recollections and perceptions of individuals with traumatic brain injury are the phenomena observed in this study and the defined time frame, or instance, is the time of accident through the present. The participants were given the opportunity to construct their memories and impressions of incurring their injuries and adjusting to them by responding to a semi-structured interview.
Transcripts were prepared from audio-recorded interviews with the participants to be analyzed. After the data transcripts were analyzed, case studies were prepared for each of the participants. Last, the properties of each of the case studies were compared with models of disability and traumatic brain injury adjustment.

**Participants**

This study intensely examined the details of survivors with traumatic brain injury. The five participants interviewed were enough, but not too many, to understand the experiences this population had of adjusting to traumatic brain injury. As Runkel (1990) stated, in order to understand the experiences within the context of individuals, it is more relevant to study one specimen at a time, rather than the entire haul caught. The participants were five adult survivors with a divided gender distribution of three males and two females of mild to moderate/severe traumatic brain injury. The rationale of the gender distribution is because 75% to 80% of adult traumatic brain injury survivors are males between the ages of 18 and 45 due to vehicular accidents and sports injuries (Krauss & McArthur, 1999). The chances of finding adult males with traumatic brain injury are higher, as females accounted for 20% to 25% of the adult survivors of TBI. As this study focused upon adults with traumatic brain injury, the participants were between 20 and 50 years of age who had participated in a rehabilitation program. The number of years post-injury could vary, as it was more relevant to include participants who had participated in a rehabilitation
program, but for the sake of defining the research parameters, participants must have been at least one year post-injury.

Research participants were invited to volunteer for this research with the "Invitation to Participate" (Appendix E). The theoretical sampling process used in qualitative statistics as opposed to traditional random sampling used in quantitative research was used to select respondents. Qualitative inquiry and theoretical sampling focuses more on the individual case of concern and conclusions are derived using inductive reasoning (Bogden & Biklen, 1992; Gall, Borg, & Gall, 1996). The volunteers were solicited by two methods. First, the researcher presented the study at various support groups in the southeastern United States. Second, mailings were sent to two southeastern universities inviting individuals with traumatic brain injury to participate. Participants were screened further by asking them if they had accepted that they were different. The final five participants responded that they were aware that they had changed since their accidents and that they accepted these changes.

The focus was upon the specifics of each case examined because of the small sample size in qualitative case study research. After choosing the participants from the pool of respondents to the "Invitation to Participate" (Appendix E), meeting times for the interviews were arranged. During the meeting times, participants read and signed the "Informed Consent" form (Appendix D), then copies were made and sent to the participants later.
The amount of time spent with participants fluctuated between 3 to 4 hours. An interview was scheduled with each participant that lasted for approximately 70 to 90 minutes each. Participants reviewed and provided feedback for their respective case studies to ensure validity and reliability on “Feedback Form 1” (Appendix B) at a second meeting during which participants read their case studies. Had a second interview become necessary, the participants would have scheduled a third meeting and would have been interviewed a second time, indicating the feedback on “Feedback Form 2” (Appendix C). All five participants indicated that they were satisfied with their case studies.

**Data Collection and Analysis**

Participants received a copy of the questions intended for data collection during semi-structured interviews (see Appendix A). The interview was semi-structured in the sense that the interviewee had the flexibility to expand or deviate from the questions to a reasonable extent. The questions initially were open-ended. For example, what was your life like before your accident? What was your rehabilitation experience like? How are your rehabilitation goals the same or different as your rehabilitation team’s goals? Describe your overall experience of adjusting to traumatic brain injury. (See Appendix A.)

Subsequent questions and topics revealed additional information leading to a more thorough understanding of relationships, coping mechanisms, helps and hindrances in adjusting to their injuries that existed for the participants. Such questions remained open-ended but were more
specific, such as "Tell me more about the experiences that your doctor helped you with," or "what other obstacles existed for you during your rehabilitation and recovery?"

The information was audio-taped and then transcribed into a computer soon after each interview. Each 70- to 90-minute interview took 4 to 5 hours to transcribe. Case studies were developed from the transcripts focusing on the participants' perceptions and experiences of adjustment and rehabilitation to traumatic brain injury. Each case study took approximately 3 hours to construct.

"Reliability and validity are determined by the participant in case study research" according to Stake (1995). Therefore, each case study was presented to each participant for review and given "Feedback Form 1" (Appendix B). Spending approximately 2 additional hours with each participant for the case study review, each participant indicated that they were satisfied with the accuracy of their case studies, making second interviews that warranted use of "Feedback Form 2" (Appendix C) unnecessary.

The data were analyzed using the constant comparative method that consistently and cyclically compared the coded raw date until it had been saturated (Strauss & Corbin, 1990). Saturation is reached when comparisons and cross comparisons of the coded date and themes yield the same themes, categories, and constructs (Strauss & Corbin, 1990; Glaser & Strauss, 1967).

Specifically, each of the transcriptions was scrutinized by line and by word by this researcher looking for specific words and topics used by the participants. Then, the codes in each set of transcriptions were recorded into
columns, scrutinized, and compared and recompared to determine common themes. The themes were recorded and were then organized into the derived categories. Further comparisons took place across the themes and compared with the derived categories in order to determine constructs; five were determined. Steps were taken to protect the identity of the participants. A same gender “pen-name” was chosen or given in place of the first name of the participant. The tapes and list with names matching the designated pen-names were stored in a locked filing cabinet in a locked office.

Summary

Case study inquiry was used in this study to ascertain the descriptions and interpretations of the participants. Five participants, two females and three males between the ages of 20 and 50 with traumatic brain injury (TBI), were selected for data collection. The purpose was to examine the perceptions of these individuals after incurring traumatic brain injury and participating in a rehabilitation program. This study was interested in accurately portraying the particulars of what is like to adjust to TBI. The impressions of the participants of their rehabilitation were of key interest. This purpose represented the premise of intrinsic case study, one that studies a case for the sake of knowing about that particular case (Stake, 1995). The case studies became instrumental, however, with its second purpose (Stake, 1995). The second purpose was to compare the perceptions and conceptions of the participants with the constructs of TBI rehabilitation theory. Instrumental case studies were
conducted in order to understand something other than the particulars of the individual case itself (Stake, 1995).

The results of these endeavors are contained in Chapter 4. A discussion of observed comparisons between the constructs derived from the participants and the constructs of TBI rehabilitation theory occurs in Chapter 5.
CHAPTER 4
CASE STUDIES AND CONSTRUCTS

There are few studies that examine the perspectives of adjustment and rehabilitation from the viewpoint of actual survivors of traumatic brain injury. This chapter presents the results of five semi-structured interviews conducted with individuals who have acquired traumatic brain injuries and participated in rehabilitation modalities. These interviews were designed to ascertain the perceptions and experiences that these individuals have of their adjustment and rehabilitation processes after becoming injured. The qualitative case study method of collecting data discussed in Chapter 3 was chosen in order to answer questions that positivist inquiry could not. In order to gain an understanding of the viewpoints of survivors, a phenomenological understanding of their contexts must occur (Prigatano, 1999; Stake, 1995). This is the only way to gain an understanding of what it is like to incur and adjust to a traumatic brain injury, given the parameters that rehabilitation and the environment provide. In doing so, an understanding of how rehabilitation helped or impeded survivors in reaching their goals may be better understood.

The results of the interviews achieve the two purposes. One purpose was to construct case studies of the individuals' experiences and perceptions of adjusting to traumatic brain injury to determine any common themes and constructs. Second, constructs derived from the data collected were to be
compared and contrasted with three models of adjustment to disability and brain injury. The first portion of this chapter presents the results of the constructed case studies. The second portion presents the results of the data analyses that derived five constructs using the constant comparative method, a systematic method for analyzing qualitative data developed by Glaser and Strauss (1967). A discussion of the second purpose, to compare and contrast the derived constructs with three models of rehabilitation to disability, takes place in Chapter 5. The case studies presented below were constructed from the transcripts and represent the perceptions of adjustment to traumatic brain injury by five participants, two females and three males.

**Case Study 1: Teresa Lynn**

Teresa Lynn, accompanied by her mother, arrived for our interview dressed casually in jeans and a shirt on a late Friday morning after attending classes at a local community college. She was in good spirits and eager to participate in the interview. She was a little embarrassed about being late and explained that her mother had a schedule conflict. Socially, she presented herself confidently and comfortably, though she admitted that she is sometimes shy.

Teresa Lynn is a childless, unmarried, 22-year-old Caucasian woman, with shoulder length, wavy, brownish hair. She currently resides with her parents in a very rural area of north-central Florida, where she has spent all but 3 years of her life. Neither of her parents works currently, as her father has a disability and her mother is not working so that she can help Teresa Lynn.
Teresa Lynn has one younger brother, 16 years old, almost 17, who resides with her and her parents. She has two older half siblings, a half-brother 7 years older and half-sister 9 years older, that she has reunited with since her accident in 1998. Teresa Lynn states, "It was really great to have them be a part of my life again, so it is another good thing that has come from my accident."

Teresa Lynn is very close with her family, whom she considers to be her closest friends. She is very active in her church, where she has a strong spiritual life and participates regularly in various volunteer activities. In her spare time, she enjoys attending to her pets and other animals on their property.

Teresa Lynn is pursuing her Associate of Science degree in Physical Therapy Assistant at a local community college. She states that she is in her first term and is doing well in this program and is hoping to work one day helping other people who have endured disability and injury. She participated in preparatory courses before being admitted because she had to repeat her last year of high school in order to regain what she lost as a result of the accident. She states untiringly, "I really did not mind taking the preparatory classes, even though it was basically a repeat of my senior year in high school." She goes on, "I knew I would need to take these courses again in order to understand the basics of my program, so it was okay."

Teresa Lynn wears glasses and ambulates independently with no assistive devices. She practices driving on safe roads, but usually lets her
mother help transport her. She is currently driving herself to and from school with mild intimidation in heavy traffic. She talks to herself to help keep calm in tense situations, “Sometimes I pray and sometimes I sing to keep calm while driving.”

Teresa Lynn is a warm and congenial person who prefers to interact socially in small groups with a few people at a time. She explains that the majority of her school years were spent in north-central Florida, but her seventh-grade year was in Nevada and her eighth- and ninth-grade years were in Colorado. Teresa Lynn enjoyed fun times in Colorado, recalling times when she and her brother would ride with her father in their pickup truck to the mountains. Her father would shovel snow into the back of the pickup truck and take it back to their house in the valley. There, he unloaded the snow where she and the other kids in her neighborhood would play until it melted. Teresa Lynn made good grades in school but states that she had to work at it. She explains that she strived to get good grades and put fun second. She was once an avid and talented photographer, having won various awards. She also had a passion for clog dancing, enjoying traveling and doing shows with her partners. For fun, she and her family ride four-wheelers, fish, and camp whenever they can find the time. She states that she did not really date much in high school and did not have a large network of friends, preferring to socialize with her family and church.

Teresa Lynn’s plans when she was in high school were to go into the military and pursue a career as a registered nurse. She graduated in 1997
from high school and delayed her plans to enter the military because she and her family experienced several major losses that year. Both of her grandmothers died that year, and then her mother incurred cancer. She decided to postpone her plans and stay home to help her family and mother. She worked two jobs, one as a retail customer service associate and the other as t-shirt printer. When her mother improved later in 1998, she decided to go ahead and commit to the military in January of 1999 and pursue her plans of becoming a registered nurse while in the military.

On November 11, 1998, Teresa Lynn’s small blue pickup truck was rear-ended and pushed into oncoming traffic, crashing head on into a larger full-size brown pickup truck, demolishing both vehicles. She sustained a broken neck, jaw, breast bone, several ribs, left knee, left hip, left shin bone, pelvic bone, and left ankle. She also had a bruised heart, lungs, fractured right hip, and a traumatic brain injury. Her right eye muscle was strained because of the impact of the accident, causing it to stray. She was transported from the scene of the accident by helicopter to the hospital where she was in a coma for approximately 3 weeks.

She indicates remembering having talks and being with her deceased grandmothers, the driver of the other vehicle, and angels while she was in a coma. She learned much later in court that the driver died the day of the accident. “I didn’t know until later that he had died that day; I guess my family was trying to protect me,” she explained. Teresa Lynn was fined $500 for her vehicle crossing the double line causing a fatality, and her license was
suspended for a year despite having been hit from behind in the beginning. She stated, "It wasn't really fair for me to be charged with the accident because I was hit from behind and that driver took off, but I didn't have the energy to fight it at the time." She added, "Besides the family of the other driver met me and decided not to sue me, so it worked out."

Teresa Lynn underwent several surgeries to set and repair her broken bones. She then participated in an inpatient rehabilitation hospital. She recalls having to participate in various modalities of rehabilitation, including physical therapy, speech pathology, cognitive remediation, counseling, and occupational therapy. She states that there were times when she hated to get up and start working and wanted just to wait until she was through resting and sleeping. Looking back, she is glad in some respects for having been pushed, while at other times it brings back bad memories. She recounts that the physical therapists attempted to have her start standing and walking before she could even sit up. Teresa Lynn indicated that her mother complained that there was no logic in having to stand before sitting. Further, Teresa Lynn had to wear a neck-stabilizing device called a halo for a period of time to help her neck to heal. This was embarrassing for her, and she refused to eat in the dining room for a few days. She finally relented and began eating in the cafeteria despite feeling self conscious about her halo. Both Teresa Lynn and her parents expressed dissatisfaction with having to transport her every time her halo needed to be adjusted.
In addition, Teresa Lynn was in a great deal of constant pain because of the extent of her injuries. As a result, her doctor forwarded a letter of concern to the rehabilitation treatment team doctor. Her doctor at the rehabilitation hospital subsequently discharged her, stating that there was nothing more that could be done for her.

Teresa Lynn was dissatisfied with this physician's decision to discharge her. She states that she only saw him two other times during her stay at the hospital. She indicates feeling unworthwhile and dejected because of the few interactions with the individual directing the rehabilitation team. If given the chance, she indicated that she would make several changes in rehabilitation treatment planning. First, she would increase doctor patient interactions so that she could feel like she was truly part of her own rehabilitation. Second, she would ensure that rehabilitation exercises were germane to the client. She felt that many of the exercises and activities were not relevant to her and were more geared to populations much older than her. Third, she would provide clients with the chance to have spiritual counsel if they wished, not just an empty chapel.

Throughout her rehabilitation, Teresa Lynn recalls some positive interactions with her team of therapists who went out of their way to make her feel good about herself and to laugh. She remembers other times feeling stupid because she could not remember how to do things. She likened this to being a baby having to start all over again with toilet training, walking, talking,
thinking, and feeling. She admits that the speech therapy helped the most because this is when she began remembering long-term memories again.

After her discharge, she returned home where she became even more frustrated. She was unable to do routine things such as caring for her animals, washing her clothes or even walking in the hall. She always was independent before and hated having to have her family help her so much, especially with washing her clothes. In her spare time, she would play hand-held video games that inadvertently served as an excellent form of cognitive remediation, she later learned. She was also given some rehabilitation tips and exercises from a physical therapist in Ocala and practiced these endlessly at her home. After much practice, perseverance, and determination, Teresa Lynn began walking again with no assistance or devices.

Teresa Lynn states that she used two sources of strength for inspiration. She explains that her father has had various injuries over the years. She witnessed him persevering, despite his own discomfort and pain. She figured that if her father could do it, so could she. Her second source of strength was and is God to Whom she turns regularly. Teresa Lynn admitted to having times when she did not feel as if she could continue and wondered why God let her live. She also confessed to having feelings of irritation and even jealousy of those who did not go through what she went through. In pondering these thoughts and feelings, she thought that God must have a purpose for her and determined through prayer and thought that she was meant to help others as she had been helped. This is how she decided upon her goal of becoming a
physical therapy assistant. "I prayed to the Lord for a reason to go on once when I was feeling down and the thought of becoming a physical therapy assistant just hit me," she relates. This is when Teresa Lynn decided to enroll in her local community college and pursue this as a goal.

There are other changes that Teresa Lynn has experienced. She states that she is nicer now and is more apt and willing to interact with others. She also is more inclined to go to her room when she gets home and focus on her schoolwork, whereas before, she would stay outside more with her dad. In addition, she used to be good at mathematics and not at English. She claims that these have now flip-flopped for her. She is now better at English and struggles in mathematics.

Teresa Lynn indicates that the hardest thing has been to keep pushing herself and persevering. A final source of support and inspiration for her has been her family, church, and realizing that she had many more friends than she thought she did. She explained that she did not think she had many friends but learned differently upon receiving so many notes and cards throughout her ordeal. "Maybe of the blessings is learning that a lot of people really care and I hope I can do the same for others someday," she explains.

Case Study 2: Bernie

Upon arriving at Bernie's house, a pickup truck with two flat tires sat in the driveway. The front porch was dressed with wet suits and two or three surfboards, one of them broken. Bernie's house was located approximately a block and a half from the Atlantic coast beach in central Florida. He was
dressed casually and warmly, as the weather was cold and he had been working outside at his job as a maintenance and custodial engineer at a nearby hotel. Bernie wore his blondish hair medium to short length. He presented himself as socially appropriate, slightly reserved, and very congenial. Bernie indicated that he is the middle son of three sons and described himself as having been the "black sheep" of the family before his accident. He laughingly states that it is because he is the only one with blond hair. His brothers both have dark hair and complexions.

Bernie graduated from high school with average grades and he participated in wrestling and surfing. He believes that his participation in organized sports helped him to learn to win and overcome adversity. He states that surfing has helped him to stay in good shape over the years and has helped him to regain his physical abilities after his injury. He states that the drawback to being a surfer is that surfers have the image of being bums and druggies. He feels that he has been labeled as such by law enforcement. "The doctors told me that it was a good thing that I surfed 'cause that was why I was in such good shape and that's what helped me pull out of the coma," he explains.

Bernie enjoys watching all sports and is a big fan of the Oakland Raiders football team. He keeps a poem written by one of the Raiders about inspiration by his bedside for motivation.

Bernie enjoys biking and surfing for exercise. Before his accident on April 4, 1989, Bernie had spent a month in Hawaii surfing. Before this, he
attended culinary school to become a chef. He was working at a hotel as first
cook and was planning to apply to be chef. Bernie described his accident
occurred while he was traveling through an intersection on a motorcycle with
his wife on the back, when an elderly lady ran a red light. In order to avoid
hitting her, he "laid his bike down" causing his injuries. He was transported to
the hospital by helicopter. He received a traumatic brain injury despite wearing
a helmet and also shattered his right wrist and broke his jaw and front teeth.
His lower back also was knocked out of alignment. He was in a coma for 6
weeks and was in therapy for 9 months.

Bernie’s wife separated from him and filed for divorce while he was in
the rehabilitation hospital and divorced him in 1991. He was required to pay
child support, which he was happy to do once he learned through paternity
testing that he was the father of the child she was pregnant with at the time.
Evidently, his wife had an extramarital affair before their divorce, and there was
a question as to which of her partners his son belonged (though Bernie
suspected that he was his child). Bernie is very proud of his son and wishes
that he could spend more time than he does with him.

Bernie expresses frustration and regret that he does not have rights as a
parent. He lost his parental rights in 1997 because of being deemed
incompetent by family courts because of his brain injury. His ex-wife argued
that he is incapable of exercising good judgment because of his injury. Bernie
states that he feels this is unfair because prior to this ruling he took care of his
son for an entire summer and fall while she was in Las Vegas with her
boyfriend. "The law does not really look out for fathers, especially fathers with brain injuries," he exclaims. He states that he took good care of his son, taking him to school, enrolling him in Cub Scouts, and teaching him to surf. He states that this is one of the reasons he does not trust law enforcement or lawyers.

His parents who live nearby and his brothers all help him when he needs it such as taking him to the grocery store. He currently does not drive because he had his license suspended because of various violations, such as driving with a suspended license.

Evidently he lost his license in 1997 because he refused to take a breathalyzer test after being stopped for driving while intoxicated. Though he had not been drinking, his ex-wife had advised him that he should never submit to a breathalyzer test. His attorney who had been defending him had been removed from his case. Therefore, Bernie's new attorney advised him to plead guilty even though he had not been drinking, according to Bernie.

Bernie was accused of drunk driving a second time when he offered to drive a girlfriend and a friend home from a bar because they were very intoxicated. Bernie had not been drinking at all. When he failed the sobriety test, he was taken to the police station. Bernie tried to show them the card he carries indicating that he was brain injured, but the police roughly handcuffed him and had him sit in the back of the squad car for 45 minutes before going to the police station. In court, instead of convicting him for drunk driving, he was convicted for driving with a suspended license. He also has a history of domestic violence disputes. His means of transportation is a bicycle.
In the rehabilitation hospital, Bernie participated in various therapies such as speech pathology, physical therapy, occupational therapy, counseling, and recreation. As part of his program, he was put in the kitchen so that he could get back to cooking and he was also put in an apartment so that he could relearn how to live independently. He relearned how to spell, write, read, do mathematics, walk, and talk again. At times, he states that he felt stupid about having to relearn everything all over again. Overall, though, he feels that his rehabilitation team was extremely caring and helped him a great deal. Bernie states that he would not change anything about his rehabilitation; he would not change a thing. He thought they did a great job with him and listened to what his goals and needs were. He states that his only frustration was that, at the time, he wanted to be closer to his pregnant wife and the ocean.

Bernie graduated from culinary school in 1994 with honors. His employer paid for his school as long as he could keep his grades up. Unfortunately, in 1995, his employer refused to allow him to advance from dishwasher to cook again, so he left this job. He enjoys his position at a nearby lodge as primary maintenance and custodial engineer. His employer works with Bernie, allowing him to take time off for medical appointment when needed. He currently goes to a cognitive speech therapist and his regular medical doctor. He also attends support groups and used to see a chiropractor for his back problem. He says he still has problems with schedules and keeping things organized, but his close friends and family help him when needed. He has made great efforts to settle down and have better
priorities, putting his son first and himself second. He uses a poem written by his favorite player of the Oakland Raiders football team to motivate him to focus on his goals. He states that his son has been a big source of motivation and inspiration to keep trying and keep going. His son became his main priority and pride now. He explained that his own inner self-determination drives him to keep going for his goals despite feeling tired at times. He attributed his successes in overcoming obstacles so far to his family and close friends.

Case Study 3: Taz

Taz's interview took place at his one-story condominium on the beach on an overcast, wintery day. His home was neatly furnished and arranged with pictures of his three sons proudly displayed. We sat at his dining room table with a plain view of the beach with the ocean rolling in and out and could have jumped in with a good running start. Taz chose his own pseudo-name, as it was a nickname that he has had since his college days. He is approximately 6 feet tall and weighs about 216 pounds, with dark hair and hazel eyes. He was neatly dressed in slacks and a button-up shirt and was well groomed. He explained that he would be attending a job interview later in the afternoon. He presents confidently and amicably socially and was eager to share his experiences in having incurred a closed head injury. He interjects a wry sense of humor in conversation with a New England accent. He is the only son of his parents who live in the same area of Florida. He has a twin sister and two older sisters. All of his sisters live in New Hampshire and visit as much as possible. He states that he did not do well in high school without the help of
his twin sister. "I weren't too big on studying," he explains, "she got the brains and I got the looks is what I tell her." He has good relationships with all of his immediate family members, with the exception of a grandmother whom he strongly dislikes.

He currently works full time as the maintenance engineer of the condominium complex where he resides alone overseeing the maintenance and repair of 55 units on the property. His father helps him part time with this endeavor. He does not particularly enjoy his work or his place of residence because the average resident age at the condominium complex is about 65, and he is 38. He described incidences of residents treating him as less their equal because of his age and was frustrated with their "entitlement" attitudes. He also would like a job that earns more than $16,000.00 per year. He explains, "Talk about adjustment, you try going from $70,000.00 to $16,000.00 per year."

Taz indicates that before he became the maintenance engineer for this condominium complex, he once held a high level management and engineering job at a community mental health hospital making $75,000.00 per year. He was Director of Engineering for this hospital with several employees under his management. He also let patients help with some of the work and routines around the hospital. He indicated that he enjoyed these interactions and could not really see why they needed to be so heavily medicated at times. He felt that they seemed just fine, even without their heavy medication given to them upon admittance to the hospital after breakdowns they had in the real
world. Before this he was the Director of Engineering at a hospital in a larger metropolitan area. He indicates that he was in charge of numerous employees and all of the maintenance operations with a $6 million operating budget. He states that this was a high-pressure job that required him to take blood pressure medication. Before this he was a drywall specialist at Disney World, with his duties consisting of drywall and carpentry work. One of his favorite jobs was a construction job, having been hired as a pipe layer but actually functioning as the backhoe operator. He explained that while he was hired as a pipe layer, he primarily drove the backhoe, as the foreman who usually did this was an alcoholic who spent most of his time shaking and drinking.

Taz has attended as many as 10 colleges and has obtained numerous certificates and his Associate of Arts and Science degrees in electrical engineering. He has attended several schools pursuing a bachelor of science degree but never finished. He is thankful that he did not receive his bachelor’s in electrical engineering because now he is afraid to do this type of work. He has lost the ability to complete detailed tasks required for this type of work. “Thank God I never finished my bachelors because I couldn’t do it now,” he acknowledges.

He was once outgoing and active having many friends and enjoying a good party anytime. He married his high school sweetheart when he was 17 years old with whom he had one son, now 17 years old. He divorced after 9 years of marriage and remarried 2 months after his divorce. This second 9-year marriage produced two more sons. His second wife divorced him
because of the changes he endured after his brain injury. Some of the changes included that he could no longer go out and be the drinking, "life-of-the-party type of guy" that he used to be. Taz chooses to refrain from drinking because he likes to be aware and focused at all times now. Further, his ex-wife did not like the reduced income that was brought on by the accident. Also, Taz became more aware of some of her traits that he overlooked before. After his accident, he was unwilling to tolerate some of these things, such as her family fights and covering for her drinking habit, for instance.

He has good relationships with his sons but admits that the relationships have changed since his accident approximately 3 years ago. Before his accident, Taz excelled in most athletics, especially golf. His drive was equivalent to Tiger Woods' drives, but now he has trouble hitting the ball straight because his vision, coordination, and strength were affected by his accident. He also played hockey, baseball, softball, and football in his youth. He used to be able to compete with his sons but now must participate as a spectator. He occasionally will play sports with his sons but admits missing the speed, coordination, and agility that he once had. He also describes instances where his sons will query him about having "half a brain" as their mother, Taz's second ex-wife tells the boys that their father is a mental case and has just half a brain now. He realizes that one day he will have to sit down with his sons and explain to them what has happened to him and how he has been affected. For hobbies now, Taz enjoys the races, cooking, and listening to country music.
Taz was injured during his second marriage that ended approximately 2 years ago. Although his ex-wife participated in his rehabilitation to his dismay, she filed for divorce soon after he returned home from the rehabilitation hospital. He explains that he actually saw a divorce attorney the week of the accident because he realized he did not love her and felt she was too controlling. Taz states that he does not believe he loved either of his ex-wives and described a current relationship as one that might be real love.

Taz’s accident occurred on New Year’s Eve 1998. His family was having a New Year’s cookout celebration and had several friends and family members present. One of the guests wanted to ride their new four-wheeler. He did not believe it was working correctly, so he decided to test drive it himself first after having had two beers. He proceeded to take it out without a helmet and admits to going a little too fast. Upon swerving to miss hitting his youngest son who ran out in front of him, he flipped the vehicle hitting the pavement head first. He was air lifted to the hospital and was not expected to live. He spent 2 weeks in a coma and upon awakening was transported to his rehabilitation hospital where he stayed for approximately 7 months and was discharged after 8 months.

Taz participated in rehabilitation from his home during the eighth month. His only injury was a traumatic brain injury to his frontal and left parietal lobes. He describes several changes since his accident. He needs bifocal glasses to drive but admits feeling self-conscious about wearing them all the time. He is now an auditory learner, whereas once his was a visual learner. Since the
accident he does not have as many mood swings. He states that before the accident, he was prone to mood swings and violence, becoming angry, ripping phones out of walls, and becoming involved in brawls frequently. After his accident, he was diagnosed with bipolar disorder and currently takes medication to help him control his anger. He is thankful for this medication and plans to continue taking it unless his insurance stops paying for it.

While his counseling and cognitive remediation therapies taught him to focus, he felt that many of the exercises were useless and inappropriate. He described one exercise that required him to complete a crossword puzzle in 60 seconds. Another exercise required him to make a certain criterion score that even his parents and doctor could not achieve. He indicated his dissatisfaction and dismay that expectations were so high. When he suggested other exercises, the rehabilitation team reconstructed his exercises accordingly. Taz recalls having hated including his ex-wife in rehabilitation planning and interactions. He did not love her anymore and became exasperated numerous times at having to include her and interact with her. He tried to let his rehabilitation providers know that he did not want to stay married to her or have her involved in rehabilitation planning. She earlier had signed papers to have him sent to a nursing home, but his parents prevented this from happening. “If it weren’t for my folks, I’d be wasting away in some home somewhere,” he explains.

If given the chance to change anything about his rehabilitation, Taz would not require spouses to play an active role in rehabilitation treatment and
planning. He would require the rehabilitation team to include his goals and to listen to his wants and needs. He also would increase doctor-patient interactions, as he feels that the physicians directing the rehabilitation team should play a more interactive role with patients. He also would like rehabilitation team members to realize that just because he does not want to participate in certain activities, he is not being noncompliant. He simply has other ideas about how to pursue certain tasks. For instance, rather than having to do crossword puzzles, he would rather read something he is interested in and then complete recall exercises from it in time intervals.

He also voices his frustration with having to stick to an unrealistic “fake budget” in his rehabilitation. Taz was given a budget of $4 to buy a meal with and explains, “That only buys a side order of potatoes!” He states, “I was always flunked for ordering balanced, nutritional meals that cost at least double if not triple the cost, depending on the restaurant.” He also admits to being distracted by attractive female therapists. He describes his motivation to participate in rehabilitation but admittedly was distracted from his rehabilitation endeavors because of his attraction to them. He has an excellent relationship with his current psychiatrist who “tells it like it is” with him. He attributes much progress with having worked with him toward rehabilitation goals.

Taz is currently distressed about having his parents so much involved with his life socially and with his rehabilitation. He feels that his doctors and parents have attributed his negative qualities, such as impulsive spending and his anger outbursts, to his accident. He states that these qualities were always
there and perhaps are a bit improved now. He sees them as using his new
disability as the explanation for any adverse qualities he has, whereas he feels
these negative qualities were always there. Further, he wishes to put distance
between himself and his parents, who perhaps over-involve themselves
because they are afraid of losing him again. At the same time, he is thankful
for his family’s support and attributes his successes so far to them, his
psychiatrist, and his own perseverance.

Taz takes full responsibility for his accident. He realizes that his own
decisions are to blame, and he attributes his adjustment to this. He also
names friends who have been sources of encouragement and inspiration for
him. These friends helped him to keep going and trying when he did not feel
like it. “One of my buddies helped me get this job and even though I don’t like
it, it has helped me begin succeeding and finding my way out,” he explains.

Case Study 4: Lex

Lex arrived early for his interview dressed casually, as he had ridden his
bicycle. He is approximately 32 years old, 6 feet tall, with dark, medium-short
hair and dark eyes. He is the oldest of two sons and grew up in the Canal
Zone of the Central America. As a youth and young adult, he suffered from
attention deficit hyperactivity disorder. He states that he also was very smart.
He made good grades all the way through school but just could not handle
sitting in the classroom. He was always outgoing and the life of a party. He
describes himself as more reserved and focused since his accident. As he
puts it, “I am much more interested in concentrating on what I am doing than I
am in getting to know people and having fun." He presents himself as being comfortable and confident in his interactions as well as congenial. Lex played sports as a youth and had many interests, one of them being the environment. He obtained his Bachelor of Science in marine biology from Eckerd College in St. Petersburg and was accepted into the College of Veterinary Medicine at University of Florida in 1991. He was in an accident that left him with a brain injury in his first semester of his veterinary school program.

Lex also states that his interests have changed somewhat. He is more interested in doing mental work than physical work. He once enjoyed working on cars, building things, and doing things with his hands. He explains that he also loves nature and currently is pursuing his Master of Science degree in natural resources and environment. He believes that nature is God and God is nature, and the way we exploit the environment is utterly stupid. He plans on being finished with coursework within the next semester and is working on his thesis, "Animal Use of Highway Underpasses," and will be using tracking devices and cameras to track black bears for 2 years. He explains that black bears adapt to the underpasses, but they tend to get hit in blind spots on the highway such as on curves or hills. Lex believes he has made considerable progress toward goals that his rehabilitation team predicted he never would make again.

In 1991 Lex and some friends attended a university football game. They had been drinking and Lex admits that he was inebriated when his accident happened. He backtracked and explained that he and one of his work-out
buddies from his program would exercise their shoulder muscles by doing handstand pushups after running. After returning from the football game, Lex decided to do a handstand on the balcony railing of his second story apartment and fell. When he landed, his head hit a parking bumper directly underneath his balcony, causing a traumatic brain injury. Specifically, his left parietal lobe was injured, and his pituitary gland was ripped off. As a result, his body no longer produced important hormones such as thyroid, hydro-cortisone, and testosterone. He spent 2 weeks in a coma. He states that he remembers having conversations with God while in a coma. From these conversations, he was given a mission. He states that he knows that it sounds strange because he never really believed in God before. He laughs, "I know it's strange because I was not a believer, but I did talk to Him and got my mission." The content of the conversation seemed to be that now that Lex is brain injured, he will no longer have a problem focusing on things as he did before with his hyperactivity and inattentiveness. So Lex was able to gain focus, concentration, and his mission to help the environment despite his losses from his accident.

Lex states that he met an internal medicine specialist locally in 1999 who was able to pinpoint what his problems were and begin a regimen of medications and hormone treatments. From 1991 until 1995, he could not form muscle mass, could not gain weight, had slowed mental processes, and had limited energy. He states that one of his biggest disappointments with his rehabilitation is that no one on his medical or rehabilitation team had thought of
resolving his physical problems resulting from his damaged pituitary gland. Therefore, it took him 8 years to find the solution on his own.

Lex explains that after he awoke from his coma, he was transferred to a rehabilitation hospital. He indicated that he had ongoing problems with his rehabilitation team and doctors, he states, “because they kept trying to pin me down and force me to do things the way they wanted it done.” He states that he had always had problems with authority and that this had not changed after the brain injury. Lex also described having conflict with the head administrator because the head administrator kept confronting him about not complying with the rehabilitation program. Lex commented, “It is just not smart to be confrontational with a person with a brain injury, especially when it should be evident that the person with a traumatic brain injury is not able to understand another point of view just yet.” After spending a year in the rehabilitation program, his parents checked him out of the hospital and took him back home in Central America.

There he spent 1 year working as a teacher’s aid in an elementary school. He spent additional time working in a veterinary clinic and doing volunteer activities. In 1995, his younger brother decided to attend a university in Florida after not liking the university he had been attending. He wanted to bring Lex with him and help him get back into school and the swing of things. Lex’s parents consented and Lex then moved with his brother to Florida. He tried some classes, but things did not work out at that point.
After taking a course in landscape ecology, Lex met two graduate students and a professor who encouraged him to keep trying and to pursue getting into graduate school. He works with one of these individuals now as an aide and with another for his thesis. After he receives his master's degree, he is planning to pursue his doctorate in the College of Natural Resources and Environment.

Lex attributes his successes so far not only to his own determination but also to his physician's interventions and to the support from these students and professors. He views his adjustment process as a learning process and not necessarily as a "losses versus gains" issue. He also minimizes his adjustment process because he does not view necessarily his recovery from brain injury as adjustment but as a new learning process that is similar to how he coped previously with having attention deficit hyperactivity disorder. Further, he views his own survival and adjustment not in terms of being different or providing an example for others but to meeting his own needs and goals. He states that it is out of sheer greed that he perseveres and keeps going. His only regret is that he is not as outgoing as he used to be but laughingly jokes that this may not be a bad thing because he wants no distraction from his mission. Last, Lex wanted to reiterate the gratitude he has for his mother, brother, and father, as they have been a vital part of his past, current, and future successes.
Arriving for the interview late, Shelley and her mother indicated they had been attending to a baby squirrel that one of their four dachshund dogs brought in from the yard. The squirrel was not injured by the dog but also was not moving, so it was transported to a squirrel caregiver nearby. Shelley lives with her mother and niece in a two-story house in the center of a north-central Florida town. Her mother, being from Germany, speaks with a German accent and works from her home teaching music, including violin and piano. Shelley’s parents are divorced, and her father resides with his second wife here in the same town as Shelley. Shelley states that she sees her father once a week for lunch and has a good relationship with him. Shelley is an attractive, 30-year-old woman with naturally blond wavy hair. She is left-hand dominant, which, as she puts it, “I now think from the right side of my mind.” She is outgoing, congenial, and was eager to participate in this interview. She has many friends and family members who provide ongoing support and inspiration for her. Shelley explains that all people who become brain injured should have a pet, especially a dog, to provide companionship and help expedite healing. Her dog “Milli” has had three litters totaling 16 puppies with her mate “Oscar Meyer.” Shelley also enjoys and collects unicorns and she explains that this is one of her signature marks.

Shelley works teaching violin and piano to children. She began playing the violin at 18 months of age and the piano at 5 years of age under the tutelage of her mother. She remained involved in music throughout her youth.
and adolescence, expanding the realm of her musical endeavors into joining a band. She also danced and was employed as a dancer as well as a musician before her accident. She received a full 4-year music scholarship to a Florida university and attended for 1 year. She explains that she lost the scholarship because she did not apply herself or live up to her potential. At the time, she was more concerned with an unhealthy dating relationship, that upon looking back, she does not understand and regrets. In fact, she describes this relationship as her “heroin fix” which she never actually tried but has heard how addictive it can be. Shelley states that she was once able to get by on sheer talent alone. She explains that everything changed in a split second for her and now she must work much harder to achieve her goals. She attributes her survival and successes so far to God and feels that her survival is nothing short of a miracle.

Her accident occurred 8 years ago in 1993, when she was 22 years old. She perceives her brain injury as having been born again. Not long after her 22nd birthday on a rainy January afternoon, Shelley had gone to lunch with the same ex-boyfriend who had given her such “mental warfare” before. She was the passenger, and he was driving. Unbeknownst to her, he had used marijuana earlier that day, causing him to have impaired judgment while driving. They were involved in a head-on motor vehicle collision that forever changed Shelley’s life. Shelley has been able to piece together what happened from stories that other people have told her. In fact, she conducted her own interviews of the emergency and medical personnel who saved her
life. She is conducting these interviews because she is in the midst of writing a book about her experiences.

Shelley states that God was really looking out for her throughout her ordeal. Evidently, Shelley and her friend were in traffic in front of someone who was a paramedic and was able to call the accident in immediately. As a result, paramedics arrived within 5 minutes, and she was under the care of a neurosurgeon within 15 minutes after impact. Shelley's injury was severe, as she sustained a traumatic brain injury and a lacerated brain stem. She did die and was revived. Initially, she was trapped in the car with the engine in her lap. The paramedic who was working to intubate her stated in his interview that he does not know nor can he explain how the engine moved off of her at the last moment. He states, "It was like the hands of God moved it." It did move, however, and she was freed from the wreckage while having a seizure and then was transported immediately to the hospital.

Shelley was in a coma for 3 months and 2 weeks. She remembers dreams of flying and flying over her house again and again, but was unable to land. She was later told that her niece would come and sing "Come Fly With Me" while she was in a coma, and she wondered if this is why she dreamt of flying. She also wondered if it were because of the medication given to her to keep her sedated while her brain was healing, or if it was because as a child, her grandmother, Oma, told her that while people dream, they fly with angels. Shelley remembered her grandmother fondly and had great admiration for her.
Her grandmother lived through the two World Wars in Germany and imparted many stories and words of wisdom to Shelley in her youth.

Shelley explained that she was in a rehabilitation hospital for approximately 2 weeks and then was discharged. Evidently, the rehabilitation team at the hospital felt they could do no more and that she would be "vegetable-like" for the duration of her life. Her mother explained that had the medical doctors treating her been allowed, Shelley would have been pronounced dead while in the hospital. Her mother insisted on keeping her alive despite the poor prognoses. Shelley’s family studied and worked hard to help her come out of her coma and continued to work with her after she awakened. Shelley had home nurses and rehabilitation personnel come to her house to administer various rehabilitation therapies to her. For instance, they would keep her muscles stretched and work them in the event that she would walk again.

Shelley explains that she truly had to learn everything all over again. As she puts it, “It is how God intended it anyway . . . you have to sit before you can crawl, crawl before you can walk, and walk before you can run.” Not to anyone’s surprise, Shelley and her family used music as a modality for her cognitive rehabilitation. After all, according to Shelley, playing the violin uses 48 brain processes, so why not try playing and reading music again. Shelley finally was admitted to a rehabilitation hospital after it could not be disputed that she was not a vegetable and could participate and make progress.
Shelley participated in rehabilitation therapies including physical therapy, occupational therapy, speech therapy, and counseling at the rehabilitation hospital but could tolerate only 10 minutes a day in the beginning. Shelley was unable to state that she was satisfied with the services administered to her there. Upon asking her if the rehabilitation team attended to her goals, she acknowledges that they did attend to one of her goals, but her other goals were ignored. She entered the program with the goal in mind of walking again, and they did help her to achieve this goal. She feels that the rehabilitation team limited her, however, because they would not consider larger goals for her. She feels that they were unwilling to consider bigger goals because they did not believe she could reach them and did not have much faith in her potential.

However, Shelley also wanted to improve socially. She feels that her goals were dismissed as being unimportant. Specifically, she wanted more social interaction with other brain-injured patients and to participate in a support group. She also wanted to have more incentives, as she felt that the staff was there to focus on physical gains and regains primarily. She feels that little attention was given to her psychosocial needs and questions. Shelley has always been a socially inclined person and feels that this would have helped her in some of her struggles to recover some of her physical abilities as well as emotionally.

Shelley has always been a determined person and feels that her determination, supported by a team of people including her mother, close friends, attorney, exercise physiologist, and God, have all helped her to stay
focused upon her past goals. Her accomplishments since 1993 include doing many things that she was expected never to do again. She walks and is planning on running and driving again one day. She gave an international speech in Japan on recovering from traumatic brain injury, along with other local speaking engagements to support groups. She entered a local community college and completed her Associate of Arts degree in 1998. Her current plans are to write about her own experiences and to help other people with traumatic brain injury on their healing journey.

Another dream of hers is to marry and have a family one day. She indicates that this is a very important goal for her that she feels has been minimized. Although she is appreciative and indebted to all of those who have supported her and continue to support her, she wants to be taken seriously with all of her goals, including this one. She indicates that she works daily to implement and practice good judgment in all of her endeavors and goal setting and plans to do so with this goal as well. Shelley indicates that she has wondered from time to time what her purpose is in life, having survived an accident against all odds. She prays and meditates about this and keeps getting the feeling that it is to show others that there is hope and reason for living. Overall, her goal is to be an example of survival and life to those who wonder or have doubt that it can be done, especially against all odds.
Themes and Categories of Participants

The following pages contain the themes and categories derived for each participant. A theme was determined after initial comparisons yielded common topics. These common topics became themes. The themes were then organized into categories of which there were nine, including "family," "coping mechanisms," "post-accident," "losses," "emotional phases of adjustment," "starting life all over," "things rehabilitation should change," "positive things about rehabilitation," and "spirituality." Constructs were then developed after multiple comparisons and cross-comparisons. In order to become a construct, all five participants must have experienced the elements of the category and theme similarly.

Teresa Lynn

Teresa Lynn is a 22-year-old, single female with brown wavy hair and glasses. She dresses casually in jeans and a nice tee-shirt or button-ups and needs no assistive devices to ambulate. Her gait was normal, despite having multiple broken bones in her left leg because of a motor vehicle accident that left her with multiple broken bones and a traumatic brain injury in 1998. Teresa Lynn enjoys spending time with her pets and family. She currently is enrolled at a local community college in north central Florida to obtain and Associate of Science degree in Physical Therapy Assisting. One day she plans to help others who have gone through similar experiences as hers. Teresa Lynn is pleasant and confident in her interactions. She prefers one-on-one people interactions rather than interacting in large groups or crowds. She discussed
events that happened before her accident as well as afterward to give the researcher comparisons to her before and after her accident.

**Family.** Theresa Lynn is very close with her family. She lives with her mother, father, and brother on their property in a rural area of Marion County, Florida. According to Theresa Lynn, “They are my closest friends and if it weren’t for them, I may not have gotten this far.” “They came to see me all the time while I was in the hospital, even if I don’t remember all of it.” “Especially my mom . . . she came and stayed every day reading, talking, and singing to me.” They have been very important to her recovery from her acute injuries and traumatic brain injury. She described memories of spending time with her family as very special and meaningful. She states, “We always do things together as a family, like church, camping, four-wheeling, froggin. . . .” “We really have fun.” She told of how her father used to drive her and her brother to the mountains and load their pickup truck full of snow and then unload it in their yard so they could play with friends. She used her disabled father as an example of tolerating and persevering through her pain to reach her goals.

**Coping mechanisms.** Teresa Lynn is a spiritual person and describes her religious preference as Christian. She utilized prayer to Jesus and God as means to help her with her challenges in adjustment. She also relied on her own independence and determination. As she puts it, “I would just tell myself to keep going, Theresa Lynn, you can do it.” “You can deal with this pain.” She also used her father as a source of inspiration as he has had many injuries over the years that have left him disabled. She stated, “If Dad can do it, so can
"Dad has had a lot of pain because of a lot of injuries over the years." She described having had talks with angels and the driver of the other vehicle while she was in a coma. She later found out that the driver died the day of the accident. She interpreted this as another testimony to her survival and all the more reason to help others with experiences similar to hers. Last, Teresa Lynn uses her own strengths, such as determination, motivation, and drive, to survive. When her rehabilitation hospital discharged her after only 6 weeks, she began doing things to rehabilitate on her own. She operates from an internal drive or locus of control to ensure that she reaches her goals.

**Post accident.** Teresa Lynn states that before her accident, she was more withdrawn and not as friendly with people. She states that now she is much more inclined to engage people in conversations and enjoys getting to know new people. She says, "I actually like talking to new people now." "Before, I was probably a little meaner, but now I am a lot nicer." She also states that since her accident she has changed her goals from becoming a nurse practitioner to becoming a physical therapist assistant. Teresa Lynn described cognitive changes such as having a more difficult time with mathematics when it came easier for her before her accident. "It was really weird. I was great at math before; now I am better at English." She also states that she is much more focused and less distracted at home and is more inclined to go to her room to study than becoming distracted with her animals and family.
Losses. Teresa Lynn lost both of her grandmothers in 1998. Her mother also contracted cancer that same year. Teresa Lynn postponed her plans to enter the military and begin college to help her mother. Later in 1998, she was in the accident that left her with multiple injuries and a traumatic brain injury.

Emotional phases of adjustment. Teresa Lynn described having experienced several prominent emotions during the course of her recovery. She states that she felt jealousy and anger at certain points because she observed other patients and now students who do not have to work as hard as she does. She also experienced grief and sadness for her losses and lost time.

Starting life over/rebirth. This participant expressed feeling of frustration and disgust about having to learn how to walk, talk, feel, think, and toilet train all over again. She described feeling "stupid" because she knew she once knew the things she was repeating; she felt that having to go through this as an adult was humiliating at times.

Things rehabilitation should change. Teresa Lynn discussed several things that she did not like about her rehabilitation. She states that she did not like the minimal interactions with her doctor. She states that she saw him only twice in a 6-week period at the rehabilitation hospital. She also advised that the rehabilitation team should attempt to make the goals relevant to her. She felt that she was expected to adhere to goals that were standardized for the majority population in the hospital most of whom were senior citizens or middle
aged. Last, she thought that having a spiritual leader or advisor should be available as she values this type of intervention and leadership more than she does dealing with "head-shrink" doctors.

Positive things about rehabilitation. The rehabilitation team helped Teresa Lynn to feel better about herself when she was not feeling good. She states, "They really made me laugh and it really lifted my spirits." She also relates that she was thankful for her speech pathologist because he helped trigger her memory. She states that a language exercise caused her to remember going frog gigging with her older half brother and father. From there she was able to retrace many memories, "I was really excited because once I remembered going froggin' with my older half brother and Dad, I remembered more and more about school and everything!"

Spirituality. Teresa Lynn discussed her faith and spirituality. She explained that she has a very active spiritual life and prays to God regularly. She also participates in church activities several times weekly. Teresa Lynn described feeling like she wanted to die a couple of times and remembered asking God to show her why He allowed her to live. From this type of praying, she developed the idea to return to school to become a physical therapy assistant. She stated, "The idea just popped in my head." Teresa Lynn stated that she believes that this was God's answer to her question. She maintains that her faith and perseverance have worked together to help her to see the good that can come from something bad.
Teresa Lynn also felt inspired after hearing and remembering the discussions that she had while she was in a coma. Teresa Lynn's mother stayed with her in her hospital room 24 hours a day. Evidently, Teresa Lynn "talked in her sleep" while she was in a coma. It appeared that Teresa Lynn was having discussions with angels as well as the individual whom she crashed into on the day of her accident. Teresa Lynn had never met the individual that she wrecked with. While in a coma, however, she knew the name of the individual and learned details about him and his family. "Strange as it sounds, I knew that he was worried about his wife and other family members. I also knew what he looked like," she said. "I was looking forward to meeting him in person and sort of picking up where we left off... I found out six months later that he died the day of the accident," she explained. She stated that she was very upset that he died, but knows that he is in a good place, now.

Bernie

Bernie is a 38-year-old divorced male who lives on the east coast of Central Florida. He originally is from Ohio and moved to Florida as a pre-adolescent. In high school he learned to wrestle and surf and attributes his drive to succeed and overcome obstacles to having participated in these sports. He works as a maintenance engineer at a nearby hotel and enjoys his work. He has a good work ethic and puts in additional hours as much as possible. He bought his house near the beach approximately 5 years ago and pays his mortgage, child support, and bills using his salary. He enjoys surfing
and cooking in his spare time. Cooking was once his profession; he was employed as a cook before his motorcycle accident in 1989 that left him with a crushed right wrist and a traumatic brain injury. Since then, he has graduated from culinary school with honors, but finds the pace of his present job less taxing.

Family. Bernie states that he is close to his family and feels that their support has been one of the largest contributing factors to his success in recovering from his accident and traumatic brain injury. He states, “My parents helped a lot and joked around with me too.” His parents and two brothers all live in the area and visit him regularly and assist him, if need be. He also has an 11-year-old son and is very active with him and proud of him. Bernie feels that his son has been a tremendous source of inspiration and reason to persevere despite many obstacles. He states, “He is such a cool kid!” “He is a good kid too, you know, good, but good at sports, surfing.” Bernie states, “He is all of the things I wanted in a son.”

Coping mechanisms. Bernie copes by using his son as a reminder that he has a reason to keep going whenever he is feeling down. He says, “My accident has forced me to slow down and calm down so I can be more responsible as a father.” He also relies on support from friends and family to help him overlook obstacles and keep his focus on his goals. He states that he also is pretty funny and uses humor to “lighten” heavy situations. He states, “I have always been a jokester. My ex-wife hated it. When I was in the hospital, I would crack a bunch of jokes and my ex-wife would complain. And my aunt
would tell her to leave me alone 'cause my humor is a good sign that I'm going to get better."

**Post-accident.** Bernie states that he has changed significantly since his accident, in that he is no longer a "party-goer" like he used to be. He states, "I used to be able to think straight even when I wasn't, if you know what I mean."

"Now I don't like being out of control and I don't think straight when I drink, so I just don't." He also has become more settled and focused on his responsibilities such as his job, son, house, and health. Bernie had a significant legal history before his accident because of domestic violence and drinking and driving violations. Having this past record has not served him since incurring his brain injury. He once was "First Cook" at a restaurant and would have become a chef had he not become injured in his accident. He still surfs but admits that he now has arthritis in his injured wrist that makes surfing painful in the winter because of the cold water. He states that he has gained awareness of what is really important in life since his accident as well. Another change that he has experienced is that he is less extroverted, preferring the company of only a few people. He also has less energy and has problems with scheduling and organizing his time. He says, "I have to admit, I do get tired more easily. But that's okay 'cause I ain't getting any younger anyway. I can deal with that 'cause I have dealt with worse."

**Losses.** Since his accident, Bernie states that he has had many losses. His marriage ended as a result of the accident; his ex-wife did not like the changes caused by the accident. According to him, "She really did me wrong
just leaving me while I was still in the hospital.” He lost his career as a cook for
the time being. Although he currently does not cook for a living, he did graduate
from culinary school after his accident. He indicates, “It took me a while, but I
did graduate from culinary school with honors!” Bernie’s parental rights were
terminated as a result of his accident, as his ex-wife felt that he was not
capable of being a custodial father. Bernie states, “Fathers get the raw end of
the deal most of the time when divorces happen. Those legal people just don’t
treat fathers, especially fathers who have brain injuries, fairly.” Also, he lost his
license as a result of driving with a suspended license too many times.

**Emotional phases of adjustment.** Bernie describes times when he has
felt angry or depressed because of the losses that he has experienced. He
told of an incident when he was arrested for drinking and driving when he had
not been drinking. Because he has balance problems and slowed speech, the
officers did not believe him, despite having a “Traumatic Brain Injury” card and
a zero Blood Alcohol Level. He blames himself for having a significant history
for drinking and driving but also blames the “legal people” for giving him a
rough time. He speaks of his brain injury in terms of it being reality now and
something that he deals with and accepts. “You know,” he states, “I really have
lost faith in the justice system. . . . It seems like they are just out to make things
worse, not help.” He states, “That’s OK, I deal with it and my life is on track
now.”

**Starting life over/rebirth.** Having had to learn to talk, read, walk, write,
think, and feel as if he were a little child again frustrated Bernie. He indicated
feeling "stupid" and upset that he had to go back in time as if he were a young boy again. "It was almost like being back in the second grade or something, man." "But my hand writing is neater now than ever before! So it really was good for me to learn those things again. Besides, I can help my son with some of his school-work a little better."

**Things rehabilitation should change.** Bernie stated that he had no complaints about his rehabilitation team's efforts other than they did not help him process some of the emotions that he was experiencing. He also thought the rehabilitation mind exercises were not what he needed all the time. He complied nevertheless in order to "go along with the program."

**Positive things about rehabilitation.** Bernie stated that he was satisfied with the efforts of his rehabilitation team. The team really listened to what his goals and needs were and constructed a rehabilitation treatment plan that met those needs. For instance, Bernie wanted to be independent again and help his wife at the time to raise their baby. He also wanted to cook again. The rehabilitation team set him up in an independent living apartment and put him to work in the rehabilitation hospital cafeteria with a coach to help him succeed in both places. He also felt the rehabilitation team helped him to re-establish more meaningful values. He states, "They really listened to me and did a good job with me." "They did real well considering what they had to work with," said Bernie.

**Spirituality.** Bernie was the one participant who did not seem to have a remarkable spiritual experience during or as a result of his accident. He states
that he believes in God, but does not recall any specific prayers or experiences that were spiritual or religious since his accident.

Taz

Taz is a 38-year-old, divorced male with three children—boys, 9, 11, and 17 years old. He grew up in New Hampshire and moved to Florida with his first wife and first son and currently is residing on the coast of Central Florida. His biological parents are married and live nearby. His fraternal twin is one of his sisters, and they have two older sisters all of whom live in New Hampshire. Taz obtained his Associate of Science degree and has worked toward a Bachelor of Science degree in electrical engineering. He explains that he earned his nickname, Taz, while attending college and has many fond memories of college. He states that he now is thankful that he never finished his bachelor’s degree now because he does not think he could handle the responsibility of the detailed work involved in electrical engineering since his accident that left him with a traumatic brain injury. As he puts it, “Thank God I never finished that bachelor’s because it would be useless now.”

His current job is as a manager and maintenance engineer of a 55-unit condominium complex on the beach. He does not enjoy this job and is currently considering returning to his previous position as the maintenance engineer of a mental health hospital near Orlando. Taz explains that this would be an exciting move for him, and he believes he can handle the pace of the job. In his opinion, he has not had meaningful employment since his accident on New Year’s Eve of 1997 during which he flipped his four-wheeler without
wearing a helmet. The following paragraphs describe the themes derived from his experiences.

**Family.** Taz states that his parents and sisters were instrumental in helping him to return to a normal lifestyle. He explained that his ex-wife had signed papers to have him committed to a nursing home because she could not handle the behavioral changes that occurred as a result of his injuries. "If it were up to her, I would have wasted away in some old folks home by now," according to him. His parents and sisters prevented this move and helped him to learn to live independently. He is thankful for his family but admits that he does not show it the way he feels he should. "I should be nicer to them. . . . In fact, they will be surprised to read how I really feel about them." "I guess I shouldn't give them such a hard time," he states.

**Coping mechanisms.** One of his coping mechanisms is to use his sons as sources of inspiration. He explains that while in a coma, he had conversations with God and that one of the topics of these conversations was that God wanted him to focus more on being a good father and to calm down. Hence, Taz has done so. Taz explains that he was a regular brawler before his accident and had a tendency to get into a lot of fights. As he puts it, "I was a real hell-raiser." Taz feels fortunate that he has found a psychiatrist that he respects and can talk to about his adjustment issues. He has felt very supported by this psychiatrist and trusts his judgment. In addition, he also likes the medication that his psychiatrist prescribes for him because it helps him to keep his temper under control. He also accepts full responsibility for his
accident. He blames no one but himself and his own “stupidity.” He states that by accepting responsibility he has been better able to focus on reaching his goals and avoid feeling victimized by the accident or what caused it. “Why should I waste a lot of time on being mad, when it was my own stupidity that caused the accident?”

Post accident. Taz describes having experienced several changes as a result of his accident. Before his accident, he was a rowdy “life of the party guy” who would think nothing about singing for crowds after having a beer or two. He was also prone to fighting and brawling in bars. “I used to wind up in some hellacious fights with the biggest son-of-a-bitches in the bar,” he explains. He now refrains from fighting and limits his alcohol intake to an occasional glass of wine on special occasions. He refrains from alcohol because it could affect his medication that he feels has really helped him. “First of all, I don't want to mess up my medication, because I enjoy being nice to people,” according to Taz. “But I also hate feeling out of control, now. I don’t want to be that way again.”

He also states that he prefers interacting with just a few people now whereas before he preferred crowds. He explains that he likes to focus on just one person, whereas before he did not care to get to know individuals as deeply. He also explains that he is less impulsive with money than he was, but he admits he still will spend it if he has it. He is more inclined to think through how he will spend it now as opposed to before when he would just spend it.
**Losses.** One of Taz’s biggest losses was his ability to excell in sports. He explains that he can still play but moves much slower; he has lost his agility. His eyesight also was affected by his accident. He once was a proficient golfer who could outdrive Tiger Woods on the golf course. He states, “I was good. . . . I could outdrive Woods and he’s the best.” He states that now he is lucky to keep the ball on the fairway at all. He also explains that the changes in his temperament and behavior were contributors to his second divorce. While he welcomes the fact that he is a nicer, calmer person, he recognizes that had the accident not happened, he would still be married, perhaps. He does state that he really did not think this marriage was a good one to begin with, however, it was a loss nonetheless.

His relationship with his sons also has changed. His second ex-wife apparently tells his boys that he is “half-brained” now and “retarded.” Her lack of understanding and anger toward him has caused his younger two boys to view him differently, he feels. He is planning on consulting a counselor with them and talking with them about everything so that they may obtain a better understanding. He states his older son basically ignores and avoids talking about the changes Taz has experienced. Taz states he allows this to an extent, but maintains that “reality is reality” and things are different now.

**Emotional phases of adjustment.** Taz describes going through anger and grief regarding the changes brought on by his brain injury. He states that having no one to blame but himself has helped him to adjust, and he is able to accept the changes rather than seeing himself as a victim.
Starting life over/rebirth. Taz describes having had to learn to walk, talk, think, and feel again has been frustrating, but inevitable. He feels that he has been given a new chance to live life better and that is now his intention. “I tell you, some of the stuff they had me doing, just didn’t make no sense,” he states. “But I’ll tell you one thing, they did teach me to focus better and to remember what was important.”

Things rehabilitation should change. Taz describes several things that he was dissatisfied with regarding his rehabilitation. He states that the rehabilitation team used “cookie cutter” exercises for everyone there. He felt that the exercises, physical and cognitive, should have been more germane to his cognitive and emotional needs. Further, he felt that the rehabilitation team ignored his preferences. For instance, he states that the team included his ex-wife despite his protests. He states that he informed his rehabilitation helpers regularly that he did not want to include her in rehabilitation treatment planning. He also wanted to be more of a part of planning and carrying out his rehabilitation. He did not like having a group of people and a doctor that he barely knew planning how his life was to be spent.

Positive things about rehabilitation. Taz states that the only thing that rehabilitation helped him with was to focus better on his goals. He states that overall it did not help him, as his rehabilitation team viewed him as rebellious and noncompliant when his ideas were different than theirs. According to Taz, “They should stop and listen because there were things that they wanted me to do and say that had nothing to do with me anymore.” “The things that were
different, they wouldn’t recognize, and the things that stayed the same had always been there. . . . Some of those things weren’t so good and they wanted to blame the accident.” “The thing they don’t realize is that it weren’t the accident; I had always been impulsive with money and had expensive tastes, for example.”

**Spirituality.** Taz became inspired to change his ways after having had conversations with God while in a coma following his accident. Before his accident he was a partier and self-described “hardass.” “I really had problems with my temper.” “I was the kind of guy who was always in bar fights or looking for them.” His conversations with God were about having a second chance to change his ways. Apparently, God wanted him to pay more attention to his sons and to stop being a “hardass.”

Taz is thankful in some ways for his accident because he has been motivated to calm down and work on his anger problem. He is even willing to take medication for it. Further, he refuses to drink excessively now. He enjoys being sober and in control of himself. He tries to focus more on his sons, but his ex-wife makes it difficult for him to see his youngest two sons at times. He states that he has a lot more patience and he will wait for the day when his sons are older and they can spend more time together without his ex-wife’s interference.

**Lex**

Lex is a 32-year-old, single male who resides in north central Florida along with his family. He currently is working on his Master of Science degree
in natural resources and environmental sciences at a state university in Florida. He has begun working on his thesis and is wrapping up his course work. Lex grew up in the Republic of Panama and had no problems academically as he is very intelligent and excelled. He did have problems focusing, however, because of having attention deficit hyper activity disorder. As he puts it, "I had a very difficult time focusing and sitting still." He graduated from college with a Bachelor of Science degree in Marine Biology from a private college on the west coast of Florida. In 1991 he had entered the College of Veterinary Medicine at the University of Florida when he had an accident from which he sustained a traumatic brain injury that severed his pituitary gland from his brain, ceasing the production of vital hormones such as thyroid, testosterone, and hydrocortisone.

After awakening from his coma 2 weeks later, he was transferred to a rehabilitation hospital for approximately 1 year. His progress there was poor as he and the head administrators and doctor did not agree, and he was viewed as noncompliant. His parents picked him up and took him back to the Republic of Panama where he began his recovery. In late 1999, he met an internal medicine specialist who began a vigorous hormonal and medical regimen that replenished the hormones that his brain stopped producing 8 years earlier. The following themes and categories were derived after receiving comparisons from his story.

Family. Lex states that his family has been extremely important in his recovery and adjustment process to traumatic brain injury. His mother has
advocated for him and believed in him, and that has been one of the biggest reasons that he has surpassed all of the expectations that his rehabilitation team originally had of him. His brother also has been a source of support, helping Lex to begin working toward a degree. He mentioned several times during the interview how thankful he is for his family and how it important it is to have supportive family when trying to adjust to brain injury. “My whole family deserves a lot of credit for my successes, especially my mom. . . . We are very close,” he states.

**Coping mechanisms.** Lex used several strategies consciously and unconsciously through his adjustment process. First, he views his adjustment as a discovery and learning process rather than a state of overcoming or surpassing obstacles. He views adjustment differently, he thinks, because before his accident, he had to compensate and adjust to having attention deficit hyperactivity disorder. “To me, adjustment was not a matter of loss and compensation, it was merely another pace of learning,” he states. Lex iterates, “I had one type of learning that was different than most before, now it’s just a different learning process.”

Second, he refused to settle on the goals that his rehabilitation team suggested. He states that he knew he would always get back to graduate school and absolutely refused to settle for working a menial labor job for the duration of his life as his rehabilitation team recommended.

Third, he avoids acknowledging things he can do nothing about. For instance, upon asking him what happened to his pituitary gland since it was
severed from his brain, he replied, "I don't know, it's in the background now."
Upon asking him why he replied this way, he responded by explaining that he
sees no sense in scrutinizing things that about which nothing can be done.
"It's not important to dwell on those things. . . . I can't do anything about them. . .
. I only focus on things that have solutions to be found," Lex states. He is more
focused on finding solutions to problems, and since he cannot regenerate his
pituitary gland, he is more interested in finding ways to compensate for its loss.

Last, he attributes his successes to having no agenda other than
personal greed, drive, and tenacity in reaching his goals. He states, "I do
nothing that isn't for me and me only. . . . I am not trying to be an inspiration for
anyone, anyone at all." "So, I deserve no credit in that respect, I am basically
greedy," says Lex. He states that while in a coma, he and God discussed the
changes that could help Lex to achieve his mission of helping the environment.
Lex states that this conversation was surprising, as he considers himself to be
atheist, but it happened nevertheless. From it his mission to help save our
natural resources was validated along with the capacity to focus because of the
accident.

Post-accident. Lex describes several changes that he has experienced
since his accident. He states that he is able to focus without being distracted
or impulsive. He states that he could never really attend well before his
accident and that his accident afforded him the ability to stay on task, a trait he
feels is necessary for research. He also has become much more reserved.
He is much less interested in meeting people and partying and much more
interested in concentrating on his research. He also is much more interested in doing mental work, whereas before he liked physical activity and labor.

**Losses.** Until he met his internal medicine specialist who helped him with replacing the hormones that his body stopped producing as a result of his brain injury, Lex had many losses. He could not produce muscle mass, he had no energy and his mental processes and speech were slowed. He also lost most of his friends because he could not relate to them anymore socially and they to him. Since he began hormone therapies 2 years ago, he has regained his muscle mass, virility, energy, and quickened, integrated mental processes. His social life also has improved. He wishes at times that he were outgoing again, but not at the expense of his ability to focus.

**Emotional phases of adjustment.** In listening to Lex's story, he describes being angry primarily with his rehabilitation team. For 8 years, he grieved his losses and experienced feelings of depression but never gave up hope. He acknowledges and accepts the changes his accident brought openly because he feels there is no reason to deny or hide what happened. As he puts it, "it's obvious if you spent any time with me, so why deny it." He has interpreted the changes such that they facilitate him in reaching his goals.

**Starting life over/rebirth.** While in the rehabilitation hospital, Lex described how tedious it was to learn how to walk, talk, and toilet train again. He spoke of feeling that his mind and soul were trapped by physical limitations, to which there must exist a solution. He described the process of relearning as a process of redeveloping pathways in his mind. As he describes it, "Basically,
there are two parts to all of us... the physical and the spiritual." "For me, my physical domain had been trapped for eight years until meeting my doctor," he states, "and the disappointing part is that no one explored hormone replacement in rehabilitation after my pituitary gland was destroyed."

**Things rehabilitation should change.** Lex had many disappointments with his rehabilitation treatment, the biggest being that efforts were not taken initially to begin hormone replacement within the first 12 months post-injury. Another source of disappointment was the way he was treated by his doctors at the rehabilitation hospital. His goals, beliefs, and preferences were dismissed as him lacking awareness, being in denial, and being noncompliant. Lex interpreted this as confining and limiting his potential and was disappointed in the physician's expectation that Lex should limit himself.

He expressed extreme disappointment that his rehabilitation team made prognoses and predictions based on only the physical aspects of his injury, not taking into consideration Lex's drive, determination, and will to succeed in his mission and goals. And he expressed disappointment of the rehabilitation team's unwillingness to take into consideration and explore his perspective. "First of all, why butt heads with someone with a brain injury?" "That is just stupid to begin with because they are not capable of understanding, initially. The doctors should explain reasons for creating certain goals instead of forcing me to do it their way."

**Positive things about rehabilitation.** While Lex could not find anything positive about his experience with his treatment at the rehabilitation hospital,
he has many positive things to say about his internal medicine doctor. He explains that his life turned around when he met this doctor. Within 5 minutes, the physician pinpointed his problem, and Lex no longer feels like his mind and soul are trapped. Rather, he is able to integrate the physical and mental components of himself so that he may achieve his mission.

**Spirituality.** Lex was once an atheist. He described himself as having been a scientist who believed that God is nature, much as the American Indians believed. After his accident he was in a coma during which he had conversations with God. “I know it seems weird for an atheist to claim to do this, but it happened.” “I cannot deny talking with God.” Lex described the conversations as peaceful and “cool.” Lex and God talked about what Lex is going to do with his life and how things will change for him. “Basically, God told me that the effects of my brain injury were going to help me to focus better and eliminate my attention deficit disorder.” Lex stated that God also gave him a mission that was to dedicate his life to save the environment.

Lex had always loved nature and the environment, but was never able to focus long enough to become serious about it. He believes that surviving his accident and injury has provided him the opportunity to pursue his passion that became his mission. He now is agnostic because he believes in a Higher Being, but not organized religion.

**Shelley**

Shelley is a 30-year-old, single woman who resides in north central Florida. She is the second youngest of five siblings and lives with her mother.
She is confident and pleasant in her interactions and openly shares her experiences since acquiring a traumatic brain injury in 1992. She is attractive, naturally blond, congenial, walks with a limp, and sometimes has slowed speech. She currently works instructing students in violin according to the style of Dr. Suzuki. She prefers one-on-one interactions to large crowds though she can deal with crowds because of her many performances as a musician and dancer before her accident.

She began playing the violin at 18 months of age under her mother's tutelage and the piano at 5 years of age. She was very talented and earned a full scholarship in music to a Florida university. She attended for only 1 year, however, because as she puts it, "I wasted my talent and opportunities because of an addictive, unhealthy relationship." After losing her scholarship, she used her talents to support herself by performing in bands and dancing.

Since her accident, she has graduated from a community college with an Associate of Arts degree and had once planned on pursuing her Bachelor of Arts degree in childhood education. She has changed this goal and currently is writing a book about her experiences. Shelley's accident was severe, as she sustained a traumatic brain injury and a lacerated brain stem. She was in a coma for 4 months and was not expected to live. She was expected to remain in a "vegetable-like" state of awareness that she has clearly overcome and surpassed. The themes derived from her experiences are given below.

Family. Shelley believes that her mother, family, and friends have been the biggest reason for her survival and successes in adjusting to her brain
injury, other than her own drive and determination. "My mother has basically brought me into this world twice, and I want her to know that I am thankful more than twice," she states. She feels that having a solid support system of family and friends is vital in recovering from a traumatic brain injury. She also believes that having a pet is important as well. "Every person who goes through surviving a brain injury should have a pet, especially a dog because dogs give back so much," she states.

Coping mechanisms. Shelley explains that she is very spiritual; Christianity is her religious preference; and she uses prayer frequently as a means for coping and adjusting to the changes brought on by her injuries. She also considers her survival to be a miracle, so she believes her purpose for living is to provide hope and inspiration to others who face adversities. "Too many things at the scene of the accident just worked out uncannily," she states. "It had to be unseen, spiritual forces that moved the engine off of me," she said. She adds, "I interviewed the paramedic who tried to free me, and even he agrees that that is the only explanation for it, moving just enough with no explanation so that I could be freed and transported to the hospital." Last, she relies on her friends; family; and dog, Milli, for support and comfort during times she feels low or depressed.

Post-accident. Shelley has undergone several changes since her accident. First, she does not play the violin or piano with as much ease anymore. She states that she actually has to practice now and admits that this troubles her. She also is more reserved. She states that before her accident,
she was much more outgoing and popular. She is nicer now, whereas before her accident she was conceited and did not treat people well. She prefers being nicer to people. She is no longer able to dance or run but vows that she will run again one day. She took life for granted before and now feels that she has been given another chance to live and vows that she will not waste it.

Losses. Shelley's losses are many from her accident. She describes the feelings of having lost her musical and physical abilities. While she has not lost her musical abilities totally, she admits that she has to work at it now. “That really makes me feel very sad,” she states. “I used to be so good without having to practice,” she states wistfully. She has lost time with her social goals. She aspires to live independently, marry, and have a family when it is time. She feels that this goal will be delayed as she spends more time adjusting to the emotional and physical changes caused by her injury. She focuses more readily on what she has gained from her accident. These gains include a “new lease on life,” as she puts it. Additionally, she has gained insight and wisdom into what is important about life and endeavors to never take it for granted again.

Emotional phases of adjustment. Shelley recognizes having various emotions about her injuries and adjustment. She admits feeling both anger and pity toward the driver who caused her accident. She was the passenger of the driver who had a head on collision while driving under the influence of illegal substances. She admits her own regret in having made the decision to keep his company to begin with and feels it is unfair that he is now graduating
from law school and getting married. She is able to reframe this anger to pity but admits that she still feels angry at times. She also experiences grief for her losses. She acknowledges and accepts the changes she has experienced because they are her new reality. She sees no reason to deny them because to do so will not serve her mission to provide hope and help others.

Starting life over/rebirth. Shelley described herself as being reborn in the truest sense. After having to relearn to do everything including crawling, walking, talking, thinking, and feeling again, "what else can it be called," she wondered aloud. She states that this was a humiliating process because she could remember having to do it the first time, and she now had to relearn to do it as an adult woman. "I will run again one day, even if it takes me longer than it did to walk again," she affirms.

Things rehabilitation should change. Shelley was dissatisfied overall with her experiences and treatment in the rehabilitation hospital. She states that her rehabilitation team caused her to feel worse about herself in several ways. "I call that program 'Downreach instead of Upreach' because I felt worse about myself there," according to her. "I don't think they did a very good job in boosting morale or giving inspiration," she related.

She thought that the goals decided upon for her were limiting and confining. She wanted to focus on her emotional and social adjustment issues and felt that her providers minimized and dismissed these issues. Specifically, she wanted more social interaction and support with other patients and to focus on her goals of one day marrying and having a family. She feels that
these are goals that many women in their 20s and 30s focus upon and even have biological drives toward. Her rehabilitation team dismissed her as being unaware and in denial. She protested because she more than anyone was acutely aware of her new limitations. Shelley also felt that more incentives could have been provided and that the rehabilitation team should not make predictions or recommendations to settle for lesser goals without understanding the patients more fully.

**Positive things about rehabilitation.** Shelley felt that her home rehabilitation providers did help her, including her mother who worked with her cognitively through music, her exercise physiologist, who helps her balance and walking without a limp, and the nurses and physical therapists, who came to her home and helped her stretch and use her muscles.

**Spirituality.** Shelley has always believed in God and claims to be Christian. She grew up in the Lutheran church and still actively participates in this denomination. She attends church at least once per week.

Shelley now believes in miracles. She maintained that her survival is nothing short of a miracle. She states, "Making it to the hospital was phenomenal in itself because I was trapped under the engine, but it miraculously moved 12 inches off of me." After having been in a coma for 4 months, she was expected to be a "vegetable" and totally dependent. She now works, teaching violin lessons to children. She also has obtained her Associate of Arts degree and is writing a book about her story.
Shelley is thankful to God and for her mother for carrying her through this experience. She does not recall having specific conversations with God or angels, but knows that she survived to serve some higher purpose. She believes that this purpose is to inspire and provide hope for others who endure harrowing accidents.

Constructs of Participants

Constructs were derived after applying the constant comparative method to the transcribed data of the perceptions of adjustment and rehabilitation of the participants after acquiring traumatic brain injuries. Constructions of case studies were used to ascertain the perceptions of the participants about whether or not rehabilitation modalities helped or obstructed them from aspiring to their goals and adjustment. Five constructs were derived from the accounts of the participants, including the importance of family support, the sense of being "reborn" and beginning everything all over again, the development of coping mechanisms, the experiencing of emotional adjustment phases, and believing that rehabilitation expectations and goals should be congruent with client contexts.

Family Support

The importance of family support was discussed by each of the participants. Each of the participants was fortunate enough to have had strong family support systems that advocated for them in the acute and immediate stages of acquiring their injuries. Further, all of the participants believed that
their families believed in them and that they could surpass the expectations of the medical and rehabilitation teams. Two participants had family members who were not supportive.

**Sense of Rebirth**

All five participants described the feeling that they have had to start all over again with life. Each of the participants described their experiences of having to relearn how to toilet train, walk, talk, think, and feel all over again. In relearning to think again, most described changes such as “I was once good with English, now I am better with mathematics.” All participants also described changes in preferences and personality styles. For instance, four participants stated that they were more outgoing before their accidents, and now they are more introverted and reserved. One stated that she was introverted before her accident, and now she is more outgoing.

**Development of Coping Mechanisms**

Various means of coping with the changes brought on by their injuries and striving toward new goals were described. All of the participants told how they developed a purpose or mission for their lives as a result of their accidents. Three of the five participants specifically described conversations they had with God or angels while in a coma. From these divine conversations came the development of meaning for the changes with a new capacity to accomplish these tasks, whereas before the accomplishment of such tasks was either not possible or not meaningful. For instance, one participant states
that she feels that her purpose is to help and lead others through the experiences of adjusting to traumatic brain injury. She states that before her accident, this goal would not have occurred to her and would not have been as meaningful. Another participant states that before his accident, he had volatile temper that led to many altercations and fights. He states that during his coma God told him that his accident had created changes to help keep him calmer and that he needs to stop the fighting and focus more on his children. Therefore, this participant interpreted his injury as a positive change that allowed him to calm down and become a better father as well as having given him a new purpose that did not occur to him before.

Another form of coping with the changes brought on by traumatic brain injuries was reliance on a source of inspiration and motivation. Each of the participants described people or inner strengths as resources that inspired them to keep going despite adverse circumstances. One participant stated that whenever she was in so much pain from her injuries that she thought she could not go on, she would think of her father who persevered despite several disabling accidents. Another participant used her grandmother as a source of inner strength because her grandmother had survived the two World Wars in Germany and had much wisdom to depart to her. Another participant used the quarterback of the Oakland Raiders as a model of motivation and perseverance and even saved a copy of a poem about winning against the odds, written by one of the Raiders, to read from time to time. Last, all of the
participants relied upon inner strengths such as motivation, tenacity, and determination to reach goals.

**Emotional Phases of Adjustment**

Each of the participants experienced varying levels of emotions such as denial, frustration, anger, grief, and depression while adjusting to their injuries. These emotions have been conceptualized by Livneh and Antonak (1997) and discussed in earlier chapters as phases of adjustment and adaptation to disability. Prigatano (1999) also discussed these emotions along with confusion as being common emotions that individuals with traumatic brain injuries experience in the adjustment processes.

**Contextual Rehabilitation**

All of the participants discussed the changes within themselves and the things and people they lost as a result of the differences. Each discussed these changes on some level and the need for rehabilitation goals to address who they were after the accident. Consequently, "losses" and "post-accident" categories were absorbed by this contrast. All of the participants gave descriptions of how rehabilitation goals either were or were not relevant to them. Of the five participants, one states that he was satisfied with the efforts and goals that were set by his rehabilitation team. He also states, however, that his rehabilitation team listened to his goals. He had been a chef in training before his accident and wanted to finish his training as a chef and cook again. He also wanted to live independently. Hence, his rehabilitation team set him
up in an apartment on the grounds of the hospital and worked with him to re-teach his activities of daily living. They also coached him while working in the rehabilitation cafeteria.

The other four gave accounts of their rehabilitation teams arguing with them about their chosen goals for work, driving, or school. The participants were aware that their teams were pointing out that their long-term goals might never be reached because of the changes caused by each of their injuries. However, the participants each "knew somewhere inside" that they could aspire to their goals eventually and felt that their rehabilitation teams were limiting their propensity to do so.

These constructs represent the themes and categories found to be common with each of the participants after analyzing the transcripts. The reader may notice that certain categories disappeared or were absorbed by a construct. For instance, the "losses" and "post-accident" categories were included under "contextual rehabilitation." The "spirituality" category could not become a construct because only four of the five participants experienced or included spirituality as a part of the rehabilitation process. The first purpose of this study was to ascertain the experiences and perceptions of adjustment to traumatic brain injury from the perspective of survivors. By doing so, the aim was to discover common constructs and to compare them with existing brain injury rehabilitation paradigms. The following chapter presents the contrasts and comparisons between the constructs discovered from the data and Livneh and Antonak's Psychosocial Adaptation and Adjustment to Disability (1997), O’
Hara and Harrell's Empowerment Model for Brain Injury Rehabilitation (1990), and then with Prigatano's Principals of Neuropsychological Rehabilitation (1999).

**Summary**

Five case studies were constructed from transcriptions of five audio-recorded semi-structured interviews with five survivors of traumatic brain injury. Then the constant comparative method (Glaser & Strauss, 1967) was applied to the transcripts of five interviews with survivors with traumatic brain injury that ascertained their perceptions of adjustment to their injuries. The data produced five constructs including "Family Support" that indicated the importance of supportive family members to participant adjustment. A second construct included "Sense of Being Reborn" that described frustration at having to relearn everything from fundamental tasks such as walking, talking, and toilet training as well as more complex tasks such as learning to think and feel again. A third construct was "Development of Coping Mechanisms" that suggested that participants adopted adaptive strategies to facilitate their adjustment to their injuries. A fourth construct included "Emotional Phases of Adjustment" that discovered two emotions common to all five participants—anger and grief. The fifth construct was "Contextual Rehabilitation" that indicated the importance of understanding the survivor perspective phenomenologically before imposing treatment objectives. The case studies and the derived constructs achieved what was intended in the first purpose. The results of the second purpose is presented next in Chapter 5 focusing on...
the comparisons between the derived constructs and the constructs of three existing models of disability and brain injury rehabilitation.
CHAPTER 5
COMPARISON AND CONTRAST OF CONSTRUCTS AND MODELS

Chapter 4 contained five case studies and common themes, categories, and constructs derived from semi-structured interviews conducted with survivors of traumatic brain injury. Examination of the congruence between theory and the survivors' perspectives is the next step and may present two distinct possibilities. The constructs discovered in this research could reveal that gaps between client and brain injury rehabilitation theory are consistent and remarkable. This would indicate a need for traumatic brain injury (TBI) rehabilitation theory and practice to incorporate the additional constructs of the client with TBI. Incongruence indicates that current theories used to rehabilitate populations with traumatic brain injury may not be appropriate and need further exploration (Crisp, 1993). Second, the findings may be compatible with existing theoretical constructs, thereby providing qualitative validation.

Psychosocial Adaptation to Disability

Various stage and phase models exist purporting that adjustment to trauma and disability happens as the individuals enduring such traumas experience certain emotional reactions. Livneh and Antonak (1997) developed a conceptual model that incorporates these emotional phases but maintain that the process of adjustment is multi-dimensional rather than linear. Livneh
and Antonak's (1997) conceptual model of adaptation to disability states that humans experience certain universal emotional reactions to trauma and illness when adventitious disabilities occur. These reactions include shock, anxiety, denial, depression, internalized anger, externalized hostility, acknowledgement, and adjustment (Livneh & Antonak, 1997) (Appendix F).

Studies reveal that no particular sequence or required phases that individuals must pass through after trauma or disability occurs, but rather that these or a combination of these phases may be present (Livneh & Antonak, 1997). Further, Livneh and Antonak (1991) maintained that reactions to disability are nonlinear, multi-dimensional, and hierarchical after results of phase ordering included maladaptive reactions blended in with the hypothesized order of adaptive reactions. In their study, Livneh and Antonak found relationships among the variables that varied with time such as anxiety and depression having different intensities for individuals after time passed (Livneh & Antonak, 1991). Assumptions are also made, such as that permanent, significant changes and psychological dissonance must be experienced, and that the phases do not occur in sequence or in isolation of other phases (Livneh & Antonak, 1997).

Adjustment is considered the last stage of adaptation, whereas adaptation is the continuous evolvement through which an individual with acquired illness or disability achieves maximal independence within the environment (Livneh & Antonak, 1997). Adjustment connotes acceptance of disability and integration of pre-injury and post-injury psychological
components. Four categories of adjustment and adaptation exist and are presented as Class I variables, Class II variables, Class III variables, and Class IV variables according to Livneh and Antonak (1997).

Class I variables contain disability characteristics such as age, extent of injury, type of injury, degree of neurological impairment, and lethality. Class II variables consist of socio-demographic information including gender, ethnicity, developmental stage, education, marital status, and job title. Class III variables include values, self-image, pre-trauma psychosocial adaptation, attitudes, locus of control, and defense mechanisms. Class IV variables are socio-environmental factors such as home environment, social groups, friends, and attitudinal barriers imposed upon the client (Livneh & Antonak, 1997).

These four classes of variables affect each stage of progression while adjusting and adapting to disability. These stages of progression include an early stage that involves shock, anxiety, and denial of the trauma. Intermediate states focus upon steps toward acceptance of the incurred trauma and include anger and depression. The later stages move the survivor toward acceptance and adjustment. A circular accounts for different reactions and decisions regarding the trauma at any given point during the process, eliminating the model from being a linear stage model entirely (Livneh & Antonak, 1997).

**Psychosocial Adaptation to Disability Model and the Constructs**

Of constructs that were derived from the data analysis of the five participants, two seem to have points of comparison. The construct “Sense of Being Reborn” contains elements of frustration, humiliation, and anger. All five
participants described the sense of having to relearn everything and start all over with walking, talking, toilet training, thinking, and feeling again. All five also indicated a level of irritation and frustration with having to recomplete these fundamental tasks.

It should be delineated that the individual tasks that had to be relearned had different anger reactions. Specifically, the participants described having to relearn tasks such as toilet training, walking, talking, and writing as being frustrating because these are things they originally learned to do during the first several years of life. These tasks were frustrating because it is embarrassing simply because these had to be relearned as adults. All of the participants could remember doing these tasks before their accidents and found it sobering that they had to relearn these tasks.

The tasks of relearning to think and feel carried a different level of frustration for the participants that were expressed in terms of not wanting to be expected to relearn to think and feel again according to a group agenda, set protocol, or like they did before. It seemed that the participants were indicating that they preferred having input into planning rehabilitation exercises while they were learning to be perhaps, different individuals. Concurrently, several of the participants experienced grief and sadness, realizing that they would be permanently different than they were before. Implications of this can be seen in the in the construct of "Contextual Rehabilitation" as well. The participants all indicated that rehabilitation needed to take into account the individual goals and preferences of each survivor.
Livneh and Antonak (1997) indicated that anger and grief were two of the necessary emotional components of the model to experience in order to achieve acknowledgement and adjustment. The data supported this premise, as all five participants experienced varying levels of frustration and depression over aspects of their rehabilitation and adjustment processes. The construct “Emotional Phases of Adjustment” discussed the commonalities discovered from the data, uncovering that this small sample of individuals did in fact experience at least these two emotions in reaction to their traumas.

The participants' experiences of anger and grief were different among each participant, however. Teresa Lynn directed her anger and grief at God and the rehabilitation staff. Bernie directed his anger and grief toward his ex-wife and law enforcement. Taz was angry with his ex-wife and rehabilitation staff as was Lex and Shelley. Taz and Shelley expressed further frustrations with parents. So, while phenomenological inquiry elicited results that support Livneh and Antonak's supposition that anger and grief are usually experienced, it does not explain anger, grief, or any of its emotional phases with respect to treatment. The model does not address how to treat the various contexts containing grief, anger, shock, denial, and adjustment.

The construct “Family Support” is represented in the Psychosocial Model of Adaptation to Disability as a Class II Variable. The key trait about the construct of “Family Support” derived from the data is that all participants recognize how important it was for them to have supportive family members. The Psychosocial Model of Adaptation to Disability lists family as a socio-
demographic variable that affects the adjustment process. How it affects the
adjustment process and its significance is perhaps better answered
quantitatively. Since all five participants have reached varying levels of
adjustment and adaptation, the assumption is that supportive family members
facilitate adjustment.

Out of the five participants, two reported having unsupportive family
members and a third participant viewed a family member as mostly supportive,
but at times unsupportive. Livneh and Antonak’s model accounts for such
paradoxes by depicting the classes containing variables as overlapping and
moving circularly through time. The Psychosocial Model of Adaptation (Livneh
& Antonak, 1997) again does not give treatment teams tools to address
variances within the same variables; rather, the model simply depicts that such
variances can occur.

The last construct, “Development of Coping Mechanisms,” is a Class III
variable having to do with how individuals manage their interactions with the
world. Incorporated in these Class III variables are the defense mechanisms,
pre-accident psychosocial adaptation, locus of control, and attitudes that
individuals had adopted to interact within the environment. The data from this
study produced at least one coping mechanism that was common to all the
participants and that was that each used something or someone as a source
of inspiration. Another coping mechanism was that most of the participants
interpreted their accidents and injuries as a means for creating new purposes
for their lives.
The Psychosocial Model of Adaptation to Disability developed by Livneh and Antonak (1997) explains how coping mechanisms, emotions, environmental influences, and intrinsic qualities occur concordantly. As such, this model best answers questions of "Why." This model addresses why individuals achieve various rehabilitation outcomes but does not answer questions of "How." How can rehabilitation outcomes be optimized for and by the individual with incurred brain injury.

**Empowerment Model**

The Empowerment Model by O'Hara and Harrell (1990) suggests that a vital component of rehabilitating individuals with traumatic brain injury is to instill and reinforce survivor efficacy, the belief in survivors' capacities to succeed. The rehabilitation team and clients then must embrace goals that encompass empowerment and planting efficacy beliefs in the survivor. These goals include enhancing motivation, providing clients with information about their injury, creating structure until the clients are able to do so on their own, teaching skills and strategies to compensate for losses, and facilitating acceptance of differences before injury and after injury (O'Hara & Harrell, 1991). The underlying basis of this model is that fostering these goals leads to a stronger internal structure and plants the seeds for motivation to flourish. The model is presented nonhierarchically as EXTERNAL STRUCTURE + MOTIVATION + INFORMATION + ACCEPTANCE + SKILLS = EMPOWERMENT (O'Hara & Harrell, 1991). All of the components must be included, or else the goals of empowerment are likely to be unrealized.
The Empowerment Rehabilitation Model (Appendix G) (O'Hara & Harrell, 1991) is unique in that it is not sequential or linear, so that clients may enter treatment at any point after becoming injured. Psychotherapeutic interventions are emphasized in order to facilitate emotional adjustment, mastery of cognitive skills, and social skills. The Empowerment Model's guiding principle maintains that cognitive, emotional, physical, and interpersonal foundational domains re-assimilate at rates chosen by the clients in order to move victims to survivors (O'Hara & Harrell, 1991).

The external structure of the model contains the variables in the immediate environment of the survivors. These variables may be fixed including family, finances, living facilities, or transportation, but also include implementing additional structure for the survivors in order to assist them with survival until they can manage structure for themselves.

Motivation is implemented and managed in the environment through appropriate reinforcers, setting reasonable goals, and development of a therapeutic relationship. In developing motivation, the survivors adopt a sense of purpose and commitment to reach goals.

In order to fully accept and adjust to their injury, the survivors must be given information about their injuries through discussion and literature. This leads to creating a better understanding of how the brain injury has caused changes and is the only way that reasonable goals and expectations may be set and achieved.
Coming to terms with the injury and merging pre-accident "self" with post-accident "self" connotes acceptance. Psychotherapeutic interventions are implemented through a variety of modalities. Survivors are given the opportunity to participate in whatever "recipe" of modalities works best for them including individual, group, support, family or other interventions. In doing so, self-confidence, self-awareness, and self-respect may be incorporated by the survivor.

Last, clients are given opportunities to practice cognitive skills, vocational skills, academic skills, emotional skills, communication skills, and recreational skills in order to enhance reentry into the corresponding arenas requiring such skills. Having the chance to practice these tasks may improve mastery of such tasks in the environment thereby enhancing self-esteem and empowerment.

The Empowerment Model and the Constructs

The construct "Family Support" supports the Empowerment approach in that the "Acceptance" component maintains that family support is vital in facilitating adjustment. All of the participants maintain that they do not know if they could have achieved their goals to date had it not been for the support of family members. Another element to this is that all the participants suggest that their supportive family members believed in them. This is congruent with the Empowerment Model's premises that belief and empowerment foster survivor efficacy. Again, the impact and significance of having the support of family is not known. The data construct "Family Support" indicates that family
support was vital for the participants’ successes. This study does not reflect whether maladjustment or disempowerment occurs if family support is absent. However, three of the five participants had family members who were not supportive of all their goals. For instance, both Bernie and Taz had wives who divorced them as a result of their accidents. Both of these ex-spouses had signed papers to have their husbands live in long-term care facilities. Coincidentally, both Bernie’s and Taz’s parents took steps to prevent these things from happening. Both Bernie and Taz saw their parents as being supportive for doing this. Shelley felt similarly toward her mother and family. Paradoxically, Taz and Shelley reported that they now see their parents as less supportive. In fact, both Taz and Shelley reported feeling that their parents disempower or admonish them for some of their current goals. So in this sense, “Family Support” does not support the “Empowerment Model.”

The constructs “Sense of Being Reborn,” “Development of Coping Mechanisms,” and “Emotional Phases of Adjustment” all have elements that can be seen in the component of “Acceptance” of the Empowerment Model. In the construct “Sense of Being Reborn,” the reality of the participants’ repeating the learning of fundamental tasks such as toilet training, walking, and talking again brings to surface feelings of acknowledging that they are different and feelings of frustration that they have to do it again as adults. The “Acceptance” component of the Empowerment Model views this as a component of reintegrating the old self with former capabilities with the new self and new capabilities.
The "Development of Coping Mechanisms" construct contains elements of the participants' strategies used to integrate the shock and reality that they are different people and to foster goal attainment. These participants all indicate that they possess traits of determination, tenacity, and motivation that have helped them to achieve their successes thus far. Further, all describe family members who empowered them to continue striving for their goals. One participant, Bernie, attributed motivation and empowerment to his rehabilitation team, while the others felt that their rehabilitation teams did anything but empower them.

The Empowerment Model suggests that empowerment and instilling efficacy in the clients is vital to facilitating adjustment. Four out of five participants indicated that motivation did not come from their rehabilitation providers but rather from within or elsewhere in the environment. While this point in no way indicates any significance, the importance of motivation, efficacy, and empowerment in the adjustment process should be noted.

The construct "Emotional Phases of Adjustment" included two common emotional reactions among the participants--anger and grief. The "Acceptance" component of this model suggests that processing these emotional reactions to acquiring a brain injury fosters the reintegration of the old identity and new identity. Most of the participants in this study processed and worked through their emotional reactions independently in contrast to using psychotherapy to process these emotions. The Empowerment Model stresses the importance of survivors adopting adaptive versus maladaptive
coping mechanisms that foster adjustment such as empowerment, efficacy, and motivation.

It is important that these variables exist in the process of adjustment to traumatic brain injury. The construct “Contextual Rehabilitation” suggests that it is more important that the rehabilitation teams listen to the individual contexts of survivors and not “dismantle” them or limit them. While both the data and the Empowerment Model indicate that developing treatment plans should include survivor input if not authorship, the data indicate that this notion is not practiced. At least four of the five participants described their rehabilitation experiences as disappointing because they felt that rehabilitation created limitations and provided little inspiration for them. Listening to client goals and empowering them may seem unrealistic to some rehabilitation providers, as the survivor of traumatic brain injury may not have recovered awareness fully. In such instances, the model endorses education and practicing decision-making skills that are realistic. In instances when client goals are unrealistic, counseling strategies are implemented concurrent with empowerment techniques that specifically encourage clients to endorse realistic goals. This model provides for strategies that address various problems throughout the adjustment process.

**Prigatano’s Holistic Model of Neuropsychological Rehabilitation**

George Prigatano (1995, 1999), a practitioner and researcher in brain injury rehabilitation, developed a “Holistic Model of Neuropsychological Rehabilitation” that maintains that awareness and judgment need to be
restored or compensated to best facilitate adjustment. He emphasized that cognitive remediation and psychotherapy best address the deficits and provide avenues for survivors to compensate for or recover their lost skills. He suggested several components that help to achieve this adjustment such as the development of a therapeutic atmosphere and bond between treating therapist teams and client, cognitive retraining, small-group cognitive retraining hour, cognitive group therapy, individualized cognitive retraining, psychotherapy, family involvement and education, and the protected work trial.

Survivors are able to maximize therapeutic goal attainment in the presence of a well-developed therapeutic atmosphere. In addition, the rehabilitation team should endeavor to understand the perspectives of clients phenomenologically (Prigatano, 1999). Prigatano also suggested cognitive remediation and retraining in order to address confusion and frustration, emotional variables he states are common to this disability group.

Group and individual treatment are additional therapeutic modalities implemented to help restore and restructure cognitive functioning (Prigatano, 1999). He introduced small-group cognitive therapy hour as another means of implementing this concept, yet in a short, concise time frame that is germane to client interests (Prigatano, 1999). Family education informs and supports the immediate support systems so that both the survivors and their families may learn and incorporate strategies to optimize adjustment. Last, supported return-to-work programs are introduced to enhance the transition in returning to and maintaining work (Prigatano, 1999).
Holistic Model of Rehabilitation and the Constructs

The "Family Support" construct that having supportive family members foster adjustment and goal attainment for survivors supports Prigatano’s inclusion of a "Family Education" component in rehabilitation. Prigatano carries family inclusion a step farther and endeavors to provide education and training in order to increase understanding and adjustment both within the survivor and the environment. Prigatano recognized the importance of including supportive family members in the rehabilitation process because many times these are to become or were the survivor’s immediate environment. The data supported this in the "Family Support" construct. The data delineate farther by stressing that all outsiders, that is, both rehabilitation professionals and family members, need to understand that the survivor cannot return to a previous state. In plain language, the survivor rarely returns to family members as the individual they once knew. Therefore, the adjustment process is for family members, too, as both the survivor and family are likely to find that all of their needs and goals have changed.

The "Sense of Being Reborn" construct does not support this model directly despite the fact that both Prigatano and this derived construct address frustration and confusion. The "Sense of Being Reborn" construct presents frustration and confusion about having to relearn fundamental tasks and identity. Prigatano suggests that frustration, confusion, and learning new identity should be addressed through cognitive restoration and restructuring exercises. Prigatano’s model seems to conceptualize the variable of learning
new identity as a restoration process. The data from this study support restoration and restructuring but suggest that it must be individualized to who the survivor is, not was.

The "Development of Coping Mechanisms" and "Emotional Phases of Adjustment" constructs also are addressed by either cognitive remediation exercises or psychotherapeutic intervention. Mentioned earlier are two emotions identified by Prigatano (1999, 1995) that he observes survivors with traumatic brain injury to experience. The "Emotional Phases of Adjustment" construct identified anger and grief as emotions common to the five participants. Last, Prigatano's model seems to suggest that coping mechanisms are best developed by the rehabilitation team and hopefully with the client.

Both Prigatano's Holistic Model and the data's "Contextual Rehabilitation" construct support that an understanding of the individual survivor's context must occur to best facilitate adjustment. The accounts from the participants indicate that the establishment of an optimal therapeutic relationship did not occur for most of them. While both the data and this model support the importance of establishing a trusting, caring therapeutic relationship and understanding the perceptions and milieus of survivors, the data suggest that neither happened in practice.

The data indicate that the constructs derived from the raw data transcripts are present in the models of rehabilitation. Each of the models contains elements of the constructs. For instance, the Psychosocial Model of
Adaptation to Disability (Livneh & Antonak, 1997) is comprised of four classes of variables that represent the constructs found. In the Empowerment Model of Brain Injury Rehabilitation (O’Hara & Harrell, 1990), evidence of the constructs is noticed as aspects of this model’s constructs of “Acceptance,” “Motivation,” “Skills,” and “External Structure.” Prigatano (1999) incorporated these constructs as elements to be addressed in cognitive remediation and psychotherapy through individual, groups, and family education. Though the existence of these constructs is consistent in the models and the findings of this study, it appears that the perceptions of these survivors indicate that something is lost during practice.

Summary

Chapter 4 presented the results of the first purpose of this study that was to ascertain the perceptions of survivors of traumatic brain injury and to determine common themes and constructs among them. The results of the semi-structured interviews were presented as case studies that aimed to learn about the experiences of the survivors during rehabilitation and adjustment to traumatic brain injury. Then, an analysis was performed on the transcripts that revealed themes leading to five constructs that the participants had in common. In Chapter 5, these five constructs were then compared and contrasted with Livneh and Antonak’s (1997) “Psychosocial Adaptation to Disability,” O’Hara’s and Harrell’s (1990) “Empowerment Model of Rehabilitation,” and Prigatano’s (1999) “Holistic Model of Neuropsychological Rehabilitation.” Elements of the derived constructs could all be observed in the model; however, the models all
emphasized different aspects of the constructs. Premises such as understanding, empowering, and including client perspective in rehabilitation treatment are supported by constructs in the models and data. The data suggest, however, that these premises are lost in practice and implementation at times. Chapter 6 contains a discussion of the limitations, recommendations, and implications for future research.
CHAPTER 6
DISCUSSION

Introduction

This chapter contains four sections. The first section presents a review of the results from Chapter 4 and 5. The second portion indicates limitations of this study and reminds the audience of the intent of qualitative inquiry. The third section discusses implications for practice and theory, and the last section discusses recommendations for future research. Within the body of the discussions, potential explanations and interpretations of the results are offered. Last, this chapter encourages readers, practitioners, and researchers to explore the parameters of existing paradigms in traumatic brain injury research and practice so that survivors may all reach their contextual potentials.

Review of Results

The literature in traumatic brain injury has grown significantly over the past 25 years. More and more individuals who sustain traumatic brain injuries are surviving because of more advanced technology in neurosurgical treatment and care. Traumatic brain injury is caused by blunt trauma to the head during acceleration or deceleration impacts resulting in neurological damage to the brain (Krauss & McArthur, 1999). The results of this type of injury to the brain present unique challenges for medical care and rehabilitation because
damaged areas are difficult to predict (Krauss & McArthur, 1999). The primary impact damages one area of the brain, but secondary injuries caused by swelling and neurochemical complications may cause further damage in the brain. The sequella from traumatic brain causes potentially permanent changes in foundational cognitive, emotional, or physical domains so that survivors may never recover previous functioning.

In the process of adjusting to their injuries, survivors face any number of unique challenges, such as regaining awareness, learning their new identities, assimilating residual "old identities," and learning to feel, learning think; or any number of fundamental tasks, such as walking, talking, or toilet training (O'Hara & Harrell, 1990; Prigatano, 1999). Rehabilitation teams are asked to implement and carry out treatments designed to facilitate restoration of previous functioning or compensation for permanent deficits (O'Hara & Harrell, 1990; Prigatano, 1999). Because personality, cognitive processing, and emotional processing may be forever changed, both the survivor and the rehabilitation team face a precarious task in trying to restore functions that may no longer exist (Hill, 1999).

Extensive literature exists that addresses various issues regarding traumatic brain injury. The bulk of this literature presents issues from the perspectives of those involved with treatment, research, or family support systems for the survivors. Scarce literature addresses traumatic brain injury in conjunction with adjustment to traumatic brain injury psychosocially (Crisp, 2000; Prigatano, 1999). Even more scant is literature that presents adjustment
to traumatic brain injury from the perspectives of survivors (Crisp, 2000; Hill, 1999). As such far too little is known about whether awareness, denial, or non-compliance by survivors lead to poor rehabilitation outcomes or if other factors are to blame. Likewise, too little is known about those survivors who far surpass rehabilitation expectations and then are labeled anomalies to explain the confounded reliability and validity of original prognoses (Hill, 1999). The literature does not account for these discrepancies very well. Rather than speculating from the “outside in,” perhaps it is time to begin asking questions and learning from the “inside out.” That is, it is time to ask questions of those who actually know what it is like to live with and adjust to traumatic brain injury.

The first purpose of this study was to examine in depth the perceptions and experiences of adjustment and rehabilitation to traumatic brain injury of five survivors. To gain this phenomenological perspective, questions were posed that could not be answered by surveys or other quantitative assessment techniques. These questions included the following, among others. “What was it like to incur and adjust to a traumatic brain injury?” “How did your rehabilitation team help you with your goals?” “How did your rehabilitation team impede you from reaching your goals?” (Appendix A).

The methodology chosen to best address these questions was qualitative case study. Case studies endeavor to examine the context and particular phenomenon of a defined occurrence (Stake, 1995). The defined occurrence(s) in this study were the experiences of adjustment and rehabilitation to traumatic brain injury from the perspectives of survivors. The
case studies were constructed from semi-structured interviews with the five participants that were audio-taped and transcribed.

The second purpose of this study was to compare any common constructs derived from the data transcriptions with three models of disability and traumatic brain injury. In order to do this, the transcriptions were systematically and cyclically analyzed using the constant comparative method developed by Glaser and Strauss (1967). The constructs were derived after multiple level comparisons that developed themes and categories, presented in Chapter 4. These constructs were then compared with the constructs described in the Psychosocial Adaptation Model of Disability (Livneh & Antonak, 1997), the Empowerment Model for Rehabilitation of Brain Injury Survivors (O’Hara & Harrell, 1990), and the Holistic Model for Neuropsychological Rehabilitation (Prigatano, 1999).

Review of the Case Studies and Constructs

Five transcriptions were produced from five semi-structured interviews and were used to construct case studies and to analyze to determine themes, categories and constructs. Themes were uncovered and then organized into nine categories after multiple comparisons and cross comparisons.

The nine categories include “family,” “coping mechanisms,” “post-accident changes,” “losses,” “emotional phases of adjustment,” “starting life over/ rebirth,” “things rehabilitation should change,” positive things about rehabilitation,” and “spirituality.” The themes for each participant were then cross-compared to derive constructs. After these comparisons, categories
were absorbed into constructs. A theme or category could not become a construct unless all five participants experienced the category similarly. For instance, spirituality was experienced by only four participants and therefore could not become a construct. The eliminated or absorbed categories were post-accident changes, losses, things rehabilitation should change, positive things about rehabilitation, and spirituality.

The constructs that were derived from the multiple level comparisons and cross-comparisons include “Family Support,” “Coping Mechanisms,” “Emotional Phases of Adjustment,” “Sense of Rebirth/Starting Over,” and “Contextual Rehabilitation.” In the “Family Support” construct, participants all referred to the importance of having supportive family members that believed in them and their propensities to achieve their individual goals. The “Coping Mechanisms” construct also contained common elements among the participants. One was the development of purpose. The participants all for one reason or other decided that their accident had brought a new purpose or mission for living. Second, each participant used upon a source of inspiration for motivation for persevering such as a role model or spirituality.

The “Emotional Phases of Adjustment” construct revealed that all of the participants experienced times of anger and depression during their adjustment to their injuries. All of the participants discussed frustration and acknowledgement of their brain injury at having to start life over again seen in the “Sense of Rebirth” construct. Last, in the “Contextual Rehabilitation” construct, all of the participants indicated the need of rehabilitation treatment
teams and planning to address their specific needs and preferences relevant to their own individual adjustment and goals. Four out of five of the participants indicated disappointment and anger with rehabilitation for limiting and confining them to goals that they felt were either not relevant to them or were not wanted by them.

Review of Comparison and Contrast of Constructs and Models

The derived constructs from the data transcripts of five semi-structured interviews were compared and contrasted with the constructs of three disability and traumatic brain injury models relevant to adjustment. These models included the "Psychosocial Model of Adaptation to Disability" (Livneh & Antonak, 1997), the "Empowerment Model of Traumatic Brain Injury Rehabilitation" (O'Hara & Harrell, 1990), and the "Holistic Model Neuropsychological Rehabilitation" (Prigatano, 1999). These three models were chosen because they represent three different approaches to rehabilitation and they all appeared to contain elements of empowerment and phenomenology.

The Psychosocial Model of Adaptation to Disability is a multi-dimensional, nonlinear model that incorporates four classes of variables that depict the interchange between the environment, the survivor, and the acquired injury. The theory contains elements derived from stage theories and social learning theory. The Empowerment Model of Traumatic Brain Injury was chosen because it represents a constellation of constructs that are reduced to or equal empowerment. The constructs such as "Acceptance" and "Skills" attempt encapsulate emotional and cognitive variables that need to be
addressed for the survivors and present efficacy, goal setting, humanistic
principles, and cognitive-behavioral modalities to address the variables. Last,
the Holistic Model of Neuropsychological Rehabilitation was chosen because it
purports to incorporate a combination of psychotherapeutic and cognitive
restructuring modalities. The difference between this model and the
Empowerment Model of Traumatic Brain Injury Rehabilitation is that the Holistic
Model of Neuropsychological Rehabilitation draws more heavily from cognitive
and cognitive-behavioral theories. The Empowerment Model introduces more
of the elements of humanism such as the goals of increasing “self-respect”
and “self-esteem.”

The purpose of comparing and contrasting the derived constructs from
this study with those in these three models was to determine whether
elements of the derived constructs were contained in the models. The results
revealed that elements of all five constructs indeed existed somewhere in each
of the models. Contrasts existed between the constructs and models relevant
to implementation.

For instance, in the “Family Support” construct, most participants
wanted and had supportive family members. Two of the males, however, had
unsupportive wives. In one case, the participant did not want the spouse to be
included in rehabilitation planning and treatment, but she was despite his
protests. The key point here is that the participant’s perception of her
participation was that he was being forced to include her in order to proceed to
other rehabilitation goals. In the “Coping Mechanisms” construct, the
participants shared two traits. All used something or someone as a source of inspiration to improve and heal. Also, all found ways to turn their accident into something that changed them for the better, not worse. He felt that he was being forced to accept the agendas of other people that were more powerful than him at the time.

This was also the perception of most of the participants regarding the "Contextual Rehabilitation" construct. The participants all indicated that they believed it important to make rehabilitation treatment and cognitive exercises relevant to them. Most felt that they were completing meaningless rote rehearsal exercises that had little application germane to them. In several of the cases, the participants perceived that the rehabilitation team thought that the purposes or goals chosen by the participants were unreasonable. Lex, for instance, wanted to return to graduate school. He and his rehabilitation team fought over this goal and he believed that his rehabilitation team wanted him to accept goals that were meaningless to him.

In summary, with the exception of the "spirituality" theme, it seems that although elements of the constructs described by the participants exist in the models, the implementation of these constructs from the models are not evident in implementation. Hence, the mere existence of the elements in the models is not enough. This provides insight for application and implementation of the models to be discussed.
Limitations

In reviewing the results, several limitations of this study should be stressed. Case studies are intended to represent only those cases examined. The aim of this research was to examine the particular events in the lives of five individuals who survived and adjusted to traumatic brain injury. In doing so, readers were able to peek inside the lives of five survivors and come to a better understanding of what it might be like. This information has the capacity for providing comparison points for future research with survivors of traumatic brain injury, but does not purport to represent all survivors of traumatic brain injury. The sample size was small, consisting of just five individuals who were carefully screened from pools of volunteers for this study. This number of individuals was large enough to conduct comparisons and data analysis so as to saturate the data. The sample was small enough to able to conduct thorough interviews.

This population consisted of individuals who reside in northern central Florida in the United States of America from middle level socioeconomic backgrounds and all obtained post-secondary education or training. Therefore, commonalities and differences were found among individuals who shared similar rather than diverse socioeconomic backgrounds and education. In addition, the age range of these individuals was 22 to 38 years old. While the focus was upon adult populations, there were no participants in their 40s or 50s to give examples of middle adulthood adjustment issues. Further, the participants were not representative of a racially diverse population as they
were all primarily Caucasian, with only one having Hispanic heritage in his lineage. There were two female and three male participants, giving a gender distribution congruent with the statistics documenting the ratio of male to female survivors of brain injury.

Another possible limitation of this study is that the research has been shaped by the perceptions of this researcher and pre-conceived notions that may have excluded possible directions of exploration for this study. As such, this researcher developed questions that guided the conversations and the data.

Another limitation is that time did not permit additional explanations into the issues of the participants such as why most of the participants were dissatisfied with rehabilitation. Had more time been available and defined, additional exploration of preexisting variables such as personality, substance abuse, or other disabilities could have been pursued. Another topic worthy of additional exploration would have been the spirituality issues that arose unexpectedly. Additional time would have provided the opportunity to follow up with such issues.

**Implications**

The construct “Family Support” indicates that having the support of family members was vital to perseverance and persistence of striving toward goals for the participants. Specifically, the participants felt that the inclusion of family members who believed in their capabilities to achieve past, present, and future goals was of utmost importance. Because the survivor and family members
reciprocally affect each other within their environment, the effects of traumatic brain injury result in changes for the entire family system, not just the survivor. It is important for rehabilitation team members to include family members in treatment and to educate family members about changes and focusing on the efficacy of the survivor, not personal agendas or those of the rehabilitation team. The survivor and family must make decisions separately and together about individual and family goals. Then negotiations must be made after differences are discovered between survivor goals and family goals in order to meet the needs of the survivor and family.

The construct "Coping Mechanisms" presented two strategies used by the participants to integrate the reality of acquiring a brain injury with them. One strategy described by the participants included using their accidents for defining new purposes for their lives. All of the participants "re-framed" their accidents as a good thing that helped them to finding new meaning and goals for their lives. Also, all of the participants used a source of inspiration such as a person, poem, or spirituality to persevere and continue striving for their goals. In some instances, the two were combined. For instance, all but one of the participants named spirituality or a spiritual encounter that helped them to redefine their lives.

Teresa Lynn even stated that she thought that a spiritual guidance component should be a part of every rehabilitation program. She stated that it was not enough to have a chapel present in her rehabilitation facility; she wanted spiritual counseling. Here lies one of the dilemmas in treating and
counseling populations with disabilities. In the past, the medical, counseling, and rehabilitation professions have regarded spirituality and faith as values and have shied away from including this as a common component in practice (Lane, 1991). Ethically, rehabilitation programs cannot impose values such as religion or spirituality on clients and patients. More recently however, attention has been given in the literature to spirituality and faith as a component of wholeness and wellness concepts, but few rehabilitation programs actually incorporate such into treatment (Lane, 1991; Stanard, Sandhu, & Painter, 2000). Spirituality is recognized by a growing number of counseling sectors and journals, but unless it falls under the auspices of some other title or component, it is often not a part of rehabilitation programs. Appropriate counseling interventions must be developed for inclusion in such programs (Stanard, Sandhu, & Painter, 2000).

The construct "Emotional Phases of Adjustment" revealed that anger and grief are possibly steps that facilitate ultimate adjustment of acquired injuries. All five participants conveyed having experienced these emotions because of deficits and losses accepted and caused by their brain injuries. They experienced memories progressively of being able to conduct various activities more easily before becoming injured. Further inquiry might have determined whether the participants who were dissatisfied and angry at their rehabilitation programs were experiencing anger as part of the adjustment processes. It is possible that participants targeted their anger and grief about their accidents toward their rehabilitation providers. If this were the case, a
philosophical paradox may have existed for the participants who coped by “re-framing” their accidents as positive, rather than being angry because it happened. Various cognitive behavioral, experiential, rational-emotive counseling interventions may be utilized to process feelings of anger, grief, and sadness. These feelings were also discussed in the construct “Sense of Rebirth” because over time participants remembered having once been able to do the activities that they were re-learning as a result of their brain injuries.

The construct “Sense of Rebirth” contained the participants’ recounts of having to learn how to do, feel, and learn things over again. As participants were able to remember, feelings of frustration were acknowledged about having to relearn what was once a routine. The participants conveyed various goals ranging from learning to walk to completing a graduate degree or writing a book. The emotions conveyed in “Emotional Phases of Adjustment” have the ability to foster or impede clients from their goals. Rehabilitation professionals and programs are presented with a unique paradox many times because on one hand they are trying to support client efficacy, empowering clients to attain reasonable goals while not imposing agendas on clients. On the other hand, rehabilitation professionals are the unwitting models and teachers of how to think, feel, and be, remembering that survivors of traumatic brain injury are re-learning to think, feel, and be. The scenario is unintentionally similar to infants and toddlers learning from primary caregivers, except that brain injury survivors have the interfering memories and variables of their lives before their injuries.
The ethical responsibility faced by the medical and rehabilitation community is enormous while practicing rehabilitation as they facilitate client habilitation.

Last, the “Contextual Rehabilitation” construct suggests that the participants want and need their rehabilitation exercises to be relevant to their individual needs and preferences. Most of the participants indicated that they wanted their rehabilitation providers to respect, empower, and facilitate their goals. However, because of training, rehabilitation teams adhere to protocols and understood treatment paradigms in order to facilitate client goals. As such, yet another paradox exists because having set programs, templates and models contradicts what efficacy and empowerment purport. The recipients of implemented treatment modalities may reject or confound treatment, if “cookie cutter” cognitive and emotional exercises designed to restore skills or compensate for permanent deficits are not meaningful and relevant. Worse, treatment may be perceived as an authoritarian measure of imposing irrelevant exercises upon the client.

**Theoretical Considerations**

The different implications for practice that the derived constructs provide feedback for theory. The term “rehabilitation” was developed as a need to help the injured and ill return to optimal states of functioning. It is philosophically impossible to habilitate, that is, to learn to live, without the influence of others in the environment. It also is impossible to rehabilitate without the same influence. Therefore, it can be said that habilitation is a social concept and that rehabilitation was constructed to suit society, both the disabled the non-
disabled. In this sense the rehabilitation staff and the client are equal entities within the same context or environment. The interactions between the two continuously and reciprocally affect each other. As such rehabilitation staff cannot help but influence the adjustment process with the training that afforded them the opportunity to work with the individual with a brain injury or other disability.

However, rehabilitation ethics and philosophies also endorse treatments from a humanist philosophy that believes that individuals inherently possess the answers to problems and conflicts. Adhering to this philosophy, rehabilitation professionals are merely facilitators of goals that clients have developed. From this perspective come concepts such as empowerment and efficacy. Empowerment and efficacy techniques encourage and nourish the processes involved in achieving goals that the clients believe that are able to reach. The participants in this study wanted their goals to be respected, recognized, and facilitated by rehabilitation staff. However, it is not possible for true and pure empowerment and efficacy to occur phenomenologically because of the influence exerted by the training that professionals implement during practice. Therefore, Prigatano’s (1999) “Holistic Model of Neuropsychological Rehabilitation” that encourages building a therapeutically warm, phenomenological relationship would not accommodate the participants in this study without some level of conflict. In addition this is the more linear model of the three examined in this research adhering primarily to cognitive-behavioral paradigms. The “Empowerment Model” by O’Hara and
Harrell (1992) and the "Psychosocial Model of Adaptation to Disability" by Livneh and Antonak (1997) are both nonlinear and multidimensional, allowing for any variety of therapeutic techniques required.

Another consideration is that it is not possible for clients with traumatic brain injury to purely habilitate if memories interfere and impose on the process of learning to live again. On one hand, such memories may elicit feelings of anger and grief about not being able to complete tasks as before. On the other hand, these memories may expedite the process of goal attainment and learning to live again. Nevertheless, true habilitation connotes learning to live and rehabilitation is the process of relearning this process. In asking whether the process of adjustment rehabilitates during habilitation or habilitates during rehabilitation, circular reasoning is unavoidable. Perhaps the process occurs developmentally, concurrently, and multi-dimensionally.

As such the need for the survivors to be understood subjectively and phenomenologically is pertinent. As memories and habits return, survivors may assimilate the old with the new, but must inevitably forage ahead with learning to live and function again. As such, survivors are in essence developing who they are all over again. Viewing this process from a developmental perspective may be an alternative to paradigms that endeavor to re-teach, restore, and rehabilitate. Perhaps traumatic brain injuries present the opportunity for survivors to once again habilitate, to learn to live again.

Survivors who incur traumatic brain injury during adult years are plunged back
to earlier stages of development and need to perhaps repeat the learning processes inherent in those earlier stages.

Erikson introduced his developmental perspective over the life span. In review, he introduced nine stages in which individuals must learn to accomplish a given task before being able to proceed with addressing the tasks in subsequent stages. For instance, in the first stage is basic mistrust versus trust, the infant and caregiver establish whether the world is trustworthy as the infant's needs are met (Erikson, 1982, 1997). The value to be attained in this stage is hope (Erikson, 1982, 1997).

In the second stage, shame and doubt versus autonomy, during which the child attempts to master tasks and assert will. The value to be attained at the second stage is will (Erikson, 1982, 1997). The third stage is guilt versus initiative is when toddlers attempt to master control of their bodies and the world around them. The value to be attained in the third stage is a sense of purpose (Erikson, 1982, 1997). The value to be attained in the fourth stage is competence. In this stage, industry versus inferiority, children learn about themselves as workers related to schoolwork and tasks. In the fifth stage, identity confusion versus identity encompass adolescent aged youth who are trying to explore the boundaries of themselves in relation to society (Erikson, 1982, 1997).

The sixth stage is isolation versus intimacy, during which young adults make commitments to identity and now seek relationships characterized by reciprocal love and devotion. The value to be attained in this sixth stage is to
find love (Erikson, 1982, 1997). The seventh stage, generativity versus stagnation, encompasses the middle adult years and is characterized by a want to give or teach others for the greater societal good. The last stage, despair and disgust versus integrity, individuals in their senior years reflect on their lives and decide whether they have been productive and worthwhile (Erikson, 1982, 1997).

As each participant was an adult when injured, each was thrust from the adult stages of either intimacy versus isolation or generativity versus stagnation to basic trust versus mistrust. The participants were forced by their injuries to learn to do fundamental tasks such as toilet train, walk, talk, eat, and drink. Later participants learn to complete tasks completed in early childhood years such as writing and spelling. Even later, participants are faced with the challenge of learning to complete tasks congruent with Erikson's adolescent and adulthood stages again, but with the addition of the changes that their injury has brought.

Marcia's adult identity development model presents stages differently in terms of having encountered crises and committing to identity. Recall that the four stages outlined in Marcia's model consisted of foreclosed identity, diffused identity, moratorium, and achieved identity. Marcia (1999) stated that individuals with foreclosed identity have not encountered significant conflicts, but have made commitment to identity. Individuals with diffused identity not encountered crises and have made no commitments to identity. Individuals with moratorium identity status have experienced conflicts, but have not made
commitments to identity and those with achieved identity have encountered conflict made commitments to identity (Marcia, 1993).

Assuming that the survivor of traumatic brain injury has acknowledged and incorporated the changes brought upon them by their injury, then they have experienced crisis. The decision to commit to an identity after acknowledging the brain injury evidences the achieved identity stage. Lex, Shelley, Theresa Lynn have all made commitments to their new identities and are pursuing goals accordingly. Those who do not make a commitment to a new identity, but acknowledge the injury or crisis are in moratorium. Bernie and Taz both acknowledge and accept that they are now very different than before their accidents, but both list aspirations that they have not committed to yet. For instance, Bernie wants to own his own restaurant one day and has not yet financially or vocationally committed to this goal. Taz knows he does not want the job he has now. While he may take his old position at the mental health hospital as a maintenance engineer, he has not committed to this yet because he is unsure of his capability with it.

Survivors of traumatic brain injury who commit to an identity based on recollections of the past or previous identity and have not acknowledged deficits from the injury have been typically viewed as lacking awareness or being in denial. However, considering this from Marcia's model, they are foreclosing their identity in conjunction with denial. They are making commitments to an identity that has not been explored with the sequella of the injury. The same may be said for survivors who make commitments to an
identity based on modeling after others in the environment or even modeling
goals based on lessons taught by rehabilitation professionals. This is
because the survivors who make such commitments to goals and identities
without having had the opportunities to explore the new parameters imposed
by a brain injury are merely adhering to someone else's parameters and goals.

Paradoxically then, rehabilitation theory endeavoring to return individuals
to optimal states of functioning based on social learning theory may also limit
the survivor to foreclosed identity. Returning individuals with traumatic brain
injury to optimal states of functioning may only take place after residual
capabilities as well as new capabilities and possibilities are determined. For
individuals with traumatic brain injury, this may not happen for many years.
Rehabilitation programs are typically designed for terms that are much shorter
than the healing process for this population. Therefore, having survivors
commit to goals may prematurely rob them of exploring the long-term
parameters of their potentials.

Social Learning Theory is phenomenological in that it encapsulates the
continuous and reciprocal interaction that occur between the environment and
the individual. Bandura also endorsed efficacy that also impacts the
interactions through the cognition of the clients. However, as pointed out
earlier, rehabilitation professionals are trained according to various paradigms
that unavoidably influence the efficacious process of clients. In this sense,
Social Learning Theory shares the same paradox and dilemma as the "Holistic
Model of Neuropsychological Rehabilitation" by Prigatano (1999).
Being that several paradoxes that have been presented, the process of adjustment can be viewed as a socially occurring phenomenon depicted by developmental and social models within a multi-dimensional, circular model such as in the "Psychosocial Model of Adaptation to Disability" by Livneh and Antonak (1997). This model depicts the interactions of past and present cognitive, emotional, and behavioral external and internal variables interacting over time.

In viewing the experiences of the participants through this perspective, the expectations of practitioners and survivors can both be accounted for and possible served. Hill (1999) a rehabilitation researcher in New South Wales and a survivor of traumatic brain injury emphasized the need for brain injury treatment to be contextual. Rehabilitation treatment that expects cognitive, emotional, or physical function to be "restored" is inappropriate as individuals with traumatic brain injury may be forever changed (Crisp, 1994; Hill, 1999). The process of habilitating during rehabilitation then could be an exciting process for survivors and rehabilitation staff to work together to develop new pathways or "maps" that meets the contextual needs and expectations of each individual survivor.

To suggest that one particular paradigm may defeat the purpose of developing contextual goals. New neuropsychological research supports the idea of the need for brain injury rehabilitation to be relevant and contextual to each survivor. Ingles and Park have collaborated their research endeavors after Ingles discovered that survivors were successful in completing cognitive
tasks that were relevant to them. Park in recognizing that clients were more successful when cognitive exercises were meaningful to them, set about the task for having cognitive restructuring and remediation target specific, relevant skills for survivors instead of improving general cognitive function (Carpenter, 2001).

Considering new individual and separate paradigms and "maps" for traumatic brain injury rehabilitation seems to be appropriate because this is what the survivors and their environments are forced to do. The constructs of this study offer valuable insights into the perceptions of adjustment for survivors of traumatic brain injury. Paradoxes were discovered within each of the constructs and also with the interaction that occurred between rehabilitation models designed to facilitate adjustment. No immediate solution exists for the paradoxes, but perhaps no solution is needed. Rather, acknowledgment and awareness that such contrasts exist and may always.

Recommendations

This research presents numerous possibilities for future research. Researchers are encouraged to continue examining the perceptions of survivors of traumatic brain injury to build a richer and broader base of client contexts in adjusting to their injuries. The following recommendations are offered for future research.

1. The adjustment processes of survivors of traumatic brain injury should be explored further through qualitative methods. In order to understand further the common constructs among individuals with traumatic brain injury, this study should be repeated with populations of survivors that come from culturally and racially diverse
backgrounds, various geographic locations, various ages, and various socioeconomic backgrounds. It is suggested that the constructs developed from this study be compared and contrasted with those developed from future studies to discover new constructs or differences among individuals.

2. Additional qualitative research should be conducted with survivors of traumatic brain injury at varying intervals regarding their adjustment. For instance, qualitative inquiry should take place with survivors who are five years post-accident, ten years post-accident, 15 years post-accident, and so on. In doing so differences among the groups may provide insight into the healing and adjustment process.

3. The perspectives of survivors with traumatic brain injury should be compared with the perspectives of rehabilitation treatment providers that have been ascertained qualitatively in order to explore differences in the foci of rehabilitation.

4. The perspectives of rehabilitation treatment providers should be compared with the perspectives of supportive family members or other members of the survivors' support systems. This should be done in order to qualitatively ascertain differences that may exist in the adjustment process of the survivor of traumatic brain injury.

5. From these qualitative inquiries, it is suggested that new instruments might be developed to accurately ascertain perceptions, constructs, and issues of adjustment among representative populations. Existing assessments may be based on the language of those who view these issues from the "outside in" versus from the survivor perspective.

6. It is suggested that categorizing individuals as "mild," "moderate," and "severe" be assessed and evaluated periodically over a reasonable time span so that individuals are not limited to the parameters of such labels.

7. Implementing efficacy and empowerment phenomenologically is a paradox within itself. Models that purport to both empower clients and that recognize client efficacy phenomenologically needs further examination. For now, practitioner should be aware of the conflicts that could arise with such contradictions.

8. Habilitating during rehabilitation such as what occurs with traumatic brain injured populations also presents a philosophical dilemma that warrants further discussion and exploration by researchers. Further examination of these paradoxes should be explored.
9. Last, longitudinal studies of survivors of traumatic brain injury that are followed for 10 to 20 years may provide valuable information about how humans acclimate to this injury. As infeasible as this type of research can be, it could provide specific and intensive feedback from each individual followed.

After ascertaining the perceptions of adjusting to traumatic brain injury from five survivors, constructs developed from inquiries of these survivors were compared with models of brain injury rehabilitation. During this process, several philosophical and practice paradoxes were discovered. Phenomenology seems to be competing with humanism within the same theories and models that purport to treat brain injured populations. As such, additional research is warranted and anticipated.
APPENDIX A
INTERVIEW QUESTIONS

1. What was your life like before your accident? What did you do for fun? What did you do for work? If in school, what were you studying? What kind of student were you? Who was your primary family support system? What were you like; specifically, what were your moods, personality & outlook on life like? What were your goals?

2. What changes happened for you after your accident?

3. Describe what happened or what you remember happening when you were hurt.

4. What goals, if different than before your accident, did you plan for yourself?

5. Were your goals the same as your rehabilitation helpers' goals?

6. How were they the same? How were they different?

7. How would you interpret the difference(s) between your goals and your rehabilitation professionals' goals, if any exist?

8. How would you describe what it's like to participate in rehabilitation?

9. Describe what processes you went through during your rehabilitation. How did rehabilitation help you to obtain your goals? How did rehabilitation prevent you from your goals, if they were prevented?

10. What would you change about your rehabilitation program? What would you not change? What would you do to improve a rehabilitation program?

11. Please describe the overall experience of acquiring a traumatic brain injury, participating in a rehabilitation program, and assimilating back into your life like?
APPENDIX B
FEEDBACK FORM 1

Please take the time to complete the following form after you have read your case study. Where applicable, please circle a number that indicates how you rate your answers to the following questions.

The numbers from 1 to 5 indicate: (1) Very inaccurate (2) somewhat inaccurate (3) neutral (4) somewhat accurate (5) very accurate for the following questions.

1. How would you rate the accuracy of your case study?

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

For the following questions, please circle Yes or No.

2. Are you satisfied with your case study that has been produced?
   Yes No

3. Would you like to add or change anything about your case study?
   Yes No

4. Would you like a second interview to add or change your case study so that it will be more accurate?
   Yes No

On a scale of 1 to 5, indicate the following in regard to the statement below: (1) not confident (2) somewhat not confident (3) neutral (4) somewhat confident or (5) confident.

5. I am confident that I am satisfied with the results and accuracy of my case study.

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Please give comments or suggestions
APPENDIX C
FEEDBACK FORM 2

Please take the time to complete the following form after you have read your case study. Where applicable, please circle a number that indicates how you rate your answers to the following questions.

The numbers from 1 to 5 indicate: (1) Very inaccurate (2) somewhat inaccurate (3) neutral (4) somewhat accurate (5) very accurate for the following questions.

1. How would you rate the accuracy of your case study?

1  2  3  4  5

For the following questions, please circle Yes or No.

2. Are you satisfied with your case study that has been produced?
   Yes            No

3. Would you like to add or change anything about your case study?
   Yes            No

On a scale of 1 to 5, indicate the following in regard to the statement below: (1) not confident (2) somewhat not confident (3) neutral (4) somewhat confident or (5) confident.

4. I am confident that I am satisfied with the results and accuracy of my case study.

1  2  3  4  5

Please give comments or suggestions:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

197
APPENDIX D
INFORMED CONSENT

Department of Counselor Education
1215 Norman Hall
PO Box 117046
Gainesville, FL 32611-7046

Title of Study:
“Adjustment of Adults with Traumatic Brain Injury: A Qualitative Inquiry”

PLEASE READ THIS CONSENT DOCUMENT CAREFULLY BEFORE YOU DECIDE TO PARTICIPATE IN THIS STUDY.

Purpose of this research study:

The purpose of this study is gain a better understanding of what your experiences were of acquiring and adjusting to traumatic brain injury. It is important for rehabilitation researchers and practitioners to understand what has happened to you from your point of view. The focus of this research will be upon how you have adjusted to your disability emotionally, cognitively, vocationally, and recreationally. This is because it is believed by this researcher that you are the expert on what it is like to have and adjust to this disability and that you have valuable information that may help rehabilitation researchers and practitioners enhance treatment models and methods.

The second purpose of this study is to compare what is learned from you with existing treatment models of disability and traumatic brain injury in order to see if there are any differences.

What you will be asked to do in this study:

You will be asked to participate in an interview that will ask questions about your injury, your rehabilitation, and your opinions about your adjustment. These interviews will be recorded with an audiotape recorder. You have the flexibility to answer the questions or expand on your answers. You may decide to share stories and memories having to do with your accident and recovery. You may decide to give your opinions and ideas on how your adjustment and rehabilitation could have been improved. In sum, this study would like to know as much as possible about your experiences of acquiring and adjusting to traumatic brain injury. So you will have the opportunity to provide the researcher with as much or little information as you think is necessary.
After this interview, the researcher will perform an analysis of the information and provide what is called a case study, or a thorough representation of the information that you provided. It is supposed to provide an accurate account of your experiences. You will be given the opportunity to review your case study and respond to it. If you believe that information needs to be corrected or information needs to be added, you will be able to indicate such.

In this instance, you will be asked to participate in a second and final interview. The researcher will then perform another analysis of the new information and old information and revise your case study. This is all to ensure that your story is accurately told.

Time required:

Your time commitment is 1 to 2 hours per interview. An hour should be added for your case study review time so that you have time to read it. The total time should you decide that a second interview is necessary is about 4 hours or less.

Risks and benefits:

Most research with human participants contains some risks. This research is designed to keep the risks to a minimum. Since the interviews will be recorded with an audio-recorder, the hazard exists of someone other than the researcher hearing the tape. In order to prevent and reduce this risk, the researcher will keep the tape in a locked filing cabinet in a locked office. When your interview(s) have been analyzed and the case study completed, the tapes will be destroyed by a shredder within 24 hours.

Another potential risk is that of confidentiality. The information that you share will be used solely for the purposes of enhancing the knowledge base in rehabilitation research. Your identity will be kept confidential and protected to the extent provided by the law. Your information will be assigned a same gender pen name of your first name only with nothing to indicate your last name. For instance, if your name is Al E. Gator, then your name in the study will be referenced as Steve. If your name is Allison Gator, your name will be referenced as Donna. A list connecting your pen name with your whole name will be kept in a locked file cabinet in a locked office. When the study is completed and the data analyzed, the list will be destroyed within 24 hours. Your whole name will not be in any report.

A last potential risk is that you will be asked to recall information about yourself that may be sensitive. You may experience painful memories of your recollection of acquiring a traumatic brain injury. While all precautions will be taken to prevent this in the interview, it still may occur. You may decide at any time should this happen, to withdraw from the study with no consequence. Should you desire counseling services to address these circumstances, a list of three counseling resources will be provided upon request. You are
responsible for any counseling costs incurred. Please understand that this is not the responsibility of the researcher or University of Florida.

This study may not provide any immediate benefits to you. The potential benefits include broadening the knowledge base of brain injury rehabilitation; deepening the understanding of what it is like to live with and adjust to traumatic brain injury; and potentially enhancing ethical rehabilitation research and methods. Should you decide that you would like to participate, your help will be greatly appreciated.

Compensation:

There is no compensation for participating in this research.

Confidentiality:

In order to protect your confidentiality, the following measures will be implemented. Since the interviews will be recorded with an audio-recorder, the researcher will keep the tape in a locked filing cabinet in a locked office. When your interview(s) have been analyzed and the case study completed, the tapes will be destroyed by a shredder within 24 hours.

The information that you share will be used solely for the purposes of enhancing the knowledge base in rehabilitation research. Your identity will be kept confidential and protected to the extent provided by the law. Your information will be assigned a same gender pen name of your first name only with nothing to indicate your last name. For instance, if your name is Al E. Gator, then your name in the study will be referenced as “Steve.” If your name is Allison Gator, then your name will be referenced as “Donna.” A list connecting your pen name with your whole name will be kept in a locked file cabinet in a locked office. When the study is completed and the data analyzed, the list will be destroyed within 24 hours. Your whole name will not be in any report.

Voluntary participation:

You participation in this study is completely voluntary. There is no penalty for not participating or for deciding to withdraw from the study at any point in time.

Whom to contact if you have questions about the study:

1. Alice Diane Scharf-Locascio, Graduate Student (aka: “Dee Dee”)
   University of Florida
   Department of Counselor Education
   1215 Norman Hall or 2912 W. University Avenue
   Gainesville, FL 32611-7046 Gainesville, FL 32607
   (352) 392-0731 (352) 373-6375
2. Dr. Mary Howard-Hamilton  
   Department of educational Leadership, Policy, and Foundations  
   PO Box 117049  
   Gainesville, FL 32611-7049  
   (352) 392-2391 X277  

   Whom to contact about your rights as a research participant in the study:  
   
   UFIRB Office  
   University of Florida  
   Gainesville, FL 32611-2250  
   (352) 392-0433  

   Agreement:  
   
   I have read the procedure(s) described above. I voluntarily agree to participate in the procedure and I have received a copy of this description  

   Participant: _______________________________ Date: _______________  
   
   Principal Investigator: _____________________ Date: _______________
APPENDIX E
INVITATION TO PARTICIPATE

Adjustment of Adults with Traumatic Brain Injury: A Qualitative Inquiry

The above title describes a research project that I am conducting to fulfill research dissertation requirements at the University of Florida. The study is to be conducted from a qualitative point of view meaning that I will try to portray your impressions, perceptions, and opinions as accurately as possible. This is in order to enhance and perhaps improve the knowledge base of traumatic brain injury rehabilitation. Your identity will remain entirely confidential.

Candidate

The candidate must be at least 20 years old and not more than 50 years old. Two females and three males will be selected who have been through with their rehabilitation program for at least one month and not more than 10 years. Further, the severity of injury must be mild to moderate according to medical records.

Purpose

There are two purposes for conducting this study. One is to learn what it is like to acquire and adjust to mild to moderate traumatic brain injury from your perspective. The second purpose of this study is to compare the experiences and perspectives of individuals with the traumatic brain injury with current traumatic brain injury (TBI) and disability rehabilitation theories. The problem is that few inquiries have been done from the perspective of the individual with TBI. This study endeavors to obtain and understand the perspectives of the survivor of TBI as they do through rehabilitation and adjustment processes.

Methodology

The best methodology for achieving the purpose is to conduct case study research. Case study research as defined by Stake (1995) as “an intensive, thorough examination of the particular phenomenon in a bounded instance.”

The scope of inquiry is limited to the content of the questions in the accompanying format for the interview. The procedure used for collecting data...
is a semi-structured interview. This type of interview allows the participant to deviate to other relevant information deemed important for a thorough understanding. The interviews will be audio-recorded and then transcribed for data analysis. After the transcripts are analyzed, you will be provided a copy of your case study to read. After reading your case study, you will receive a feedback form to respond to the results. If you decided that information is missing or incorrect, you will be asked to participate in a second interview. Should a second interview become necessary, you will be given your revised case study to review with a second feedback form with which to respond.

The goal is to provide an accurate account of what happened and how you view your adjustment from your point of view. A detailed description is provided in the informed consent form.

You are invited to participate in this research project. You are guaranteed your complete confidentiality and measures will be taken to ensure this (details provided in the "Informed Consent Form." Should you decide to participate, please read, sign and fill out the "Informed Consent Form" so that we may make arrangements to meet. If you decide to not participate, simply do not sign this form or the "Informed Consent Form."

Name:
Address:

Phone:

My contact information is (352) 373-6375 should you have any questions. Thank you for your consideration in this matter.

Dee Dee Scharf-Locascio
Doctoral Candidate, University of Florida
APPENDIX F
CONCEPTUAL MODEL OF ADAPTATION TO DISABILITY

Psychosocial Maladaptation ← Psychosocial Adaptation

Early Reactions:
Shock, Anxiety, Denial

Intermediate Reactions:
Depression, Internalized Anger, Externalized Hostility

Later Reactions:
Acknowledgement, acceptance, adjustment

Class IV Variables: EXTERNAL
- Physical Environment
- Socioeconomic Environment
- Attitudinal Barriers
- Social Supports
- Family Supports

Class I Variables:
- Disability Related

Class II Variables:
- Sociodemographic

Class III Variables:
- Personality

(Livneh & Antonak, 1997)
APPENDIX G
EMPOWERMENT MODEL

EXTERNAL STRUCTURE

+ MOTIVATION

+ ACCEPTANCE + SKILLS

UNDERSTANDING (COGNITION)

+ ACCEPTANCE (EMOTION)

INTERNAL STRUCTURE/MOTIVATION

EMPOWERMENT

(O'Hara & Harrell, 1991)
APPENDIX H
THEMES AND CATEGORIES OF PARTICIPANTS
Table H-1. Themes and Categories

<table>
<thead>
<tr>
<th></th>
<th>Family</th>
<th>Coping Mechanisms</th>
<th>Post-Accident</th>
<th>Losses</th>
<th>Phases of Adjustment</th>
<th>Rebirth</th>
<th>Rehabiliation should change</th>
<th>Positive things about rehabilitation</th>
<th>Spirituality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theresa Lynn</td>
<td>Supportive Best-Friends Activities</td>
<td>Spirituality Father Determined Mission from talks with God</td>
<td>Outgoing P.T. Assist. English Focused</td>
<td>Grand-mothers Military Injuries</td>
<td>Anger Sadness Depression</td>
<td>Felt &quot;stupid&quot; and frustrated</td>
<td>More dr. contact Relevant goals Spiritual Counsel</td>
<td>Humor Helped memory</td>
<td>Prayers Church Talks with victim angels</td>
</tr>
<tr>
<td>Bernie</td>
<td>Parents and brothers helped</td>
<td>Son Humor Overlooks Determined</td>
<td>Non-drinker Job No license Graduated Introverted</td>
<td>Marriage Custody Career License</td>
<td>Anger Grief Depression</td>
<td>Frustration re-learning walk, talk, etc.</td>
<td>Nothing</td>
<td>Values Goals contextual</td>
<td>Nothing</td>
</tr>
<tr>
<td>Tax</td>
<td>Parents, sisters &amp; son supportive</td>
<td>Talk with God Sons tenacity</td>
<td>Introverted Less impulsive Calmer</td>
<td>Sports Second wife Salary and career</td>
<td>Grief Anger toward self</td>
<td>Frustration restarting career, walk, talk, think &amp; feel</td>
<td>Exercise should be relevant More Dr contact</td>
<td>Helped to focus</td>
<td>Talks with God Change in attitude</td>
</tr>
<tr>
<td>Lex</td>
<td>Family supportive especially mother</td>
<td>Mission: from God maps Back-ground Greed</td>
<td>Introverted Focus Deter-mined</td>
<td>Hormones Eight years</td>
<td>Anger Depression Sadness</td>
<td>Felt trapped physical limitation Re-Learning</td>
<td>Relevant goals Listen to client goals and context</td>
<td>Hormone replacement</td>
<td>Talks with God Mission</td>
</tr>
<tr>
<td>Shelley</td>
<td>Mother, family and friends</td>
<td>Spirituality Goals determined</td>
<td>Less adept musically Reserved Nicer.</td>
<td>Independence Physical Music Dance</td>
<td>Anger Depression</td>
<td>Learning everything again Frustrating pace</td>
<td>Listen to &amp; respect all client goals Motivate Social goals</td>
<td>Helped her walk again</td>
<td>Prays Church</td>
</tr>
</tbody>
</table>
Table I-1. Constructs and Models

<table>
<thead>
<tr>
<th>FAMILY SUPPORT</th>
<th>REBIRTH</th>
<th>COPING MECHANISMS</th>
<th>EMOTION PHASES OF ADJUSTMT.</th>
<th>CONTEXTUAL REHABILITATION</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Psychosocial Model of Adaptation to Disability</strong></td>
<td>Class II Sociodemographic Variable</td>
<td>Frustration with relearning fundamental tasks related to anger. Delineates as different type of frustration with relearning to think and feel.</td>
<td>Class III Variable Encompasses Intrapersonal and Environmental exchanges: Defense Mechanisms, Locus of control.</td>
<td>Model does not indicate relevance or importance of client goals. Not evident in model.</td>
</tr>
<tr>
<td><strong>Empowerment Model</strong></td>
<td>Present in the Acceptance Component</td>
<td>Function of re-integrating old and new skills in Acceptance</td>
<td>Model suggests fostering positive efficacy and empowerment in Acceptance &amp; Skills Components</td>
<td>Suggests therapy modalities to work through anger &amp; grief.</td>
</tr>
<tr>
<td><strong>Holistic Model of Neuropsychological Rehabilitation</strong></td>
<td>Supported in Family Education Component albeit cognitive</td>
<td>Frustration levels in common. Frustration of two levels for participants vs. in general in model. No mention of confusion. Model relies on cognitive restructuring and cognitive-behavioral psychotherapy</td>
<td>Addressed through cognitive therapies.</td>
<td>To be processed in cognitive psychotherapies in model</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Supported in model as means of facilitating cognitive restoration goals.</td>
</tr>
</tbody>
</table>
REFERENCES


BIOGRAPHICAL SKETCH

Alice Diane Scharf-Locascio, also known as "Dee Dee," daughter of Richard Shreve Scharf and Judy Owens-Earl, was born in Atlanta, Georgia, on December 16, 1964. She attended public schools in Valdosta, Georgia, graduating from Valdosta High School in June 1983. In August 1983, she entered Valdosta State College and graduated with a Bachelor of Arts degree in Psychology in 1988. In 1989 she entered the University of Florida to obtain a Master of Health Science in Rehabilitation Counseling degree and graduated in December 1990.

After working as a rehabilitation consultant and therapist in south Georgia until 1994, she entered the University of Florida, Counselor Education Department doctoral program in Mental Health Counseling. While working toward her doctorate, she became licensed as a mental health counselor and has worked as a rehabilitation consultant and licensed therapist in north central Florida. She married Paul A. Locascio in 1999 and is expecting her first child in May 2001. She is currently working on publishing an anger management model to be used in group therapy with children and adolescents and is involved with implementing this model with juvenile male adolescents. She expects to graduate with a Doctor of Philosophy degree in mental health counseling from the University of Florida in August 2001.
I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

Mary Howard-Hamilton, Chairperson
Associate Professor of Educational Leadership, Policy, and Foundations

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

Ronald J. Spitznagel
Associate Professor of Rehabilitation Counseling

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

Peter A. D. Sherrard
Associate Professor of Counselor Education

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

M. Harry Daniels
Professor of Counselor Education
I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

Robert R. Sherman
Professor of Foundations of Education

This dissertation was submitted to the Graduate Faculty of the College of Education and to the Graduate School and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

August 2001

Dean, College of Education

Dean, Graduate School