THE DAILY LIVED EXPERIENCES OF TRAUMATIC BRAIN INJURY SURVIVORS: AN EXAMINATION OF THE EMOTIONAL, COGNITIVE, AND SPIRITUAL REPERCUSSIONS

by

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A Dissertation Presented in Partial Fulfillment

Of the Requirement for the Degree

Doctor of Education School of Behavioral Sciences

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Abstract

The purpose of this transcendental phenomenological study was to describe the experiences of traumatic brain injury survivors, seeking to understand their lived experiences by examining the emotional, cognitive and spiritual daily experiences. The study participants were adult male and female survivors of a life altering moderate to severe traumatic brain injury who live within the United States of America. The theories guiding this study are Jean Piaget's (1896-1980) Constructivism Theory and John Watson's (1878-1958) Behavioral Approach Systems Theory. Jean Piaget believes that all cognitive development progresses towards complex levels of organization. When an individual acquires new knowledge, it is received, evaluated and processed through the lens of the old knowledge (Piaget, 1968). John Watson's Behavioral Approach Theory believes that behavior is something that can be measured. Watson believes that the environment shapes the development of behavior in an individual and that behavior can be controlled and manipulated (Watson, 1930). For the purpose of this study, these theories provide relevant information concerning how individuals learn and process information surrounding their experiences with traumatic brain injury. Personal interviews were conducted using research questions designed to encourage information and personal sharing. An information gathering questionnaire provided additional detailed information about the emotional, cognitive, spiritual and daily lived experiences surrounding traumatic brain injury. Data analysis consisted of the dissection and analysis of collected themes, relationships, and patterns. The purpose of this study was to provide information and understanding surrounding the daily lived experiences of traumatic brain injury survivors in an effort to help clinicians and therapists serve their clients' personal healing process.

The findings of this study point toward common themes in addition to certain character traits that either lead to greater or less dysregulation. Common emotional dysregulation experiences by traumatic brain injury survivors included depression, fear, and anxiety. Participants reported grasping for words, memory, and balance as the most difficult cognitive challenges. Spiritual responses varied based on the participants' previous relationship with God: if the participant was close to God prior to their traumatic brain injury, then they became closer to God through these experiences. If, however, the individual was distanced from God previous to the traumatic brain injury, then they become more distanced from God through this experience. The participants were asked to identify their most significant daily struggle. The data suggests that the participants struggled daily with emotional and physical fatigue, feelings that they are not themselves, and balance. Other study findings suggest that individuals who spend time and energy comparing their old life to their previous life show more dysregulation and a tendency towards depression and suicide ideation. Those participants who can look to the future with hope for a healthy new daily experience, appear to have less emotional dysregulation.

Keywords: emotion, cognitive, daily, healing, knowledge, spiritual, traumatic brain injury

Dedication

To the struggling, resilient traumatic brain injury survivors who get out of bed every day: I know.

Acknowledgments

Jeremiah 29:11-13: 11. For I know the plans I have for you, declares the LORD, plans to prosper you and not to harm you, plans to give you hope and a future. 12. Then you will call on me and come and pray to me, and I will listen to you. 13. You will seek me and find me when you seek me with all your heart.

God, His mercy, grace, never-ending love, and direction.

Dr. Richard Green, his guidance, patience, and persistent encouragement.

Dr. Alysha Blagg, her guidance and suggestions.

Dr. Steven Hopkins, his brilliant perspective.

Michael, Rhett, Hailee, Soren, Baby Girl, Riley, Tilly, Catherine, Annie, Henry, Benjamin, my loves.

Therapy, family, friends, and cheerleaders, their constant love and support.

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Chapter One: Introduction

The Overview

Traumatic Brain Injury is a uniquely personal event. As much as no two humans are the same, no two traumatic brain injuries exist. Each survivor experiences different emotional, cognitive and spiritual struggles. Every story is unique. To be able to help them heal, therapists and counselors need to understand what they experience. In order to provide successful therapy, survivors of traumatic brain injury experience must be invited to share their stories, their experiences around dysregulation and recovery. Common experiences and themes have been identified to help therapists and counselors create personalized plans for health and recovery. Personal interviews were conducted using research questions designed to encourage information sharing and personal sharing. An information gathering questionnaire asked the participants for brief detailed information about the emotional, cognitive, spiritual and daily experiences of traumatic brain injury.

Transcendental phenomenology method focuses on understanding the human experiences. I sought to look at the emotional, cognitive, spiritual and daily responses to traumatic brain injury. I sought to find understanding through hearing the individual experiences of these survivors told in their own voice from their own personal perspective. Stepping into the world and seeing what life looks like for these individuals provides enlightening understanding. Listening to stories from the perspective of the individual survivor promotes knowledge and deeper insight. This knowledge and insight can help therapists and counselors develop individual plans uniquely designed for individual survivors of traumatic brain injury.

In chapter one, I introduced the history and background of traumatic brain injury. I discussed current literature surrounding traumatic brain injury and the literature gap that exists

surrounding the emotional, cognitive, spiritual, and daily struggles from the voice of survivors. I introduced the importance of the study including the research questions, definitions, potential application and relevance of this research study.

Background

Traumatic Brain Injury is defined as a head injury resulting from a single blow to the head up to and including puncturing into the brain (Georges & Das, 2023). George and Das (2023) state that, of the 1.5 million Americans who survive traumatic brain injury every year, moderate and severe traumatic brain injuries account for 20 percent of all of these injuries. Eighty percent of traumatic brain injuries are distinguished as mild head injuries. A diagnosis of mild, moderate and severe is determined by the varying degree of trauma associated with the traumatic brain injury. Common cognitive traumatic brain injury symptoms include problems with attention, headaches, sleep disturbance, slow processing, difficulty multitasking, and feeling foggy. Emotional symptoms include increased irritability, emotional dysregulation, anxiety and depression. A mild concussion will become asymptomatic within a couple weeks post injury. Moderate and severe traumatic brain injuries can have lifelong lasting consequences (Prince & Bruhns, 2017). George and Das (2023) continue stating that men are twice as likely to suffer a traumatic brain injury than women. Each year traumatic brain injury accounts for 52,000 deaths in the United States (Georges & Das, 2023).

The Glasgow Coma Scale, first developed in 1974 by neurology professors Graham Teasdale and Bryan Jennett at the University of Glasgow, is widely used to objectively describe the severity of traumatic brain injury. The test can be used as a self-assessment tool or observation and judgment by a clinician. The scale measures visual skills, motor skills and verbal skills following a traumatic brain injury. The lower the score, the more severe the

traumatic brain injury. The lower the score, the lower the expected recovery outcomes (Iverson, 2022). Recovery can be a long and arduous process taking months and years of rehabilitation and therapy of all kinds.

Historical

Not enough is known about the daily experiences of survivors of traumatic brain injury. Although every traumatic brain injury is unique, common elements exist in the areas of emotional dysregulation, cognitive dysregulation and spiritual response to the injuries.

Traumatic brain injury is a devastating and life changing experience for many survivors. Their life is altered in ways they could never imagine. Often their freedom is taken away and their quality of life is threatened. Among the most difficult consequences can be the emotional dysregulation they experience on a day-to-day basis thereafter. Barch et al. (2019) examined adolescents and their struggles with emotional regulation, life stress, life adversity and depression. Clark (2014), in an effort to seek understanding, looked at the distress traumatic brain injury survivors experience in some of life's key areas. These key life areas include mental and physical health, home and family relationships, finances and career, and spirituality. Increased emotional distress and poor emotional regulation are the result of traumatic brain injury (Clark, 2014). Emotional regulation, resulting from traumatic brain injury, was studied by Mohammedi et al. (2018). Specifically they looked at the rate of positive and negative emotions. The study found that regulating positive and negative emotions was one of the crippling effects of head trauma.

Traumatic brain injury affects all levels of the individual. Cognitive impairments are very common and include various levels of impairment. Barman et al., (2016) examines rehabilitation strategies for survivors of traumatic brain injury. By looking at the spectrum of

injury, Barman et al. (2016) researched different rehabilitation techniques that can be used to minimize permanent and long-term disability. Morbidity and disability are often the results of cognitive damage from traumatic brain injury.

The role spirituality plays in the road to recovery of traumatic brain injury is illustrated by Jones et al., (2018). Attitudes toward God, religious attendance and commitment, spiritual growth, relationship with God and others are all religious and spiritual factors. Zeligman and Fakhro (2023) discovered, through research, that a healthier mental outlook is directly influenced by the level of the individual's integrated religious and spiritual life.

Sudden brain injury affects the deterioration of life on a daily basis. Stocchetti and Zanier (2016) examine the day-to-day life of individuals who have suffered traumatic brain injury and the permanent lifelong consequences that affect these individuals. Providing emotional support is critical to the work of healing and is necessary for healing in addition to the physical support promoting living full happy lives.

Traumatic brain injury impacts some aspects of cognitive dysregulation, emotional dysregulation, daily life, and spiritual reactions. What has not been studied is the combination of these factors, heard from the voices of the survivors of traumatic brain injury. Personal, intimate stories discussing emotional, cognitive and spiritual struggles told by those that experienced them. This study provided a personal, individual view by a group of adult men and women who have survived and struggled through traumatic brain injury.

Social

In addition to those personally affected, are the family and loved ones of the survivors of traumatic brain injury. Studies have been conducted looking at how traumatic brain injury affects loved ones of these survivors (Bayen et al., 2013; Ennis et al. 2013). Of great concern in

the study of traumatic brain injury is caretaker mental health. Bayen et al., (2013) study investigates the progression of the disease in the individual survivor and predictors of care burden following 1 year post severe traumatic brain injury.

More relevant in the current study is the application of information for use by therapists and counselors who help in the healing work of survivors of traumatic brain injury. Understanding the daily life of these participants creates mindful therapeutic plans that are individualized for traumatic brain injury survivors.

Theoretical

Constructivism theoretical framework is defined by Sharkey and Gash (2020) as a learning process. Constructivism assumes one uses prior knowledge and experiences to understand and process new knowledge. Additionally, constructivism teaches that knowledge is acquired through social interactions with others, personal experiences, and through active meaningful engagement (Sharkey & Gash, 2020). As the researcher, I engaged mindfully with the participants seeking knowledge through their personal stories. I desired an intimate knowledge of what they experience on a daily basis as a result of their traumatic brain injury.

Alloy and Abramson (2010) introduce the Behavioral Approach System Dysregulation Theory. Originally designed to understand bipolar disorders, this theory emphasizes an association between the individual, behaviors, and various forms of psychopathology. Behavioral approach systems dysregulation theory looks at how these factors influence an individual's goal setting and reward seeking. For the purpose of this study, the behavioral approach systems dysregulation theory examined the influence of goal setting and reward seeking in survivors of traumatic brain injury. Traumatic brain injury creates emotional and cognitive dysregulation. The behavior approach systems dysregulation theory examines how

these dysregulations affect these survivors' ability to set meaningful goals and seek a rewarding life.

Situation to Self

Through my own personal experiences, and from being involved with family members who have experienced illness, I intimately understand how illness changes an individual's sense of self. Illness disrupts an individual's emotional, cognitive, and religious self. I sought not only to understand traumatic brain injury response for the overall betterment and health for traumatic brain injury, but I also sought for personal understanding. I am aware of how isolating illness can feel. Hearing these participants' stories, observing their struggles and successes, will be enlightening on my own personal struggles with illness and those of my loved ones. I sought to understand their lives through their stories. I evaluated the information shared, identified themes, interpreted the data collected and presented the findings. I hope to provide therapists and other helping professionals knowledge and information that will help them treat survivors of traumatic brain injury. My goal is to participate in the healing of these individuals.

Bradshaw et al. (2017) describes philosophical assumptions as what dictates how a phenomenon will be studied. It provides the researcher with a template that guides the study's procedures and data analysis.

Ontological assumption asks what is reality (Matta, 2022)? Reality is subjective and unique to each of these traumatic brain injury survivors. As the researcher, I utilized the participants' own words to describe their own experiences. This provided first person data. Approaching the interviews using an ontological assumption provided me with a pattern to classify and explain traumatic brain injury. Ontology provided the platform that allowed me to discover the answers to my research questions and deep dive into the lives and experiences lived

by the participants. It looked at not only the event (traumatic brain injury), but how the event has shaped their lives.

Similar to ontological assumption, epistemological assumption asks what can be known (Matta, 2022). With an epistemological assumption the researcher is taking the problem, asking the research question and discovering what can be learned and discovered about the phenomenon. The "what" is the daily life of traumatic brain injury survivors. Research questions provided the answers to the daily experiences of these participants. It answers questions regarding the emotional dysregulation they experienced. It answers the questions about the cognitive dysregulation and the spiritual response to their traumatic brain injury. The data is a true reflection of the participants' lived experiences.

As the researcher, I am aware of the axiological assumption and recognize that my worldview influences the questions that are being asked and my personal biases will be present in the study (Matta, 2022). My own personal experiences with illness influenced the research questions. I sought to mitigate my influence by placing safeties throughout the study design, procedures, and data analysis. These safeties include structured interviews, recorded interviews and identified themes. Creswell and Clark (2018) state that axiology deals with the self awareness of the researcher. My goal was to conduct a study where the objective phenomenon has intrinsic value. Similar to rhetorical assumptions, where what is created is universal applicable knowledge (Matta, 2022), understanding the intimate struggles of traumatic brain injury survivors will provide knowledge to those who help these survivors heal and thrive.

Post-positivism acknowledges that the researcher's personal biases will influence the study methods, procedures, data collection and data interpretation (Brown and Duenas, 2019). I recognize my own personal biases and experiences with personal and family illness had an

influence on the study. I made mindful efforts to keep my influence at a minimum by creating recorded interviews and using direct quotes from the participants in the data collecting process. As the researcher, I took what I already know about traumatic brain injury survival and added to that knowledge by hearing about and engaging in conversations with these study participants. Constructivism teaches that individuals acquire knowledge as they engage in the learning process (Brown and Duenas, 2019). The personal interviews provided me with the experience of learning from these particulars. They have lived experiences that I didn't understand and I desired to learn from them. An information gathering questionnaire asked for brief identification of emotional, cognitive, and spiritual dysregulation. The participants were asked to identify the most difficult aspects of their daily lives. They were invited to share any final thoughts they wanted to share surrounding their experience with traumatic brain injury. I took this collected data and organized, evaluated, labeled and presented the information for the purpose of providing learning opportunities for others.

As the researcher participated fully in the research study using research questions and methods that encourage pragmatism within the research process. Pragmatism incorporates procedures that will best answer the questions of the study (Brown and Duenas, 2019). I answered the questions of what daily life looks like for traumatic brain injury survivors. I focused especially on the areas of cognitive dysregulation, emotional dysregulation, spiritual response, and greatest daily struggle.

Problem Statement

The problem is that there is not enough known about the personal struggles of traumatic brain injury to support these survivors in their recovery. Traumatic brain injury is a life changing experience for many survivors; their life as they knew it, altered in ways they could never

imagine. Their quality of life is often threatened as is their freedom to pursue the life they want to live. Many of the most difficult consequences can be the emotional dysregulation, the cognitive dysregulation and the spiritual struggles they experience on a daily basis.

Recent studies have examined the connection between depression and traumatic brain injury (Barch et al., 2019). Research has looked at the impact of traumatic brain injury on caretakers and loved ones (Ennis et al., 2013). Emotional regulation as a result of a traumatic brain injury was studied by (Mohammedi et al., 2018). Spirituality has been studied and determined that a close connection with God limits isolation when struggling with illness (Jones et al., 2018). What has not been studied is the daily life of a survivor of traumatic brain injury from the voice of the survivors. Additionally, what has not been heard are the stories of traumatic brain injury and the cognitive, emotional, and spiritual struggles that these survivors experience. Understanding their intimate personal experiences and how it has affected their daily life from onset through their life today will help therapists and other professionals who work with this unique community create individualized healing plans.

This personal in-depth information about the daily life of a survivor of traumatic brain injury is valuable for this unique community and the therapists and other professionals who work in the healing of these survivors. This data can be used to create personalized plans based on a deeper understanding of the cognitive, emotional, spiritual, and daily living of survivors of traumatic brain injury. I collected this data through in depth personal interviews and an information gathering questionnaire.

Purpose Statement

The purpose of this transcendental phenomenology study is to understand the real life day-to-day experiences of survivors of traumatic brain injury by using in-depth interviews with

survivors of traumatic brain injury and an information gathering questionnaire. Traumatic brain injury is defined as a sudden trauma that causes damage to the brain which can include blunt force trauma or an object being inserted into the brain. The theories guiding this study are constructivism and behavioral approach systems dysregulation theories. Constructivism emphasizes that knowledge is acquired through meaningful personal social interactions with others. Behavioral approach systems dysregulation theory examines how cognitive and emotional dysregulation influence goals setting and reward seeking. I sought to create a personal connection with the participants and create a safe environment where they can share their story of traumatic brain injury. I sought to learn and acquire knowledge through personal interviews looking at the emotional, cognitive and spiritual effects of traumatic brain injury on these individuals.

Significance of the Study

Traumatic brain injury afflicts millions of individuals worldwide every year. Galgano et al.(2017) states that traumatic brain injury is defined as a combination of anatomical and functional damage to the brain. It affects the structural, cellular and vascular aspects of the brain.(Galgano et al., 2017) A research gap exists in understanding the cognitive, emotional, and spiritual outcome of individuals suffering from traumatic brain injury. Understanding the short-and long-term personal consequences of traumatic brain injury on individual survivors will help clinicians and therapists be more effective in serving their clients' healing process. Detecting common themes will help clinicians and therapists create efficient therapeutic plans towards health and healing. The personal stories and questionnaires will provide collected data that will be organized, evaluated, and labeled for therapeutic application. This information is

important to survivors of traumatic brain injury and the therapists and helping professions who seek these individuals in their healing process.

Research Questions

The participants were invited to share their stories of traumatic brain injury in its entirety beginning with the injury itself through the journey of seeking health and recovery up to and including their daily life today.

Research Question One. *How do survivors describe the effect of their traumatic brain injuries on daily emotional regulation/dysregulation?*

Research Question One will examine specifically the emotional effects of traumatic brain injury. Stubberud et al. (2020) defines emotional regulation as the ability to control and express emotions. Emotional control is a key factor of executive functioning and among the most common and most difficult consequences of traumatic brain injury. Examining the emotional aspects of traumatic brain injury provides insight into a very difficult aspect of traumatic brain injury. I looked for themes, similarities and differences among the participants. I examined the collected data to find knowledge that can be used in treating the emotional struggles of survivors of traumatic brain injury.

Research Question Two. *How do survivors describe the effect of their traumatic brain injuries on daily cognitive regulation/dysregulation?*

Cognitive dysregulation includes memory impairment, attention and concentration impairment, processing speed, memory loss and other mental deficiencies (Robert, 2020). Research Question Two will be a dissection of the stories collected looking for common themes surrounding cognitive dysregulation. This information can help therapists and healing

professionals create personalized plans for treatment of traumatic brain injury. Additionally, understanding the cognitive struggles surrounding traumatic brain injury can help with the presentation of therapy. An awareness is made known that not all patients may have capabilities in the areas of understating, memory retention and other cognitive functioning.

Research Question Three. *How do survivors describe the effect of their traumatic brain injuries on daily spiritual regulation/dysregulation?*

Surviving traumatic brain injury affects every aspect of the surviving individual's life including the survivor's spiritual life. Research Question Three asks the question, what does a believer do with such an experience? I examined the spiritual responses of traumatic brain injury survivors. How does God fit into the traumatic brain for the individual survivor? Spirituality is defined as a connection to a higher power or God. Deep connection to God creates peace and protection through the process of healing traumatic brain injury. Being intrinsically connected creates greater self-awareness, a sense of purpose and a heightened sense of gratitude throughout the recovery process of traumatic brain injury (Gillespie, 2019).

Research Question Four. *What does the daily life of a survivor of traumatic brain injury look like?*

Andelic et al. (2019) discuss the impact of traumatic brain injury on everyday level of functioning. Long-term physical, cognitive and emotional impairment can impact an individual's quality of life and freedom. Research Question Four invites the researcher and reader to step into the participants' life after surviving a traumatic brain injury. The participants spent energy comparing what their life looked like before the traumatic brain injury and what it looks like today. What can be learned from this question is a realistic view into the daily life of surviving a traumatic brain injury.

Definitions

1. Glasgow Coma Scale - GCS- The Glasgow Coma Scale (GCS) is used to objectively describe the extent of impaired consciousness in all types of acute medical and trauma patients (Iverson, 2022).
2. Transcendental Phenomenology- the researcher's effort to capture a phenomenon by exploring the lived experiences of individuals. Phenomenology dissects what was experienced, how it was experienced and the effect on those that experienced it (Neubauer et al., 2019).
3. Traumatic Brain Injury -TBI Traumatic brain injury (TBI), occurs when a sudden trauma causes damage to the brain which can include blunt force trauma or an object being inserted into the brain. TBI typically disturbs brain functions such as executive actions, cognitive grade, attention, memory data processing, and language abilities (Crupi et al., 2020).
4. Constructivism Theory- Constructivism theory assumes one uses prior knowledge and experiences to understand and process new knowledge (Sharkey & Gash, 2020).
5. Behavioral Approach System Theory- BAS- Behavioral approach system theory examines how individual personality traits, behaviors, and psychosocial dysregulation affects goal setting and reward seeking (Alloy & Abramson, 2010).

Summary

Surviving a serious traumatic brain injury can be an extremely isolating and frightening experience. The survivor will experience a unique range of emotional, cognitive and spiritual effects as a result of the traumatic brain injury. Therapeutic interventions are best formed when

the impact of disease and injury are understood. Identifying themes help therapists and counselors create individual interventions to help survivors of traumatic brain injury heal.

Understanding the individual experiences of these survivors told from their personal perspective in their own voice is important research that benefits not only survivors, but their families and therapists who work with this clientele. Hearing the stories of survival and the day to day impact was stepping into the world and seeing what life looks like for these individuals. Listening to stories from the perspective of the individual survivor provided knowledge and understanding.

In addition to hearing and understanding the individual stories, collecting information from the questionnaire, and identifying common themes was another goal of this study. By using a transcendental phenomenology method, my goal was to understand the human experience. The structure of this study consisted of in-depth interviews of survivors of traumatic brain injury, and information gathering questionnaires completed by all participants, for the purpose of understanding their day to day world. Themes I sought for included emotional, cognitive, and spiritual dysregulation including daily lived experiences.

Chapter Two: Literature Review

Overview

Surviving a serious traumatic brain injury can be an extremely isolating and frightening experience. The survivor will experience a unique range of emotional, cognitive and spiritual effects as a result of the traumatic brain injury. Therapeutic interventions are best formed when the impact of disease and injury are understood. Inviting participants to share their unique experiences will benefit the individual survivor by promoting health and healing through sharing their stories. Additionally, identifying themes can help therapists and counselors create individual interventions to help survivors of traumatic brain injury heal.

Previous studies have looked at common emotional, cognitive, spiritual and day to day responses to traumatic brain injury (Andelic, et al., 2019). A literature gap can be found in hearing and understanding the individual experiences of these survivors told from their personal perspective in their own voice. Hearing the stories of survival and the day-to-day impact is stepping into the world and seeing what life looks like for these individuals. Listening to stories from the perspective of the individual survivor will promote knowledge and understanding. Using a transcendental phenomenology method, my goal is to understand the human experience. The structure of this study will consist of in-depth interviews of survivors of traumatic brain injury, for the purpose of understanding their day-to-day world. Areas of concentration I will look at include emotional, cognitive, and spiritual dysregulation including day-to-day lived experiences. The review of literature brought a gap in hearing the stories from traumatic brain injury survivors; understanding their day to day struggles and experiences.

Theoretical Framework

Jean Piaget's Constructivism Theory and John Watson's Behavioral Approach Systems theory were used as the theoretical framework for this study. As a means of introduction, Piaget's constructivism theory examines how knowledge is acquired. For the purpose of this study, I examined the knowledge that was acquired by traumatic brain injury survivors through their lived experiences. Constructivism theory additionally proposes that previous understanding and knowledge influences how new knowledge is acquired and how new knowledge is processed and applied to daily life (Dennick, 2016; Sharkey & Gash, 2020).

John Watson's behavioral approach systems theory, originally designed to understand bipolar disorders, examines an individual's goal setting and reward seeking strategies (Alloy & Anderson, 2010). These strategies are influenced by an individual's behavior and various forms of psychopathology.

These two theories, constructivism and behavioral approach system, intersect well together as they examine two important aspects of a traumatic brain injury survivors' experience.

Piaget's Constructivism Theory assumes the survivor acquires new knowledge from their injury. The survivor has experienced life one way and now they are forced into a new way of life. The knowledge of how their world works and how they work inside the world has been drastically altered. In that work of creating the new normal is the setting of personal goals seeking a rewarding and meaningful life. The behavioral approach system looks at the traumatic brain injury survivors' unique struggles and watches how the individual creates a new life for themselves because of these challenges. The two theories work together as the survivors understand their new day to day world and build from that place.

Constructivism Theory

Jean Piaget (1896-1980) is known as the father of constructivism theory. As a well-known biologist, his focus was on the adaptation of an organism into the world and how previous knowledge influenced that adaptation. Piaget's act of learning is an awareness of old knowledge and a connection between old and new knowledge (Dennick, 2016). Jean Piaget's (1968) constructivism theoretical framework assumes that new knowledge is acquired using the framework of what the individual already knows. Piaget proposed that the acquisition of knowledge is an active dynamic process of assimilation. All cognitive development, Piaget believes, progresses towards complex levels of organization. The individual's new knowledge is then evaluated and processed through the lens of the old knowledge.

Sharkey and Gash (2020), state that constructivism stresses acquired knowledge through social interactions with other individuals, the actions of personal experiences and through intimate active meaningful engagement (Sharkey & Gash, 2020). Dennick (2016) explains that new knowledge is constantly being assimilated through previous knowledge. New knowledge is added to the individual's previous knowledge. In every way personal interpretation of data is subjective according to the individual. A learning environment that supports constructivism recognizes that a survivor's previously acquired knowledge strongly influences the processing of their traumatic brain injury (Dagar & Yadav, 2016).

For the purpose of this study, Piaget's constructivism theory dictates that these traumatic brain injury survivors acquired new knowledge through their lived experience. The new knowledge was processed and understood through the lens of their previous knowledge and previous lived experiences.

Behavioral Approach Systems Theory

John Watson (1878-1958), American psychologist, is known as the father of Behavioral Approach Systems Theory. John Watson's work focused on behavior development in animals, children and adults. John Watson's (1930) approach is illustrated by this quote:

> Give me a dozen healthy infants, well-formed, and my own specified world to bring them up in and I'll guarantee to take any one at random and train him to become any type of specialist I might select—doctor, lawyer, artist, merchant-chief and, yes, even beggar-man and thief, regardless of his talents, penchants, tendencies, abilities, vocations, and race of his ancestors.

John Watson's (1930) Behavioral Approach Systems Theory believes that behavior is something that can be measured, that the environment shapes the development of behavior in the child and influences the behavior of the adult. Additionally, learning is a process of association between stimuli and learned behavior. Watson believes that behavior can be controlled and manipulated (Watson, 1930).

Behavioral approach system theory looks at an individual's personality traits and behavior tendencies and then explores how these characteristics affect the individual's goal setting and pursuit of a meaningful life (Alloy & Abramson, 2010). The behavioral approach system theory provides a framework to understand what motivates an individual to set goals and seek rewards (Liu et al., 2018).

For the purpose of this study, behavioral approach system theory looks at how traumatic brain injury is processed through the individual's previous life experiences and previous knowledge. This study will examine how survivors of traumatic brain injury seek healthy meaningful lives.

Review of Literature

I desired an intimate knowledge of the experience of traumatic brain injury as told through the stories of the survivors. This information has been gathered through individual personal interviews. I felt privileged to step into their world and understand the cognitive, emotional and religious struggles they experience daily.

Many aspects of traumatic brain injury have been researched, including generalized emotional, cognitive, spiritual, and day to day isolated experiences. What had not been heard or seen is the personal impact on the individual in their own words. Every traumatic brain injury is as unique as the survivor and peeking into their struggles, failures, successes and day-to-day world will provide evidence of what is needed to support these survivors. Therapeutic measures and more effective individual healing plans can be put into place when therapists are knowledgeable about what this trauma really looks like on a daily basis for these individuals. Additionally, the honest voice of one individual can be a powerful source of understanding and knowledge. My goal was to personalize traumatic brain injury.

Emotional Dysregulation among Traumatic Brain Injury Survivors

Traumatic brain injury is a devastating and life changing experience for many survivors. Their life is altered in ways they could never imagine. Often their freedom is taken away and their quality of life is threatened. Among the most difficult consequences can be the emotional dysregulation they experience on a day to day thereafter. Clark et al. (2014) examines emotional distress, specifically anxiety and depression following a traumatic brain injury. Conclusively Clark et al. (2014) found evidence that anxiety and depression showed measurable levels of increase following traumatic brain injury. This is a pure example of emotional dysregulation post traumatic brain injury. Shulman (2020) discusses the emotional shift that takes place in the brain

following a traumatic brain injury. Shulman (2020) specifically identifies emotional stress that affects physical and emotional dysregulation. Shields et al. (2016) uses a transdiagnostic approach to understanding the psychological processes associated with traumatic brain injury. Shields et al (2016) aimed to identify psychological processes similar to depression, anxiety and distress post traumatic brain injury. What is found is conclusive evidence that traumatic brain injury disrupts the normal healthy functioning of a brain and the stress of the event creates emotional dysregulation that often expresses itself in the form of anxiety and depression. This information is foundational in understanding the role traumatic brain injury plays in the day to day world of traumatic brain injury survivors.

Tull and Aldoa (2015) and Gross (2015) share new directions in the science of emotional regulation. Prominent models of emotional regulation have moved from trying to cancel out or control negative emotion to acceptance and adjusting the power of emotional dysregulation. Gross (2015) discusses the 5 key aspects of emotional regulation. They are situation selection, situation modification, attentional deployment, cognitive change and response modification. Gross (2015) explained that strong emotional regulation skills will affect an individual's work, personal relationships, mental health and overall health. Emotional self-regulation is defined as the ability to control one's emotions. The capacity to control one's emotions and impulses is referred to as emotional self-regulation. Grow (2015) explained that the key to emotional regulation occurs in the window of time between experiencing an emotion and then responding to that emotion. This information is valuable in identifying the trigger moments of emotional dysregulation. Gross (2015) states that self awareness is the first step to emotional regulation. When an individual is self aware, they can identify and name their feelings.

Kwak et al. (2020) examined factors of traumatic brain injury that affect the emotional stability of survivors. These factors include lesion placement following a traumatic brain injury that affect executive functioning, memory loss, and neuropsychological emotion regulation. These findings present parameters that need to be applied to the individuals' rehabilitation treatments. Kwaks et al. (2020) findings present useful information when seeking treatment options for traumatic brain injury survivors.

Hu et al. (2014) looks at the relationship between emotional regulation and mental health measured by life satisfaction. This meta-analysis examined life satisfaction, positive affect, depression, anxiety and negative as influenced by emotional dysregulation. Hu et al. (2014) found conclusive evidence that emotional regulation is a core foundation of positive mental health which correlates with life satisfaction. These findings suggest the strong need to help survivors of traumatic brain injury develop emotional regulation for their mental health and overall happiness in life.

Emotional regulation is one of the most common life altering consequences of traumatic brain injury (Stubberud et al., 2020). Emotional dysregulation leads to a complete change in quality of life. Suicide ideation is very real, social functioning can be challenged as well as leisure and work opportunities. A once enjoyed way of life is suddenly altered in a way that creates emotional chaos. Emotional dysregulation refers to an inability to self monitor or control emotional arousal. Identifying features may include increased emotion and disruptive behavior, reduced emotional and social awareness (Stubberud et al., 2020). Often survivors describe this experience as "crazy brain" or a "disordered mind," a feeling of a mental loss of control contributing to increased anxiety and depression (Stubberud et al., 2020). Understanding the life

altering effects of emotional dysregulation following traumatic brain injury provides a framework for the necessity for quality, aggressive care and rehabilitation treatment options.

Chronically Ill Patients

Individuals with chronic diseases are challenged with a complex physical, emotional, cognitive and spiritual burden to carry (Wierenga et al., 2017). These complex struggles of managing their illness adds greatly to their emotional struggles. Everyday responsibilities that may include self-care, family and even work become immediately increasingly difficult. Poor processing of emotional stimuli can increase these struggles and reduce the individual's ability to self manage their emotions. Physical health, mental health, social health, psychological health and spiritual health are affected by distorted thinking and emotional dysregulation (Wierenga et al., 2017).

Previous studies have examined the direct negative relationship between emotional dysregulation and mental well-being (Ajele et al., 2017). Ajele et al. (2017) found that negative mental well-being is strongly influenced by emotional dysregulation. Bahrami et al., (2015) and Barberis et al. (2017) examined chronically ill patients with emotional dysregulation and found that stressful events such as cancer leads to difficult emotional regulation and healthy thought processes all of which influence the individual's quality of life. The study finds that patients on dialysis benefit from comprehensive care, treating the emotional, cognitive and physical needs. Overall comprehensive care promotes total well-being. Understanding that emotional health is foundational for healthy mental health strengthens the need for studies that not only study these connections but provide therapeutic options to help remedy the struggles of traumatic brain injury survivors.

Bahrami et al. (2015) examines the relationship between emotional regulation and managing stressful life events. The study examines the quality of life among cancer patients. The study concluded that emotional regulation strategies help cancer patients deal with their highly stressful life events.

Zahra et al., (2017) looked at breast cancer patients and how the level of emotional dysregulation affected their quality of life. They found that conclusively, emotional dysregulation negatively affected the patient's ability to cope with their stressful diagnoses and pending life struggles.

Children and Youth

The effects of emotional dysregulation on children has been a topic of research. Barch et al. (2019), Bunford et al. (2018), Dugal et al., (2018), and Dvir et al. (2014) examined the effects of childhood maltreatment and childhood abuse. They concluded that childhood maltreatment and childhood abuse universally negatively affected a child and young adults emotional regulation, happiness and quality of life. Dvir (2014) found wide-range psychosocial, developmental and medical deficits present in children, adolescents and adults who experienced trauma. This information is valuable in understanding the broad effects of trauma on the individual. It points to the importance of evaluating the broad effects of traumatic brain injury on the individual survivor.

Barch et al., (2019) examine the relationship between an individual's cognitive deficits and the development of depression. The study found that life stress, cognitive deficiencies, and emotional dysregulation are a predictor of early onset depression amongst adults. The repercussion of said trauma resulting in severe emotional dysregulation experienced by these children and adult survivors. These children are at risk for many psychiatric struggles and

maladaptive coping mechanisms. Understanding what influences depression will be valuable in therapeutic interventions towards health and healing.

Norona et al., (2017) found that parenting was a predictor of emotional dysregulation in children. Parenting can either be a protective factor or a devastatingly strong negative factor in emotional stability in children and adults. Additionally, Nusslock et al., (2016) found that early life adversity heavily influenced the emotional well-being of adolescents and adults. Childhood adversity influences the trajectory of an individual's life.

Emotional dysregulation in children is visual to others as an inability to organize emotions and behave appropriately in social situations (Moehler et al., 2022). Additionally, intensity of emotions and the inability to return to a healthy emotional state is often seen when children lack emotional regulation. Emotional dysregulation in childhood can seriously impair a child's growth. Psychiatric disorders, attention hyperactivity, oppositional defiant behavior, personality disorders, self-harm and suicide ideation are all consequences of emotional dysregulation. It is estimated that 26 to 30 percent of children admitted to child and adolescent mental health facilities or psychiatric clinics struggle with emotional regulation (Moehler et al., 2022). Additionally, 30 percent of adults with emotional dysregulation admit to self-harming behaviors when they were young children. Directly related maladaptive coping strategies include smoking, alcohol abuse, overeating, sleep problems (Moehler et al., 2022). This is valuable information understanding the importance of treating the emotional dysregulation aspect of traumatic brain injury.

Paulus et al. (2021) examined emotional dysregulation among children and adolescents with psychiatric disorders. Psychiatric disorders are found to be a risk of emotional dysregulation. Factors that influence emotional dysregulation include genetic disposition,

physical abuse, sexual abuse, emotional neglect during childhood and overwhelming personal stress. Understanding the factors that contribute to emotional dysregulation provides understanding and a framework for therapeutic intervention strategies.

Loevaas et al. (2018) and Folk et al. (2014) look at the influence emotional regulation plays in the diagnosis of anxiety and depression of children. Emotional dysregulation influences the overall ability for childhood success and overall functioning. Loevass et al. (2018) found that childhood success in school and life is greatly diminished when emotional dysregulation is found. These childhood struggles have long term effects on the individual's life. Intervention at an early age is critical for these individuals.

Fussner et al. (2016) looks at the possible long term emotional dysregulation of peer rejection. The study compared childhood ages, genders and school grades. Fussner et al. (2016) found that boys are at higher risk of emotional dysregulation from peer rejection as adolescents than females. This is important information in the treatment of childhood emotional dysregulation.

Smith et al. (2014) looked at generational trauma. Smith et al. (2014) found that a mothers' experience of personal childhood abuse influences the risk of her abusing her own children. Generational trauma is collective trauma that is experienced by one or more and passed down to the next generation. Understanding how generational trauma works emphasizes a need to break the cycle through early detection and healthy interventions.

Tahmouresi et al. (2014) compared emotional dysregulation and psychopathology in Iranian and German school children to better understand the effect culture has on emotional dysregulation. Tahmouresi et al. (2014) found that culture can be an influence on childhood emotional stability, however; emotional dysregulation and psychopathology universally

negatively affects children's functioning and emotional regulation. This allows for a world-wide universal baseline in treating all children, regardless of demographics, for emotional dysregulation.

Children diagnosed with oppositional defiant disorder and its relationship with emotional dysregulation were studied by Tonacci et al. (2019). The relationship is cyclical, one affects the other and they continue to influence one another. Tonacci et al. (2019) discussed how the increased sensitivity of children diagnosed with oppositional defiant disorder is heightened by emotional dysregulation. Understanding that these children are more extreme in their dysregulation helps clinicians treat multiple disorders.

Vacher et al. (2020) and Groves et al. (2020) examined emotional dysregulation in children diagnosed with attention deficit hyperactivity disorder. They found that the severity of attention deficit hyperactivity disorder is influenced by emotional dysregulation. Attention deficit hyperactivity disorder with the addition of emotional dysregulation looks like a child without self-awareness or self-control. Clinicians need to be aware of comorbid issues when treating children for emotional dysregulation.

Suicide

Emotional dysregulation influences children and adults that have a risk for suicide (Grattan et al., 2020). Suicide rates are steadily increasing among adolescents and young adults (Janiri et al., 2021). Hospitalization and emergency visits for suicide attempts and suicide ideation have doubled. Suicide ideation in children has shown to be a predictor of psychiatric morbidity and psychopathology. Identifying suicidal ideation early is the greatest chance for safety long term (Janiri et al. 2021). Both bipolar and major depressive disorders are

consequences of emotional dysregulation. Comorbid treatment options are important for these individuals.

Suicide ideation and suicide attempts among traumatic brain injury survivors has been an important topic in research. Brenne et al. (2011), Bowen et al. (2019), Davis et al., (2014), Knight et al., (2020), Silva et al., (2017), and Young et al. (2018) examine the reality of living with suicide ideation, self-harm, depression and suicide attempts as a result of traumatic brain injury. They concluded traumatic brain injury universally increases the risk of suicide ideation and suicidal behavior in children, adolescents, and adults. This information is critically important when stabilizing and treating traumatic brain injury survivors.

The traumatic brain injury populations studied were veterans (Breene st al., 2011), patients suffering from other diagnosed mental illnesses (Bowen et al., 2019), college students (Silva et al., 2017) and adults (Davis et al., 2014; Knight et al., 2020). The importance of diverse populations creates universally applicable conclusions. Bowen et al., (2019) concluded that compulsive behavior is a strong indicator of suicidal behavior and suicide ideation including compulsive thoughts about death. Traumatic brain injury changes an individual's life. The new life may be filled with fear and dysregulation of all sorts. Recognizing the high risk of suicide is important to the treatment of traumatic brain injury survivors by all helping professionals.

Ennis et al., (2013) examines depression in the caretakers of traumatic brain injury survivors. Conclusively, the findings suggest that the more severe the traumatic brain injury, the higher the risk of suicide ideation, suicidal depression, and suicidal behavior. In addition to altering the life of the survivor, traumatic brain injury alters the life of family members and caretakers. Recognizing the far-reaching effects of traumatic brain injury is important in providing for the welfare of all affected.

Treatment Options

Bjureberg et al. (2016) examines the validity of the Emotional Regulations Scale widely used to measure emotional regulation. It is a theoretically driven self-report measure of emotional regulation. The study concluded that the Emotional Regulations Scale is a valid and relevant test in adequately evaluating emotional regulation. This tool can be used to effectively determine the level of emotional regulation of an individual who experienced traumatic brain injury. Weiss et al. (2015) and Weiss et al. (2019) examined a tool for determining the level of emotional dysregulation. This study concluded that the Emotional Regulation Scale was effective in measuring clinically relevant difficulties. This information is valuable not only for clinicians but for the individual survivor as well. Self-awareness is a foundational tool for healing.

Using imaging technology, Bertocci et al. (2014), and Etkin et al., (2015) examined the frontal lobe of the brain looking for signs of depression in youth and adults. Additionally, Bertocci et al. (2014) examines neuroimaging seeking to find markers that identify behavioral and emotional dysregulation. The neuroimages found that unique markers exist and can predict the probability of behavioral and emotional dysregulation in individuals. Using modern technological advances helps in the understanding and treatment of depression and other struggles that result from traumatic brain injury.

Spechler et al. (2019) examined neuroimaging of the right orbitofrontal cortex seeking treatment options. These treatment options include psychotherapy and rehabilitation of all types. Spechler et al. (2019) shares information that can be used to treat brain injury survivors as technology is used to make diagnosis and individual treatment plans. Additionally, Van Roekel et al. (2018) looked at serotonin transporter polymorphism and inertia in treatment of emotional

dysregulation. Treatment options targeted to help with depression were researched by Chen et al. (2019). Treatment options include medications, therapy and physical therapy. A nontraditional therapy option, acupuncture, was shown in association with decreased risk of developing stroke in patients struggling with depression (Liao et al. 2023). Studied and proven eclectic treatment options are vital when creating individualized plans for treatment, health and healing for survivors of traumatic brain injury.

Cognitive behavioral therapy was studied with traumatic brain injury survivors. Zelenick et al., (2020) and Thornback et al. (2015) conclude that cognitive behavior therapy showed positive results with those suffering from anxiety and depression. Cognitive behavioral therapy is targeted to behavioral treatment by working through the triangular relationship of beliefs, thoughts, and feelings and the resulting behavior. Cognitive behavior can be a method of treatment used with traumatic brain injury survivors.

Neumann et al. (2017) examined the effectiveness of a comprehensive treatment protocol to help with emotional dysregulation following a traumatic brain injury. Troy et al. (2018) tested two emotional regulation strategies, cognitive reappraisal and acceptance, in an effort to create long term positive health outcomes. Cognitive reappraisal and acceptance are proven treatment options that bring about healthy psychological health. Individuals show lower levels of depression, healthier mental health and closer interpersonal relationships.

Researchers are seeking treatment options for emotional dysregulation among traumatic brain injury survivors, diverse populations, chronically ill patients, adults, children and adolescents. Identifying valuable treatment options helps survivors of traumatic brain injury progress in their recovery towards health and healing.

PTSD and Trauma

Post traumatic stress disorder is a common struggle with many traumatic brain injury survivors (Dieter & Engel, 2019). A relationship has been shown between emotional regulation and post traumatic brain injury. This relationship has been linked to the onset of anxiety and depression (Shepherd and Wild, 2014). Weiss et al., (2018) studied individuals with post traumatic stress disorder and their struggles with emotional regulation. These studies point to the importance of treating comorbid diagnosis when working with traumatic brain injury survivors.

Rizeq and Mccann (2019) examined emotional dysregulation as a predictor of negative affect in individuals who have suffered trauma. Trauma survivors and emotional dysregulation among mothers and children exposed to trauma was studied by Pat-Horenczyk et al. (2015). They found that increased depression and anxiety and emotional dysregulation was present in both mothers and children exposed to PTSD. Mohammandi et al., (2018) compared positive and negative emotional regulation between patients with traumatic brain injuries and healthy patients while Van der Horn et al. (2016) specifically looked at emotional dysregulation and trauma following mild traumatic brain injury. They concluded that trauma exposure is a high risk predictor of emotional dysregulation.

Diverse Groups

When studying emotional dysregulation, it is valuable to examine diverse groups of individuals to ensure broad application of gained knowledge. Raghibi et al. (2013) aimed to show a relationship between emotional intelligence and sexual satisfaction of married women. Raghibi et al. (2013) found that emotional intelligence and sexual satisfaction are strongly linked. Traumatic brain injury affects all aspects of our lives, including sexual health.

Understanding the importance of emotional health on sexual relationships helps clinicians broach this important subject with survivors of traumatic brain injury.

Shaw et al. (2014) examines emotional dysregulation in adults diagnosed with attention deficit hyperactivity disorder. Borderline personality and emotional regulation was studied by Grat et al. (2017). Emotional dysregulation was found to be prevalent in individuals diagnosed with either attention deficit hyperactivity or borderline personality disorder.

Vajda et al. (2014) examined the connection between emotional dysregulation, emotional abuse and eating disorders. Emotional abuse and eating disorders have a relationship with emotional dysregulation, adding to the struggles individuals experience. Jamali et al. (2017) examine the role of emotional regulation and mental health in nulliparous women. Nulliparous women are women who have never physically been pregnant. Jamali et al. (2017) found that these women struggle with more mental health issues. Weiss et al. (2015) noted that the threat of risky behaviors increased with the severity of emotional dysregulation. Understanding predispositions for emotional dysregulation is important in the treatment of mental health.

Examining diverse populations helps identify universal struggles and universal hope in the treatment of traumatic brain injury. Diversity can be measured in terms of race, gender, ethnicity, culture, and age. Additionally, diversity can include cognitive and physical abilities and other characteristics that distinguish groups of individuals. Diversity provides an increase in validity and significance.

Cognitive Dysregulation among Traumatic Brain Injury Survivors

Traumatic brain injury is a devastating injury that can create long lasting daily results including loss of consciousness, memory loss, neuropsychological impairment, neuroglial struggles, and death. A traumatic brain injury can be a blunt, accelerating force that adversely

affects the brain (Dang et al. (2017). Dang et al., (2017) state that traumatic brain injury is the leading cause of disability to individuals 40 years of age and under. Herrmann et al. (2013) examines the brain and cognitive functioning based on lesions and trauma. These lesions can be seen through brain imaging technology. Kwak et al. (2020) examine the cognitive dysregulation following traumatic brain injury. Trauma resulting in cognitive dysregulation affecting one's belief about the world, oneself and others was studied by Lilli et al. (2013). Cognitive dysregulation demonstrates itself as the loss of mental and intellectual functions that include memory, concentration, and choice making that affects daily functioning. These processes are at the core of brain activity and can be severely altered with the onset of a traumatic brain injury.

Troy et al. (2018) examined two emotional regulations strategies, cognitive reappraisal and acceptance. Cognitive reappraisal and acceptance emphasize what is possible and points out the cognitive strengths (Shulman, 2020). These processes increase self-esteem and decrease depression. Both were found to be beneficial in long term physiological health.

Cognitive dysregulation caused by traumatic hemorrhagic brain injury is explained by Martin et al. (2017). This study examined individuals with brain lesions and the consequent results of lesion eruption. Lesion eruption was found to cause severe disruption in the cognitive processing of individuals and in some extreme cases, can lead to death. Marten et al. (2017) stresses the importance of early detection and medical intervention to avoid lesion eruption.

Chronically Ill Patients

Bahrami et al. (2015) examined the relationship between cognitive regulation and quality of life in cancer patients. Bahrami et al. (2015) found that cancer patients' cognitive regulation is hugely impactful on their quality and satisfaction in life. Cancer patients who could remain calm and grounded during their treatments appeared to also connect with hope for recovery.

Treatment Options

Various treatment options for cognitive repair following a traumatic brain injury are examined by Whiting et al. (2017). These options include rehabilitation in all aspects of life and strong therapeutic measures. Barman et al., (2016) examine the cognitive impairment and treatment options following a traumatic brain injury. Additionally, they examine current rehabilitation strategies used to treat these cognitive impairments. The study concludes that there is a need for more research and new rehabilitation strategies to treat cognitive impairments post traumatic brain injury.

Examining brain functioning through neuroimaging has been a source of study and knowledge towards treatment options. Buhle et al. (2014) conducted a study using human neuroimaging of the brain functions to illustrate the power of cognitive thoughts. Buhle et al., (2014) examines a strategy to change an individual's perception of an event or stimuli and examines the effect on the brain. It was found that the perception change affects the functioning of the brain. This shows power in the way we think and believe about life experiences. Additionally, Waldron et al. (2013) looks at cognitive behavior therapy for depression and anxiety in adult survivors of traumatic brain injury. The study concluded that cognitive behavior therapy is successful therapy when working with traumatic brain injury survivors. This is important information that can be used in creating individualized treatment plans for traumatic brain injury survivors.

Wang et al. (2017) examined the effects of cognitive reappraisal on memory loss. Cognitive appraisal refers to the power the individual gives to a thought or experience (Wang et al., 2017). The study found cognitive appraisal a successful therapeutic tool in treating memory loss.

Spiritual Dysregulation among Traumatic Brain Injury Survivors

Clarity in daily choices, connection with a higher power, with one's-self and with others are byproducts of spiritual health. Physical health, healthy coping mechanisms, positive mental health, productivity in life, life satisfaction, growth as a person and life longevity are all influenced by spiritual health. Traumatic brain injury influences every aspect of an individual's life including spiritual health. Spiritual responses to traumatic brain injury are as varied as the individual survivor. Sekely et al. (2020) and Jones et al. (2018) and Jones et al. (2020) look at spiritual well being as a predictor of dysregulation following traumatic brain injury. They concluded that spiritual health has a strong relationship with emotional health. Spiritual health and its relationship with psychological health is examined by Akbari and Hossain (2018) and Neumann et al. (2014). Akbari and Hossain (2018) study the relationship between spiritual health and psychological health. The study found that there is a nonlinear complex connection between spiritual health and psychological health. The defining factor is emotional regulation. Individuals who possess emotional regulation experience greater psychological health.

Diverse Groups

Mesri et al. (2014) examines the spiritual health of military staff following trauma. They found that spiritual health is a protective factor against exposure to trauma. Cristofori et al. (2021) specifically looks at spirituality among traumatic brain injury war veterans. Christofori et al. (2021) found a correlation between religious belief and empathy for others. This information presents the importance of understanding spiritual health to help all individuals. Spiritual health is a foundation to healthy mental health and overall life satisfaction (Christofori et al. (2021),

Spirituality in the Australian elderly population and spiritual training is examined through the perspective of the chaplaincy; a study conducted by Best et al. (2023) and Jones et al. (2021).

The chaplaincy studied felt their work as spiritual leaders was a protective factor against clinical mental illness. Another Australian study conducted by Best et al., (2023) sought out Australian chains to study their views on spirituality. Four dominant themes were identified through semi structured interviews. The themes include the concepts that spirituality is a source of connectivity with something greater than oneself, spirituality provides hope and comfort, illness and hospitalization can lead to existential struggle and healthy spiritual practice is holding space between struggle and growth.

Ajele et al. (2021) examines the spiritual health and overall mental health of individuals with diabetes during the COVID-19 pandemic. During the pandemic, increased spiritual health correlated with increased mental health. Ajele et al. (2017) examine the relationship between spiritual intelligence and emotional regulation, mental health and depression. Ajele et al. (2017 found a direct positive connection between spiritual intelligence and mental health. Spiritually minded individuals experience less depression and mental health issues. Understanding how spiritual health influences mental health can be an important factor in helping heal traumatic brain injury survivors.

Spirituality in individuals with mild Alzheimer's disease was researched by Lima et al. (2020). There was no conclusive relationship between Alzheimer's disease and spiritual health.

Hanks et al. (2020) and Gibbs et al. (2020) look at the spiritual health of the caregivers of traumatic brain injury survival. They concluded that spiritual health is a protective factor in this very difficult work of service they provide for traumatic brain injury survivors. Hossindokht et al. (2013) examines spiritual health and marital satisfaction and concludes that spiritual health has a positive influence on marital satisfaction.

Jones et al. (2022) evaluated spiritual care leaders and what they believed the benefit was of their spiritual teachings on the lives of individuals. Jones et al. (2022) concluded that spiritual leaders believe their role and teaching to be influential on the happiness and life satisfaction experienced by their parishioners and congregations.

The relationship between spirituality and resilience in the quality of life of individuals with spinal cord injury and their family members was studied by Jones et al. (2019). Spirituality was found to be a strong indicator of mental well being during this difficult life altering event.

Jacob et al. (2020) looked at the perceptions of pharmacy and nursing professionals and the role of spirituality in their treatment of patients. They felt a connection between medical science and spirituality strengthened the potential recovery of their patients. Jones et al. (2022) examines spiritual training among rehabilitation professionals, their perceptions and practice with patients. Those individuals with spiritual training reported greater empathy and compassion for those they served. This information can be a valuable asset if the traumatic brain injury survivor is spiritually minded and would desire a spiritually tainted professional to work with in their journey to healing.

Jamali et al. (2017) examined the spiritual health of nulliparous women. Jamai et al. (2017) concluded that spirituality was a protective factor for women who grieved the loss of childbirth in their lives. Raghibi et al. (2013) examined the role spirituality plays in the sexual satisfaction of married women. Women with strong spiritual connection embodied other additional factors that created more content relationships including a more satisfying sex life in their marriages. Sexual health is an important discussion to have with traumatic brain injury survivors. These studies provide foundational evidence of sexual health.

Zeligman and Fakhro (2023) examine spiritual growth and spirituality among adults diagnosed with chronic illness. Those individuals with spiritual health had less emotional dysregulation than those without this protective factor. Zimmer et al. (2016) examined spirituality and religiosity among the aging population and the influence it has on health and longevity. Both Zeligman and Fakhro found spirituality as a source of comfort in their personal struggles. Mumby et al. (2019) uses a single case narrative to examine spirituality after a traumatic brain injury. This single case narrative lays a good foundation to this study which provided a case narrative with twelve participants.

Treatment Options

Thompson et al. (2022) and Simon (2020) examine Grace Notes, an intervention that is created to help support clients with traumatic brain injury. Grace Notes is a program that provides sessions and tools designed to support spiritual well-being in survivors. The goal of Grace Notes is to help survivors create stronger relationships with their Higher Power in an effort to create peace in their lives. Study results show that traumatic brain injury survivors who feel a spiritual connection to a Higher Power do access emotions such as hope and peace more than survivors who do not have spirituality in their lives. This is important for therapists and other helping professionals to take into account as they work with their traumatic brain injury clients, in creating therapy plans. Spiritual counseling or Christian counseling is an option that may be very beneficial for some clients.

Day to Day Dysregulation among Traumatic Brain Injury Survivors

Long term impairment and death are the leading tragic results of exposure to a traumatic brain injury. Survivors of traumatic brain injury experience daily struggles that include limited

mobility, isolation, and depression. Day to day dysregulation looks at any unusual event that exists today but did not exist prior to their traumatic brain injury. Goldman et al. (2022) and Stocchetti & Zanier (2016) define traumatic brain injury and explain some of the unique struggles these survivors face on a daily basis. These unique struggles include Tyagi et al. (2016) takes it further and examines the global effects of traumatic brain injury. Bramlett et al. (2015), Maas et al. (2017) and Crupi (2020) explore the long-term consequences of traumatic brain injury and broad treatment options. These long-term consequences can include memory retention, balance, and emotional dysregulation such as anxiety and depression. Treatment options include all areas of therapy including psychological, occupational, and physical.

Ownswirth (2014) studies an individual's self-identity after brain injury. Owsnwirth (2014) examines the personal struggle surrounding thoughts about oneself, ones' purpose, and ones' self-worth following traumatic brain injury. Traumatic brain injury shakes the very foundation of a person's self-awareness. This study presents valuable information on the areas on which a clinician can explore with a traumatic brain injury survivor.

Diverse Groups

Golden et al. (2016) and Valera & Kucyi (2017) examine traumatic brain injury among groups of women exposed to intimate partner violence. Their findings suggest that these women struggle with traumatic brain injury resulting from trauma exposure in addition to physical violence. Additionally, Lagdon et al. (2014) examine mental health outcomes of intimate partner victimization. This study examines both female and male partner victimization. Both studies identified the devastating effects of intimate partner violence in the victims in these relationships.

Ford et al. (2018) work towards a comprehensive diagnosis for children who have experienced traumatic brain injury. Ford et al. (2018) concludes that a comprehensive diagnosis

would provide more effective treatment opportunities. Spinazzola et al. (2018) and Spencer et al. (2014) examine the impacts of trauma exposure on children. Treatment of children who are survivors of traumatic brain injury needs to be focused on the possibility of comorbid diagnosis that needs to be addressed.

Fulford et al. (2015) looks at differentiating between mania and borderline personality disorder in individuals exposed to trauma while Sophie (2020) examines a connection between traumatic brain injury with survivors diagnosed with mood disorders. Both Fulford et al (2015) and Sophie (2020) conclude that exposure to trauma is a leading factor in developing psychosis and other psychological disorders. This is important data when creating individual treatment plans for diverse populations with varied mental illness.

Bayen et al. (2013) and Kratz et al. (2017) look at caretakers of individuals with traumatic brain injury one year post injury. Additionally, Bayen et al., (2013) examine the role of the caretakers of traumatic brain injury survivors. These studies concluded that the caretaker's mental health and sense of burden was a direct correlation to the severity of the traumatic brain injury. Additionally, when looking at demands on caretakers, the PROMIS test was evaluated for effectiveness in understating these high demands. The test was found to be very effective. The study was conducted by Carlozzi et al. (2019). Caretakers in Danish families of individuals with traumatic brain injuries was studied by Norup et al. (2016). Similar conclusions were found in both studies. This illustrated that traumatic brain injury caretaker struggles are universal and not isolated to one demographic area. This is important to note when working with survivors of traumatic brain injury and their families and caretakers.

Lu et al. (2022) study the risk of developing brain cancer following traumatic brain injury. The study concludes that individuals with a traumatic brain injury are at increased risk of

developing brain cancer. Continuous monitoring by neuroimaging is a suggestion given by Lu et al. (2022). This information is valuable for medical professionals when working in the rehabilitation of traumatic brain injury.

Kuriakose et al. (2020) examine traumatic brain injuries in stroke victims looking for daily struggles and dysregulations. Given the high number of stroke survivors, this is important information when working to help rehabilitate stroke survivors. Stroke is one of the leading causes of traumatic brain injury.

Treatment Options

Hanks et al. (2012) examines peer mentoring to help support survivors of traumatic brain injury. The study concludes that peer mentoring helps survivors feel supported in their present struggles. They also provide an example of healthy development. Horn et al. (2015) and Galgano et al. (2017) examine treatment centers, outcomes and future endeavors for traumatic brain injury survivors.

Gomez-de-Regil et al. (2019) examines the role of psychological intervention in traumatic brain injury survivors. Gomex-de-Regil et al. (2019) provides valuable treatment options that have been successful in treating traumatic brain injury survivors.

Villamar et al. (2012) examines noninvasive brain stimulations to help treat individuals who have experienced traumatic brain injury. This alternative treatment has shown to be successful in clinical studies at reactivating brain pathways that promote healing and recovery. Brain stimulants have shown to positively affect the mood of the individual being treated.

Teeratakulpisarn et al. (2021) and Quinones-Ossa et al. (2020) examine intracerebral hemorrhage in traumatic brain injury seeking the best use of the brain CT in clinical practice. Sarkar et al. (2014) examines nerol cell death and how to minimize the damage post traumatic

brain injury. Using brain imaging in treatment procedures provides information that can not be seen from a purely visceral experience.

Ponsford et al. (2014) conducted a longitudinal follow-up assessment of survivors of traumatic brain injury; a 2, 5, and 10 year follow up post injury. This is an important study as it provides a long-term view of traumatic brain injury.

Traumatic brain injury as a result of stroke has been a topic of study. As a treatment option, Liao et al. (2023) examine acupuncture as reducing the risk of stroke and the effecting struggles of traumatic brain injury. Turner et al. (2021) and Chugh (2019) additionally examine the risk of stroke following traumatic brain injury. Both Turner et al. (2021) and Chugh (2019) found an increased risk of stroke following traumatic brain injury. Chugh (2019) studies efficient stroke care especially focusing on response time by helping professionals. They explored how earlier emergency response can lessen the damaging effects of the stroke on the individual.

Zhang et al. (2017) explore Fucoxanthin as a neuroprotection against complications from traumatic brain injury. Fucoxanthin shows success in helping survivors of traumatic brain injury. Corrigan et al. (2012) examines the traumatic brain injury national database to seek care effectiveness. This database provides resources and information to traumatic brain injury survivors.

Kelso et al. (2014) examines a bridge between neuroimmunity and traumatic brain injury while Alexander & Brown (2018) examine the individual frontal cortex function and interventions for minimizing damage. Alexander and Brown (2018) study the frontal lobes of the brain . The front lobes influence human ambition. The study examples how damage to the

frontal lobe of the brain directly influences an individual's goal setting behavior and life's ambition.

Brain tumors remain one of the most deadly cancers. Aldape et al. (2019) studied brain tumor development and brain tumor reduction. Aldape et al. (2019) studied the details of brain tumors. They examined how brain tumors change the brain and how treatment for brain tumors additionally changed the chemistry of an individual's brain. They concluded that increased research and understanding leads to advanced and new treatment options for individuals suffering with brain tumors.

When studying traumatic brain injury health, protective factors are sought for. Melatonin is studied as a protector against neurological atrophy in individuals with traumatic brain injury by Ding et al. (2015). Downing et al. (2021), McConeghy et al. (2012) and Dang et al. (2017) examine factors that promote recovery following severe traumatic brain injury. Important information in the treatment of traumatic brain injury patients.

To create more public health awareness, Dams-O'Connor et al. (2014) examines a self-reporting screening tool for traumatic brain injury. This tool, *The Brain Injury Screening*, has been found to create understanding and opportunities for rehabilitation.

Summary

Traumatic brain injury is a sudden life changing often devastating event. The multiple effects of traumatic brain injury on survivors is permanently life altering. Research has been conducted on the many aspects of traumatic brain injury.

Emotional dysregulation following traumatic brain injury has been a topic of research. Researchers have examined many varied emotional struggles that present themselves following a traumatic brain injury. Survivors may experience emotional dysregulation with anger,

depression, anxiety, fear, substance abuse, self-harming, suicide ideation and suicide attempts. Researchers have focused on many varied populations such as children, adolescents and adults. They have examined emotional dysregulation with chronically ill survivors and survivors from varied demographics. Researchers have examined the role traumatic brain injury plays in suicide. Researchers have additionally provided suggestions for recovery treatments and methods. There is a literary gap in hearing the unique stories of traumatic brain injury. Listening to the stories and identifying the emotional struggles of survivors of traumatic brain injury.

Cognitive dysregulation can appear as a dissociative response to a stressful situation or trauma. Additionally trouble with memory, concentration, judgment or making decisions that affect daily life can be identifiers of cognitive dysregulation. Researchers have studied chronically ill patients and treatment options among other aspects of cognitive dysregulation. A gap in the literature exists in hearing from traumatic brain injury survivors. Hearing their stories of cognitive struggles post traumatic brain injury; understanding the new world they are living in. I seek to hear and understand their personal stories and journeys surrounding cognitive dysregulation.

Research has shown that an individual's spiritual life is influential on other aspects of their life. Traumatic brain injury disrupts what an individual has always known and often creates chaos including disrupting one's spiritual life. Researchers have examined diverse groups of individuals to see how spirituality influences their unique circumstances. A literature gap exists in the study of traumatic brain injury survivors and how said injury affects their lives post injury. I would like to understand how traumatic brain injury affects their spiritual connections and spiritual awareness. Hearing survivors' lived experiences will provide this knowledge and understanding.

Every traumatic brain injury is as unique to the individual and the circumstances surrounding the injury. The day-to-day reality of traumatic brain injury will best be understood through the lived experiences of these survivors. Research has been conducted in the areas of diverse populations and treatment options. A literature gap exists in hearing the stories and identifying the unique personal experiences of these traumatic brain injury survivors.

Understanding the short and long term personal consequences of Traumatic Brain Injury on individual survivors will help clinicians and therapists be more effective in serving their clients' healing process. Detecting common themes will help clinicians and therapists create efficient therapeutic plans towards health and healing. Research has been done in the areas of emotional, cognitive, and spiritual consequences of traumatic brain injury. The devastation traumatic brain injury has caused on communities and families and the individual has been examined looking for treatment methods, reliable tests and accessible interventions.

A research gap exists in identifying common experiences, hearing the stories of individual survivors and looking at emotional, cognitive, spiritual after effects and their day by day functioning. Every traumatic brain injury is a unique experience, as unique as the individual themselves. That said, there are common experiences and results that these survivors have in common. Research has not evaluated the common experience in a way that would produce information to help therapists intervene and help these individuals in their healing and recovery. To hear the stories in the voices of these survivors can be a powerful weapon towards understanding the emotional, cognitive, spiritual and day to day experiences of individuals who have been faced with traumatic brain injury and are seeking to find a new life in a world, where everything is now different.

Chapter Three: Methods

Overview

Human experiences are best understood through the sharing of those living events. This research study included in-depth personal interviews and an information seeking questionnaire seeking to understand the lived personal experiences of someone who is a survivor of Traumatic Brain Injury (TBI). I sought to understand what these individuals experience on a daily basis due to their traumatic brain injury. I invited these survivors to use their own voice to share their stories and their experiences. The study sought to identify common themes from the stories and information shared by the study participants. The study was primarily concerned with identifying themes surrounding the emotional, cognitive, and spiritual experiences of these survivors of traumatic brain injury. The objective of this study was to help therapists create personalized therapeutic healing plans for their clients who suffer daily from traumatic brain injury. In this chapter I will be discussing the purpose, design and method used to discover answers about living with traumatic brain injury. Additionally, the methods of research and data collection and information gathering will be introduced.

Design

The focus of this transcendental phenomenology study is understanding the daily effects of traumatic brain injury. With transcendental phenomenology, I sought to understand the human experiences from the voice of the participant. Neubauer et al., (2019) describe phenomenology as the researcher's effort to capture a phenomenon by exploring the lived experiences of individuals. Phenomenology dissects what was experienced, how it was experienced and the effect on those that experienced it. The goal of phenomenology is to discover universal themes

through these lived experiences. To do so, Neubauer et al., (2019) emphasize that researchers must reject their preconceived notions about the phenomenon in order to focus solely on the participants' lived experiences. Transcendental phenomenology is defined as an unbiased study examining the participants' lived experience. The participants shared their lived experiences with traumatic brain injury. I invited the participant to look at the emotional, cognitive, and spiritual impact of their traumatic brain injury on their everyday life. The foundation of this study was the stories being shared and an information gathering questionnaire. These interviews lasted about 60 minutes and took place in the location of the participant's choice, a safe environment for sharing. As common themes from their stories emerged, this data will be collected, evaluated, and reported.

An information gathering questionnaire asked specific brief details about their experiences surrounding traumatic brain injury. Ricci et al. (2019) recommends that the questionnaire items include questions targeted to the population, in this case survivors of traumatic brain injury. This safety measure ensures that the questionnaire fully reflects the perspective of the participant and not the researcher. These questionnaires provided organized details that will be used in the data collection process (See Appendix).

Prior to approval for the study, two forms were given to the potential participants. Potential participants were asked to answer a self-reporting traumatic brain injury assessment, the Glasgow Coma Scale (see Appendix). The score on this assessment was the qualifier for participation in this study. For those participants who qualify for the study by the Glasgow Coma Scale, a separate participation form was given to them. The participation outlined the design, purpose, and procedure of the study. My efforts to control confidentiality and other

ethical considerations were explained. To participate in the study the participants were asked to sign the participation form (see Appendix).

Study Research Questions

Research Question One: What does the daily life of a survivor of traumatic brain injury look like?

Research Question Two: How do survivors describe the effect of their traumatic brain injuries on daily emotional regulation/dysregulation?

Research Question Three: How do survivors describe the effect of their traumatic brain injuries on daily cognitive regulation/dysregulation?

Research Question Four: How do survivors describe the effect of their traumatic brain injuries on daily spiritual regulation/dysregulation?

The participants were invited to share their stories of traumatic brain injury in its entirety beginning with the injury itself through the journey of seeking health and recovery up to and including their daily life today.

Setting

The participants were not isolated to one geographic location and were welcome from all over the United States of America. Interviews took place wherever convenient for the participant including in person or in video conferencing. Consent for recording was given to participate in the study. For video conferences, I encouraged the participants to find a private location where they can share openly without any fear of being overheard. I conducted the interviews from my office which is private and isolated. All recordings will be held in confidence on a computer that is passcode protected. My priority was to provide an emotionally

and physically safe environment in which the participant can share their personal experiences. I sought to make a personal connection with the participants by conducting the interviews either in person or online.

Participants

Potential participants will be given a traumatic brain injury assessment test, The Glasgow Coma Scale. This self-reporting test asks specific questions regarding the individuals' responses, mostly physical, at the time of the traumatic brain injury. A score from the Glasgow Coma Scale which indicates moderate or severe head injury is a qualifying score for participation. Mild traumatic brain injuries will not be included because I was looking for injury that permanently alters the survivors life in some way. I was seeking to understand how traumatic brain injury survivors dealt with the new day to day following their injury.

The research study is seeking a sample size of 10-12 participants. I am seeking saturation. Saunders et al., (2018) defines saturation as the point where no additional data is required to show proof of the category being studied. When the same evidence is found repeatedly the category is saturated. Especially important is to provide a diverse population in order to demonstrate a large range of data on that specific category. I sought to show common experiences from the stories of traumatic brain injury. Specifically, I sought understanding in the areas of emotional, cognitive and spiritual struggles. Essential inclusion criteria includes being an adult man or woman at least 18 years old, traumatic brain injury survivor, and identifying as a Christian, a believer in God. I sought to understand the effects traumatic brain injury would have on an individual's relationship with God. I was seeking understanding of what someone who believed in God and has a traumatic brain injury does with all of that. Questions I had included; Does an individual feel closer to God or distanced from God during this experience? Can a

traumatic brain injury promote a closeness to God? The Christian faith was chosen to narrow the spiritual field for the ease of understanding and reporting. Additionally, I wanted to align with Liberty University and my own personal belief system.

An adult who is responsible for life decisions can better illustrate what traumatic brain injury looks like rather from the experiences of a child being cared for inside their parents' home. For clarifying reasons, to participate in this study, an individual must have experienced a life altering, serious traumatic brain injury. An important part of this study is to look at the traumatic brain injury survivors and how their relationship with God has been affected by their injuries. As God is defined differently by each person, I believe having Christianity as a requirement brings individuals who have a similar religious and spiritual foundation. I am hoping those similarities will adequately reflect the spiritual journey of individuals who have experienced traumatic brain injury. These participants were selected through personal contacts and referrals from other therapists. There was no discrimination based on gender, race, ethnicity, economic standing or geographic location. The participants were compensated for their time with a $25.00 gift card.

The process of analyzing data includes the reading and dissecting of transcripts looking for differences, similarities and themes (Busetto, 2020). I defined the questions I am looking to research. These questions include looking at the daily life of survivors of traumatic brain injury. I was especially interested in the cognitive, emotional and spiritual world of these individuals. I gathered the data through interviews and an information seeking questionnaire. The information seeking questionnaire gathered knowledge about their personal details of traumatic brain injury. The information was organized and evaluated and added to the information gathered in the personal interviews.

Data analysis progressed as I dissected the collected data; seeking themes, relationships, and patterns. Once the information had been organized, the next step in data analysis was to present the information in a way that expresses the intimate struggles of these participants. I hope to present information that can be used to help traumatic brain injury survivors in their health and recovery.

Instrumentation

The Glasgow Coma Scale focuses on visual, oral and mobile responses experienced immediately following the traumatic brain injury. This test is designed to rate the level of injury and immediate dysregulation following the traumatic brain injury. The participant will be asked to self-report using the Glasgow Coma Scale and identify the severity of their traumatic brain injury. The assessment will be delivered in person or emailed to each participant to fill out. The questions are centered around visual response, oral response, and motor response. To calculate the patient's severity using the Glasgow Coma Scale, the numbers are added together. The total score gives the potential participant an overall score between 1 and 15. The lower the score indicates the more severe trauma. A score of 9-15 would indicate a mild brain injury. To qualify for the study a potential participant must have a total score between a 3-8 on the Glasgow Coma Scale, indicating a severe traumatic brain injury. For the purpose of this study, it is important the participants had life altering responses to their traumatic brain injury (see Appendix).

An information seeking questionnaire will be given to each participant at the conclusion of each personal interview. The participants will fill out the questionnaire providing detailed brief promotion surrounding their emotional, cognitive and spiritual experiences. The participants were asked to identify their most difficult daily struggles and invited to add any extra

thoughts they want to share. The data collected from these questionnaires was used to identify common themes.

Procedures

The ability to allow individuals to participate safely in clinical studies and to ensure ethical safety is the goal of institutional review boards (Qiao, 2018). My first step in this study was to seek and receive IRB approval. This approval ensures safety for all involved participants in the study. The IRB seeks to provide physical and emotional safety and wellbeing for the participants and for myself the researcher. Following IRB approval, I carefully evaluated the Glasgow Coma Scale scores, the self-reporting test taken by all potential participants. I invited those individuals who qualify for the study to participate. I thoroughly explained the study procedures, confidentiality, and expectation of participating in the study. All names and any other identifying information was changed to protect the privacy of the participant. I required all of the participants to sign a separate participation form. Additionally, I was available for all concerns and or questions they had. Following these ethical procedures, a future date and time was decided upon when and where the personal interview will take place. An audio and or video recording will be made of the interview. I interviewed the participants asking them to share their personal stories of traumatic brain injury. The participants were encouraged to talk freely but I also asked guiding questions.

At the conclusion of the interview, the participant was asked to fill out a brief information gathering questionnaire detailing some key words and phrases describing their experience as a survivor of traumatic brain injury. This information was added to the information gathered and organized from the in depth interviews.

The participants were immediately compensated for their time and personal contribution to the research study, a $25.00 gift card.

The process of analyzing data includes the reading and dissecting of transcripts looking for differences, similarities and themes (Busetto, 2020). I have done the first step of analyzing data, defining the questions I am looking to research. These questions include looking at the daily life of survivors of traumatic brain injury. I was especially interested in the cognitive, emotional and spiritual world of these individuals. I gathered data through interviews and an information gathering questionnaire.

Data analysis progressed as I dissected the collected data seeking themes, relationships, and patterns. Once the information had been organized, the next step in data analysis was to present the information in a way that expresses the intimate struggles of these participants. I presented information that can be used to help traumatic brain injury survivors in their health and recovery.

Researchers Role

I have been sick and I have watched family members suffer with severe illness. I have an understanding of what illness can do to a person's sense of self, emotional state, cognitive functioning and spiritual life. I have my own biases based on my personal experiences with illness. I minimized these personal biases by creating a plan of action regarding the research procedures and the evaluation of data. I listened to the study participants to gather their personal experiences rather than any of my own experiences. I relied on the words written on the information gathering questionnaire rather than my own experiences with illness. I kept my themes; cognitive, emotional and spiritual dysregulation in separate categories and placed the data into each category.

As a therapist I am aware of what it means to have therapeutic alliance and congruence. I was aware that with these participants, as the researcher, I had to put aside my personal feelings and experiences and open myself to experience empathy and understanding with each of their experiences independent of my own. My role, as the researcher, was to connect with the participants. My role was to help the participants feel safe to share these difficult traumatic brain injury experiences with me. My role was to create meaning out of the collection of thoughts, feelings and experiences of the individuals. Collins and Stockton (2022) compare the researcher to an actor in the theater examining life by stepping into the theoretical shoes of the participants. The researcher is seeking to access the deeply held beliefs of the participant in addition to their thoughts and feelings. The researcher seeks to understand the deep complexities of life. All along the researcher is to be mindfully present in the process of interviewing and simultaneously aware of the larger picture. I hoped to be able to step into these participants' lives and understand their world through their own lived experiences with traumatic brain injury. My role as the researcher was to take the stories shared with me, evaluate the information, identify themes, present the data collected and interpret the findings.

Once the stories were collected I transcribed the records and analyzed the data. I sought common themes in the areas of emotional, cognitive and spiritual dysregulation. I took the information gathering questionnaire answers and created categories. I sought common themes. My goal in this study was to provide information to therapists and healing professionals about the intimate details of traumatic brain injury response and recovery.

Data Collection

The participants were asked to share their personal stories of traumatic brain injury. These stories represent the bulk of the data. These personal stories were shared with me in

individual interviews, in person and online, at the discretion of the participant. These stories were recorded and evaluated seeking common themes and intimate information about the participants cognitive, emotional and spiritual responses to their traumatic brain injuries.

Interviews

Personal interviews took place with each participant. The interviews took place in person or online, whichever is most convenient for the participant. I, the researcher, conducted the interviews which will last approximately one hour each. The interviews were recorded for research evaluation and data collection. The interviews took place within a short amount of time from each other, approximately 2 months. Each participant was asked the same questions in the same order. The participants were asked to answer the proposed questions about their cognitive, emotional and spiritual responses based on their personal experiences with traumatic brain injury. The participants were also invited to add any additional information they would like to share. The following are the open-ended questions that were used in the personal interviews.

1. Please introduce yourself, including your name, age, demographic location and the age when you experienced your traumatic brain injury?
2. How are you feeling about sharing with me today?
3. Please share your story of traumatic brain injury.
4. Concerning the emotions following your traumatic brain injury, what have you experienced?
5. Concerning the mental challenges following your traumatic brain injury, what have you experienced?
6. How was your spiritual life affected by your traumatic brain injury?
7. In the areas of emotional, cognitive, spiritual healing, what transitions have you noticed throughout the healing process?
8. How does your traumatic brain injury affect your life today?

9. How does your traumatic brain injury influence your feelings about yourself?
10. How are your interpersonal relationships influenced by your traumatic brain injury?
11. Is there anything else you would like to share?

Question One asks the participant to introduce themselves. I encouraged them to include their age and geographical information and the age of their traumatic brain injury. This information helped establish transferability. Question Two established the participants' present feelings and emotions before we began the interview. As a phenomenological study, the emphasis was on describing traumatic brain injury through the participants' narrative and real world experience (Tomaszewski et al., 2020). As the researcher I helped create a safe environment for the participants.

Question Three encouraged honest reflection and the sharing of details concerning the participants' traumatic brain injury. I sought to discover what is important and impactful for each individual participant. DuBois et al., (2018) explain that researchers are filters of content and have the task of identifying common themes.

Questions Four, Five, and Six focused the participants sharing on the specific areas I was seeking to research; cognitive, emotional and spiritual responses to their traumatic brain injury. DuBois et al., (2018) continue that generating themes and information is the responsibility of the researcher. My role was to take the shared stories and dissect useful data.

Question Seven invited the participants to reflect on their personal healing process and their range of experiences. Qualitative interviews answer not only the “what works” but the “what worked for whom, when, how and why” (Busetto et al., 2020).

Question Eight will focus on the participants' life today. The goal of this question was to see what lasting effects of the traumatic brain injury the participant is experiencing on a daily basis. Ponnamperuma & Nicolson (2018) describe how previous trauma and current stress

combine to contribute to an individual's poor mental health and can additionally impact psychopathology and day to day functioning.

Question Nine invited the participant to be self-reflective about how traumatic brain injury has affected their personal beliefs about themselves both positive and negative. Trauma can overwhelmingly affect the individual's sense of self (Lanius et al., 2020).

Question 10 invited the participant to compare their personal life before the traumatic brain injury compared to present day post traumatic brain injury. Lanius et al., (2020) explain that individuals who have experienced trauma are often plagued with negative core beliefs about themselves. Additionally, trauma can have lasting physical results that include back pain, muscle pain and digestive issues; all which negatively affects the individual's sense of self.

Question 11 concluded the interview inviting the participant to share anything they deem important or impactful that they would like me to know about them and their traumatic brain injury experience. Currently, there is a lack of effective treatment for traumatic brain injury. Because of medical technology and acute response, the number of survivors of traumatic brain injuries has dramatically risen. Additionally, traumatic brain injury survivors suffer from challenges today that were not survivable in the recent past. Further research is needed to support these survivors and help them heal (Galgano et al., 2017).

Information Gathering Questionnaire

The participants were given an information gathering questionnaire at the conclusion of the interview. The questionnaire was to be filled out at the conclusion of the in-depth interview. The questionnaire asked open ended questions regarding their experiences with traumatic brain injury. The questionnaire was used in conjunction with the interviews for data collection purposes. Ricci et al. (2019) discusses how content validity, which refers to how relevant the

information is, is a foundational aspect of questionnaire validity. The information gathered through the questionnaire was used in the identifying of themes and data assessment for the purpose of acquiring knowledge. Following are the questions asked on the questionnaire.

1. Please identify the most difficult emotion you have experienced following your traumatic brain injury.
2. Please identify the most difficult cognitive deficiency you have experienced following your traumatic brain injury.
3. Please identify the most significant spiritual response you have experienced following your traumatic brain injury.
4. Please identify your largest challenge on a day to day basis.
5. Please add anything else you would like to me to understand about your experiences with traumatic brain injury.

Asking participants to use descriptive words or statements on this information gathering questionnaire will allow the participants to simplify their experiences into brief descriptive statements about their cognitive, emotional, spiritual and day-to-day responses to traumatic brain injury.

Question One was asking the participant to identify their strongest emotion felt in conjunction with their traumatic brain injury. Stubberud et al. (2020) describe emotional regulations as the capacity to control one's emotions and being able to control the expression of emotions. Additionally, emotional regulation is the ability to differentiate emotions and general emotional awareness. Emotional regulation is important to executive functioning. Examples of emotions include angry, confused, joyful, sad, calm, scared, and loved.

Cognitive deficiencies include memory loss (short and long term), struggles with abstract concepts, attention, and information processing. Traumatic brain injury is a leading cause of morbidity worldwide. Cognitive deficiencies significantly impact life satisfaction, function and the recovery process (Robert, 2020). Question Two asked participants to identify their most difficult cognitive deficiency they have experienced because of the traumatic brain injury.

Question Three asked participants to discuss their most significant spiritual response to their traumatic brain injury. Jones (2018) concludes that spirituality plays an important role in traumatic brain injury recovery. Examples of spiritual responses are turning to God for peace and understanding, turning to God in anger, rejecting spirituality, and embracing spirituality.

Daily challenges are a part of traumatic brain injury. Identifying the participants' greatest struggles helped determine similarities and differences in their lived experiences. Question Four asked participants to identify their most difficult daily struggle. Andelic (2019) emphasizes that individuals with traumatic brain injuries struggle with long-term emotional, cognitive, physical and spiritual impairment that affect their daily life in areas of work, functioning and life satisfaction.

Question Five invited participants to share any last thoughts, impressions or ideas that they feel is important to share. The information the participants shared was personal and intimate and invaluable to data collection and application.

Data Analysis

The purpose of these interviews was to identify common themes from the stories shared of traumatic brain injury. I desired to know the personal stories, hear the struggles and success, and feel the pain and joy experienced by these participants. The personal interviews were recorded and the transcriptions were carefully evaluated seeking to identify common encounters

in the daily life of the individual. The areas of research will focus on the participants emotional, cognitive and spiritual experiences surrounding their traumatic brain injury. Understanding human experiences surrounding traumatic brain injury was the goal of this study. The objective was to provide additional knowledge of traumatic brain injury for therapists and counselors and others seeking to aid in the healing, growth, and overall life satisfaction of survivors of traumatic brain injury.

Information gathering questionnaires were given to each participant at the conclusion of each personal interview. These questionnaires asked the participants to identify emotions, share brief experiences surrounding cognitive and spiritual responses in addition to identifying their most difficult day struggles and anything else they would like to add. It was a comprehensive and brief look at their experience as a survivor of traumatic brain injury.

As the study researcher I am aware of my own biases and assumptions. I sought to mitigate these biases by adding safety measures to the study. In the data analysis I used direct words from the participants from both the recorded interviews and the information gathering questionnaires. I used the designated research questions and did not use additional leading questions. This process of stepping into the lives of these participants and understanding their experiences through their eyes is called *bracketing* (Aspers & Corte, 2019). Bracketing assumes that interview questions are free from manipulative or leading questions. Bracketing also includes an effort to seek new understanding not previously researched and honoring the stories and experiences being shared from the study participants. Additionally, in that process, I gave equal importance to each individual participant and each story that is shared, that process is called *horizonalization* (Aspers & Corte, 2019). Alhazmi and Kaufmann (2022) introduce a descriptive *attitude.* Descriptive attitude is being mindfully attentive with the information I

acquired through the interviews. It is not just about the words said, but reporting what I perceived and observed during the interviews. *Interpretive data* is the strategy used to find meaning in the shared experiences (Alhazmi & Kaufmann, 2022). The data and stories collected went through the process of *phenomenological reduction* (Alhazmi & Kaufmann, 2022). This process was designed to pull meaning and themes from the human experience. Alhazmi and Kauffman (2022) introduce the *texture* of the experiences. The texture is the thickness, the meat of what the experience is like for the individual, in this study the survivors of traumatic brain injury.

Data analysis includes clustering, and textualization. Kousgaard et al., (2022) describe *hierarchical clustering*, also known as hierarchical cluster analysis. It is the organizing of similar themes into groups of clusters. Each cluster is distinct yet related to one another. *Textualization* is the process of putting into text the data that has been collected, evaluated, organized and relevance has been established (Kousgaard et al., 2022).

Trustworthiness

Purposeful sampling, also known as selective sampling, was used in selecting participants. I was seeking to understand the phenomenon of traumatic brain injury and how these experiences personally affect survivors' daily lives. Purposeful sampling seeks to recruit participants who can provide personal insight into a phenomenon (Campbell et al., 2020). Personal sampling aligns the participants with the objectives of this study; to understand the emotional, cognitive, and spiritual effects of traumatic brain injury. To improve trustworthiness, I sought to keep my personal biases in check, setting aside my own perspectives and beliefs.

Qualitative researchers are motivated to coordinate study research methods, assumptions, theoretical orientations, study procedures, data collection and data analysis (Rose & Johnson, 2020). This practice encourages trustworthiness, quality and credibility (Rose & Johnson, 2020).

Credibility

Credibility is looking for the accuracy of the research. Credibility examines the researchers, the data collected, the research methods and the study findings (Johnson et al., 2020). Details of the study including design, procedures, data collection and results will be detailed for dependability and the sharing of information. Clear communication with the participants, clear defining of themes, interpretation of data, and empirical support encourage credibility (Nyirenda et al., 2020). As the researcher, I sought to be vigorous in my disclosure of all procedures, methods, data and information gleaned throughout the study. I shared these details and all data and information gathered through the research study in the written portion of this project.

Dependability

Dependability, the measure of the ability of the study to be replicated by another researcher, is available and presented in detail. The interview process included the gathering of participants, questions, and data collection will be detailed. The information gathering questionnaire was written by the participants' hands through their own voices. Forero et al., (2018) explains that dependability relies on rich descriptions of procedures and methods, and a complete replication of the data. To ensure dependability, I kept immaculate records of my procedures throughout the study and collected detailed records of the data collection.

Transferability

Broad application of these results, transferability, is enhanced by identifying crucial inclusion criteria and demographics. The goal of this study was to identify themes that can be applicable to traumatic brain injury survivors. To encourage transferability, I used purposeful sampling techniques in my gathering of study participants and created data saturation (Forero, 2018). To participate in the study, the participants were tested to determine the level of injury based on their scores from the Glasgow Coma Scale. Additionally, participants were not discriminated against based on geographic location, race, ethnicity or financial situation. The requirements for the study included a qualifying score on the Glasgow Coma Scale, an adult (18 years and older), and identification as a Christian. This purposeful sampling helps the data results be transferable (Forero et al., 2018) .

Confirmability

Confirmability, the ability for the study to be repeated finding the same results, is also strengthened by identifying essential inclusion and exclusion criteria (Campbell et al., 2020).

Foreo et al. (2018) suggests incorporating triangulation techniques to insure confirmability. I did this by collecting data in two different ways. I gathered data through the information shared in the personal interviews and a self reporting information gathering questionnaire.

In depth interviews were conducted with each participant to gather information surrounding their experiences surrounding emotional, cognitive, spiritual and daily struggles. I used the transcripts to identify themes, relationships and other relevant information.

An information gathering questionnaire was given to each participant at the end of each personal interview. The questionnaire provided additional information from each participant

about the cognitive, emotional, spiritual and daily living of the participants. I took the information provided on these questionnaires and organized the data into themes.

Ethical Considerations

Taquette and Borges da Matta Souza (2022) discuss that when using human beings in qualitative research, there must be clear and relevant justification for the study. Additionally, all safety measures and confidentiality procedures must be put in place to protect the participants. The most important factor for the study is ensuring the safety of the participants. All participants were informed of the procedures, the data collection methods, and any potential risks of participating in the study. Participants' names and any identifying information were changed for the safety and confidentiality of those participating. All participants were required to sign a participation form ensuring that they understand the study and what they would be participating in and the purpose of the study (See Appendix). Participants who have suffered from traumatic brain injury are an at risk and vulnerable population. As the researcher, I made their safety and protection my priority in this study. Additionally, I sought to protect the participants' anonymity and privacy. The gathered stories and information will be protected on a password protected computer where no identifying inflammation can be found. Revisiting trauma can open wounds and cause emotional dysregulation (Berfield et al., 2022). It also brings healing. Being able to talk about trauma details shares the story, the pain with another and breaks the cycle of isolation. I created the safety that if the participant felt unsafe or too emotionally distressed, they could choose to leave the study at any time. None of the participants made the choice to leave the study.

Summary

In this chapter, the study methods, data collection and procedures are introduced. Conducting a transcendental research study taught the lived experience of individuals who have experienced traumatic brain injuries. My role as the researcher was to gather information using in depth personal interviews and a self reporting information gathering questionnaire. I invited participants to share their personal stories and experiences of traumatic brain injury through in depth personal interviews and an information gathering questionnaire. Selecting participants and the ethical considerations to ensure their safety has been introduced in this chapter. Additionally, the focus areas; cognitive, emotional and spiritual effects of traumatic brain injury and interview questions have been presented. In this study I sought understanding of the lived human experiences surrounding traumatic brain injury in an effort to gather information to help in the healing process of those who have suffered.

Chapter Four: Findings

Overview

The purpose of this transcendental phenomenological study was to describe the experiences of traumatic brain injury survivors, seeking to understand their lived experiences by examining the emotional dysregulation, cognitive dysregulation, spiritual response and daily experiences associated with traumatic brain injury. For the purpose of this study, 12 adult survivors of a significant life-altering traumatic brain injury were invited to share their stories of injury and recovery and agreed to be studied and evaluated. Chapter Four begins with an introduction to each of these survivors. The Glasgow Coma Scale, a test created for the evaluation of traumatic brain injury severity, was used to identify traumatic brain injury survivors qualified to participate in this study. Data was collected through consented, in-depth, structured, and semi structured interviews and through in-depth self-reported information gathered from written Information Gathering Questionnaires. Themes of dysregulation, struggle, and hope presented themselves through the collected data. These themes have been evaluated, organized and presented here. The 12 participants have been given the pseudonyms Alfred, Daniel, Edward. George, Peter, William, Alice, Beatrice, Caroline, Elizabeth, Jane, and Margaret. The study's research questions have been clearly answered and summarized. The research questions for this study were as follows:

> Research Question One: How do survivors describe the effect of their traumatic brain injuries on daily emotional regulation/dysregulation?
>
> Research Question Two: How do survivors describe the effect of their traumatic brain injuries on daily cognitive regulation/dysregulation?

Research Question Three: How do survivors describe the effect of their traumatic brain injuries on daily spiritual regulation/dysregulation?

Research Question Four: What does the daily life of a survivor of traumatic brain injury look like?

Participants

Twelve survivors (See Table 1) of traumatic brain injury took part in the study to share their emotional dysregulation, cognitive dysregulation, spiritual response and daily lived experiences following their personal traumatic brain injury. All of the participants experienced significant brain injury and qualified for participation through the Glasgow Coma Scale with a scoring level of moderate or severe injury. The participants were all mentally and emotionally capable of giving consent to participating in the study and being interviewed for the purpose of collecting data . The collected data was gathered through personal,semi-structured interviews and through the Information Gathering Questionnaire. All interviews were recorded and participants were invited to share in person or online. The research questions for this study provided a framework for the development of questions used in the personal interviews and the Information Gathering Questionnaire.

All twelve participants self-identified as Caucasian. The median age of the male participants was 58. The median age of the female participants was 49. The participants had varying time between their traumatic brain injuries ranging from one year to 15 years. This pertinent information and other information is noted in Table 1.

Table 1

Participant Demographics

Pseudonym	Age	Gender	Age at onset of TBI	Type of TBI
Alice	50	F	42	Stroke
Beatrice	61	F	55	Brain Tumor
Caroline	50	F	49	Brain Tumor
Elizabeth	65	F	64	Stroke
Jane	24	F	19	Brain Seizures
Margaret	43	F	32	Vertebral Artery Dissection
Alfred	62	M	61	Assault
Daniel	63	M	52	Parkinson's Disease
Edward	45	M	30	Vehicle Accident
George	53	M	52	Stroke
Peter	53	M	43	Acromegaly Brain Tumor
William	75	M	72	Vehicle Accident

Alice

Alice is a married, 50-year-old Caucasian woman and currently self-reports as being semi-active in her religious congregation. She reports that she feels close to God. She is a mother and works as a mental health counselor. After running a marathon, Alice collapsed and experienced a massive stroke at the age of 42. Alice reports that her traumatic brain injury changed her life dramatically. Alice states, "The person I am today approaches the world in

significantly different ways than the person I was before. I am still the same person on the outside, but inside I feel like a different person. It is so hard."

Beatrice

Beatrice is a 61-year-old Caucasian woman and currently self-reports as being very active in her local Christian church. Beatrice is currently married to her second husband. Her first husband died of suicide 10 years ago after a 30-year marriage. She is a mother and step-mother, and works in finance. When Beatrice was 55 years old she was diagnosed with a large brain tumor that required surgery. The brain tumor was removed successfully, but resulted in a traumatic brain injury. Beatrice reports that her traumatic brain injury has made it harder to cope with her first husband's passing, and she longs for the life she used to have. Beatrice reports, "I am devastated when I think of the life I had with Paul, my first husband. His death was the beginning of my death."

Caroline

Caroline is a divorced, 50-year-old Caucasian woman who reports as being very active in her Christian faith. Caroline was diagnosed at age 49 with a massive brain tumor that required surgical extraction. The tumor's placement destroyed her left-side facial nerve and the hearing on her left side. Caroline works in the event planning industry. Her traumatic brain injury and her physical consequences have left Caroline feeling insecure about her appearance. She fears it negatively affects her interaction with clients and her ability to find a potential life partner. Caroline states, "I don't like to be stared at. I notice when people are looking at my drooping eye and mouth rather than my whole face or listening to what I am saying."

Elizabeth

Elizabeth is a 65-year-old married Caucasian woman and retired artist. Elizabeth reports as being very active in her religious community. Elizabeth suffered a massive stroke when she was 64 years old. At the time of her traumatic brain injury, she was heavily involved in a non-profit organization helping the people of Guatemala. Elizabeth's traumatic brain injury required her to leave that work behind. She was very sad about that, but reports that she is focused on the "good" that came from her injury. She states, "I have re-prioritized my life. I feel a need to spend time with my children and grandchildren because I now fear my time here is shorter than I once hoped for."

Jane

Jane, our youngest participant, is a 24 year old married Caucasian woman who currently self reports as being actively involved in her Christian community church. Jane is the mother of a young boy and is now expecting her second child. At the age of 19, Jane began suffering from brain seizures that resulted in a traumatic brain injury. These spontaneous seizures existed for over a year. During that time, Jane lost the ability to drive and be independent. Jane explains that she occasionally thinks about the possibility of recurring seizures. The doctors explained to Jane that the seizures were caused by emotional, psychological, and physical stress. Jane purposefully works towards life balance because of this diagnosis. Jane states, "Although I do not think about the seizures everyday, I worry they will occur again and will limit how I can parent my children and live my life."

Margaret

Margaret is a married 43-year-old Caucasian woman who reports being very active in her local church. When Margaret was 32 years old she experienced a vertebral artery dissection

which was a precursor to several strokes and a brain bleed. Margaret suffers from migraines that can be debilitating in her life. Since the traumatic brain injury Margaret reports that the migraines have increased and also reports having feelings of being trapped inside her body and home. Margaret's traumatic brain injury initially affected her ability to parent and spend time with her husband and children. Currently, Margaret is focused on building a career and pursuing clarity in life, as she states, "I am seeking for what God has in store for me."

Alfred

Alfred is a married, 62-year-old Caucasian man. Alfred reports being very active in his Christian church. Alfred suffered a severe brain injury following a vicious physical assault. This assault took place when Alfred was 61 years old. Alfred's work as a university professor has been permanently affected by his traumatic brain injury. Alfred spent weeks in rehabilitation recovery after his assault. Alfred recalls, "I don't feel like the same man. My injury has changed every important aspect of my personality and my life. It affects my relationships and the way I teach my students."

Daniel

Daniel is a 63-year-old Caucasian man. He is currently separated from his wife of 40 years. Although Daniel identifies as a Christian, Daniel is not currently involved with any religious congregation. Daniel was diagnosed with Parkinson's Disease at 53 years old. Daniel owns his own successful company in which he spent much of his time connecting with and entertaining clients at sporting events and extravagant dinners. He had always been physically active; enjoying water skiing, skiing, golfing, and snowmobiling. Daniels' diagnosis has significantly affected his daily life, his work life, and his relationship with family members. Daniel no longer entertains clients or spends time doing activities he once loved. Daniel states,

"I'm very self-conscious of my shaking hands. I embarrass myself. It's hard for me to be the man I once was."

Edward

Edward is a 45-year-old married Caucasian man. Although Edward identifies as Christian, since his traumatic brain injury, Edward no longer attends his community church. Edward suffered a massive brain injury following a car accident when he was 30 years old. Edward has suffered from a range of never-before-experienced emotions including rage, depression and anxiety. He continues to heal from many cognitive and physical repercussions from the traumatic brain injury. Edward states, "The injury sparked anger and aggression in me that I never knew existed."

George

George is a married, 53-year-old Caucasian man. George reports being very active in his community church. George experienced a massive stroke at the age of 52 years old. George, a successful business owner, struggled with the lack of ability to control his health. George states that he struggles with his lack of healing and feelings of fatigue. George explains that his relationship with God has been altered from his injury. George actively seeks for more understanding and guidance from God in understanding his purpose. George recalls, "I had a moment where I knew I was going to die but I didn't want to leave. Now that I have lived, I want to know God's purpose for me."

Peter

Peter is a married, 53-year-old Caucasian man. Although Peter identifies as a Christian, he no longer connects with the religion he was raised with. Peter's spiritual life has been

influenced by his traumatic brain injury and diagnosis. At the age of 43, Peter was diagnosed with acromegaly and a large brain tumor. This diagnosis has resulted in a traumatic brain injury that for Peter seems to be always evolving. Peter has struggled to manage his life post-diagnosis. Peters' emotional and cognitive struggles have contributed to coping mechanisms that have led to addictive behaviors. A very successful designer, Peter has seen the effects of his brain injury in his work life. Peter recalls that he feels slower in his work and not as intellectually sharp as he once was. Peter states, "My diagnosis and traumatic brain injury has permanently altered the trajectory of my life and everything and every relationship in it."

William

William, our oldest participant, is a divorced, 75-year-old Caucasian man. William reports as being very active in his Christian faith. William experienced a severe brain injury following a car accident at the age of 72. William spent months in the hospital and in rehabilitation following his car accident and traumatic brain injury. William reports that his life was largely impacted from his injury. A successful surgeon, William was forced into permanent retirement. William states, "I was devastated when I had to stop working. I lost my sense of purpose in life."

Results

This study has provided thorough insights into the emotional, cognitive, spiritual and daily experiences of traumatic brain injury survivors. Through in-depth interviews and a self-reported questionnaire, valuable themes developed in the areas of emotional dysregulation, cognitive dysregulation, spiritual response and daily life

Theme Development

Similar words and phrases and common experiences were expressed by the 12 participants in the personal interviews and written on the Information Gathering Questionnaire. During the interview, questions were asked to probe for specific experiences related to the emotional, cognitive, spiritual and daily life experiences of the participants following their traumatic brain injuries. The following are the open-ended questions that were used in the personal interviews:

1. Please introduce yourself, including your name, age, demographic location and the age when you experienced your traumatic brain injury?
2. How are you feeling about sharing with me today?
3. Please share your story of traumatic brain injury.
4. Concerning the emotions following your traumatic brain injury, what have you experienced?
5. Concerning the mental challenges following your traumatic brain injury, what have you experienced?
6. How was your spiritual life affected by your traumatic brain injury?
7. In the areas of emotional, cognitive, spiritual healing, what transitions have you noticed throughout the healing process?
8. How does your traumatic brain injury affect your life today?
9. How does your traumatic brain injury influence your feelings about yourself?
10. How are your interpersonal relationships influenced by your traumatic brain injury?
11. Is there anything else you would like to share?

The Information Gathering Questionnaire was filled out by the participants at the conclusion of the in-depth interview. The questionnaire asked the participants open-ended questions regarding their experiences with traumatic brain injury. The questionnaire was used in

conjunction with the interviews for data collection purposes. The questions from the Information Gathering Questionnaire are as follows:

1. Please identify the most difficult emotion you have experienced following your traumatic brain injury.
2. Please identify the most difficult cognitive deficiency you have experienced following your traumatic brain injury.
3. Please identify the most significant spiritual response you have experienced following your traumatic brain injury.
4. Please identify your largest challenge on a day to day basis.
5. Please add anything else you would like to me to understand about your experiences with traumatic brain injury.

One major theme presented itself in each of the four focus areas: emotional dysregulation, cognitive dysregulation, spiritual reaction and greatest daily struggle. These are referred to below as "Major Themes."

Two sub themes emerged for each respective area: emotional dysregulation, cognitive dysregulation, spiritual response, and greatest daily struggle. These are referred to below as "Subthemes."

Refer to Table 2 for a summary of findings.

Emotional Dysregulation

Major Theme- Depression

Individual survivors experience depression following traumatic brain injury. Common phrases shared by study participants include, "hard to get out of bed," "sadness every day,"

“everyday tasks are exhausting.” Depression for these participants struggling with a traumatic brain injury looks like overwhelming sadness, hopelessness, anger, and tears. Participants report a decreased interest in sex and other activities they once enjoyed.

Peter states,

> Depression has plagued me for over ten years. I just can't wrap my head around the new me. I have always actively worked to be healthy physically, mentally and sexually. I am resigned to a life of getting older, fatter and not having the same sexual power I once had.

Beatrice reports times of deep sadness and great emotion. She states, “I go along and do good for a while and then I can barely get out of bed for days on end. I cry and mourn for the life I wanted. It is gone.”

Alice states, “My depression never really goes away, there is always a low lying feeling of sadness and loss.”

Subtheme One- Fear

Individuals experience fear following traumatic brain injury. Participants report fear as “crippling,” "stuck," and “life altering.” Fear of death and fear of recurring injury were the most reported *fears* by study participants.

Alice reports,

> I could not leave the house without paralyzing fear that I would have another stroke or just die. I had to use prescription drugs to calm myself to be able to go grocery shopping or take my kids to their lessons. I cried every single day and was consumed with thoughts of death.

Jane recalls,

> I moved home with my parents and they would have to drive me to school and anywhere else I needed to go. I was scared to go into class without them in case I had another seizure…I was afraid I would never live the life I planned, marriage and a family.

Subtheme Two- Anxiety

Participants experience anxiety following traumatic brain injury. Study participants report anxiety symptoms that include feeling nausea, a racing heartbeat, and physical illness. Panic attacks were common among participants that experienced anxiety. One participant reported several trips to the emergency room from resulting panic attacks:

> Caroline reports,
>
> For weeks I would wake up feeling panicked. I could barely breathe. I would want to hibernate to avoid people seeing me. I could barely even look at a mirror. How would anyone else ever see past my injury and see me again?…The thought of returning to work put me into intense anxiety.

Cognitive Dysregulation

Major Theme- Grasping for Words

Traumatic brain injury survivors struggle to find the right words to express their thoughts, grasping for the words. Phrases participants used to describe this experience include "embarrassing", "devastating," "felt stupid," and "inadequate." Grasping for words is described by participants as not being able to recall the simplest words or phrases to verbally express the thoughts they have in their heads. Participants state that the lack of word recall forces them to stop and pause mid-sentence or mid-conversation.

As a professor, Alfred reports that grasping for words continues to be an area of struggle for him, he states,

> Following my traumatic brain injury, I changed how I prepare for my lectures. I have short term memory loss, and I struggle finding the right words to describe what I am trying to express. Instead of a lecture based on free talking, I wrote everything down so I can not only present the material but describe what I am trying to express. It can be a very long and tedious process, but it is my new norm and necessary.

Caroline reports,

> My work presentations take twice the time to prepare since my traumatic brain injury. I have a very social job, and when I am meeting with clients I know what I want to say but the words do not come out. It's awful and makes me feel stupid sometimes.

Edward also reports, “I feel frustrated that after all of this time, my vocabulary recall has never fully returned. Sometimes I just can’t think of the word I need. I pause to think a lot when I speak. I hate it.”

Subtheme One- Memory Loss

Traumatic brain injury survivors struggle with memory loss. Memory loss was reported by participants as both short-term and long-term memory loss. Participants would recall reading an article or book chapter and then not remembering anything they had read, or walking to a room and having no idea why they were there. Forgetting names and life details was a common reported memory problem for these survivors of traumatic brain injury.

Daniel states,

My wife and kids tell me I am forgetful. They often tell me that they already told me something. It's very frustrating because I genuinely don't remember things I probably should. I also get comments at work, but no one calls me out there like they do at home.

William explains,

I forget names, never faces, but I am always at a loss with names. I feel embarrassed when I can't remember a name that I should. This may be a factor of growing old, but it seems so much worse than it used to be.

Elizabeth recalls, “My short-term memory was non-existent for many months after my traumatic brain injury. It continues to improve daily, but I still struggle with remembering daily details.”

Subtheme Two- Loss of Balance

Individuals struggle from a loss of balance following a traumatic brain injury. Participants report feeling unsteady and lightheaded, often having to sit or lean against a wall to steady themselves. Common words expressed by participants include “spinning” and “floating.”

George reports,

I feel very unsteady and often dizzy. When I walk I have to hold the stair rail, especially when going down stairs. I feel like it takes mental effort to take each step. I also feel unsteady when walking on grass or areas where the ground is not level. I veer to the left when I walk; it's a weird experience to have walking not a natural thing anymore.

Spiritual Response

Major Theme- Close to God

Individual survivors feel closer to God following a traumatic brain injury. Participants who were close to God before their traumatic brain injury report feeling closer to God following their injury. Participants used words and phrases such as "protected," "carried by God," "preserved by God," and "He walks with me…on this journey."

George states,

> God is where I turn to understand what I need to learn from this experience in my life. God was there every minute of this experience to watch over me and He continues to walk by my side through the healing process. He preserved my life and I now seek to understand what I need to learn from Him and do for Him.

Margaret states,

> I felt protected by God. I felt in my heart that God stepped in and preserved my life. The upcoming weekend we were supposed to go camping as a family. Had I gone, I would have died. I would have been too far from any medical help. God saved my life that day.

Subtheme One- Gratitude to God

Survivors of traumatic brain injury experience gratitude to God. Participants who had a positive existing relationship with God expressed gratitude to God following their traumatic brain injury. Participants used statements such as "my life was sustained through God's grace." Participants report that *gratitude* helps them see hope in their recovery.

Elizabeth states, “I feel grateful for God who sustained me through my traumatic brain injury and continues to heal me today. I feel God with me every day, healing me and blessing me.”

Jane expressed gratitude to God. She states, “I am so grateful for my family. For my husband and son. I believe God has protected me from further injuries and seizures."

Subtheme Two- Peace in God

Individuals experience peace following a traumatic brain injury. Participants report that peace brings rest to their souls in their process of recovery. For these participants, peace is reported as daily “rest,” “calm,” and “safety in God.”

Elizabeth recalls,

> I have never felt panicked. Even after I came to after my stroke I have felt nothing but peace. I struggle with so many little things, but God is with me every step of the way. I feel peace in my heart and in my mind. I know that, if it is God's will, I will live, and if it is not God's will, then my time has come. I am at peace with whatever God's plan is for me.

William states,

> I have felt nothing but peace and God's love for me throughout this difficult time. I don't know what God has in store for me next, but I know He will show me if I seek Him. My gratitude for my life is overwhelming.

Daily Struggle

Major Theme- Fatigue

Survivors of traumatic brain injury struggle daily with fatigue. Participants report that fatigue affects every aspect of their lives. Fatigue was described as both emotional and physical fatigue. Common words and phrases used to describe fatigue by participants include “body aches,” “trouble sleeping,” “headaches,” and "distracted.” Participants describe daily struggles with feelings of overwhelming fatigue that spirals into hopelessness.

George describes his daily fatigue. He states, “I only have the energy for half a day's work. I feel unable to feel fully rested. I take naps every day and hope to wake refreshed; I rarely do.”

Alfred reports,

> I struggle with mental and physical fatigue every day. I just don't have the stamina or longevity I used to have. I want to be the grandpa I used to be, sledding and playing in the snow with my grandkids. I can do that, just not as long as I used to be able to.

Beatrice reports, I struggle with energy. A nap is part of my every day. If I work too hard, I can feel it at night. I can't think too hard, when I do, I feel it in my whole body.”

Elizabeth states, “I am lucky I am retired now. I would never have the energy I would need to work. I try to make bread several times a week. Sleeping and baking is how I spend most of my days.”

Subtheme One- Loss of Self-identity

Daily traumatic brain injury survivors experience a loss of self-identity. Participants describe this as a lack of connection with self. Phrases expressed by participants include, "losing

desire for things I once enjoyed," "I don't take care of myself like I used to," and "I don't feel like the person I used to be."

Peter states,

> I am a lone island, isolated. My family and those closest to me don't understand the way I feel. I struggle explaining how I feel like a different man. I don't feel like the same person. Although many things are the same, I approach the world differently. I approach problems and people differently than I did before. It's a very lonely reality.

William explains, "I am no longer a surgeon. I do not know what my life purpose is now. I am a father and grandfather but who am I? I am not the man I used to be."

Alice reports,

> I feel like a completely different person every day and it has changed my life. I am lonely and isolated. I seek connection with people who have trauma so I will not feel so alone. My role in life has changed but I don't know what my new role is yet.

Subtheme Two- Loss of Balance

Survivors of traumatic brain injury experience loss of balance on a daily basis. Participants report struggling to get out of bed in the morning because they feel unsteady and dizzy. Throughout the day, participants report the loss of balance affects every aspect of their freedom to participate in normal life events such as cleaning, cooking, shopping, work, and exercise. Participants report that they fear going places alone in case they need help or fall.

Alfred reports,

> I have to use something to steady myself when I walk. Sometimes it is a chair or table or even a person. I feel safer using a railing when walking up or down stairs. I hope with time it will get better. I think I am too young for a walker or cane.

Caroline reports, “I feel unsteady when I walk. I tend to walk to my left. I take deliberate steps, like walking is new for me…especially when I am walking on grass or on stairs.”

Table 2

Table 2 includes a charted view of the data collected from this study. The data was collected, organized and evaluated using the stories shared from the personal interviews and the Information Gathering Questionnaire. Included on Table 2 are the shared experiences, major theme, subtheme one and subtheme two in the areas of Emotional Dysregulation, Cognitive Dysregulation, Spiritual Response and Daily Struggles. Each number of mentions is out of twelve total participants.

Shared Experiences and Theme Development from Data Analysis

Area of Focus	**Shared Experiences**		**Number of Mentions By Participants**
Emotional	Depression	Main Theme	7
Emotional	Fear	Subtheme 1	4
Emotional	Anxiety	Subtheme 2	3
Emotional	Anger		2
Emotional	Frustration		2
Emotional	Suicide Ideation		2
Cognitive	Grasping for Words	Main Theme	8
Cognitive	Memory	Subtheme 1	5
Cognitive	Balance	Subtheme 2	3
Cognitive	Disorganized Thoughts		2

Area of Focus	Shared Experiences		Number of Mentions By Participants
Spiritual	Close to God	Main Theme	7
Spiritual	Gratitude to God	Subtheme 1	5
Spiritual	Peace	Subtheme 2	4
Spiritual	Distance from God		3
Daily Struggle	Fatigue	Main Theme	6
Daily Struggle	Loss of Self-Identity	Subtheme 1	5
Daily Struggle	Balance	Subtheme 2	4
Daily Struggle	Depression		3

Research Question Narrative

Research Question One

How do survivors describe the effect of their traumatic brain injuries on daily emotional regulation/dysregulation?

Participants were asked to identify the emotional struggles they experienced following their traumatic brain injuries. Seven of the twelve participants reported that depression is the number one emotion they experienced following their traumatic brain injury. The participants expressed long hard battles with debilitating depression. Depression was described by participants as feeling “empty and sad”. “Despair and the inability to function” at a healthy level were common phrases used by the participants. This is an important emotional response to identify because depression affects an individual's thoughts, behaviors, and overall sense of well being. Participants also report feelings that led to suicide ideation. Alfred reports debilitating

suicide ideation, “The emotional pain was so great. I didn’t know how I was going to survive. I remember sitting at a family birthday party where I just cried and asked my children to help me survive this.” Daniel’s sadness has led to suicidal thoughts and crushing feelings of self-doubt, “I have slowly lost everything and everyone that matters to me. I have made some harmful choices since my diagnosis that have ruined everything.

Additional emotional struggles include fear; four participants identified fear as the number one emotion they experienced following their traumatic brain injury. Fear was described by the participants as a general fear of living, fear of a recurring traumatic brain injury, and fear of death. Alice reports, “I cried every day for months. I feared leaving my house and was consumed with fear of a recurring traumatic brain injury.”

Anxiety was the next most identified emotional struggle. Participants describe anxiety as feeling nervous, a sense of dread, racing heartbeat, and panic. Two participants reported recurring medical checks and Emergency Room visits fearing a recurring traumatic brain injury that was diagnosed as panic attacks and anxiety.

Participants reported anger and frustration at the lack of healing. Daniel reports, “I am so angry this is happening to me.” Edward experienced unchecked rage,

> I had so much rage after my accident. I would try to explain what I was feeling and no one could understand. I struggled to communicate. I remember throwing glasses and plates against the wall and on the floor…and books across the room. It scared my family. I am not like that anymore.

George reports,

> I have a bottle of pills I must take every day. I am tired all of the time and I don't have the energy to even mow the lawn….I feel like my freedom has been taken away. I am frustrated every day that I am not better. I should be healing faster.

Identifying daily emotional struggles of traumatic brain injury survivors gives an accurate view of their daily life. This information answers the first research question, how do survivors describe the effect of their traumatic brain injuries on daily emotional regulation/dysregulation?.

Research Question Two

How do survivors describe the effect of their traumatic brain injuries on daily cognitive regulation/dysregulation?

Participants were asked to identify cognitive struggles they have experienced since their traumatic brain injury. The number one mentioned cognitive struggle expressed by eight of the twelve participants was grasping for words. Alice described grasping for words as knowing what she wanted to say and not being able to communicate those thoughts through adequate word recollection. Caroline reports, “I’m talking and then I just have to stop, I can’t think of the words to describe my thoughts. It’s embarrassing and frustrating.”

The next most reported cognitive struggle is loss of memory. William states, “I can’t remember things I knew before. I love to cook and I have forgotten recipes that I have made 100 times.”

Participants reported loss of balance as a difficult and prominent daily struggle. George reports the daily struggles he has walking and performing chores such as mowing the lawn and household chores. At work George uses handrails and purposely uses the stairs every day hoping to strengthen his balance.

Participants also mention experiencing disorganized thinking following a traumatic brain injury. Beatrice and Margaret use the phrase “trapped inside my head” when describing their lack of clear thinking.

Beatrice states,

> Sometimes I just forget what I am doing because there are so many thoughts in my head at the same time. I have a really hard time staying on track especially with things like paying bills or recipes. I get very confused about what I just did. It's alarming how often I experience this.

Margaret recalls, “For a long time I couldn't shut my brain off and it made it impossible to finish small easy tasks on a daily basis. It was really hard and I often felt discouraged.”

Cognitive struggles of traumatic brain injury survivors can be very difficult. This data provides an accurate view of their daily life. This information answers the second research question, how do survivors describe the effect of their traumatic brain injuries on daily cognitive regulation/dysregulation?.

Question Three

How do survivors describe the effect of their traumatic brain injuries on daily spiritual regulation/dysregulation?

Seven of the twelve participants identified feeling closer to God as the primary spiritual response they experienced following a traumatic brain injury. Through this study with these participants, I found that their spiritual responses were impacted or influenced by the traumatic brain injury but not caused by them. I found that the participants' relationship with God became closer or distanced depending on how it was before the traumatic brain injury. If they were close to God, for example, then they became closer after the traumatic brain injury. If they were

distanced from God prior to their traumatic brain injury, then they became more distanced to God post traumatic brain injury. The traumatic brain injury was not a catalyst for drastic change in any of the participants' lives, but it remained an influence in every participant's life. Beatrice reports, “Although I am sad every day, I feel God in my life. I am strengthened by the love I feel from Him. He knows me, and my struggles intimately.” Alfred reports, “I have relied on my testimony of God's love for me to survive this traumatic brain injury.”

In addition to being closer to God, participants reported feelings of gratitude and peace. Elizabeth praises God in gratitude for the extended time she has to live and spend time with her family.

Two participants reported that they feel abandoned by God and angry towards God. Peter reports,

> God is not there for me. I have not felt Him in this journey. Sometimes I question the very existence of a high power that takes an active role in our lives. I think I have felt him in my life at times, but I do not know why he has abandoned me now.

Daniel states, “I have spent my life serving God. I am angry that He took my parents away and now gave me this illness. I feel alone in this.”

Understanding the daily spiritual response of traumatic brain injury survivors answers question number three which asks survivors to discuss their spiritual response following their injury. This information may be useful in therapy and other rehabilitation work with Christian survivors.

Research Question Four

What does the daily life of a survivor of traumatic brain injury look like?

The participants were asked to identify the number one struggle that they experience on a daily basis, regardless of what they answered in previous sections. Fatigue was the most identified daily experience, reported by half of the participants.

Alice reports that she feels fatigue every day, "Every day I wake up tired and I have to push myself to do the things I need to do for work and for my family. I feel tired trying to be healthy all day long."

Loss of identity and balance were the next most reported daily struggles. Alfred states, "I strive everyday to find the man inside me that I used to be." Loss of identity was described by participants as feeling separated from yourself. Participants described loss of identity as not being able to define who you really are, feeling stressed in interpersonal relationships, and lacking connection. Peter reports, "I have lost a connection to myself. Sometimes I feel like a completely different person. I am close with my wife, but something is different. I am different and I can't be who I used to be."

Depression, the most reported emotional dysregulation by participants, was the next most identified daily struggle.

Question number four asks traumatic brain injury survivors to discuss what their daily life looks like; to identify their most difficult daily struggle. The data collected from this study answers that question.

Summary

Emotional Dysregulation

Depression was reported as the number one emotional struggle of traumatic brain injury survivors. Participants described depression as not being able to get out of bed sometimes, feeling low and unproductive. Depression also looks like an overall sadness that doesn't go away including isolationist behaviors and a lack of caring for activities that once sparked joy for these survivors. Four participants, all female, reported feelings of fear as their number one emotional response to their traumatic brain injury. Fear was described as being fear of another traumatic brain injury, fear of leaving the house, and/or an increase in irrational fears such as death of family members and loved ones. Anxiety and panic attacks were reported by three of the participants. Medication, calming skills, and even occasional ER visits to manage the anxiety were reported by the participants. Devastating suicide ideation was reported by two participants in addition to feelings of anger and frustration.

Cognitive Dysregulation

Grasping for words was reported by eight of the twelve participants as the greatest cognitive struggle following their traumatic brain injury. Participants reported pausing for words mid speech making them feel “dumb” and “embarrassed.” These participants described the process as knowing what they want to say and having an empty brain. Five participants reported memory loss as their greatest cognitive struggle. William reported forgetting names to faces, and Alice reported short-term memory loss. Memory loss was also deemed “embarrassing” to the participants. Physical wellness and mental wellness are entwined and interactive. This cohesive relationship is known as the mind-body connection (Zhang et al., 2021). Struggle with balance

was reported as a cognitive struggle. Participants describe holding onto stair rails and people for support. Participants described taking steps as deliberate and purposeful, as if they have forgotten how to walk. Disorganized thinking and being lost in thoughts were also mentioned by participants.

Spiritual Response

Seven of the twelve participants reported feeling closer to God following their traumatic brain injury. Participants who reported an increase in closeness to God also reported that they were close with God before their traumatic brain injury. These individuals also reported that they turned to God to help them spiritually throughout this injury. Participants also expressed gratitude to God for their life and their paths of recovery. Elizabeth and William expressed the feeling of peace that they have felt through the whole process of their traumatic brain injury. Peter, Daniel, and Edward reported a decrease in closeness to God since their traumatic brain injury. These participants also report a decreased closeness to God prior to their traumatic brain injury. For these participants spiritual responses appear to correlate with their prior relationships with God. If they were close to God, they became closer; if they were not close to God, they experienced a decreased closeness to God.

Daily Struggle

The participants were asked to identify their one most impactful daily struggle since their traumatic brain injury. Fatigue was identified as the largest struggle experienced by participants on a daily basis. Fatigue was identified by participants as both physical and emotional fatigue. Beatrice reports that everything feels hard. Loss of self identity was reported as the largest daily struggle by four participants. They described experiences of not feeling like the people they used

to be, not knowing how to approach life anymore. Peter described his experience as feeling uncomfortable in his own skin, not knowing who he is anymore. Participants also reported that balance was a problem they experienced daily. Lack of balance and stability was reported by participants as a life-altering experience because it could limit mobility and physical activity. Access to everyday life activities were also reported limited by balance issues. Participants also reported depression as a prominent daily struggle.

Chapter Five: Conclusion

Overview

The purpose of this transcendental phenomenological study was to describe the experiences of traumatic brain injury survivors; seeking to understand their lived experiences by examining the emotional dysregulation, cognitive dysregulation, spiritual response and daily experiences. There was a lack of qualitative research concerning the encompassing experiences of traumatic brain injury survivors. The motive of this study was to invite adult survivors of traumatic brain injury to tell their personal stories and describe the experiences they went through, including examining changes to their personal everyday lives. The research questions guiding this study are as follows:

Question One: How do survivors describe the effect of their traumatic brain injuries on daily emotional regulation/dysregulation?

Question Two: How do survivors describe the effect of their traumatic brain injuries on daily cognitive regulation/dysregulation?

Question Three: How do survivors describe the effect of their traumatic brain injuries on daily spiritual regulation/dysregulation?

Question Two: What does the daily life of a survivor of traumatic brain injury look like?

Presented through this chapter are the results of this study. The findings will be presented through the lens of two independent theories that combined work together to provide a glimpse into the lived experiences of traumatic brain injury survivors. Jean Piaget's Constructivism Theory and John Watson's Behavioral Approach Systems Theory were used as the theoretical framework for this study.

Summary of Findings

Data analysis revealed one major theme per research question; emotional dysregulation, cognitive dysregulation, spiritual response and daily struggles. Additionally, two sub themes emerged for each area. The gathered evaluated data sought to answer the research questions.

Emotional Dysregulation

The purpose of the first research question was to allow survivors of traumatic brain injury to discuss openly the emotional struggles they experienced. Depression was found to be the most difficult emotional struggle of traumatic brain injury survivors and the major theme for emotional dysregulation. Participants described depression as not being able to get out of bed, feeling low and having a lack of productivity. For the participants, depression also looks like an overall sadness that doesn't go away. Isolationist behaviors and a lack of caring for activities that once sparked joy for these survivors was evident in the lives of these participants. Fear was the second most reported emotional response to traumatic brain injury. Fear was described as fear of another traumatic brain injury, fear of leaving the house, even an increase in irrational fears such as death of family members and loved ones. Anxiety was the third most reported emotional response to traumatic brain injury. Anxiety accompanied by panic attacks were also common responses to traumatic brain injury. Medication, calming skills and even occasional ER visits to manage the anxiety were reported by the participants. Suicide ideation was also found as an emotional response to traumatic brain injury.

Cognitive Dysregulation

The second research question asked participants to share their experiences with cognitive dysregulation following their experience with traumatic brain injury. The most reported

response by the participants for cognitive dysregulation was identified as grasping for words. Participants reported pausing for words mid-sentence making them feel "dumb" and "embarrassed." Traumatic brain injury survivors described the process as knowing what they wanted to say and having an empty brain. Memory loss was the second most reported cognitive struggle following traumatic brain injury. Both long-and-short term memory struggles were reported. The third most identified cognitive struggle was balance. Participants describe holding onto stair rails and people for support. Participants described taking steps as deliberate and purposeful, as if they were learning how to walk again. Disorganized thinking and being lost in thoughts were also reported significant cognitive struggles.

Spiritual Response

The third research question asked participants to discuss their spiritual response to their traumatic brain injury. Closer to God was the most common spiritual response following a traumatic brain injury and identified as the major theme. Participants who reported an increase in closeness to God also reported that they had a close relationship with God before their traumatic brain injury. These individuals also reported they turned to God to help them spiritually throughout this injury. The second most reported spiritual response was feeling peace in their journey followed closely by the next most reported response which was identified as gratitude to God for their life and their paths of recovery. Distance from God was also a spiritual response to traumatic brain injury, reported by three of the twelve participants. Those participants who reported distance from God also report that their relationships with God were distant before their traumatic brain injury. For these participants spiritual responses appear to correlate with their prior relationships with God. There appears to be a strong connection between the spiritual attitudes and practices of participants before their traumatic brain injury

and following their traumatic brain injury. In other words, traumatic brain injury appears to have intensified their typical response to God. The participants who reported increased closeness to God experienced increased closeness, while the participants who reported decreased closeness to God experienced decreased closeness to God following their traumatic brain injury.

Daily Struggle

The fourth research question looked at the overall greatest daily struggle of traumatic brain injury. The participants were asked to report their personal greatest daily battle regardless of what they previously reported in the areas of emotional dysregulation, cognitive dysregulation and spiritual response. Fatigue was the largest struggle experienced by participants on a daily basis. Fatigue was identified by participants as physical and emotional fatigue. Participants report that fatigue negatively affects the productivity and pleasure of daily life. Loss of self-identity was identified as the second most reported significant daily struggle following traumatic brain injury. Described were experiences of not feeling like the people they used to be and not knowing how to approach life anymore. Participants describe this as not feeling at the core themselves, almost an out of body experience; watching themselves go through the motions but everything feeling foreign to them. The third most identified significant daily struggle was balance. Lack of balance and stability was reported by participants as a life altering experience because it limits mobility and physical activity. Participants reported that access to shopping and other daily activities were limited by balance issues.

Although depression was reported by participants as the leading emotional response to traumatic brain injury, depression was not found as the leading daily struggle. The study data shows that physical struggles; fatigue and balance ranked higher than depression as a leading

daily struggle. Participants did, however, report that their daily physical struggles contribute to their struggles with depression.

Discussion

Jean Piaget's Constructivism Theory and John Watson's Behavioral Approach Systems Theory were used as the theoretical framework for this study. These two theories, Jean Piaget's Constructivism Theory and John Watson's Behavioral Approach Systems Theory, work together as the survivors understand their new day to day world post traumatic brain injury and build from that place and build a future for themselves.

Piaget's Constructivism Theory examines how knowledge is acquired. This study examined the knowledge that was acquired by traumatic brain injury survivors through their lived experiences. Piaget's *act of learning* is an awareness of old knowledge and a connection between old and new knowledge (Dennick, 2016). Sharkey and Gash (2020), state that constructivism stresses acquired knowledge through the actions of personal experiences. Dennick (2016) explains that new knowledge is constantly being assimilated through previous knowledge. For the purpose of this study, Piaget's constructivism theory dictates that these traumatic brain injury survivors acquired new knowledge through their experiences surrounding a traumatic brain injury. The new knowledge was processed and understood through the lens of their previous knowledge and previous lived experiences. New knowledge is acquired through the process of comparing old knowledge to the new knowledge gained from what is experienced. Because Piaget's Constructivism Theory indicates that new knowledge is processed from an individual's previous knowledge base, each lived experience is as unique as every person is unique; no two people ever have the same experience.

John Watson's Behavioral Approach Systems Theory examines an individual's goal setting and reward seeking strategies (Alloy & Anderson, 2010). Watson's (1930) Behavioral Approach Theory argues that behavior is something that can be measured and that the environment shapes the development of behavior. Behavioral Approach emphasizes the growth that happens as a traumatic brain injury survivor, for the purpose of this study, seeks after future happiness and wellbeing. Additionally, learning is a process of association between stimuli and learned behavior. Watson believes that behavior can be controlled and manipulated (Watson, 1930). For the purpose of this study, the Behavioral Approach System Theory looks at the traumatic brain injury survivors' unique struggles and watches how the individual creates a new life for themselves because of these challenges. The Behavioral Approach Systems Theory provides a framework to understand what motivates an individual to become future oriented (Liu et al., 2018).

Discussion of Findings through Piaget's Constructivist Theory

Jean Piaget (1896-1980), a Swiss psychologist is known as the Father of Genetic Epistemology. Jean Piaget's Constructivist Theory studies the acquisition and processing of knowledge (Dennick, 2016).

Emotional Dysregulation

Participants report depression and fear as the most significant emotional struggles of traumatic brain injury. Participants experience severe dysregulation suddenly having their world change so drastically and suddenly. Words used to describe this new lived experience were "chaos and unrecognizable." Participants report that the comparison of their two lives, before and after traumatic brain injury, contributed to their depression. Peter describes feelings of

longing for the life he used to have. He states, “I want to feel the way I used to feel inside, everything is different now.” Beatrice longs for the world she knew before her traumatic brain injury, she cries daily about her perceived loss. Through the theoretical lens of Constructivism Theory the study data reveals that depression and fear were so significant because these participants' lives altered so dramatically from what they previously understood life to be like. Participants report feelings of emotional dysregulation as they contemplate the life they used to have compared to their new lived experience.

Participants reported emotions that include anxiety, anger, frustration and devastating suicide ideation. Daniel expresses anger when he examines the physical freedom he has lost compared to what he used to know. Daniel’s ability to enjoy physical activity continues to decline because of his traumatic brain injury. Constructivism Theory would suggest that the participants' emotional responses to their traumatic brain injuries were a response to their previously understood life.

Cognitive Dysregulation

Grasping for words was reported as the greatest cognitive struggle following their traumatic brain injury. These participants described the process as knowing what they want to say and yet not having access to a vocabulary to describe what they are trying to communicate. Caroline describes the frustration she feels when trying to communicate her thoughts especially with clients at her work as an event planner. Caroline spends energy on word recollection that was not a problem before her traumatic brain injury. Constructivist theoretical framework would support the dysregulation experienced by the participants based on not being able to access the knowledge that previously existed.

Memory loss, both short and long term, was reported as a significant cognitive struggle. William expresses frustration about not being able to remember names of people he has known for decades. Participants described fear and frustration associated with memory loss. Struggle with balance was reported as a cognitive struggle. George reports his frustration with balance stating, “my loss of balance makes me feel old.” George's frustration is directly related to his lived life prior to his traumatic brain injury. Participants described taking deliberate and purposeful steps and using guard rails, walls and people as walking supports. Through the lens of Constructivist theoretical framework, the participants lost access to knowledge that once existed. Thus, begging the question “How do you build upon something that is lost?”.

Spiritual Response

Overwhelmingly, the participants report feeling closer to God following their traumatic brain injury. Participants also expressed gratitude to God for their life and feeling of peace they experienced on their journey to recovery. Jane reports that she felt peace and hope about her future following her traumatic brain injury. Elizabeth reports that her closeness to God increased following her traumatic brain injury. Elizabeth's perspective on her current relationship with God is a comparison to what her relationship was prior to her traumatic brain injury. Those that reported distance from God also report that their relationships with God were distanced before their traumatic brain injury. For these participants spiritual responses appear to correlate with their prior relationships with God. Edward experienced a decreased closeness to God following his traumatic brain injury compared to the relationship he had with God prior to his injury. Through a Constructivism theoretical lens, the participants' spiritual responses began with a certain level of closeness to God or distance from God and were then magnified in the same direction following their traumatic brain injury.

Daily Struggle

Emotional and physical fatigue was identified as the largest reported struggle experienced by participants on a daily basis. Emotional fatigue is described by participants as feeling exhausted after working all day at being "healthy and normal." Margaret expressed both physical and emotional fatigue as she struggles with migraines and working to care for her young family. The second most reported daily struggle was loss of self identity. Participants described experiences of not feeling like the people they used to be. Alice reports that she struggles every day trying to access the person she used to be. Alfred struggles accepting the new limitations his traumatic brain injury has gifted him, stating that he doesn't feel like himself. Constructivism would suggest that being unable to access the knowledge and feelings of your previous self would be extremely dysregulating. Participants also reported that balance was a problem they experienced daily. Lack of balance and stability were reported by participants as a life altering experience because it can limit mobility and physical activity. Constructivism Theory explains that these new experiences will be interpreted by each individual participant and based on the participants previous knowledge will acclimate well or poorly to their new life post traumatic brain injury.

Discussion of Findings through Watson's Behavioral Approach

John Watson (1878- 1958), American psychologist, advanced the scientific theory of behaviorism. John Watson's Behavioral approach examines behavior, he believed that behavior can be controlled and predicted (Alloy & Anderson, 2010).

Emotional Dysregulation

Behavioral Approach would examine the personal response of each participant as they sought understanding and looked to their unique future. Depression and fear were identified by participants as the leading emotional dysregulation following traumatic brain injury. Edward reports struggling daily with low level depression. While Alice described crippling fear to leave her house and her reliance on prescription medication to function. Previous lived experiences would account for the unique emotional response of each participant in addition to what the participants will do with this new life they have. Each participant has a new reality and Behavioral Approach would observe the creation of goals and the creation of a new normal. The desire and ability to seek for a better life following traumatic brain injury will vary with each participant. Behavioral Approach would examine how these participants take their current dysregulation and move forward to create a new future for themselves.

Cognitive Dysregulation

Behavioral Theory would examine what cognitive process can be healed and what measures can be taken to promote healing. Participants report that grasping for words and memory loss as the greatest cognitive struggles following their traumatic brain injury. Alfred, a university professor, reports exhausting struggles as he prepares long written out lectures that once came spontaneously to his mind. Loss of balance was reported as a disruptive cognitive consequence of traumatic brain injury. George reports struggling to walk stairs and relies on others for support. Behavioral theory would suggest that how each participant responds to these struggles would vary greatly depending on each unique individual and their desire and/or ability to work towards healing. A futuristic perspective would be the goal of Behavioral Theory;

planning, setting goals and making steps towards a purposeful future for each individual. This is an individual work since each individual is unique as is their traumatic brain injury.

Spiritual Response

Participants reported feeling closer to God following the traumatic brain injury or farther away from God following the traumatic brain injury. Through the lens of a Behavioral Approach, the participants are responding based on their previous relationship with God and what they desire their future relationship to be with God. Margaret and Jane report relying on their closeness to God to sustain them through this difficult time. Daniel reports anger towards God for allowing his traumatic brain injury. Those that grew closer to God felt close to God before the traumatic brain injury. Those participants who felt distanced from God following their traumatic brain injury reported a distance from God prior to their traumatic brain injury. Behavioral theory would explain that the spiritual responses by the participants are based on the participants ability to have a future perspective and a desire to step towards that future following their traumatic brain injury.

Daily Struggle

Emotional and physical fatigue were identified as the greatest daily struggle. Elizabeth and Beatrice report daily physical fatigue that requires excess sleep compared to what they needed prior to their traumatic brain injury. Behavioral theory would suggest that the level of dysregulation felt by the study participants can be explained by their ability to move forward and their ability to heal emotionally. Through the lens of behavioral theory, loss of self identity would be very dysregulating. Peter reports struggling to access the part of him that gave him his confidence and drive in life. The premise of behavioral theory is that an individual processes new

experiences and seeks for growth and has a future driven perspective. If an individual survivor cannot access "who they are", it will be very difficult to move forward towards creating a better life. Loss of balance was also reported by participants as a significant life altering daily struggle followed closely by depression.

Implications

Findings from this study have theoretical, empirical and practical implications. Hearing the lived experiences of traumatic brain injury survivors from their own voice, adds to previous research. The goal being to potentially impact real-world problems by providing new knowledge and information surrounding the daily life of traumatic brain injury survivors.

Theoretical

Piaget's Constructivism Theory proposes that previous understanding and knowledge influences how new knowledge is acquired and how new knowledge is processed and applied to daily life (Dennick, 2016;, Sharkey & Gash, 2020). Watson's Behavioral Approach System Theory provides a framework to understand what needs to be put into place to motivate an individual to become future oriented (Liu et al., 2018). The two theories work together as the survivors understand their new day to day world and build from that place to create purposeful futures. Study participants report life altering implications from experiencing a traumatic brain injury. What is evident is that each individual is unique, what they experienced was unique. How these survivors process, seek for understating and even make steps towards a 'new normal' is unique to the individual. To understand the lived experiences of traumatic brain injury survivors one must know and understand the individual survivor. Although there are identified common responses; even within those themes are varied levels of dysregulation based on their

previous life experiences, current knowledge and desire for a better life; all of which are unique to the individual. Some participants seemed more overwhelmed with challenges than others. Some participants appeared more motivated and driven than others. Some appeared to be constantly comparing their old life pre traumatic brain injury to their new life, post traumatic brain injury.

Empirical

Traumatic brain injury has been previously researched, including generalized emotional, cognitive, spiritual, and daily isolated experiences. What is not prevalent in empirical research is the seen and heard personal accounts of traumatic brain injury survivors. This study adds depth and understanding to the literature by inviting participants to share their unique experiences surrounding traumatic brain injury; expressing personal accounts told in their own voices. The participants shared details of the emotional struggles they experienced. Participants talked about depression and fear. They discussed feelings of anger and suicide ideation. They discussed the cognitive dysregulation they experienced which included grasping for words to communicate, memory loss and loss of balance. The participants shared their spiritual responses which demonstrated God's role in the lives of these individuals. The participants shared their most difficult daily struggles which include emotional and physical fatigue, grasping for words, self awareness, and balance.

Practical

The knowledge gained through this study is especially relevant to therapist and counseling professionals who work with the traumatic brain injury population. Understanding the unique nature of the injury and its far-reaching personal consequences can help the guiding

professional choose testing measures and create treatment plans tailored to each individual survivor. The necessity to approach each and every client as an individual uniquely affected by their traumatic brain injury is an important finding of this study. The way an individual either grows closer to God or more distant to God, based on their previous relationship with God can be very valuable information for spiritual counselors and therapists using a Christian counseling model. Participants who spent time and energy comparing their new life to their old life tend to struggle more in the areas of emotional and cognitive healing. Examining the unique abilities of the participants to move forward following a traumatic brain injury can be impactful in therapeutic work.

Delimitations and Limitations

The boundaries of this study were mindfully designed and the limitations have been identified. Delimitation is the process of narrowing the focus of the study by setting specific boundaries. Limitations, for the purpose of this study, measures the transferability of the data.

Delimitations

The purpose of this transcendental phenomenological study was to describe the experiences of traumatic brain injury survivors; seeking to understand their lived experiences by examining the emotional, cognitive and spiritual daily experiences. I chose phenomenological design because the central purpose of the study was to invite adult traumatic brain injury survivors to share their stories and lived experiences. Participants were required to be adult survivors, over the age of 18, so they could participate without any need for parental consent and ideally have adult conversations about their experiences. Six adult males and six adult females qualified and participated in the study. Participants were required to score between 9-12 using

the Glasgow Coma scale to qualify. A score between 9 and 12 identifies as a moderate traumatic brain injury. For my own convenience, participants were required to be living within the United States. I required all participants to self-report as a Christian, a follower of Christ. Spiritual response to traumatic brain injury was an important part of my study. I chose participants who identify as Christians to align with Liberty University's and my own personal belief system, and for understanding if and how their relationship with God changed during this experience.

Limitations

One of the largest study limitations is recall bias. These participants are discussing traumatic events that can be affected by memory and time. All of the participants identify as Caucasian and live within the United States, which contributes to participation bias. The goal is always external validity, but phenomenological study results may be difficult to duplicate.

Phenomenological studies naturally limit sample size. This study included 12 participants. Biological gender was accounted for with an even number of males and females.

Recommendations for Future Research

One of the subtle themes that emerged that was not part of my study was coping mechanisms and addiction. Participants reported different coping mechanisms to their trauma and a risk of addictive behavior. Looking deeper at the participants' coping mechanics and identifying addictive behavior would be an additional interesting factor to examine.

Future research could include interviewing family members or close partners of the traumatic brain injury survivors to add to the stories of these survivors. It would be interesting to hear an observation of the emotional dysregulation, cognitive dysregulation, spiritual response and the largest daily struggle that was described by the participants from their perspective. An

interesting future study could examine therapeutic methods that could help traumatic brain injury survivors stop comparing their current lives to their past lived experiences in an effort to get to a place of acceptance and growth in their new reality.

Summary

The purpose of this transcendental phenomenological study was to describe the emotional dysregulation, cognitive dysregulation, spiritual response and largest daily struggle of traumatic brain injury survivors. Although many researchers have examined parts of the life of traumatic brain injury, looking at the whole picture allows for greater understanding of what a day in the life of a traumatic brain injury survivor looks like.

Data from this current study suggests although common themes were identified among the participants, what was recognized is the very uniqueness of traumatic brain injury. In addition to the uniqueness of traumatic brain injury itself is the uniqueness of each individual survivor's response, physically, emotionally and spiritually. Survivors who struggle most with emotional dysregulation tend to spend time and energy comparing their old life to their new life. The participants in the study who exhibited this tendency struggled with high levels of depression, fear and emotional fatigue. Additionally, participants who described *not being able to access themselves or not feeling like themselves,* suffered great emotional distress and reported high levels of depression and suicide ideation. Cognitive struggles, partially *grasping for words,* caused great distress to the participants in this study. The data also indicates that fatigue, both emotional and physical, contributes to difficult days for these survivors of trauma brain injury.

The data from this study shows a strong correlation between an individual's previous relationship with God and their post traumatic brain injury response. If the survivor was close to

God before the injury they tend to get closer to God following the injury, The same is also true for individuals who were distant from God before their traumatic brain injury and became more distant following their traumatic brain injury.

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Appendix A

IRB Approval

Approved

	Title:
IRB-FY23-24-821	THE DAILY LIVED EXPERIENCES OF TRAUMATIC BRAIN INJURY SURVIVORS: AN EXAMINATION OF THE EMOTIONAL, COGNITIVE, AND SPIRITUAL REPERCUSSIONS

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Approval Date:

12-20-2023

Expiration Date: N/A

Organization:

Community Care and Counseling, Psychology

Admin Check-In Date: N/A

Closed Date: N/A

Current Policy

Post-2018 Rule

Active Submissions:
N/A
Sponsors:
N/A

Nanette Haney	Principal Investigator	[redacted]
Nanette Haney	Primary Contact	[redacted]
Richard Green	Co-Principal Investigator	[redacted]

Appendix B

Glasgow Coma Scale

- The Glasgow Coma Scale Brain injury classification:
  - Severe: Glasgow Coma Scale 3-8
  - Moderate: Glasgow Coma Scale 9-12
  - Mild: Glasgow Coma Scale 13-15

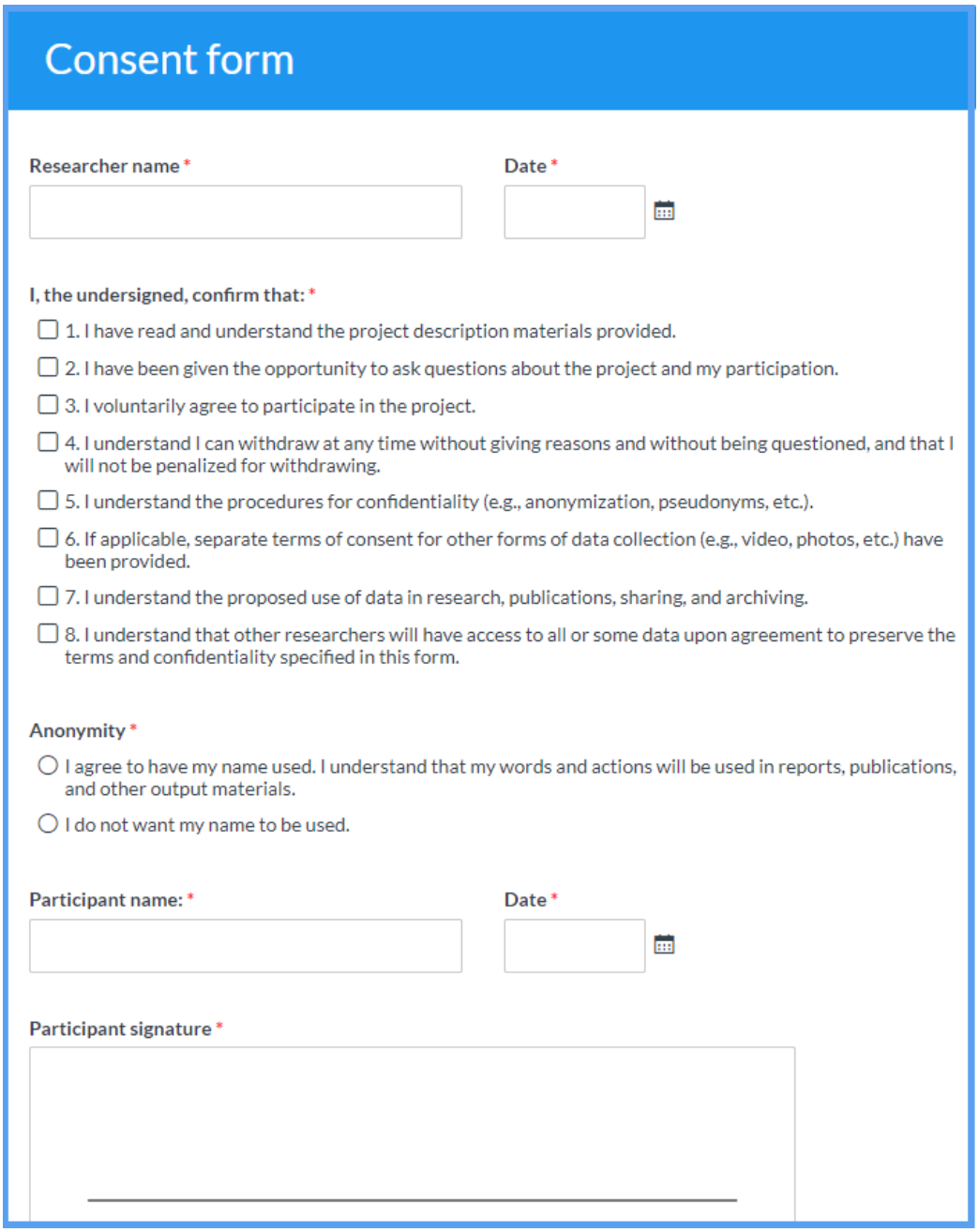
Total Score:_____ Identified type of Traumatic Brain Injury: _____

Glasgow Coma Score

Eye Opening	
Spontaneous	4
Open to verbal command	3
Open to pain	2
No eye opening	1
Verbal Response	
Oriented	5
Confused	4
Inappropriate words	3
Incomprehensible sounds	2
No verbal response	1
Motor Response	
Follows commands	6
Localizes to pain	5
Withdrawals from pain	4
Flexes to pain	3
Extends to pain	2
No Movement	1
Total score	3-15

Appendix C

Consent To Participate Form



Consent form

Researcher name *

Date *

I, the undersigned, confirm that: *

- [ ] 1. I have read and understand the project description materials provided.
- [ ] 2. I have been given the opportunity to ask questions about the project and my participation.
- [ ] 3. I voluntarily agree to participate in the project.
- [ ] 4. I understand I can withdraw at any time without giving reasons and without being questioned, and that I will not be penalized for withdrawing.
- [ ] 5. I understand the procedures for confidentiality (e.g., anonymization, pseudonyms, etc.).
- [ ] 6. If applicable, separate terms of consent for other forms of data collection (e.g., video, photos, etc.) have been provided.
- [ ] 7. I understand the proposed use of data in research, publications, sharing, and archiving.
- [ ] 8. I understand that other researchers will have access to all or some data upon agreement to preserve the terms and confidentiality specified in this form.

Anonymity *

- ○ I agree to have my name used. I understand that my words and actions will be used in reports, publications, and other output materials.
- ○ I do not want my name to be used.

Participant name: *

Date *

Participant signature *

Appendix D

Information Gathering Questionnaire

(Please use brief descriptive language)

1. Please identify the most difficult emotion you have experienced following your traumatic brain injury?

2. Please identify the most difficult cognitive deficiency you have experienced following your traumatic brain injury?

3. Please identify the most significant spiritual response you have experienced following your traumatic brain injury?

4. Please identify your largest challenges on a day to day basis?

5. Please add anything else you would like to me to understand about your experiences with traumatic brain injury.

Appendix E

Interview Sample

Alice- 50 years old

Caucasian

Traumatic Brain Injury- Stroke

Age of injury- 42.

1. **Please introduce yourself, including your name, age, demographic location and the age when you experienced your traumatic brain injury?**

Alice: Hi, my name is Alice. I am 50 years old. I live in a suburb of Salt Lake City Utah. I am a mom of 6 children and I am married. I have 2 dogs. When I was 42 years old I suffered a massive stroke after running a marathon in Seattle Washington.

2. **How are you feeling about sharing with me today?**

Alice: I am a little bit nervous to be talking to you today, not because I don't want to share but this always brings up emotions and feelings when I talk about it. I rarely talk about it. I would say the majority of people who know me don;t know anything about this part of my life.

3. **Please share your story of traumatic brain injury.**

Alice: When I was about 40 years old, I lost someone who I loved very much. We loved her as if she was a part of the family, she was in many ways. I loved her dearly. I was so sad and angry and I was struggling in other parts of my life as well, my marriage and having young kids and just life. I was heavier than I wanted to be since the birth of my youngest son. Anyway, in response to this loss I started running. At first it was moderate and then it became quite extreme.

For the next year I ran and at some point was running hours a day and miles and miles a day. I would do that while my kids were at school or in bed at night time. I had lost more weight than I needed and I wasn't healthy in my eating, not eating enough. It was a weird reaction to grief I think but I didn't know how to slow it down. My oldest was coming home after being away at college and out of the country for a while. We decided to take a daily trip to Hawaii. Right before we left I was running extreme lengths every week. I remember weekly doing 16 a day a couple times a week. The day before the trip to Hawaii, I ran a marathon, 26 miles. I was on the treadmill. I remembered that I ran that same distance once the week before. Anyway.. I was exhausted and stayed up most of the night packing and making sure we were ready to go. We had 8 of us on the trip. The trip over to Hawaii had two layovers. My youngest son was sick and was diagnosed with the flu so I was very concerned about him. We had all the medicine and he wasn't contagious any more but I was really worried about traveling with him. On the flight I remember feeling sick and was nervous I was getting sick. We arrived really late in Kauai. We went to Walmart, the only store open this late to grab groceries for the condo we were staying at. I felt really weak and tired and just really sick. I bought some generic brand nyquil to take when we got to the condo. I took the medicine once we arrived and went to bed. I remember getting up once in the night to give my son some medicine and check on him and then I went back to bed. I remember waking up to the sounds of my family in the kitchen talking about what they wanted to do that day. I remember feeling a pop in my head and I stood up and walked to the door of the room. I looked out at my family. My husband said, "what is wrong with your face?" I was worried about my son and just asked, "where is (he)?" I could hear that my words weren't coming out right. I tried to say, "it is just the medicine" but I couldn't talk so it just stayed in my

head as a thought. I turned to my left and stepped back inside the room and I fell over, like my whole body gave out.

I was in and out of consciousness from that point on. I remember hearing my son call for the ambulance and being held by my husband. I remember being moved from the bed onto the gurney to be moved into the ambulance. I then remember being in the emergency room and being asked questions about my health. I was life flighted to Oahu to the Stroke Center there. I don't remember the flight at all.

The next thing I remember is waking up and looking out onto the hills of Oahu. I had compression machines on my lower legs that were massaging like, moving up and down. I was peaceful but unaware of what was really going on. I would typically be very worried about my kids but I was pretty out of it.

To be released from the stroke center, I was there for three days. I had to demonstrate certain skills. I had been working with occupational and physical therapists. I had to be able to use the bathroom on my own and walk the stairs, dress myself, things like that. I remember the "test" and it took a lot of brain power to get myself to walk up and down stairs and do these regular daily things. Right next to me, the room next to me, was an older man. He just lay there. I never saw any movement in him. It made me sad. I was so much younger than anyone there. The head of the stroke center came to talk to me when I was about to check out. He told me that they didn't know what caused the stroke adn that I needed to take aspirin starting that day. He also gave me verbal and written instructions for tests when I returned to Seattle. He cautioned me to be calm in Kauai and not do anything too adventurous with my family. My husband took a computer plane and came and picked me up and I returned to Kaui for the next ten days. I was

exhausted and remained so the whole trip although I had a good time on the beach with my family.

4. **Concerning the emotions following your traumatic brain injury, what have you experienced?**

Alice: The whole time I was in Hawaii I was really calm, like really calm. No opinions and just very unaware of what was going on. Once I returned to normal life and began seeing doctors and having all sorts of medical tests run on me, I was very sad and scared. I remember feeling like I should be able to engage in normal life but I could not, I could not engage in that. I was so sad and cried a lot. I tried to hide that from my kids. I was very anxious and began having panic attacks. I even ended up in the Emergency Room fearing I was having another stroke, it was just a panic attack. I was afraid I would have another stroke. I feared death all of the time. I started running again which was a horrible mistake and ended up getting really sick and falling that caused injury to my face, and required another trip to the emergency room. I would start having these tests with a cardiologist and neurology and general doctors. All of them were scary for me.

5. **Concerning the mental challenges following your traumatic brain injury, what have you experienced?**

Alice: I would say the first strong deficit I noticed was short term memory loss. I would read and not remember anything I read. I couldn't follow a recipe. I would read an ingredient then turn and forget immediately what I had read. I was pretty consumed with thoughts of fear and sadness all of the time. I could not leave the house without paralyzing fear that I would have another stroke or just die. I had to use (prescription) drugs to calm myself to be able to go grocery shopping or take my kids to their lessons. I cried every single day and was consumed with thoughts of death.

I forgot to pay the bills, all of them. It is as if I had no memory that the mail came or that it was my responsibility. I could run the house as far as getting the kids to their activities. I never forgot one of them thank goodness lol. And I could keep the house clean but it just affected certain tasks.When I did pay bills, it wouldn't work. I really had no sense of money. That sounds weird but I couldn't balance a budget or do anything with math. It was as if I had never done that before.

I also remember my balance being off. During the stroke, my left side was affected. I had funny numb places on my face and on my left side. I could walk fine and when I ran on the treadmill, the treadmill would keep me centered but I strayed to the left when I walked and I had to take deliberate steps to go up and down the stairs. I recall telling myself "step, not lift your leg and step again". I always had to hold onto the guard rail. All of it, emotional and physical energy was exhausting. I was exhausted all of the time.

6. How was your spiritual life affected by your traumatic brain injury?

Alice- Like I mentioned before, I had suffered a very difficult loss the year before and my coping mechanism was to run. So what I used to cope with was now taken away from me and not only that, most likely contributed to my traumatic brain injury. I was always very religious and believed in God. I had this idea that God was involved in my life. I also believed that I could use knowledge and lifestyle to control my health to some degree. I guess what happened is I began to question that I could control anything and question how involved God is in our lives at all. I resented people who would say God saved you, because I didn't want to ever place any blame on God in the first place for it happening at all. I have come to peace with it all, and I think I learned more of God during this time. Really in many ways I created a new healthier relationship with God. So overall, I would say it was strengthened but maybe not with the old

God I was raised with, He was pretty punitive. I found a new lore loving God to worship and rely on.

7. **In the areas of emotional, cognitive, spiritual healing, what transitions have you noticed throughout the healing process?**

Alice: I never struggled with depression before my brain injury. I struggle with depression every day. It has ebbed and flowed over the healing process but it never has fully gone away. I even had moments of suicide ideation throughout the last couple years. I have watched my brain heal and it feels like it is still healing. I am not afraid of a recurring stroke anymore. After years of not having one and several doctors telling me it's unlikely as a "lightning strike" I am beginning to believe them. I take baby aspirin every day just to be sure, I think it's more for peace of mind than anything else.

My memory has healed as have most of my cognitive abilities. I still struggle with math skills but they are better than they used to be. Walking is fine now, but I still feel a pause when I go up and down stairs and always use a support.

Like I mentioned, my core spiritual beliefs were shaken a bit, but my relationship has evolved into a stronger relationship with a much more loving and compassionate, understating and forgiving God then I had ever known.

8. **How does your traumatic brain injury affect your life today?**

Alice: The person I am today approaches the world in significantly different ways than the person I was before. I am still the same person on the outside, but inside I feel like a different person. It is so hard.

Every day I wake up tired and I have to push myself to do the things I need to do for work and for my family. I feel tired trying to be healthy all day long. It's exhausting. Although things are significantly better than the first year after the brain injury, it is still a battle.

9. How does your traumatic brain injury influence your feelings about yourself?

Alice: I feel like a completely different person every day and it has changed my life. I am lonely and isolated. I seek connection with people who have trauma so I will not feel so alone. I really seek a connection with anyone. I struggle with low self esteem, I have made deliberate efforts to do things to prove to myself and others I am still smart. No one judges me so it's really just about me. I feel insecure in how I look. I have some scars from fall post brain injury but it’s not that as much as it is how I present myself. It's super weird coming from a place of not feeling like yourself and trying to build off that, it's almost like I don't have a foundation anymore.

10. How are your interpersonal relationships influenced by your traumatic brain injury?

Alice: I read once that 75-80 percent of marriages fail when one of the partners suffers a brain injury. I can completely believe that. I am still married but it has been a really hard several years. To cope, I made some very damaging life choices and continue to struggle with things that would not even be a thought in the mind of the previous me. I feel a bit lost from the person I used to be and it affects how I show up in my marriage and other close relationships. Something interesting is my sense of judgment about others. I have been very judgemental but whatever was there, it is gone now. I have an open mind and heart. In most ways I would say that is a good thing but sometimes I think I miss redflag that can potentially be dangerous. I love large and hard, always have, but now it is as if I don't have a natural filter like I once had. I feel like some healthy boundaries I used to have, don't exist anymore.

As far as my children are concerned, we are close and my acceptance of them is even more untethered than it was before.

My marriage is better than it's been in years and my family relationships are really good.

11. Is there anything else you would like to share?

Alice: Maybe just that as a person today I am pretty healthy and functioning. It's as if I have learned to do the “new normal”. I work hard. I play with my family and I feel close to God. I struggle with depression, anxiety, low self esteem, fatigue and some ill chosen coping mechanisms. I see a counselor regularly to deal with these issues. I don’t want you to think I am not doing well, I really am. I have lots of joy in my life every day, I just also have a new set of struggles that didn't exist 7 years ago and so there is that.

Appendix F

Information Gathering Questionnaire Sample

Peter- 53 years old

Caucasian

Traumatic Brain Injury- Acromegaly, Brain Tumor

Age of injury- 43

1. **Please identify the most difficult emotion you have experienced following your traumatic brain injury.**

Peter: Depression

2. **Please identify the most difficult cognitive deficiency you have experienced following your traumatic brain injury.**

Peter: Grasping for Words

3. **Please identify the most significant spiritual response you have experienced following your traumatic brain injury.**

Peter: Distance from God

4. **Please identify your largest challenge on a day-to-day basis.**

Peter: Feeling like self, isolation

5. **Please add anything else you would like to me to understand about your experiences with traumatic brain injury.**

Peter: Has led to struggles with an addiction