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# COLLABORATION FOR SUCCESS IN YOUNG ADULTS WITH TRAUMATIC BRAIN INJURY

BY

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#### DISSERTATION

Submitted in Partial Fulfillment of the Requirements for the Degree of **Doctor of Philosophy** 

Nursing

The University of New Mexico Albuquerque, New Mexico

December 2014

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# DEDICATION

To my husband David; children Tina and Aaron, Laura and Greg, and Alan and Ali;

and grandchildren Keaton and Ainsley

### ACKNOWLEDGMENTS

To my mentors in Neurosurgery Blaise Audet, MD, and Erich Marchand, MD; Dissertation Chairperson Jennifer Averill, PhD; Clinical Expert Rex Jung, PhD; and to each of my Committee Members

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#### ABSTRACT

**Aim.** The aim of this study was to explore self-efficacy and success in young adult survivors of traumatic brain injury (TBI) and provide the opportunity for participants to communicate their perceptions, thoughts, emotions, and concerns.

**Background.** Many of those affected by TBI are young adults who are establishing their social and work lives. Young adults face challenges and choices that are pivotal in establishing a course for their lifetime. Self-efficacy theory provided the conceptual framework for the study. The TBI Self-Efficacy Questionnaire and General Self-Efficacy Scale were used to measure self-efficacy, and the Glasgow Outcomes Scale-Extended was used to measure outcomes after TBI and situate qualitative data in the context of known scales of measurement.

**Methods.** The research was approached as a collective instrumental case study delving deeply into the complexity of each case, using ethnographic methods, in the milieu of a collaborative orientation. Ethnographic methods directed attention to the everyday lives and contexts of the participants. Triangulation with established quantitative instruments

increased descriptive validity and strengthened reliability of the study. The collaborative orientation influenced the author to consider barriers to and facilitators of success. **Findings.** The context and setting of the human experience of recovery and adaptation in the 2 young adult participants at 9 and 12 months after a TBI were critically analyzed from interviews and descriptive questionnaires. The research questions evoked participants' voices and focused awareness on the challenges and transformation associated with their TBI and the role of family in recovery. Self-efficacy and success theory illuminated the process of achieving success and life satisfaction after TBI. Barriers to health, independence, connectivity, mobility, and productivity were some of the challenges faced by participants. Success in navigating the barriers was found to be crucial to continuing life patterns of self-belief and confidence.

**Conclusions.** This study comprised a needs assessment phase of collaborative research and has potential to become foundational in developing a self-management program targeted to optimizing health, self-efficacy, and success. Young adult survivors of TBI may benefit from ongoing collaborative research, improved health care access, comprehensive care planning, and educational content designed to facilitate self-efficacy and success.

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# CHAPTER 1

#### INTRODUCTION

This study was an exploration of self-efficacy and success in young adult survivors of traumatic brain injury (TBI) affecting the frontal lobe(s) of the brain. The purpose of this study was to provide the opportunity for participants to communicate their perceptions, thoughts, emotions, and concerns. Ethnographic methods directed attention to the everyday lives and contexts of the research participants, enhanced by a case study approach. Triangulation of qualitative methodology with established quantitative instruments increased descriptive validity and strengthened reliability of the study. This study has the potential to provide knowledge that may be used in planning interventions and educational programs, with the aim of optimizing self-efficacy and success in young adults after a TBI.

I anticipated that the knowledge generated from this study would uncover new insights into the needs of young adult survivors of TBI and provide a platform for delineating action-focused goals based on increased knowledge and awareness of the challenges associated with TBI. Specific action-focused goals of this research were to identify barriers to and facilitators of successful living, as derived from the cases presented in the study. Collaborative research processes provided a forum (between participants and researcher) for analysis of social problems and health determinants, with the aim of supporting young adult survivors of TBI through advocacy and action.

This chapter opens with an overview of the background and context that frame the content of the study. The problem statement, statement of purpose, and research questions will follow. A description of the research approach, researcher's perspective, and

researcher's assumptions will then be delineated. The rationale and significance of the study will be explained. This introductory chapter will conclude with definitions of the key terms that were used in the study.

#### **Background and Context**

#### **TBI Statistics**

Globally, TBI affects approximately 10 million new people each year (Ownsworth et al., 2011). TBI is a leading cause of death and disability in the United States (Centers for Disease Control and Prevention [CDC], 2010). In each year from 2002 to 2006, an average of 1.7 million traumatic brain injuries occurred in the United States annually (CDC, 2010). Of the 1.7 million people who sustained a TBI annually, approximately 1.365 million were treated and released from an emergency department, 275,000 were hospitalized, and 52,000 died (Faul, Xu, Wald, & Coronado, 2010). TBI was a contributing factor in an alarming 30.5% of all injury-related deaths in the United States, and there was a reported 27% increase in TBI-related deaths from 2002 to 2006 (Faul et al., 2010).

#### Young Adult TBI Statistics and Distinctive Characteristics

Many of the people affected by TBI are young adults who are establishing their social and work lives (Corrigan, Selassie, & Orman, 2010). Rates for both motor vehicle trafficrelated and assault-related TBI were highest among adults aged 20 to 24 years. Motor vehicle traffic accidents were the second leading cause of TBI (17.3%) and resulted in the highest percentage of TBI-related deaths (31.8%; CDC, 2010).

After a TBI, young adults face unique challenges that impact their quality of life. They often have related physical, cognitive, social, and emotional disturbances. Injury to the frontal lobes of the brain can lead to deficits in fine motor function and diminished strength in the upper extremities; reduced executive function, including reduced goal selection and planning ability; attention and memory deficits; decreased problem solving ability; changes in social behavior; and a decreased ability make moral distinctions between good and bad choices. Impulsivity and risk taking may increase after frontal lobe damage (Floden, Alexander, Kubu, Katz, & Stuss, 2008). This study included young adult participants who sustained a TBI involving the frontal lobes.

#### Self-Efficacy and Success After TBI

The phenomena of interest in this study were self-efficacy and its implications for success after TBI. The conceptual framework was self-efficacy theory. *Self-efficacy* is defined as a one's belief in the ability to succeed in specific situations (Bandura, 2004) and is based on self-perception. People with high levels of self-efficacy believe that they are in control of their lives, with their decisions and actions shaping their lives and futures, whereas people with low self-efficacy feel that their destiny is out of their control. The worldview of self-efficacy theory is reflected in the core assumption that people can exercise influence over their own behavior. The role of intention is described as personal agency. Free will and freedom of choice are central concepts in the theory. The concept of interaction inherent in the theory is termed "triadic reciprocity." Personal factors, including behavior, cognition, and environmental influences, interact as determinants of each other, as shown in Figure 2.1: Self-Efficacy Model (Peterson & Bredow, 2009).

#### **Problem and Purpose Statement**

#### Problem

In spite of the fact that TBI is prevalent in young adulthood, when risk-taking behavior is more common, there is a scarcity of both qualitative and quantitative research dedicated to the study of TBI in young adults. Young adults face challenges and choices that will set them on a course for their lifetimes, which provides strong motivation to perform research that may help to create pathways to successful living after TBI. The meaning of selfefficacy and success is embedded in experience and is dependent on individuals' pathways through the environment.

#### Purpose

Barriers to health, independence, mobility, and productivity are challenges that young adult survivors of TBI may face. Success in navigating the barriers is crucial to developing a pattern of self-belief and confidence. Furthermore, outcomes including health, quality of life, and self-defined success in life may be compromised after TBI and may vary with the severity of the injury and the region of the brain that has been injured. This study will begin to fill a gap in knowledge by providing insights into the behavioral, social, and emotional functioning of young adult survivors of TBI with injury to the frontal lobe(s). The study functions as a needs assessment phase of work and has potential to become foundational in developing a self-management program for young adult survivors of TBI that is targeted to optimize health, self-efficacy, and success.

#### **Research Questions**

In this study, empowerment of research participants through increasing awareness of self-efficacy concepts and elicited voice was integral to the study design. The following research questions evoked participants' voices and focused awareness on the challenges associated with TBI:

1. How do young adults who have had a TBI define success in their lives?

- How do young adults who have had a TBI make sense of their everyday lives, specifically in terms of self-efficacy?
- 3. What are the barriers to and facilitators of success in young adults who have had a TBI?

#### **Research Approach and Methods**

#### **Case Study Approach**

The University of New Mexico Institutional Review Board (IRB) approved this study. The researcher studied the everyday lives of 2 young adults aged 20 and 25 years who had sustained a TBI affecting the frontal lobe(s) using a case study approach. A case study research approach is distinctive in the attention given to the complexity and individuality of the case(s), coming to understand the activity of the case in the context of the situation (Stake, 1995). Descriptive data in the form of questionnaires to investigate demographics, self-efficacy, and outcomes after TBI were documented. The context and setting of the human experience of recovery and adaptation in the 2 young adult participants at 9 and 12 months after a TBI was explored and critically analyzed from interviews and descriptive questionnaires administered in a clinical setting. An Interview Guide directed the face-to-face interview toward the everyday life of each participant, with an emphasis on goal setting, creative problem solving, self-efficacy, success, support, and successful living. Participants were asked open-ended questions during a 1-hour interview.

#### **Ethnographic Methods Triangulated With Descriptive Questionnaires**

Ethnographic methods were employed in the face-to-face interviews, with a focus on the context of the research participants' everyday lives. The setting, social and human environment, historical perspective, and language conveyed in the interviews were analyzed to present emerging themes in the contexts of their lives. Emphasis was placed on participants' meanings and interpretations of the data. Descriptive quantitative instruments, including the 8-point Glasgow Outcome Scale Expanded (GOSE; Wilson, Pettigrew, & Teasdale, 1998); the six-question TBI Self-Efficacy Questionnaire (TBI-SE; Cicerone & Azulay, 2007); and the 10-question General Self-Efficacy Scale (GSE; Schwarzer & Jerusalem, 1993) were used to situate qualitative data in the context of known scales of measurement. The Glasgow Outcome Scale Expanded was administered in the traditional manner of a semistructured interview, and the self-efficacy instruments were selfadministered.

Qualitative data included observations of naturally occurring data discoverable by ethnography, conversation, and discourse analysis. Qualitative data analysis is iterative, creative, and circular in nature. The fundamental process for analysis of the data was coding of transcripts with an open, line-by-line extraction of meaning. The result of this process was a set of data-grounded descriptive codes, which were then selectively clustered, recoded, and synthesized further to identify distinct themes and patterns (Flick, 2007). This process involved the classification of concepts, ideas, themes, people, events, objects, and the properties that characterized them, with synthesis of thoughts and ideas expressed as themes and patterns (Patton, 2002; Silverman, 2010).

#### **Collaborative Orientation**

Collaborative research is an *orientation to research* rather than a method. It is an overarching strategy in which the researcher and participants contribute strengths and share responsibilities to enhance understanding of a given phenomenon, including the social and cultural dynamics of the community. A collaborative orientation meshes well with

ethnographic methodology. In this study on collaboration for success in young adults with TBI, the phenomena of interest were self-efficacy and success in young adult survivors of TBI.

#### **Researcher's Perspective**

#### **Researcher Experience**

My interest in young adults with a history of TBI stems from many years of working in the fields of neurosurgery and rehabilitation, coupled with a desire to help the most vulnerable persons in society. While working in both pediatric and adult neurosurgery, it became clear to me that the period of transition from childhood to adulthood is a particularly vulnerable time for individuals who have had a TBI. The continued existence and future quality of life for patients with TBI requires prompt delivery of emergent and acute care services, technical hardware, and well-trained health care providers in rehabilitation and home settings. Optimizing the ability of young adults to live productive and happy lives after brain injury was a motivating objective for me to perform this study.

#### Bias Balanced by Explanation of Assumptions, Theory, and Study Rigor

I acknowledge that the same experience that is valuable to me in providing insight into the research topic may also serve as a liability, with the potential for bias in the research design and interpretation of data. To minimize the liability, my assumptions and the theoretical framework for the study will be explained at the outset. In addition, rigorous documentation of the methodology and contextualizing were essential elements of qualitative analysis that were implemented in conducting the study.

#### **Researcher's Assumptions**

#### Self-Defined Success Is Positively Affected by Increased Self-Efficacy

Based on the researcher's background and experience, and grounded in the literature reviewed, three primary assumptions were made regarding this study. The first was that in these young adults with TBI, *self-defined success is positively affected by increased selfefficacy*. Gracey, Evans, and Malley (2009) found that an individual's perception of his or her post-injury self is influenced by his or her attempts to maintain pre-injury lifestyle. Cicerone's and Azulay's (2007) findings support the view that perceived self-efficacy beliefs may mediate the relationship between the individual's expectations and achievements, thereby contributing to overall subjective well-being after TBI. In their study sample of 97 adults with TBI, Cicerone and Azulay also found that a person's self-efficacy (particularly perceived self-efficacy for the management of cognitive symptoms) made the greatest contribution to prediction of global life satisfaction.

#### **Research Findings Will Have Transferability**

The second assumption was that the *research findings will have transferability*. Transferability is a quality criterion used in qualitative research and was proposed by Lincoln and Guba (1985) and in a seminal article by Firestone (1993) as a model of generalizability for qualitative research. Readers interested in transferability will have a solid framework for conceptualizing a gradient of contexts, times, settings, and participants who have experienced a TBI (Silverman, 2010).

#### Voice Was Expected to Heighten Awareness and Empowerment for Participants

The third assumption was that *providing an opportunity for participants to voice their thoughts, feelings, and concerns was expected to provide some degree of heightened*  *awareness and empowerment for the individuals*. Positive health outcomes require empowering patients and families to access care and optimize health and recovery within the parameters of internal capabilities and external resources. Empowerment is crucial to the collaborative orientation of this study. In summary, the researcher's assumptions are (a) selfdefined success is positively affected by self-efficacy; (b) research findings will have transferability; and (c) providing opportunity for voice through the research may provide heightened awareness and empowerment. A revisiting of the assumptions follows the findings, to reflect on their relevance and impact on the work.

#### **Rationale and Significance**

#### **Contribution to Theory**

Parallel with the researcher's assumptions, this research will contribute to practice and policy related to TBI. There is a paucity of research in the realm of self-efficacy post-TBI. Further research into the application of self-efficacy principles among young adults with TBI is essential to understanding the role of self-efficacy with regard to individuals' successful recovery, well-being, and quality of life. The benefit to the participants in this study is a potential for increased awareness and understanding of self-efficacy leading to self-confidence, mastery, goal setting, and self-defined success, as well as identification of barriers to and facilitators of successful living in two cases of young adults who have sustained a TBI.

#### **Contribution to Practice**

The brains of young adults continue developing through age 25 (Lebel & Beaulieu, 2011). These developmental stages occur in predictable sequences but at variable times throughout a person's lifetime. Therefore, a study such as this one has the potential to

uncover facets of recovery and adaptation that are unique to young adults and are applicable in practice. The unique challenges for young adult survivors of TBI are partly related to disruption in the normal stages of development, and in many cases, may be amenable to improvement. This study highlights the developmental continuum with an organization of energy that can be channeled constructively through patient, family, and societal dialogue.

#### **Contribution to Policy**

There is compelling evidence that social and economic inequality is biologically expressed and literally embodied from birth to death, producing social inequalities across a wide continuum of outcomes, including health outcomes (Jayasinghe, 2011). To elucidate the societal problem of TBI in young adults, analysis of embedded economic and societal factors took place. There is potential and promise in the investment of societal resources in young adults. If a young adult has the opportunity to reach optimal health, the potential to embark on a productive and satisfying life course may be increased in measurable ways. Societal resources expended on homelessness, incarceration, and inefficient use of health care dollars could decrease (Farrer & Hedges, 2011; Hwang et al., 2008). Individually, quality of life and self-defined success may result. Groleau, Zelkowitz, and Cabral (2009) emphasize the fact that actions of health policy decision makers affect the health and well-being of people. Therefore, shaping opinion and policy is a crucial and important goal of qualitative studies and is congruent with the action-focused goals of this study.

#### **Key Terminology**

*Ethnography* is a qualitative study method and body of knowledge attuned to human cultures. Given a sample size of two, ethnographic methods were enriched using a *case study approach*. Key *neuroscience* terms will be defined, including fluid and crystallized

intelligence, executive functions, metacognition, and meaning. Central concepts of *self-efficacy* and *success*, to be measured using scales and discussed in face-to-face interviews, as well as the four primary sources of input toward self-efficacy, will be defined. The four primary sources of input toward self-efficacy include performing behavior, or mastery experience; modeling, or vicarious experience; social persuasions; and physiological factors. Finally, key concepts of success will be introduced.

#### Key Terms Related to Methodology

- *Ethnography* is defined as "the branch of anthropology that deals with the description of specific human cultures, using methods such as close observation and interviews" ("Ethnography," 2014). It is a qualitative research *method* traditionally used in multiple academic disciplines, most notably, anthropology, sociology, and nursing (McFarland, Mixer, Webhe-Alamah, & Burk, 2012).
- *Culture* is defined by the author as "the *bridge of human connection*, an animation with unifying frames of experience, patterns, and connections." Agar (2002, p. 28) proposed that "language fills the spaces between us with sound; culture forges the human connection through them."
- *Case Study Approach* is defined as follows: "Case study is not a methodological choice but a *choice of what is to be studied*.... We could study it analytically or holistically, entirely by repeated measures or hermeneutically, organically or culturally, and by mixed methods—but we concentrate, at least for the time being, on the case (Stake, 2000, p. 435).
- *Collaborative Research* is an *orientation to research*, rather than a method, and is an overarching term for a wide variety of approaches, such collaborative action research.

Research partners contribute strengths and share responsibilities to enhance understanding of a given phenomenon, including the social and cultural dynamics of the community and to "integrate the knowledge gained with action to improve the health and well-being of community members" (Israel, Schulz, Parker, & Becker, 1998, p. 177).

#### **Key Neuroscience Terms**

- *Crystallized intelligence* is the fund of information that is available for use based on learning (Catell, 1963).
- *Fluid intelligence* involves the ability to solve problems, find meaning in complexity, draw inferences, understand relationships between multiple concepts, recognize patterns, and perform abstract reasoning (Catell, 1963).
- *Executive functions* are a set of processes that have to do with managing oneself and one's resources to reach a goal; it is umbrella term for the neurologically based skills involving mental control and self-regulation (Floden et al., 2008; Shorland & Douglas, 2010).
- *Metacognition* is a model in which individuals build, verify, and modify stories in situational awareness to account for an unrecognized situation (Cohen, Freeman, & Wolf, 1996).
- *Meaning* comprises both cognitive/descriptive and non-cognitive/emotive elements; "traffics in patterns, images, qualities, feelings, and eventually concepts and propositions" (Johnson, 2007, p. 9); and grows from bodily perceptions, movement, emotion, and feelings (Damasio, 1994; Johnson, 2007).

#### **Key Concepts of Self-Efficacy Theory**

- *Self-efficacy* is one's belief in one's ability to succeed in specific situations (Bandura, 2004) and is thus based on self-perception.
- Self-belief is a person's judgment of his or her capability to organize and execute courses of action required to attain designated types of performances (Bandura, 2004).
- *Encoding behavior* puts action into memory using symbols, cognitive organization, and both symbolic and motor rehearsal (Bandura, 2004).
- *Performing behavior* is performing and being able to perform a behavior; it involves physical capability, self-observation/reproduction, and accuracy feedback (Bandura, 1977, 1986).
- *Mastery experience* occurs when a success in life endeavors raises self-efficacy (Bandura, 1977, 1986).
- *Modeling*, or *vicarious experience*, occurs when a person compares himself or herself favorably with another person in which behavior is learned through observation and then modeled or imitated (Bandura, 1977, 1986).
- *Social persuasions* take the form of encouragement or discouragement (Bandura, 1977, 1986).
- *Physiological factors* are primarily focused on how a person perceives stressful situations (Bandura, 1977, 1997, 2004).

### Key Concepts of Successful Living

• *Success* is "the achievement of something desired, planned, or attempted" and is selfdefined (Pinker, 2014, p. 1). *Success* as defined in this study is a complex spiral process through which internally and externally mediated self-assessments construct a state of life satisfaction substantiated by action and interaction.

- *Quality of life* is defined as "a state of complete physical, mental and social wellbeing and not merely an absence of disease and infirmity" (World Health Organization [WHO], 1946).
- *Well-being* is defined as "a relative state where one maximizes his or her physical, mental, and social functioning in the context of supportive environments to live a full, satisfying and productive life" (Kobau, Sniezek, Zack, Lucas, & Burns, 2010).
- *Successful living* is a life characterized by a record of goals achieved.
- *Life satisfaction* is a feeling of accomplishment that may serve as a self-administered award derived from internally and externally mediated self-assessments.
- *Transformative act* is an expression of knowing in nursing practice that is integrated with aesthetic, personal, empiric, and emancipatory knowing and knowledge (Chinn & Kramer, 2011).
- Transformation is a redirection of energies toward found meanings (Peat, 1987).
- *Emancipatory knowing* is a "pattern of knowing that makes social and structural change possible; the ability to recognize barriers that create unfair and unjust social conditions and to analyze complex elements of the social and political context to change a situation to one that improves people's lives" (Chinn & Kramer, 2011, p. 248). Emancipatory knowledge is a goal for young adults recovering from TBI.
- *Praxis* is constant and value-motivated reflection and action to transform the world and the fundamental process associated with emancipatory knowing (Chinn & Kramer, 2011).

After this introduction to the study, its conceptual foundations, and key terms, it is important to next consider the literature that surrounds the knowledge of young adult TBI. Details of the research methods used to answer the research questions will be then be presented in Chapter 3.

#### **CHAPTER 2**

#### LITERATURE REVIEW

This critical review of the literature explores the foundations of my study in historical, neuroscientific, theoretical, and methodological contexts. My objective in reviewing the literature was to set the stage for understanding the methodology, results, analysis, and interpretation of the research and to create a pathway to study conclusions. Bandura's (1977, 1986, 1997, 2004) self-efficacy theory was chosen as the conceptual framework for the study. Self-efficacy is a pivotal theory in motivational, behavioral, and educational research with potential for impacting both long- and short-term outcomes after TBI. Relationships among self-efficacy, success, resilience, empowerment, health promotion, and quality of life were mapped.

#### **Overview of Chapter Content**

The literature review will begin with a problem statement and overview of TBI, followed by an examination of the historical development of self-efficacy theory and discussion of the implications of self-efficacy in the context TBI. Self-efficacy theory was explored in detail through examination of empirical studies used by researchers to develop the questionnaires that were chosen for use in this study. Established research questionnaires chosen for the descriptive quantitative components of this study include the GOSE, the TBI-SE, and the GSE, details for which appear in Chapter 3. The GOSE was used to measure outcomes after TBI, and the TBI-SE and GSE were used to measure self-efficacy. Selfefficacy theory is readily applicable to a wide range of research and clinical practice initiatives and problems, as will be seen from the reviewed literature. Literature was also reviewed to facilitate analysis and interpretation of emerging patterns, themes, and concepts in historical, philosophical, and operational contexts. The challenge in moving from TBI to success was reviewed from the perspectives of adaptability and transformation. I will identify and synthesize related factors and relationships, find patterns, and draw inferences from extant literature, thereby initiating a search for the meaning of self-efficacy, success, and life satisfaction after TBI. The major focus of this research was to provide the opportunity for a cohort of young adults with TBI to communicate their perceptions, thoughts, emotions, and concerns. Collaboration of the researcher with participants was integral to the study.

#### **Problem Statement**

This study provides insights into the dynamics of behavioral, social, and emotional functioning of young adults with TBI using a qualitative approach, augmented by reliable and valid descriptive questionnaires. A study such as this one, focusing on young adults, has potential to uncover facets of recovery and adaptation that are unique to the young adult age group. The brains of young adults through the age of 25 are still developing. Indicators of the development are evidenced by *biological measures*, including brain metabolism and myelination; *neurocognitive measures*, such as executive function and inhibitions; and *social measures*, most notably, the beginnings of independence and transition to adult privileges and responsibilities, such as work and productivity (Shorland & Douglas, 2010). Maturation of the brain, mastery of tasks, and personal experiences are all taken into account when gauging progress of development (Harris, 2006). There is a scarcity of research concerning the impact of TBI on development and subsequent quality of life in young adults.

After sustaining a TBI, transition from the acute phase to successful rehabilitation can be a turbulent time, particularly in young adults. Psychosocial challenges become more complex and demanding, whereas support becomes less structured and less reliable for these young adults survivors of TBI who are in transition to both adulthood and an altered state of health (Chaves et al., 2012). It may be difficult to find a team of caregivers to help manage necessary medical care, especially if the individual lives in a rural or underserved area with limited access to subspecialty care (Pletcher et al., 2010). After leaving the acute care or rehabilitation environment for home, he or she may begin to see how the injury affects independence, future plans, work, and relationships (Tate & Broe, 1999; Turner, Ownsworth, Cornwell, & Fleming, 2009). The sense of self may be threatened by changes in abilities such as driving, maintaining relationships, and working, disassembling lifestyle and quality of life.

A landmark study of 5,600 patients aged 14 years and older with severe TBI showed that "poor patient outcomes increased with age" (Hukkelhoven et al., 2003, p. 669). Mortality rates were calculated at 21% for participants younger than 35 years and 72% for participants older than 65 years. Statistics for unfavorable outcomes were 39% and 85%, respectively. Vegetative state and severe disability occurred in 20% of survivors at age 20 and in approximately 50% of survivors at age 60. Considering the 21% mortality and 20% severe disability rates in the young adult age group, it is imperative to find ways to optimize the health and quality of life of young adult survivors of TBI. Despite the fact that TBI is prevalent in young adulthood, when risk-taking behavior is more common, there is a scarcity of both qualitative and quantitative research dedicated to the study of TBI in young adults. Young adults face challenges, choices, and behaviors that are pivotal in establishing a course for their lifetime. This realization motivated me to carry out this study, in the hope that it may help to create pathways to successful living after TBI.

#### **Consequences of Developmental Impairment**

The developmental continuum highlights a powerful and dynamic whole person across time, with an organization of energy that can be channeled constructively through nurse, patient, family, and societal dialogue. The unique challenges for young adults who have sustained a TBI are partly related to disruption in development and, in many cases, are amenable to improvement with suitable intervention. To contribute to creating efficacious interventions, an understanding of developmental impairment is foundational.

Developmental theorists have delineated stages of development in moral, cognitive and problem solving realms (Burns, Dunn, Brady, Starr, & Blosser, 2004). People with intellectual disabilities, including those who have sustained a TBI, follow similar stages of characteristic development, but may fail to progress and meet expected norms in moral, cognitive, and problem-solving realms. What remains constant are the rewards of the successful completion of tasks, connecting socially, proper handling of moral dilemmas, and problem solving.

Morally, Kohlberg (1973) places the adolescent and young adult at the stage of universal ethical principle orientation. Kohlberg's stages are planes of moral development that help to explain moral reasoning. Kohlberg's model is based on doing right and is linked to reasoning in decision making and mental age. In contrast, Hogan (1973) places emphasis on the emotive response to others and a sense of mercy based on empathy. When considering moral personhood in those with intellectual disability, Hogan's model is more applicable. Compassion, pro-social behavior, and emotional sensitivity are elements that can be drawn out to accomplish successful moral education in those with intellectual disability (Carter, Harris, & Porges, 2009). Cognitively, Piaget (1932) places the adolescent and young adult at the formal operational stage, with development of logical abstract thinking and the ability to integrate and synthesize concepts into larger schemes. When a brain injury occurs, there may be regression to an earlier stage, such as the concrete operational stage. Failure to progress, or a regression in reasoning and learning, is associated with intellectual disability due to cognitive impairment.

Psychosocially, Erikson (1968) proposed that the adolescent in years 18 to 24 is working through issues of personal identity versus role confusion, whereas the young adult in years 25 to 40 is working on the challenges of relationships and intimacy and their derivative isolation issues. Themes in adolescence surround being oneself, and themes in the young adult surround losing and finding oneself in another. Progress through developmental stages requires interaction and can be enhanced through education and environment. When a young adult has sustained TBI, cognitive deficits and psychological effects may manifest and persist, requiring both internal and external resources to optimize quality of life and achieve a measure of social equity.

# **Incidence, Prevalence, and Consequences of TBI**

TBI is considered a "silent epidemic." One aspect of the silence regarding TBI is that acute TBI becomes a chronic condition after the injury and may be associated with multiple conditions (Levin, Shum, & Chan, 2014), including those described in the following sections.

# **Psychological Changes**

Psychological changes are common in TBI, including post-traumatic stress disorder (PTSD; 3%-59% prevalence), depression (8%-61% prevalence), mania (1%-22% prevalence), psychosis (20% incidence), post-traumatic aggression (20%-40 % prevalence),

high rates of suicide, and a disproportionate percentage of substance abuse in young adults with TBI (Kim et al., 2007).

With regard to post-traumatic aggression, Farrer, Frost, and Hedges (2013) found that juvenile offenders are significantly more likely to have had a TBI compared with controls and that TBI may be related to the etiology of recidivism of criminal behavior. Across nine studies, they found that approximately 30% of juvenile offenders had sustained a previous brain injury, with a summary odds ratio of 3.37.

TBI is associated with high rates of suicidal ideation, attempted suicide, and completed suicide (Levin et al., 2014, Wasserman et al., 2008). Aggressiveness and impulsivity may be preexisting traits that place a patient at risk for TBI and suicide or may be the result of the disinhibiting effects of frontal lobe damage (Wasserman et al., 2008).

# **Potential TBI-Related Symptoms**

Pituitary dysfunction is a recognized consequence of TBI, which causes psychological, cognitive, and metabolic impairment. The prevalence of hypopituitarism (total to isolated) among patients with TBI ranges from 5% to 90 %. The wide variation is due to varying time intervals between TBI and pituitary function evaluation (Richmond & Rogal, 2014).

Complaints about sexual dysfunction occur in 40% to 60% of patients with TBI (Zasler, Katz, & Zafone, 2007). Transient hypogonadism is common acutely and persists in 10% to 17 % of long-term survivors (Agha & Thompson, 2006).

# **Impaired Social Cognition**

Impaired social cognition has been found in most studies. Turkstra, Dixon, and Baker (2004) found that adolescents with TBI are likely to have impairments in processes such as

mental state attribution, also known as Theory of Mind. Theory of Mind is the capacity to attribute mental states, such as thoughts, beliefs, desires, and intentions, to others. It is pivotal to the ability to make sense of social behavior, support knowledge exchange, and maintain personal relationships and interpersonal communications.

### **Impaired Cognitive Function**

Residual cognitive effects of TBI are often significant and long-lasting, and may include impairments of attention, decision-making, language, memory, and executive function (Ciaramelli, Serino, Santantonio, & Ladavas, 2006). Dementia risk is also increased in the long term (Draper & Ponsford, 2008).

# Epilepsy

Brain injury is the leading cause of epilepsy in the young adult population (Anneger, Hauser, Coan, & Rocca, 1998). The risk of sudden death in patients with epilepsy is more than 20 times that of the general population (Shorvan & Tomson, 2011).

# **Potential Outcomes After Frontal Lobe Brain Injury**

There are linkages among frontal lobe brain injury, executive function, and selfefficacy. These linkages provided the rationale for inclusion criteria of injury to the frontal lobes of the brain and for choosing self-efficacy as the conceptual framework for the study.

Frontal lobe functions include thinking, planning, problem solving, emotions, behavioral control, and decision making. Frontal lobe brain injury may lead to deficits in fine motor function, upper extremity strength, and executive function, including (1) goal setting and planning; (2) attention and memory; (3) problem solving; (4) social behavior; and (5) ability to decide between good and bad choices (Floden, et al., 2008). In frontal lobe brain injury, there are also disruptions of connections in the brain that underlie metacognitive processes, such as self-awareness, self-evaluative ability, self-monitoring of performance, and strategies for solving problems and learning (Ownsworth et al., 2010; Spikeman & van der Naalt, 2010).

Executive function is defined as a set of processes that have to do with managing oneself and one's resources to reach a goal. It is an umbrella term for neurologically based skills involving control and self-regulation and comprises the substantive knowledge on which self -efficacy theory is built. The originator of self-efficacy theory was Bandura (2004), who defined self-efficacy as "one's belief in his ability to succeed in specific situations" (p. x). Control is a major tenet of the theory. The dictionary definition of success is "achievement of something desired, planned, or attempted" (Pinker, 2014, p. 1). Thus, the association among executive function, self-efficacy, and success is established at the level of basic tenets and definitions.

Impulsivity and risk taking may increase after frontal lobe brain injury. The brains of young adults are still developing connections in the frontal lobes for tasks such as attention, inhibition, and high-level functioning (Lebel & Beaulieu, 2011). At the onset of adolescence and into young adulthood, the frontal cortex is the only brain region that has not undergone a competitive pruning that allows for more complex and optimized neural circuitry. This delay of maturation in the frontal cortex means that adolescents and young adults have not reached adult levels of expertise regarding various cognitive tasks, executive function, theory of mind (mental state attribution), and the ability to calm the activity of the limbic system, which is a brain region involved in emotion. The delayed maturation of the frontal cortex explains the phenomenon of increased risk taking in adolescence and young adulthood (Sapolsky, 2014).

Maturation of the brain, mastery of tasks, and personal experiences are all taken into account when gauging the progress of development (Harris, 2010). Indicators of development are evidenced by biological measures, including brain metabolism and myelination; neurocognitive measures, such as executive function and inhibitions; and social measures, most notably, the beginnings of independence and transition to adult privileges and responsibilities such as work and productivity. The focus of this study was on executive functions and psychosocial indicators.

### Historical Background and Demographics for New Mexico TBI

New Mexico is an ethnically diverse state, with a rich Hispanic and American Indian heritage that can be seen in every realm of public and private life. Current census data show that 47% of its citizens are of Hispanic/Latino descent, compared with 16.9 % nationally (Hubbard, 2012). The leading causes of TBI nationally (including, but not limited to, deaths, hospitalizations, emergency department visits) from 2002 to 2006 were falls (35.2%), motor vehicle traffic accidents (17.3%), being struck by or against an object (16.5%), and assault (10%). From 2007 to 2011, the leading causes of TBI-related death in New Mexico were firearm injuries, falls, and motor vehicle traffic-related injuries (Hubbard, 2012).

In the state of New Mexico, most of the *firearm injuries* are due to suicide. Substance abuse and mental health disorders are the two most common psychiatric disorders associated with suicide. According to injury epidemiologist Glenda Hubbard's (2012) report, *Traumatic Brain Injury Deaths, Hospitalizations and Emergency Department Visits in New Mexico,* 2007-2011, prepared for the New Mexico Department of Health, approximately 85% of suicide attempts using a firearm are fatal. *Fall-related injuries* were the leading cause of TBI-related hospitalizations among the people aged 0 to 4 years and 45 years and older. The *motor vehicle traffic accident* hospital discharge rate was highest among 15- to 24-year-olds and was two times higher among males than females (Hubbard, 2012). Motor vehicle traffic deaths in New Mexico have decreased sharply since 2007; however, the motorcycle death rate increased 100% from 1999 through 2009. *Being struck by or against and object* is the third leading cause of TBI-related hospitalization in New Mexico.

There are several additional facts of interest. The first is that New Mexico passed a "return to play" law in 2010 to protect young athletes from deadly or disabling consequences of returning to play too soon after a TBI (Hubbard, 2012). Second, the reason for the sharp decline in motor vehicle traffic deaths and increase in motorcycle deaths may be traced to a "primary enforcement seat belt law but only a partial helmet law for motorcycle riders" (Hubbard, 2012, p. 16). Third, in 2007, the New Mexico Legislature passed the Child Helmet Safety Act, which is "the most comprehensive helmet law for children and youth in the nation" (Hubbard, 2012, p. 16). Increased awareness of TBI and its consequences, coupled with the proactive legislative action outlined above, may have had some part in the paucity of potential participants for this study, which was conducted in the state of New Mexico.

However, Hubbard (2012) also reported, "Over 1.7 million people sustain a TBI in the United States each year, of whom about 52,000 die, 275,000 are hospitalized, and 1,365,000 are treated and released from an emergency department" (p. 2). Our young adult research participants were among the numbered 275,000 individuals who sustained a TBI and were hospitalized for TBI related to motor vehicle traffic and struck by or against an object. Kraus and McArthur (2000) noted that the highest incidence of TBI is in young adults, predominantly males aged 15 to 24 years. "Traumatic brain injury is the most common cause of death and disability in young people with an annual financial burden of over \$50 billion per year in the United States" (Zammit & Knight, 2013, p. 1).

To gain a perspective on the magnitude of the national and worldwide impact of TBI, it is striking to note that direct medical costs and indirect costs (e.g., lost productivity) "totaled an estimated \$60 billion in the United States in 2000" (Hubbard, 2012, p. 2). According to current estimates, about 3.2 to 5.3 million persons (1.1%-1.7% of the U.S. population) live with long-term disabilities resulting from TBI (Selassie et al., 2008; Zaloshnja, Miller, Langlois, & Selassie, 2008). Worldwide, TBI is the leading cause of morbidity, disability, and mortality in individuals under the age of 45 (Werner & Engelhard, 2007; Zappala, Thiebaut de Schotten, & Eslinger, 2012).

# What We Have Learned Overall About Young Adult TBI

Current literature reveals a scarcity of studies dedicated to young adult TBI and the aims of this study. The brief summary below suggests more emphasis on interventions and outcomes (not my focus), and I present these findings only as a *context* for the study I completed. The basic content of these studies serves to enrich the overall understanding of TBI in young adults.

According to findings from an international workshop focused on TBI comparative effectiveness research, "Advances in provision of care for TBI patients have resulted from observational studies, guideline development, and meta-analyses of individual patient data. In contrast, randomized controlled trials have not led to any identifiable major advances due to the fact that rigorous protocols and tightly selected populations constrain generalizability" (Maas et al., 2012, p. 32). Approaches, including systems biology (aimed at identifying multiple factors and complex interactions contributing to a disease) and comparative effectiveness research (measuring benefits and risks of systems of care and interventions in ordinary settings and broader populations), were recommended, as they have great potential for TBI research (Maas et al., 2012)

• Functional outcomes: Eilander and colleagues (2007) investigated long-term functional outcomes in children and young adults with severe brain injury using the GOSE and the Disability Rating Scale. They concluded that more patients with TBI than expected reached a semi-independent level of functioning, possibly an effect of the early intensive neurorehabilitation program that they investigated.

Anderson, Brown, and Newitt (2010) investigated the research question, "What contributes to quality of life in adult survivors of childhood TBI?" They found that poor quality of life was more likely with low levels of perceived independence, younger age at injury, severe TBI, failure to complete high school, and psychological problems. They concluded that in adult survivors of childhood TBI, quality of life was better than expected and most consistently associated with the individual's perception of the level of independence.

• Executive functions (self-efficacy and control): Hornich and Marshall (2009) found that change in self-efficacy was a significant predictor of change in productivity, and change in internal locus of control was a significant predictor of change in home integration.

Hart, Vaccaro, Hays, and Maiuro (2012) examined the feasibility and efficacy of an eight-session psychoeducational treatment for irritability and anger after TBI, called anger self-management training. Ten persons with moderate to severe chronic TBI, significant cognitive impairment, and elevated levels of anger and irritability participated in this study. Significant improvement in three measures of self-reported anger was shown. The treatment model appears worthy of further study in persons with TBI who have both problematic anger and cognitive impairment.

Foy and Somers's (2013) study of 106 young adults with moderate to severe TBI who had attended a residential program revealed that clients benefitted from the mixed inpatient educational and neurorehabilitation program. The benefit was predicted by their length of stay and functional abilities at admission.

Draper and Ponsford (2008) found that injury severity affects executive function in the acute as well as chronic stages of TBI and that patients at 10 years post-injury were still impaired in processing speed, memory, and executive function. Greater severity of injury was found to be related to poorer test performance across all domains.

- **Physical activity and life satisfaction**: Jacobsson and Lexell (2010) found that individuals' self-appraisal of the impact of TBI and vocational productivity were strongly associated with their current physical health and life satisfaction.
- Self-efficacy and cognitive symptoms: Cicerone and Azulay (2007) developed the TBI-SE used in our study. In their investigation, the primary finding was that participants' self-efficacy in the management of cognitive symptoms made the greatest contribution to prediction of quality of life, as measured by the Satisfaction with Life Scale (SWLS) and Perceived Quality of Life scale (PQOL), and was also significantly related to the Community Integration Questionnaire (CIQ).

Till, Colella, Verwegen, and Green (2008) found that the best predictor of cognitive decline was the amount of therapy received at 5 months post-injury, providing supporting evidence for early rehabilitation after TBI.

Interestingly, Ramanathan, Wardecker, Slocomb, and Hillary (2011) found that higher levels of dispositional optimism in survivors of moderate-to-severe TBI are related to better psychological functioning, which in turn predicts improved functional and cognitive outcomes.

- Self-efficacy and multiple related constructs: Luszczynska, Gutierrez-Dona, and Schwarzer (2005) found that the GSE used in our study was positively related to constructs similar to self-efficacy, including, but not exclusive of orientation to the future, dispositional optimism, life satisfaction, self-regulation, social comparison tendencies, stress perceived of as challenge, school grades, and job satisfaction.
- Social role and community integration: In their study on community integration outcomes after TBI, Kim, Colantonio, Dawson, and Bayley (2013) findings suggest that interventions should be targeted to the daily functioning realms of recreation and family role.

In a study focused on health-related quality of life, Hawthorne, Gruen, and Kaye (2009) found that TBI participants experienced worse general health and labor force participation, social isolation, and a higher probability of depression compared with matched comparators. The most affected areas were social function, role emotion, and mental health. They noted that a challenge is to provide and evaluate long-term services targeted at the most affected areas of life. Topolovec-Vranic and colleagues (2012) reviewed the current state of the literature on TBI and homelessness to identify knowledge gaps and direct future research. Eight research studies were identified. They found that the rate of TBI is higher among persons who were homeless compared with the general population. The rate of TBI among homeless persons varied across studies, ranging from 8% to 53%.

Health-related quality of life: Health-related quality of life has been studied more frequently in the past 5 years due to a call by funding agencies for research on this outcome. After their investigation regarding health-related quality of life predictors at 1 to 2 years after moderate-to-severe TBI, Forslund (2013) concluded that future interventions should focus on health-related quality of life aspects that are more easily modified, such as physical functioning, home integration, social integration, mental and emotional status, and productivity.

A review of existing literature pertaining to Wilderness Adventure Therapy (WAT), cognitive rehabilitation approaches, and adolescent TBI was conducted by Shanahan, McAllister, and Curin (2009). No studies dedicated to adolescents or young adults with TBI were found. The authors concluded that a trial study investigating the application of WAT with adolescents with TBI is warranted. They recommended that outcomes for executive functioning skill development, self-esteem development, and quality of life post-program be compared with results from adult programs.

These studies suggest a progression toward identifying potentially useful interventions for young adults with a TBI. No new treatment for TBI has been approved in the past 30 years (Lancet Neurology, 2010). The slow rate of research progress may be

largely due to the heterogeneity of TBI and poor understanding of its pathology and prognosis, which mean that potential therapies are not always tested in those most likely to benefit (Lancet Neurology, Leading Edge, 2010). Randomized controlled trials remain a goal for future studies, as relatively few have been performed within TBI populations. Only 3% of the recommendations in the National Institutes of Health (2010) TBI guidelines are based on class I evidence.

Little is known about the effects of TBI on the developing brain, contributions to and mechanisms of secondary injury, or the effects of genetics on prognosis. Much progress has been made in the search for a TBI biomarker. The newly validated blood-based glial proteomic biomarkers have been shown to reliably detect the presence and severity of brain injury on CT scan (Okonkwo et al., 2013). Surgical intervention, including intracranial pressure monitoring and hemicraniectomy, have been shown to be effective for treatment of TBI (Whitmore et al., 2012). Presently, coordinated research efforts are concentrated on brain mapping and connectivity, and the International Mission on Prognosis and Clinical Trial Design (IMPACT Project, 2014) group has been collaborating on identifying which common data elements should be collected in clinical TBI studies.

### **Self-Efficacy Theory**

### **Central Concepts of Self-Efficacy Theory**

Self-efficacy outcome expectations are a consequence of success, and self-efficacy is enhanced by patterns of success, displaying a bidirectional relationship. Efficacy and outcome expectations are antecedents to behavior and are reinforced when one succeeds in carrying out a desired behavior. *Success* is the achievement of something desired, planned, or attempted and is most often self-defined. *Successful living* is a life characterized by a record of goal attainment and is accompanied by a personal sense of accomplishment. A pattern of recurrent success may increase one's motivation, energy, and interest in striving to achieve additional goals. A focus on strengths and assets, rather than deficits, is a major underpinning of best practice, and an underlying assumption is that self-efficacy is built on a pattern of success.

Psychologist Albert Bandura expanded social cognitive theory to the theory of selfefficacy (1977, 1986, 1997, 2004). He proposed that motivation is cognitively generated and is enhanced by self-efficacy. Self-efficacy is composed of a person's knowledge, training, education, learned skills, attitudes, beliefs, and characteristics. Self-efficacy beliefs are a foundation for action. The decision to proceed with a given action may be influenced by motivation to achieve desired outcomes or avoid unwanted outcomes. A key concept in the theory is mastery. Processes of behavioral and psychological change function by their impact on a person's mastery.

Self-efficacy theory focuses on a person's confidence or belief that he or she can succeed in making a change in behavior. It encompasses the belief that one can achieve a desired goal by engaging in a chosen behavior (Clark & Dodge, 1999). Thus, if individuals feel confident that they can succeed in their ability to carry out a behavior, they will be more likely to try the behavior or course of action (Pajares, 2009). Confidence is a product of personal, behavioral, and environmental factors.

# **Historical Development of Self-Efficacy Theory**

Miller and Dollard (1941) proposed a theory of social learning based on drive reduction principles. However, their learning theory did not account for creation of novel responses, delayed processes, or nonreinforced imitations. Bandura (2004), who designed social cognitive theory, used antecedent knowledge from the field of social learning theory to develop the self-efficacy theory. Processes that are involved in observational learning include attention and retention, with encoding through the use of words, image formation, or a combination of the two. Encoding behavior involves putting action into memory using symbols, cognitive organization, and both symbolic and motor rehearsal. The ability to perform a behavior correctly is important and may involve highly skilled acts that are essentially motor reproduction processes. Performing behavior is the doing or being able to perform a behavior involving physical capability, self-observation and reproduction, and accuracy feedback.

In 1977, Bandura identified the important element of *self-belief*, which is defined as an individual's judgment about his or her capability to organize and execute courses of action required to attain performances. Bandura expanded on his theory in 1986, identifying the characteristics of people as self-organizing, proactive, self-reflecting, and self-regulating (Bandura, 1986). He also noted that persons with high self-efficacy believe they are in control of their lives, with their decisions and actions shaping their lives and futures, whereas people with low self-efficacy believe that their destiny is out of their control (Bandura, 1997, 2004). According to Bandura's self-efficacy theory, most behavior is regulated by an ongoing process of self-reinforcement. A feeling of satisfaction or accomplishment may serve as a self-administered reward; conversely, self-administered punishment may take the form of depression, shame, or guilt with respect to how one behaved.

### Strengths, Weaknesses, and Gaps of Self-Efficacy Theory

Analysis involves identification of a theory's strengths and weaknesses, providing insight into the concepts, aims, and usefulness of the theory. Criteria for analysis of a theory

include three components: theory scope, theory context, and theory content (Fawcett, 2000). Theory analysis "may determine the need for additional development or refinement of the original theory" and may result in creating new relationships that are unclear or not included in the original theory (Walker & Avant, 2011, p. 194).

**Theory scope.** Middle-range theories are more specific and concrete than grand theories and may be classified as predictive, explanatory, or descriptive. The middle-range theory of self-efficacy is integral to the middle-range theories of hope, empowerment, support, resilience, health promotion, quality of life, and role-modeling. It has provided a framework within which hypotheses have been generated and tested, making a significant contribution to knowledge development in the realms of clinical care, patient education, and nursing competency. "In the past 10 years there have been approximately 400 articles in nursing journals that focus on the measurement and use of self-efficacy expectations and/or outcome expectations to predict behavior" (Peterson & Bredow, 2009, p. 124).

Self-efficacy theory has been used in nursing research to explain the dynamics of and motivation for patient participation in health-promoting activities, such as exercise, smoking cessation, weight loss, and cancer screenings, (Resnick, 2002; Resnick, Luisi, & Vogel, 2008), as well as restorative care activities (Resnick & Simpson, 2003) and medication adherence (Resnick, Wehren, & Orwig, 2003). However, not much consideration has been given to self-efficacy in neurologic conditions (Dixon, Thornton, & Young, 2007). This may be due to the fact that neurologic disability is often accompanied by cognitive deficits that may, by definition, produce a study of outliers. Expansion of self-efficacy theory beyond the bounds of behavior change may be needed to increase its scope so that it is relevant to a wider range of patient populations. Thinking in terms of successful living expands selfefficacy theory to integrate life satisfaction and other emotive content with behavior change.

**Theory context.** Self-efficacy has been a particularly useful theory in the context of health promotion associated with behavior change and is embedded in health promotion models. Nola Pender's health promotion model includes key concepts of self-efficacy theory, including *behavior*, benefits and barriers to action, *perceived self-efficacy*, *control*, and plan of action, all of which contribute to health-promoting behavior (Pender, Murdaugh, & Parsons, 2006). Bandura's (2004) publication on the topic of health promotion by social cognitive means shows associations and logical linkages between self-efficacy concepts and health promotion. *Motivation* is pivotal in most theories used to study health behavior for prediction of behavior change (Brawley & Culos-Reed, 2000). Bandura (1997) delved into the relationship between motivation and cognition. He proposed that motivation is cognitively generated and is enhanced by self-efficacy. Self-efficacy beliefs are the foundation for action and reflect adequacy in dealing with life and health challenges. Thus, free will and freedom of choice are central concepts in the theory. The worldview of selfefficacy is reflected in the core assumption that people can exercise influence over their behavior. The role of intention is described as personal agency.

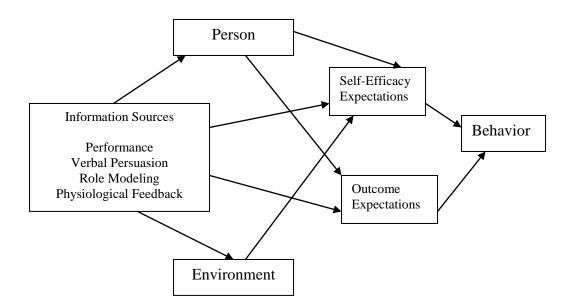
Personal agency may be compromised after TBI. For example, if dysinhibition results from a TBI, the degree of influence that one has over his or her behavior may decrease. In this study, investigation of success is designed to fill in the gaps in self-efficacy theory and focus on the positive characteristics to help individuals achieve adaptive success. Moving toward one's core conceptualization of feeling satisfied and successful in life is imperative, enabling each individual to know success in life endeavors, including personal health promotion and well-being.

Goal setting and executive function may also be compromised after a TBI. In these situations, success may start with learning how to set a single goal. A basic tenet of success is that "success creates success." Success is the inner feeling of accomplishment and reward that provides the impetus for taking on the next challenge. Lessons learned from alterations in brain function have historically been profound. It is my hope that this research based on self-efficacy and success will effectively benefit individuals who have sustained a TBI.

Theory content. The fundamental theme of self-belief as the impetus for action and behavior is consistent throughout self-efficacy theory and is supported by its concepts. The construct is dynamic, with changing judgments regarding efficacy over time, and it is adaptive to fit changing situations. According to self-efficacy theory, human functioning is a dynamic interaction of environmental, personal, and behavioral influences. Cognitive, vicarious, self-reflective, and self-regulating processes are central in human change and adaptation. Bandura differentiated outcome and self-efficacy based on his observation that a person may believe that a behavior will result in a certain outcome, but may not believe that he or she is capable of executing the required behavior (Bandura, 2004; Pajares, 2009). Self-efficacy includes the belief that one is capable of, and has the power to produce, a desired effect by performing a particular course of action (Pajares, 2009). From its inception, the self-efficacy framework has been recognized as "a predictor of health behavior change and maintenance" and for its direct applicability to health behavior modification (Strecher, Devellis, Becker, & Rosenstock, 1986, p. 73).

### Self-Efficacy Model

Bandura's (1977, 1986, 1997, and 2004) self-efficacy model suggests that *person*, *environment*, and *behavior* operate as interlocking and interdependent determinants of each other, representing the concept of *reciprocal determinism*. Information sources impact all other elements of the model. The four primary information sources of input toward selfefficacy comprise the focal concepts of the theory: (a) performance (or mastery experience), in which successes in life endeavors raise self-efficacy and failures lower self-efficacy; (b) verbal (or social) persuasions, which take the form of encouragement or discouragement; (c) role modeling (or vicarious experience), in which people learn behaviors through observation and then imitate the behavior; and (d) physiological feedback, which is focused on how a person perceives stressful situations (Figure 2.1). Outcome expectations involve the ability to



*Figure 2.1.* Self-efficacy model (Reprinted with permission from *Middle-Range Theories: Application to Nursing Research*, 2nd ed., by Sandra J. Peterson and Timothy S. Bredow, 2009, p. 123. © Wolters Kluwer Health/Lippincott Williams & Wilkins).

appreciate and anticipate the outcome of consequences observed in others, whereas selfefficacy expectations are rewards expected for successful performance by oneself. The theory of self-efficacy has provided a framework within which hypotheses have been generated and tested, making a significant contribution to knowledge development. The theory has been used in nursing research with a focus on application for clinical care, patient education, and nursing competency. Impacting and understanding the dynamics of behavior change are fundamentals that are indispensable in the practice of both nursing and medicine. Self-efficacy measures have been used in research and clinical settings extensively within multiple disciplines. Identification of persons with low self-efficacy, with subsequent interventions designed to improve self-efficacy and promote healthy behavior, is at the heart of effective health care delivery.

#### Additional Theoretical Foundations for the Study:

#### **Resilience, Empowerment, Quality of Life, and Health Promotion**

Self-efficacy is integral to numerous middle-range theories and is embedded both overtly and covertly in multiple theories, most notably, resilience, empowerment, quality of life, and health promotion theories, with respect to this study.

# Resilience

There is a wealth of literature on *resilience*, which has been defined as the process of identifying and developing resources and strengths to flexibly manage stressors and gain a positive outcome (Haase, Heiney, Ruccione, & Stutzer, 1999). Haase (2004) studied adolescents with chronic illness, incorporating the concepts of resilience, self-esteem, self-transcendence, confidence, mastery, quality of life, and well-being. Haase and colleagues (1999) developed an instrument to measure resilience. A model of social participation for

adults with TBI was developed by Dumont, Gervais, Fougeyrollas, and Bertrand (2004). Their study revealed that *dynamism* and *self-efficacy* account for 51% of the variance in social participation and are the main resiliency factors. It is evident from the literature that success, resilience, self-efficacy, and quality of life are intertwined with and affect health promotion.

Stewart, Reid, and Mangham (1997) synthesized and reviewed literature on resilience and health, including protective factors at the individual, family, and community levels. The concepts of self-efficacy, social support, confidence, and intelligence were noted to be among factors that afforded protection, enabling individuals to cope successfully in the face of risk, change, and adversity. Hunter (2001) used triangulation and cross-cultural comparisons in his study of homeless adolescents and resilience. He found that connected or survival resilience, self-esteem, self-efficacy, connectedness, ego-resilience, and sociability were positive attributes that contributed to survival and allowed a person to overcome adversity without suffering long-term negative consequences.

### Empowerment

The human rights paradigm motivates people to participate in promoting health based on a fulfillment of personal obligation to help others gain dignity and opportunity through empowerment, voice, and transparency. Austin's (2001) work emphasizes the history of philosophy and public policy in the setting of a human rights paradigm. Viewed from a different perspective, Jones and Meleis (1993) focused on the societal context of health and the concept of empowerment. Constraints on health imposed by societal conditions limit the ability of underserved and disenfranchised groups to achieve optimal health. Jones and Meleis (1993) proposed a model of health based on empowerment of human potential in individuals and groups, linking people with resources and mobilizing energy for realization of health potential. Positive health outcomes require empowering families to access care and optimize health within the parameters of internal capabilities and external resources.

### Quality of Life

Quality of life literature originated in ancient times. Aristotle asserted that happiness, or the good life, is an outcome of a life of virtue. Medical doctors Wilson and Cleary (1995) developed a model quality-of-life framework that was revised by Ferrans, Zerwic, Wilbur, and Larson (2005). Central concepts in Wilson and Cleary's (1995) work include characteristics of the individual, environmental supports, and nonmedical factors impacting symptoms, function, and health perceptions. Each factor contributes to overall quality of life. Hampton (2000) found that general self-efficacy predicts quality of life in patients with spinal cord injury. Nursing theorist Pender and colleagues (2006) define health as "the actualization of inherent and acquired human potential through goal-directed behavior, competent self-care, and satisfying relationships with others, while adjustments are made as needed to maintain structural integrity and harmony with relevant environments" (p. 23). Enrichment of internal and external environments to maximize quality of life and promote health is essential in nursing.

#### Health and Health Promotion

Smith's (1981) philosophical inquiry into the concept of *health* reveals models that fall into four categories: eudaimonistic, adaptive, role-performance, and clinical. The eudaimonistic model dates back to ancient Greece and as far forward as Maslow (1943) and his theory of human motivation. Maslow's hierarchy is portrayed as a pyramid, with the most basic needs forming the foundation, including (beginning with the most fundamental) physiologic needs, safety, love and belonging, esteem, self-actualization, and selftranscendence. For example, food and shelter would be physiologic needs, and self-efficacy would be in the category of esteem. The eudaimonistic model encompasses the ideas of health as general well-being. On the positive end of the health continuum, there is "exuberant well-being."

Neuman (1989) developed adaptive models, in which disease is a failure of adaptation and health is the engagement of the organism in effective interaction with the social and physical environment. The role-performance model based on Parson's (1951) work calls sickness an inability to do one's job or to perform one's relevant role, and health constitutes maximal performance of social roles. Health in the role-performance sense may be at a much lower level than at the eudaimonistic criteria embedded in Maslow's selfactualization. Clinical health is based on modern medicine and is characterized by the absence of the signs and symptoms of disease.

Pender's health promotion theory and model is pivotal to successful living and incorporates self-efficacy as a concept (Pender et al., 2006). The final and key step in Pender's model is commitment to a plan of action that results in health-promoting behavior. Motivation underlies most theories used to study health behavior for prediction of behavior change (Brawley & Culos-Reed, 2000). The relationship of self-efficacy to quality of life and promotion of health by successful self-management are fundamental to the current study.

### Linkages With Complex Adaptive Systems

Complex adaptive systems theory posits that interactions are self-organized and naturally tend toward levels of higher complexity (Paley, 2007). The framework of complex adaptive systems can be integrated with concepts of self-efficacy and success to reach higher levels of abstraction. Complex adaptive systems theory has strong ties with nursing theory development and practice. An ethnographic iterative–inductive approach to research—respecting the irreducibility of human experience in the context of participants' lives—was used to represent the higher levels of complexity and is congruent with complex adaptive systems theory (O'Reilly, 2005).

# **Complex Adaptive Systems Concepts Linked With Self-Efficacy Concepts**

Complex adaptive systems theory is useful in viewing the person in his essence moving through time and as a descriptor of being from the patient perspective in his unique environment. Appreciation for the developmental and recovery continuum of the young adults in this study reveals a dynamic process; with self-organized energy that was channeled constructively through participant and family dialogue. The broad world view of complexity science is congruent with the tenets of self-efficacy theory, including (a) persons who are able to adapt and create increasingly complex environmental innovations; (b) individuals as agents who are actively engaged in their own development and can make things happen by their actions; (c) concepts of interdependent role modeling and social persuasion; and (d) self-organization, reflected in concepts of motivation and control. Efficacy and outcome expectations are antecedents to behavior and are reinforced when one succeeds in carrying out a desired behavior.

# **Complex Adaptive Systems Theory Linked With Nursing Theory**

As defined by nurse researcher Paley (2007), *complex adaptive systems* are composed of elements (e.g., atoms, chemicals, neurons, genes, people) that follow simple rules and emerge in a structured self-organization. Similarly, Roy's adaptation model (Whittemore & Roy, 2002) is holistic, viewing the *person as an adaptive system* composed of physical, emotional, intellectual, and spiritual elements, with internal and external stimuli as inputs. The stimuli are processed, and the person adapts continually. Outputs may be adaptive or may constitute an ineffective response. The nurse's role is to promote adaptive responses, directing energy toward health and wellness. Roy (1984) defines *health* as a state of adaptation manifested in free energy to deal with other stimuli, the process of promoting integrity and wholeness, and being and becoming integrated. *Environment* is defined by Roy as the internal and external stimuli, and the conditions, circumstances, and influences surrounding and affecting the development and behavior of humans as adaptive systems, while considering personal and earth resources.

Evolution of Roy's (1984) model to complex adaptive systems as described by Holden (2005) expands the model to include complexity science, which investigates patterns and complex adaptive systems. Connections, interactions, energy, non-linearity, and holism are antecedents that are played out in individual persons, interpersonal relationships, and social systems as a complex adaptive system. These nursing theory models expand on creative scientific and philosophical thought that is historically grounded and wide in scope. Holden (2005) defines a *complex adaptive system* as "a collection of individual agents with freedom to act in ways that are not always totally predictable and whose actions are interconnected" (p. 651). Furthermore, she elaborates, stating that a complex adaptive system "represents the dynamic interactions of diverse agents who self-organize and produce adaptations that emerge in ways that can neither be predicted nor controlled" (Holden, p. 656).

Historically, nursing theory provides a rich tradition that is congruent with the complex adaptive systems and may be viewed as foundational to complex adaptive systems

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theory. Nurse theorist Martha Rogers (1970) defined the *unitary human being* and the environment as energy fields that are open to exchange, transcend time and space, exhibit resonance, and may have imaginary boundaries that are changeable. She also wrote that the second law of thermodynamics was inconsistent with the observation that living systems tended toward increasing complexity. This is a notion she called "negentropy" (Rogers, 1970, p. 51), which is a central idea of complex adaptive systems. Roy's (1970) adaptation model elaborates on the adaptive component of complex adaptive systems, whereas Rogers' unitary concept focuses on energy and systems. The construct is also in synchrony with Agar's (2002) emphasis on culture and human connectedness.

#### **Complex Adaptive Systems Linked to Case Study**

# **Approach and Ethnography Methods**

The concepts and continuum inherent in complex adaptive systems theory provide a framework for the understanding of TBI in young adults as an interconnected and contextsensitive state of human experience. This framework is congruent with the case study approach and ethnographic methodology chosen for this study. Stake's (1995) approach to case study research emphasizes delving into the complexity of the case, broadening the research goals toward distinguishing the circumstances and particularities of the TBI experience from the perspective of the research participant. *Complex adaptive systems* may be defined as "collections of many different components (agents) interacting in nonlinear ways in the absence of any external supervisory influence...complex adaptive systems show emergent behaviors" (Sturmberg, Martin, & Katerndahl, 2014, p. 66). Emergent behaviors in our research participants revealed a slower pace of life more focused on family. This was perceived by them as a welcome and positive change after the somewhat frantic pre-injury pace the participants were keeping. This case study approach using ethnographic methods revealed dynamic persons with an organization of energy that was channeled constructively through participant, family, researcher, and, it is hoped, ultimately societal dialogue in the tradition of collaborative action research.

### **Philosophic Perspectives: Critique and Synthesis**

# **Dualism in Philosophy and Linguistics**

Our brains operate as organic wholes with our functioning bodies and actively engage in physical, social, and cultural human environments. Current thinking in the discipline of the philosophy of mind is focused on the unity of mind and body. A group of philosophers is now of the persuasion that meaning grows from bodily perceptions, movement, emotion, and feelings (Damasio, 1994; Johnson, 2007). This is in contrast to Descartes' (1596-1650) dualistic mind–body perspective. It also diverges from Frege's (1892-1970) claim that propositions (statements that may be either true or false) are the basic units of human meaning and thought.

There are two kinds of meaning identified in current literature: cognitive or descriptive and noncognitive or emotive. Unity of mind and body highlights the inadequacy of a philosophy of language approach, as explicated by philosophers such as A. J. Ayer (1910-1989). Ayer was a British philosopher known for his logical positivism, or the idea that observational evidence is necessary for knowledge of the world. In his book *Language*, *Truth, and Logic* (Ayer, 1936), he discounted emotive meaning to maintain a restricted focus on conceptual and propositional meaning as the only rigorous and scientific mode of knowing. Ayer popularized the verification principle, which is that a sentence can only be meaningful if it has verifiable import; otherwise, it is meaningless. Diverging from Ayer's verification principle, Johnson (2007) asserts, "Meaning traffics in patterns, images, qualities, feelings, and eventually concepts and propositions" (p. 9). As such, self-efficacy and success are embedded in nonpropositional meaning and are dependent on individuals' pathways through the environment. Barriers to mobility, education, and health are around every corner for young adults with TBI. Success in navigating the barriers is crucial in developing a pattern of self-belief and confidence typical of self-efficacy.

### **Pragmatism in Methodology and Theory**

Use of descriptive quantitative measurements triangulated with qualitative interview data reflected pragmatic knowledge claims in performing this study. Combining descriptive data from the questionnaires with perceptual data from the interviews was a practical way to conduct the study and obtain the data needed to understand the research problem and answer the research questions. The American pragmatist James (1907) conceived of truth as rooted in human experience and connected to evidence. His pragmatic approach examined truth in the context of the real world, as experienced by human beings. He differentiated two ways of knowing and truth. The first method of knowing is by intuitive direct experience by visualizing the phenomenon with one's own eyes. As such, truth becomes a matter of direct consciousness flowing from experience. Alternatively, one may attain knowledge through conceptual or representative intellectual processes connecting thoughts with things. A visual representation may clarify truth, such as in a theoretical model. The philosophical distinction between intuitive and intellectual truth is significant when thinking in terms of self-efficacy and success. Self-efficacy theory is generated from a worldview that is primarily pragmatic, constructivist, and focused on behavior; whereas thinking in terms of success tends more toward constructivist and collaborative knowledge claims and is focused on both the *emic* and the *etic*, or the internal and external aspects of human beings. A fresh perspective on truth was advanced by American pragmatists. James' (1907) perspective was that truth can be measured by its practical value: "The true', to put it very briefly, is only the expedient in the way of our thinking, just as 'the right' is only the expedient in the way of our behaving" (p. 86). Likewise, self-beliefs drive behavior in accordance with what one believes to be true. In the context of self-efficacy and successful living, if an individual believes that certain things can be accomplished, he or will perform the necessary tasks to achieve self-defined goals leading to success.

### **Constructivism in Theory and Methodology**

Epistemologically, self-efficacy theory is constructivist, connoting that human beings have the ability to interpret and construct reality. The socially constructed world of human perception is not real like an object, but it is real as perceived and experienced by people. Sociologist and founding symbolic interactionist, W. I. Thomas (1863-1947) formulated the theorem: "If men define situations as real, they are real in their consequences" (Thomas, 1928, p. 572). Likewise, in self-efficacy theory, the connection between self-belief and the inner world of a human being is actualized in actions and accompanying consequences.

Methodologically, the distinction between intuitive and intellectual truth is a thread of thought that is evident when using a case study research approach with ethnographic methodology, in which humans are viewed as creative and active participants who creatively construct their social world. Constructivism is naturalistic and is based on the premise that the human world is different from the natural world; therefore, it must be studied in a different way (Lincoln & Guba, 1985). Knowledge claims in ethnography are in the constructivist, advocacy, and collaborative frameworks (Creswell, 2007). Human perception is shaped by linguistic and cultural constructs. When conducting an ethnographic study, setting, social and human environment, historical perspective, and the language and human interaction are analyzed to present emerging themes in context.

Stake (1995) posits that "human construction of knowledge appears to begin with the sensory experience of external stimuli" (p. 100). He writes about three realities: *external* reality, stimulating a person in simple ways (e.g., seeing a face); *interpretations* of simple stimulations, which is an experiential reality one is unable to verify (e.g., interpreting a look on that face); and universally integrated interpretations, an individual's *rational* reality (e.g., surmising that the face is a human face). The second and third realities merge with each other. Case study research shares the burden of clarifying descriptions and sophisticating interpretations, constructing a comprehensible and more complicated reality by providing readers with "good raw material for their own generalizing" (Stake, 1995, p. 102).

# Rationale, Development, Reliability, and Validity

### **Behind the Selected Quantitative Instruments**

### **Purpose and Development of the Instruments**

In this study, administration of three brief questionnaires provided supportive descriptive data to triangulate with qualitative interviews. The questionnaires were administered prior to the interview. The use of the GOSE places the research participants in context of prior research studies, as it is widely used in TBI research (Laxe et al., 2012; Weir et al., 2012). Instruments have been chosen for their reliability, validity, unique utility in the proposed study, and appropriateness for use with young adult survivors of TBI.

Descriptive quantitative instruments, including the 8-point GOSE (see Appendix A), the six-question TBI-SE (see Appendix B), and the 10-question GSE (see Appendix C) were used to situate qualitative data in the context of known scales of measurement. The questionnaires helped in identifying areas that produce lower than average test results, which may then be targeted through action-based goals emerging from the research. Results of both questionnaires and interviews may also aid in identification of treatment and/or access needs, which is in keeping with collaborative and advocacy knowledge claims of this proposed study.

Self-efficacy instruments have been developed by researchers for use as outcome measurements. Operationalization of self-efficacy expectations is based on Bandura's (1977) work with snake phobias. He developed a paper-and-pencil instrument measuring behavior and activity arranged from least to most difficult, providing a model for future self-efficacy measurement instruments. Participants watched a film in which people became progressively closer to a snake; models first handled plastic and then real snakes. The research participants entered the room with the model; they then touched the model and snake with and without gloves. Participants rated themselves on a scale of 1 to 10, corresponding to the extent of confidence that they had in performing a given behavior, adding up to a 100-point scale.

Thus, from the genesis of the theory it has been testable. Numerous instruments designed to test self-efficacy have been developed and refined. There are hundreds of self-efficacy measurement instruments that cover many domains, including but not exclusive of school, health, career, military, and use of computers. Many researchers approach self-

efficacy from a domain or task-specific standpoint. A lack of attention to outcome expectations in self-efficacy research is noted by Resnick and Simpson (2003), who has been a leading nurse researcher investigating self-efficacy in the domain of exercise behavior in older adults, focusing on outcome expectations.

In the domain of neurologic-focused health applications, there are self-efficacy measures for people with epilepsy (Dilorio, Faherty, & Manteuffel, 1992); self-efficacy measures for restorative care activities (Resnick & Simpson, 2003); outcome expectations focusing on exercise (Resnick, 2005) and functional activities (Resnick, 1999); researchers who consider overall physical function (Schuster & Waldron, 1991); neuroscience selfefficacy (Dilorio & Price, 2001); and self-care and self-agency self-efficacy (Lev & Owen, 1996). Very few neurologically oriented measures were discovered in this literature search, revealing a dearth of literature linking self-efficacy and neurologic conditions. These preliminary studies showed promise that a wide range of future applications will be revealed. They are particularly cogent in the realm of rehabilitation, which is a key building block of success following TBI.

The GOSE provides a way to measure impairment and disability after TBI. The extended form of the GOS was developed to place more emphasis on cognitive and emotional problems; while retaining questions directed toward physical problems that are used in the GOS. The GOSE is designed to "achieve greater objectivity and reliability than the traditional method of assigning an outcome category" (Wilson et al., 1998, p. 574). In this study, the GOSE was administered in the traditional manner of a semistructured interview, and the self-efficacy instruments were self-administered.

#### **Overview of Reliability and Validity Issues**

Reliability issues arise when one studies the fit between the true score and the obtained score (Knapp, 1985). There are several classes of reliability estimates. *Internal consistency* is based on correlations between different items on the same test or the same subscale on a larger test; it is measured by Cronbach's alpha. *Test–retest reliability* assesses the degree to which test scores are consistent from one administration to another. *Inter-rater reliability* assesses the degree to which test scores are consistent scores are consistent when measurements are obtained by different people using the same methods.

Validity issues arise when one studies the fit between the construct and the true score (Knapp, 1985). *Construct-related measurement validity* is defined as the degree to which an instrument measures the construct under investigation. *Discriminant validity* tests whether measurements or concepts that are supposed to be unrelated are unrelated. *Concurrent validity* is demonstrated when a test correlates well with a previously validated measure (for either the same construct or different related constructs). The tests are taken at the same time. *Predictive validity* measures the degree to which a test can predict (or correlate with) other measures of the same construct that are measured at a future point in time. Both reliability and validity data will be discussed with respect to each of the measurement instruments chosen for use in this study.

### **GOSE Reliability and Validity**

Semistructured interviews were utilized in the 8-point GOSE. Therefore, inter-rater reliability is important because it assesses the degree to which test scores are consistent between different people administering the questionnaire. Inter-rater reliability was previously tested, and overall agreement between raters was found to be 92% for the GOS

and 78% for the GOSE (Wilson et al., 1998). The weighted kappa statistic was computed to take into account how seriously the raters disagreed. The weighted kappa was .89 for the GOS and .85 for the GOSE. Thus, kappa values for both the GOS and GOSE were categorized as very good. On the basis of inter-rater reliability data, Wilson et al. (1998) concluded that the instrument is reliable as well as practical. In a study based on a sample of 50 neurosurgical patients, Sander (2002) also found that inter-rater agreement between two independent raters was 78% using the GOSE semistructured interview. It is important to note that the GOS was found to be the second most frequently used measurement instrument reported in clinical studies on TBI out of 193 studies examined by Laxe and colleagues (2012).

In a study based on a sample of 37 TBI patients and 44 general trauma patients, Levin et al. (2001) found that "the validity of the GOSE generally exceeded the GOS" (p. 575). Levin and his research team (2001) used a series of 15 functional outcome measures, affective status assessments, and neuropsychological tests, with testing performed at 3 months and 6 months post-TBI/general trauma. In the 37 TBI patients at 3 months, only a single outcome measure, the Social Support Questionnaire Satisfaction Score, had a better fit with the GOS ( $R^2 = .10$ , p = .05) than did the GOSE ( $R^2 = .12$ , p = .23). The GOSE appears to have a better fit than the GOS with the following measures: the Community Integration Questionnaire–Total, GOSE ( $R^2 = .35$ , p = .00), and GOS ( $R^2 = .26$ , p = .00); the Paced Auditory Serial Addition Test-Trial 1, GOSE ( $R^2 = .37$ , p = .00), and GOS ( $R^2 = .19$ , p = .01); and Grooved Pegboard–right hand trial, GOSE ( $R^2 = .21$ , p = .06) and GOS ( $R^2 = .09$ , p = .08). All three of the above measures had significant or approaching significant p values and demonstrated significant linear prediction. Overall, Levin and colleagues (2001) concluded

that the GOSE demonstrated a stronger relationship with most neuropsychological and functional outcome measures and enhanced sensitivity to changes in the time between 3 and 6 months post-injury.

Lastly, in a study by Wilson, Pettigrew, and Teasdale (2000, p. 204) assessing 135 patients with head injury using the GOS and GOSE, it was shown that the GOS and GOSE were related to the following measures: depression, as measured by the Beck Depression Inventory, GOS (spearman correlation = -.61, p < .01), and GOSE (spearman correlation = -.64, p < .01); mental well-being, as measured by the General Health Questionnaire, GOS (spearman correlation = -.57, p < .01), and GOSE (spearman correlation = -.59, p < .01); and all subscales of the Short Form-36 (SF-36), including physical functioning, role-physical, pain, general health, social functioning, role-emotional, energy and fatigue, and mental health. Respective GOS spearman correlations for the Short Form-36 were reported as .55, .61, .49, .58, .67, .55, .41, and .54, respectively, each with p < .01. Respective GOSE spearman correlations for the Short Form-36 were reported as .56, .62, .50, .59, .71, .57, .47, .56, respectively, each with p < .01. Comparative findings with the Beck Depression Inventory, the SF-36, and the General Health Questionnaire showed good agreement between these subjective measures of health outcome and both the GOS and GOSE, capturing aspects of outcome significant for emotional adjustment and quality of life (Wilson et al., 2000). In a recent study by Weir et al. (2012), the authors asked the question: Does the GOSE add value to the conventional GOS? Their answer is in the affirmative, and they recommend that the GOSE be used in place of the GOS in trials of TBI.

#### **TBI-SE Reliability and Validity**

Both the TBI-SE and GSE were used to assess self-efficacy. The TBI-SE demonstrated a high degree of internal consistency, with a Cronbach's alpha of .93 for the total scale (Cicerone & Azulay, 2007). The primary finding was that participants' self-efficacy in management of cognitive symptoms made the greatest contribution to prediction of quality of life, as measured by the SWLS and PQOL. The SWLS accounted for 24% of the variance, and the PQOL accounted for 40% of the variance. Self-efficacy for the management of cognitive symptoms was also significantly related to CIQ scores (p = .011). Construct validity was demonstrated through significant correlations between assessment of participant *satisfaction with his or her cognitive function* (QCOG) and *total self-efficacy* (r = .69, p < .001), particularly with *self-efficacy in managing and compensation for cognitive symptoms* (SEcog; r = .72, p < .001; Cicerone & Azulay, 2007). There are limited studies on use of the TBI-SE in the research literature; therefore, the current study has the potential to contribute to the fund of research knowledge using the TBI-SE scale in the context of descriptive data for qualitative research.

# **GSE Reliability and Validity**

On the contrary, there is abundant information in extant literature examining the reliability and validity of the GSE. Schwarzer and Jerusalem's (1993) GSE was examined among 1,933 participants aged 16 to 86 years in Germany (n = 633), Poland (n = 359), and South Korea (n = 941; Luszczynska, Scholz et al., 2005). Internal consistency was measured using Cronbach's alpha. Cronbach's alphas for the GSE were as follows: patients with cardiovascular disease in Germany, .94; students in Poland, .90; patients with gastrointestinal

disease in Poland, .87; swimmers in Poland, .87; and South Korean participants, .86 (Luszczynska, Scholz et al., 2005).

The Greek version of the GSE was shown by Mystakidou, Parpa, Tsilika, Galanos, and Vlahos (2008) to have a Cronbach's alpha of .927. Thus, high levels of internal consistency have been demonstrated. Construct validity was investigated by comparing the GSE with indicators of the Anxiety subscale of the Hospital Anxiety and Depression (HAD) scale. The GSE total score showed a high correlation with HAD-Anxiety (r = .507, p < .0005; Mystakidou et al., 2008).

In a study of 97 cancer patients by Luszcsynzka, Mohamed, and Schwarzer (2005), descriptive statistics for the self-efficacy scale were reported as follows: response range, 1-4; number of items, 10; item mean (SD), 3.11 (.47); and Cronbach's alpha, .92. Correlations between variables were calculated at r = .23, p < .05; r = .40, p < .001; r = .11, no p reported; and r = .27, p < .05, respectively. Luszczynska, Gutierrez-Dona et al. (2005) noted that high construct validity, reliability, and stability of the GSE scale have been confirmed in many prior studies, including those performed by Leganger, Kraft, and Roysamb (2000); Schwarzer, Babler, Kwiatek, Schroder, & Zhang (1997); Schwarzer and Born (1997); and Schwarzer, Mueller, and Greenglass (1999).

A study of 8,796 respondents in Costa Rica (n = 1,865), Germany (n = 5,106), Poland (n = 660), Turkey (n = 626), and the United States (n = 539) was performed by Luszczynska, Gutierrez-Dona et al. (2005). The researchers expected and found that the GSE was positively related to constructs similar to self-efficacy, including, but not inclusive of, *orientation to the future* (range of Cronbach's alpha, .70-.81, difference, 15.16, p < .001); *dispositional optimism* (range of Cronbach's alpha, .70-.84, difference, 7.79, p not reported);

*life satisfaction* (range of Cronbach's alpha .81-.88, difference 29.05, p < .001); *self-regulation* (range of Cronbach's alpha, .75-.82, difference, 1.10, *p* not reported); *social comparison tendencies* (range of Cronbach's alpha, .77-.81, difference, .98, *p* not reported); *stress perceived as challenge* (range of Cronbach's alpha, .61-.64, difference, 30.56, *p* < .001); *school grades* (range of Crohbach's alpha not reported, difference, 13.36, *p* < .001); and *job satisfaction* (Cronbach's alpha, .69, difference 24.00, *p* < .001). Statistical tests of differences were used, and test statistics were reported by the authors as outlined above for chosen constructs. Hypothesized relations between general self-efficacy and social cognitive variables, health behaviors, behavior-specific self-efficacy, well-being, and coping were confirmed by coefficients that were low to moderate in size (Luszczynska, Scholz et al., 2005), confirming the concurrent validity of the GSE.

Cross-cultural applicability of the GSE scale is well established. It has been adapted to 28 languages and was found to be equivalent across 25 to 28 nations (Scholz, Gutierrez-Dona, Sud, & Schwarzer, 2002). The GSE may be most useful as an adjunct to situationspecific self-efficacy measures (such as post-TBI) and in qualitative studies across cultures.

#### Conclusion

This review of the literature has examined the historical foundations, current thinking, research, theoretical contributions, and instrumentation surrounding the topic of collaboration for success in young adults with TBI. The personal and societal problems related to TBI in young adults were also included. Rationale for a research focus on young adults includes the paucity of research in the literature for this age group, coupled with the goal of providing an opportunity for young adult survivors of TBI to voice their perceptions, thoughts, emotions, and concerns in the setting of collaborative research with advocacy knowledge claims.

Self-efficacy theory was summarized and critiqued, delineating the scope, context, and content of the theory. The conceptual framework of self-efficacy provided an organizing structure for reporting, analyzing, and interpreting the findings of this study. Additional theories and models that complement both self-efficacy and the aims of this study were summarized. Enhanced self-efficacy has the potential to improve health behaviors and may lead to improved quality of life, creating a pattern of life satisfaction and successful living. The focus on self-efficacy and success helped to place the research in a broader context within the body of extant literature, informing the study design, approach, methodology, and orientation of the research. Linkages with complex adaptive systems theory were delineated, setting the research within a larger theoretical and methodological context.

Philosophic perspectives were explored, including dualism in philosophy and linguistics, pragmatism in methodology and theory, and constructivism in epistemology and methodology. The American pragmatist James (1907) and his conception of knowing and truth are still vital to our perception of truth becoming a matter of direct consciousness flowing from experience, particularly with respect to ethnographic inquiries and case studies represented in this investigation. The next important consideration is a detailed look at the methods used to answer the research questions.

#### CHAPTER 3

## **METHODS**

The purpose of this chapter is to describe and detail the methods used to explore TBI in young adults. The following research questions were designed to evoke participants' voices and focus awareness on the challenges associated with TBI:

- 1. How do young adults who have had a TBI define success in their lives?
- 2. How do young adults who have had a TBI make sense of their everyday lives, specifically in terms of self-efficacy?
- 3. What are the barriers to and facilitators of success in young adults who have had a TBI?

## **Research Design**

## Case Study Design

**Definition.** A case study may be defined as a detailed study or examination of an individual unit, such as a person, family, social group, or some other entity, focusing on specific issues and relationships with the environment or context, usually to compare with some larger group ("Case Study," 2014). Stake (1995) described case study as a strategy for inquiry that explores an experience, activity, process, and/or one or more persons in depth or detail. Stake (2000) stated, "A case study is both a process of inquiry about the case[s] and the product of that inquiry" (p. 436). Recognizing the abundance of case study reports and authors in the literature, this study followed conceptual and methodological guidelines of the most often cited and recognized expert in case studies, Robert Stake (1995, 2000, 2005).

Case studies have been used extensively in research activities and appear in the literature of anthropology, sociology, medical science, nursing, and other disciplines. The case study produces context-dependent knowledge that allows people to develop from beginners to experts in their fields. Experts commonly function on the basis of several thousand concrete cases in their area of expertise (Flyvbjerg, 2011). In nursing, case study approaches illuminate the increasingly complex issues in health care that typically comprise nursing research topics (Anthony & Jack, 2009). Young adult TBI is an example of such a topic.

Stake (1995) notes that "most contemporary qualitative researchers nourish the belief that knowledge is constructed rather than discovered" (p. 99). The case study researcher constructs meaning by gathering interpretations and performing the role of interpreter, sharing "the burden of clarifying descriptions and sophisticating interpretations" (Stake, 1995, p. 102). From the perspective of its constructivist knowledge claims, case study research is written to provide readers with descriptions of places, events, and people, "providing readers with good raw material for their own generalizing" (Stake, 1995, p. 102). In keeping with Stake's viewpoint, Denzin and Lincoln (2011) posed the question, "Can our co-created constructions be trusted to provide some purchase on some important human phenomenon?" (p. 120). The effort here is to respond affirmatively.

Stake (1995, 2005) recommends use of a conceptual framework to guide the study and the identification of issue statements. Issue questions direct attention to the major concerns and complexities involved in the case study, and issue statements flow from the questions (Stake, 1995). For example, in this study we ask, "What are the barriers to and facilitators of success in young adults with TBI?" Issues may also be called "problems" inherent in the case. The researcher looks at issues because they are "good windows for examining the conditions, the complexity, and the coping behavior of the case" (Stake, 1995, p. 127), each of which is central to our understanding of the interplay between self-efficacy and success in young adults after a TBI. The conceptual framework of self-efficacy theory guided this study, and issues were explored as reflected in the research questions. Stake's (1995, 2005) process of case study research is flexible and inductive, with interpretation and discovery occurring concurrently.

**Rationale.** Stake (1995) noted that "often the case is handed to us—we don't choose it" (p. 134). In the data collection phase, recruitment was difficult due to a precipitous drop in potential participants who met criteria at the institution where the research was conducted. Thus, a collective case study approach was utilized, meshing with the originally intended ethnographic methodology.

Specifically, an instrumental collective case study design using ethnographic methods was employed in this research. An instrumental case study is undertaken when "a particular case is examined mainly to provide insight into an issue or to redraw a generalization" (Stake, 2005, p. 445). The case facilitates our understanding of something else; in this study, understanding of self-efficacy and success is facilitated. A collective case study is an instrumental case study that is extended to several cases.

**Components.** In terms of process, descriptions were prepared for the following components of case study research: (a) the nature of the cases, (b) relevant historical background, (c) the physical setting in which the participants were located, (d) relevant contexts for the two individuals/cases, and (e) details about the informants through which the case study can be known.

*Nature of the cases.* Two bounded cases were selected to explore the issue of success after TBI in young adults. The cases were bound by time, location, age, and experience of TBI. First, qualitative interviews were transcribed word for word as the basis for telling the individual story of each participant using thick description. Content was analyzed and core meanings between cases identified. While the study consisted of two cases and included cross-case pattern analysis, emphasis was placed on maintaining "responsibility of doing justice to each individual case" (Patton, 2002, p. 449), in keeping with the priorities of a case study approach.

*Historical background.* A variety of contexts were considered when doing this case study research approach. "Issues are not simple and clean, but intricately wired to political, social, historical, and especially personal contexts . . . . Issues help us expand upon the moment, help us see the instance in a more historical light, help us recognize the pervasive problems in human interaction (Stake, 1995, p. 17)." The setting, social and human environment, historical perspective, and language conveyed in the text were analyzed to present emerging themes and theory in context. The social and human environments were crucial elements in interpretation of results. The text had a poignancy and depth because of its place in history. Language and human interaction were analyzed from the data.

*Physical setting.* The setting and site for this study was in the outpatient Neuropsychology Clinic at the University of New Mexico (UNM), in collaboration with neuropsychologist Dr. Rex Jung, who screened and helped to recruit potential participants. The setting had potential to provide a socioeconomic and ethnic diversity that is typical of the population and surrounding communities. Additionally, UNM Hospitals are the only Level-1 Trauma Center in the state of New Mexico, potentially increasing the likelihood of finding young adults living with a TBI.

*Relevant contexts.* The context of this case study has a deeper focus on the cases using ethnographic methods. Qualitative data included observations of naturally occurring information discovered by ethnographic interviews, careful documentation of observed features of the environment and the individuals, and discourse analysis. The use of varied research methodologies strengthened the exploration and analysis of the complex research problems.

Stake (1995) acknowledges and accepts potential bias in case study research, but points out that all studies and all researchers wrestle with this issue. Flyvbjerg (2011) argued that case studies have their own rigor with which to reduce this bias, namely, "The advantage of the case study is that it can close in on real-life situations and test views directly in relation to phenomena as they unfold in practice" (p. 309), such as during the actual interview encounters with the TBI participants. In support of this notion, a gentle dialectic was used in the interviews to question and respectfully challenge what the individuals had to say, causing them to re-explain or rethink a response enabling them to comfortably persevere. For purposes of this study, *gentle dialectic* is defined as showing a kind and quiet nature while examining and discussing opposing ideas in order to find the truth ("Dialectic," 2014; "Gentle," 2014). In addition, qualitative interviews were combined with descriptive data represented in scales for additional insight.

The following contextual, perceptual, demographic and descriptive, and theoretical information was gathered for the study:

- 1. Contextual: The setting of the study's interview encounters was the UNM Neuropsychology Clinic. In addition, contexts of participants' lives were captured in their stories and responses, and documented in either the transcripts or my field notes following the encounters. Polkinghorne (1988) observed that language capability and context for any event or experience inform the meaning it has for the person. "The realm of meaning is not static: it is enlarged by the new experiences it is configuring as well as by its own configuring process, which is carried out through reflection and recollection" (Polkinghorne, 1988, p. 15). Thus, the stories were about their own evolving responses to the injury and their own cognitive work in reconciling it.
- 2. Perceptual: Participant perceptions related to self-efficacy and self-defined success were the focus of this study. Interviews and descriptive questionnaires were the methods of data collection employed. Perceptions as revealed in the participants' own words were the essence of this content, with my reflection on these elements residing in the field notes and journal. This is congruent with Stake's (1995) description of multiple roles for the case study researcher, including biographer and interpreter for the individuals. Interpreting perceptions supports his perspective that knowledge is constructed rather than discovered in human experience.
- Demographic and descriptive: Information was collected via a demographic survey, as well as through demographic questions that are included on the GOSE.
   All questionnaires may be examined in the Appendices (Appendix A: Glasgow

Outcome Scale-Extended; Appendix B: TBI Self-Efficacy Questionnaire; Appendix C: GSE English Version; and Appendix D: Demographic Survey).

4. Theoretical: A consideration and analysis of self-efficacy, especially as revealed in items 1-3 above, provided the theoretical foundation for the study. Additional details on the theoretical foundation for this study appear in Chapter 2.

*Informants.* The sample included 2 participants. Convenience sampling was employed due to limited population availability. Participants who were between 2 and 12 months post-TBI were recruited from among UNM Neuropsychology Clinic patients who had sustained a TBI (see Appendix E: Recruitment Flyer).

## Use of Ethnographic Methods for the Case Study

Ethnographic methods direct attention to the everyday lives and contexts of people. The foundational question of *ethnomethodology* is: "How do people make sense of their everyday activities so as to behave in socially acceptable ways?" (Patton, 2002, p. 111). From the *critical ethnography* perspective, Scheper-Hughes (1992) asserts that ethnography can "be used as a tool for critical reflection *and* as a tool for human liberation" (p. 28). The possibility exists that when truth or insight is realized, uncovered, or interpreted in a mutual discourse, it may impact how participants act, behave, or work to change something that has limited them. *Collaborative research processes* provide a forum (between participants and researcher) for analysis of social problems and health determinants, and move toward the objective of supporting individuals through advocacy and action (Minkler & Wallerstein, 2008). *Action-focused goals* of this research are to identify barriers to and facilitators of successful living in young adults with TBI.

#### **Data Collection**

Descriptive data to investigate demographics, self-efficacy, and outcomes after TBI were collected and documented. Emphasis was placed on participants' meanings, responses, and interpretations of the questions asked. The context and setting of the human experience of recovery and adaptation in the 2 to 12 months after a TBI was explored and critically analyzed from interviews in a clinical setting. The Interview Guide (Appendix F) directed the face-to-face interview toward the everyday life of the participant, with an emphasis on goal setting, creative problem solving, self-efficacy, success, support, and successful living.

Consistent with ethnographic strategy, participants were asked open-ended questions during a 1-hour face-to-face interview. Interviews were digitally audio-recorded, focusing on the everyday lives and contexts of the research participants. The case study approach using ethnographic methodology promoted an exploration of implied or stated assumptions, hidden or unexpressed meanings, and any strong perceptions or ideas that the informants held. The setting, social environment, historical perspective, and language conveyed in the interviews were analyzed to explore emerging themes and concepts/ideas in context. In this study, providing an opportunity for participants to voice their thoughts, feelings, and concerns in an unhurried, nonjudgmental environment was anticipated to provide a degree of heightened awareness and empowerment for these individuals (Denzin, Lincoln, & Smith, 2008).

Congruent with qualitative methods, field notes and researcher reflections were written on the day of the interviews to certify the details and capture the nuances of the case, including: (a) the nature of the participants and their cases; (b) life history and family history of participants; (c) physical setting of their lives and physical setting of the interviews; (d) contexts of the TBI experience; and (e) impressions and biases of the interviewer who acted as the informant through which the case would be known. As the human instrument, the *qualitative researcher* engaged in interviewing, observing behavior, and gathering information integral to the inquiry (Creswell, 2007). Kincheloe, McLaren, and Steinberg (2011) reinforced the notion of the critical researcher as one who acknowledges and addresses the recognized issues of power inequities, socially constructed meanings, patterns of interaction, and importance of language in forging conscious awareness of human experience, such as a recent TBI.

**Data management.** The data management process for interviews was as follows: audiotaping of the interviews, transcribing the interviews by the Co-Investigator (myself), and transferring the interview content from Word to CDC EZ-Text software (CDC, 2012). Field notes were maintained as Word files on a password-protected computer. A Demographic Survey, the TBI-SE, and the GSE were completed by each participant prior to the interview, were stored in a locked cabinet, and were also maintained as de-identified Word files on a password-protected computer.

Only the Co-Investigator tested and interviewed participants and then transcribed the interviews. After transcription, each interview was reviewed and verified for accuracy and congruency of intended meaning by prescribed methods (Lincoln & Guba, 1985; Silverman, 2010). Participants were given opportunities to add or clarify the content during the interview. Per the UNM Health Sciences Center Human Research Protections Office (HRPO) guidelines, all identifiers in the transcriptions were eliminated.

The data obtained were numerically coded to protect participant identity, and no personal identifiers remain attached to individual data sets. Data were stored without patient identifiers in a secure location in a locked file cabinet without identifiers, and data that were stored in a computer were password-protected. Personal identifying information and contact information were kept in a separate file not associated with the data. Only the Principal Investigator and Co-Investigator had access to the personal contact information, coding information, and data. The Information Technology Department of the research institution provided ongoing monitoring and security of the computers. The sources of material obtained in this investigation were limited to the general research data described above. No specimens from participants or information was extracted from participant records.

Participant information linked to direct identifiers through a study code were retained through completion of the study and defense of the dissertation. No information was released through the whole process. All data, such as audiotapes, transcripts, measurement instruments, demographic data, and codebook will be destroyed by shredding or deleting from computer files within 7 years of completion of the study. The identities of the participants have been and will be protected throughout the research, publication, and presentation processes.

**Data analysis.** Data were analyzed by hand using the CDC EZ-Text qualitative software program for comparison and enhanced rigor. CDC EZ-Text was developed to assist researchers in creating, managing, and analyzing semistructured qualitative data (CDC, 2012).

The fundamental process for analysis of the data was coding of transcripts with an open, line-by-line extraction of meaning. The result of this process was a set of datagrounded descriptive codes, which were then selectively clustered, recoded, and synthesized further to identify distinct themes and patterns, which are larger units of meaning than the individual codes (Flick, 2007). Themes comprise the findings of the inquiry and were generated inductively from codes. Throughout the process, attention to detail and openness to unanticipated findings facilitated precise representation of the voices and data collected. Data were checked and verified prior to write-up in an effort to accurately capture emerging themes and patterns. In addition, I debriefed frequently with my dissertation chair and Dr. Jung.

The general flow for *qualitative data analysis* may be summarized as follows (Silverman, 2005, 2010): (a) detailed reflexive reading of the textual data; (b) open coding of the transcripts, in which each line of data was analyzed for meaning and text was reduced to concise, named segments; (c) reporting of the identified segments into distinct conceptual categories for additional analysis; (d) rereading, interpreting, and extracting recurring ideas, patterns of meaning, or language from the coded categories; and (e) synthesizing and integrating the recurrent patterns, emergent across all of the data, into distinct themes, each conceptually unique, yet internally consistent with regard to the research questions.

The general flow for quantitative data analysis was limited to summarizing descriptive numeric data in tables. The numeric data from questionnaires will aid readers of this research in conceptualizing a gradient of similarity for context, time, setting, and people. Demographic data included age in years, education in years, occupation before and after TBI, cause of TBI, length of acute-care hospital stay, length of rehabilitation hospital stay, living arrangements, and race/ethnicity. The TBI-SE numeric answers were added for an overall score of 0 to 60/60, and the GSE numeric answers were added for an overall score of 10 to 40/40. The GOSE was administered in face-to-face format using a semistructured interview process, which is the traditional means of arriving at outcomes using the GOSE (Wilson et al., 1998). The self-efficacy questionnaires were administered in a test format.

Case study analysis using criteria developed by Stake (1995) was implemented, including (a) review of data according to various possible interpretations; (b) search for patterns of data; (c) search for linkages between arrangements, activities, and outcomes; (d) derivation of tentative conclusions, organized according to issues, writing of report; and (e) review of data and examination of new data, deliberately seeking to disconfirm findings. In accord with Stake's (1995) procedures, data collected from the ethnographic interviews, demographic survey, and three descriptive questionnaires were reviewed, interpreted, synthesized, organized, and critiqued in the analysis phase of the research.

The blending of data collection and methodology of case study with ethnography is in keeping with Stake's view of case studies. Stake (1995) explained, "I develop a view of case studies that draws from naturalistic, holistic, ethnographic, phenomenological and biographic research methods" (p. xi). Multiple realities were preserved, and both emic and etic issues were investigated through interview and descriptive data collection in this study. The complexity and contextuality of the cases draws attention to participants' problems and concerns.

Triangulated data, obtained using blended case study and ethnographic methods, provided pertinent material for analysis and synthesis. Stake (1995) notes that: "Somehow I have come to expect to become familiar with an entity by observing how it struggles with constraints, copes with problems . . . I don't think that it is a fixation on failure, rather a belief that the nature of people and systems becomes more transparent during their struggles" (p. 16). For example, in this study, meeting challenges after TBI were the substance of subsequent successes. In analysis, the qualitative researcher "concentrates on the instance trying to pull it apart and put it back together again more meaningfully, analysis and synthesis in direct interpretation" (Stake, 1995, p. 75).

## Ethics

Protection of human subjects and informed consent procedures were followed per HRPO/IRB guidelines. An HRPO/IRB expedited review was completed and approved (see approval letters, Appendices G and H). Additionally, the research project was monitored by the HRPO/IRB members, with annual reports made to the committee. Each member of the research team had mandatory education about human participant issues and research protocol training prior to contact with potential participants.

To minimize the risk of physical or psychological harm to the participants and to protect against the risk of psychological distress due to any research questions, participants were advised of their ability to terminate the study at any time per their request. The following precautions and protocols were implemented to minimize and address participant distress that may have occurred when discussing the participant's TBI and related issues.

- When interviews were conducted, the participant's primary caregiver or family member would have been asked to come into the interview room if the participant had requested his or her presence.
- Encouragement was provided in a supportive interview setting. Gentle dialectic
  was employed in conducting the interview, allowing participants the freedom to
  express themselves in an open way while examining and discussing their
  experiences.
- 3. The interview content was redirected as needed.

- 4. A caring and encouraging tone was maintained during the interview through sharing the joys of their successes and demands of their challenges.
- 5. If deemed necessary by the investigator and/or if requested by the participant, appropriate referrals would have been initiated to the participant's primary care provider and/or psychologist.

To minimize the risk of harm due to a breach of confidentiality, the following precautions were taken: (a) administration of questionnaires and interview took place in a private office; (b) information on individual testing and interviews were not disclosed; (c) all data were numerically coded to prevent identification of the participant and to ensure confidentiality.

Precautions that were taken with potentially disabled and vulnerable participants of the population included: (a) rigorous informed consent procedures; (b) inclusion criteria of ability to speak and read, which necessitated a higher level of functional capacity; and (c) inclusion criterion of decision-making capacity. Inclusion criteria for participants were: (a) either gender, age 18 to 26; (b) ability to speak, read, and understand English; (c) moderate to severe brain injury affecting the frontal lobes, which required hospitalization in an acute-care setting; (d) 2 to 12 months post-TBI at the time of the interview; (e) willingness to participate; (f) decision-making capacity; and (g) ability to respond to questionnaires and interviews independently (see Appendix I: Inclusion Criteria).

Some young adults with TBI may not be able to make typical informed consent decisions. Screening of participants was performed by their neuropsychologist, Dr. Rex Jung, who determined whether the young adult participants with TBI had impaired decisional capacity. If a potential participant's decisional capacity was deemed to be impaired by Dr. Jung, the individual did not meet inclusion criteria. Thus, an assessment of capacity was made by Dr. Jung with two options, either (a) capacity was demonstrated through use of standard questions on the Evaluation to Sign a Consent Form for Research that the participant has sufficient decisional capacity, with standard consent signed and documentation of capacity assessment in their research record (University of California, San Diego, 2012; see Appendix J: Consent Evaluation, Appendix K: Consent to Participate, 2012, and Appendix L: Consent to Participate, 2013)); or (b) the potential participant did not have decisional capacity; therefore, did not meet inclusion criteria for the study. If at any point in the course of the study it was determined by Dr. Jung that a participant did not have decisional capacity, permission would have been requested to use a legally authorized representative. However, this situation did not arise.

#### Methodological Rigor

Rigorous documentation of methodology and contextualizing are key elements of qualitative analysis utilized to mitigate the limitations associated with the open-ended qualitative interviewing techniques that were used for gathering data. Study rigor and credibility were enhanced by verifying findings with participants, detailing documentation of all procedures and evidence (an audit trail), maintaining field journals, analyzing deviant cases, considering of alternative findings, and debriefing with peers and faculty members (Lincoln & Guba, 1985; Silverman, 2005). During the interview process, participant responses were confirmed by asking the same question in two different ways, looking for consistency with the aim of verifying findings.

*Validity* as applied to qualitative research refers to research that is defensible because it is plausible, credible, and trustworthy (Denzin & Lincoln, 2011; Lincoln & Guba, 1985).

Across the literature in qualitative research, no clear consensus exists as to whether investigators should call study integrity *validity*, *trustworthiness*, or some other term. For consistency, in this study, the term *validity* will be used to refer to all phases of inquiry.

Qualitative data analysis is iterative, creative, and circular in nature. Qualitative research involves the classification of concepts, ideas, themes, people, events, objects, and the properties that characterize them. The synthesis of thoughts and ideas is expressed as themes (Silverman, 2010). Rigorous documentation of methodology, data-related activities, and contextualizing were key elements of qualitative analysis that ensure rigor. In case study work, Stake (1995) advocated clarity and transparency in all communications (oral, written), attention to detail in data content, and practicality with regard to human ethics and engagement.

Silverman (2010) suggested five ways of thinking about qualitative data analysis to arrive at more valid findings. The ways of thinking represent *criteria for validity* and include the refutability principle, the constant comparative method, comprehensive data treatment, deviant-case analysis, and using appropriate tabulations. Each of these strategies was used in this study. The refutability principle "demands that we must seek to refute assumed relations between phenomena" (Silverman, 2010, p. 279), overcoming the temptation to jump to interesting or easy conclusions. The constant comparative method involves inspecting and analyzing all data to arrive at comprehensive data treatment. Deviant case analysis involves identification and thorough analysis of cases that appear to be outliers. Finally, Silverman (2010) suggested that the quality of data analysis can be improved by use of simple tabulations to increase the validity of a qualitative study. All of these criteria were implemented in this study.

The qualitative analogues for *internal validity* in qualitative research include descriptive, interpretive, and theoretical dimensions (Johnson, 1997). First is the factual accuracy of the account as reported, which is referred to as descriptive validity. Triangulation was used to increase descriptive validity (Silverman, 2010) in that both quantitative and qualitative data were collected including interview data, three questionnaires, and a demographic survey. Second, the degree to which participants' intentions, thoughts, perceptions, and experiences are accurately reported and understood is referred to as interpretive validity (Denzin & Lincoln, 2011). Interpretive validity is a reflection of the phenomenological inner world of the participants. It was sought by looking at the world through the participants' eyes and by seeking to comprehend participants' sense experiences. Member checking is also known as participant feedback, or respondent validation, and is a critical strategy that was employed to accomplish interpretive validity (Lincoln & Guba, 1985; Silverman, 2010; Stringer, 2007). Finally, theoretical validity is the degree to which a theory or theoretical explanation fits the data, is credible, and defensible. In this study, theoretical validity was scrutinized with respect to self-efficacy theory.

*Transferability* is a quality criterion used in qualitative research and was proposed by Lincoln and Guba (1985) and later by Firestone (1993) as a model of generalizability for qualitative research. Transferability has also been called "reader generalizability" (Misco, 2007) and "proximal similarity" (Campbell, 1986). The proximal similarity model suggests that researchers not only provide adequate description of contexts, but that they also communicate and develop a theoretical perspective that places research findings in context. Readers interested in transferability can then achieve a framework for conceptualizing a gradient of similarity for contexts, times, settings, and peoples (Silverman, 2010).

Strategies to increase transferability used in this study included using detailed descriptions, comparing qualitative results with triangulated data obtained from well-known and reliable descriptive measurement instruments, and setting the research in the context of self-efficacy theory (Greenwood & Levin, 2005).

#### **Study Limitations and Strengths**

## Limitations of Methods and Approach

One of the limitations of this study was a restricted sample size of 2 participants. As the data collection phase of the study progressed, I found that there was a paucity of available participants who met the inclusion criteria, even though early estimates by my consultant indicated that there might have been more potential participants. At the institution where the research was done, a trauma registry search revealed that there were seven potential participants for the year 2012 and zero for the year 2013, which was the time span of the study. We applied to HRPO/IRB for an extension of the study; however, no further participants who met inclusion criteria materialized, and after several months, we decided to refocus on how to perform a meaningful investigation with interesting and useful findings.

The sample size may have been limited due to specific inclusion criteria, including participants aged 18 to 26 years, with decision-making capacity and the ability to respond to questionnaires and interviews independently. Among the research team, it had been decided and was confirmed that although the inclusion criteria were restrictive, this was the cohort that we truly wanted to study to answer our research questions. Thus, due to the time frame of the study coupled with the agreed-on inclusion criteria, the number of participants did not grow beyond the two cases that comprised the study.

Limitations of this study parallel known weaknesses of case study approaches, including (a) selection bias may overstate or understate relationships; (b) weak understanding of occurrence of the phenomena in the population under study; and (c) statistical significance is unknown (Flyvbjerg, 2011). These limitations were managed using case study analysis criteria by seeking to disconfirm findings, reviewing data according to several possible interpretations, using established measurement instruments to place the participants on known continuums, and using an iterative case study approach seeking patterns and linkages, drawing conclusions, and then reviewing the data again.

Finally, there was the limitation of possible researcher bias in this study. To assist in the data collection phase, I kept a field log, which provided a detailed account of all research activities, dates, locations, and observations. I also kept a researcher's journal of my reflections, feelings, thinking, experiences, and perceptions throughout the research process (Fetterman, 2010; Silverman, 2005).

## **Strengths of Methods and Approach**

The fundamental strength of this study is that it was an interpretive study using detailed, thick descriptions to depict both researcher and participant interpretations. The data are presented using sufficient description for readers to develop an interpretation of the data (Creswell, 2007). Thick description refers to a narrative explanation or description that is sufficiently vivid to generate a clear picture or idea about something, thereby "approaching the complexities and contradictions of real life" (Flyvbjerg, 2011, p. 311). Thick description is a term used by ethnographers to describe research reports that analyze multiple levels of meaning in situations (Geertz, 1973). Thick description in qualitative research involves all

forms of critical information, including but not limited to interview data, and demographic, epidemiologic, and numeric data derived from questionnaires.

In this study, interview data were triangulated with data obtained from two wellknown and reliable descriptive instruments measuring self-efficacy. Approaching the data from the perspective of self-efficacy theory framed the findings within a sociobehavioral context. Demographic data served to place each participant in his personal historical context. The GOSE is widely used in studies on TBI and provided a familiar benchmark with which to contextualize outcomes and glean information about barriers and facilitators of success after TBI.

Known strengths of a case study approach that are parallel to the strengths of this study include (a) providing depth; (b) ensuring high conceptual validity; (c) understanding of process and context; (d) understanding of what causes a phenomenon, linking causes and outcomes; and (e) fostering new research questions and hypotheses (Flyvbjerg, 2011). Case studies allow for the development of a nuanced view of reality. The case study can be viewed as a "virtual reality" (Flyvbjerg, 2011, p. 312) into which a reader has entered and explored, increasing sensitivity to issues that may forge connections with new or existing theoretical frameworks.

#### Summary

In summary, the methods used in this study were adapted to a case study approach using the data collection methods of critical ethnography. The foundation was an exploratory study of self-efficacy and self-defined success in two young adults who had sustained a TBI. Ethnographic methods directed attention to the everyday lives and contexts of the participants, evoking participants' voices and focusing awareness on the challenges experienced after their TBI. A visual representation of the integration between case study and ethnographic methods appears in Table 3.1.

Table 3.1Integration of Case Study and Ethnographic Methods/Activities

Case Study Activities <sup>a</sup>	Overall Process	Ethnographic Activities <sup>b</sup>
Organize, observe, describe	Data gathering	Organize, observe, interview,
concepts, interview, relevant		record field/reflective notes
document review		
Aggregation of concentual	Data analysis and	Immersion in data, detailed
Aggregation of conceptual categories, search for patterns	interpretation	reading of textual data, levels of
and meaning, consider		coding, thematic derivation,
naturalistic generalizations		finding meaning
Communication (written oral)	Methodological rigor	Mombar abacking audit trail
Communication (written, oral), clear/transparent content and	(reliability, validity,	Member checking, audit trail, consideration of alternative
method, practicality	trustworthiness)	interpretations, debriefing with
		colleagues

<sup>a</sup>Stake, 1995, 2000, 2005. <sup>b</sup>Creswell. 2003, 2007, 2013; Patton, 2002; Silverman, 2005, 2010.

# CHAPTER 4 FINDINGS

This chapter presents the results of the case study, including the nature of the cases, informants, background and demographics, physical setting, and relevant contexts. Demographic and descriptive data summaries appear in tables. Research findings from interviews that answer the research questions will be explained in narrative format and in tables, with comparisons to larger reference groups where appropriate or helpful. Field notes consist of my account of what went on before, during, and after the interviews—a kind of log with added description. Using what Stringer (2014) calls "the verbatim principle" (p. 110), I captured what was said and done, using the informants' own words, gestures, body language, and ideas in the notes. Field notes differ from the qualitative researcher's *reflective notes*, which aimed to explore inner dilemmas, problem-solving, or researcher responses to the activities of the interaction. In both cases, these notes were selectively coded to leverage insights, meaning and response to the research questions. I wrote descriptions of settings, contexts, and individual participants, followed by analysis of the data for themes and patterns (Bloomberg & Volpe, 2008; Stake, 1995).

#### **Components of Case Study Design**

## Nature of the Cases and Change to Case Study Design

I noted the serenity of the young adult research participants who, in the midst of tumultuous and difficult times in their lives, quietly relayed stories of their will to survive and thrive after their TBI. Available avenues of recruitment had been exhausted, and my clinical committee member (Dr. Rex Jung) confirmed through a trauma registry search that there were no more potential participants who met inclusion criteria for the study, even after HRPO granted our modification request to keep the study open longer. After months of waiting for more participants, we decided to proceed with the research using a case study design, supported by ethnographic methods.

#### **Physical Setting and Sample**

This research was performed at the University of New Mexico in Albuquerque. One of our participants marked "Hispanic" and the other "Mexican" in their demographics, situating them in a large community of young NM adults. Consistent with literature describing patterns of Latino families and culture, Mahoney, Clouterbuck, Neary, and Zahn (2005) found that Latino families feared that acculturation would end their ability to provide family home care. Both informants mentioned the importance of intensive family support in their struggles for rehabilitation.

The physical setting for the interviews was the office of the neuropsychologist in the UNM Department of Neurosurgery, Dr. Rex Jung. On the day of the interviews I met him in his office. In his absence, I then conducted the interviews in a separate office that provided a safe and private setting. It was a quiet place, well suited for listening to the young men's stories.

#### **Relevant Participant Contexts and Process**

Interviewer field notes for Participant #1, Ted: pre-interview. I arranged the consent forms, questionnaires, and Interview Guide (Appendix F) in advance of the interview. I received a phone call from Ted (a pseudonym) for specifics on the way to the building, so I described how he could locate me in the facility. We met at the door to the building and made our way to Dr. Jung's office.

Ted had driven in from his job out of town, fitting in the appointment for this interview at the end of the day on a Friday after a busy work week. I expressed my appreciation, and we had a friendly chat on the way back down the hall to Dr. Jung's office. He was eager to participate, share his story, and possibly help some people who were going through experiences similar to his.

Interviewer field notes for Participant #2, Cal: pre-interview. I began to feel that finding one's way to the Neuropsychology Clinic where our research interviews were held was a maze of sorts, requiring ingenuity and perseverance. Today, Cal (a pseudonym) and I were on our phones outside the building when he spotted me. Young adults are often in the midst of multiple obligations, and Cal was no exception. He took time out from his job at a jewelry store, working with his father, to come to the interview today. He came dressed in professional attire, with an enthusiastic smile on his face.

Cal quickly conveyed that he was motivated to participate in the research. When he asked, I told him that I would email the final report to him and he was very pleased. He had been on research teams for three chemistry research studies during his undergraduate studies; therefore, he had an accurate conception of the risks and benefits of research. I explained that we were using a qualitative approach, looking at our participants' everyday lives in context. Cal had previously realized the limitations of some of his own research in the past and was interested to learn of our approach. He was eager to share his story and learn from others' experiences.

**Informants and interview questions through whom the case is known.** The faceto-face ethnographic interview included the interviewer and the two research participants who were interviewed; both informants were unaccompanied. Field notes and my reflective notes on the process were used to place the findings in context. Consistent with Stake's (1995) vision and language merging case study approach and ethnographic methods, I define *issues* or *issue statements* as "ideas, problems or concepts that predominate in the emerging data" (p. 16). In fact, issues or issue statements (Stake, 1995) can be seen as the research questions themselves, according to Stake. Such was the case here, as I worked to evoke participants' voices and focus awareness on the challenges associated with TBI.

To summarize the data gathered in the interviews and place it in context of the research questions, a research questions—interview questions matrix for Ted and Cal was created. These tables show the extent to which the interview questions were covered by the questions used in the Interview Guide when interviewing participants. The research questions—interview questions matrix was used to organize each participant's responses from the perspective of the research questions and will appear before each narrative interview. Themes and issues that emerge from the data became evident, and answers to the research questions began to take form.

## **Demographic and Descriptive Data**

#### **Demographic Characteristics**

Demographic data in Table 4.1 present a preliminary view of Ted and Cal's past education, current occupation and living situation, circumstances of the TBI, age and ethnicity. This brief demographic survey yielded information that contextualizes their lived experience of TBI.

## Table 4.1

Data collected	Ted	Cal
Age, y	20	25
Years of education	10 plus GED	18, BS, Chemistry
Occupation	Erecting structures; ironworker	Jewelry store work, school to become a pharmacist
Cause of TBI	Partying, young, and dumb	Bicycle accident, hit by a car door
Length of hospitalization	8 days, in coma for 2 days prior to hospitalization	Approximately 5 days, revived 3 times, in coma during hospitalization
Rehabilitation after hospitalization	None	Outpatient rehabilitation for 3 months, and now "rehab on my own"
Living arrangements Ethnicity	Lives with mother Hispanic	Lives with mother Mexican

## Demographic Characteristics

*Note*. GED = General Education Diploma.

## **Descriptive Data Tables**

Glasgow Outcome Scale-Extended. The GOSE includes relevant demographic

characteristics pertinent to the outcomes investigated, expanding and not duplicating the data

collected in the demographic table, Table 4.1. The GOSE outcome categories are as follows:

- (1) Dead
- (2) Vegetative State (VS)
- (3) Lower Severe Disability (Lower SD)
- (4) Upper Severe Disability (Upper SD)

- (5) Lower Moderate Disability (Lower MD)
- (6) Upper Moderate Disability (Upper MD)
- (7) Lower Good Recovery (Lower GR)
- (8) Upper Good Recovery (Upper GR) (Wilson, Pettigrew, & Teasdale, 1998).

Ted's scores on the GOSE revealed no diminished capacity, whereas Cal had reduced work capacity in that, at the time of the interview, he was unable to work in the X-ray crystallography laboratory as he had before the TBI. Therefore, with respect to work, Cal's outcome translated to an "Upper Moderate Disability." The GOSE revealed that Ted is at an "Upper Good Recovery."

An awareness of GOSE outcome categories as outlined above is a reminder of how extensively an individual may be affected by TBI, as substantiated by the statistics on death, disability, and cost presented in the discussion of the historical background and demographics of TBI in New Mexico, the United States, and worldwide. Results of the GOSE for Ted and Cal is shown in Table 4.2.

**TBI Self-Efficacy Questionnaire.** The TBI-SE was self-administered. Ted scored 92%, and Cal scored 87% on this brief questionnaire, indicating high levels of self-efficacy post-TBI (see Table 4.3).

**General Self-Efficacy Scale.** On the GSE, Ted scored 83%, and Cal scored 93%. It is interesting to note that these scores are inverse to the scores recorded on the TBI-SE (see Table 4.4).

QUESTIONS	TED	CAL
Date of interview	7/26/13	8/1/13
Date of injury	August 2012	October 2012
Gender	Male	Male
Age at injury	19	24
Interval post-injury	12 months	9 month
Respondent	Patient alone	s Patient alone
Interviewer	Co-Investigator	Co-Investigator
Any seizures since the injury?	No	Yes, on the day of the injury
Have you been told that you are at risk of developing epilepsy?	No	Yes
What is the most important factor in outcome? Effects of head injury? Other injury?	Yes Possible broken hand	Yes Hit asphalt on left side of body and chipped bones in elbow; nothing too bad
<b>CONSCIOUSNESS</b> 1. Able to say words, obey commands?	Yes	Yes
<b>INDEPENDENCE IN THE HOME</b> 2a. Assistance needed at home for activities of daily living?	No	No
<b>INDEPENDENCE OUTSIDE THE HOME</b> 3a. Able to shop without assistance?	Yes	Yes
4a. Able to travel locally without assistance?	Yes	Yes
5a. Currently able to work to your previous capacity?	Yes, more calm now	No, not lab work; physical labor, Yes
5b. How restricted are you?	Not restricted	Reduced work capacity (Upper
<b>SOCIAL AND LEISURE ACTIVITIES</b> 6a. Able to resume regular social and leisure activities outside the home?	Yes	Moderate Disability) Yes
<b>FAMILY AND FRIENDSHIPS</b> 7a. Any psychological problems resulting in ongoing disruption with family or friends?	No	No

Table 4.2Glasgow Outcome Scale-Extended

Source: Wilson, Pettigrew, & Teasdale, 1998.

QUESTIONS	TED	CAL
Scale 0-10: 0 = Very Uncertain to 10 = Very Certain		
1. How certain are you that you can prevent your TBI or cognitive disorder		
from interfering with your relationships with family and friends?	10	7
2. How certain are you that you can manage problems related to TBI or		
cognitive disorder so that you can do the things you enjoy?	10	10
3. How certain are you that you can deal with frustration, sadness, or other		
emotions related to TBI or cognitive disorder?	5	10
4. How certain are you that you can solve problems related to TBI or		
cognitive disorder?	10	9
5. How certain are you that you can prevent your TBI or cognitive disorder		
from interfering with your ability to manage important affairs such as money,		
health care, and legal matters?	10	7
6. How certain are you that you can manage problems related to the TBI so		
that you can work, go to school, and/or take care of other similar life		
responsibilities?	10	9
TOTAL SCORE out of possible 60	55/60	52/60

Source: Cicerone & Azulay, 2007.

STATEMENTS	TED	CAL
Scale 1-4: 1 = not at all true, 2 = hardly true, 3 = moderately true, 4 = exactly true		
1. I can always manage to solve difficult problems if I try hard enough.	4	4
2. If someone opposes me, I can find the means and ways to get what I want.	1	3
3. It is easy for me to stick to my aims and accomplish my goals.	4	4
4. I am confident that I could deal efficiently with unexpected events.	3	4
5. Thanks to my resourcefulness, I know how to handle unforeseen situations.	3	4
6. I can solve most problems if I invest the necessary effort.	4	4
7. I can remain calm when facing difficulties because I can rely on my coping		
abilities.	2	3
8. When I am confronted with a problem, I can usually find several solutions.	4	4
9. If I am in trouble, I can usually think of a solution.	4	4
10. I can usually handle whatever comes my way.	4	3
TOTAL SCORE out of possible 40	33/40	37/40

Source: Schwarzer and Jerusalem (1993).

## Perceptual Data, Case Study #1: Ted

This section includes perceptual data findings reported in the form of a matrix based on interview and research questions, narrative responses from participants, researcher field notes, and journal reflections. A matrix of themes drawn from Ted's responses to questions in the Interview Guide appears in Table 4.5. The matrix precedes Ted's "Life Continuum Narrative," and its' purpose is to summarize the perceptual data that emerged from each research question.

Table 4.5Research Questions/Interview Questions Matrix: Case Study #1, Ted

	RESEARCH QUESTIONS				
#	INTERVIEW QUESTIONS	#1 How do young adults who have had a TBI define success in their lives?	#2 How do young adults who have had a TBI make sense of their everyday lives in terms of self-efficacy?	#3a What are the barriers to success in young adults who have had a TBI?	#3b What are the facilitators of success in young adults who have had a TBI?
1	What are some of your goals since your TBI?	+pursuit of happiness +live content	+reaching practical goals +self-care +help parents +care for son	-past mistakes -DWI -dyslexia -anger	+productive work +relaxation +earning and saving money
2	<i>Tell me about how you have met one of your goals.</i>	+independence +being a provider	+bought truck +driver's license	-bad friends	+family support
3	When confronted with stress or a problem, how do you go about finding a solution?	+no arguments with friends anymore	+set objective, decide on steps to take, put steps in order to make it go faster	-anger -arguments -difficult relationships -abandonment -speech losses	+release energy with exercise +don't argue, not worth it +stick with family +talk with mother
3a	Please share a specific example for a particular problem.	+work	+ironworking +practical solutions using math and creative problem solving	-can't write poetry/songs as in the past	+father is role model at work +concentrate on positives, improved reading ability
3b	Do you see yourself as a creative problem solver?	+work	+can-do approach using skills	-loss of usual creative outlet/writing	+good at math and problem solving +uses backward thinking to his advantage
3c	In what ways?	+work +family	+create solutions to fit the problem		
4	Describe how you handle stress and challenges that come your way.		+look at big picture	-harder to put words together -sadness -depression	+talk it out with mother
5	How would you define success in your life?	+be content and happy +make family happy			+satisfied with life
5a	What makes something successful for you?	+slowly live life day by day	+happiness and contentment		

# Table 4.5 (cont.)

	RESEARCH QUESTIONS					
		#1	#2	#3a	#3b	
	INTERVIEW QUESTIONS	How do young adults who have had a TBI define success in their lives?	How do young adults who have had a TBI make sense of their everyday lives in terms of self-efficacy?	What are the barriers to success in young adults who have had a TBI?	What are the facilitators of success in young adults who have had a TBI?	
5b	Can you give an example of when this happened?	+after TBI	+change in behavior			
6	What things do you feel have held you back from being successful?			-immaturity -the girl who found him comatose	+family support	
ба	What things have made it easier for you to succeed?	+sense of well being +life is good		-avoid bad friends	+concentrate on family +independent re: finances and transportation	
7	What kind of support do you have:	+helping family +making family happy			+family +cousin and father are good role models	
7a	Family?		+family: sister, mother, father, grandmother, cousin			
7b	Friends?			-friends, bad influence		
7c	Health care providers?		Minimal input	-one appointment with health care provider after TBI -no therapy -no rehab -needs dental work	+mother as counselor, and therapist +now has health insurance with job	
7d	Others?		+co-workers		+co-workers	
8	Are you satisfied with your life?		+completely, life is good +TBI wake-up call, silver lining		+life satisfaction	
8a	If not, what would you change?			-abandonment by girlfriend		
8b	If so, tell me about what gives you a sense that things are going well.	+meeting goals	+independence +taking care of things +helping parents +being a provider			
9	What are your plans for the future?	+continue the same	+live in the moment		+enjoy life	
10	Is there anything else you want to tell me?	+live life, happy and simple		-sadness -depression -couldn't read -couldn't speak	+need someone there for your feelings +use money wisely	

*Note.* DWI = driving while intoxicated offense; + indicates a facilitator or description of success; - indicates a barrier to success.

#### **Face-to-Face Participant Interview, Ted**

Ted's definition of success. I will begin the narrative of Ted's interview data with his definition of success. When asked how he would define success in his life, Ted replied: "Just to be content. As long as I'm content, that's success. Money doesn't mean a thing, you know. . . . Just be content, as long as I make myself happy that's all that matters, and to make my family really happy." Ted's serene demeanor in the context of his recent TBI convinced me that he is satisfied in the moment. He appears to be pleased that he able to provide for himself, and for other people in his life.

Life continuum narrative. *Life pre-injury*. Attention deficit hyperactivity disorder (ADHD) and dyslexia were part of the fabric of Ted's life, so he was very active in and since childhood. Around middle school, he started "doing bad things and getting disruptive" and says, "I just went crazy, like up the wall crazy." At that time he stopped hanging out with his cousins who had been his "best of friends" and a good influence in his life. He did not graduate from high school; instead, he finished his high school studies with a General Education Diploma (GED). His math skills were his strength; verbally, he was more of a writer and did not read as much as he wrote. Writing and playing his songs occupied a lot of his time and were a passion. He "actually wanted to be a song writer." By age 19, he had worked at two different jobs, roofing and iron fabricating. And he was writing volumes of songs since age 15, filling about 15 college composition books with songs he had written. The words came easily. Writing poetry and songs was natural for him. His efforts were self-motivated.

Ted stated that he had an anger problem and would "scream, fight, and have arguments with friends." He was "doing bad things and didn't care about what other people

thought, hurting other friends" that he "was crossing boundaries on." His living arrangements were primarily "couch surfing." At age 19, Ted was living life at a rapid pace. He had a son, a job, partied a lot, and stated that he was "immature." His head injury occurred in the midst of his partying, and he said that the cause of his injury was "being a teenager and going to a party, young and dumb." He was left comatose for 2 days, when a girl found him and he says "she saved me; if it wasn't for her I would be dead."

*Transformative experience.* Ted's TBI proved to be a life-changing event. As Ted describes it: "God had to come along and snap his fingers and say 'you're doing bad" for him to snap out of his old ways. "Bring me close to death, and then bring me back. The head injury is my silver lining, the whole silver lining. I would have ended up dying if I had stayed in my same old ways. It changed the world for me. Yeah, if it don't break you, it makes you stronger."

*Post-injury challenges.* Right after Ted's head injury he "was going crazy, just sitting at home, not being able to work, not being able to drive. I didn't want to go see my friends. I just got on my bicycle and tried doing stupid shit and broke my tooth." When I asked Ted if there was anything from his experience that he thought may help other people after TBI, he shared the following: "I gotta say sadness is bad after head injury. If you feel depressed or anything like that, it is the worst thing. That is the only thing you need help on."

When I asked Ted how he handled his depression, he continued:

Make sure you got someone there for your feelings. Like after the injury, my girlfriend ended up finding me, and then she wasn't there for me at all. She saw me and left, and never freakin' didn't want any part of me, nothing to do with me anymore. . . . But I can talk to my Mom about any problem like that.

He related that another problem was that he could not read or speak correctly after his injury:

I used the wrong words, like I would want to say 'that's on the table over there' and I would say 'boat, it's on the boat.' I would get frustrated, and my Mom would say 'you gotta calm down and just think about where it's at.'

I wondered and asked Ted if he had a counselor or therapist to help him through these times. He said he had his mother. Ted explained further:

That's why I live with my Mom, and I would do anything for her. She talked me out of every problem I had before the incident and after the incident. That's what really helps me now. I have someone to talk to and relate to, it's a counselor basically. You need someone not so much for advice, but someone there to ask questions whenever you need it the most. That's what you need, support in that direction.

As Ted spoke these words, he became visibly more relaxed, having had this occasion to express his thoughts and feelings about the difficulties associated with his recovery.

*Post-injury progress.* Ted's goals have changed since the TBI. Now, he has a "pursuit of happiness, just to be happy and live content, not so out there anymore." He works out of town with his father and other co-workers. He pursues happiness by working, relaxing, taking it easy, and "saving his money for a nice life." One of his biggest goals was to buy a truck and get his driver's license reinstated. It had been revoked since he had a driving while intoxicated offense (DWI) at age 18. He accomplished both goals and worked his way to "a new vehicle and a new license." His next goal is to buy a motorcycle. Ted said that his father loves working with him. One reason is that Ted has a different style of problem solving in which he thinks of things backwards by starting at the end of a problem and working to the

beginning of it, which is valuable in ironworking. He thinks that his dyslexia may have a bit to do with that, as well.

Ted turned to examples from work when asked about problem solving, since he "solves problems at work every day." As he described it, "The solutions you gotta think about are the objective and the steps you gotta take, and you gotta know the steps and which steps you can put together in order to make it go faster." For example, "My job is to get up the steps, go up another 20 feet in the same section; I am always using math to figure things out, like the lengths going up the tower and the weight that you are allowed to pull up there with the wench that you are on." The problem solving and math are what Ted enjoys about being an ironworker, according to his disclosure.

One of the changes that Ted has noticed since his head injury is that he tends to look at the big picture rather than little details. He has found that he is "not good at putting words together" like he used to be when writing and editing his songs. He has not been able to edit his poetry and songs since the injury. For his songs to make sense, he needs to make changes to the wording, and said, "I am kinda not so good at that no more." On the other hand, he has become better at reading and feels that "everything just clicked with reading." He still admits to having an anger problem, but it has changed. Ted now manages his anger in a more productive way. Instead of "going out and punching someone, he just drops down and does 50 push-ups," releasing some of his energy. He does not "really scream or fight anymore" or have arguments with friends. Arguments are "no longer worth it" to Ted, he told me.

As noted, Ted has returned home to live with his mother after his injury and reconnected with his cousin, who is a good influence in his life. His social life has changed to "less friends and more family." He now cares about the people in his life and not doing wrong or bad things. He is focused on being content and happy, and making his family happy. "Family, family, family, that's what I gotta say: my sister, mother, father, grandma are the big people in my life." Ted said, "I am completely satisfied with my life, life is good."

He explained that he has a sense that things are going well "because I am taking care of things and not being taken care of anymore." He helps his parents financially when they are running low. He shared this example:

Like the other day, my Mom said she was going to have to save some money to buy new tires. I asked her to let me borrow her car and bought the new tires for her. I do things like that, and I feel like I am able to provide now, instead of being provided for.

Ted is grateful to have his father as a role model in his life and attributes his success at work to their close working relationship. My father has really helped me to be successful. "I've always looked up to him, so I just gotta follow what he does, follow in his footsteps, and I have good footsteps to follow."

*Plans for the future*. At the end of the interview, I asked Ted about his plans for the future. Ted paused, and then responded, "Hmmm, doing what I am doing right now [he laughs]. Continue the same, slowly live life. No fast life anymore, just slow. It goes day by day, minute by minute, hour by hour." I asked "Enjoying it?" Ted confirmed "I am. I am."

#### Interviewer Field Notes and Journal Reflections: Post-Interview #1, Ted

**Field notes post-interview.** Throughout the interview, I thought that Ted's generosity, wisdom, and honesty were noteworthy, given his experience. The descriptive questionnaires were an excellent way to break the ice and start moving in a parallel direction with Ted. During the interview, he expressed that the most helpful thing was to be asked

questions about what was going on in his life. I learned that being asked questions and having a listener were his favorite form of support. As I transcribed the interview, I noticed that I had picked up wording that the participant was using and that the interview had morphed into more of a discourse.

Journal reflections post-interview. On reflection, I became aware that my lenses as a practicing clinician and ethnographer were merging. I realized that I was able to take a step back from my usual clinical approach and listen to the participant's meanings in the wider context of his environment and recent brain injury. There was a poetry and fluidity in Ted's speech that made his meanings remarkably clear. The interview was only 12 months after his TBI, and had a history of speech difficulties, which are typically associated with expressive aphasia immediately after the TBI. He had no formal rehabilitation, and his only health care contact after his injury was one follow-up visit at 3 months post-TBI. As I reread the interview, I realized that many segments could represent the lyrics of a song in themselves. It was gratifying to hear his story and have the luxury of letting him express what was on his mind.

#### Emerging Codes and Self-Efficacy Indicators, Case Study #1, Ted

**Codes listed.** After several iterations of codes, I synthesized the codes that emerged from Ted's interview to the following codes: contentment, transformation, silver lining, independence, creative thinking, productivity, goal achievement, family support, networking, caring, adaptability, anger management, abandonment, sadness, depression, recovery, resiliency, losses. A complete listing and definition for all final codes is shown in Appendix M.

**Self-efficacy indicators derived from descriptive and perceptual data.** To bring to light additional codes in the coding process, the matrix shown below was created to synthesize the two self-efficacy questionnaires with the interview data (Table 4.6).

Ted scored 10, or "Very Certain" on five of the six questions on the TBI-SE; however, he scored a 5 on the question, "How certain are you that you can deal with frustration, sadness, or other difficult emotions related to TBI or cognitive disorder?" In the interview, Ted was open about his anger management difficulties and how he was still struggling with ambivalence toward the girl who had abandoned him after his TBI. When answering the questions in the GSE, with respect to "Overcoming opposition," Ted chose the response, "Not at all true" for the statement, "If someone opposes me, I can find the means and ways to get what I want. With respect to "Calm, relies on coping abilities," Ted chose the response "Hardly true" to the statement, "I can remain calm when facing difficulties because I can rely on my coping abilities." Ted's TBI experience itself presented a momentous difficulty for him, and he stated that it happened because of his immaturity in handling a situation; in his words, he was "young and dumb." Just as success increases self-efficacy, a failure may lower it (Bandura, 2004). The measures of self-efficacy related to overcoming opposition and calmness/coping ability draw attention to why Ted may have gotten into a difficult situation when the TBI occurred. Now, in retrospect, he may see the situation as a failure to cope and/or overcome opposition.

These findings answered the research questions by providing participants' experiences of sadness and depression, anger, and problematic personal relationships. Working through those feelings required intensive counsel, which Ted's mother provided,

	Indicators From	TBI Self-	General Self-	Interview Data
	Scales	Efficacy Scale	Efficacy Scale	
1.	Manage relationships	10/10		Self-control
2.	Enjoy activities	10/10		Happy/content
3.	Deal with emotions	5/10		Anger, sadness Depression Abandonment
4.	Solve problems, can think of solutions	10/10	4/4, 4/4, 4/4, 4/4	Creative solutions Can-do attitude
5.	Manage matters: financial, legal, and health care	10/10		Saving money DWI gone Insured
6.	Work, take care of life responsibilities	10/10		Ironworker Productive
7.	Overcoming opposition		1/4	Recovery Family support Anger issues
8.	Stick to aims, accomplish goals		4/4	Work, buy truck, drive, save money
9.	Confidence, dealing with the unexpected		3/4	Recovery Self-confidence
10.	Resourcefulness, handling unforeseen		3/4	Adaptability Survival
11.	Calm, relies on coping abilities		2/4	Issue: Anger Management
12.	Can handle whatever comes my way		4/4	Independence Adaptability

Table 4.6Self-Efficacy Descriptive and Perceptual Data Matrix: Case Study #1, Ted

bringing to light the possibility that professional counseling might have been a helpful adjunct in his recovery. However, the self-efficacy data also highlight Ted's strengths as a creative problem solver, effective manager of his life affairs, dedicated employee, enjoyer of life, manager of personal relationships and challenges, and goal achiever. He has effectively handled the difficult situations of clearing up a DWI, providing for his own means of transportation, and being present in his son's life. He has shown a can-do attitude in creatively managing his anger through recognition of impending anger and decompression through exercise.

#### Perceptual Data, Case Study #2: Cal

This section includes perceptual data findings reported in the form of a matrix based on the interview and research questions, narrative information from participant interviews, researcher field notes, and journal reflections. A matrix of themes drawn from Ted's responses to questions in the Interview Guide is shown in Table 4.7. The matrix precedes Ted's "Life Continuum Narrative," and its purpose is to summarize the perceptual data that emerged from each research question.

#### **Face-to-Face Participant Interview, Cal**

**Cal's definition of success.** When asked how he would define success in his life, Cal replied, "Going to work every day and being happy with the people I'm around. I think success is more of a feeling of joy inside. Like, say, if I was doing a barbeque or something, watching everybody eat it. I would be happy. Their reactions to it would be success." Cal's demeanor was warm and fun-loving during our encounter. He told me he enjoys laughing and extending himself to others. His definition of success appears to be congruent with his easy and outgoing mannerisms.

Table 4.7Research Questions/Interview Questions Matrix: Case Study #2, Cal

		RES	SEARCH QUESTIONS		
		#1	#2	#3a	#3b
#	INTERVIEW QUESTIONS	How do young adults who have had a TBI define success in their lives?	How do young adults who have had a TBI make sense of their everyday lives, in terms of self-efficacy?	What are the barriers to success in young adults who have had a TBI?	What are the facilitators of success in young adults who have had a TBI?
1	What are some of your goals since your TBI?	+independence +keep people smiling +being happy with myself and what is going on in my life	+do things for myself +drive for myself +try to save money		+able to work again +go back to school
2	Tell me about how you have met one of your goals?	+attitude change, peace within +letting go of anger toward the person who caused his injury	+getting to the point of college graduation	-first college graduate in his family	+family support
3	When confronted with stress or a problem, how do you go about finding a solution?	+look at the problem from different perspectives	+change in perspective on life and relationships +taking his time	-anger	+forgiveness
3a	Please share a specific example for a particular problem.		+cooking creatively +fixing things at home	-PTSD	+saw psychiatrist for treatment
3b	Do you see yourself as a creative problem solver?	+most definitely, he is a creative problem solver	+finds solutions daily		+trained as a chemist to look problems from every angle
3c	In what ways?		+able to figure things out on the spot		
4	Describe how you handle stress and challenges that come your way.	+organize my problems to get in a situation to solve them day by day	+laugh about the stress, after laughing, say OK, this is what I can do	-was used to doing a quick fix	+takes more time to think through solutions
5	How would you define success in your life?	+going to work every day +being happy with people			
5a	What makes something successful for you?	+feeling of joy inside	+doing a barbeque and enjoy watching people eat the food		
5b	Can you give an example of when this happened?		+peoples good reactions would be the success		
6	What things do you feel have held you back from being successful?		+working hard to be successful, doing	-the idea of success itself -always being in a rush	
ба	What things have made it easier for you to succeed?		+watching the sacrifices others were making for him		+taking time to smell the flowers
7	What kind of support do you have?		+family members divided up helping roles with therapies at home		

#### Table 4.7 (cont.)

	RESEARCH QUESTIONS					
		#1	#2	#3a	#3b	
#	INTERVIEW QUESTIONS	How do young adults who have had a TBI define success in their lives?	How do young adults who have had a TBI make sense of their everyday lives, in terms of self-efficacy?	What are the barriers to success in young adults who have had a TBI?	What are the facilitators of success in young adults who have had a TBI?	
7a	Family?		· · · · ·		+family, mother, father, brother	
7b	Friends?			-girl who caused injury	+friends	
7c	Health care providers?		+medical marijuana, helps him take step back and mellow out		+speech and physical therapy +visit with psychiatrist	
7d	Others?				+co-workers	
8	Are you satisfied with your life?	+most definitely, I can't complain	+connection felt in new relationship		+new girlfriend	
8a	If not, what would you change?		+would not change anything about my life +like it the way it is			
8b	If so, tell me about what gives you a sense that things are going well.		+get together with friends regularly +laugh it up +pass the time +go out with family +gardening		+being with the people I love gives me a sense of well- being, warm fuzzy feeling	
9	What are your plans for the future?	+be successful enough to build a home +use my education	+become a pharmacist +travel +have a family			
10	Is there anything else you want to tell me?	+feels well equipped +published as an organic chemist +finished BS in Chemistry	+work on reading, math, everything consistently every day and it gets easier	-losses still requiring therapy	+not giving up +perspective on how he made it through the TBI	

Note. + Indicates a facilitator or description of success; - indicates a barrier to success.

Life continuum narrative. *Life pre-injury*. Cal presented himself as an ambitious young man, evidenced by his being the first of his extended family to graduate from college. Cal's family was completely supportive throughout this endeavor. He said he actually never thought he would graduate from high school. His college degree is in chemistry, and before his injury, he was working in an X-ray crystallography laboratory. He is a published author on two or three chemistry research articles. His problem-solving skills were well honed

through his academic training. "In chemistry," he said, "you have to know how things are made so that helps with problem solving and figuring things out on the spot." He said he was accustomed to being independent, out and about, socializing, and participating in other activities common among his peer group.

Busy with school and work, Cal was in the habit of speeding his way through problems just to solve them quickly, not really thinking about doing his best job. Along with his "quick-fix mentality" he told me,, "My responses to things were just the first thing that came to my head, not really a brain to mouth filter if you will." Cal says he was a "worrywart," tended to "hold grudges for a long time," and had an "anger issue." He said, "People were always telling me 'life is too short,' but I was thinking it was taking forever." Interestingly, he perceived that the very idea of success held him back from being successful before his injury because he was always in a rush and working so hard to become successful that he did not take time to relax and enjoy life with friends and family.

*Transformative experience.* Cal said that most of the changes after his TBI had been positive. After his injury he had one appointment with a psychiatrist to be evaluated for medical marijuana use, so he "had to talk to somebody about the whole PTSD thing." He said he "felt a huge weight lifted off of myself" when he "sat and actually talked to the psychiatrist." The marijuana helps to mellow him out so that he can "just take a step back and look at things." The marijuana is by prescription only.

He stated that "prayer, churchgoing, family, and friends" also helped him "immensely" after the injury. He looks back on the injury, realizing now how dramatic it was, and says to himself, "Look I made it past that, so now it's only up for me." He feels as though he gained a different perspective after his injury. In his words, "I definitely don't look at things the same, as far as relationships, and as far as life for that matter." Cal shared that "after the injury I had an attitude change, and the peace I have within myself."

*Post-injury challenges.* Cal described himself as "pretty depressed for a while, actually extremely depressed" after his TBI. He said:

I was really hating life there for a minute; I felt useless, handicapped, and withdrawn from society. It was simply because I could not do things on my own. I came to a screeching halt in my life to where I could barely talk or read or feed myself.

In recovery, his first goal was to become independent again, be able to do things for himself, drive, work again, and get back on his feet. He said, "It was extremely hard, reading, math, everything. Very hard, but I noticed that every day if you do it consistently, it gets a little bit easier." His motor skills were "pretty weak" and not "fluid," so he did physical therapy and participated in speech therapy to regain his speech. He said, "Relearning everything is pretty tough, but it's been 9 months, so I think I am doing pretty good."

*Post-injury progress.* After the injury, Cal began reading more for enjoyment, as opposed to the scientific reports he was reading before the accident. Cal is still building his math skills, and can do algebra, but has not progressed to the matrices and calculus that he "could do in his head previously." He is working on that so that he will be ready to move on with his education, hopefully to become a pharmacist. Cal reported that he saw a change in his problem-solving strategies after his TBI. For example, he started to take the time to think about solutions and look for and buy the right part to fix things at home instead of just duct-taping a problem spot. He uses his problem-solving skills when cooking. When he does not have the ingredients, which he said "usually happens," he just "puts together something." He said that he is "definitely a creative problem-solver."

Cal used to hold grudges. However, he has forgiven the girl who inadvertently caused his injury, even though she did not visit him in the hospital and he has not seen her since the accident. He has found that emotional filter that staves off grudges and promotes kindness and thoughtfulness, and has found happiness in the process. Now, when he wants to say something without hurting anyone, he goes about it using a thoughtful process. He said, "Being happy with myself is what is going on in my life, and is like a goal I have reached."

Cal's idea of success now has to do with the satisfaction of going to work and being happy with the people there, as well as doing things to make others happy, such as cooking and gardening. His ordinary everyday goal is to "keep people smiling." He says that now "success is more of a feeling of joy inside." Watching "everyone around him do a lot of sacrifice for him when they didn't have to" has made it easier for him to succeed. His family "helped him with therapy—reading, writing, vocabulary, exercise. . . . anything." Somehow the injury and recovery have lessened self-absorption and opened his eyes, heart, and mind to a more satisfying way of living.

When asked if he is satisfied with his life, Cal replied "Most definitely, I can't complain. Plus, I've just met somebody so I'm pretty happy . . . we met up about 3 weeks ago and just hit it off. It's awesome and something I have not felt before." They have known each other since childhood, and she was in the same grade in school. Now, he understands what people were talking about when speaking of "the connection that you feel with somebody else." Before he was thinking, "What connection?"

According to Cal, the sense that things are going well for him in his life comes to him when he gets together with friends, has a drink ("but not getting drunk or anything"), and just laughs it up to pass the time. He likes to spend time with his nephews and nieces and often takes them to the movies. He has a garden that is "getting big." He and his brother enjoy gardening together and are growing vegetables, potatoes, and flowers. The garden "helps to create order and is therapeutic." He said that gardening was a "huge help in my recovery and also helped a lot with the physical therapy; it's huge, being able to till the soil, get dirty, and get sweat on my brow." He said, "I get that sense of well-being just being with the people I love, and laughing gives me a sense of well-being." He laughed and described it as "that warm fuzzy feeling."

*Plans for the future.* Cal has goals for his future. One goal he has set for himself is to become successful enough to build a home for himself and his family. Because he did not come from "a real beneficial background," he would like to "exploit the education part." He has plans to go to school to become a pharmacy technician and then go to pharmacy school. After that, he wants to travel and have a family.

#### **Interviewer Field Notes and Journal Reflections:**

#### **Post-Interview #2, Cal**

**Field notes post-interview.** I learned that Cal is an accomplished student of chemistry. He has a warm personality that was immediately apparent in his visage. In the course of the demographic survey, he shared that he had been working in an X-ray crystallography laboratory just prior to his injury. The bicycle accident that caused his head injury occurred when a girl that he knew from the lab opened her car door as he rode by. He had not seen her since the accident, and she did not come to see him in the hospital. "But I forgive her," he said. He also shared that before the accident, he would hold grudges, but since the accident, he does not look at life or relationships in the same way.

Journal reflections post-interview. When I finished the interview, I felt uplifted by the courage of both of the research participants. I was struck by the similarity of the interviews in that the major life event of a serious TBI had transformed the participants' lives for the better and set them on a successful path in life. Not only were they moving forward in their lives, but were taking care of those around them. I asked myself, "How did this happen?" The answers to that question would need to come later, with close examination of the data collected. As I reflected further on the interview with Cal, I was struck by the sheer willpower he had exhibited in recovery from his TBI. He held true to form as he had become the first person in his family to graduate from college just prior to his injury. I could see that there was much to learn from this young man.

#### Emerging Codes and Self-Efficacy Indicators, Case Study #2, Cal

**Codes listed.** After several iterations of codes, I synthesized the codes that emerged from Ted's interview to the following codes: independence, engagement with people, education, transformation, abandonment, sadness, slowing down, ambition, creative problem solving, work, happiness, successful rehabilitation, cognitive changes, positive change, depression, PTSD, medical marijuana, anger, prayer, targeted family support, new relationship, connections, life satisfaction, gardening, not giving up, weathering the storm, inner peace. A complete listing and definition for all final codes is shown in Appendix M.

**Self-efficacy indicators derived from descriptive and perceptual data.** To bring to light additional codes in the coding process, the matrix shown in Table 4.8 was created to synthesize the two self-efficacy questionnaires with interview data.

Cal scored 7/10 in two categories on the TBI-SE, indicating that he was 70% certain that he was able to manage relationships and manage matters such as money, legal issues,

	Indicators From Scales	TBI Self- Efficacy	General Self- Efficacy Scale	Interview/Perceptual Data
		Questionnaire		
1.	Manage relationships			New relationship
•	<b></b>	7/10		Connected
2.	Enjoy activities	10/10		Engaged with people
				Keep people smiling Work
3.	Deal with emotions	10/10		Happy now
				Forgiveness
				Abandonment
				Was sad and hating life
				Felt useless
				Perceived as handicapped
4.	Solve problems	9/10	4/4, 4/4, 4/4,	Creative problem solver
	Can think of solutions		4/4	Look at problem from every angle
5.	Manage matters:	7/10		Earning money
	financial, legal, and health care			Rehab at home, on own now
6.	Work, take care of	9/10		Independent and inter-dependent
	life responsibilities			Lives with mother
7.	Overcoming		3/4	Prayer
	opposition			Not giving up
8.	Stick to aims,		4/4	College graduation
	accomplish goals			Pharmacy school
				Regaining skills
9.	Confidence, dealing		4/4	Feels well equipped
	with the unexpected			Creative problem solver
10.	Resourcefulness,		4/4	First-generation college student
	handling unforeseen			Never thought he would graduate from
	-			high school
				Able to get back on feet after TBI
11.	Calm, relies on		3/4	Peace within myself
	coping abilities			Taking my time
				Doing my best job solving problems
12.	Can handle whatever		3/4	Weathered the storm
	comes my way			Now I can only go up
				Did not give up

Table 4.8Self-Efficacy Descriptive and Perceptual Data Matrix: Case Study #2, Cal

and health care. His scores on the remaining questions were divided equally between 90% and 100%. Cal was profoundly affected by his TBI, both cognitively and physically. In fact, during his hospitalization, he reported that he had to be resuscitated three times. His road to recovery has been one of hard work, which was willingly shared by supportive family members. He remains tentative with managing legal, health care, and financial matters, as revealed in the TBI-SE, and in the interview, Cal said, "I try to save money, but I really can't." Management of these matters speaks to executive function losses common with frontal lobe injuries to the brain.

In gradual steps, Cal is overcoming the losses and regaining his ground. His responses to the self-efficacy questions suggest that he believes that he has strong problem-solving skills, resourcefulness, the ability to stick to his aims and achieve his goals, confidence, and joy in life and that he is able to deal with his emotions well, with ratings of 4 out of 4, or *exactly true*. These qualities are typical of a person with high self-efficacy and have carried over from his pre-injury life patterns. They are serving him well in recovery. Cal rates his inner qualities of calmness, handling whatever comes his way, and overcoming opposition at 3 out of 4, or *moderately true*.

#### **Data Analysis Process**

#### Coding and Use of CDC EZ-Text Case Study Functions

Use of CDC EZ-Text. CDC EZ-Text case study functions were utilized and provided a different way of looking at the interview data. Rather than a verbatim transcription, the data were entered according to the exact EZ-Text Interview Guide template. Due to the nature of the case study as an in-depth complex rendering of few cases, the CDC EZ-Text functioned best with regard to sorting and compiling code frequencies; it was used as a resource and for checking, but the actual coding and compilations were done by hand.

**Coding process.** I performed five iterations of codes in the coding process. Initial codes were listed immediately after the interviews, on the day of the interview for Ted and Cal individually. A rereading-review of the data was performed with a more detailed approach to capture nuances of meaning, resulting in a second iteration of the codes. Then a rereading-review was performed to collapse common ideas into fewer distinct ideas or conceptual categories that included critical incident-TBI, success defined, self-efficacy elements, self-reorganization, barriers to success, comorbidities, and facilitators of success. The data were reviewed again in the same manner described above, resulting in a fourth iteration, expanded to 72 codes, and then synthesized again, resulting in the fifth and final iteration of 35 codes, shown in Table 4.9.

The interview transcripts were then coded line by line and tallied. The codes were not overlapping. The final coding scheme was organized by conceptual categories and appears in Table 4.9 and in Appendix M: Final Codebook. Interview data and descriptive questionnaire data were focused on self-efficacy and self-defined success, and have provided data needed to answer the research questions. Table 4.9 lists the 35 codes that emerged from the interviews with Ted and Cal. The three columns shown in the tally of codes, (a) Critical incident TBI and Success defined, (b) Self-efficacy characteristics and Self-reorganization, and (c) Barriers to success and Facilitators of success, arise from the three research questions.

Methods applied were outlined by Silverman (2010), designed to increase validity in qualitative studies. Data were coded using ethnographic methods noting comparisons and differences between and within cases, and inspecting and analyzing all data to arrive at

comprehensive data treatment. *Simple tabulations* were created to display the data in different configurations to examine the data from varying perspectives. Throughout the process, this researcher remained *open to unanticipated findings*, reading and rereading the interviews and comparing the interview data with descriptive data meticulously.

# Table 4.9Tally of Codes From Interview Data for Ted and Cal

					Self-Efficacy			Barriers to
Ted	Cal	Critical Incident TBI	Ted	Cal	Characteristics	Ted	Cal	Success
3	9	Transformation	11	8	Creative thinking	2	5	Sadness/depression
4	0	Silver lining	3	5	Adaptability	0	2	PTSD
2	3	Weathering the storm	5	3	Anger management	3	5	Anger
16	17	Positive change	12	17	Recovery	2	6	Losses
			11	10	Not giving up	4	4	Abandonment
			8	9	Creative problem solving	14	14	Cognitive changes
			11	7	Resiliency			
								Facilitators of
		Success Defined			Self-Reorganization			Success
7	1	Contentment	10	7	Productivity/work	7	7	Independence
5	11	Happiness	9	11	Goal achievement	17	12	Family support
4	3	Life satisfaction	0	3	New relationship	9	11	Caring
1	1	Inner peace	7	10	Slowing down	0	7	Education
2	4	Ambition	15	22	Successful rehabilitation	0	5	Medical marijuana
12	13	Engaged with people	7	13	Networking/connections	0	4	Prayer
						0	6	Gardening

In this stage, I applied the *refutability principle* seeking to refute any assumed relations between phenomena (Silverman, 2010) as a strategy to increase validity. For example, initially the two cases were striking in the similarity of TBI as a transformative experience, dedication to work and family, anger management challenges, and the experience of abandonment by a girl. On closer examination I saw their differences more clearly, such as their pre-injury lifestyles, personal relationships outside of family, cognitive losses post-TBI, ability to save money, and goals for the future. I also saw a transformation pre-injury to postinjury. Therefore, I chose to write the narrative as a life continuum to capture the dynamic of their lives and not assume relations among phenomena outside of the context of time. I did not remain strictly fixed on self-efficacy theory. Instead, I looked for emerging concepts that expanded or illuminated the findings from theoretical perspectives, as well as from neuroscience.

Themes, patterns and issues identified and explained. Themes comprise the findings of this ethnographic inquiry and were generated inductively from the codes listed in Table 4.9. Discovery of patterns, themes, and categories is central to inductive analysis in the qualitative tradition (Patton, 2002). Patton characterized a *theme* as taking on a "more *categorical or topical* form," for example, "dealing with fear," and he characterized a *pattern as a "descriptive finding*" (p. 453), for example, a pattern of being afraid when rapelling down cliffs and running rapids. Agar (2002) stated that, "*Themes* summarize the key concerns of the informant(s) that recur" (p. 211), adding clarity to this point. Agar further described a *pattern* as a larger idea that consistently flows through the themes and may serve as a guiding principle or model for some phenomenon of interest. Fetterman (2010) described patterns as "a form of ethnographic reliability" (p. 97)—thoughts and actions that are

repeated in multiple situations and with numerous participants, not necessarily synonymous with interview responses to questions. The theme–pattern distinction, then, may be conceptualized as a matter of scale, starting with codes, then themes, and maybe continuing to patterns that encompass both spoken and observed modes of behavior and activity. Additional studies and interviews with more participants will be necessary to see whether the themes and patterns here remain intact or change.

Silverman (2010) defined *inductive* as "based on the study of particular cases rather than just derived from a theory" (p. 435) and *naturally occurring data* as "data which derive from situations which exist independently of the researcher's intervention" (p. 436). Stake (1995) defined *naturalistic generalization* as "interpretation based largely on experience" (p. 172), and Fetterman's depiction of *patterns* as a form of ethnographic reliability seems a logical extension of these arguments.

After coding, I searched for meaning, themes, and patterns in the interview and descriptive data, following a *naturalistic inductive* process. Similar to the coding process, derivation of meaning in the form of themes and then patterns was a reflective and timeintensive process. I developed themes and patterns that captured the *voices and experiences* of the research participants, which reflected their thoughts, feelings, concerns, strengths, challenges, life patterns, actions, and successes. The *patterns* each described a dynamic process in the lives of the research participants, experienced as a transformation after TBI, along with self-efficacy and success. Table 4.10 presents the research questions with themes and patterns derived from the questions.

The theme, subthemes, and pattern derived from Research Question #1 were as follows:

Table 4.10Research Questions, Themes, Subthemes, and Patterns

1. How do young adults who have had a TBI define success in their lives?	2. How do young adults who have had a TBI make sense of their everyday lives in terms of self- efficacy?	3. What are the barriers to and facilitators of success in young adults who have had a TBI?
<i>Theme:</i> One's definition of success is derived from both external and internal elements, creating a self-assessment of success.	<i>Theme:</i> Connection and support flow to and from friends and family.	<i>Theme:</i> Feelings of abandonment are associated with anger and depression.
Subtheme: External elements of		<i>Theme:</i> Facilitators of success are in some measure relationship and environment dependent.
success are productivity and independence		
<i>Subtheme:</i> Internal elements of success are contentment, peace, joy, and happiness		
<i>Pattern:</i> Transformation followed the critical incident of TBI.	<i>Pattern:</i> Indicators of self-efficacy were present before and after the TBI.	<i>Pattern:</i> Self-efficacy underlies success and is built on a pattern of success.

Theme: One's definition of success is derived from both external and internal

elements, creating a self-assessment of success.

Subtheme: External elements of success are productivity and independence.

Subtheme: Internal elements of success are contentment, peace, joy, and happiness.

Pattern: Transformation followed the critical incident of TBI.

Theme and Pattern derived from research question #2

*Theme:* Connection and support flow to and from friends and family.

*Pattern:* Indicators of self-efficacy were present before and after the TBI.
The themes and pattern derived from Research Question #3 were as follows: *Theme:* Feelings of abandonment are associated with anger and depression. *Theme:* Facilitators of success are in some measure relationship and environment dependent.

Pattern: Self-efficacy underlies success and is built on a pattern of success.

Stake (1995) defined *issues* as "problems about which people disagree, complicated problems within situations and contexts" (p. 133), and he made a point that "the researcher takes a close look at the problems, sometimes called issues, because issues are good windows for examining the conditions, the complexity, and the coping behavior of the case" (p. 127).

The issues identified in Ted's case study correspond with the research questions and arise as follows: from Question #1, anger and salvation through a girl; from Question #2, only his mother as his counselor and therapist; and from Question #3, sadness and depression, abandonment by a girl, and heath care access difficulties. Each of these issues presents further rationale for the themes and patterns identified.

The issues identified in Cal's case study also correspond with the research questions and arise as follows: from Question #1, anger toward the girl who caused the accident; from Question #2, loss of motor skills, speech, and math skills and treated like he was handicapped by some friends; and from Question #3, abandonment by a girl, sadness and depression, "hated life and felt useless, handicapped and withdrawn from society for a minute."

## Synthesis of Findings, Blending Both Cases and Additional Data Sources What Was Learned Overall About the Experience of Young

#### Adults' TBI in These Case Studies?

Overall findings are most easily understood from the perspective of the participants' life continuum. On the surface, it appears that these are two very different young men. Ted was getting into trouble before his injury, and Cal was moving forward with his ambitions, achieved his goal of college graduation, and became a published author. Yet, both were being endangered and threatened by the sheer speed with which they were living life. Then, snap, came the leveler and epiphany of their lives—the TBI—a near-death experience, leaving them temporarily disabled and unable to move or speak, and bringing a halt to almost every aspect of their lives completely and abruptly, leaving them poised in a condition of uncertainty.

Much to my surprise, only 12 and 9 months post-injury, they are now contributing members of society, working, content, happy, engaged, and smiling. They have both slowed down and are enjoying the moments of their lives. As young adults with strong family support systems, Ted and Cal have been able to progress along the developmental continuum of transition to adulthood and independence after TBI. The challenges faced in young adulthood may be greater than those in other stages of life in which the immediate future is not as demanding, such as in the very young who are expected to be dependent on their parents and caregivers.

Participant perceptions may be divided into their (a) definition of success, (b) selfefficacy, (c) TBI as a critical life incident, (d) barriers to success, and (e) facilitators of success. Each of these divisions represents broad categories from which themes have been derived and loosely follow the continuum of their young lives. Additionally, each of these five broad categories originates from the research questions.

#### How Do These Findings Compare With Other Descriptive

#### **Studies on Young Adults' TBI Experiences?**

There are relatively few studies concerning young adults who have had a TBI; however, a literature search revealed several that were generally congruent with the findings in our study. Kao and Stuifbergen (2004) and Wongvatunyu and Porter (2008) studied young adult TBI survivors focusing on the mother–child relationship. Kao and Stuifbergen described the meaning of the mother–child relationship of 12 young adults who were at least 2 years post-TBI and currently living with their mothers. They found that "survivors acquired a sense of being abnormal from various sources, including social pressures, dynamics within the family, and intrapersonal changes" (Kao & Stuifbergen, 2004, p. 73). Correspondingly, Ted had separated himself from his former friends because they were a bad influence, and Cal felt that some of his friends treated him as though he was "handicapped." In our study, family dynamics were described by both participants as being positive and essential to their recovery and rehabilitation.

Mothers "often struggled to balance protecting their children and letting them become independent (Kao & Stuifbergen, 2004, p. 73)." This did not seem to be problematic for the participants in our study, which may have been due to the dedicated involvement of the participants' fathers in their lives. However, both Cal and Ted worked with their fathers, which may be viewed as a limitation of their independence. Kao and Stuifbergen (2004) also found that the role of health professionals in designing more long-term community interventions would be helpful in improving family quality of life, increasing self-esteem of survivors, and decreasing the burden of injury and resultant stress.

Community interventions and integration may take the form of improved access to health care, including ongoing medical and psychological support and participation in TBI support groups, such as the Brain Injury Alliance in New Mexico. In addition, there must be systems to provide access to health care insurance coverage for those in transitional stages of health and development. The role of health care professionals in Ted's recovery was minimal, and the burden of depression and rehabilitation fell exclusively to the family. Ted would have received long-term benefits from referrals to counseling and speech therapy immediately post-TBI, with family involvement and training so that the treatment would be sustainable long-term. Cal had formal outpatient rehabilitation and one very helpful visit with a psychiatrist. However, his ongoing recovery would have been eased with a long-term plan incorporating community and health care resources. For example, the ability to continue his therapy at a community pool or gym once formal therapy had ceased would have been an excellent adjunct to his home family therapies. Furthermore, referral to the Brain Injury Alliance support group could have put him in a position to learn of community resources and given him the opportunity to share common experiences with other people who had survived a TBI.

In their study of seven young adult TBI survivors and their families, Wongvatunyu and Porter (2008) found that family life underwent five basic changes after a family member receives a TBI: getting attention from each other for different reasons, getting along with each other, facing financial hurdles, going separate ways, and splitting the family apart. Cal described his family pitching in and taking on different roles to help him with rehabilitation at home. He became more settled in with home life, such as cooking, gardening, and fixing things around the house. Ted said that he "would do anything for his Mom" and that she had effectively served as his counselor and therapist. He now feels that his parents do not have to deal with his immaturity and the bad behavior that characterized his life before the TBI. Both participants have returned to work with their fathers and feel that they are productive contributing members of the family. They are both pleased that they are becoming independent in work, transportation, and relationships, and both live with their mothers. The strong thread in their lives is, as Ted put it, "family, family, family." It seems that their injuries have brought the immediate and extended family closer together, rather than splitting the family apart. It is primarily at this point that their experiences diverge from those reported by Wongvatunyu and Porter (2008).

A classic case study reported in 1919 by Viennese neurologist Otto Marburg (1874-1948) described the experience of a patient who in spite of having motor aphasia also had preserved ability to sing. This case demonstrated to Marburg that "while linguistic expression is an ability mediated almost exclusively by the left cerebral hemisphere, increasing evidence shows that the right hemisphere ensures the ability of musical expression" (Marburg, 2010, p. 5). The patient was a 23-year-old soldier wounded by a tangential gunshot to the head. His most striking symptom was the motor aphasia: "while he could understand everything that was said to him and could also recognize symbols without any problems, he was unable to say or repeat another person's words spontaneously" (Marburg, 2010, p. 5). Similarly, both of our research participants were temporarily unable to talk after their TBI. Neither exhibited the ability to sing when unable to talk, possibly because their injuries affected different areas of the brain than did those of the young soldier. However, it is interesting to note that after his TBI, Ted found himself unable to compose songs and poetry in the fluid and prolific way he had in the past.

Phineas P. Gage's (1823-1860) experience is perhaps the most famous TBI case study in history (Chaves et al., 2012). Gage was an American railroad construction foreman who was born in New Hampshire and died at the age of 36 of status epilepticus at the home of his brother-in-law in California. At the age of 25, he survived a rock-blasting accident, even though his head had been impaled by an iron rod. The tragedy destroyed most of the left frontal lobe of his brain. After the TBI, his personality changed. Dr. John Harlow (1868) reported that before the accident, Gage had been hard-working, responsible, and a favorite of the men he supervised and that his employers regarded him as their most efficient and capable foreman. After the accident, Gage's mind had changed so much that he was no longer employable at his former job. He had a dramatic change in personality (Chaves et al., 2012). He became irreverent, impatient, obstinate, capricious, and childlike intellectually. Gage is considered the index case for personality change caused by damage to the frontal lobes. Harlow (1868) presented Gage's case to the Massachusetts Medical Society in 1868.

After his injury, Gage was employed as a stagecoach driver, worked on the family farm, and lived independently. Therefore, he did make adjustments resulting in a measure of social recovery. Eventually, his mental faculties recovered to the point that an American doctor in Chile, where he worked for 7 years after his injury, reported that he saw "no impairment" in Gage. Our research participants are similar to Gage with respect to good social recovery, but also dissimilar in that their recovery appears to have been more rapid and their personality changes were more favorable. Gage traveled to Chile and California, focused on his work after his TBI, lived independently, and provided his own transportation. Similarly, Ted and Cal are back to work, are now able to drive, and are living with a large measure of independence. All three had an injury to the frontal lobes of the brain. It seems that all three exhibited a "can-do" approach to life both before and after their TBI, consistent with high levels of self-confidence and self-efficacy.

The case study of a 22-year-old male sergeant who worked as a gunner in an armed vehicle in Afghanistan will illustrate the distinction between TBI and PTSD and will help to define the issue of care after TBI. The word "trauma" refers to both a physical blow to the brain (TBI) and to an emotionally stressful event. "In situations in which the physical blow occurs within the context of an event that also evokes intense fear or helplessness, for instance, an enemy combat assault, both TBI and PTSD may result" (Pitman, Kaelin, & Zafonte, 2010, p. 1051). In the military, Kaelin (Pitman et al., 2010) reported that "for soldiers experiencing a complex array of symptoms, including cognitive decline, physical dysfunction, pain and the emotional sequelae of combat-related trauma, a comprehensive interdisciplinary treatment program is recommended" (p. 1053). The treatment would include physical therapy, occupational therapy, speech therapy, and psychological counseling (Pitman et al., 2010). After his injury, Ted had none of these treatments, except as delivered by his family, whereas Cal had physical and speech therapy and one visit with a psychiatrist for treatment of PTSD. Both Cal and Ted had to relearn to talk after their TBI, and Cal had not yet regained his full physical strength in the 9 months following his TBI. Adequate health care after TBI emerges as an issue in this study and has been an issue for wounded warriors with TBI and/or PTSD, as well.

Meininger (2005) described 'life story work," emerging in Britain and The Netherlands. Life story work represents an approach to care and support for persons with intellectual disabilities. With respect to life story, Ted said that what helped him the most in his times of struggle after TBI was simply having someone close by who would ask questions and listen to him as he responded. Life story work may serve to initiate a dialectic process of self-understanding and facilitate meaningful connections. As such, during the interview process, Cal explained that he had made a new positive connection with a significant person in his life. The TBI triggered an "epiphany" for both Ted and Cal: a critical moment of engagement, recognition, and insight, which rippled into many aspects of their lives (Meininger, 2005). They were pleased to share their experiences and hoped that in some way, telling their stories would help others going through similar struggles in recovery after TBI.

#### Conclusion

Epiphanies (otherwise known as sudden insights) are characterized by their "intensity, resonance and mystery" (Bidney, 2004, p. 471). The critical incident of TBI was transformed into an epiphany for both research participants. It was described by Ted as his "whole silver lining" in the snap of his fingers and by Cal as a "wake-up call," after which his life changed for the better in many ways. Ted's view of the transformation as a "snap" is congruent with Ramsland's (2012) view of snaps as sudden flashes of inspiration that show us how to nurture our inner epiphanies to gain an edge in our imaginations, careers, and goals. The epiphany was a metamorphosis; the cocoon began with post-TBI coma, followed by an awakening, after which our research participants revealed a profound perceptual awareness of their actualized success.

As shown here, TBI is a major health event that may affect young adults at the beginning of their independent lives. Moderate to severe TBI often disrupts the frontal lobes

of the brain and the connections that underlie metacognitive processes, such as selfawareness, self-monitoring of performance, and strategies for solving problems and learning (Ownsworth, Quinn, Fleming, Kendall, & Shun, 2010; Larson, Kaufman, Schmalfuss, & Perlstein, 2007). Each of these processes has been explored through the interview process and descriptive questionnaires; each is potentiated by self-efficacy. How could something as frightening and grievous as a potentially fatal TBI have had such positive, enlightening, and affirmative repercussions for our research participants? This is a mystery. The clues needed to solve it are found in our participants' everyday lives and contexts, including their candid descriptions of emotions, thinking patterns, challenges, and successes.

The self-efficacy conceptual framework utilized to guide this study is central to analysis and interpretation of the data. In the self-efficacy model, self-efficacy expectations involve the ability to appreciate and anticipate the outcome of consequences observed in others, whereas outcome expectations are rewards expected for successful performance by oneself. I saw outcome expectations and self-efficacy expectations at work in the dynamic recovery of Ted and Cal and will explore and expand this tentative understanding further as I proceed to interpret and discuss the findings in multiple contexts in Chapter 5.

### CHAPTER 5 INTERPRETATION OF FINDINGS

The content of this chapter focuses on interpretation of the findings that were reported in Chapter 4, as well as a reprised look at study limitations, implications, and conclusions. Interpretation in this instance was developed from contextual, methodological, neuroscience, and theoretical perspectives. Most importantly, the findings were interpreted from the research participants' responses in an effort to articulate the meaning of the TBI experiences in their lives. As Patton (2002) described it, "Interpretation means attaching significance to what was found, making sense of findings, drawing conclusions, extrapolating lessons, making inferences, considering meanings, and otherwise imposing order on an unruly but surely patterned world" (p. 480). I interpreted the findings after comprehensive analysis and reflection, open to disconfirming cases, and accounting for irregularities in the data (Patton, 2002). I considered possible contributors or causative factors, relationships, and consequences from a holistic and qualitative perspective that described the "interdependence and interrelatedness of complex phenomena" (Patton, 2002, p. 481) in context of the times, places, and people in the lives of the two young adult research participants.

#### **The Interpretation Process**

As a primarily qualitative researcher, I worked to "capitalize on ordinary ways of making sense" (Stake, 1995, p. 72) when analyzing the findings, having both a specific and general interest in the meaning of the data. *Analysis* means "taking something apart" (Stake, 1995, p. 71). In the analysis, *observations and impressions* were examined in an effort to determine how the parts related to each other. *Interpretation* involves formulation of an

explanation to increase understanding. Patton (2002) explained that in qualitative research, interpretation asks and attempts to answer the questions "What does this mean? What does this tell me about the nature of the phenomenon of interest?" (p. 477). As shown in Chapter 4, through the presentation of study results and comparison of results with prior case studies, cases seldom exist alone. Often, another case is found that either confirms or disconfirms a solitary case at multiple points. In this study, I presented data from two in-depth case studies that both converged and diverged. The next phase of interpretation focused on "the instance trying to pull it apart and put it back together again more meaningfully—analysis and synthesis in direct interpretation" (Stake, 1995, p. 75).

The goal of the interpretation was to clarify the meaning of first impressions and final conclusions. Interpretation was iterative, akin to the sense-making and search for meaning that participants engaged in during the interview process and through their experience of TBI. The research approach, methods, and orientation were revisited in light of research findings. As Stake (1995) observed, the source of our thoughts and meaning often remains a mystery. We find "for analysis the right ambience, the right moment, by reading and rereading the accounts, by deep thinking, then understanding creeps forward" (p. 73), and the account is written. A summary of findings and framework for this interpretation is shown in Table N1 (see Appendix N).

#### **Categorical Aggregation and Direct Interpretation**

This study assessed the needs of young adult survivors of TBI and investigated barriers to and facilitators of their success using direct interpretation and categorical aggregation between informants. The aim was to provide an opportunity for participants to voice their thoughts, feelings, and concerns, and to thoughtfully assess their needs post-TBI. Two strategies were used in this case study research to discover new meaning: direct interpretation of the *individual instance* and *categorical aggregation*, which was defined by Stake (1995) as "sums or distributions of coded data" (p. 169). Additionally, this was an *instrumental* case study in which the effort was directed toward understanding the phenomena and relationships within the theoretical framework of self-efficacy.

Therefore, in the interpretive process, I considered theoretical relationships, aggregating categorical data regarding self-efficacy and success in young adult survivors of TBI, and exploring issues surrounding the barriers to and facilitators of success. When using categorical aggregation, "the need for categorical data and measurements is greater" (Stake, 1995, p. 77). Tables were used to display categories of numeric data (see Appendices N-R), enabling readers to more easily capture the phenomena and emerging relationships under study. The measurements and tables were subordinate to understanding the participants and making sense of observations using ethnographic methods.

#### **Literature Review Approaches to Interpretation**

Depending on the qualitative tradition chosen for a study and researcher preferences, the literature review may be done before or after data generation. Both before and after approaches are used when doing case study and narrative inquiry. In ethnographic studies, the literature is often reviewed before data are collected and serves as background and context for the study (Bloomberg & Volpe, 2008). Literature as context was examined again in the context of the findings, then reviewed after data collection, to further define and clarify the findings and view the findings through the lenses of the participants' realities. Selfefficacy theory and successful living are integrated to demonstrate conceptual linkages.

#### **Themes and Patterns Described and Interpreted**

#### Introduction

Ted and Cal had frontal lobe brain injuries (one of the inclusion criteria for participation in the study). The kinds of changes associated with frontal lobe injury were reported in the well-known index case of Phineas Gage (Macmillan, 2008), whose radical personality change was due to his injury. Paradoxically, in both Ted's and Cal's stories, their deficits seem to have been minimized, and they have maintained focus on the positive changes in their lives after the TBI. In Chapter 1, I defined *executive function* as a set of processes that have to do with managing oneself and one's resources to reach a goal, and noted that it is an umbrella term for the neurologically based skills involving mental control and self-regulation. Successful living was defined as "a life characterized by goals achieved" and is congruent with executive function. Both Ted and Cal exhibited strong goal setting and achievement patterns. The definition of *success* itself is "the achievement of something desired, planned, or attempted" (Pinker, 2014, p. 1) and is self-defined. I define success, in the context of success theory, as a complex spiral process through which internally and externally mediated self-assessments construct a state of life satisfaction substantiated by action and interaction. For clarification, Table O1 (Appendix O: Research Questions) shows a summary of the research questions, themes, subthemes, and patterns

#### **Reflections on the First Research Question**

The theme "One's definition of success is derived from both external and internal elements, creating a self-assessment of success," the subtheme "External elements of success are productivity and independence," the subtheme "Internal elements of success are contentment, peace, joy and happiness," and the pattern "Transformation followed the critical incident of TBI" answered the first research question, "How do young adults who have had a TBI define success in their lives?" The theme, pattern, and research question will be viewed from multiple perspectives. The in-depth strength of a case study approach focuses on the interpretation of success and life satisfaction. Participants' definitions of success were interpreted in the context of their transformative TBI experience.

**Perspective on methodology of case study approach.** The search for meaning in research findings is often a *search for patterns* and for consistency within certain conditions, which Stake calls "correspondence" (Stake, 1995, p. 78). One might look for *patterns* while reviewing documents, observing, or interviewing. Alternatively, a researcher can aggregate, make naturalistic generalizations, search for frequencies, and find patterns. As I noted, sometimes there was significant meaning in a single instance, for example, Cal's thoughts on prayer and forgiveness. Usually, important meanings emerge from repeated appearances, such as the high frequency of family support, and the participants' frequent self-reflective statements. Both categorical aggregation and direct interpretation are dependent on the search for patterns. When patterns drawn from research questions are known in advance, the research questions may serve as a template for analysis (Stake, 1995). Additionally, Stake (1995) suggested that patterns sometimes emerge unexpectedly from the analysis, such as TBI as a positive transformative experience, as appeared to be true in this study.

Keeping in mind that it was each individual case I tried to understand, I analyzed episodes of text with a *sense of correspondence* (i.e., consistency within certain conditions). For example, Ted and Cal both had difficulty managing their anger (as revealed in the interviews), with concomitant self-identified weaknesses in overcoming opposition and remaining calm when coping (as revealed in the self-efficacy questionnaires), and both were better able to manage anger post-TBI. As Stake (1995) advised, my efforts were directed toward understanding behavior, issues, and contacts with regard to the particular cases, trying to find the pattern or the significance through direct interpretation. For important episodes or text, I examined them repeatedly and reflectively for deeper meanings.

Success and life satisfaction interpreted. Each person defines success differently, and the definition may change, depending on values and the situations encountered. Success is a journey. Before a person can achieve success, he or she must have a clear vision of what constitutes success. One success leads to another and builds on the prior success. A pattern of success may increase one's motivation, energy, and interest in pursuing future goals. Ted's and Cal's definitions of success harmonize with an overall feeling of *life satisfaction*, serving as a self-administered reward derived from internally and externally mediated self-assessments. For example, Ted described the process of problem solving that he employs as an ironworker. He said, "You have to know the steps, and which steps you can put together in order to make it go faster." Ted was satisfied with meeting challenges and being productive in the context of his work, and experienced the rewards of a mastery experience using his creative problem-solving skills every day at work.

When asked if he was satisfied with his life, Ted said, "Completely, life is good, life has always been good." When I asked Cal the same question, he replied, "Yes, definitely. I can't complain. Plus, I've just met somebody, so I'm pretty happy." Ted's response confirms that he has a global sense of life satisfaction that is a thread in his life, and Cal's response connected his life satisfaction with being happy in a new relationship. As shown in these examples, and as occurred throughout the interviews, Ted and Cal were shown to be selfreflective in the interview data and to diverge and converge on various points. Their definitions of success are reiterated in Table P1 (Appendix P: Success Defined by Research Participants).

**Definitions of success interpreted.** In ethnographic terms, the emic aspect of success for Ted is summed up in two words: "content" and "happy." Ted placed a high priority on being content and happy as a measure of his own success. The etic aspect of work and productivity are also integral to his idea of success. Work has become Ted's pathway to success. He is focused on working to create a "nice life" for himself and his family and experiences a sense of satisfaction when he achieves goals that he has set for himself. Examples of Ted's goal setting and achievement are his becoming independent with respect to transportation by buying a truck, taking care of a DWI so that he can get a license, being self-sufficient by working, being part of his son's life, and providing for himself and his family.

Cal explained that he has reached the "goal of being happy" with himself. He is primarily focused on the emic aspect of success, that "feeling of joy inside" and "peace within." Work and productivity are also an important part of Cal's conception of success in his life. Cal reflected on the period of time just after his TBI when he felt "useless" and "could barely talk or read or feed myself," and how he is now back to his usual independent and social lifestyle. Like Ted, Cal values his ability to work and be productive. Cal is outgoing and centered on others, including his co-workers, friends, and family. He enjoys entertaining for the sake of others. If others around him are happy, able to "laugh it up" and have fun, that is success to Cal. The etic aspects of success are also important to Cal. He has outlined several concrete goals for his life, including becoming successful enough to build a house, using and advancing his education, traveling, and having a family. **Transformation interpreted.** *Transformation* is a key concept identified in the findings. The shift from a focus on individual behavior in self-efficacy theory to a focus on self-defined meaning of success has the potential to be transformative in individuals. Appropriately, transformation is interpreted in the context of the participants' TBI experiences. When patterns in the brain are disrupted by injury or illness, the ensuing chaos can be transformed to order through adaptation. The brain is remarkably plastic, and the organization of brain circuitry adapts and changes constantly as a function of experience. Brain plasticity and behavior can be impacted by multiple structural and physiological factors, which may include injury, hormones, maturation, diet, disease, and stress (Kolb & Gibb, 2003). In Ted's and Cal's everyday lives, creative adaptation led to self-reorganization. Interdependence of participants with their families was a major factor in their recovery. The key element in the transformative experience for Ted and Cal was the emergence of family systems that were self-organized around them, with multiple family members collaborating toward the goal of recovery after TBI.

My interpretation was that transformation followed the chaos of a near-death experience due to TBI in Ted's and Cal's lives. The operational definition of a *transformative experience* is a redirection of energies toward found meaning (Peat, 1987). After his TBI, Ted's energy became directed toward working for a "nice life," helping his family as needed, and just being "happy and content." It was clear to Ted that his TBI was a turning point in his life. He said, "I would have died if I had continued in my old ways" and that "God had to [snap his fingers] and say 'you are doing wrong." Ted described his TBI as the "whole silver lining" of his life because of the positive changes that occurred post-TBI. He rearranged his priorities, changed his behavior, and now feels content and happy. His energies have changed and are now directed toward newly found meanings in his life, which is the essence of transformation. Cal's energy also became directed more toward home and family after his TBI. Instead of being focused solely on his school work, he takes time to garden and fix things around the house, and enjoys cooking for others. His success lies in making himself and other people happy. Cal said that he "most definitely" saw positive changes in his life after the TBI. Now he looks at things differently, such as relationships, and says that he is just "taking his time."

**Interpretation through data mapping.** "Data mapping involves 'matching' between a source and a target, such as between two databases that contain the same data elements but call them by different names" (McBride, Gilder, Davis, & Fenton, 2006, para 1). Mapping of data patterns may be seen here in terms of consequences for Ted and Cal. Three sets of consequences from the collective findings were (a) change, crisis, and chaos; (b) creativity, adaptation, emergence; and (c) transformation, collaboration, and self-organization.

Ted and Cal experienced a sequence of brain injury, coma, severe neurologic deficits, and then recovery, rather than a tip over the edge of chaos into persistent disorder and debilitation. A few facts are telling regarding the extent of their traumatic brain injuries. Ted was in a coma for 2 days before he was found and taken to the hospital. Cal was resuscitated three times while he was hospitalized and was in a coma for several days. They emerged from these experiences with profound losses. Once Ted and Cal woke up and realized the extent of their deficits, including the loss of independence, speech, and ability to perform self-care activities, a period of profound sadness and depression set in. After facing a neardeath experience, their recovery stage was guided by common sense in the midst of the chaos of personal and family reorganization surrounding them. Ted and Cal are successfully working their way through the recovery and rehabilitation process, supported by family at each step of the way. Through the course of their rehabilitation and recovery, Ted and Cal regained their independence, valuing it highly after having lost it temporarily. They emerged as transformed individuals after going through the processes of *chaos, crisis,* and *change*.

The second triad of *creativity, adaptation*, and *emergence* is illustrated in Ted's and Cal's TBI work experiences. Ted described his creative problem solving at work in sorting out everyday, complicated math and logistical problems. Before his TBI, his creative outlet was directed at the more aesthetic pursuits of writing poetry and song lyrics. Ted also related that he worked with his father, who appreciated Ted's unique style of problem solving by working a problem from back to front. Ted said that he thinks his problem-solving strategies are an adaptation to his dyslexia. Ted is well integrated into the system that exists in his workplace, having taken on the role of creative problem solver and work partner with his father. Likewise, Cal's father is also his co-worker at their place of employment. Before his injury, Cal's creativity was directed toward creative scientific processes. After his injury, Cal has redirected his creative energies into his home environment in the form of cooking, gardening, and repairing things using his problem-solving skills.

New and innovative ideas and behaviors are often processed, refined, cultivated, and established in the *creativity, adaptation*, and *emergence* of new systems (Holden, 2005; Rouse, 2008). *Attractors* are catalysts that promote spontaneous emergence of new behaviors that creatively contribute to order. A major attractor in Cal's life was a new connection with a girl. The major attractor in Ted's life was his work, which cultivated his creativity and problem-solving skills. Systems are interconnected and new whole systems may emerge. Family systems designed to help in Ted's recovery included his mother as his counselor and

therapist. In Cal's case, multiple family members took on key roles in his home therapy. Doig, Fleming, Kuipers, and Cornwell (2011) performed a systematic review of the literature comparing rehabilitation outcomes in home and day hospital settings and found that "there has been a recent trend towards shifting rehabilitation from hospital settings to community based settings such as the individual's home environment in the form of both early supported discharge and community based rehabilitation services" (p. 1203), in keeping with Ted and Cal's experiences after TBI.

Ted and Cal's individual experiences after TBI demonstrate that *transformation*, *collaboration* and *self-organization* are intertwined. Transformation for both Ted and Cal was described as a spiritual experience. As Ted said, "God had to come along and [Ted snaps his fingers] and say 'you're doing bad' for me to snap out of it and bring me close to death and then bring me back; silver lining is like that." He stated, "I would have ended up dying if I had stayed in my same old ways." Cal pointed to "family, prayer, and friends" as the most helpful things after his TBI, making it easier for him to feel "inner joy." Medical marijuana was helpful in "mellowing" him out, enabling him to take "a step back and look at things." In the case of our research participants, the primary organization was the family, through which the participants' self-belief and confidence were reinforced, leading to self-reorganization.

Evolving organizations are created through enhancement of *transformation*, *collaboration*, and *self-organization*. The working definition of *transformation* is a movement of energy toward found meaning (Peat, 1987). Cal and Ted were transformed individually, and their family systems also adapted, reorganized and transformed, directing energy toward Ted's and Cal's recovery. Elements within systems enhance one another, as occurred with Ted's and Cal's family members. For example, Cal's family members took on various roles in assisting him with home rehabilitation. The unifying consequence of the adaptive systems resulted in patterns of self-organization. An example of this may be drawn from neuroscience. When connections in the brain have been disrupted, an individual's fluid intelligence may be optimized by environmental adjustments, enabling adaptation and reorganization, such as occurred in Ted's and Cal's cases (Harris, 2010; Kolb & Gibb, 2003).

Advocacy viewpoint, health equity. The action-focused goals of this research were to identify barriers to and facilitators of success in young adult survivors of TBI. Minimization of societal and physical barriers is essential to successfully realizing one's potential after sustaining a TBI, because impairments after TBI may limit a person's ability to adapt. In this study, a collaborative orientation led to advocacy for barrier-free psychological and physical environments to potentiate successful living. Considerations specific to this study are community factors, including resiliency and support, social inclusion and exclusion, and relative social status. These social and community factors are integral determinants of health (WHO, 2011).

After TBI, young adults may require substance abuse treatment and/or psychiatric, rehabilitation, or other subspecialty care, as voiced at the Brain Injury Alliance of New Mexico (2011) Forum in Las Cruces, NM. Likewise, the participants in this study voiced the need for ongoing psychiatric and rehabilitation care, and have faced the challenges of reintegration into their communities and peer groups. Full access to needed care, as well as full reintegration into social life, represent dimensions of health equity for TBI patients.

Advocacy viewpoint, health care access. A young adult with TBI may become stable medically; however, in the aftermath of recovery, ongoing support and mitigation of barriers to successful living, such as sadness and depression, are essential to optimize health and quality of life. Societal barriers may take the form of limited access to medical care, which is particularly problematic for young adults due to the transition from pediatric to adult medical care that occurs during young adulthood. Additionally, young adults who live in rural areas may not have immediate or easy access to medical care. The care of young adults treated for moderate to severe TBI requires diligent monitoring for extent of injury and complications, as well as psychosocial health care across the developmental continuum. It may be difficult to find a team of caregivers to help them manage their medical care. Psychosocial challenges and interpersonal relationships become more complex and demanding, while support becomes less structured and unreliable in the transition to adult health care, as shown in our case studies. Kim and colleagues (2007) found that the prevalence of depression was 18% to 61% and the prevalence of PTSD was 3% to 59% in TBI patients. After TBI, both participants experienced depression, and 1 experienced PTSD. Their formal treatment via health care providers was minimal, but was augmented by family support and connection.

# **Reflections on the Second Research Question**

The theme "Connection and support flow to and from friends and family" and the pattern "Indicators of self-efficacy were present before and after the TBI" answered the second research question, "How do young adults who have had a TBI make sense of their everyday lives, in terms of self-efficacy?" Ethnographic methods, like case study approaches, involve a search for patterns and themes. In this section, ethnography and culture (i.e., the bridge of human connection) will be explored using Hall's (1984) three levels of culture—tertiary, secondary, and primary. Answering the second research question will be focused on sense-making in the context of the everyday lives of the research participants. Participants'

self-reported assessments of their self-efficacy via questionnaires will be integrated with interview results, facilitating interpretation of the findings. Examining the participants' TBI experiences from the perspective of self-efficacy will place their behavioral, health, family, and supportive structures in the context of an advocacy perspective, specifically examining health care access and care systems that either supported or slowed their recovery.

**Methodology perspective, ethnography.** From an ethnographic perspective, actions are understood in the context of family, culture, and society. Similarly, self-efficacy is composed of a person's knowledge, training, education, learned skills, attitudes, beliefs, and characteristics. American anthropologist Edward T. Hall (1984) proposed that in each human group, there are three levels of culture. Tertiary-level culture is explicitly manifested and superficial. Secondary-level culture includes the grammar of a group, with implicit assumptions, beliefs, and rules. Primary culture is the deepest level, in which rules are so ingrained that they are generally out of awareness. The levels of culture proposed by Hall give life and form to human connectedness, enabling management, understanding, and manipulation of the physical world, through what French sociologists have labeled collective representations (Carrithers, 1992). As such, Ted and Cal were connected with their families in a way that enabled them to recreate the ability to manage their lives, return to work, regain independence, speak, read, and regain fluid movement of their bodies after losses due to their traumatic brain injuries.

Primary culture is especially important in the interpretation of study findings here. It is at a level that is so deep that it is often out of awareness. The rules are known instinctively by those who are in the culture. Norms are implicit, such as the manner in which families care for the sick and injured. Rules and norms are generally obeyed, even though they are not explicitly stated. Adaptability, creativity, and engagement with deity and humanity are the substance of primary level culture. Each of these elements was prominent in Ted and Cal's stories. They adapted to change after TBI, and became engaged in creative problem solving and relationships with God and fellow humans. The essence of their sense-making was in found meaning, their perceptions of God's presence and hand in their lives and experiences, and their networking and connections with friends and family.

Sense-making interpreted. In answering the second research question, "How do young adults who have had a TBI make sense of their everyday lives, in terms of selfefficacy?" it is first necessary to clarify the concept of making sense. Sense-making is generally defined as the process by which people give meaning to experience and is an active two-way process in which data fit into a frame/mental model, and the frame is then fitted around the data (Klein, Moon, & Hoffman, 2006). Both Ted and Cal made sense of their lives in terms of the people they loved and with whom they were connected in relationships. Family support and relationships were strong key factors in their recovery, reinforcing their relationship with a higher being. The theme "Connection and support flow to and from friends and family" became evident in the participants' descriptions of their relationships with family and friends.

Prior to the TBI, Ted and Cal had drifted away from their families in pursuit of relationships and activities that were most important to them at the time, as is the norm for their age group (Erikson, 1968). The TBI was an awakening experience in which they believed that their families and God were there supporting them in their time of need. Both also found that some of the other people in their lives, with whom they thought were close, either dropped out of their lives or, as Cal related, treated him as though he was "handicapped." The TBI experience resulted in a rearrangement of the priorities of everyday life. Their emotions and giving natures were redirected primarily toward family instead of friends in Ted's case, and instead of friends and school work in Cal's case.

Sense-making is akin to the metacognition model in which individuals build, verify, and modify stories and models in situational awareness to account for an unrecognized situation (Cohen et al., 1996). Both participants relied heavily on building, verifying, and modifying their TBI experiences to account for unrecognized situations, including coma, near-death experience, survival, loss of speech and ability to care for self, cognitive losses, physical weakness, rejection by girls, and intensive family support in recovery. Their selfconfidence and self-belief did not waver under these extreme circumstances. Thus, the selfefficacy they demonstrated pre-injury actually became stronger post-injury with each success achieved, providing supportive evidence for the pattern "Indicators of self-efficacy were present before and after the TBI."

The pattern of self-efficacy was seen in the participants' self-assessments regarding problem solving, enjoyment of activities of life, setting aims and accomplishing goals, working and taking care of life responsibilities, and confidence in dealing with the unexpected. Cal specified that his ability to organize his problems and "solve them day by day" was a skill that he first acquired in his undergraduate college years and that his creativity in problem solving has actually improved after his TBI. Ted said that he likes being an ironworker because he uses his creative problem-solving skills in his daily work. He says that there is always some sort of "problem solving to go through" and the need to "figure things out" using his math skills. Both participants exuded a joy in life and enthusiasm for work. **Self-efficacy perspective.** Bandura (1997, 2004) defined *self-efficacy* as one's belief in his or her ability to *succeed* in specific situations. A major tenet of the theory is that individuals with high self-efficacy believe they are in *control* of their lives. The conceptual framework of self-efficacy is the theoretical centerpiece of this research and can help answer the research question, "How do young adults who have had a TBI make sense of their everyday lives, in terms of self-efficacy?" Both Ted and Cal exhibited strong goal setting and achievement patterns, which is characteristic of people with high self-efficacy.

Self-efficacy characteristics derived from the self-efficacy conceptual framework and identified in the participants' interviews and questionnaires included adaptation, self-belief, self-confidence, self-control, self-organizing, self-reflecting, self-regulating, self-reinforcement, self-sufficient, self-administered reward or punishment, accomplishment, coping, interdependent, proactive, and satisfaction. Tables Q1 and R1 in Appendices R and S, respectively, are matrices that map both questionnaire and interview findings regarding self-efficacy.

**Thread of self-efficacy.** Threads of self-efficacy can be seen throughout Ted's and Cal's lives both before and after their experience of TBI, as related in their narrative stories and self-efficacy questionnaire. Higher-than-average levels of self-efficacy represent a pattern in their everyday lives. Harris (2010) identified overall goals of care after TBI as optimizing self-efficacy, providing support in decision making, and helping individuals to reach their potential with their cognitive capacity. Identification of optimizing self-efficacy as an overall goal of care after TBI supports the importance of the discussion of self-efficacy.

Ted's efforts pre-injury were characterized by him as "doing bad things," "immaturity," "not caring much" about other people, living arrangements as a "couch surfer," early parenthood, hanging with "bad friends," getting into fights, and ultimately partying into a comatose state for 2 days after sustaining a TBI. In the midst of this lifestyle, he was also a musician and prolific writer of poetry and songs. He had finished his GED and had worked at two responsible jobs by the age of 19, demonstrating a self-organizing and proactive approach to his life as it was. After the TBI, Ted began managing self-control by channeling his anger into exercise and implementing self-regulation regarding anger situations by "not hanging out with friends who argue." Other than difficulty coping, ongoing anger issues, and the depression that set in shortly after his TBI, Ted rated himself highly in self-efficacy on the questionnaires.

Ted's experience of post-TBI sadness and depression were likely multifactorial in origin. One of the primary sources was his feeling of abandonment by the girl who found him comatose and "saved his life" after his TBI. Looking only at his self-described "bad" behaviors, it is evident that his self-efficacy and self-control improved after the TBI. However, it must be remembered that he was actively pursuing his pre-injury lifestyle by choice. What is very telling is his perception, supported by the everyday changes he describes in his life, that there has been global improvement in his behavior and maturity post-injury, reflecting TBI as a mastery experience that transformed his life.

Cal's before-and-after TBI story yields further insights into the discussion of selfefficacy, particularly as it relates to the continuum of self-efficacy. Cal was motivated, hardworking, and a high achiever before his injury. He continued to pursue his ambitions post-TBI. His life pre-injury was one of dedication to his studies and to his self-formulated ideas of success. In fact, in retrospect, he related that his pursuit of success pre-injury actually became a barrier to his success. Prior to his TBI, Cal was living at such a fast pace that he denied himself the time to enjoy his friends, engage in detailed problem solving in everyday life, or take the time to garden or cook at home. Cal has held true to his form as a responsible, successful, and goal-driven person. His mastery experience of graduation from college was congruent with his mastery experience of rehabilitation after his TBI. Both experiences required high levels of self-belief, self-confidence, and self-organization on a daily basis. Cal and Ted expressed a keen awareness of their need for anger management and actively strategized to achieve it. Cal looked to "peace within" as a self-administered reward and as a strategy to motivate avoidance of anger situations.

Cal described sadness and depression that set in immediately after his TBI. He has had to struggle with reconciling himself with abandonment by a girl who was part of his life before the TBI. One of the most poignant moments of Cal's interview was when he mentioned that the girl who opened her car door, causing his TBI, never came to see him in the hospital. Cal said, "That explains how the anger comes in. It's like, what's going on . . . but I forgive her." This ability to decide on and set a positive course of action demonstrates strong self-belief and self-confidence, which are pillars of self-efficacy. It is easy to understand the established utility of self-efficacy theory, especially when seeing how Ted's and Cal's descriptive data and life experiences are illuminated through the lens of selfefficacy theory.

**Flow of connection and support.** The theme "Connection and support flow to and from friends and family" also pertains to the second research question. Ted's and Cal's tendency to emphasize the positive aspects of their lives may be tied to their generally high levels of self-efficacy, coupled with intense family support in recovery. Ted's and Cal's self-efficacy was mobilized to focus on recovery and rehabilitation after TBI. According to

Bandura's self-efficacy theory, most behavior is regulated by an ongoing process of selfreinforcement.

The feeling of satisfaction or accomplishment may serve as a self-administered reward, such as Ted's feeling of accomplishment from doing his job efficiently. Conversely, self-administered punishment may take the form of depression, shame, or guilt with respect to how one behaved. Ted's support comes from family members and co-workers. He also describes an ambivalent relationship with a "girl." His social contacts outside of his family were primarily work connections. He was determined not to get back with friends who "argue and fight," demonstrating increased maturity and decisiveness. Instead, Ted was focused on his family connections and was receiving full and effective family support in his rehabilitation and recovery after TBI.

Ted has taken control of his life toward a "contented, happy, and nice life," exhibiting devotion to his family rather than pursuing the "fast" and "crazy" lifestyle he had been living. However, before and after the injury, Ted had been living life he chose, demonstrating the problem-solving skills, creativity, and goal directedness typical of individuals with high self-efficacy. His self-efficacy ratings were high on the descriptive questionnaires with a few exceptions: dealing with the emotions (anger, sadness, depression, and abandonment; 5/10); overcoming opposition (1/4); and calmness with ability to rely on coping abilities (2/4). He also rated himself moderately (3/4) in the areas of confidence (dealing with the unexpected) and resourcefulness (dealing with the unforeseen). His challenges with anger management may account for his difficulties in overcoming opposition, regaining calmness, and developing coping skills, which he is currently managing successfully using avoidance and exercise strategies.

Cal now takes time for his friends, family, and work contacts and finds the joy of giving in his interactions. Additionally, he is beginning to understand the concept of "connection," owing to his new relationship with a girl. Cal sees gardening as a physical activity that puts him in touch with his environment, as represented by the soil, which also gives him an opportunity to work together and spend time with his brother. Cal said that gardening has been a "huge" factor in his recovery after TBI.

Cal's self-efficacy ratings are high in most categories and moderate in the categories of managing relationships (7/10); managing money, legal, and health care matters (7/10); overcoming opposition (3/4); and calm, relies on coping abilities (3/4). Cal explained that he struggles with anger management, and shares a measure of Ted's difficulties with overcoming opposition and remaining calm in connection with managing his anger. His executive function with respect to managing matters may have been affected by his TBI. Overall, Cal's life pre-injury demonstrates high levels of self-efficacy, which have carried through to his post-injury determination to continue recovery toward the goal of pursuing a graduate degree, "just being happy with myself," and "being happy with people," which are goals he said he has reached.

**Neuroscience perspective, fluid and crystallized intelligence.** The concepts of fluid and crystallized intelligence were originally articulated by Cattell (1963). These concepts are helpful in seeing potential for recovery and adaptation after TBI. Executive function and short-term memory are fundamental to fluid and crystallized intelligence, as they are to selfefficacy. Self-efficacy is also integral to metacognitive processes, including awareness, selfmonitoring, and self-regulation, which are operative in executive function and are functionally dependent on the frontal lobes of the brain. Executive functions, including goal setting, self-regulation, decision making, and problem solving, are central concepts in selfefficacy. Testing of executive function parameters was evident in the literature on reliability and validity testing of the self-efficacy instruments used in this study. Injury to the frontal lobes, as occurred in the research participants, may lead to deficits in the following areas: fine-motor function and strength in the upper extremities; executive function, including goal selection and planning; attention and memory; problem solving; social behavior; the ability to decide between good and bad choices; and impulsivity and risk taking (Floden et al., 2008).

When *crystallized intelligence* is compromised after TBI, fluid intelligence can compensate for losses. Crystallized intelligence is the fund of information that is available for use based on learning (Christensen, 2001). It involves both access and accumulation of memories. On IQ tests, crystallized intelligence is represented by vocabulary, fund of general information, and analogy subtests (Catell, 1963; Christensen, 2001). It is believed to be stored in the areas of the brain involved with long-term memories, such as the hippocampus.

*Fluid intelligence* involves the ability to solve problems, find meaning in complexity, draw inferences, understand relationships between multiple concepts, recognize patterns, and perform abstract reasoning. It involves the dorsolateral prefrontal cortex, the anterior cingulate gyrus, and other brain systems related to short-term memory and attention. Compensation for losses and adaptation after TBI may be more difficult when fluid intelligence is compromised (Christensen, 2001).

Fluid intelligence in some measure is a key ingredient in developing and perpetuating self-efficacy and may be optimized by environmental adjustments (Catell, 1963). In support of this notion, Rindermann, Flores-Mendoza, and Mansur-Alves (2010) investigated the

effects of fluid and crystallized intelligence in relationship to parents' socioeconomic status and education. Their results revealed that although fluid intelligence has been shown to be largely dependent on biological factors, such as genetic predisposition, it also seems to be influenced by nonbiological environmental factors, such as socioeconomic factors, displaying a pliable character. *Self-regulation* is a prominent characteristic of self-efficacy. It is defined as the capacity to manage one's thoughts, feelings, and actions, displaying adaptation and flexibility in a variety of contexts (Ganesalingam, Sanson, Anderson, & Yeates, 2006). Self-regulation has been shown to play a pivotal role in recovery and rehabilitation after TBI. Ganesalingam and colleagues (2006) found that self-regulation acted as a mediator of the effects of TBI on the outcomes of social and behavioral functioning in children with TBI.

Harris (2010) also found that environmental enrichment, such as social stimulation and education, can facilitate the elaboration of brain circuitry sustaining higher order cognitive processes. After a young adult survivor of TBI becomes medically stable, ongoing support and mitigation of environmental barriers to successful living, such employment, transportation, and interconnection with family, friends, and community, are essential to optimize health and quality of life. This dynamic has been shown in Ted's and Cal's experiences. Adjustments in a patient's environment of care, as shown in the research participants' home support systems, have the potential to become transformative for patients. Fluid intelligence and self-efficacy may be seen as resources that can be accessed to achieve self-defined success and adaptation after TBI. Awareness and augmentation of the characteristics of self-efficacy through educational efforts have the potential to increase the motivation and means for young adults with TBI to achieve their desires, goals, and plans.

#### **Reflections on the Third Research Question**

The theme "Feelings of abandonment are associated with anger and depression," the theme "Facilitators of success are in some measure relationship and environment dependent, and the pattern "Self-efficacy underlies success and is built on a pattern of success" answered the third research question, "What are the barriers to and facilitators of success in young adults who have had a TBI?"

**Barriers to success interpreted.** Success can be measured and tracked in spiritual, emotional, physical, health, family, work, and community spheres. Values are questioned, and one decides what is of greatest importance to personally define success. At different times in life and in different states of health, success is defined differently. Ted and Cal have definite ideas on their definitions of success and what has made it easier for them to succeed after their TBI. They each explained their individual barriers to and facilitators of success in the interview process.

Given the extent of his depression, underlying ADHD, dyslexia, and speech deficits post-TBI, Ted would have benefited from professional counseling and speech therapy, which were not available to him at the time because he was uninsured. As Ted said, "Sadness is bad after head injury, if you feel depressed or anything like that is the worst thing. That is the only thing you need help on." He received the needed help from his mother, who filled the roles of counselor and speech therapist for Ted. Just after the TBI, Ted's fracturing a tooth while doing "stupid shit" on his skateboard showed that his underlying ADHD was still a factor in his life. He is in the process of overcoming the barrier of access to health care, as his health care insurance from work will soon be in force, displaying Ted's increased selfsufficiency in his life affairs. Another prominent barrier to success for Ted was a girl for whom he "would do anything." He is still working through his conflicting feelings toward her. For example, Ted mentioned that girls expect to have new phones and "appliances," and she would ask him to buy these items, which he viewed as unnecessary and wasteful. His mindset was to save money and spend it wisely, not to waste it on unnecessary purchases. His feelings of gratitude conflict with his anger toward this girl who "saved his life" and then essentially abandoned him after the TBI, presenting what Ted sees as a "barrier" to his success. The ambivalence he feels contributes to his sadness and depression. When asked if anything was holding him back from being successful, Ted said, "This may seem a little bit rude, but probably that girl that found me. She's the one that keeps me thinking that I will not be too successful."

Cal explained the following when I asked about barriers to his success. He said that the "idea of success itself held me back" before the TBI because he was always in a hurry and unable to enjoy times with his friends and family. Then he went through a period immediately post-TBI when he was "hating life for a minute and felt useless, handicapped, and withdrawn from society." He relates that he was "pretty depressed for a while, actually extremely depressed" and did not take a turn for the better until about 8 months after his injury. He said, "It was simply because I couldn't do things on my own. I was so used to being independent, out and about, socializing, everything. And then I came to a screeching halt in my life, to where I could barely talk, or read, or feed myself . . . relearning everything is pretty tough."

Due to his losses after the TBI, Cal, like Ted, was isolated from friends; however, he is working his way through that stage and has reconnected with many of his friends. Also

like Ted, thoughts of the girl who was involved in his TBI presents a barrier to Cal's success. The lack of resolution bothers and sometimes angers him, but he has forgiven her and is moving on with a new relationship, demonstrating that he is in the psychosocial stage appropriate for his age group, identified by Erikson (1968) as intimacy versus isolation. Cal's cognitive losses after the TBI have been profound and present what Cal sees as a temporary barrier until he regains his skills. At the time of the interview, Cal was determined to regain his physical strength and his academic skills to the level of pursuing a graduate degree.

Abandonment interpreted using development insights. Bandura (1997, 2004) defined *self-efficacy* as one's belief in his or her ability to succeed in specific situations. In this definition, it is evident that success emerges from the foundations of self-efficacy theory. A major tenet of self-efficacy theory is that individuals with high self-efficacy believe they are in control of their lives. This tenet of control was observed and expressed by Ted and Cal, who believed that they had control over their decisions, actions, and futures, with only a few notable exceptions. Ted and Cal were angry, bewildered, and depressed by the girls with whom they were close friends before the injuries and by whom they felt abandoned after the TBI. They did not see these as successful relationships. On the contrary, they felt disempowered by the abrupt absence of communication imposed by the girls. Ted and Cal's responses to this situation diverged and may be linked to their age and differences with respect to variant developmental stages. Ted still thinks of the girl as a barrier to his success; his reasoning is, as he said, "I would do anything for that girl . . . and would spend my life on her." In Cal's case, he describes an exciting connection with a new girl in his life. Cal has moved on, let go, and is happily pursuing a new relationship. Ted is still struggling to avoid

the pitfalls of an ambivalent and ongoing relationship with the girl who saved him and then abandoned him after his TBI.

Ted was age 19 at the time of his interview. In terms of Erikson's (1968) psychosocial stages of development for the 18- to 24-year-old age group, Ted is on target, as he is working through *identity versus role confusion* challenges. His identity is tied primarily to family and work. He is dedicated to his family and conflicted about the girl who "saved" his life when she found him comatose after his TBI. These two situations present decisionmaking dilemmas for Ted concerning how to wisely spend his income. At the time of the interview, his priorities were to "save money for a nice life," help his parents as needs arise, and not "spend his whole life" on the girl.

Cal was 25 at the time of his interview. Considering Erikson's (1968) psychosocial stages of development for the 25- to 40-year-old age group, Cal is on target, as he is working through *intimacy versus isolation* challenges. Cal has forgiven the girl who, it seems, caused his TBI accident. He experienced "extreme" depression post-TBI and was disappointed that the girl did not ever visit or talk to him after his brain injury. He has moved on and is now in a new relationship in which he feels "connected" in a way that he never had before experienced. Cal is focused on his family and his network of friends, and is appreciative of the sacrifices his family has made in helping him to recover from his TBI.

**Facilitators of success interpreted.** Each person defines success differently, and the definition may change, depending on values and the situations encountered. Before a person can achieve success, he or she must have a clear vision of what constitutes success. Success is a journey. One success leads to another and builds on the prior success. A pattern of

success may increase one's motivation, energy, and interest in pursuing future goals. Facilitators of success are in some measure environment and relationship dependent.

Ted's primary facilitators of success are his capacity for setting, working toward, and reaching his goals, and family support. Ted had just bought a new truck, had taken care of a DWI, and was pleased to see himself as a "provider" for himself and his family. His focus was on family, work, saving money, and being content and happy in the moment— establishing his present everyday life identity. He was generous with his family, and felt that he was "providing" when he spent money on his family. Ted's mother was his confidante, and counselor, and had seen him through recovery of his speech after his TBI. His father was his role model. Ted was determined not to get back with his "bad friends" from the past. At the time of the interview, he was happy to spend time with his work associates and family, rather than friends. However, he was isolated from the usual peer network common to his age group, with the exception of his cousin and co-workers. His cousin was a positive peer-group influence for Ted. Erikson's (1968) identity-versus-role-confusion stage again lends clarity through which we can see that in keeping with his age group, Ted has multiple roles vying for his attention.

Supportive family and friends have facilitated Cal's success after his TBI through their helpfulness and encouragement. He seemed to have re-established his social connections and also valued his work experiences. Interface with a psychiatrist, speech therapist, and physical therapists set Cal on a realistic course for recovery after his TBI. Cal's one visit with a psychiatrist after his TBI was very effective, and he pointed to treatment with medical marijuana as a facilitator of his success. When I asked what made it easier to succeed after his TBI, Cal affirmed that it was his family and the sacrifices they had made to help him move forward with therapy and recovery. Family members assigned roles for themselves in helping Cal with his reading, writing, vocabulary, exercise, or essentially anything that he needed. When I asked if there were any other helpful things, Cal said, "Prayer was real helpful, very, very helpful, and I am a Christian so I go to church and everything. Prayer works, definitely. Family, prayer, friends." Cal appreciates the time that people have spent on him and realizes now that he can do the same for others by slowing down his pace.

The final tally of codes from interview data (see Appendix M) reveals that Ted and Cal diverge most widely in the coding category of "facilitators of success"; however, the code frequency for family support, work, engagement with people, and connection/networking was high for each of them. Cal networks with friends and family, whereas the focus of Ted's networking is his family. Although Cal's TBI seems to have affected his cognition more profoundly than has Ted's, he remains focused on his educational goals and future. Both Ted and Cal rearranged their priorities post-TBI with respect to the people in their lives. Cal is more "careful not to hurt somebody," at the same time saying what he is feeling, activating his "brain to mouth filter," and being more "professional" with people. Ted no longer engages in "screaming, fighting, or arguments with friends" after his TBI, realizing that it is just "not worth it."

Life satisfaction and successful living. Outcome expectations in self-efficacy theory are focused on behaviors, whereas in successful living, the primary outcome expectation is life satisfaction. Life satisfaction is predicated by self-defined success, as seen in the interpretation of the themes and subthemes derived from the first research question. We will now explore life satisfaction and successful living. Measurements of success may show elements of mastery in endeavors, confidence in abilities, resilience in the face of difficulties, empowerment to do what one desires, support from family, friends, and community, life satisfaction, and quality of life. Facilitators of success were concentrated on both internal and external factors that created a self-assessment of success in individual participants.

Self-motivation is unidirectional flowing to mastery. In self-efficacy theory, *mastery experiences* are sources of information explained in terms of success-goal achievement. As shown in the discussion of self-efficacy theory, a success in life endeavors raises self-efficacy and, conversely, a failure lowers self-efficacy. Ted's behavior patterns leading up to the critical incident of TBI likely contributed to his low ratings on self-efficacy questionnaires in the areas of "coping" and "handling whatever comes my way." In his transformed lifestyle post-TBI, he has found ways to successfully cope with his anger. Ted said that he is "completely satisfied" with his life. Looking at his interview data as a whole, it is apparent that he is pleased with his productivity and work life, which has led to financial independence and which includes providing his own means of transportation. Ted was motivated to reach his goal of buying a truck, and now that he has reached that goal, he is working toward buying a motorcycle. Likewise, Cal has progressed from feeling "useless" immediately after his TBI to becoming independent and productive in work. He is motivated to achieve his goal to pursue graduate education.

Ted's and Cal's self-motivation is manifested in the mastery of their current situations. Their self-belief is evidenced as confidence in their ability to accomplish future goals. They were both satisfied with their daily lives, reflecting self-reward and quality of life in both emic and etic realms. In spite of being depressed by abandonment and lack of communication with the girls who were closely aligned with their TBI, they have become empowered by the energy of what turned out to be a transformative experience of TBI. Connection and support have flowed to and from their friends and family. Against the odds of TBI, depression, functional losses, and abandonment, their ego-resilience has manifested as resilience in the face of serious and life-threatening challenges to their survival and success in life endeavors.

The shift from a focus on individual behavior in self-efficacy theory to a focus on self-defined meaning of success has the potential to be transformative in individuals, as seen in the lives of the research participants. Asking questions and listening to the stories of transformation related by Ted and Cal gave them voice and helps in finding meaning in their experiences. Together, as collaborators in this research effort, we hope that the telling and interpretation of their stories may help others to find their own personal and inimitable meaning of success after TBI.

Advocacy, community integration, and interconnectedness. Whiteneck, Gerhart, and Cusick (2004) found that the natural environment, aspects of surroundings, availability of transportation, others' attitudes, and governmental policies were the most predominant barriers identified by survivors of TBI. Rutherford and Wood (2006) performed a study that supports the theory of self-efficacy as a framework for explaining the nature of predictive relationships between psychosocial variables and long-term multidimensional outcomes after brain injury. The variables included employment, *community integration*, life satisfaction, and emotions. Fleming, Kuipers, Foster, Smith, and Doig (2009) reported that, like most aspects of brain injury, rehabilitation, community re-engagement, and adjustment is not a simple process. They found that the wide variation in outcomes is influenced by multiple contextual and individual factors. Viewing the issue of community integration and interconnectedness from an epistemological perspective, emancipatory knowledge claims are integral to success and may be operationalized as goals achieved (i.e., transportation, productive employment) in the context of life satisfaction. *Emancipatory knowing* is defined here as "the human ability to recognize social and political problems of injustice or inequity, to realize that things could be different, and to piece together complex elements of experience and context to change a situation as it is to a situation that improves people's lives" (Chinn & Kramer, 2011, p. 64). For instance, the return to driving has been identified as the most important goal by many TBI survivors. It supersedes any other functional limitation (Rapport, Hanks, & Bryer, 2006), which seemed to be consistent with Ted and Cal's experiences. Furthermore, Rapport and colleagues (2006) found that "survivors who had not resumed driving showed poorer community integration that did those who had resumed driving" (p. 34), highlighting a linkage between driving and community integration.

The International Classification of Functioning, Disability and Health (ICF; WHO, 2001) is a framework that describes the contribution of participation in life roles in the community, health condition, and personal and environmental factors. The ICF defines environmental factors as the social, physical, and attitudinal environment in which people conduct their lives (WHO, 2001). Ted and Cal were fortunate to have a supportive environment in the homes of their mothers, which facilitated reentry to family life and support in recovery and rehabilitation, as well as support from their fathers in their work environments. Their living and working environments resonated with their spiritual, emotional, and physical well-being, enhancing their satisfaction with life and quality of life. The ability of young adults to optimize function and live productive lives in their

communities after TBI depends in part on social determinants of community support and integration, especially in the area of access to adequate health care.

The participants looked at their community and the reality of their lives through their own lens, thought and talked about specific issues of concern, and then voiced those ideas to me, hoping to help others who may go through similar experiences. Agar (2002) proposed, "Language fills the spaces between us with sound; culture forges the human connection through the. (p. 28)." A shared perception of the world allows for perpetuating and thriving of human groups. Individuals think and feel and are wired to form interrelationships with others for social interaction and for survival. The connection extends to communities where there is interdependence for the means of survival. Layers of consequence unfold with patterns and ways of life that are meaningful and familiar to each member in a community. Each person reaches out and adapts for survival, as shown in the research participants' lived experience of TBI. Comprehension and appreciation of the interconnectedness of people within their environments is pivotal to this research to understand the barriers to and facilitators of success after TBI.

## **Reflections on Method**

## **Methodological Rigor**

My aim in conducting this study was to produce work that is defensible because it is plausible, credible, and trustworthy (Denzin & Lincoln, 2011; Lincoln & Guba, 1985). Keeping field notes, journaling, and using iterative processes in data analysis provided the audit trail and reflective backdrop for rigor. Collaborative efforts, including member checking and debriefing with peers and faculty members, were vital additional components of the study. All of Johnson's (1997) types of internal validity in qualitative research were sought, including descriptive, interpretive, and theoretical components. Factual accuracy throughout the research process afforded a high degree of descriptive validity. Understanding and accurate reporting of participants' intentions, thoughts, emotions, and experiences was integral to study design and strengthened the interpretive validity of the study. Theoretical validity was scrutinized with respect to self-efficacy using tabulations for clarity of presentation.

## Merging Ethnography and Case Study

*Ethnographic* methods were congruent with the case study processes of sequencing action, categorizing properties, and tallying intuitive aggregations. The purpose of traditional ethnography was to write descriptions of the study participants based on observation and interviews of participants in the context of place, customs, culture, and language. It is important to remember that in both instrumental case study and ethnography, some important features appear only once (Stake, 1995). Examples of this are the experience of forgiveness that Cal reached or the sense of survival that Ted expressed. Merging case study research with ethnography yielded findings that present a deeper, more explanatory view of the participants' TBI experiences.

## **Review of Assumptions and Discussion of Limitations**

## **Researcher Assumptions**

The assumptions for the study were: (a) self-defined success is positively affected by self-efficacy, (b) the research findings will have transferability, and (c) providing an opportunity for participants to voice their thoughts, feelings, and concerns was expected to provide some degree of heightened awareness and empowerment for the research participants. I anticipated that, in correspondence with the assumptions, the research would

contribute to theory, practice, and policy. In retrospect, I found that the assumptions for the study worked well and were valid. It would have been better and more informative to conduct a longer term study with ongoing dialogue.

#### Self-Defined Success Is Positively Affected by Self-Efficacy

After examining the findings, it is evident that self-defined success and self-efficacy are bidirectional, as shown in the life experiences of the research participants. A review of terms will clarify the assumption that self-defined success is positively affected by selfefficacy. The definition of *self-efficacy* is one's belief in one's ability to succeed and is based on self-perception. The definition of *success* is the achievement of something desired, planned, or attempted.

Characteristics of self-belief, self-regulation, self-control, and creative problem solving are typical in individuals with high self-efficacy and were communicated in the interviews by both participants. The emphasis on success and successful living proved to be particularly useful in interpretation of the barriers and facilitators of success, revealing that although Ted and Cal had significant barriers to face after TBI, they were successful in overcoming the challenges and reaching a state of life satisfaction. Both participants communicated that they were completely satisfied with their lives. The focus on success also helped to elucidate the dynamic of individual and family systems that emerged through the experience of TBI, facilitating successful recovery and rehabilitation. Ted's and Cal's sensemaking process was streamlined by the participants' supportive family and home environments. The support was synergistic, empowering Ted and Cal to recover and reach their everyday goals and proceed with confidence toward their long-term goals. Productivity in work and independence were found to be key factors of success for our participants, providing a source of positive ongoing self-assessments for them.

The research design using two descriptive quantitative self-efficacy questionnaires, coupled with interview data, provided evidence of high levels of self-efficacy before and after the TBI experience in our research participants. The questionnaires provided a self-assessment of self-efficacy primarily at the time of administration of questionnaires, whereas the interview covered both pre-injury and post-injury states. Thus, coupling of the descriptive and interview data was necessary to determine whether self-efficacy levels were high before and after TBI.

Ted and Cal had a myriad of challenges to overcome after TBI. Just a few of those included feeling marginalized and disabled, inability to speak, feeling useless and unable to care for themselves, depression, PTSD, inability to drive, and dealing with rejection and abandonment by girlfriends. Neither Ted nor Cal was overcome by the challenges. Instead, they systematically faced each barrier and found a way to adapt and succeed.

## The Research Findings Will Have Transferability

My second assumption was that the research findings would have transferability. The case study approach triangulated with ethnographic methods enabled the reader to capture the depth of experience in the context of the participants' everyday lives, increasing transferability. Care was taken to set the data in the context of the extant literature, in both the literature review and interpretation of findings, allowing the reader to establish gradients of similarity for contexts, times, settings, and people between the data and the literature. This researcher acknowledges that the participants' stories portray index cases for successful recovery after moderate to severe TBI, representing possibilities rather than probabilities.

Nonetheless, Ted's and Cal's experiences are real and provide a measure of hope and a potential pathway of success for those who have experienced TBI. Therefore, the research findings may have transferability in some contexts and may be useful in empowering and encouraging young adult survivors of TBI, along with their families. However, transferability is something best judged by additional researchers using different samples and settings (Lincoln & Guba, 1985).

## **Providing an Opportunity for Voice**

My third assumption was that providing an opportunity for participants to voice their thoughts, feelings, and concerns would provide some degree of heightened awareness and empowerment for the research participants. Ted and Cal were motivated to participate in the research so that they might help others who may be going through similar experiences. Ted said that one of the things that had helped him most in his recovery was having someone to ask him questions. The interview process gave Ted the opportunity to voice his thoughts, feelings, and concerns in the context of helping others. Ted is a young man who likes to help and provide for others. He enjoys sharing. The research experience was a positive experience for him, as he became the expert, teaching about how TBI affected his life.

Cal has a warm personality, and he obviously enjoys making other people happy. Cal explained how helpful and cathartic it was for him to tell his psychiatrist about his feelings and experiences. In the research process, Cal again had the opportunity to voice his thoughts, feelings, and concerns in a different context. In the interview process, Cal, like Ted, became the expert. It was an empowering position for him, and by the end of the interview, it was apparent that he had a grasp on self-efficacy theory. Cal came into the research experience with an informed stance in that he had written several research projects for publication during

his undergraduate studies in chemistry. The hope is that he left the research experience feeling that he was making a contribution to expanding knowledge concerning success after TBI.

## **Limitations of the Study**

Limitations of the study included the following:

1. The limited sample size of two interviews. It was challenging to (a) recruit for the study due to the paucity of potential participants, and (b) schedule the interviews due to the busy working lives of the participants. These challenges resulted in several instances of participants being unable to make the interview after having scheduled the time. Discussions with the clinical expert prior to the study posed the belief that sufficient numbers of eligible participants would materialize. Additionally, following the participants over time would have been preferable, if researcher and participant time constraints had allowed. As it turned out, however, the interviews provided rich narratives of their experiences.

2. The diversity of the sample was limited to young Hispanic males. Both participants self-identified as Latino—one as "Hispanic" and one as "Mexican." With respect to codes for ethnicity and race, Hispanic or Latino may refer to a person of Mexican or other Spanish culture or origin, regardless of race (Census Data, 2014). In New Mexico, there are numerous other categories of young adults living with a TBI. Future studies of this population should include a more detailed and diversified recruitment strategy.

3. Selection bias manifested as a lack of participants who met inclusion criteria, necessitating the change to the instrumental case study approach that was used in conjunction with ethnographic methods. One aspect of inclusion criteria was being able to speak and read English after a moderate to severe TBI injury. This likely filtered for individuals who had

achieved a higher level of recovery. Both of our participants were unable to speak, read, or write for a short time after their TBI. However, both had recovered these skills to a large extent by the time of the interviews at 9 and 12 months post-TBI. It was primarily the decision to study the young adult age group that limited the number of participants available for recruitment at the institution where the study was conducted, resulting in the need to use a case study approach with only two participants (see Chapter 3 for details).

As it happened, the two participants had surprising similarities in many respects and diverged widely with respect to the path of their lives, particularly in their lifestyles preinjury. I recognize and accept that these two case studies may be viewed as outliers, exhibiting extraordinarily good recovery with exemplary family support. The advantage of this limitation is that the participants' experiences may demonstrate index cases of recovery and interconnection with family, providing reason for hope that success is achievable by young survivors of TBI, and charting a course for family involvement as part of a comprehensive care plan after TBI in young adults.

4. Limitations of this study parallel known weaknesses of case study approaches, including: (a) selection bias may overstate or understate relationships; (b) a weak understanding of the occurrence in the population with the phenomenon under study; and (c) statistical significance is unknown (Flyvbjerg, 2011), although in an ethnographic study, statistical significance is neither the point nor the outcome of sample selection. To mitigate these limitations, incidence and prevalence statistics were used to convey an understanding of the occurrence of TBI in the young adult population. Additionally, statistics regarding the reliability and validity of measurement instruments were explained in the context of the literature. The limitations common to case study approaches were also managed using case study analysis criteria, including seeking to disconfirm findings, reviewing data according to several possible interpretations, using established measurement instruments to place the participants on known continuums, and using an iterative case study approach seeking patterns and linkages, drawing conclusions, and then reviewing the data again (Stake, 1995).

5. Finally, there was the limitation of possible researcher bias. As individuals in a sociocultural context, we hold biases acquired since birth and shaped by work, education, and environmental influences. This researcher has worked for many years as a nurse and as a physician assistant in emergency, neurosurgical, and rehabilitation care settings. Reflexivity may serve as an approach to acknowledging, processing, and contextualizing one's bias (Lincoln & Denzin, 2002). Before conducting the interviews. this researcher reflected on what impression my person might make on the participants, and attempts were made to neutralize my presence to maintain the attention on the importance of their role in the research endeavor. For example, this researcher wore plain clothing and listened attentively to their stories. To assist in the data collection, phase field notes were kept, detailing all research activities, dates, locations, and observations. A researcher's journal of reflections, feelings, thinking, experiences, and perceptions was also kept throughout the research process (Fetterman, 2010; Lincoln & Denzin, 2002; Silverman, 2005).

#### **Conclusions and Implications for Future Investigations**

This study provided insights into the dynamics of behavioral, social, and emotional functioning of two young adult survivors of TBI through the use of ethnographic methods, augmented by reliable and valid descriptive questionnaires and case study analysis. The brains of young adults through age 25 are still developing connections in the frontal lobes for

tasks such as attention, inhibition, and high-level functioning (Lebel & Beaulieu, 2011). Although modest, the study may contribute knowledge and information that can enhance interventions to optimize self-efficacy and increase the level of self-defined success in young adults in their first year after TBI. Future investigations might explore questions such as: What are the elements of a transformative experience? How do young adults progress at 1 year, 2 years, and 5 years post-TBI? Would an educational program designed to increase selfefficacy result in increased levels of self-defined success in young adult survivors of TBI? Additionally, future studies should include adult family members in the sample, since their perspectives as caregivers would enrich the overall understanding of life after a TBI. Similarly, it would be valuable to do a comparison study between young adult TBI survivors from the public sector and TBI survivors with military injuries to examine where perceptions, experiences, and recoveries diverge or converge.

## **Implications for Young Adult Survivors of TBI**

Of the important findings reported, what was most unanticipated was that the two very different young men had a similar transformative experience after their TBI. Their experiences fueled their energy into positive lifestyle changes post-TBI. Their personal cultures diverged, even though their family cultures had close similarities. Evidence here suggested that family participation in recovery was pivotal for both Ted and Cal. Thus, a second conclusion was that both of their family systems self-organized to facilitate successful recovery for these young men after their TBI. Lessons learned about family dynamics and potential roles in recovery may be valuable to others in similar situations.

Finally, abandonment by a girl occurred in both cases. Responses to both abandonments included anger, followed by forgiveness, making sense, and finding meaning in the experience of loss. Both men experienced simultaneous losses of relationships and their usual states of health. The men's capacity for rebounding and remaining resilient provides valuable insights into how young people may approach life after a TBI. These are true stories of courage from which lessons of life can be learned. Knowledge of recovery gleaned from the research participants may contribute to understanding how to improve outcomes, including self-efficacy, successful living, life satisfaction, rehabilitation, health promotion, and quality of life, in young adult survivors of TBI.

## **Nursing Practice Implications**

Favorable outcomes may be achieved for patients and nurses through implementation of theory-based actions. Self-efficacy is a key theory and is seen in health promotion, educational studies, and motivational and behavioral research. It is also common to the disciplines of nursing, sociology, and psychology. Implementation of protocols derived from self-efficacy theory has provided nurses with frameworks for patient education initiatives, strategies for professional growth and development, and increased understanding of how people are motivated to action.

## **Policy Implications**

The state of New Mexico stands out as an example of how legislative action and enforcement of laws, or inaction in the case of motorcycle helmet laws, can impact injury prevention. Deaths related to motor vehicle traffic injuries have dropped precipitously since 2007, presumably due to stricter enforcement of DWI laws and the primary seat belt law, whereas motorcycle deaths are up 100% (Hubbard, 2012). Helmet laws for children in New Mexico are exemplary, and the effect of children becoming socialized to wearing helmets will likely benefit young adults as well. It is hoped that the decline in young adults with moderate to severe brain injury requiring hospitalization at the institution where the study was conducted during the time frame of this study (2012-2013) reflects the overall downward trends reported by health epidemiologist Hubbard (2012) and that the downward trend will continue.

For those young adults who have had a TBI, adequate insurance coverage and access to supportive care after the injury for therapies and counseling is a top priority. Community resources, such as the Brain Injury Alliance of New Mexico (2011), serve to identify needs in the community, provide support, and hopefully ease transition for survivors of TBI to an optimal state of health after injury. A *comprehensive plan of care* should be developed by nurse case managers, including family education and support, at the time of discharge from the inpatient hospital stay. To activate a plan of care, health systems must provide for the services needed, and funding agencies need to allocate resources for rehabilitation and counseling. In the context of the Affordable Care Act in the United States, comprehensive care planning after TBI may become more difficult to achieve due to the increasingly segregated aspects of funding, accountability, and labor-intensive nursing and administrative tasks involved in activating such a plan. Proactive planning and directive policies may ease the transition.

#### **Final Thoughts**

Future critical ethnographic exploration of self-efficacy and success may possibly contribute to insight regarding how social determinants and contexts of health can become either barriers to or facilitators of success. Strategies are needed for developing and integrating educational, community, and systems-level responses, as well as consistent health care access for young adults who have had a TBI. In summary, self-efficacy, successful living, and quality of life in young adults with TBI may be benefit from mixed methods, collaborative research, improved health care access, and educational content designed to facilitate self-efficacy and success. In Bandura's words, "In order to succeed, people need a sense of self-efficacy, to struggle together with resilience to meet the inevitable obstacles and inequities of life" (BrainyQuote, 2014). Ted and Cal enriched what is known about these components of TBI in New Mexico.

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# APPENDICES

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# Appendix A

# Glasgow Outcome Scale-Extended

Patient's name:		Date of Interview:	
Date of Birth:	Date of Injury:	Gender: M / F	
Age at injury:	Interval post-injury:		
Respondent: Patient alone	Relative/friend/carer alone	Patient+relative/friend/c	carer
Interviewer:			
CONSCIOUSNESS			
1. Is the head injured person	able to obey simple commands	or say any words?	1=No (VS) 2=Yes
specifically in any other way is not reliable evidence of meaning	bey even simple commands, or u no longer considered to be in the gful responsiveness. Corroborate n the Royal College of Physiciar	e vegetative state. Eye me e with nursing staff. Con	ovements are
INDEPENDENCE IN THE HO	ME		
2a. Is the assistance of anothe	r person at home essential even	ry day for some	1=No
activities of daily living?			2=Yes
For a "No" answer, they should be able to look after themselves at home for 24 hours if necessary, though they need not actually look after themselves. Independence includes the ability to plan for and carry out the following activities: getting washed, putting on clean clothes without prompting, preparing food for themselves, dealing with callers, and handling minor domestic crises. The person should be able to carry out activities without needing prompting or reminding, and should be capable of being left alone overnight.			

2b. Do you need frequent help or someone to be around at home most	1=No (Upper SD)
of the time?	2=Yes (Lower SD)
For a 'No' answer they should be able to look after themselves at home for up to day if necessary, though they need not actually look after themselves.	8 hours during the
2c. Was assistance at home essential before the injury?    1=No	
2=Yes	

## INDEPENDENCE OUTSIDE THE HOME

3a. Are you able to shop without assistance:	1=No (Upper SD)
	2=Yes
This includes being able to plan what to buy, take care of money them appropriately in public. They need not normally shop, but must be able	
3b. Were you able to shop without assistance before the injury?	1=No
	2=Yes
4a. Are you able to travel locally without assistance?	1-No (Upper SD)
	2=Yes
They may drive or use public transport to get around. Ability to use a person can phone for it themselves and instruct the driver.	taxi is sufficient, provided the
4b. Were you able to travel without assistance before the injury?_	1=No
	2=Yes
5a. Are you currently able to work to your previous capacity?	_ 1=No
5a. Are you currently able to work to your previous capacity?	_ 1=No 2=Yes
5a. Are you currently able to work to your previous capacity? If they were working before, then their current capacity for work should were seeking work before, then the injury should not have adversely at obtaining work or the level of work for which they are eligible. If the injury then their capacity for study should not have been adversely affe	2=Yes ld be at the same level. If they ffected their chances of patient was a student before
If they were working before, then their current capacity for work shoul were seeking work before, then the injury should not have adversely a obtaining work or the level of work for which they are eligible. If the	2=Yes ld be at the same level. If they ffected their chances of patient was a student before
If they were working before, then their current capacity for work should were seeking work before, then the injury should not have adversely a obtaining work or the level of work for which they are eligible. If the injury then their capacity for study should not have been adversely affe	2=Yes ld be at the same level. If they ffected their chances of patient was a student before
If they were working before, then their current capacity for work should were seeking work before, then the injury should not have adversely at obtaining work or the level of work for which they are eligible. If the injury then their capacity for study should not have been adversely affe 5b. <b>How restricted are you</b> ?	2=Yes ld be at the same level. If they ffected their chances of patient was a student before fected.
If they were working before, then their current capacity for work should were seeking work before, then the injury should not have adversely at obtaining work or the level of work for which they are eligible. If the injury then their capacity for study should not have been adversely affe 5b. <b>How restricted are you</b> ? a) Reduced work capacity	2=Yes ld be at the same level. If they ffected their chances of patient was a student before fected.
If they were working before, then their current capacity for work should were seeking work before, then the injury should not have adversely at obtaining work or the level of work for which they are eligible. If the injury then their capacity for study should not have been adversely affe 5b. <b>How restricted are you</b> ? a) Reduced work capacity b) Able to work only in a sheltered workshop or non-competitive job,	2=Yes ld be at the same level. If they ffected their chances of patient was a student before ected. 1=a (Upper MD)

#### SOCIAL & LEISURE ACTIVITIES

6a. Have you been able to resume regular social and leisure activities	1=No
outside the home?	2=Yes

They need not have resumed all their previous leisure activities, but should not be prevented by physical or mental impairment. If they have stopped the majority of activities because of loss of interest or motivation then this is also considered a disability.

6b. What is the extent of restriction on your social and leisure activities?	
--	--

a)	Participate a bit less: at least half as often as before injury	1=a (Lower GR)
b)	Participate much less: less than half as often	2=b (Upper MD)
c)	Unable to participate	3=c (Lower MD)
6c. Did you engage in regular social and leisure activities		1=No
outside home before the injury?		2=Yes

## FAMILY AND FRIENDSHIPS

7a. Have there been psychological problems which have resulted	1=No
in ongoing family disruption or disruption to friendships?	2=Yes

Typical post-traumatic personality changes: quick temper, irritability, anxiety, insensitivity to others, mood swings, depression, and unreasonable or childish behavior.

If there were some problems before injury, but these have become markedly worse since injury then answer 'No" to Q7c.

#### Epilepsy:

Since the injury have you had any epileptic fits (seizures)? No / Yes

Have you been told that you are currently at risk of developing epilepsy? No / Yes

#### What is the most important factor in outcome?

Effects of head injury\_\_\_\_ Effects of illness or injury to another part of the body\_\_\_\_

A mixture of these\_\_\_\_\_

Scoring: The patient's overall rating is based on the lowest outcome category indicated on the scale. Refer to guidelines for further information concerning administration and scoring.

1 Dead

Score

2 Vegetative State (VS)

3 Lower Severe Disability (Lower SD)

4 Upper Severe Disability (Upper SD)

5 Lower Moderate Disability (Lower MD)

6 Upper Moderate Disability (Upper MD)

7 Lower Good Recovery (Lower GR)

8 Upper Good Recovery (Upper GR)

(Wilson, Pettigrew, & Teasdale, 1998)

## **Appendix B**

#### **TBI Self-Efficacy Questionnaire**

In each of the following questions, we would like to know how you feel about your TBI-related problems or cognitive disorder. For each of the following questions, please rate how certain you are that you can now perform the following activities or tasks. The scale ranges from 0-10. 0 indicates "Very Uncertain" and 10 indicates "Very Certain." *Please circle a number between 0 and 10*.

#### 0 = Very Uncertain, Very Certain = 10

1. How certain are you that you can prevent your TBI or cognitive disorder from interfering with your relationships with family and friends? 0 1 2 3 4 5 6 7 8 9 10

2. How certain are you that you can manage problems related to TBI or cognitive disorder so that you can do the things you enjoy? 0 1 2 3 4 5 6 7 8 9 10

3. How certain are you that you can deal with frustration, sadness, or other difficult emotions related to TBI or cognitive disorder?  $0 \ 1 \ 2 \ 3 \ 4 \ 5 \ 6 \ 7 \ 8 \ 9 \ 10$ 

4. How certain are you that you can solve problems related to TBI or cognitive disorder? 0 1 2 3 4 5 6 7 8 9 10

5. How certain are you that you can prevent your TBI or cognitive disorder from interfering with your ability to manage important personal affairs such as money, health care, and legal matters? 0 1 2 3 4 5 6 7 8 9 10

6. How certain are you that you can manage problems related to the TBI so that you can work, go to school, and/or take care of other similar life responsibilities? 0 1 2 3 4 5 6 7 8 9 10

(Cicerone & Azulay, 2007)

## Appendix C

#### **General Self-Efficacy Scale, English Version**

1. I can always manage to solve difficult problems if I try hard enough. 1=Not at all true, 2=Hardly true, 3=Moderately true, 4=Exactly true

2. If someone opposes me, I can find the means and ways to get what I want. 1=Not at all true, 2=Hardly true, 3=Moderately true, 4=Exactly true

3. It is easy for me to stick to my aims and accomplish my goals. 1=Not at all true, 2=Hardly true, 3=Moderately true, 4=Exactly true

4. I am confident that I could deal efficiently with unexpected events. 1=Not at all true, 2=Hardly true, 3=Moderately true, 4=Exactly true

5. Thanks to my resourcefulness, I know how to handle unforeseen situations. 1=Not at all true, 2=Hardly true, 3=Moderately true, 4=Exactly true

6. I can solve most problems if I invest the necessary effort. 1=Not at all true, 2=Hardly true, 3=Moderately true, 4=Exactly true

7. I can remain calm when facing difficulties because I can rely on my coping abilities. 1=Not at all true, 2=Hardly true, 3=Moderately true, 4=Exactly true

8. When I am confronted with a problem, I can usually find several solutions. 1=Not at all true, 2=Hardly true, 3=Moderately true, 4=Exactly true

9. If I am in trouble, I can usually think of a solution. 1=Not at all true, 2=Hardly true, 3=Moderately true, 4=Exactly true

10. I can usually handle whatever comes my way.1=Not at all true, 2=Hardly true, 3=Moderately true, 4=Exactly true

Response Format: 1=Not at all true, 2=Hardly true, 3=Moderately true, 4=Exactly true

(Schwarzer & Jerusalem, 1993)

# Appendix D

# **Demographic Survey**

1.	What is your age in years?
2.	How many years of education have you had starting with Grade 1?
3.	What was your occupation before your TBI?
4.	What is your occupation now?
5.	What was the cause of your TBI?
6.	How long were you hospitalized in an acute care setting after your TBI?
7.	Did you go to inpatient Rehab after you were hospitalized?; if so, how many
	days did you stay at inpatient Rehab
8.	What are your living arrangements?
9.	Do you consider yourself to be Hispanic/Latino?
Yes	
No_	
	addition, select one or more of the following racial categories to describe yourself: American Indian or Alaska Native Asian Black or African American Native Hawaiian or Pacific Islander White
	winte

Appendix E

**Recruitment Flyer** 

# Volunteers Wanted for a Study at the University of New Mexico

Study Title: Collaboration for Success in

Young Adults with Traumatic Brain Injury

*Purpose* of the research is to explore how young adults can achieve success and have a sense of satisfaction in life after a TBI.

*Eligibility criteria*: age 18-26; able to speak, read, and understand English; moderate to severe brain injury affecting the frontal lobes of the brain that required hospitalization; 2-12 months post-TBI at the time of the interview; willingness to participate; and decision making capacity.

Benefits of participation: There is a potential for increased awareness of selfefficacy leading to self-confidence, mastery, goal setting, and self-defined success. A \$20 gift card will be given to thank you for your time and participation at the conclusion of the study.

Principal Investigator: Jennifer Averill PhD, RN, UNM College of Nursing Co-Investigator: Barbara Cechanowicz, RN, MS, PhD(C) UNM College of Nursing

# To learn more about this research

Please call (505) 280-3728, or email <u>bcechanowicz@salud.unm.edu</u>

## Appendix F

## **Interview Guide**

- 1. What are some of your goals since your TBI?
- 2. Tell me about how you have met one of your goals.
- 3. When you are confronted with stress or a problem, how do you go about finding a solution?

Probe: Please share a specific example of how you did this for a particular problem. Do you see

yourself as a creative problem solver? In what ways?

- 4. Describe how you handle stress and challenges that come your way.
- 5. How would you define success in your life?

Probes: What makes something successful for you? Can you give me an example of when this

happened? For second interview: How have things changed since the last time we talked about this?

- 6. What things do you feel have held you back from being successful? And what things have made it easier for you to succeed?
- 7. What kind of support system do you have?

Probes: Family? Friends? Health care providers? Others?

8. Are you satisfied with your life?

*Probes*: If not, what would you change? If so, tell me about what gives you a sense that things are going well?

- 9. What are your plans for the future?
- 10. Is there anything else you want to tell me?

Version Date: 9/3/12

HRRC#: 12-506

#### Appendix G

#### **IRB** Approval Letter, 2012



Human Research Review Committee MSC 08 4560 BMSB Room B71 1 University of New Mexico-Albuquerque, NM 87131-0001 (505) 272-1129 Facsimile (505) 272-0803 http://hsc.unm.edu/som/research/hrrc/

30-Oct-2012

Averill, Jennifer B, Ph.D. College of Nursing

SUBJECT: HRRC Approval of New Research Protocol HRRC#: 12-506 Study Title: Collaboration for Success in Young Adults with TBI Type of Review: Expedited Review Approval Date: 30-Oct-2012 Expiration Date: 29-Oct-2013

Dear Dr. Averill:

The Human Research Review Committee (HRRC) has reviewed and **approved**\* the above-mentioned research protocol including the following:

1. Study application submitted 10/29/12.

2. Consent version 102912.

3. Demographic survey submitted 09/19/12.

4. Evaluation to consent submitted 09/19/12.

5. Self efficacy scale submitted 09/19/12.

6. TBI self efficacy questionnaire submitted 09/19/12.

7. Glasgow outcome scale 09/19/12.

8. Inclusion criteria worksheet submitted 09/19/12.

9. Interview guide submitted 09/19/12.

10. Recruitment flyer submitted 09/19/12.

11. Study protocol submitted10/29/12.

Consent decision: Requires a signed consent form Consent and HIPAA included in same document

If a consent is required, we have attached a date stamped consent that must be used for consenting participants during the above noted approval period.

If HIPAA authorization is required, the HIPAA authorization version noted above should be signed in conjunction with the consent form.

This study is approved to enroll only the number of subjects listed in the application, protocol and consentform(s). If the PI wants to enroll additional subjects, it is the responsibility of the PI to submit an Amendment/Change to the HRRC before the approved number of enrolled subjects is exceeded. If increased enrollment is requested, the application, protocol and/or consent form(s) must also be amended to include the new target.

Sincerely,

116 123

Mark Holdsworth, PharmD Executive Chair Human Research Review Committee

\* Under the provisions of this institution's Federal Wide Assurance (FWA00003255), the HRRC has determined that this proposal provides adequate safeguards for protecting the rights and welfare of the subjects involved in the study and is in compliance with HHS Regulations (45 CFR 46), FDA Regulations (21 CFR 50, 56).

## Appendix H

## **IRB** Approval Letter, 2013



Human Research Review Committee Human Research Protections Office

October 30, 2013

Jennifer Averill JAverill@salud.unm.edu

Dear Dr. Averill:

On 10/29/2013, the HRRC reviewed the following submission:

Type of Review:	Continuing Review
Title of Study:	Collaboration for Success in Young Adults with TBI
Investigator:	
Study ID:	12-506
Funding:	None
Grant ID:	None
IND, IDE, or HDE:	None
Documents Reviewed:	Continuing Review submitted 9/14/2013     Last Signed Consent     Progress Report 9/13/2013     COI Disclosure Cover sheet v10/2013     Combined Consent HIPAA Form v10/29/2012
	12-506 Protocol v9/3/2012     Study Personnel List v10/2013- Attachment 1     Demographic Survey v9/3/2012     Evaluation to Sign Consent Form v9/3/2012
	Glasgow Outcome Scale Extended v9/3/2012     Recruitment Flyer v9/3/2012
	Diagram Self-Efficacy Theory v9/3/2012     General Self-Efficacy Scale v9/3/2012     Inclusion Criteria Form v9/3/2012
	<ul> <li>Interview Guide v9/3/2012</li> </ul>
	TBI Self-Efficacy Questionnaire v9/3/2012
Review Category:	Expedited
Determinations/Waivers:	Consent and HIPAA included in same document

The HRRC approved the study from 10/29/2013 to 10/29/2014 inclusive. Before 10/29/2014 or within 30 days of study closure, whichever is earlier, you are to submit a continuing review with required explanations. You can submit a continuing review by navigating to the active study and clicking Create Modification / CR.

If continuing review approval is not granted before the expiration date of 10/29/2014, approval of this study expires on that date.

The University of New Mexico + MSC08 4568 + 1 University of New Mexico + Alimpsorque, UM \$7131-0001 + Phone 505.072.0109 + Fax 505.072.0503 + hsc.unm.edu/som/research/hrvc + BRSR 877

Page 1 of 2

This determination applies only to the activities described in the submission and does not apply should any changes be made to these documents. If changes are being considered and there are questions about whether HRRC review is needed, please submit a study modification to the HRRC for a determination. A change in the research may disqualify this research from the current review category. You can create a modification by clicking Create Modification / CR within the study.

In conducting this study, you are required to follow the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library.

Sincerely, Uh

Mark Holdsworth, PharmD Executive Chair

The University of New Mexico + MSC00 4560 + 1 University of New Mexico + Albuquergue, NM 87131-0001 + Phone 505 272.0129 + Pax 505 272.0801 + hzzunm.edu/som/research/hurc + BMSB 871 Page 2 of 2

## Appendix I

## **Research Participant Inclusion Criteria**

1) Age 18-26? YES\_\_\_ NO\_\_\_\_

2) Ability to speak, read, and understand English? YES\_\_\_\_ NO\_\_\_\_

3) Reported medical diagnosis of moderate to severe traumatic brain injury affecting the frontal lobes that required hospitalization in an acute care setting? YES\_\_\_\_ NO\_\_\_\_

4) 2-12 months post-TBI at the time of the interview? YES\_\_\_\_ NO\_\_\_\_

5) Willingness to participate? YES\_\_\_\_ NO\_\_\_\_

6) Decision-making capacity? YES\_\_\_\_ NO\_\_\_\_

7) Able to respond to questionnaires and interviews independently? YES\_\_\_\_ NO\_\_\_\_

1. Initials of participant \_\_\_\_\_

2. Email address \_\_\_\_\_

3. Phone number \_\_\_\_\_

# Appendix J

## **Consent Evaluation**

## Study Title: Collaboration for Success in Young Adults with Traumatic Brain Injury Principal Investigator: Jennifer Averill, RN, PhD Co-Investigator: Barbara Cechanowicz, RN, PhD Candidate

# EVALUATION TO SIGN A CONSENT FORM FOR RESEARCH

Name: \_\_\_\_

Date of birth:

Direction: Make a subjective judgment regarding item 1 below. Ask the patient questions 2 through 5. The evaluator may select the appropriate language to use in formulating the questions in order to assist the subject's understanding.

Items:

- 1) Is the patient alert and able to communicate with the examiner? \_\_\_\_ Yes \_\_\_\_ No
- 2) Ask the patient to name at least two (2) potential risks incurred as a result of participating in the study.
- 3) Ask the patient to name at least two things that will be expected of him/her in terms of patient cooperation during the study.
- 4) Ask the patient to explain what he/she would do if he/she decides that they no longer wish to participate.
- 5) Ask the patient to explain what he/she would do if he/she is experiencing distress or discomfort.

I hereby certify that the above patient is alert, able to communicate, and able to give acceptable answers to items 2, 3, 4 and 5 above.

Evaluator
-----------

Date

Witness

Date

(University of California, San Diego, 2012)

### Appendix K

### **Consent to Participate**, 2012

#### 1

### The University of New Mexico Health Sciences Center

#### **Consent to Participate in Research**

### Collaboration for Success in Young Adults with Traumatic Brain Injury

#### October 29, 2012

### Purpose and General Information

You are being asked to participate in a research study that is being done by Jennifer Averill, RN, PhD in Nursing, who is the Principal Investigator, and Barbara Cechanowicz, RN, PhD Candidate in Nursing. This research is being done to evaluate and explore how young adults with TBI make sense of their everyday lives; and to answer the question "What are the barriers to and facilitators of success in young adults who have had a traumatic brain injury?" You are being asked to participate because you meet the inclusion criteria for participation in the study. Approximately 10-15 people will take part in this study at the University of New Mexico.

This form will explain the study to you, including possible risks as well as the possible benefits of participating. This is so you can make an informed choice about whether or not to participate in this study. Please read this Consent Form carefully. Ask the investigators or study staff to explain any words or information that you do not clearly understand.

#### What will happen if I participate?

HRPO #

If you agree to be in this study, you will be asked to read and sign this Consent Form. After you sign the Consent Form, the following things will happen: You will participate in a study exploring self-efficacy and success after traumatic brain injury. The objective is to support individuals through advocacy and action. The Co-Investigator, Barbara Cechanowicz, will talk with you about how things are going in your life. She would like to know what success means to you; and about your self-confidence, self-efficacy, your goals, and problem solving; as well as your activities, relationships, and health. Sample questions might include: (1) Tell me about how you have met one of your goals since your TBI. (2) How would you define success in your life?

The study will involve patients who are seen in the UNM Neuropsychology Clinic in the first year after their TBI. Data collection will take place at your Neuropsychology Clinic and will include: 10 minutes to take two short questionnaires (6 questions and 10 questions) and a demographic survey; and then a 60 minute face-to-face interview which will also include talking about questions on an outcomes questionnaire. The study will

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The Univer	sity of New Mexico Institutional Review Board	(HRRC/MCIRB)

conclude after questionnaires are answered, and the interview is complete. Participation in this study will take a total of 1 hour and 10 minutes on one day. A \$20 gift certificate will be given to you as a thank you for your time and participation.

Participation in this study will take a total of one to two hours over a period of one day required for participation.

What are the possible risks or discomforts of being in this study? Every effort will be made to protect the information you give us. However, there is a small risk of loss of privacy and/or confidentiality and/or stress.

## How will my information be kept confidential:

Your name and other identifying information will be maintained in locked files, available only to authorized member of the research team, for the duration of the study. For any information entered into a computer, the only identifier will be a unique study identification (ID) number. Any personal identifying information and any record linking that information to study ID numbers will be destroyed when the study is completed. Information resulting from this study will be used for research purposes and may be published; however, you will not be identified by name in the publications.

Information from your participation in this study may be reviewed by federal and state regulatory agencies, and by UNM Human Research Review Committee (HRRC) which provides regulatory and ethical oversight of human research. There may be times when we are required by law to share your information. However, your name will not be used in any published reports about this study.

### What are the benefits to being in this study?

There may or may not be direct benefit to you from being in this study. However, your participation may help find out how self-efficacy and self-confidence can positively affect self-defined success in young adults after a traumatic brain injury.

#### What other choices do I have if I don't participate?

Taking part in this study is voluntary so you can choose not to participate.

### Will I be paid for taking part in this study?

A \$20 gift certificate will be given to you as a thank you for your participation at the conclusion of your interview.

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The Univer	sity of New Mexico Institutional Review Board	(HRRC/MCIRB)	

What will happen if I am injured or become sick because I took part in this study? If you are injured or become sick as a result of this study, UNMHSC will provide you with emergency treatment, at your cost.

No commitment is made by the University of New Mexico Health Sciences Center (UNMHSC) to provide free medical care or money for injuries to participants in this study.

In the event that you have an injury or illness that is caused by your participation in this study, reimbursement for all related costs of care will be sought from your insurer, managed care plan, or other benefits program. If you do not have insurance, you may be responsible for these costs. You will also be responsible for any associated co-payments or deductibles required by your insurance.

# How will I know if you learn something new that may change my mind about participating?

You will be informed of any significant new findings that become available during the course of the study, such as changes in the risks or benefits resulting from participating in the research or new alternatives to participation that might change your mind about participating.

#### Can I stop being in the study once I begin?

Yes. You can withdraw from this study at any time without affecting your access to care.

The investigators have the right to end your participation in this study if they determine that you no longer qualify to take part, if you do not follow study procedures, or if it is in your best interest or the study's best interest to stop your participation.

# HIPPA Authorization for Use and Disclosure of Your Protected Health Information (HIPAA)

As part of this study, we will be collecting health information about you and sharing it with others. This information is "protected" because it is identifiable or "linked" to you.

#### Protected Health Information (PHI)

By signing this Consent Document, you are allowing the investigators and other authorized personnel to use your protected health information for the purposes of this study. This information may include: medical history, date of injury, and type of injury. In addition to researchers and staff at UNMHSC and other groups listed in this form, there is a chance that your health information may be shared (re-disclosed) outside of the research study and no longer be protected by federal privacy laws. Examples of this HRPO #:

Varian

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The Unive	ity of New Mexico Institutional Review Boa	rd (HRRC/MCIRB)

include disclosures for law enforcement, judicial proceeding, health oversight activities and public health measures.

### **Right to Withdraw Authorization**

Your authorization for the use and disclosure of your health information for this study shall not expire unless you cancel this authorization. Your health information will be used or disclosed as long as it is needed for this study. However, you may withdraw your authorization at any time provided you notify the UNM investigators in writing. To do this, please send letter notifying them of your withdrawal to:

Jennifer Averill, RN, PhD MSC 1 University of New Mexico Albuquerque, New Mexico 87131

Please be aware that the research team will not be required to destroy or retrieve any of your health information that has already been used or shared before your withdrawal is received.

#### **Refusal to Sign**

If you choose not to sign this consent form and authorization for the use and disclosure of you PHI, you will not be allowed to take part in the research study.

#### What if I have questions or complaints about this study?

If you have any questions, concerns or complaints at any time about the research study, Jennifer Averill, RN, PhD, or her associates will be glad to answer them at (505) 272-0859 from 9:00am-3:00pm / Monday-Friday. If you would like to speak with someone other than the research team, you may call the Human Research Review Committee (HRRC) at (505) 272-1129. The HRRC is a group of people from UNMHSC and the community who provide independent oversight of safety and ethical issues related to research involving human participants.

#### What are my rights as a research participant?

If you have questions regarding your rights as a research participant, you my call the Human Research Protections Office (HRPO) at (505 272-1129 or visit the HRPO website at

http://hsc.unm.edu/som/research.hrrc/.

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The Universit	y of New Mexico Institutional Review Board	(HRRC/MCIRR)

#### **Consent and Authorization**

You are making a decision whether to participate in this study. Your signature below indicates that you read the information provided (or the information was read to you). By signing this Consent Form, you are not waiving any of your legal rights as a research subject.

I have had an opportunity to ask questions and all questions have been answered to my satisfaction. By signing this Consent Form, I agree to participate in this study described in this Consent Form. A copy of this Consent Form will be provided to me.

		Name of Adult Participant (printed)
		Signature of Adult Participant/Date
OR		
		Name of LAR (printed)
	/	Signature of LAR/Date

I have explained the research to the participant and answered all of his/her questions. I believe that he/she understands the information in this consent form and freely consents to participate.

\_\_\_\_\_ Name of Research Team Member (printed)
\_\_\_\_\_/ \_\_\_\_ Signature of Research Team Member/Date

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The Universit	y of New Mexico Institutional Review Board	(HRRC/MCIRB)

## Appendix L

### **Consent to Participate, 2013**

#### The University of New Mexico Health Sciences Center

#### Consent to Participate in Research

#### Collaboration for Success in Young Adults with Traumatic Brain Injury

#### October 29, 2012

#### **Purpose and General Information**

You are being asked to participate in a research study that is being done by Jennifer Averill, RN, PhD in Nursing, who is the Principal Investigator, and Barbara Cechanowicz, RN, PhD Candidate in Nursing. This research is being done to evaluate and explore how young adults with TBI make sense of their everyday lives; and to answer the question "What are the barriers to and facilitators of success in young adults who have had a traumatic brain injury?" You are being asked to participate because you meet the inclusion criteria for participation in the study. Approximately 10-15 people will take part in this study at the University of New Mexico.

This form will explain the study to you, including possible risks as well as the possible benefits of participating. This is so you can make an informed choice about whether or not to participate in this study. Please read this Consent Form carefully. Ask the investigators or study staff to explain any words or information that you do not clearly understand.

### What will happen if I participate?

If you agree to be in this study, you will be asked to read and sign this Consent Form. After you sign the Consent Form, the following things will happen: You will participate in a study exploring self-efficacy and success after traumatic brain injury. The objective is to support individuals through advocacy and action. The Co-Investigator, Barbara Cechanowicz, will talk with you about how things are going in your life. She would like to know what success means to you; and about your self-confidence, self-efficacy, your goals, and problem solving; as well as your activities, relationships, and health. Sample questions might include: (1) Tell me about how you have met one of your goals since your TBI. (2) How would you define success in your life?

The study will involve patients who are seen in the UNM Neuropsychology Clinic in the first year after their TBI. Data collection will take place at your Neuropsychology Clinic and will include: 10 minutes to take two short questionnaires (6 questions and 10 questions) and a demographic survey; and then a 60 minute face-to-face interview which will also include talking about questions on an outcomes questionnaire. The study will conclude after questionnaires are answered, and the interview is complete. Participation in this study will take a total of 1 hour and 10 minutes on one day. A \$20 gift certificate will be given to you as a thank you for your time and participation.

Participation in this study will take a total of one to two hours over a period of one day required for participation.

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	The University of	f New Mexico Institutional Review	Board (HRRC)	

### What are the possible risks or discomforts of being in this study?

Every effort will be made to protect the information you give us. However, there is a small risk of loss of privacy and/or confidentiality and/or stress.

#### How will my information be kept confidential:

Your name and other identifying information will be maintained in locked files, available only to authorized member of the research team, for the duration of the study. For any information entered into a computer, the only identifier will be a unique study identification (ID) number. Any personal identifying information and any record linking that information to study ID numbers will be destroyed when the study is completed. Information resulting from this study will be used for research purposes and may be published; however, you will not be identified by name in the publications.

Information from your participation in this study may be reviewed by federal and state regulatory agencies, and by UNM Human Research Review Committee (HRRC) which provides regulatory and ethical oversight of human research. There may be times when we are required by law to share your information. However, your name will not be used in any published reports about this study.

#### What are the benefits to being in this study?

There may or may not be direct benefit to you from being in this study. However, your participation may help find out how self-efficacy and self-confidence can positively affect self-defined success in young adults after a traumatic brain injury.

#### What other choices do I have if I don't participate?

Taking part in this study is voluntary so you can choose not to participate.

#### Will I be paid for taking part in this study?

A \$20 gift certificate will be given to you as a thank you for your participation at the conclusion of your interview.

#### What will happen if I am injured or become sick because I took part in this study? If you are injured or become sick as a result of this study, UNMHSC will provide you with emergency treatment, at your cost.

No commitment is made by the University of New Mexico Health Sciences Center (UNMHSC) to provide free medical care or money for injuries to participants in this study.

In the event that you have an injury or illness that is caused by your participation in this study, reimbursement for all related costs of care will be sought from your insurer, managed care plan, or other benefits program. If you do not have insurance, you may be responsible for these costs. You will also be responsible for any associated copayments or deductibles required by your insurance.

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	The University of New Mexico Institutional Review Board (HRRC)					

#### How will I know if you learn something new that may change my mind about participating?

You will be informed of any significant new findings that become available during the course of the study, such as changes in the risks or benefits resulting from participating in the research or new alternatives to participation that might change your mind about participating.

### Can I stop being in the study once I begin?

Yes. You can withdraw from this study at any time without affecting your access to care.

The investigators have the right to end your participation in this study if they determine that you no longer qualify to take part, if you do not follow study procedures, or if it is in your best interest or the study's best interest to stop your participation.

# HIPPA Authorization for Use and Disclosure of Your Protected Health Information (HIPAA)

As part of this study, we will be collecting health information about you and sharing it with others. This information is "protected" because it is identifiable or "linked" to you.

#### Protected Health Information (PHI)

By signing this Consent Document, you are allowing the investigators and other authorized personnel to use your protected health information for the purposes of this study. This information may include: medical history, date of injury, and type of injury. In addition to researchers and staff at UNMHSC and other groups listed in this form, there is a chance that your health information may be shared (re-disclosed) outside of the research study and no longer be protected by federal privacy laws. Examples of this include disclosures for law enforcement, judicial proceeding, health oversight activities and public health measures.

#### **Right to Withdraw Authorization**

Your authorization for the use and disclosure of your health information for this study shall not expire unless you cancel this authorization. Your health information will be used or disclosed as long as it is needed for this study. However, you may withdraw your authorization at any time provided you notify the UNM investigators in writing. To do this, please send letter notifying them of your withdrawal to:

Jennifer Averill, RN, PhD MSC 1 University of New Mexico

Albuquerque, New Mexico 87131

Please be aware that the research team will not be required to destroy or retrieve any of your health information that has already been used or shared before your withdrawal is received.

#### **Refusal to Sign**

If you choose not to sign this consent form and authorization for the use and disclosure of you PHI, you will not be allowed to take part in the research study.

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	The University o	f New Mexico Institutional Review E	Board (HRRC)	

### What if I have questions or complaints about this study?

If you have any questions, concerns or complaints at any time about the research study, Jennifer Averill, RN, PhD, or her associates will be glad to answer them at (505) 272-0859 from 9:00am-3:00pm / Monday-Friday. If you would like to speak with someone other than the research team, you may call the Human Research Review Committee (HRRC) at (505) 272-1129. The HRRC is a group of people from UNMHSC and the community who provide independent oversight of safety and ethical issues related to research involving human participants.

### What are my rights as a research participant?

If you have questions regarding your rights as a research participant, you my call the Human Research Protections Office (HRPO) at (505 272-1129 or visit the HRPO website at

http://hsc.unm.edu/som/research.hrrc/.

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		f New Mexico Institutional Review Bo		

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#### **Consent and Authorization**

.

You are making a decision whether to participate in this study. Your signature below indicates that you read the information provided (or the information was read to you). By signing this Consent Form, you are not waiving any of your legal rights as a research subject.

I have had an opportunity to ask questions and all questions have been answered to my satisfaction. By signing this Consent Form, I agree to participate in this study described in this Consent Form. A copy of this Consent Form will be provided to me.

		Name of Adult Participant (printed)
	////////	Signature of Adult Participant/Date
OR		
11		Name of LAR (printed)
	1	Signature of LAR/Date

I have explained the research to the participant and answered all of his/her questions. I believe that he/she understands the information in this consent form and freely consents to participate.

	Name of Research Team Member (printed)
//	Signature of Research Team Member/Date

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		NM Human Research Protect		

# Appendix M

## **Final Codebook**

# Final Codebook With Tally of Codes From Interview Data for Ted and Cal

Ted	Cal	Critical Incident TBI	Ted	Cal	Self-Efficacy Characteristic	s	Ted	Cal	Barriers to Su	ccess
3	9	Transformation C-1	11	8	Creative thinking	E-1	2	5	Sadness/depression	B-1
4	0	Silver lining C-2	3	5	Adaptability	E-2	0	2	PTSD	B-2
2	3	Weathering the storm	5	3	Anger management	E-3	3	5	Anger	B-3
16	17	C-3 Positive change C-4	12	17	Recovery	E-4	2	6	Losses	B-4
			11	10	Not giving up	E-5	4	4	Abandonment	B-5
			8	9	Creative problem so	-	14	14	Cognitive changes	B-6
			11	7	Resiliency	E-6 E-7				
		Success Defined			Self-Reorganizatio	n			Facilitators of Suc	cess
7	1	Contentment S-1	10	7	Productivity/Work	R-1	7	7	Independence	F-1
5	11	Happiness S-2	9	11	Goal achievement	R-2	17	12	Family support	F-2
4	3	Life satisfaction S-3	0	3	New relationship	R-3	9	11	Caring	F-3
1	1	Inner peace S-4	7	10	Slowing down	R-4	0	7	Education	F-4
_					Successful rehabilita	ation	_	_		
2	4	Ambition S-5	15	22		R-5	0	5	Medical marijuana	F-5
12	13	Engaged with people <b>S-6</b>	7	13	Networking/connect	tions <b>R-6</b>	0	4	Prayer	F-6
		5-0				1 <b>1</b> -0	0	6	Gardening	F-6

# Appendix N

# Table N1. Summary of Findings and Framework for Interpretation of Findings

Research Questions Lenses	How do young adults who have had a TBI define success in their lives?	How do young adults who have had a TBI make sense of their everyday lives in terms of self- efficacy?	What are the barriers to and facilitators of success in young adults who have had a TBI?
Neuroscience viewpoint		Fluid and crystallized intelligence	
Advocacy viewpoints	Social determinants of health	Health equity Health care access	Interconnectedness and community integration
Participant viewpoints	<b>Critical incident/TBI:</b> Transformation Silver lining	<b>Self-efficacy characteristics:</b> Creative thinking Adaptability	Barriers to success: Sadness/depression PTSD
CODES	Weathering the storm Positive change	Anger management Recovery	Anger Losses
Demographics Questionnaires Interview data	C	Not giving up Creative problem solving Resiliency	Abandonment
	Success defined: Contentment Happiness Life satisfaction Inner peace Ambition Engaged with people	Self-Reorganization: Productivity/work Goal achievement New relationship Slowing down Successful rehabilitation Networking/connections	Facilitators of success: Independence Family support Caring Education Medical marijuana Prayer Gardening
Methodology viewpoints	<i>Case Study Approach</i> Complexity Chaos Transformation	<i>Ethnography Methods</i> Patterns of culture Adaptation Self-reorganization	<i>Collaborative Orientation</i> Connectivity Collaboration
PATTERNS	Pattern: Transformation followed the critical incident of TBI.	Pattern: Indicators of self- efficacy were present before and after the TBI.	Pattern: Self-efficacy underlies success and is built on a pattern of success
Theoretical viewpoints	Data mapping	Self-efficacy theory	Success
THEMES	Theme: One's definition of success is derived from both external and internal elements, creating a self-	Theme: Connection and support flow to and from friends and family.	Theme: Feelings of abandonment are associated with anger and depression.
	assessment of success.		Theme: Facilitators of success are in some measur relationship and environment dependent.

# Appendix O

# Table O1. Research Questions, Themes, Subthemes, and Patterns

1. How do young adults who have had a TBI define success in their lives?	2. How do young adults who have had a TBI make sense of their everyday lives, in terms of self- efficacy?	3. What are the barriers to and facilitators of success in young adults who have had a TBI?
<i>Theme</i> : One's definition of success is derived from both external and internal elements, creating a self-assessment of success.	<i>Theme:</i> Connection and support flow to and from friends and family.	<i>Theme:</i> Feelings of abandonment are associated with anger and depression.
<i>Subtheme:</i> External elements of success are productivity and independence.		<i>Theme:</i> Facilitators of success are in some measure relationship and environment dependent.
<i>Subtheme:</i> Internal elements of success are contentment, peace, joy, and happiness.		
<i>Pattern:</i> Transformation followed the critical incident of TBI.	<i>Pattern:</i> Indicators of self-efficacy were present before and after the TBI.	<i>Pattern:</i> Self-efficacy underlies success and is built on a pattern of success.

# Appendix P

# Table P1. Success Defined by Research Participants

Ted's Definition: Success	Cal's Definition: Success
<i>"Just to be content</i> , as long as I am content, that is success. Money doesn't mean a thing, you know Just be content. I can <i>work</i> for so much that I can work years, and not worry about whether I am good or not. Just be content, as long as I <i>make myself happy</i> that's all that matters, and to <i>make my family</i> <i>really happy</i> ."	"Going to <i>work</i> every day, and being <i>happy</i> with the <i>people</i> I'm around. I think success to me is more of a <i>feeling of joy inside</i> . Like, say, if I was doing a barbeque or something, watching everybody eat it. I would be happy. Their reactions to it would be success <i>Just being happy with myself</i> , that's what's going on in my life, and it is like a goal that I have reached."

# Appendix Q

# Table Q1. Self-Efficacy Matrix, Including Information Sources and Elements: Ted

	Indicators From Scales	TBI Self- Efficacy Scale	General Self- Efficacy Scale	Interview Data	Self-Efficacy Primary Information Sources/Focal Concepts	Self-Efficacy Characteristics
1.	Manage relationships	10/10		Self-control Use of exercise to manage anger	Physiologic feedback	Self-organizing Adaptation
2.	Enjoy activities	10/10		Happy/content	Performance experience Social persuasions	Self-reflecting Proactive Satisfaction
3.	Deal with emotions	5/10		Anger, sadness, depression, abandonment	Social persuasions Social persuasions Performance experience	Self-reflecting Self- administered punishment
4.	Solve problems Can think of solutions	10/10	4/4, 4/4, 4/4, 4/4	Creative solutions Can-do attitude	Role modeling Social persuasions Mastery experience	Self-belief Self-confidence Proactive
5.	Manage matters: Financial, legal, and health care	10/10		Saving money DWI gone Insured	Mastery experience Role modeling	Self-regulating Self-organizing
6.	Work, take care of life responsibilities	10/10		Ironworker, productive Provides for himself and others/family	Role modeling Mastery experience	Self-belief Self-sufficient Satisfaction Accomplishment
7.	Overcoming opposition		1/4	Recovery Family support Anger issues	Mastery experience Social persuasions	Accomplishment Interdependent Self-control
8.	Stick to aims Accomplish goals		4/4	Work, buy truck, drive, save money	Performance experience	Self-confidence Self-organizing Self-regulating

	Indicators From Scales	TBI Self- Efficacy Scale	General Self- Efficacy Scale	Interview Data	Self-Efficacy Primary Information Sources/Focal Concepts	Self-Efficacy Characteristics
9.	Confidence, dealing with the		3/4	Recovery	Physiologic feedback	Adaptation
	unexpected			Self-confidence	Mastery experience	Self-belief
10.	Resourcefulness, handling		3/4	Adaptability	Role modeling	Adaptation Self-organizing
	unforeseen			Survival	Physiological feedback	Self organizing
11.	Calm, relies on coping abilities		2/4	Issue: anger management	Social persuasions	Self-control
					Physiologic feedback	Self-regulating
12.	Can handle whatever		4/4	Independence	Mastery experience	Self-reflecting
	comes my way			Adaptability	Physiological feedback	Self-organizing
				· · ·		Self- reinforcement

# Appendix **R**

# Table R1. Self-Efficacy Matrix, Including Information Sources and Elements, Cal

	Indicators	TBI Self- Efficacy Scale	General Self- Efficacy Scale	Interview Data	Self-Efficacy Primary Information Sources/Focal Concepts	Self-Efficacy Characteristics
1.	Manage relationships	7/10		New relationship Connected	Social persuasions	Self-organizing Adaptation
2.	Enjoy activities	10/10		Engaged with people	Social persuasions	Self-reflecting
				Keep people smiling Work	Performance	Proactive Satisfaction
3.	Deal with emotions	10/10		Happy now Forgiveness Abandonment Was sad and hating life Felt useless Perceived as handicapped	Performance experience Success raised Self-efficacy Failure lowered Self-efficacy	Self-reflecting Self-organization Self- administered reward and punishment
4.	Solve problems Can think of solutions	9/10	4/4, 4/4, 4/4, 4/4	Creative problem solver Look at problem from every angle	Performance experience	Self-belief Self-confidence
5.	Manage matters: financial, legal and health care	7/10		Earning money Rehab at home, on own	Performance experience Social	Proactive Self-sufficient
				now	persuasions	Accomplishment
6.	Work, take care of life responsibilities	9/10		Back to work	Mastery experience	Self-belief Self-sufficient
	responsionnes			Enjoys social interactions at work, gardening with his brother, cooking for others	Social persuasions	Satisfaction

	Indicators	TBI Self- Efficacy Scale	General Self- Efficacy Scale	Interview Data	Self-Efficacy Primary Information Sources/Focal Concepts	Self-Efficacy Characteristics
7.	Overcoming opposition		3/4	Prayer	Mastery experience	Accomplishment
				Not giving up	Physiological feedback	Self-belief
8.	Stick to aims Accomplish goals		4/4	College graduation Pharmacy school	Mastery experience	Self-organizing Self-belief
	goais			Regaining skills	Social persuasions	Self-confidence
9.	Confidence, dealing with the unexpected		4/4	Feels well equipped Creative problem solver	Performance Social persuasions	Self-confidence Self-belief
10.	Resourcefulness, handling		4/4	First-generation college student	Role modeling	Satisfaction
	unforeseen			Never thought he would graduate from high school	Performance experience	Self- administered reward
				Able to get back on feet after TBI		Proactive
11.	Calm, relies on coping abilities		3/4	Peace within myself	Mastery experience	Self- administered
				Taking my time	_	reward
				Doing my best job solving problems		Self-regulating
12.	Can handle whatever comes		3/4	Weathered the storm Now I can only go up	Mastery experience	Self-reflecting
	my way				_	Self-organizing
				Did not give up	Physiological feedback	Self- reinforcement