A Mental Minute: A Qualitative Exploration of Work-Related Stress in Brain Injury Rehabilitation Professionals

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Abstract
Work-related stress is a concern for brain injury rehabilitation professionals, and several research studies concluded this leads to burnout. There is limited research to identify what about working in brain injury rehabilitation increases the risk of work-related stress. This qualitative study utilized semi-structured interviews to explore what about working in brain injury rehabilitation is difficult, how brain injury rehabilitation professionals experience stress and what strategies professionals utilize to reduce stress. Results of this study suggest the lack of funding and resources, the nature of brain injury as a lifelong disability, and the arduous and lengthy rehabilitation process to be the most difficult aspects for professionals working in the brain injury rehabilitation field. Brain injury rehabilitation professionals identified anosognosia, poor insight, to be the most stressful cognitive deficit to treat. Frustration was expressed in regards to the challenge of balancing the completion of administrative duties with providing quality clinical care to survivors with brain injuries. Brain injury rehabilitation professionals experience the effects of work-related stress in both their work environments and in their personal lives. Brain injury rehabilitation professionals noted the importance of collaborating on an interdisciplinary team and utilizing their peers and supervisors for support when faced with stressful situations. Additionally, the term compassion fatigue appears to be the most relevant term to describe the nature of work-related stress experienced by brain injury rehabilitation professionals.

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A Mental Minute: A Qualitative Exploration of Work-Related Stress in Brain Injury Rehabilitation Professionals

Gillian Michelle Norah Murray

A DISSERTATION

in

Social Work

Presented to the Faculties of the University of Pennsylvania

In

Partial Fulfillment of the Requirements for the

Degree of Doctor of Social Work

2016

Andrea Doyle, PhD
Dissertation Chair

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Dean, School of Social Policy and Practice

Dissertation Committee
Casey Bohrman, PhD
Tessa Hart, PhD
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Dedication:

This dissertation is dedicated to all of my clients I have had the pleasure to work with throughout my career, now, and in the future.

A Stranger in My Place
by Sandra Linley, a survivor
http://www.bindependent.com/poems.htm

My husband has a new wife
My daughter, a new mother.
And sometimes I think I hate
The stranger who has taken my place.

It's painful just to watch her
Do what I once did.
She cooks (a little), cleans (not well),
And dreams her little dreams.

But where is the laughter, the passion,
The two of us used to know?
Where, the bright hopes and the wonder
That bound us, heart and soul?

And yet my husband loves her
(I wonder how he can)
A person slow and awkward,
Limited and sad.

The accident that brought her
Saw the old me die
Left this strange new person
To carry on in my stead.

Now my daughter calls her Mommy,
And trusting takes her hand.
My husband calls her Dearest
And draws her into his arms.

But deep within me something
Remembers and protests,
I refuse, I will not be
This stranger who has taken my place!
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ABSTRACT

A MENTAL MINUTE: A QUALITATIVE EXPLORATION OF WORK-RELATED STRESS IN BRAIN INJURY PROFESSIONALS

Gillian Michelle Norah Murray
Andrea Doyle, PhD

Work-related stress is a concern for brain injury rehabilitation professionals, and several research studies concluded this leads to burnout. There is limited research to identify what about working in brain injury rehabilitation increases the risk of work-related stress. This qualitative study utilized semi-structured interviews to explore what about working in brain injury rehabilitation is difficult, how brain injury rehabilitation professionals experience stress and what strategies professionals utilize to reduce stress. Results of this study suggest the lack of funding and resources, the nature of brain injury as a lifelong disability, and the arduous and lengthy rehabilitation process to be the most difficult aspects for professionals working in the brain injury rehabilitation field. Brain injury rehabilitation professionals identified anosognosia, poor insight, to be the most stressful cognitive deficit to treat. Frustration was expressed in regards to the challenge of balancing the completion of administrative duties with providing quality clinical care to survivors of brain injuries. Brain injury rehabilitation professionals experience the effects of work-related stress in both their work environments and in their personal lives. Brain injury rehabilitation professionals noted the importance of collaborating on an interdisciplinary team and utilizing their peers and supervisors for support when faced with stressful situations. Additionally, the term compassion fatigue appears to be the most relevant term to describe the nature of work-related stress experienced by brain injury rehabilitation professionals.

Keywords: brain injury rehabilitation professionals, brain injury rehabilitation, burnout, work-related stress, compassion fatigue, qualitative research, grounded theory
Chapter 1
Introduction, Background, and Significance

The Academy of Certified Brain Injury Specialists (2009) refers to brain injury as a “silent epidemic.” As of 2012, there are 5.3 million Americans living with traumatic brain injury (TBI) and at least 1.7 million Americans sustain a TBI each year (CDC, 2012). The Brain Injury Association of America (2013) reports 917,000 Americans suffer each year from an acquired brain injury (ABI) such as stroke, brain tumors, and aneurysm. There are physical, cognitive, emotional, behavioral, and mental consequences of brain injuries.

Whyte, Ponsford, Watanabe, and Hart (2010) discussed etiology and injury severity after sustaining a TBI. Severity ranges from mild to severe. Mild TBIs, or concussions, cause brief confusion or period of unconsciousness. Individuals briefly experience symptoms and return to their previous level of functioning after a period of days. Most survivors receiving brain injury rehabilitation services have a moderate to severe brain injury. Men are the most susceptible to sustaining a TBI; African Americans and Native Americans are at greater risk than other ethnicities. Alcohol is also a risk factor: 50% of those who sustained a TBI had blood alcohol levels indicating intoxication (United States Department of Education National Institute on Disability and Rehabilitation Research, 2001).

Individuals of a lower socioeconomic status are more likely to sustain a TBI (Corrigan, Selassie, & Orman, 2010; Kraus & McArthur, 1996). Kraus and McArthur (1996) explored, “families at the lowest income levels have been shown to incur the highest numbers of injuries of all types on a per capita basis” (Kraus & McArthur, 1996, p. 10). Kraus and McArthur (1996) further identified, “minority populations of the urban United States are often of lower socioeconomic status, epidemiologically they may have an elevated risk for injury” (p. 10). In a
study conducted in South Carolina by Selassie, Pickelsimer, Frazier, and Ferguson (2004), 26% of individuals who sustained a TBI did not have health insurance and individuals who did not have private health insurance were twice as likely to acquire a TBI. 18% of individuals with moderate to severe TBI were released from the emergency department without inpatient treatment (Selassie et al., 2004). Given this epidemiological profile of individuals most affected by TBI, social work, with its focus on those most marginalized in society, is uniquely positioned to contribute to the understanding and treatment of this population and those who care for them.

Treatment teams providing brain injury services are highly collaborative and interdisciplinary. Treatment for the physical consequences of brain injuries includes therapies such as occupational, physical, and speech therapy. Cognitive Rehabilitation addresses behavioral, emotional, and cognitive consequences of brain injury. This complex intervention includes psychoeducation, restorative exercises, behavioral modification, and the development of compensatory strategies. Brain injury rehabilitation staff includes a variety of clinical professionals. An interdisciplinary team may include: physiatrists, neurologists, physical therapists, vision therapists, neuropsychologists, neuropsychiatrists, psychologists, speech therapists, occupational therapists, social workers, vocational outcome specialists, recreation therapists, and cognitive therapists. These professionals collaborate to provide rehabilitation to address the complex cognitive, behavioral, emotional, and physical sequelae experienced by survivors of brain injuries. Brain injury rehabilitation professionals possess degrees in a variety of human services disciplines such as psychology, counseling, physical therapy, speech therapy, occupational therapy, recreation therapy, social work, disability services, vocational rehabilitation, or health care administration. The Academy for Certified Brain Injury Specialists (ACBIS) offers three accreditations for brain injury professionals: Provisional Certified Brain
Injury Specialist (PCBIS), Certified Brain Injury Specialist (CBIS) and Certified Brain Injury Specialist Trainer (CBIST). Individuals who hold a CBIS or CBIST must meet specific requirements, such as having a specific number of hours of direct clinical experience with survivors of brain injuries and passing a vigorous exam. For the purpose of this study, the term brain injury rehabilitation professional refers to clinicians who provide cognitive, behavioral, and vocational rehabilitation in an outpatient community reintegration setting.

Treatment after brain injury involves management of physical, cognitive, emotional, and behavioral symptoms. In addition, mood disorders, depression, and substance abuse after brain injury further complicate treatment interventions and outcomes. Recovery is difficult for survivors of brain injuries, their families, and rehabilitation professionals. The recovery process is long and providers typically have limited time to provide the needed care and to accomplish rehabilitation goals due to limited funding.

The literature utilizes the term, burnout, to describe work-related stress experienced by brain injury rehabilitation professionals. Maslach, Schaufeli, and Leiter (2001) defined burnout as a psychological sequence: emotional exhaustion, depersonalization of patient interactions to self-protect, and a decreased sense of job satisfaction. Saban et al. (2013) conducted a study investigating burnout in healthcare professionals treating Veterans with TBI and discussed that “the intense emotional and demanding work of caring for those with TBI can also take its toll on professional healthcare providers” (p. 307-308). Saban et al. (2013) concluded there are higher levels of emotional exhaustion experienced by those workers who spent more than 50% of their work treating TBI as compared to workers who spent less than 50% of their time treating TBI.

There are a limited number of brain injury rehabilitation professionals and providers who specialize in brain injury rehabilitation and to provide care for an increasing population of
survivors of brain injuries. The experience of brain injury rehabilitation professionals working in the brain injury rehabilitation field has not been explored and subsequently is not understood. The majority of research conducted in this focus area has been quantitative. There are only two mixed methods research studies (Mooney, Doig, & Fleming, 2009; Wittig, Tilton-Weaver, Patry, & Mateer, 2003) previously conducted, to this researcher’s knowledge. Qualitative research on this topic would provide valuable information to identify exactly why brain injury rehabilitation professionals are susceptible to work-related stress and what would be helpful and effective in decreasing work-related stress.
Chapter 2
Literature Review

Introduction

Continuous exposure to trauma experienced by survivors of brain injuries affects brain injury rehabilitation professionals who provide services to survivors of brain injuries. Devilly, Wring, and Varker (2009) stated:

It makes intuitive sense that engaging with another person in an empathetic relationship characterized by the identification with and understanding of their emotional experience, similarly impacts upon the emotional experience of the therapist, both at a conscious and subconscious level” (p. 373).

Professionals’ reactions will depend on their personal characteristics as well as the environmental nuances of their organizations (Sprang, Clark, & Whitt-Woosley, 2007).

In recent years, research on work-related stress considered “burnout” to be an outdated term. Researchers identified a variety of alternative terms to describe this phenomenon and are preferred in human services fields as a replacement of the term “burnout” such as vicarious traumatization, secondary traumatic stress, and compassion fatigue. Researchers determined the need to conduct further research to better understand and identify professional’s experiences of providing services to clients. “The stress introduced by these encounters is an expected by-product of the work” (Craig & Sprang, 2010, p. 319) and causes a “significant toll on clinicians who work with them over the long haul” (Sprang et al., 2007, p. 273). Craig and Sprang (2010) further discussed the general populous is not exposed to such trauma except for “the protective lens of television or film” (p. 319). Professionals are susceptible to significant levels of stress that can affect their self-efficacy, lead to burnout, affect psychological well-being and sense of identity (Craig & Sprang, 2010) or challenge beliefs of faith, worldview, and increase vulnerability (Canfield, 2005). Canfield (2005) described the most common clinician responses
when dealing with trauma are: “doubting or denial of the patient’s reality, dissociation or numbing, minimization or avoidance of traumatic material, professional distancing, or abandonment of the patient” (p. 82). Other responses explored by Canfield (2005) include maintaining poor personal boundaries that jeopardize empowerment of the client. Jenkins and Baird (2002) explored secondary trauma, vicarious trauma and professional burnout as having similar etiologies. Both constructs result in “exposure to emotionally engaging clients via interpersonally demanding jobs, and represent debilitation that can obstruct providers’ services” (Jenkins & Baird, 2002, p. 425). These similarities led to an examination of these terms to clarify the terminology utilized for this study.

**A Review of the Terminology**

**Burnout.**

The literature reviewed identified that the term, burnout, relates to stress caused by organizational and environmental factors. The onset of burnout is gradual as the experience of difficulty performing job responsibilities increased (Stamm, 1997). As Canfield (2005) stated, “The literature on burnout often focuses on external causations of the clinician’s reaction such as large caseloads, the isolation of the work, and other bureaucratic factors” (p. 83). Stamm (1997) described the etiology of burnout as being associated with agency characteristics as opposed to the reactions or countertransference experienced by clinicians when working with clients who have histories of trauma. In addition to environmental or agency factors, poor control or inclusion in decision, ethical or moral conflicts of opinions, poor compensation/benefits, and poor sense of community also resulted in burnout (Maslach & Leiter, 1997).

Research also suggested that there is a relationship between levels of burnout and quality of patient care. Leiter, Harvie, and Frizzell (1998) found an inverse correlation between nurse
burnout and patient evaluations of the quality of care. Patients cared for on units where nurses felt exhausted or frequently expressed a desire to quit were less satisfied with their care. The phenomena of burnout and compassion fatigue are significant for healthcare organizations because of the demonstrated correlations to nurse retention and turnover, patient satisfaction, and patient safety (Garman, Corrigan, & Morris, 2002; Halbesleben, Wakefield, Wakefield, & Cooper, 2008).

**Compassion fatigue.**

Joinson (2002) first used the term compassion fatigue, and identified compassion fatigue as emotionally devastating, certain personalities are more at risk, external forces that cause it cannot be avoided, and it is very difficult for professionals to recognize the symptoms. Compassion fatigue causes emotional, cognitive, and behavioral changes in clinicians who treat survivors of trauma (Bride, Radey, & Figley, 2007; McHolm, 2006). Compassion fatigue is a natural response to working with survivors of trauma (McHolm, 2006) and is an “inherent risk of significant emotional, cognitive, and behavioral changes in the clinician” (Bride et al., 2007, p. 155). Compassion fatigue, as explored by Figley (2002b), is a “state of tension and preoccupation with the traumatized patients by re-experiencing the traumatic events, avoidance/numbing of reminders, persistent arousal associated with the patient” (p. 1435). Pearlman and Saakvitne (1995) found that cognitive changes impacted the clinician’s sense of meaning, self-identity and worldview. Compassion fatigue is defined as “the formal caregiver’s reduced capacity or interest in being empathetic” (Adams, Boscarno, & Figley, 2006, p. 2). This type of reaction causes the “sufferer to lose the ability to experience satisfaction or joy professionally or personally” (McHolm, 2006, p. 14).
The literature identified compassion fatigue as a combination of the symptoms of burnout in addition to emotional stress experienced when working with clients with trauma. Figley (2002a) defined compassion fatigue as a form of burnout. Newell and MacNeil (2005) conducted a literature review of compassion fatigue and concluded that compassion fatigue is a “combination of the symptoms of secondary traumatic stress and professional burnout” (p. 61). McHolm (2006) described compassion fatigue as a “more complex problem that stems from working in a difficult work environment with patients who have debilitating or serious illness or trauma” (p. 13).

Research identified several factors that predicted compassion fatigue. Compassion fatigue and burnout is reported more by female professionals than males (Sprang et al., 2007). However, this study reported limitations due to the amount of female respondents in comparison with males. Professionals who had specialized training reported lower levels of compassion fatigue than those without specialized training (Sprang et al., 2007). Sprang et al. (2007) concluded, “Knowledge and training might provide some protection against the deleterious effects of trauma exposure” (p. 272).

**Secondary traumatic stress.**

Empathy and exposure to traumatic experiences are the two main concepts of secondary traumatic stress (Beck, 2011). Canfield (2005) differentiated secondary traumatic stress from compassion fatigue stating that secondary traumatic stress is the “direct result of hearing emotionally shocking material from clients, while burnout can result from work with any client group” (p. 84). Newell and MacNeil (2005) discussed symptoms of secondary traumatic stress, unlike in vicarious traumatization, do not include changes in cognition. Figley (1995) defined secondary traumatic stress as “the natural consequent behaviors and emotions resulting from...
knowing about a traumatizing event experienced by a significant other – the stress resulting from helping or wanting to help a traumatized or suffering person” (p. 7). Figley (2002b) further discussed secondary traumatic stress as a “syndrome with symptoms nearly identical to post traumatic stress disorder, except that exposure to knowledge about the traumatizing event experienced by the significant other is associated with the set of STSD symptoms” (Figley, 2002b, p. 1435).

Secondary traumatic stress results when clinicians engage empathetically with clients and discuss the details of their traumatic experiences causing a negative emotional response (Canfield, 2005; Figley, 2002a; Figley, 200b). Secondary traumatic stress disorder (STSD) results when therapists experience the symptoms of secondary traumatic stress for six months or more (Canfield, 2005). Symptoms experienced for less than a month are “normal, crisis-related reactions” (Canfield, 2005, p. 85). STSD is “a syndrome nearly identical to PTSD except that exposure to a traumatizing event experienced by one person becomes a traumatizing event for the second person, be it a family member, friend, mental health professional, or some other helper” (Canfield, 2005, p. 85).

**Vicarious traumatization.**

Vicarious traumatization refers to the cognitive, schematic, and psychological reactions experienced by therapists when working with individuals who are traumatized. McCann and Pearlman (1990) first defined this term as the resulting changes in clinicians’ views of the world, beliefs, and cognitive schemas. Unlike burnout and compassion fatigue, vicarious traumatization does not result from organizational structures or the workplace environment (Jenkins & Baird, 2002). Jenkins and Baird (2002) discussed the term, vicarious traumatization, is “salient for therapists who help victims of violence, particularly sexual assault and incest survivors” (p. 424).
Canfield (2005) explored, “as a therapist experiences increasing levels of vicarious trauma, counter-transference responses become stronger and/or less available to conscious awareness” (p. 88). As a therapist continues to be exposed to trauma experiences, “strong reactions of grief, rage, and outrage grow,” resulting in “sorrow, numbing, and a deep sense of loss” (Canfield, 2005, p. 88). Jenkins and Baird (2002) discussed that “intrusive imagery and other PTSD symptoms also appear as disruptions to the therapist’s imagery system of memory, yielding painful experiences of images and emotions associated with the client’s traumatic memories” (p. 424). Newell and MacNeil (2005) described vicarious traumatization as the “resulting cognitive shifts in beliefs and thinking that occur in social workers in direct practice with victims of trauma” (p. 60). Pearlman and Saakvitne (1995) discussed vicarious traumatization can have a negative impact on the personal life of the therapist and therapists who experience vicarious traumatization are more likely to change careers as well as develop burnout and cynicism.

**Interchangeable use of secondary traumatic stress and compassion fatigue.**

There is research that used compassion fatigue and secondary traumatic stress interchangeably. Figley (2002a) and Boscarino, Figley, and Adams (2004) described compassion fatigue as a secondary traumatic stress reaction. Craig and Sprang (2010) explored the tendency to interchangeably use compassion fatigue and secondary traumatic stress to describe these reactions. Beck (2011) used compassion fatigue and secondary traumatic stress interchangeably. Beck (2011) stated that secondary traumatic stress “can develop suddenly and without warning” (p. 3) and symptoms include “a sense of helplessness and confusion and feeling isolated from supporters” (p. 3). While Devilly et al. (2009) concluded, “Secondary traumatic stress will not be
used interchangeably with the term compassion fatigue because the constructs are clearly distinct” (p. 375).

**Terminology Utilized for the Purpose of this Study**

The literature reviewed in regards to the experience of work-related stress in brain injury rehabilitation professionals specifically utilized the term “burnout.” Therefore, for the purpose of this literature review, “burnout” will refer to work-related stress experienced by brain injury rehabilitation professionals.

**Definition of Burnout**

Felton (1998) explored the origin of the word, “burnout.” Burnout, in its original use, describes engine failure in a jet or rocket in the 1940s. Freudenberger first applied this term to humans during the mid-1970s. Maslach et al. (2001) defined burnout as a psychological sequence: emotional exhaustion, depersonalization of patient interactions to self-protect, and a decreased sense of job satisfaction. Maslach and Leiter (1997) described emotional exhaustion as “the basic individual strain dimension of burnout” (p. 498) and “feelings of being overextended and depleted of one’s emotional and physical resources” (p. 498). “The helping professional develops negative and indifferent attitudes towards those they care for” (Duffy, Oyebode, & Allen, 2009, p. 516) to cope with emotional exhaustion. Cordes and Doughtery (1993) defined depersonalization as a defense mechanism to “limit involvement with others and distance themselves psychologically” and “provides an emotional buffer between the individual and the imposing job demands” (p. 624). Fernet, Guay, and Senecal (2004) described depersonalization as a “detached attitude that employees used toward others in order to protect themselves from the psychological stress coming from people with whom they interact” (p. 40). “Further, burnout may also result in feelings of ineffectiveness and lack of personal achievement (Maslach &
Leiter, 1997). Newell and MacNeil (2005) discussed “the single largest risk factor for developing professional burnout is human service work in general” (p. 59).

Felton (1998) explored there are physical, emotional, and behavioral symptoms experienced by those suffering from burnout. Physical signs include fatigue, insomnia, hypertension, headache, muscle aches, anger and irritability, and gastrointestinal distress. Maslach and Leiter (1997) discussed exhaustion is the “most widely reported and the most thoroughly analyzed dimension of this syndrome” (p. 499). Health care professionals report emotional signs such as: loss of meaning in performing job related responsibilities, loss of the feeling of making a difference, and disillusionment (Felton, 1998; Rizzolo, 2007). Canfield (2005) discussed that anger “can create feelings of helplessness, frustration, depression, and burnout” (p. 83). There is an increased risk for healthcare professionals experiencing burnout to develop issues with substance abuse (Felton, 1998; Rizzolo, 2007). Rizzolo (2007) identified further behavioral signs such as increased caffeine use, procrastination, and increased use/abuse of prescription anti-anxiety medications such as tranquilizers. Rizzolo (2007) also explored the cognitive symptoms of burnout as “helplessness, loss of meaning and hope, and difficulty with completing complex tasks” (p. 31). Health care professionals experiencing burnout reported loss of positivity, disappointment, and boredom.

Prevalence

There are limited studies investigating burnout specifically in brain injury rehabilitation professionals. Therefore, studies exploring burnout in related professions, such as rehabilitation counselors, social workers, vocational rehabilitation professionals, nurses, mental health professionals, and nurses were reviewed. Gosseries et al. (2012) conducted a study investigating burnout and emotional exhaustion in healthcare professionals providing care for individuals with
severe brain injuries. Gosselies et al. (2012) concluded that 18% of the 523 respondents reported burnout, 33% reported emotional exhaustion, and 36% reported depersonalization. Saban et al. (2013) researched levels of burnout in 233 polytrauma team members caring for veterans with traumatic brain injury (TBI). The authors concluded that 30.6% reported moderate levels of burnout and 23.7% reported high levels of emotional exhaustion (Saban et al., 2013). Rizzolo (1997) conducted a study researching burnout in vocational rehabilitation counselors and found that 30% of American respondents reported emotional exhaustion and 20% reported depersonalization.

**Identification of Signs and Symptoms**

There are identifiable signs of burnout: excessive absences, tardiness, excessive sick leave, searching for alternative employment, lack of focus, decreased productivity, loss of motivation, diminished work performance, and depersonalization towards clients (Ducharme, Knudsen, & Roman, 2008; Felton, 1998; Rizzolo, 2007). Co-workers may also notice signs and may voice concerns to supervisors or may request alternative shifts or assignments. Rizzolo (2007) identified that burned out health care professionals changed their behavior when interacting with both clients and coworkers such as “irritability, being oversensitive, and lessened emotional empathy with recipients” (p. 32). The most significant behavioral change caused by burnout in social workers was “depersonalization of clients, the deprivation of their clients’ sense of personal identity” (Felton, 1998, p. 242).

**Factors Attributing to Burnout**

**Population and amount of time interacting with clients.**

The population being served, such as individuals with severe disabilities or life-threatening illness, is a factor that attributes to burnout (Cocco, Gatti, de Mendonca Lima, &
Camus, 2001; Felton, 1998; Maslach et al., 2001; Sahraian, Fazelzadeh, Mehdizadeh, & Toobaee, 2008). Rizzolo (2007) concluded, “The work of professional rehabilitation professionals can be emotionally draining, which can lead to cynical attitudes towards clients” (p. 192). Felton (1998) explored, “Those individuals who work with the public or special populations such as those persons with disabilities” (p. 239) are at increased risk for experiencing burnout. Perron and Hiltz (2006) conducted a literature review of burnout and secondary trauma experienced by forensic interviewers who investigated child abuse and found research linking stress with high caseloads (Buckhalt, Marchetti, & Bearden, 1990) and client characteristics and behaviors (Chung, Corbett, & Cummella, 1995; Dyer & Quine, 1998; Mitchell & Hastings, 2001).

Prigatano (1989) explained, “Teaching TBI patients about their disabilities and improving their psychosocial adjustments can be a demanding task that leaves many rehabilitation therapists tired, frustrated, and eventually angry” (p. 135). Prigatano (1989) further explored the behavioral sequelae of TBI survivors leaves rehabilitation staff feeling frustrated and despairing. Those recovering from brain injuries often exhibit “catastrophic reactions” (Prigatano, 1989, p. 139), which result in angry outbursts that can be challenging and potentially dangerous for rehabilitation professionals to deescalate. In a study conducted by Mooney et al. (2009), providers of community based rehabilitation to survivors with TBI reported frequent home visits, increased hours spent driving to survivors’ homes, and working in an isolated setting as risks for stress and burnout. Wittig et al. (2003) conducted a study of 133 brain injury professionals researching variables related to job satisfaction. 53.1% of respondents reported that they have felt uncomfortable or unsafe when clients have become aggressive and 66.9% reported fear that they could be hurt at work (Wittig et al., 2003).
Those who spend extensive amounts of face-to-face time interacting with clients are at increased risk for burnout (Felton, 1998; Schaufeli & Bakker, 2004). For example, social workers and nurses are at an increased risk due to “repetitive and continuing exposure to the ill, the dying, and death (Felton, 1998, p. 240). Interactions with clients/patients during times of crisis and the severity of client/patient difficulties increased emotional exhaustion for rehabilitation/healthcare professionals (Dietzel, 1995).

**Age, level of education and experience.**

Age and level of experience is a contributing factor to burnout. Kumar, Fischer, Robinson, Hatcher, and Bhagat (2007) concluded that professionals with more practice experience reported lower levels of depersonalization and burnout. A 1997 study conducted by Cranswick investigated burnout in rehabilitation workers who cared for individuals with developmental disabilities. Cranswick (1997) concluded that younger workers reported increased levels of job dissatisfaction and exhaustion than older rehabilitation workers. Level of education was also found to have a relationship with burnout. Workers with more education were less likely to experience burnout than those with less education (Dietzel, 1995). The amount of time employed in the same facility also predicts burnout (Turnipseed, 1994). Several studies found that workers employed for longer periods of time increased their ability to cope with job-related stress, therefore decreasing the risk of burnout (Dietzel, 1995; Gomez & Michaelis, 1995; Maslach & Florian, 1988; Turnipseed, 1994). However, a 1993 study conducted by Elman found that drug and alcohol rehabilitation counselors with more years of experience reported higher levels of depersonalization than those with less years of experience. Two other studies conducted with rehabilitation professionals found no correlation between years of experience and burnout (Cain, 1994; Fine, 1991).
Organizational factors.

Organizational factors such as workloads, caseloads, hours, and scheduling also impacts burnout. Brief and Weiss (2002) found that professionals reported administrative factors as a significant contributing factor. Devilly et al. (2009) measured work-related stress in 152 mental health professionals and found that “burnout, with its basis in work-related stressors, is the strongest predictor of therapist distress” (p. 383). Wittig et al. (2003) identified three contributing organizational factors identified by brain injury rehabilitation professionals to increase burnout: perceived importance, organizational support, and training support. Perceived importance referred to the “perceptions of participants with regard to how the organization they work for treats and supports the employee” (Wittig et al., 2003, p. 100). It also “included the sense of control or decision-making that individuals perceived they had in carrying out their duties” (Wittig et al., 2003, p. 100). Organizational support described the perception of support from supervisors and administrators. Those who perceived a lack of support from the organization reported higher scores of burnout (Wittig et al., 2003). The third finding, training support, suggested the lack of job training and professional development impacts burnout levels (Wittig et al., 2003).

The agency setting, such as inpatient versus outpatient, also contributes to burnout. Craig and Sprang (2010) found that clinicians who worked in inpatient settings reported increased burnout than those working in outpatient settings. “It is traditional practice wisdom to develop an optimal ‘caseload mix’ that includes clients presenting with ‘easier’ problems who ameliorate the extreme challenge of working with those presenting with more ‘difficult,’ and in some cases ‘intractable,’ problems” (Sprang et al., 2007, p. 273).
Limitations due to funding and resources.

Felton (1998) also reported that health care professionals are frequently reminded of the administrative demands for cost-saving measures, which professionals may feel negatively impact their ability to provide the best level of patient care and meet patient and family satisfaction. In a study conducted by Flett, Biggs, and Alpas (1995), 22% of vocational rehabilitation professional respondents identified limitations due to bureaucracy and government funding as a contributing factor to burnout. Wittig et al. (2003) also reported limitations in funding and resources to be contributing factors to the burnout levels in brain injury rehabilitation professionals as “aspects of the work that were not under the control or influence of the individuals” (p. 104).

Workload and turnover.

Several studies identified a positive correlation between work load/job demands and burnout (Houkes, Janssen, De Jonge, & Bakker, 2003; Maslach et al., 2001; Schaufeli & Bakker, 2004). Time constraints and a high workload was the most reported stressor by brain injury rehabilitation professionals (Wittig et al., 2003). There is a lack of research to identify the relationships between turnover and burnout. Riggar, Hansen, and Crimando (1987) collected data on turnover rates using a randomized sample of rehabilitation facilities accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF). Turnover rates ranged between 22% and 26%. Additional findings concluded that staff left jobs due to better financial opportunities, poor benefits, and burnout. Understaffing and turnover, as explored by Ducharme et al. (2008), is a direct cause of emotional exhaustion for rehabilitation professionals.
Support and Prevention

Newell and MacNeil (2005) discuss the “substantial gap in the literature regarding practice methods of preventing and treating these conditions” (p. 63). However, there are few empirically-based models on how to treat and prevent burnout (Newell & MacNeil, 2005). Figley (1995) discussed the importance of educating trauma workers in regards to the hazards of working with survivors of trauma. Research to better understand the causes, prevention, and treatment of this phenomenon is ongoing.

Several studies demonstrated that social support from coworkers and burnout is directly correlated (Brown, Prashantham, & Abbott, 2003; Houkes et al., 2003; Schaufeli & Bakker, 2004). There is an increased risk of burnout if healthcare and rehabilitation staff did not perceive their supervisors as supportive (Dietzel, 1995; Maslach et al., 2001). Webster and Hackett (1999) examined burnout among clinical staff members in community mental health agencies and found that burnout is systematically related to the leadership behavior and quality of supervision provided by their clinical supervisors. Rizzolo (2007) concluded “managers should focus on organizational practices to prevent or cope with burnout rather than on individual characteristics” (p. 213). Stebnicki (2000) also stressed the importance of clinical supervision where the “clinical supervisor should monitor the counselor’s emotional hardiness and resiliency and adaptive coping mechanisms for dealing with the secondary stressors” (p. 26).

Felton (1998) and Stebnicki (2000) explored several solutions to prevent burnout and how to support those professionals who are experiencing burnout. Interdisciplinary staff meetings to review cases or to debrief can be very helpful. This offers professionals the opportunity to express their true emotions and levels of stress in a supportive and non-judgmental environment (Stebnicki, 2000). Prigatano (1989) stated, “The treatment team needs
to be capable of discussing their own feelings, thoughts, and reactions as they relate to patient care” (p. 143) in order to be more effective in facing adversity and treating patients in a therapeutic manner. Canfield (2005) explored the purpose of support from supervisors and peers “is not simply to focus on treatment process, but also to remind therapists of their own realistic limits and insist that they take as good care of themselves as they do of others” (p. 82). Brain injury rehabilitation professionals identified the following organizational strategies to decrease the risk of burnout: breaks between clients, more efficient scheduling of home visits, and flexible working hours (Mooney et al., 2009).

Promoting personal and academic growth is also a valuable method to prevent burnout. Canfield (2005) discussed the importance for professionals to “attend to the balance in his or her own personal life, and attend to personal needs” (p. 82). Supervisors should encourage and support staff in pursuing educational endeavors. Further, trainings in counseling, de-escalation of aggressive or impulsive behaviors and managing stressful situations that arise with survivors of brain injuries and their families would be helpful strategies to reduce burnout among brain injury professionals (Mooney et al., 2009). Craig and Sprang (2010) found that clinicians with specialized training reported decreased burnout than clinicians without specialized training. The investigators also found that clinicians who used evidence-based practice reported less burnout than clinicians who did not use evidence-based practice.

Wellness activities such as spending time on hobbies, socializing with friends and family, exercise, and spiritual activities also provide coping strategies for professionals experiencing burnout (Copley, 2013). Stebnicki (2000) also promoted a “focus on mindfulness and value of physical exercise, diet, nutrition, attitudes and perceptions related to loss and grief” (p. 28). Professionals have emotional responses when working with grief, loss, and suffering (Stebnicki,
and need to develop “increased awareness of our adaptive resources and coping mechanisms” (Stebnicki, 2000, p. 24). Polytrauma team members reported using the following coping strategies to manage work stress and to prevent burnout: engaging in social relationships, promoting their own physical and emotional well-being through exercise and healthy eating, pursuing hobbies and other interests, managing the work environment through organization strategies, and positive thinking (Saban et al., 2013).

**Resiliency**

Resiliency is “the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress – such as family and relationship problems, serious health problems or workplace and financial stressors” (American Psychological Association, 2016). Shakespeare-Finch, Gow, and Smith (2005) concluded the following personality characteristics are predicting factors in resilient healthcare professionals: extraversion, openness, agreeableness, and conscientiousness. Healthcare professionals who are resilient demonstrate “personal attributes such as an internal locus of control, pro-social behavior, empathy, positive self-image, optimism and the ability to organize daily responsibilities” (McAllister & McKinnon, 2009, p. 373). Resilient healthcare professionals are more flexible in adapting to change and developing coping mechanisms to be implemented when faced with difficult situations than those who are not resilient (McAllister & McKinnon, 2009). Jackson, Firtko, and Edenborough (2007) researched resiliency in nurses and concluded, “resilient people are able to see the positive aspects and potential benefits of a situation, rather than being continually negative or cynical” (p. 6). Healthcare professionals can learn and acquire characteristics to promote resiliency in their practice (APA, 2016; Jackson et al., 2007; McAllister & McKinnon, 2009).
Conclusion

Burnout, compassion fatigue, secondary traumatic stress, and vicarious traumatization are terms that have been utilized to describe the reactions of professionals in working with survivors of trauma. Research identified burnout as the term to describe how brain injury rehabilitation professionals experience stress when providing services to survivors of brain injuries. The literature suggested that brain injury rehabilitation professionals may be at higher risk for burnout due to “the intense emotional and demanding work of caring for those with TBI” (Saban et al., 2013, p. 307) as compared to other healthcare professionals. Upon review of the literature, it appears that burnout does not seem to be a good fit to describe the phenomenon experienced by brain injury rehabilitation professionals.

The reasons as to why brain injury rehabilitation professionals find working in this field challenging has not been previously explored and subsequently is not understood. It is important for a neutral term to be utilized with participants as to not cause any influence in using terms that have pre-conceived meanings. Therefore, for the purpose of this study, the term burnout will not be utilized; instead brain injury rehabilitation professionals will be questioned about their experiences of work-related stress. In exploring this area of research, efforts will be made to operationalize the work-related stress experienced by brain injury rehabilitation professionals and that a more apt term will emerge and be identified.
Research Aim and Questions

The overall aim of this study is to explore the experience of brain injury rehabilitation professionals working in brain injury rehabilitation. How do brain injury rehabilitation professionals experience work-related stress?

This study hope to address the following research questions:

1. What do brain injury rehabilitation professionals find stressful about working in brain injury rehabilitation?
2. What about working in brain injury rehabilitation is difficult?
3. How do brain injury rehabilitation professionals experience work-related stress?
4. How do brain injury rehabilitation professionals reduce work-related stress?
5. What support is offered by employers to reduce work-related stress in brain injury rehabilitation professionals?

The University of Pennsylvania’s Institutional Review Board approved this study to be conducted (see Appendix A).

Research Design

Participants engaged in a one-time in-depth interview conducted in person or using video conferencing software, Zoom. Interviews ranged from 60 minutes to 150 minutes in length. The researcher conducted interviews in a private area at their place of employment or in a private mutually agreed upon area identified by the participant. The researcher used a semi-structured interview guide (see Appendix B) to explore what it is like to work in brain injury rehabilitation, what about working in brain injury rehabilitation is stressful, how does stress affect brain injury rehabilitation professionals, and how brain injury rehabilitation professionals experience
supervision and training. Participants reviewed consent forms (see Appendix C) at the beginning of each interview with the researcher, and participants received copies of their signed consent forms. The researcher reviewed the purpose of the study, procedures involved, how confidentiality would be maintained, risks and benefits, alternatives, compensation, and rights as human subjects. Several participants initially expressed their concerns regarding confidentiality within their work environments due to the delicate nature of their experiences. The researcher spent additional time reviewing how confidentiality would be maintained due to participants discussing their experiences in their work environments during the beginning of all subsequent interviews. The researcher reviewed that participation was voluntary, and gave participants the opportunity to decline participation at the time of the interview. The researcher informed participants that they could withdraw their data from the study at anytime during and after the interview was conducted.

After consent was obtained, the researcher gave participants the opportunity to ask questions and voice their concerns. The researcher addressed all questions and concerns before proceeding. Participants provided demographic information such as age, gender, education background, ACBIS accreditation, number of years working in the brain injury rehabilitation field, and what types of brain injury rehabilitation services they provided. An interview guide helped to structure the line of questioning during the interviews. The researcher recorded each interview, transcriptions were professionally transcribed through TranscribeMe and ADA Transcription, and the researcher coded each transcription. Participants received a small gift at the conclusion of the interview.
Qualitative Methodology

The researcher purposefully chose qualitative methodology utilizing a grounded theory approach to explore the experience of participants for this research study. Due to the lack of research and prior research being predominantly quantitative in nature, the experience of brain injury rehabilitation professionals working in the brain injury rehabilitation field is not understood. Therefore, there is a need to develop a more in-depth understanding of why brain injury rehabilitation professionals are susceptible to work-related stress and identifying what would be helpful and effective in decreasing work-related stress would provide valuable information.

Qualitative research methodology utilizes an inductive approach and explores the experiences, perceptions, and meaning for subjects (Morgan, 2014). The design further emerges as data collection and analysis takes place simultaneously (Morgan, 2014). Intensive interviews of open-ended questions are utilized in qualitative research. Intensive interviewing “fosters eliciting each participant’s interpretation of his or her experience” (Charmaz, 2006, p. 25). The interviewer’s role is to “listen, to observe with sensitivity, and to encourage the person to respond” (Charmaz, 2006, p. 26). Open-ended interviewing promotes dual subjectivity that emphasizes “not only the research participant’s beliefs and interpretations but also the researchers’ subjective processes” (Morgan, 2014, p. 54). This is a major strength of qualitative research methodology as it “gives the researcher the opportunity to learn more about other’s beliefs and meanings - including the subjective preferences and expectations that underlie their outwardly observable behaviors” (Morgan, 2014, p. 54). Open-ended questions allow for the “ability to pursue topics that emerge during the course of the conversation” (Morgan, 2014, p. 50). Open-ended interviewing gives “the ability to ask about an exceptionally wide range of
factors that may be relevant and to pursue the connections among those factors” (Morgan, 2014, p. 54).

Grounded theory “begins with observations and looks for patterns, themes, or common categories” (Rubin & Babbie, 2014, p. 474). Padgett (2008) described grounded theory as an “inductive-deductive feedback loop in which hypotheses or hunches are tested as the conceptual model is built” (p. 48). Researchers then develop concepts and hypotheses from finding meaning in the patterns. Charmaz (2006) described grounded theory as “systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories grounded in the data themselves” (p. 2). As researchers conduct more interviews, constant comparisons are utilized by comparing new information to the concepts and hypotheses made in previous interviews (Rubin & Babbie, 2014) and to “examine contrasts across respondents, situations, and settings” (Padgett, 2008, p. 33). Researchers can develop new questioning based on topics and themes raised by participants in previous interviews; researchers can “challenge, refine, and extend those ideas” (Morgan, 2014, p. 54) in future interviews. Josselson (2013) further described, “The list of questions on your interview guide will evolve as the study proceeds” (p. 52). Qualitative research design focuses on the quality, not quantity of the data, as explored by Padgett (2008): “Because of a fundamental concern with quality over quantity, we sample not to maximize breadth or reach, but to become saturated with information about a specific topic” (p. 57).

Charmaz (2006) described the process of qualitative coding. Qualitative coding first involves the researcher identifying a phrase, a code, to identify the content of these phrases. These codes are then compared to other phrases, codes, in the data. As these codes are compared, the codes develop into categories. As the data continues to be interpreted, the categories become theoretical framework describing the experiences of the subjects studied.
**Instrument**

The researcher utilized a semi-structured, open-ended questionnaire as a guide during the interviews. The researcher carefully considered and composed the questions to avoid leading participants to respond in a certain way and to encourage in-depth answers (Padgett, 2008). Josselson (2013) described the best strategies for structuring a questionnaire. Interviews started with “little q” questions for the following reasons: “It must orient the interviewee and engage him or her with your research interest, but must not color the interview in a direction that doesn’t fit the interviewee’s experience” (Josselson, 2013, p. 42) and it prevents the researcher from “making assumptions about the participant’s experience, or directing attention immediately to ‘problems’ you think he or she may have” (Josselson, 2013, p. 43). The researcher carefully constructed the phrasing of questions to be open-ended so the participant talked about what is most comfortable for them (Josselson, 2013). Therefore, the structure of the interview guide for the purpose of this study asked more general questions in the beginning and then asked about more specific areas of interest as the interview progressed, as to not color the participant’s experience.

The first questions of the interview guide asked general questions about participants’ experience working in the brain injury rehabilitation field, and about their experiences working on an interdisciplinary team. Questions then asked participants to identify the most difficult and least difficult aspects of working in the brain injury rehabilitation field. Subsequent questions focused on participants’ experiences of stress related to working in the brain injury rehabilitation field. Probing questions further explored topics such as cognitive impairments, behavioral changes, and working with families. Additional questions explored stress caused by administrative duties and funding sources. Later questions asked about what circumstances
participants found their stress levels to increase, how their stress impacted their interactions in the work environment as well as their personal lives, and how participants reduced their stress levels. Subsequent questions explored participants’ experiences of supervision and opportunities for education and training. Upon conclusion of the interview, the researcher gave participants the opportunity to give advice to other brain injury rehabilitation professionals as well as supervisors and administrators.

**Recruitment**

Inclusion criteria include brain injury rehabilitation professionals who have at least two years of full-time experience in outpatient brain injury rehabilitation; provide direct clinical care to individuals with TBI or ABI, possess at least a Bachelor’s Degree in a Human Services related field such as Psychology, Social Work, Disability Services, Vocational Rehabilitation, Health Care Administration, Counseling, or Nursing. There were no exclusion criteria.

Initially, the researcher required all participants to be a Certified Brain Injury Specialist (CBIS) or Certified Brain Injury Specialist Trainer (CBIST) through ACBIS. The possession of a CBIS or CBIST certification ensured participants completed standardized training and demonstrated proficiency in providing community and home based services utilizing evidence-based practice. In 1990, 565 brain injury rehabilitation providers participated in a survey to assess the training needs of their staff. 75% of respondents reported that specialized training was needed for licensed staff, and 84% reported that non-licensed staff required further and more specialized training (ACBIS, 2015). ACBIS was created in 1996 to address these training needs, to “assure the highest possible standards of rehabilitation and care for persons with brain injuries” (Turk & Scandale, 2007, p. 31) and to improve quality of care “through the establishment of best practices for the education and training of individuals working in the field
of brain injury services” (Turk & Scandale, 2007, p. 31). This training specifically targets brain injury rehabilitation professionals who provide community and home-based services. Turk and Scandale (2007) described the creation of ACBIS as “a dynamic step toward addressing the needs and concerns of the brain injury community” (p. 32). Brain injury rehabilitation providers who require their staff to be ACBIS certified demonstrate “commitment to provide higher quality services to persons with brain injury” (Turk, Carone, & Scandale, 2012, p. 59). The researcher discovered that most brain injury rehabilitation providers accepted a license in the professional’s discipline in lieu of the ACBIS certification. Due to poor recruitment, the researcher eliminated the requirement for participants to possess ACBIS certification in January 2016.

The researcher utilized convenience and snowball sampling to locate 17 participants. The researcher used purposive sampling, “a deliberate process of selecting respondents based on their ability to provide the needed information” (Padgett, 2008, p. 53), due to the specific nature of participant eligibility requirements. Although this is a relatively small sample size, the purpose of qualitative research methodology is to understand specific contexts in depth, which “leads to studying relatively few, carefully chosen cases” (Morgan, 2014, p. 50). Padgett (2008) further explored “the smaller the sample size, the more intense and deep are the data being collected” (p. 56). The researcher recruited participants by directly contacting brain injury rehabilitation providers in such states as New Jersey, Colorado, and Pennsylvania. ACBIS also published an article in their newsletter that was distributed to all brain injury rehabilitation professionals holding a CBIS/CBIST. An email was also sent to the Traumatic Brain Injury Model Systems’ listserv.
Participants who engaged in face-to-face interviews received a small gift, which included a mug, assortment of teabags, and a $10 coffee shop gift card. Participants who engaged in interviews using Zoom, video conferencing software, received a $15 Amazon gift card.

**Setting**

The researcher conducted five of the interviews in person in a private mutually agreed upon office setting located at the participant’s place of employment. The researcher conducted twelve of the interviews using Zoom, video conferencing software. Zoom provides end-to-end encryption and secure video conferencing services (Zoom Video Communications, 2016). Participants either chose a private office space at their place of employment or chose to videoconference after business hours from their private homes.

**Participant Demographics**

The study aimed to recruit 15 brain injury rehabilitation professionals to participate in this research. After screening for eligibility, the researcher scheduled 18 interviews. One participant (P14) did not attend the interview, and did not provide an explanation, therefore, was not included in the demographic chart (Figure 3-1). No further contact occurred with P14. In total, 17 brain injury rehabilitation professionals participated in a one-time interview. Fifteen of the participants were female; two were male (see Figure 3-1). The age of participants ranged from 24 years of age to 62 years of age. Three were aged 21-29; nine were aged 30-39; two were aged 40-49; two were aged 50-59, and one was aged 60-69. Participants’ years of experience working in the brain injury rehabilitation field ranged from 2.5 years to 26 years. Eight participants had between 2-5 years experience; three had between 6-9 years experience; one had between 10-13 years experience; one had between 18-21 experience; one had 22-25 years experience; and two had between 26-30 years experience. The educational backgrounds of
participants ranged from Bachelor’s Degrees to Doctoral Degrees. Three participants held a Bachelor’s Degree; eight obtained a Master’s Degree; and six earned a Doctoral Degree. Eight of the 17 participants possessed the certification of Certified Brain Injury Specialist through the Academy of Certified Brain Injury Specialists. The disciplines of the participants were as follows: five neuropsychologists, four recreational therapists, three occupational therapists, two social workers, one rehabilitation counselor, one licensed professional counselor, and one speech therapist. Ten participants identified providing case management; 13 provided counseling; nine provided job coaching; 16 provided skills training; and 11 facilitated group therapy.
<table>
<thead>
<tr>
<th>P</th>
<th>Sex</th>
<th>Age Group</th>
<th>CBIS</th>
<th>Level of Education</th>
<th>Years experience</th>
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<th>Counseling</th>
<th>Skills training</th>
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Figure 3-1: Study participants by gender, age, level of education, years of experience, and types of services provided

**Data Collection**

**Digital recording and transcribing.**

The researcher digitally recorded the interviews and the data was transcribed verbatim into Microsoft Word documents by a professional transcription service (TranscribeMe, ADA Transcription). The researcher reviewed the transcriptions for accuracy and all identifiable
information was removed. The researcher removed the following types of identifying information: names and locations of brain injury rehabilitation facilities, names of coworkers and supervisors, names of funding resources, and names and locations of community based organizations such as the local brain injury association.

**Data storage.**

The researcher assigned participants alphanumeric codes as identifiers. The researcher labeled participants’ documentation and data, including audio recording and transcriptions, with the corresponding numeric code. A listing containing the assigned codes and corresponding participants’ identifiable information is maintained in an electronic excel document that is password protected, and only the researcher has access. Digital recordings and Microsoft Word documents of the transcriptions are stored on a password protected hard drive and a backup version stored on an external password protected hard drive. The researcher entered transcriptions into NVivo11 Software, software developed by QSR International, to assist with qualitative data analysis. Field notes are maintained in a locked file cabinet.

**Data Analysis**

The researcher utilized grounded theory to code and analyze the data collected. The researcher stored transcriptions, developed focused codes and provisional categories, coded content, and created memos as thematic content emerged using the features of NVivo 11 Software. The researcher also tracked direct quotations that strongly reflected themes using NVivo11 Software. The researcher also exported participants’ demographic information from NVivo11 Software into an excel chart.

The researcher first began by reading through the transcriptions and listening to the audio recordings. The researcher coded four interviews and created memos to reflect on thematic
contexts emerging from the data. The researcher also created memos to identify personal reactions to the data. After coding the first four interviews, the researcher created preliminary focused codes and began to code the remaining 13 interviews directly into preliminary focused codes. New codes or categories did not emerge after the first four interviews were coded. The researcher initially identified 40 focused codes, but later reduced the number of focused codes to 26 after re-reading transcriptions and memos. The code staffing was eliminated as very few participants expressed concerns about staffing.

The researcher created eight provisional categories: brain injury rehabilitation is difficult, understanding the nature of brain injury, economic factors, emotional experience, stress management, support provided in work environment, and organization factors. As the researcher continued to re-read the transcriptions and developed hierarchy of the codes, understanding brain injury was eliminated. Data coded under understanding brain injury was combined with data into the following subthemes: family challenges and challenging to collaborate with survivors. The researched developed a codebook (see Appendix D) to structure and define themes and corresponding supporting codes. An additional code, a lot to learn, emerged while creating the codebook (see Appendix D). Economic factors became limited funding and resources as the researcher further examined the data and realized the importance of this theme. The final six themes that emerged from the data were brain injury rehabilitation is difficult, emotional experience, limited funding and resources, stress management, quality of support in work environment, and organizational factors.
Strategies for Ensuring Rigor

The researcher utilized several strategies to ensure rigor in this research study to reduce threats to trustworthiness (Padgett, 2008). These strategies aimed to reduce reactivity, researcher biases, and respondent biases (Padgett, 2008). The researcher utilized peer debriefing and support (Padgett, 2008) and consulted with peers, mentors, and experts in the brain injury rehabilitation field after the completion of each interview throughout the research study, including:

- Discussions with brain injury rehabilitation professionals not participating in the study
- Discussions and emails with other grounded theory qualitative researchers from the University of Pennsylvania
This provided the researcher with the opportunity to “share the emotional ups and downs of fieldwork and data analysis” (Padgett, 2008, p. 189). The researcher also included negative case analysis to promote the “researcher to operate in a critically self-reflective way” (Padgett, 2008, p. 191). One participant’s experience significantly contradicted the experiences of the other sixteen participants. The researcher considered this case to be an outlier but the researcher analyzed the data and included the data in the analysis. The researcher also created an audit trail (Padgett, 2008) as the data analysis progressed. There is a complete list of all 5,863 open codes, as well as the organization of open codes into focused codes.

**Ethical Considerations**

The researcher followed guidelines to conduct research with human subjects and received Institutional Review Board (IRB) approval prior to recruitment (see Appendix A). The researcher carefully considered how to maintain confidentiality and anonymity, especially to ensure that participants felt comfortable openly discussing their experiences interacting with supervisors and thoughts on the quality of their employers. Participants received reassurance that their participation and information disclosed during the interviews would not put their employment at risk. The researcher removed identifiable information from the transcriptions, including names, geographic information, and names of employers, funding sources, and local brain injury resources.

**Reflexivity Statement**

I have over ten years of experience working in brain injury rehabilitation. My first experience working with this population was at a residential community-based rehabilitation program. I managed a group home of fifteen residents, all of who had severe TBIs. I was responsible for medication management, medical coordination, goal development and
implementation, financial management, benefits and entitlements, and residential staff training. The goal of the rehabilitation program was to prevent institutionalization and to care for individuals who otherwise would be unable to live in a community setting. After two years, I accepted a new opportunity in an outpatient rehabilitation setting. I have worked in my current position for almost five years, serving survivors with mild to moderate TBIs and ABIs. The program focuses on ensuring survivors continue to reside in the community independently or with their families and to have meaningful and productive activity patterns, or to assist survivors in seeking employment/re-employment after TBI or ABI.

I personally witnessed brain injury rehabilitation professionals experience difficulties with work-related stress in both the researcher’s current place of employment and previous places of employment. I recognize that this population is very challenging for a number of reasons. Survivors of brain injuries exhibit aggressive and impulsive behaviors. Rehabilitation after brain injury progresses at a slow rate; gains are made gradually over an extended period of time. Some survivors are unable to make substantial gains and treatment goals focus on habilitation as opposed to rehabilitation. I recognize that the lack of progress can be frustrating for brain injury rehabilitation professionals. I have always considered the ability to keep a survivor out of a nursing home and in his or her own home to be progress. I recognize other brain injury rehabilitation professionals may have different viewpoints and may need to witness more tangible progress in order to reach job satisfaction. Other professionals may become frustrated and feel that they are not making an impact if rehabilitation goals are either not met or accomplished slowly. I understand these factors can lead to an increased risk of work-related stress.
I developed a very high clinical standard when engaging with survivors of brain injuries. I possess a high level of emotional resilience throughout years of practice. I am self-aware of how to personally effectively reduce stress and emotional distress. I am also aware that not all brain injury rehabilitation professionals possess the same amount of emotional awareness and resilience. I acknowledge I must also be aware that other professionals may deal differently with work-related stress. I must be willing to accept these differences and not compare other professionals to my personal coping mechanisms and resilience.

I was acutely self-aware of the potential for bias when conducting interviews and engaging in the process of qualitative analysis. I identified with many of the experiences shared by participants and remained aware that the interaction was purely for research and not a therapeutic relationship. I found a few of the interviews to be difficult experiences, resulting in seeking peer debriefing to process these emotions. I carefully chose what personal information to disclose to research participants. Most were unaware that I am actively employed in the brain injury rehabilitation field.

**Plans for Dissemination**

Dissemination of the findings includes presentations at conferences and publication in scholarly journals:

- The findings will be presented at the Brain Injury Association of Pennsylvania’s annual conference in June 2016.
- Findings will be published in *The Challenge*, which is the journal published by ACBIS.
- An international webinar will be presented through ACBIS in Fall 2016.
- A journal article will be submitted to the *Journal of Head Trauma Rehabilitation*. 
Chapter 4
Findings

Organization of Findings

This study explored stress experienced by brain injury rehabilitation professionals providing rehabilitation services to survivors of brain injuries. The recovery process is long and difficult for survivors of brain injuries, their families, and rehabilitation professionals. Although the incidence of brain injury continues to grow, there are a limited number of providers and professionals who specialize in rehabilitation after brain injury and is further complicated by limited funding and resources. Semi-structured interviews with 17 brain injury rehabilitation professionals were analyzed utilizing a grounded theory approach to reach the findings.

The themes that emerged from the data are as follows: (1) Brain injury rehabilitation is difficult; (2) Emotional experience; (3) Limited funding and resources; (4) Stress management; (5) Support provided in work environment; and (6) Organizational factors.

Brain Injury Rehabilitation is Difficult

*Brain injury rehabilitation is difficult* describes the nature of providing rehabilitation services to survivors of brain injuries. *Slow progress* refers to the recovery process after a brain injury to be gradual and, at times, taking years. Brain injury rehabilitation professionals explored they *can’t fix it*, referring to the persistent and permanent sequelae after sustaining a brain injury. Working in the brain injury rehabilitation field is *unpredictable*. Brain injuries manifest differently in each person, and brain injury rehabilitation professionals face *unpredictable* situations due to the cognitive, emotional, and behavioral deficits of brain injury as well as providing services in the home and community. Due to the decreased autonomy of brain injury survivors, there is an *increased responsibility of professionals* to provide more
directive guidance in the recovery process and in decision-making. The ability to collaborate and educate survivors to accept and understand the impact of brain injury is necessary to the rehabilitation process. Brain injury rehabilitations professionals reported it is challenging to collaborate with survivors. There is also so much to learn about the consequences of sustaining a brain injury and what methods are best in rehabilitating survivors of brain injuries.

**Slow progress.**

Survivors may require several years of rehabilitation while others may require a lifetime of care. A participant discussed the long-term process of rehabilitation and stated, it “really allows time for intervention to be effective. It’s not a brief intervention.” Survivors of brain injuries experience gradual improvement over time. Participants reflected on providing services to survivors whose injuries were years ago and yet survivors continue to struggle with the persistent sequelae of their injuries.

Thirteen of 17 participants reflected on the recovery process as being slow, describing the process as “baby steps.” Cognitive deficits caused by the brain injury itself interfere with the recovery process. One participant discussed, “It also can take time as things tend to stretch out on a longer temporal plane when you’re working with people that have brain injury.” Another participant reflected on the slow progress stating, “It’s sometimes difficult to appreciate the very small gains that are being made, and it really is a game of incremental gains over a longer time than normal therapy would be.” Due to nature of brain injury, progress is slow and survivors tend to make smaller gains over time as opposed to making larger gains in a shorter period of time.

Participants appeared to appreciate the slow progress stating that the process should not be rushed, and survivors need the pace of therapy to be slow. A participant discussed, “Progress is slow, but at this program you can … that’s okay.” Participants reported it was helpful to accept
even the smallest gains and improvements as progress. Another participant shared, “You appreciate those – even just those small, rare victories.” Other participants found the lack of progress and the slow pace of rehabilitation to be frustrating and it was difficult to recognize small gains as progress. Participants described feeling as if “you’re stuck in the mud” or “you’re stuck in a rut, and you really just have to ride it out.” Participants explored their want to see improvement in survivors and wanting survivors to get better. One participant shared:

If you can break that goal down into some smaller pieces, and try and get that person onboard with focusing on some of these smaller chunks of the goal, that you can still get that – hopefully still get that collaborative or we’re moving forward feeling and action.

Goal setting should be individualized to each survivors’ needs and level of functioning, and it is important to set goals that are realistic and attainable.

Survivors after brain injuries have difficulties with memory and generalization. Therefore, it is necessary to implement interventions repeatedly in the same manner to facilitate procedural learning. One participant reflected on the need for repetition and described this as a nature of the population:

A population who has trouble carrying over from one setting to another, has trouble structuring themselves, has trouble remembering how to do things without someone helping them.

Several participants viewed the need for repetition as frustrating and challenging, and used the term setbacks to describe the experience. A participant discussed:

You’ve gotten to a point, but then you’re not there. So, it’s like going back to square one. So it’s just frustrating to have to repeat the process. I mean I understand it’s brain injury and that’s part of the course, but it doesn’t mean it’s not frustrating at times, and you work through that.

Other participants did not share this frustration. One participant commented, “I don’t mind repeating things or telling people things, having to repeat myself all the time.”
Can’t fix it.

Twelve of 17 participants identified this notion of being unable to fix the cause of survivors’ problems and challenges. Brain injury is a long term and chronic disability due to the persistent and permanent cognitive, emotional, behavioral, and physical sequelae after injury. Several participants described the nature of a brain injury as a life-long disability. A participant reflected, “Brain injury is not something that occurs and gets better.” One participant discussed, “There’s no cure for brain injury. We can’t put Humpty Dumpty back together.” Another stated, “You’re taking a glass that broke and putting the pieces back together.”

Many participants compared this aspect of brain injury to other types of medical and mental health conditions, such as depression and cancer. A participant reflected, “You can’t, can’t make the problem go away. Which is maybe a luxury that someone treating cancer might have. You can get rid of that, hopefully.” Several participants compared brain injury to other physical injuries such as, “stubbing your toe.” One participant reflected, “You break your leg and you get your leg set and it heals and you go on your way. It doesn’t … if you have a brain injury – most people are not going to be completely fixed.

Participants expressed a sense of helplessness that they are not able to fix the sequelae of brain injury. One participant shared the following thoughts, “Some clients have so many needs that there’s a feeling of no way can I possibly meet all of those needs.” A participant further reflected on this experience:

There's no fixing the cause of their difficulties. I can't reach in and heal the neurons that are permanently damaged. So there's that kind of inherent stress in that you recognize that you're dealing with something that you can only find a way to work around. You can't get rid of it like you can get rid of someone's depressive symptoms, or their anxious cognitions.
Participants explored their experience of having to educate survivors about the pervasive nature of the disability and how difficult that experience can be. A participant discussed:

They don’t ever get better. And I’ve thought about that over the years. There’s some element of truth to that. That is tough – that part that people aren’t getting better at the end of the day. We’re helping people deal with the fact that they’re not getting better at the end of the day.

Although some survivors improve, many continue to experience permanent residual effects throughout their lives. Survivors of brain injuries have to accept and adjust to life after brain injury. Participants discussed their role of helping survivors to learn how to live life after brain injury. One participant explored:

This is about changing their life. Well, their life really changed from the accident. They’re really just creating something that’s more meaningful. It’s learning to live with their limitations.

**Unpredictable.**

Sixteen participants identified working with survivors of brain injuries to be unpredictable. Participants shared experiences of never knowing what to expect in how a brain injury impacts a survivor, and how survivors react during therapeutic interventions. Brain injuries manifest differently in each and every person. One participant described this aspect as, “it’s not just on a silver platter.” Each survivor has a different experience and is impacted by their brain injury in a unique way. One participant described the nature of working in brain injury rehabilitation as “you’re consistently jumping through hoops, developing new ideas. And that’s stressful because one size doesn’t fit all in this job.” This makes it challenging to plan therapeutic intervention, as each survivor may respond differently. Participants discussed how to approach therapeutic interventions depended on a lot of other factors, such as the nature of survivors’ impairments and severity of injury, levels of irritability, and the skill being taught in that moment. In addition, survivors act in unpredictable ways due to the cognitive and behavioral
deficits caused by brain injury. One participant described this as being in gray area, “with brain-injury, it's just ... the gray is, I guess, the unexpected. You have no idea how a client is going to react to things.”

Participants identified needing to be able to observe and analyze a situation or problem and quickly come up with a plan to address the problem. Participants explored the constant need to think creatively, plan, and problem solve. One participant commented, “My clients keep me on my toes ... in some ways I have to stay a step ahead of my clients to help see what is ahead for them. So I can help guide them through that process.” Participants also reflected on having to make quick decisions, “really just deciding, in that split second, how do I deal with the situation?” Several participants used the term, “trial and error,” to describe having to try different interventions without knowing what would be effective. A participant described a good day working in brain injury rehabilitation as, “when there are no arguments between survivors, when there’s no tension between them, nobody falls; just simple ... no medical emergencies, that’s a good day.” Several participants expressed hope that their days at work would be the same, and not be different due to the *unpredictable* nature of working in the brain injury rehabilitation field.

Several participants provided brain injury rehabilitation services in the community, such as in survivors’ homes and in vocational environments. A participant reflected feeling uncertainty in those types of situations, “You don’t know where you’re going, what you could be getting into.” One participant commented, “I think there are cameras in here. I’m on Candid Camera or something” to describe the types of unpredictable situations she experienced during home visits. She further commented, “I've had some that I actually describe as walking into Silence of the Lambs.” She shared having to end home visits due to unexpected environmental conditions, “If there’s flying cockroaches or honeybees – we have to continue at a different
time.” Furthermore, participants shared feeling helpless and uncomfortable when interacting with clients in external environments as opposed to a clinical setting.

**Increased responsibility of professionals.**

Due to the reduced autonomy among survivors of brain injuries, participants take more responsibility with survivors of brain injuries, such as advocacy and provide guidance and direction in decision-making. Brain injury itself affects executive function and impairs decision-making, resulting in family, friends, and in some cases, legal guardians being involved in the decision making process. A participant commented, “Is the clinician going to be neutral or promote better client choices?” and another participant reflected, “Am I present and therapeutic or enabling?” Participants often questioned and reflected if their roles were supporting survivors in the achievement of their goals, or were enabling survivors and negatively impacting their recovery.

Several participants spoke about their role as blurring the boundaries of the therapeutic relationship when providing services to survivors of brain injuries. Participants do not take a neutral role in the recovery process. Participants explored having to decide the amount of responsibility to take, as well as where and how to set boundaries when working with survivors. Another participant described the therapeutic relationship with survivors as “a parental role” and spoke about survivors with minimal family involvement. She further elaborated:

We have six guys who come here everyday and they don’t have family. We are their family. We had one guy who was in the hospital a good three or four months and his best friend is actually his power of attorney, and he didn’t even come to visit him those three months. But I would call him up and say, “What snacks do you want to get?” and we would go see him.

A participant described this blurred role as “stressful as it’s a more emotional role and not disengaged” as therapeutic relationships may be in other healthcare or mental health fields.
**Challenging to collaborate with survivors.**

Participants reported it is *challenging to collaborate with survivors*, and preferred to work with survivors in a collaborative as opposed to directive manner. A participant commented, “They’re more likely to follow through if they had something to do with the decision.” Participants reflected it was more difficult to engage survivors if the survivor did not want to engage in a particular task. A participant discussed:

> It’s always working individually with that person on identifying what their strengths are and then trying to figure out what their weaknesses are then helping them to be able to get back to what they want to do.

Several participants commented on the nature of goals as being functional and doing real-life tasks. A participant commented that this type of goal setting of “using real life examples is great to teach people and see what their skills are.” Rehabilitation goals and development of compensatory strategies need to be individualized to be meaningful to each survivor.

Many participants commented on their experience of working with survivors who are resistant to therapeutic approaches and refuse to engage in rehabilitation activities. Participants found refusals to be challenging and commented it was easier to help survivors when they asked for help:

> I try to find some sort of balance with them, … I need to figure out and work with them on what will work best for them and having them understand it and that may be having them try their way, and then when it’s not successful, “Okay well, now are you willing to try plan B?”

Several participants discussed their experience when survivors do not want to be at therapy as challenging. One participant discussed how she coped:

> You’re not going to do what I’m asking you to do, but I’m not going to be mad at you, and I’m still going to sit here with you, and I’ll be here when you’re ready to work.
Several participants commented on reflecting for survivors how their behavior would impact their success in a vocational setting. One participant stated to a survivor, “If you were in a workplace setting and you said that to your boss, what do you think would happen?” Participants also commented on being able to provide feedback to survivors in a way that survivors can understand and the importance of knowing how to give concise clear feedback. One participant discussed:

Knowing how to give that feedback that’s really concise and clear, kind but also constructive. Then that can help change a situation that might be negative or stressful – can help change that into one of your really good moments.

Participants reflected the importance of providing survivors with information about the nature of their injury and deficits in a way they can understand. A participant further explained, survivors must “learn to accept the deficits he has and that he needs help with some things.” It is important to provide brain injury education in conjunction with therapeutic interventions.

**So much to learn.**

There is so much that is not known about the human brain and the consequences of sustaining a brain injury. Participants described wanting to learn more to develop a better understanding of the population and trying to master something that is so little understood. One participant discussed:

The underlying theme is that it’s like you’re trying to understand and master something that’s so little understood. We know more about the brain than ever before, but it’s still a brain and there’s still so much unknown to it, and there’s still so much unpredictability to it.

Participants described the learning curve as never-ending:

Even about four years in I am still learning new things and new techniques and coming across new situations on a regular basis. And that keeps me at that good challenge level as a clinician, “Oh, this still isn’t easy. I still can’t do this in my sleep.”
Another participant stated, “I feel like I could never go to sleep for the next five years and probably still not feel knowledgeable or well versed on the subject.” Participants described feeling they never knew enough about the field of brain injury rehabilitation or how to better understand the sequelae of brain injury. One participant commented, “You’re always reassessing everything and seeing if you can be doing it better.” Several participants described feelings of uncertainty and questioning their choice of interventions and treatment planning.

**Emotional Experience**

*Emotional experience* refers to the emotional distress brain injury rehabilitation professionals are exposed to when working in the field of brain injury rehabilitation. Brain injury rehabilitation professionals identified *anosognosia* as the most difficult cognitive deficit to treat after brain injury. Participants explored emotionally investing in survivors of brain injuries when *building rapport and relationships* with survivors of brain injuries. Participants shared their experiences of hearing *sad stories* and having *empathy* for survivors. Participants also discussed *family challenges* when working with the families of survivors of brain injuries.

**Anosognosia.**

All seventeen participants identified *anosognosia* to be the most difficult cognitive deficit to treat. One participant commented, “That’s something that can actually disqualify a lot of people from being eligible for treatment, and you can’t break through the awareness, you can’t really help them.” Participants spoke about the challenges of working with survivors whose goals are unrealistic given their level of functioning, “He’s expecting to go right back to what he was doing because he did it before.” This excerpt explores how survivors are more unlikely to follow treatment recommendations when affected by *anosognosia:*

We ultimately have clients who have a significant lack of awareness, and they will continue to for the foreseeable future. It doesn’t seem like that – that’s going to be
acquired. That’s really tough to see because if they don’t have the awareness of an acquired skill set of ability, they’re very unlikely to follow recommendations.

Participants spoke about their experience of treating survivors with anosognosia. One participant described the experience as feeling artificial:

> If a person isn’t aware that they don’t remember, or isn’t aware that they have the difficulties that they have, and there’s very few strategies to really teach awareness … I sometimes feel like my therapy sessions are very artificial.

Other participants commented on seeing the potential in survivors to recover and improve, however, lack of insight impacts that potential. One participant stated, “What I find stressful about it is believing that the person has the potential to improve their functioning and their lives but they’re getting in their own way.”

Participants shared having to educate survivors about their limitations, and telling survivors they are unable to do a specific activity, and reported it is not always well-received by survivors. Survivors with poor insight often blame brain injury rehabilitation professionals for not being allowed to do a certain activity. A participant discussed:

> The hardest ones are when they try to direct or blame their frustration directly at you. Like it’s your fault, you’re the one to blame, why won’t you pass me, why won’t you let me do this. It’d hard not to take that personally.

Anosognosia also increases the vulnerability of survivors. Participants expressed concerns for the safety of survivors. One participant shared:

> Because he has this lack of awareness about other things in his life, he’s already been victimized and he would continue to be in the future. And it’s tough to say, but in all honesty, it really is in his personal best interest that there are certain rules and controls put into place.

Several participants spoke about “supported or planned failures” as a last resort to increase level of awareness in survivors. This participant explores the experience of planned failure:

> If there is a lack of awareness, something that we try to do and I try to do is try building some awareness. And unfortunately, sometimes that does come in the form of a
supported failure kind of thing. Or giving them an activity where it is going to highlight those deficits. And sometimes that helps, and sometimes that still doesn’t help.

Participants discussed discharging survivors with the hopes that they would return after failing to successfully reintegrate into living with their families and return to work. One participant stated:

Sometimes after three months out in the community, you’re trying to go back to work and saying that they can’t remember what they’re supposed to do. Life is the best therapy sometimes, so … but not always. And you know, those are the sad cases.

Brain injury itself interferes with survivors’ level of insight, and there are very few interventions found to be effective in increasing awareness after brain injury.

Many participants acknowledged survivors experience emotional distress as insight increases. A participant shared, “The thing I find most stressful about doing that type of work is knowing that it’s helpful to the survivor, but it’s also going to be really painful for them when they become more aware.” Several participants shared experiences of survivors becoming tearful even when the moment of insight is fleeting. One participant spoke about tears, “Sometimes tears are actually a good sign, I think, and at least for that moment, the awareness is there.” In addition, survivors with poor insight may not be able to recognize the gains and gradual improvements being made during the recovery process.

**Building rapport and relationships.**

Participants explored emotionally investing in survivors and *building rapport and close relationships* with survivors of brain injuries during the rehabilitation process. One participant described the role of brain injury professionals as “helping people with brain injury navigate through the emotional rollercoaster that they go through.” Very few participants found building rapport to be a challenge, but commented that rapport building has to be done quickly as one participant commented, “You have to hit the ground running.” Most participants found building
rapport with survivors to be the least difficult aspect of working in the brain injury rehabilitation field. One participant discussed:

Building rapport with people has always been pretty easy… even with people that you feel are coming from way different cultures or ways of life, and still finding some common ground with them, or relating to them in some way, or finding some way of building rapport I think is fun.

Building rapport with survivors is vital to achieving successful rehabilitation outcomes and to provide a supportive environment for survivors. One participant reflected, “You have to develop the rapport with survivors in order for them to trust you and want to go along with strategies or suggestions you make with them.”

Due to the slow recovery process, participants explored having long-term relationships with survivors, often lasting years. One participant discussed, “You really get to know them and go through different life events with them” while another participant described the nature of the relationship, “It’s obviously very professional, but it’s not a very flat therapeutic relationship.” Several participants commented about the use of humor and fostering fun in their therapeutic relationships with survivors, and discussed sharing jokes with survivors. A participant discussed using humor and promoting laughter to “get your endorphins flowing, and it just feels good.” She further elaborated, “What happened to them is so serious. And a lot of what they go through is so serious.”

Participants explored having to give bad news to survivors and reflected that hearing bad news from someone they trust may make it an easier experience. Participants explored the close relationship between survivor and brain injury rehabilitation professional is a buffer and prevents reactions from escalating. One participant discussed:

It’s almost better to hear that really hard stuff from someone that you have a really good relationship with than someone that is just there to give you bad news, and then you’re
out the door.

Some participants found it difficult to be the one to share bad news with survivors. Several participants described feeling uncomfortable and experiencing anxiety and worrying about having to provide that bad news. One participant shared their experience as:

It makes me feel bad to be harping on more of the negative and the deficits versus to be looking at the disability more than the abilities. You hate to do that, and feel you’re being the bearer of bad news.

While other participants did not find this experience to be difficult. One participant discussed, “I think they’re used to hearing bad stuff all the time … you’re just reminding them of the reality of the situation, the bad news.”

**Sad stories/empathy**

Each survivor has their own sad story of how they sustained their brain injuries. All 17 participants explored the effects of hearing or reading the details of these sad stories, and described them as tragic, heartbreaking, and pulling on your heartstrings. Participants discussed these sad stories are not only about the survivor’s experience but their family’s experience as well. One participant shared:

Hearing their stories about how the injury has changed their life and their family dynamic and their stress level and how they’re trying to hold everything together. Those are some of the conversations that have been more gut wrenching in a way. Because you just can’t believe what people have gone through trying to just keep their lives and their families intact and together.

One participant shared, “How tragic it is, and I will keep that in mind as I work with them … they are carrying a certain emotional weight with them.” Several participants felt the stories become more and more tragic. One participant questioned her experience, “Have I just become so jaded that I’ve heard everything, and nothing is a surprise anymore?”
Several participants explored “compartmentalizing” the emotional distress of sad stories or reading the information from a “therapist viewpoint” to focus on the information relevant to guide and inform clinical practice. One participant shared, “It took a long time to not feel what happens inside.” Many participants expressed concern about being perceived as cold. “I don’t mean to totally come across that I’m cold hearted, because I’m not. But I just think I’ve gotten better about compartmentalizing that, and it is more factual now.” A few participants stated it was important to know if there was a loved one killed in the accident that caused a survivor’s brain injury.

Participants explored coping with hearing or being reminded of sad stories on a daily basis. One participant discussed, “Somebody else would meet people for the first time and be totally shocked about their past or how they got there, where, it’s just our norm.” Another participant shared the experience of thinking about the details of sad stories in that moment, but then “putting that back in the file and going forward.” Participants reflected on how to move past the sad stories to make meaningful changes in the lives of survivors. A participant shared:

Trying to work with that person to improve or give them a better quality of life if they’re feeling sad about certain things, what are the positives? So, trying to use those feelings in a different way, because you know that person has potential.

Participants reported the importance of brain injury rehabilitation professionals to move forward and not allow sad stories to affect them in a way that could impact providing rehabilitation to survivors. One participate described this by stating, “This person needs me to be strong for them and help them through this.” Other participants commented on the need to “emotionally shut down” in order to stay positive and be able to help survivors move forward with the recovery process.
Participants discussed how hearing sad stories and seeing the impact brain injuries has on the perception of the world. One participant shared, “Working in the field of brain injury makes me look at the world in a whole different way.” Participants also shared their views on when a survivors’ brain injury is caused by another person or due to violence. One participant reflected:

Just seconds of poor judgment on someone else’s behalf has devastated this individual’s life. And it’s difficult to bear witness to that and to not sometimes become a bit disillusioned by humanity when you can witness what people are capable of doing.

Participants explored relating to survivor experiences and living more cautiously to avoid sustaining a brain injury themselves. A participant discussed:

Of course everybody has a sad story… The ones I relate to the most are probably ones that have kids my kids’ ages and then I can think about, well what would my kids do in this situation.

A few participants shared becoming acutely aware of tragedy happening to them. One participant commented, “I try not to think too much about how it could be me, just pretend that couldn’t happen.” Participants also shared living life more cautiously as well as impacting their behavior as a parent. A participant shared:

If you ask my kids, they would absolutely say that it influences how I am as a parent. And interestingly, I worry more for my kids’ safety than for my own. So they have heard about brain injury and brain safety since they were tiny. So, it does affect the way I live my life and how cautious I am for them, and at time for myself.

Another participant shared, “I have a daughter and I think she should grow up in a bubble.”

Other participants felt grateful and thankful that they themselves did not have a brain injury, and the ability to go home at the end of the day to their families.

Participants discussed empathizing with survivors, trying to imagine and understand the experiences of survivors living through a significant medical event and learning to live with the limitations caused by the nature of their brain injuries. A few participants commented on having
experiences such as “wanting to bawl your eyes out.” The following excerpt describes a participant empathizing with survivors:

Realize that an injury brings about such change for a person, changes that they never wanted, changes that they don’t like, and for me to keep in mind that it’s absolutely a valid feeling for them to be angry at those changes, to not like this. I try to give them permission to be angry at their injury.

One participant reflected, “I think you need to allow yourself to be sad about it and just because that allows you more compassion in your job.” Most participants commented how badly they felt for survivors. A participant commented, survivors “are going through the process of coping and adjustment and coming to terms with the problems that they have, the losses, the changes.” A survivor’s sense of self-identity changes after sustaining a brain injury. A participant stated, “They really are going through a grief and mourning process. And what they’re mourning is the loss of themselves.” The recovery and rehabilitation process is very difficult for survivors, and survivors often struggle, experiencing frustration, anger and grief.

**Family challenges.**

Families often have a lack of understanding of the nature of brain injury and have unrealistic expectations. Several participants commented on families’ insight being “just as poor as the survivors” and it is difficult for families to understand that “it’s a lifetime of change.” Other participants further questioned if this lack of understanding was due to denial. One participant reflected, “There have been instances where I feel like it’s their inability to see the reality of the situation – or not even inability. Maybe they don’t want to.” Some participants explored the family may have been dysfunctional even before their loved one sustained a brain injury. A participant commented, “Some families are just not particularly functional entities pre-injury. So when we throw a brain injury into the mix, it just becomes even more difficult.” Many participants found families’ lack of understanding and unrealistic expectations to be very
frustrating. One participant stated when a survivor’s “support system is not realistic about what’s going on or is uninformed, that’s a real pain in the butt.”

Participants explored the difference between supportive families versus families who lack follow through. One participant discussed a survivor whose mother is supportive, “she just really understands how to help her son.” Many participants found families’ lack of follow through frustrating. One participant discussed telling a family:

Here’s the strategy or these tools that are helping this person do that. You just have to provide this amount of assistance to them. But then oh, well, that just takes too long. We just do it. Well, then they’re not going to be able to do that themselves if you just continue to help them.

Participants also discussed frustrations when families may hinder the rehabilitation process. Several participants commented that treatment outcomes are better when families are supportive and follow through on implementing strategies in the family home. A participant discussed:

It definitely impacts what we do and how their family member succeeds because if there’s no carryover from our program to outside of the program, at home, in the community, then it’s not going to be successful.

One participant shared, “We know our program does succeed … they have to follow through with the strategies. And when they don’t, that’s super frustrating – it’s almost like they’re sabotaging their family member.”

Several participants discussed families may unknowingly enable survivors, making it “harder for us to do our job.” Families want to help their loved ones and it is difficult for families to watch their loved ones struggling to do the things they were able to do independently prior to their brain injury. A participant discussed, “They think they’re making the person feel better about it because they’re struggling with it. But what it really does is it diminishes the feelings that they want to improve those skills.” Participants further expressed frustration when families enabled or reinforced unsafe or negative behaviors. Some participants also shared their thoughts
and feelings about families whom appeared to purposefully sabotage progress for financial gains. One participate expressed this type of frustration with a survivor she is currently treating:

I have a client right now that would benefit from a transitional living facility because he has goals of going back to school and working part time, and basically the reason that that’s probably not going to happen is because his mom wants his disability paycheck.

Several participants shared acknowledging and accepting that families are “going to do what they’re going to do” and they have to accept they have no control over what happens in the family home. Participants discussed being unable to change the existing family dynamics and the inability to change how families function.

Participants discussed the emotional toll and role changes in families, and the difficulty for the family to adjust. One participant reflected, “When you have a loved one that’s gone through a brain injury process or is in the middle of it, it’s like a death.” A few participants discussed the notion that families themselves can experience burnout. One participant reflected, “Especially when the survivor is lower-functioning and they need a lot more hands-on. And you just know that these families are probably going to burn out.” Survivors often have minimal awareness of how their injury has impacted the family, as survivors are preoccupied with their own recovery. Participants empathized with families thinking about the way in which their loved ones sustained a brain injury. One participant explored:

The way that they got into their accident, whether it was getting a gunshot wound while drug dealing, that – it plays a toll on the family right there because here, they’re thinking, here we are taking care of him and he put himself in this situation.

A few participants perceived the role changes to be harder in couples. A participant elaborated, “They’re dealing with changes in their relationships and the role changes and trying to understand what happened to their partner or family member.”
Limited Funding and Resources

There is a lack of funding for brain injury rehabilitation to provide survivors of brain injuries with the necessary treatment and care. In addition, there is a lack of providers who will treat survivors of brain injuries. Participants explored working around the system by creative thinking and problem solving how to use the funding that is available thoughtfully to provide treatment for survivors. Participants shared their frustrations with the impact of funding on treatment outcomes and professionals.

Lack of funding for brain injury rehabilitation.

There is limited funding and resources available to provide survivors with brain injuries with treatment. A few participants described survivors of brain injuries as “the underdog” or “falling through the cracks.” Most of the participants identified this topic to be the most difficult aspect of working in the brain injury rehabilitation field. One participant referred to funding resources as “a necessary evil.” Another shared, “It just makes me feel like we’re spinning our wheels and you can see what the individual needs, but there’s no way to get it to them.” One participant described developing an understanding of this systematic issue as “eye-opening.” She further elaborated, “You really get to see the shortcomings of the systems that we work within, and that can be frustrating and you can see there is a need for things.”

There is a lack of understanding and knowledge about the care required after brain injury in the healthcare system. The funding that is available often has time frames that limit the amount of rehabilitation a survivor can receive. One participant discussed:

It’s coming up against the barriers of just the healthcare system, the lack of knowledge and understanding of the long-term effects and meaning of individuals with brain injuries. And so really seeing people really fall through the cracks and not getting what they’re needing.
Health insurance does not cover cognitive remediation, which is the only treatment to address the cognitive sequelae after brain injury. A participant reflected, “Our resource system is not set up to treat brain injury across a person’s lifespan.” Another participant referred to the lack of acute rehabilitation after medical stabilization in her state. She commented, “Literally, you could be in the hospital with a head injury, have a brain bleed and go right back home and be walking on the street.” Many survivors with brain injuries require supervision and assistance with activities of daily living and return home to live with their elderly parents or another relative. One participant discussed, “If they don’t have a supportive family, then there is no one they can live with.” Some states do have funding available to provide residential care for survivors of brain injuries.

However, many of the participants resided in states where there is no funding to provide this type of care.

It is difficult to navigate the complex system of federal and state benefits. Several participants commented on how challenging it is for not only survivors but also for brain injury rehabilitation professionals to understand the process of how to apply for services. One participant shared, “The challenges of having different layers of government or the MA process that you have to work through, it’s not as simple as one would think.” Participants also shared frustration with the individuals making decisions about funding lack a background or understanding in the nature of brain injury and the rehabilitation process. One participant reflected:

Whereas when you go to college, you’re learning the skills so that you can help people and then when you come out, business people, the government, other entities that have nothing to do with health, understanding healthcare and rehabilitation, are telling you what you can and cannot do by limiting visits, by limiting funding.

Participants also expressed frustration that the individuals conducting assessments to approve survivors of brain injuries for specialized brain injury services, such as Medicaid waivers, are not
appropriately trained to understand the impact of brain injury. One participant shared their experience of a survivor being denied services due to this lack of understanding:

They come in and they have no brain injury background, and they look at someone and, “oh, she looks great. She looks nice. She uses a walker. Okay that’s fine.” But, they don’t realize how severely impaired her memory is. You can have a conversation with her, and if you don’t know her, you don’t realize how impaired she is. So then the information’s all messed up because they’re saying she’s not as impaired as she is. And, no, she is. And she needs the funding.

Several participants shared survivors’ funding being abruptly discontinued due to state case managers not understanding the impact of brain injuries are often invisible.

**Lack of providers who will treat survivors of brain injuries.**

Many participants spoke about the challenge of connecting survivors of brain injuries to specialists who will treat the population. Participants spoke about the lack of mental health providers, psychotherapists and psychiatrists, who will agree to treat survivors of brain injuries. A participant shared, “I don’t know very many psychotherapists in the community that take no fault or some of these other insurances that also understand brain injuries.” One participant discussed the impact of having only one physiatrist in her state. She commented, “That’s difficult because he can turn anybody down that he wants to turn down because he gets referrals.” She further elaborated, “I really have to jump through hoops to get providers who are going to help my people.” It is difficult to access healthcare providers who will provide care for survivors of brain injuries.

**Working around the system.**

Participants discussed getting creative to make the funding that is available work for survivors. Several participants worked for rehabilitation providers with a foundation or scholarship to provide free services to survivors. Fundraising organized by brain injury rehabilitation providers financially supported these special programs. Participants discussed the
importance of being “very persistent with trying to find resources for people.” Other participants shared developing rehabilitation goals based on funding constraints. A participant discussed, “We’re never surprised at their discharge date or when funding runs out. Usually, our goals are very realistic based on how much time we know we have with the person.”

Several participants discussed scheduling therapy visits once a week so survivors have therapy weekly for several months as opposed to therapy visits three times a week for a month. One participant explored:

We work really hard then to spread out how many visits they come for. In my 20 visit a year example, let’s say you spread that out to every other week so that way, instead of using them all within five weeks, you spread it out to ten weeks, and all of a sudden you’re bought them two and a half months instead of closer to a month.

Participants also shared developing home therapy programs and training families and friends how to guide survivors through the program. Several participants disclosed providing their phone number to survivors and their families to “do a tele-health model.” Participants shared developing and providing survivors with home programs, either through email or over the phone. One participant discussed providing a survivor with a home program:

I know I can’t see you for awhile but here’s how you can continue to improve to try and maximize peoples’ ability to heal and continue to get better even if they can’t have therapy as much as we would like them to.

Participants then “saved” visits to see survivors in a couple of months to upgrade the program and restart the cycle.

**Impact of funding on treatment outcomes and professionals.**

Funding limitations and lack of resources impact treatment outcomes and the ability for brain injury rehabilitation professionals to provide quality care. A participant discussed, “I feel I can do such a better job if I had more to work with.” Several participants shared their beliefs that funding constraints negatively impacts treatment outcomes. One participant commented, “I don’t
think they’re improving as quickly as they could be.” Other participants shared their thoughts that the rehabilitation process is much harder when survivors do not have the guidance and support of trained brain injury rehabilitation professionals.

Several participants discussed the frequency of rehabilitation services is also not adequate to meet the needs of brain injury survivors. A participant reflected, “It’s hard within an hour or maybe two hours a week of therapy plus their other disciplines to overcome the day-to-day effects of a brain injury.” Rehabilitation services are often prematurely terminated due to funding limitations. Participants shared their frustration and concern when discharging survivors knowing they need more or could benefit from additional rehabilitation. One participant shared, “Unfortunately, there are those times that we just have to cross our fingers and hope that things go okay for them, even if we don’t have full confidence.” She elaborated further, “And so it’s disappointing to feel like there’s unfinished business.” Several participants shared wondering about what happened to survivors whose funding terminates before reaching their maximum rehabilitation potential. A participant discussed, “There’s definitely people that I think about, I wonder what happened to them, and just hope for the best for them, getting screwed by the system and by life.”

Participants reported the challenges of funding limitations to increase anxiety. One participant discussed, “It’s very anxiety provoking because we anticipate that the problems might get worse without adequate support.” Several participants found funding limitations to decrease their motivation. Participants made statements such as “makes it hard to keep up my morale knowing that this is just a barrier that’s going to continually be there” and “it can sap my drive and motivation.” A few participants shared feelings of helplessness, as explored in this excerpt:

And for me to see someone at home suffering, and I can’t do anything about it, and I know they don’t have any insurance and they’re not going to the emergency room
because they don’t want another bill, that is very hard to watch.

Several participants explored having to remind themselves that their ability to help survivors is limited by funding constraints or to be less ambitious when developing rehabilitation goals. One participant shared:

There is the frustration but you know you’re doing the best you can with what you have to work with… you have to set your own goals that you think, and hope, will be helpful, knowing that there is a boundary of where you can’t go beyond.

Several participants discussed the importance of accepting that there is not much brain injury rehabilitation professionals can do about the nature of funding. One participant reflected, “I could go on being frustrated indefinitely, but that’s not going to make more money exist in the world for me to have more resources.” All 17 participants identified the lack of funding to be stressful, heartbreaking, discouraging and challenging.

**Stress Management**

Brain injury rehabilitation professionals engage in stress reduction activities as well as utilize coping strategies to reduce work-related stress. Participants identified utilizing problem-solving with coworkers, prioritizing tasks and taking short breaks as strategies for *coping with stress at work*. Participants reported engaging in a variety of activities in their personal lives to reduce their stress levels, *stress reduction away from work*. Participants explored the *effects of stress at work*, such as how their stress levels impacted interactions with coworkers and supervisors as well as interactions with survivors of brain injuries and their families. Participants discussed the *effects of stress in personal life*, such as irritability, social withdrawal, and physiological symptoms. Participants also expressed *resiliency*, the capacity to maintain positive attitudes and effectively utilize coping strategies while handling stressful and difficult situations in their work environments.
Coping with stress at work.

Participants discussed the coping strategies utilized in their work environment to minimize the effects of stress in performing their job responsibilities. Most participants identified seeking out coworkers, especially those with more experience, as well as problem solving with coworkers as effective coping strategies. One participant described having “mini sessions” with her coworker:

We’ll have mini-sessions in the morning. It’s ten minutes of, “All right, this is our problem, what are we going to do about it?” I think having that one person to, who has become my other person to problem-solve.

Another participant described taking a break to have a “bench session” with their coworkers after experiencing stressful situations. One participant discussed, “I need this time to decompress, de-stress from the crap that goes on within – with other staff members, and it’s … I just need time to process it and almost disconnect.” Numerous participants shared reminding themselves that they are not alone in dealing with stressful situations. A participant commented, “If it’s happening with me, it’s happening with someone else.” A few participants spoke about complaining being counterproductive in reducing work-related stress. One participant shared preferring to talk to coworkers who will problem solve, “I’ll vent every once in awhile but I don’t find it particularly helpful to just commiserate in misery about my life or with other people who just want to focus on the problems.”

Several participants shared prioritizing tasks and time management/organizational skills to be effective in coping with work-related stress. One participant shared her strategy of “first I try to have a plan of how to take care of – I guess my responsibilities – the things that are causing the stress.” Many participants also shared changing their environment or switching tasks to be helpful. One participant reflected, “I will go for a walk, go talk to somebody about
something unrelated and then come back.” A few other participants also mentioned talking to their coworkers about non-work related subjects to be helpful. Several participants discussed focusing on and seeking out interactions with survivors of brain injuries to reduce their stress levels. One participant commented, “I really enjoy being with the survivors and I think that tends to most of the time diffuse my stress levels, even with the more difficult ones.”

Many participants shared taking a moment to “breathe” or “kill steam.” One participant shared, “If I don’t feel like dealing with the situation at hand, I might just take some deep breaths, I’ve gotten good at breathing.” A few participants described needing a “mental reboot.” Some participants shared the opposite, such as going into “overdrive” or “go go go mode.” One participant reflected, “I handled what I needed to do, went into overdrive – all of that that we needed to help settle down.”

Several participants shared utilizing emotional distancing as a coping mechanism, but many other participants denied using this strategy. Participants shared mixed opinions about utilization of emotional distancing to cope with work-related stress. One participant explored emotional distancing may be helpful for brain injury rehabilitation professionals to be self-protective, however, “the survivor can feel that emotional distancing. And so they might not feel as supported by me. And they might go so far as to be less inclined to listen to my input.”

**Stress reduction away from work.**

Participants reported engaging in a variety of activities in their personal lives to reduce their stress levels. Physical exercise and social activities were identified as helpful in managing stress levels. A few participants shared cooking or baking to be effective in reducing stress levels. A few participants shared drinking wine after having a particularly difficult day at work. One participant commented when asked what advice she would give to other brain injury
rehabilitation professionals to reduce stress levels, “my joke answer is, have a bottle of wine ready at all times.” A few participants also emphasized the importance of taking time off work and self care. Several participants discussed ignoring stress levels or not doing something to manage stress is not helpful. One participant reported the following to be unhelpful, “Trying to just keep going, not take any time off, not get any extra sleep, not getting any exercise, basically not making any changes, is not helpful.”

Many participants reported engaging in physical activities to manage their stress levels. Yoga and meditation was also reported to be effective in reducing stress levels by a few participants. One participant shared her thoughts on yoga:

I practice yoga on a regular basis. I practice meditation, probably not as often as I’d like to… I do those things on a regular basis, and I’ve found that I just feel better myself. Maybe that has helped me just generally not get worked up about stuff. I don’t know how it works. But we all know that it works. It changes the structure of your brain.

Many participants engaged in physical exercise such as running, going to the gym, rock climbing, and barre class. One participant shared:

I like more structured classes because I have to listen to someone else tell me what to do rather than me making decisions… I have to go to these classes because I just would be a robot and follow what they tell me to do. And I can shut off my brain for that hour.

A few participants commented on their enjoyment of outdoor activities, such as biking, kayaking, paddle boarding, and hiking. Several participants mentioned engaging in more cardiovascular types of exercise to “really get the blood pumping.” Many participants reported using physical activities to take their minds off of work or to “totally black everything out from the day.” One participant reflected doing so with climbing:

It’s actually a real practice in mindfulness, so it takes my brain right out of whatever problems I had at work, or whatever survivor is decompensating, or whatever problem happened in my day. It just makes me think about where I’m going to put my feet, where I’m going to put my hands.
Several participants also discussed the importance of eating healthy and staying hydrated.

Several participants discussed “blacking out” or forcing themselves to stop thinking about work. Many participants reported watching television or movies. One participant shared, “I have to find ways to completely shut it down and think of something happy and something that doesn’t involve my clients or my job.” Others mentioned doing “something mindless” such as browsing the internet. A participant commented, “This is not my default mechanism that I actually really enjoy doing, it’s just a way to turn my brain off for a time.” A few participants shared needing to be in their home environments. One participant explored, “I tend to just hover around my home base quite literally as a way of trying to conserve my energy and conserve my resources.”

Several participants mentioned the importance of maintaining work-life balance. A few participants commented on not allowing themselves to think about work when at home. One participant explored:

There will be times where I won’t think about work at all from Friday night to Sunday night. I just think to myself, “That just felt so good to not be thinking about that.” I think if I had been thinking about that this whole time, I would not be feeling so great right now. I would not have had that time to recharge.

Many participants reported needing to separate themselves from work. One participant reflected, “I try to do stuff that’s nothing to do with here.” One participant advised other brain injury rehabilitation professionals “to definitely have those boundaries between your work life and your personal life.”

Several participants, whom self-identified as introverts, reported needing to spend time alone before engaging in social activities. A participant explored, “If I would try and do that, it just would be very counterproductive. So I guess doing more extroverted things when I didn’t
have enough introverted time would be unhelpful.” Other participants shared needing to be able to say “no” to family or friends when experiencing work-related stress. One participant commented:

I used to feel like, no, well they asked me, I should do that. I’d feel guilty about not doing certain things. But just learning when to say no, and then not feeling bad about that, that this is something that I need and that’s okay… I guess just feeling okay to say no, and when.

Several participants discussed giving themselves permission to spend time alone to recharge instead of spending time with family and friends.

Participants discussed spending times with their social network to also be effective in reducing stress levels, such as dinner dates with girlfriends and fun activities with spouses. One participant shared, “You need to have this perspective that there’s a whole world out there of people who don’t think like rehab people and that’s a good thing to be connected to that.”

Several participants reported wanting to interact with babies or animals when experiencing stress. One participant commented that when stressed she will “find a friend with a baby or a puppy.” Another participant shared how helpful it was to go home to her infant. Several other participants reported playing with their animals or walking their dogs to be effective in managing stress.

Many participants referred to confidentiality laws impacting their ability to talk with spouses, family and friends about their work. A participant reflected:

I mean the fact that we have all these HIPAA regulations, which should be in place, not saying they shouldn’t. But to protect privacy, you also have to hold a lot in from sharing with other people.

Other participants explored that talking to family and friends who do not understand brain injury is not helpful. A participant discussed:
I generally think that talking about work outside of work doesn’t really help because people don’t really understand. Even when I talk to my friends from my cohort in grad school, they get mental health but they don’t get brain injury. So, I think trying to talk to people outside of the field doesn’t help because they just don’t get it.

There were mixed opinions about whether or not talking to family and friends about work-related stress was helpful.

**Effects of stress at work.**

Stress impacted brain injury rehabilitation professionals in their work environment physiologically, cognitively, and emotionally. Many participants explored the effects stress has on their cognitive skills. Several participants discussed stress impacting problem-solving skills. One participant commented, “I just freeze and I don’t know where to start.” Some participants explored their stress levels increasing their reactivity and impulsivity when problem-solving. One participant shared, “I can be a little more reactive and just make an impulse decision. And then a little while later, I’m like, I should’ve thought about that a little longer.” Stress also impacted organizational skills and attention/concentration. Another participant reflected difficulties with attention when stressed, “Being able to pay attention to one particular task, I’m trying to do ten different things and I’m not completing them. I’m trying to do them all at one time. So I find I become disorganized.” Participants also reported their communication was not as clear when stressed. A participant described, “There has been times where it’s hard for me to think of the particular words or places.”

Stress also affected participant’s processing speed and efficiency. Participants described this experience as “teetering on the edge of just total cognitive shutdown,” “cognitive overwhelm,” and “neuro-fatigued.” A participant shared, “I can’t think ahead three steps like I usually am doing.” A few participants shared the opposite experience of becoming hyper focused. A participant described becoming “very focused and much more rigid. I will lock
myself in my office and just work." Other participants reported going into a "zone," describing it as being in problem solving mode.

Participants shared mixed opinions about stress levels impacting interactions with survivors and their families. Several participants explored stress levels affecting their interactions with survivors’ families. Participants identified their level of patience with families was reduced. One participant reflected, “You could be more brusque with the family, you could be even rude without realizing that you’re rude.” A few participants shared an opposite experience of avoiding confrontation with families. One participant discussed:

You maybe come across nicer in a way and not as firm, if you’re not on top of your game. So, ironically, if you’re under stress, you might appear to be nicer, but actually, you might not be as effective with the family.

Many participants did not feel their stress levels impacted their interactions with survivors. However, most participants reported this occurring with their coworkers or shared that stress could impact those interactions. One participant discussed approaching coworkers if their stress was impacting their interactions with survivors, “It’s like having a bad hair day. Your friends will tell you.” A few mentioned being “short” or becoming more easily frustrated with inappropriate behaviors. One participant explored, “I know I’m short with some of the survivors, at times, if they’re just a lot to handle that day or if there’s a lot of stuff going on.” A few participants discussed their tendency to focus more on the therapeutic intervention and not engaging in social pleasantries as much. One participant commented, “I’m not as chit-chatty with survivors, because then I’m spending that time trying to figure out my plan for their therapy session.” However, a few participants shared their stress levels impacting their effort in planning for treatment sessions. One participant shared:

I may be more avoidant of investing that extra time into care. For example, I typically sit down, I draft out a pretty comprehensive treatment plan with long-term goals and short-
term objectives and subcomponents of that. And instead of doing that if I’m just really feeling burnt out, I’ll just create a general plan.

Participants shared they may chose a therapeutic activity that the survivor can do more independently and with less cuing or direction from the brain injury rehabilitation professional.

One participant shared:

Sometimes I feel I do some more generic routines/activities, like stock activities, and not as much of that personalization that I want to do and should do. Because I just don’t have the cognitive means to do that at that time.

A few participants discussed being unable to hide their stress and survivors being aware of their increased stress levels. One participant commented, “They know something’s going on.”

Many participants voiced concern about their stress levels impacting their interactions with their coworkers. Several participants shared that they are short-fused, less patient, not as approachable and brusque with coworkers when stressed. Others reported being irritable or blunt. A participant shared when her coworkers are stressed, “They don’t smile, and they’re more abrupt. More focused on the task at hand, no time for chitchat.” Many participants shared limiting their interactions with their coworkers when feeling stressed. One participant commented when she or coworkers are stressed:

There’s a little more withdrawing from one another, which is intended to be respectful that all of us want to make sure that we’re not taking our stress out on our coworkers. So in that sense, it’s better to isolate a little bit than to misdirect that stress.

Several participants explored the behavior of self-isolation to be problematic to team cohesion:

I think it can help reduce the overwhelm because it gives me the opportunity to focus on what I need to, to reduce whatever is overwhelming me. It probably does not help the team collaboration because I’m pulling back a little bit.

Another participant shared being hypersensitive to how her stress levels influenced her interactions with her coworkers. She discussed, “So being aware and conscientious of my responding to other professionals that I work with, to not show the stress that I may be
experiencing, which in turn can provide more stress.” Participants expressed concerns about being rude, becoming defensive or reactive with their coworkers when stressed.

**Effects of stress in personal life.**

Work-related stress impacted the personal lives of participants physiologically and interpersonally. Participants reported increased fatigue, sleep disturbances, muscle tension, headaches, and gastrointestinal distress. Participants reported not having the energy to manage household responsibilities. A participant explored, “I would come home and all I would want to do is unwind and not really deal with the other issues at home.” Several participants explored their increased fatigue impacted their ability to exercise. One participant discussed when fatigued:

> I will start to neglect my personal activities that help me to feel rejuvenated. Maybe I will go home instead of going to the gym, I will sit on the couch and watch TV instead of doing something that for me that I would enjoy.

Most participants reported sleep disturbances. One participant shared:

> I go to bed thinking about work and I have dreams about work. And I wake my husband up talking about work to a survivor. I will wake up talking to a survivor! That’s okay, we’re just handling things in my sleep.

Other participants reported insomnia while others reported requiring more sleep. A few participants reported being unable to get out of bed. One participant discussed, “I can lay in bed for three straight days, and just sleep a good portion of that.” Many participants shared being short-tempered or less patient with their families. One participant reflected, “I’m sure my family walks on eggshells a little bit at those times, and I feel bad about that.” A few participants shared needing time alone when coming home after a stressful day at work. A participant commented, “I spend so much of my job talking to other people. But at the end of the day, even when I’m not overwhelmed, I’m not really always in the mood to talk to other people.” A few participants also
shared withdrawing from social interactions with their friends. A participant shared, “I just feel so mentally and physically fatigued that I don’t go out, I don’t see my friends as much.” Many participants discussed the importance of leaving work at work and not thinking about work when spending time with their families and friends.

**Resiliency.**

Participants shared the ability to remain positive and to effectively cope while handling stressful, emotionally distressing, and difficult situations in work environments. Several participants voiced their opinion that this is a skill that you either have or you do not have. A participant explored, “I’m convinced that’s what I can’t teach a student that comes through is the ability to let it go. You either have that ability or you don’t.” Participants acknowledged their limitations in promoting change in the lives of survivors and their families. A participant discussed:

> There are some walls that you just can’t overcome, and that’s hard to accept. Where you see what could be, but it’s not going to happen. But at the end of the day you’ve got to accept that as a therapist. That there’s only going to be so much you could do. And at the end of the day if you can say that you did your best, and you did whatever you could for that person, and then it’s in their hands you can’t do it for them.

Many participants expressed feelings of not being in control when interacting with survivors and their families. A participant reflected, “Sometimes you just have to accept that people will make their own choices, whether you think they’re the best ones or not based on your clinical experience.” Other participants discussed expecting that their work will be difficult.

Participants discussed reminding themselves that the survivors are there to get help, because they have a brain injury. One participant discussed, “trying to step back and just remember why they’re there and why I’m here.” Other participants made comments such as “it’s just really the nature of the beast” and “it’s just the way things are in brain injury.” Many
participants shared learning to not take things personally and developing a “thick skin.” A participant discussed:

That can be difficult and upsetting and sometimes, if you take things personally, like as you failed, but I think that’s the hardest, and just realizing that, no, you didn’t, that’s just part of being a healthcare professional.

Many participants discussed the importance of “letting it go,” “learning to let it roll off” and “ride it out.” A participant shared an experience with a survivor who was refusing to engage in the therapy session:

I sat with him and tried to initiate the session a couple of times. And he just was not having it. So, I just sat there with him. Whereas I think a couple years ago, I would have been, but this is our cognitive therapy session, you must – we must get this done. But now if it’s just not the time, it’s not the time… it can be just as therapeutic not to abandon someone when they’re refusing, just to be there with them.

Several participants discussed keeping their personal expectations realistic. A participant shared, “It’s hard to get past your own judgments and biases and how you think things should go.” All 17 participants demonstrated a resilient attitude when discussing stressors and what they found to be difficult about working in the brain injury rehabilitation field.

**Support Provided in Work Environment**

*Support provided in work environment* refers to the ways in which brain injury rehabilitation professionals receive support from supervisors, administration, and coworkers. Participants explored their *experience of supervision* when seeking formal and informal supervision from supervisors. Participants explored their experience working on an interdisciplinary team and the *cohesion and relationships with coworkers*. Participants discussed *opportunities for education* provided by their employer as well as external opportunities such as conferences and continuing education. *Stress reduction by employer* refers to measures and
opportunities organized by employers to reduce stress levels in brain injury rehabilitation professionals.

**Experience of supervision.**

Participants shared their experiences of seeking supervision and support from supervisors. Most participants expressed preference of informal versus formal supervision. One participant shared finding formal supervision to be stressful. A participant explored:

> Formal meetings are hard because I have to come with a list and I have to prepare and I don’t always have anything on the top of my mind. I try to write things down as I think of them. But when you’re in the moment and you need to just run something by somebody, it’s more beneficial. And I feel like it’s more productive for me unless I have to hunt them down.

One participant discussed appreciating formal supervision because “the consistency of it is good and just having it as a resource.” Many participants discussed their appreciation for supervisors with open-door policies. One participant who spoke about her supervisor stated, “She’s awesome in that I can ask her basically any clinical questions under the sun.” Participants sought supervision to discuss difficult cases, help with processing, to get a different perspective, and for guidance in emergency situations.

Participants described the types of qualities valued in a supervisor. Several participants discussed needing to feel supported by their supervisor. A participant reflected, “It’s absolutely necessary to feel a sense of genuine support from whoever I’m seeking supervision from.” A participant spoke about her supervisor with whom she has been working with for many years. She reflected, “But just professionally and working with each other for a long period of time, half the time I feel like I know what he’s going to say when I come to him with something.” Many participants discussed their experiences of working with a supervisor who micromanages. Almost every participant identified whether or not their supervisor micromanaged. A participant
commented, “He doesn’t micromanage, so he’s not always looking over me, and he appreciates my input and values my opinion.” One participant spoke about the experience of working with a supervisor who micromanages, “She likes to know the details about every single thing we’re doing. And we’re pretty competent employees, and so that gets a little frustrating. And that’s, a lot of time, a source of stress.” Another participant shared finding supervisors who micromanaged to be offensive. Several participants discussed the benefits of problem solving with their supervisors. A participant explored, “I like to come up with a plan and run it through someone, especially if I’m not as comfortable or experienced with it. I guess it’s all problem solving – bouncing it off.” Participants also shared respecting and trusting their supervisors’ opinions. One participant commented, “I trust his opinion. I don’t always have to agree with it, but I do trust it, and I know that it’s coming from a good place.” A few participants reflected on previous experiences in which the quality of supervision was poor. A participant discussed:

I speak from having had terrible supervision experiences in the past, where if I brought a question up, I would be criticized for not knowing something, or criticized for not thinking along the lines of what my supervisor thinks, and that’s a really quick way to shut somebody down. A sense of supportiveness and a sense of openness to hear what it is that I’m sharing, and what questions I have is just absolutely critical.

Several participants explored the importance of voicing stressors to supervisors. One participant commented, “It’s also important to express your frustration and stress that you’re feeling in a real format.” Several participants also shared having a supervisor who knows when they need to vent versus when they need clinical guidance.

Several participants discussed it was helpful to have a supervisor who shared a similar clinical perspective, such as being of the same discipline. One participant reflected on her supervisory relationship, “Our supervision style fits and then also certainly our clinical perspective or view is in line. How we see things is very much in line.” She elaborated further
that reaching out to her supervisor, “is almost like a comfort, but knowing that that’s there I just feel much more confident.” Many participants discussed the importance of feeling understood by their supervisor. A participant shared, “I wish she could be there just to see – what we tell her, I wish she was a fly on the wall to see what we go through sometimes. But she understands it. She understands it.” A few participants discussed their experience when a supervisor is not of the same discipline. A participant identified this as her biggest fear. One participant commented, “To be a resource is next to impossible if you’re not of the same discipline.”

**Cohesion and relationships with coworkers.**

Participants explored their experience of working on an interdisciplinary team. One participant shared, “I don’t think I’d be as good at what I do without them. And I don’t think they’d be as good at what they do without me.” Most participants reported their experiences as positive and beneficial. A participant described working on an interdisciplinary team as “everybody has an important part of the puzzle.”

Participants discussed the benefit of having different disciplines on the interdisciplinary team when conceptualizing a case. One participant reflected:

> Each discipline brings a slightly different knowledge base to the table and sees each patient in a little bit different light, and so, coming together to come up with a really solid plan for ongoing life structure for people, is tremendously helpful.

Participants explored combining different perspectives in evaluating the survivor as a whole. A participant shared, “If you are only looking at it from one small perspective, then you’re missing out on a lot about that survivor.” Participants shared gaining expertise due to working on an interdisciplinary team. A participant explored the opportunity for growth and professional development:

> One of the things that helped me really learn and grow as a brain injury therapist was having other professionals from other disciplines and really working on that
multidisciplinary team. I really think that expanded my knowledge base greatly.

Other participants discussed the benefit of developing a broader knowledge base about brain injury rehabilitation. A participant commented, “When we sit down in a team meeting, and each of us talks about the patient from their own perspective, you really get to broaden your thinking beyond the little narrow slice that you’re focused on.” Several participants shared valuing feedback from coworkers to improve their practice. A participant shared:

We as a therapy team value feedback a lot, to the point where we’re pretty free to interrupt each other’s session and say “Hey, why don’t you try it this way?” No one takes offense to that, or thinks that someone’s calling them out on being a bad therapist or something like that, they’re just giving an alternative.

Working as part of an interdisciplinary team promoted deeper case conceptualization and the growth of participants as brain injury rehabilitation professionals.

Most of the participants identified having the ability to problem solve with their interdisciplinary team to be significantly helpful. One participant explored:

If I have a situation that I come across that I’m not quite sure about, I just need to bounce ideas off somebody, I have at least two other people to bounce those ideas off of. I don’t have to play out my own experiment with something that I think, this is going to work but I’m not sure.

Participants also discussed seeking out coworkers when survivors’ goal attainment has slowed or a problem developed. One participant shared:

If you’ve run through your bag of tricks and not getting the results that you want, there’s probably somebody else who has something in their bag of tricks that you haven’t quite tried yet, or that you forgot existed.

Several participants also discussed the benefit of working on an interdisciplinary team when treating survivors with challenging issues. A participant shared:

We talk as a team about everything like that. If it happens once, everyone on the team knows about it, and so, you can support each other, set boundaries, set behavioral plans to make sure no one gets hurt, and that survivor still gets the therapy that they need.
Many participants reflected that survivors benefit because “they are hearing a consistent message and consistent information” from all members of the interdisciplinary team who are working together to achieve the same goal.

Participants described the team as a unified or united front and shared the experience of knowing the goals of each discipline when providing rehabilitation to a survivor. A participant commented:

I know what every client is doing in physical therapy, even though I know nothing about physical therapy. So I think that’s helpful, and that helps us all really know the clients really well because you know what they’re working on and what they’re doing.

Participants also discussed consistently utilizing strategies implemented by other disciplines when working with survivors in their own treatment sessions. A participant commented, “If the speech therapist puts a strategy for a skill into place, it’s not just the speech therapist who’s implementing that in their sessions. It would be everyone would be implementing the strategy.”

Many participants expressed enjoyment of working on an interdisciplinary team. One participant commented, “even though I love this field, I love TBI and learning about it, I don’t think I would love this job as much if not for the other people that I work with.” Participants also discussed the importance of sharing the same values with their coworkers. A participant discussed, “We’re not just trying to get somebody through a process, but we’re supporting the rebuilding of quality of life. And to value the individual that we’re serving in a supportive, collaborative way.” The participant further elaborated that working as a part of an interdisciplinary team who share the same values and perspectives on rehabilitation is “one of the reasons why people like working here and have stuck around for a long time.” Several participants shared their teams used humor to cope, “because you cannot have this job and not have a sense of humor.”
Most of the participants discussed feeling supported and validated by their coworkers.

One participant reflected:

Because we all recognize that there needs to be a place where we can blow off steam, and to be able to yell and scream, and be like, “I don’t know what to do,” or just be able to have that gestalt moment of like, “Bah!”

Participants also explored feeling comfortable to honestly share their thoughts and frustrations with their coworkers. One participant reflected:

A lot of times when I, not complain, but if I really express – if a client is being a flat-out jerk, if I would say that to someone who doesn’t know brain injury or doesn’t know what I do all day, they might think I’m a horrible person and why am I in the health professions field? But when you’re in it and you know how people can be, you know how the clients and people’s brain injuries can be, you know my specific people, then that doesn’t sound so crazy and harsh and horrible. So that’s helpful to have people that you can actually be honest with – and they don’t judge you or think you’re a bad therapist or anything. They understand where you’re coming from.

Participants also shared feeling comfortable to approach their coworkers about interpersonal issues. One participant discussed, “We’re encouraged to, if we have a problem if we have an issue, if we have a concern, take it to that person directly.” She further elaborated by discussing how her team informs coworkers when their stress levels are impacting the work environment:

We also call each other out on that, “Oh, you’re having a bad day.” I’m embarrassed to tell you this, but the saying in our office is, “Who pooped in your Cheerios this morning?” It’s a very nice way to point out, “You are clearly in a bad mood, and we want you to know that we recognize that you are in a bad mood, without telling you that you’re being a jerk right now.”

Many participants discussed never feeling alone due to being a part of an interdisciplinary team. One participant commented, “I don’t ever feel like I’m out there alone trying to treat this very difficult, challenging population.” Participants also shared being able to get help whenever they needed it. A participant commented, “If you need help, you know you’ll get it.”
**Opportunities for education.**

All 17 participants reported their employers provided in-services and lectures and reported these opportunities as being helpful. A participant commented, “It makes me feel like we’re on top of the latest information out there. That we’re providing the best therapy out there, by staying on top of what’s new, and current.” Many participants were also required to meet continuing education requirements due to their licensure. Some participants reported financial support from their employer to attend external educational opportunities, while others reported no financial support or reimbursement. Most participants reported the most helpful educational opportunities to be topics specifically related to providing rehabilitation services to survivors of brain injuries. A participant shared, “When I have an opportunity to attend a conference that is really related to aspects of brain injury, I find that most rewarding, most informative.” A few participants shared attending conferences not directly applicable to brain injury rehabilitation to also be helpful. A participant commented, “It takes me out of my – sometimes you get stuck in your own little world and your own little niche, and it broadens that perspective a little bit more.” Participants engaged in educational opportunities provided by both their employers and external sources such as conferences.

**Stress reduction by employer.**

Formal stress reduction programs or activities were not consistently offered to brain injury rehabilitation professionals. Few participants reported formal stress reduction efforts by their employers. Most participants reported having to personally fund stress reduction opportunities. One participant shared that her employer used to provide a free gym membership. She discussed:

If you want to be a part of something like that, you have to fund it yourself, which I’m more than willing to do, but I think it would be nice for them to offer something like that
again. I think it would encourage a lot of staff to stay healthy and use it.

A few participants reported their employers having wellness programs, such as Employee Assistance Programs (EAP), exercise or yoga classes, and employee discounts for acupuncture and massage. However, most of the participants reported never taking advantage of these opportunities due to “being busy working.” Many participants reported more random and unscheduled acts of appreciation by their employer, such as providing free breakfast or lunch. One participant discussed:

They won’t tell anybody it’s coming, but then they’ll have a random free coffee cart, or they’ll pay for everyone’s breakfast that morning – whoever happens to go buy one. Or, they will randomly give out giveaways. They’ll give off a day of paid time off.

Many participants reported their direct supervisors providing food or coffee as a way of showing their appreciation. A participant shared, “Our director wants staff to know that they do work hard and that it is valued, and so something as simple as we might have cupcakes during a staff meeting. Birthdays are recognized.” Other participants reported their individual departments organizing social events, such as potlucks and going to a restaurant. A participant reflected, “The whole department brought a potluck and then they played little games – get-to-know-you games and things like that. On Monday of this week, the staff went out for lunch.” Several participants explored the flexibility of their supervisors for accommodating vacations and time off for personal or health reasons. A participant commented, “Our director is supportive of us taking time for ourselves and is flexible with people taking days.”

Participants were asked what their employers should be doing to reduce employee stress levels. A few participants identified that a better salary would be helpful. Several participants suggested administration and supervisors should reach out to staff to hear their concerns on a consistent basis. A participant reflected, “I think one area where actually we’ve recently
recognized as something to address is that we don’t necessary do the best job at checking in before problems develop and checking in with individual people.” Other participants suggested the need for improved communication from administration. She discussed:

One of the stressors is feeling like decisions are made from the top and handed down. And I think if staff felt like there was more input and communication from the bottom up, more decisions being made from the bottom up, that would help relieve certain stressors.

Another participant suggested administrators and supervisor should have an open door policy and seek feedback from staff. She discussed, “Check in with the needs of your staff. Try to create an environment in which it feels safe for people to share their concerns.” In addition, she suggested administration needs to promote a positive workplace culture. She elaborated:

Work on fostering a positive culture within the department because that goes a long way in helping deal with stress and burnout. And I would say making every individual from the person answering the front desk to the top physiatrist, make them feel recognized because that’s what makes the departments work together.

However, a few participants shared their belief that nothing would change even if administration offered staff an opportunity to provide feedback.

**Organizational Factors**

Organizational factors refer to the dynamics within brain injury rehabilitation professionals’ place of employment and non-clinical job responsibilities. Participants explored their experience of completing administrative duties, such as documentation, scheduling, and billing. Participants expressed frustrations with having a limited amount of time to complete administrative duties while providing clinical rehabilitation services to survivors of brain injuries. Scheduled breaks refer to the ability of participants to take a scheduled break during their workday. Participants explored the quality of communication from administrators and supervisors.
Administrative duties.

Brain injury rehabilitation professionals have both clinical and non-clinical job responsibilities. Non-clinical responsibilities included documentation, follow-up phone calls, and scheduling. A participant shared, “It feels like a marathon to get through.” Some participants shared the volume of required documentation to be overwhelming, and described the amount of documentation as “unnecessary” and “annoying.” A participant reflected, “The amount of documentation that is required to make insurance companies happy is ridiculous.” A few participants explored the reality of working in health care. One participant shared her opinion of the ever-changing climate of health care, “One thing that’s consistent about health care is … there’ll always be one more thing that you will need to do. And just understanding that and being efficient and just figuring out a way to make it work.”

The majority of participants found the amount of documentation to be stressful although a few participants found documentation to be helpful. Many participants explored finding the volume of documentation to be never-ending. A participant commented, “I’m perpetually behind on my evals and notes and all that stuff.” Several participants did not find the amount of documentation to be stressful or overwhelming. A participant discussed, “Documentation helps because it appeals to my more obsessive traits of writing everything down and all that, and it assists me in remembering things.” A participant who recently changed her job appeared to come to a realization during the interview about the impact documentation has on her stress levels. She discussed, “Maybe that’s why I’m so happy now. And I don’t even mean to be funny about that—seriously, when my job changed my documentation’s easier to do now, and I have less of it.”

Participants explored the added stress of having to deal with changes in documentation methods due to the constantly changing documentation requirements of funding sources. One
participant commented, “We don’t change how our notes are written very often, but when they get switched, it’s annoying to try to figure out how to – where do I now put this section because this section is important.” A few participants shared feeling stressed when their schedule unexpectedly changed, such as providing coverage for a co-worker who is absent due to illness. One participant commented, “I’m uber-planned, and then someone else gets thrown into the mix and I have to figure out what’s going to be helpful and effective for that hour … it can throw me for a loop.”

Participants shared the build up of administrative duties can become overwhelming. One participant reported, “The unending to-do list is stressful.” She further elaborated:

When I first started and my to-do list just kept getting longer and longer and I wouldn’t check things off, that caused me an extreme amount of stress. It’s better because I’ve gotten used to the fact that I’m never going to get everything done; it’s just a matter of doing, prioritizing and getting what you can done… And it still bothers me when I look at the list, and I’d like to get everything done but it’s not possible.

In addition, many participants explored becoming overwhelmed when experiencing stress from clinical caseloads in combination with stress from administrative duties. A participant reflected becoming stressed, “when there’s a lot to do and a lot of demands – demands of administrative, demands of my caseload, demands of the staff – all at the same time.” Participants also identified increasing levels of stress when caseloads increase and when falling behind in completing administrative duties.

**Time.**

Many participants shared becoming overwhelmed with the workload. One participant elaborated:

It’s overwhelming to try to accomplish everything that you need to accomplish in one day…It’s overwhelming to try to provide high quality of care, when there’s so many demands on stuff outside of your actual therapy session such as documentation, billing, and any other aspects of your job.
Several participants shared frustration with not having enough time to perform the clinical and non-clinical aspects of their jobs. Participants made statements such as, “I don’t have as much time as I would like to have,” and “we don’t have a lot of time to really think.” Participants also explored being scheduled to see survivors of brain injuries consecutively throughout the day. A participant discussed:

Things feel overwhelming on particularly busy days when I have survivors scheduled back to back to back, and I might not feel like I have time in between to kind of clear my head and sort of catch my breath.

A few participants shared not having the time to go to the bathroom so they limit their fluid intake. One participant commented, “I can’t tell you the number of days that I haven’t even had the time to go to the bathroom.” Another participant further elaborated on not having the time to go the bathroom. The participant reflected, “Sometimes I’m grabbing a few minutes to run down the hall to go to the bathroom, which then makes me feel guilty and then I’m coming back and starting my next session late.” One participant explored not having enough time to meet deadlines set by supervisors and administration:

What’s stressful about it is the timeframes. Things have to be … are expected to be done at certain times, but at the same time you’re often not provided as a worker, adequate time to meet deadlines but you’re still expected to meet the deadline.

Several participants shared coming in early and leaving late due to not having enough time in their workday to accomplish all of their responsibilities. A few participants also shared not wanting to leave early, as this would cause their work to pile up.

Several participants expressed frustration when the amount of time required to perform administrative duties takes away from time that could be spent on clinical duties. One participant discussed:
It is overwhelming to feel like you don’t have enough time in the day to help somebody… It is overwhelming to think about how much needs to be done in the day that is going to impact your ability to provide quality care.

Several participants shared their thoughts on their workload affecting the quality of care.

Other participants discussed not having enough time when caseloads are more challenging or complex. A participant explored:

There’s times where you’ll have a caseload where everyone needs a lot of support, whether it’s physical, emotional, informal counseling. They need a lot of that, and you just don’t feel like there’s enough time to address it all.

Participants discussed the lack of time also took away from collaborating with their coworkers or to conduct research on best practices when providing services to a survivor with a particular issue or new challenge.

Scheduled breaks.

Participants discussed whether or not they had time allotted in their workday for a scheduled break. Many participants shared rarely having the opportunity to take a break. A participant spoke about cancellations as, “It’s just like Christmas come early.” There were mixed opinions on whether or not taking a break would reduce stress levels. Several participants who did not have allotted breaks expressed belief that having a scheduled break would reduce their stress levels as it would allow them an opportunity to catch up on administrative duties, treatment planning, and needed follow-up. A participant reflected:

I think what would be different if I had a scheduled break is the predictability of it, that I would be able to count on each day at that time. I know I have options, whether it’s I want to use that time for paperwork or just sit quietly and relax or actually go out and get something for lunch.

Some participants thought having a scheduled break would be helpful, while others did not share this opinion. Several participants found a scheduled break helpful to regain focus, have time
away from work, exercise, and decompress. A participant shared a positive viewpoint on scheduled breaks:

When I take a good break, a more emotional break, I can focus more on work and that things don’t – I’m more patient, I think. I’m pretty patient at work, but I can tolerate more stuff thrown at me.

A few participants explained not wanting to have a scheduled break, and this is something that was decided amongst their coworkers. A participant commented, “I might actually be more upset that the day is longer then instead of just everybody just gets to leave at 4:00.”

Even participants who had scheduled breaks reported working through their lunch breaks. One participant discussed, “We do have our breaks allotted, but a lot of time, we have other things we need to do, like documentation, do scheduling, making phone calls.” A few participants preferred to work through lunch. A participant commented, “I think I’d worry about all the stuff I had to do, and then I’ll just be here later at night, so I don’t know that taking a break is an answer.” Participants who did have scheduled breaks expressed annoyance at staff meetings being scheduled during their lunch breaks. A participant commented, “We deserve to have a lunch where we’re not having to talk about or not having to do stuff where that’s our time to decompress and then get ready for the afternoon.” Participants expressed mixed opinions on having scheduled breaks in their workday.

**Communication.**

Many participants expressed poor communication from supervisors and administration as a frustration. Participants discussed not being included in decision-making that impacted the workplace and rehabilitation programs. A participant discussed working for an administration with poor communication and shared it “felt like there were a lot of impulsive unilateral decisions made that had effects down in the trenches that weren’t really being heard.” Many
participants spoke about the importance of good communication amongst administration, supervisors, and coworkers. A participant reflected, “Communication is key, so being able to be open with staff and allowing them to voice their concerns or opinions or stresses.”

Participants explored not being made aware of the reasons as to why there were policy changes and additional administrative duties assigned. Participants spoke about having to do new satisfaction surveys or other questionnaires with survivors and not receiving an explanation from administration. A participant reported telling survivors, “Don’t shoot the messenger. I didn’t do this.” Another participant reported she would be more motivated if she understood the reason for the additional task. She discussed:

I think if I understood what was going on, then I could help, well – if I understand what’s going on, then obviously I’m probably going to be more apt to do it. Or at least I can have a better idea of why we are doing it.

Participants also shared frustration when provided a short timeframe to complete additional administrative duties.
Chapter 5
Discussion and Implications

This study explored the experience of 17 brain injury rehabilitation professionals providing rehabilitation services to survivors of brain injuries. Seventeen brain injury rehabilitation professionals engaged in interviews to share their experiences of what about working in brain injury rehabilitation is stressful, what about working in brain injury rehabilitation is difficult, how brain injury rehabilitation professionals are affected by stress, how brain injury rehabilitation professionals reduce work-related stress, and what support is provided by employers to reduce work-related stress.

Brain Injury Rehabilitation is Difficult

*Brain injury rehabilitation is difficult* emerged from the data and refers to the nature of providing rehabilitation services to survivors of brain injuries. Brain injury survivors often require years of rehabilitation services due to *slow progress*. The consequences after brain injury are pervasive and permanent, and brain injury rehabilitation professionals *can’t fix it*. There is an increased responsibility of professionals in the role they have in providing rehabilitation services. Brain injury professionals face *unpredictable* situations due to the cognitive, emotional, and behavioral deficits presenting uniquely in each and every survivor of brain injury. It is challenging to collaborate with survivors to educate survivors about the impact of brain injury and the ways in which survivors can learn to compensate. Brain injury rehabilitation professionals have *so much to learn* about how a brain injury impacts a survivors’ life and how to help survivors live their life after brain injury.
**Slow progress.**

Survivors may require years of rehabilitation after sustaining a brain injury. Other survivors may require long term care after brain injury. The very nature of sustaining a brain injury requires the rehabilitation process to progress slowly and although survivors show improvement, improvement is gradual. Goal setting needs to be thoughtful in setting achievable and realistic goals that consider survivors’ current level of functioning. Some participants found the gradual progress and slow pace to be frustrating. Interventions must be implemented repeatedly due to memory impairments after brain injury (Wittig et al., 2003), and there are often setbacks. Several participants found the need for repetition to be frustrating and challenging.

**Can’t fix it.**

Brain injury is a long term and chronic disability due to the persistent and permanent cognitive, emotional, behavioral, and physical sequelae. Many participants compared brain injury with other chronic illness such as mental health conditions and even cancer. Participants shared that there is more potential to cure or permanently resolve the problems caused by mental health and cancer than there is in brain injury rehabilitation. Participants expressed feeling helpless in their inability to fix the problems survivors experience after brain injury (Wittig et al., 2003). Survivors must accept, adjust, and learn to compensate for the chronic deficits resulting from their brain injuries.

**Unpredictable.**

Participants found working with survivors of brain injuries to be *unpredictable* and reported this aspect to be difficult (Mooney et al., 2009; Wittig et al., 2003). Brain injury impacts each and every survivor in a unique way, and each survivor responds differently to treatment. Treatments interventions must be individualized to each survivor, taking into
consideration the severity of injury, emotional deficits, and the nature of the goal. There is no treatment manual that provides detailed interventions that are guaranteed to be effective. Brain injury rehabilitation professionals have to quickly perform assessments and quickly make decisions about what treatment interventions to implement. Brain injury rehabilitation professionals cannot determine what treatment interventions will be effective until the intervention is trialed. Brain injury rehabilitation professionals often provide rehabilitation services to survivors in their communities, places of employment, and in their homes. This further increases the unpredictability in these situations (Mooney et al., 2009), as there is more control over a clinical environment than there is in a community environment.

**Increased responsibility of professionals.**

The boundaries between brain injury rehabilitation professionals and survivors are blurred. Brain injury rehabilitation professionals feel more responsible for survivors’ success and recovery (Wittig et al., 2003). Due to reduced autonomy and vulnerability of survivors, brain injury rehabilitation professionals are more directive in their therapeutic approach and play an active role in decision-making. The therapeutic relationship and role is not as neutral as it would be in other healthcare fields. A study conducted by Mukherjee, Brashler, Savage, and Kirschner (2009) found similar findings among hospital rehabilitation professionals. Participants found this more emotionally engaging role to be stressful.

**Challenging to collaborate with survivors.**

Brain injury rehabilitation professionals prefer to collaborate with survivors, although this can be challenging. It can be challenging to engage survivors in rehabilitation activities, especially if the survivor is not receptive. Survivors often refuse to engage in therapeutic activities, and may be resistant to implementing compensatory strategies suggested by brain
injury rehabilitation professionals. Brain injury education must be provided in conjunction with
the development of compensatory strategies and other therapeutic interventions. Survivors must
understand how their brain injury affects them in a personal way and accept their deficits.
Participants found it helpful to use real life examples when working with survivors of brain
injuries, such as reflecting for survivors the impact their behavior might have in a competitive
work environment.

So much to learn.

There is much that is not known about the consequences of sustaining a brain injury and
how the human brain heals. Brain injury rehabilitation professionals constantly strive to
understand a topic that is so little understood. Even after working in brain injury rehabilitation
for years, the learning curve is never-ending. Participants described feeling uncertain and often
question their choice of interventions and treatment planning.

Emotional Experience

Emotional experience emerged to describe the emotional distress brain injury
rehabilitation professionals encounter when providing rehabilitation services to survivors.
Anosognosia was identified as the most difficult cognitive deficit to treat. Brain injury
rehabilitation professionals invest emotionally when building rapport and relationships with
survivors of brain injuries. Brain injury rehabilitation professionals hear numerous sad stories
about how survivors sustain brain injuries, and have empathy towards the difficulties
experienced by survivors after brain injuries. Brain injury rehabilitation professionals identified
family challenges when collaborating with survivors and their families.
Anosognosia.

Participants identified anosognosia to be the most difficult cognitive deficit to treat. Anosognosia impacts the ability of survivors to set realistic goals and affects survivors’ receptiveness to implement compensatory strategies and treatment recommendations. There are few interventions found to be effective in increasing awareness after brain injury. Supported failures are utilized as a last resort, and even then may not be effective. This impacts rehabilitation potential and treatment outcomes, which is supported by Winkens, Van Heugten, Visser-Meily, and Boosman (2014). 71.2% of 163 brain injury rehabilitation professionals surveyed identified self-awareness as an important factor in the rehabilitation process, and 69.3% identified self-awareness as important for successful treatment outcomes (Winkens et al., 2014). Participants reported that the process of increasing a survivor’s level of awareness is distressing to the survivor, and also distressing to the professional. Brain injury rehabilitation professionals often have to educate survivors on their limitations that may limit their ability to perform certain activities, and survivors often blame brain injury rehabilitation professionals for these limitations.

Building rapport and relationships.

Brain injury rehabilitation professionals develop close relationships with survivors during the rehabilitation process. Participants reported building rapport with survivors to be the least difficult aspect of working in brain injury rehabilitation and enjoyed working with this population (Wittig et al., 2003). Building rapport with survivors is vital to providing survivors with a supportive rehabilitation environment and achieving successful outcomes. Brain injury rehabilitation professionals often used humor and fostered fun during therapeutic interactions.
Brain injury rehabilitation professionals have to frequently provide bad news to survivors and some participants found this to be difficult.

**Sad stories/empathy.**

Brain injury rehabilitation professionals hear, read, or are reminded of sad stories on a daily basis working in the field of brain injury rehabilitation. Brain injury rehabilitation professionals compartmentalize the emotional distress to focus on the relevant information needed to inform treatment planning and therapeutic interventions. Participants reported the importance of not allowing sad stories to affect them in a way that could impact providing rehabilitation services to survivors. Brain injury rehabilitation professionals need to stay positive and strong to help survivors continue to progress in the recovery process. Participants reported living more cautiously in their personal lives due to hearing survivors’ sad stories and the impact it had on the lives of survivors and their families. Participants expressed genuine empathy for survivors who often struggle and experience anger, frustration, and grief during the recovery process.

**Family challenges.**

It is very challenging for the families of survivors of brain injuries to understand the nature of brain injury and to adjust to life after brain injury. Families often have unrealistic expectations of the rehabilitation process and the functional capabilities of survivors. Brain injury rehabilitation professionals identified families’ lack of understanding and unrealistic expectations to be very frustrating (Wittig et al., 2003). Participants identified the frustrations of working with families who lack follow through, as this ultimately impacts the success of the rehabilitation process. Participants expressed frustrated when families enabled or reinforced unsafe or negative behaviors.
Limited Funding and Resources

Participants identified *limited funding and resources* to be one of the most difficult and challenging aspects of working in the brain injury rehabilitation field. All seventeen participants reported *limited funding and resources* to be a contributing factor in increasing work-related stress (Flett et al., 1995; Wittig et al., 2003), and shared feelings of frustration, heartbreak, and discouragement when exploring this topic. There is a lack of funding for brain injury rehabilitation. There is also a lack of providers who will treat survivors of brain injuries. Brain injury rehabilitation professionals reported working around the system to provide the rehabilitation services survivors so desperately need. There is an impact of funding on treatment outcomes and professionals in how rehabilitation services are provided to facilitate meaningful change in the lives of survivors of brain injuries.

**Lack of funding for brain injury rehabilitation.**

There is a lack of funding for brain injury rehabilitation. Most insurance will not cover cognitive remediation, the identified treatment to address the cognitive sequelae after brain injury. In addition, the healthcare system does not provide the continuum of care required for survivors of brain injuries. It is difficult for survivors and their families to navigate the complex system of federal and state benefits, and it is challenging to apply for services. The individuals who make decisions about funding do not understand the nature of brain injury and the rehabilitation process (Wittig et al., 2003). Furthermore, the individuals who determine eligibility for specialized brain injury rehabilitation services do not understand how a brain injury may present in a survivor, resulting in survivors desperately in need of services being denied and having to reapply.
Lack of providers who will treat survivors of brain injuries.

There are few specialists who will treat survivors of brain injuries. There are few mental health professionals, such as psychotherapists and psychiatrists, who will agree to treat survivors. There are often a limited number of physiatrists who specialize in brain injury rehabilitation. It is challenging to connect survivors of brain injuries to specialists.

Working around the system.

Brain injury rehabilitation professionals utilize creative thinking to make the funding that is available work for survivors. Survivors’ rehabilitation goals are realistic and based on funding constraints. Brain injury rehabilitation professionals schedule therapy once a week instead of multiple times a week to extend the length of services. Home therapy programs are developed and families/friends are trained to implement the therapy program. Brain injury rehabilitation professionals often develop and upgrade home therapy programs over the phone or through email with survivors and their families.

Impact of funding on treatment outcomes and professionals.

Funding limitations and lack of resources impact treatment outcomes and the quality of care. The frequency of covered rehabilitation services is not adequate to meet the needs of survivors. Services are often terminated prematurely due to funding constraints, such as a maximum number of covered visits. Participants expressed frustration and concern when survivors were prematurely discharged knowing that those survivors could benefit from additional rehabilitation services. Participants expressed a lack of control when discussing funding constraints (Wittig et al., 2003). Funding constraints increase anxiety levels and decrease motivation and positivity. Brain injury rehabilitation professionals need to acknowledge
and accept the nature of funding limits their ability to guide survivors through the recovery process.

**Stress Management**

Brain injury rehabilitation professionals utilize coping strategies and engage in stress reduction activities to reduce the effects of work-related stress. Brain injury rehabilitation professionals problem solve with coworkers, prioritize tasks, and take short breaks, as strategies for *coping with stress at work*. Brain injury rehabilitation professionals engage in *stress reduction away from work* by participating in a variety of activities. The *effects of stress at work* impacts interactions with coworkers, supervisors, survivors, and their families. Participants identified irritability, social withdrawal, and physiological symptoms as the *effects of stress in personal life*. Brain injury rehabilitation professionals demonstrated *resiliency* by maintaining positive attitudes and adapting to stressors while facing difficult situations when providing rehabilitation services to survivors of brain injuries.

**Coping with stress at work.**

Brain injury rehabilitation professionals rely on their coworkers when experiencing work-related stress, which is supporting by findings of brain injury rehabilitation professionals connecting with coworkers as a coping strategy (Saban et al., 2013). Brain injury rehabilitation professionals found problem solving and decompressing with coworkers to be helpful in reducing work-related stress. Complaining is not an effective strategy for stress reduction. Brain injury rehabilitation professionals prioritize tasks and utilize time management skills to resolve items causing work-related stress. Short breaks were effective for some participants while others reported becoming hyperfocused to tackle stressors. Only a few participants acknowledged using emotional distancing or depersonalization to cope (Saban et al., 2013), which is contradictory to
the findings of Gosseries et al. (2012), and voiced an awareness of the impact this may have on their rapport with survivors.

**Stress reduction away from work.**

Brain injury rehabilitation professionals engage in a variety of activities in their personal lives to reduce work-related stress. Activities such as running, biking, hiking, yoga, and group exercise classes are effective in reducing stress levels (Saban et al., 2013). Participants reported these activities were a distraction from thinking about work. Participants also reported doing mindless activities such as watching television and browsing the internet to force themselves to stop thinking about work. Participants identified self-care, such as eating healthy, staying hydrated, exercising (Saban et al., 2013), and taking time off work to be effective coping strategies in reducing work-related stress.

Participants shared varying experiences on interactions with personal social networks in reducing work-related stress levels. Some participants reported this to be helpful, which reflects findings of brain injury rehabilitation professionals connecting with friends and family as a coping strategy (Saban et al., 2013). However, participants who self-identified as an introvert reported needing time alone to recharge before socializing. There was a difference in opinion about whether or not participants found it helpful to talk to friends and family about work-related stress. In addition to privacy laws, friends and family do not have the capacity to understand the nature of brain injury or what it is like to work in the field of brain injury rehabilitation.

**Effects of stress at work.**

There are physiological, cognitive, and emotional impacts of work-related stress. Problem solving, attention, and organization/planning are affected. Decision-making is impacted by increased reactivity and impulsivity. Processing speed is affected and efficiency in thinking
and task completion is decreased. Some participants reported going into problem solving mode, where they became hyperfocused on the task or issue at hand until completion.

Participants reported that they would like to think that work-related stress does not impact their interactions with survivors of brain injuries and their families. Stress causes brain injury rehabilitation professionals to be short and less patient with survivors and their families, especially when handling a difficult behavior or other types of frustration. Some brain injury rehabilitation professionals are less confrontational with families when stressed, and are therefore, less effective in their role with families. Brain injury rehabilitation professionals are more likely to focus on the therapeutic intervention when stressed and are less talkative and social with survivors. If a professional is stressed, they may choose to a therapeutic activity that requires less cuing or direction from the professional. Although most participants denied their stress levels affecting interactions with survivors, they reported their coworkers’ stress levels impacting interactions with survivors.

Brain injury rehabilitation professionals are acutely aware and concerned about their stress levels impacting interactions with coworkers. Brain injury rehabilitation professionals are short-fused, less patient, brusque, and not as approachable with coworkers when experiencing work-related stress. Some participants also reported being irritable and blunt. Brain injury rehabilitation professionals limit their interactions with coworkers and socially withdraw when stressed. This is because professionals do not want to be rude or reactive with their coworkers. However, this becomes problematic to team cohesion and when needing to collaborate with coworkers on a clinical problem.
**Effects of stress in personal life.**

There are physiological effects of stress, and work-related stress impacts personal relationships. Fatigue, sleep disturbances, muscle tension, headaches, and gastrointestinal distress were reported. Sleep disturbances include insomnia, vivid dreaming, and the need for excessive amounts of sleep. Brain injury rehabilitation professionals are also less patient and short-tempered with their friends and family when stressed. Several participants reported difficulty in leaving work at work (Wittig et al., 2003). They advised other professionals to leave work at work and not think about work when interacting with their families and friends.

**Resiliency.**

Brain injury rehabilitation professionals showed *resiliency* when faced with adversity and challenges that arise while providing rehabilitation services to survivors of brain injuries. Brain injury rehabilitation professionals demonstrated flexibility and the ability to adapt while being exposed to emotionally distressing and difficult situations (APA, 2016; McAllister & McKinnon, 2009; Shakespeare-Finch et al., 2005). Furthermore, brain injury rehabilitation professionals continued to maintain a positive attitude in adverse circumstances (Jackson et al., 2007). Several participants viewed *resiliency* as an un-teachable skill; you either have it or you do not have it. This is contradictory to the literature on *resiliency* (APA, 2016; Jackson et al., 2007; McAllister & McKinnon, 2009). Brain injury rehabilitation professionals acknowledge their limitations and lack of control in promoting change in the lives of survivors and their families. Brain injury rehabilitation professionals expect their workday to be difficult. Brain injury rehabilitation professionals remind themselves that survivors have brain injuries, and survivors are in rehabilitation programs to seek help after brain injury. It is important to not dwell on difficult situations and to let go. Additionally, it is important to keep personal expectations realistic.
Support Provided in Work Environment

This theme refers to the ways in which brain injury rehabilitation professionals receive support from supervisors, administration, and coworkers. Brain injury rehabilitation professionals discuss their experience of supervision and cohesion and relationships with coworkers. Brain injury rehabilitation professionals have opportunities for education. Stress reduction by employer refers to opportunities organized by employers to reduce work-related stress levels in brain injury rehabilitation professionals.

Experience of supervision.

Brain injury rehabilitation professionals have opportunities for both informal and formal supervision. Most participants identified their preference for informal versus formal supervision. Brain injury rehabilitation professionals seek supervision to problem solve, process, get a different perspective, and for guidance in emergency situations. Brain injury rehabilitation professionals prefer supervisors who do not micromanage, and several shared feeling offended and not trusted by supervisors who do micromanage. Brain injury rehabilitation professionals appreciate supervisors who have an open door policy, and prefer supervisors to be of the same discipline. It is important for brain injury rehabilitation professionals to feel safe to openly share their thoughts and feelings with supervisors.

Cohesion and relationships with coworkers.

Brain injury rehabilitation professionals view working on an interdisciplinary team to be beneficial for a variety of reasons. The quality and depth of case conceptualizations improve when different disciplines share different perspectives and view survivors from different lenses. Brain injury rehabilitation professionals believe working on an interdisciplinary team promotes
personal growth and increases expertise. Brain injury rehabilitation professionals value
constructive feedback from coworkers and actively seek out coworkers for feedback.

Survivors benefit when brain injury rehabilitation professionals work on a cohesive
interdisciplinary team. This results in survivors obtaining clear and consistent information from
all the members of the team. Interdisciplinary teams are described as a united front working
together to achieve the same goal. All brain injury rehabilitation professionals, regardless of their
discipline, consistently implement strategies developed by all interdisciplinary team members.

Brain injury rehabilitation professionals enjoy working on an interdisciplinary team. It is
important to share the same values and have the same perspective on rehabilitation as their
coworkers. Brain injury rehabilitation professionals feel supported and validated by their
coworkers and feel comfortable to honestly share their thoughts and frustrations without fear of
judgment or retaliation. Due to the dynamics of working on an interdisciplinary team, many
participants shared they never feel alone.

**Opportunities for education.**

Educational opportunities include in-services and trainings offered by employers and
external opportunities such as conferences and continuing education requirements for licensure.
Participants found educational opportunities helpful in staying current in the latest research and
evidence-based practices. Brain injury rehabilitation professional prefer educational
opportunities specific to brain injury rehabilitation. However, some participants appreciated
other topics that could be adapted to brain injury rehabilitation.

**Stress reduction by employer.**

Formal stress reduction programs or activities are not consistently offered to brain injury
rehabilitation professionals. Few employers offer formal stress reduction programs. Most brain
injury rehabilitation professionals have to seek out and fund their own stress reduction activities. Participants reported more consistent efforts by their direct supervisors to show appreciation of professionals’ hard work and dedication. For example, supervisors provide food or coffee during meetings or recognize birthdays. Some participants shared attending social events organized by their individual departments or supervisors, such as potlucks and going out to lunch. Brain injury rehabilitation professionals also appreciated the flexibility of their supervisors when accommodating vacations and time off requests.

Participants were asked what employers should be doing to address and reduce work-related stress. Only a few participants identified the need for a better salary, and a few participants shared their belief that nothing would change even if administration provided an opportunity to hear employee feedback. Administration and supervisors need to seek feedback from their staff and give employees an opportunity to voice their concerns and opinions (Wittig et al., 2003), especially when major decisions are being made by administration. Administration and supervisors need to have an open door policy and create a safe environment for brain injury rehabilitation professionals to voice their concerns or grievances.

Organizational Factors

Organizational factors refer to work place dynamics and non-clinical job responsibilities. Brain injury rehabilitation professionals are required to perform administrative duties, and many expressed not having enough time to complete these duties. Participants shared mixed opinions about the positive and negatives of having scheduled breaks. Participants reported feeling frustrated by poor communication from supervisors and administration.
**Administrative duties.**

Brain injury rehabilitation professionals are required to complete non-clinical duties such as documentation, follow-up phone calls, and scheduling. Many brain injury rehabilitation professionals find the volume of documentation to be overwhelming and unnecessary. When documentation policies change, participants report this further adds to the stress of completing documentation. Brain injury rehabilitation professionals find unexpected changes to their work schedules stressful, such as having to provide coverage for a coworker who is absent due to illness. Brain injury rehabilitation professionals become overwhelmed when these *administrative duties* build up, and especially when experiencing stress from clinical caseloads.

**Time.**

Brain injury rehabilitation professionals are overwhelmed by the heavy workload of clinical and non-clinical job responsibilities (Wittig et al., 2003). Brain injury rehabilitation professionals do not have enough time in the workday (Wittig et al., 2003) and have a to-do list that is perpetually unaccomplished. Brain injury rehabilitation professionals often do not have the time to go to the bathroom, and therefore limit their fluid intake while at work. Brain injury rehabilitation professionals arrive at work early and stay late due to not having enough time during business hours to accomplish all of their responsibilities.

Brain injury rehabilitation professionals experience frustration when the amount of *time* required to perform *administrative duties* detracts from time that could be spent on performing clinical duties. Several participants viewed their workload as negatively impacting the quality of care provided to brain injury rehabilitation professionals. Furthermore, the lack of *time* reduced opportunities to collaborate with coworkers or conduct research when faced with a difficult or new clinical issue.
Scheduled breaks.

Brain injury rehabilitation professionals rarely have the opportunity to take a scheduled break. There were mixed opinions on whether or not having the opportunity for a scheduled break would be beneficial to reduce stress levels. Several participants thought a scheduled break would be helpful as it would allow extra time to catch up on administrative duties and treatment planning, or to allow time to regain focus, get away from work, exercise, or decompress. Other participants did not share this opinion. Several participants shared not wanting to have scheduled breaks as the workday would be longer. Even participants who had scheduled breaks reported working through their breaks to catch up on their work, and many preferred to work through lunch because they would otherwise have to stay late. Many participants also expressed frustrations when staff meetings are scheduled during scheduled breaks.

Communication.

Poor communication from supervisors and administration is frustrating. Brain injury rehabilitation professionals would like to be included in the decision-making process that impacts the workplace and rehabilitation programs. Brain injury rehabilitation professionals are frustrated when the reasons behind policy changes and additional administrative duties being assigned is not communicated. Participants also expressed frustration when the timeframe to complete additional administrative duties is short.
Chapter 6
Conclusion

Terminology to Describe Work-Related Stress in Brain Injury Rehabilitation Professionals

This research study hoped that a more apt term to operationalize the work-related stress experienced by brain injury rehabilitation professionals would emerge from the data. The literature identified compassion fatigue as a combination of the symptoms of burnout from organizational factors in addition to emotional stress experienced when working with individuals with trauma. Brain injury rehabilitation professionals described the contributing factors of work-related stress to include organizational factors in addition to the emotional experience of working with survivors of brain injuries. The term compassion fatigue best fits with the experience described by the brain injury rehabilitation professionals interviewed during this study.

Brain injury rehabilitation professionals described contributing organizational factors to include excessive documentation, time constraints to perform clinical and non-clinical responsibilities, and poor communication from administration and supervisors. Brain injury rehabilitation professionals identified stressors due to the emotional experience of providing rehabilitation services to survivors of brain injuries. Brain injury rehabilitation professionals are exposed to the sad stories of survivors on a daily basis and are often the bearer of bad news to survivors. Brain injury rehabilitation professionals have to educate survivors with anosognosia to increase their awareness of the nature of their brain injury and subsequent limitations. It is disturbing and upsetting for survivors to become more aware of their deficits, and this process is distressing to brain injury rehabilitation professionals.

Compassion fatigue causes emotional, behavioral, and cognitive changes. Brain injury rehabilitation professionals reported changes to cognition when experiencing work-related stress.
Brain injury rehabilitation professionals reported effects to the following cognitive skills: attention, concentration, organization and planning, and problem solving. Brain injury rehabilitation professionals reported emotional changes such as irritability in both their professional and private lives. Compassion fatigue also affects the worldview and sense of meaning of clinicians. Brain injury rehabilitation professionals reported living more cautiously out of fear of sustaining a TBI themselves, and the impact this would have on their family.

Brain injury rehabilitation professionals identified work-related stress to be a combination of organizational factors with stressors resulting from the emotional experiences of providing rehabilitation services to survivors of brain injuries who face pervasive and persistent deficits. Furthermore, one participant utilized the term compassion fatigue to describe her experience of work-related stress. The term compassion fatigue appears to be the most relevant term to effectively describe the nature of work-related stress experienced by brain injury rehabilitation professionals based on the data.

**Direct Practice Implications**

The themes *brain injury rehabilitation is difficult, emotional experience, limited funding and resources*, and *organization factors* should aid brain injury rehabilitation professionals and social workers to better understand the potential risk and contributing factors for work-related stress. The themes *stress management and support provided in work environment* should aid brain injury rehabilitation professionals and social workers to develop more awareness of effective coping strategies to reduce work-related stress in the work environment, and to better manage how work-related stress impacts personal lives and relationships outside of the work environment. In addition, *support provided in the work environment and organizational factors* should aid supervisors and administrators to better understand the perspectives of their
employees and to develop more effective means to not only reduce but to prevent work-related stress amongst brain injury rehabilitation professionals and social workers.

In addition, it is apparent that there are inequities in funding opportunities for survivors of brain injuries to receive the vital treatment that is necessary to recovery. Individuals who sustain brain injuries are more likely to be of a lower socioeconomic status (Corrigan, Selassie, & Orman, 2010; Kraus & McArthur, 1996). Brain injury rehabilitation professionals shared frustrations with lack of funding and the lack of healthcare providers who will provide treatment to survivors of brain injuries. The Brain Injury Association of Pennsylvania (BIAPA) recognized the lack of healthcare providers who either understand the nature of brain injury or who will provide treatment to survivors of brain injuries. A current initiative of the BIAPA is to provide education about brain injury to medical professionals and social services agencies, including mental health professionals, domestic violence workers, crisis teams, case managers, emergency medical services staff, and drug and alcohol counselors (BIAPA, 2016). Survivors, due to being of a lower socioeconomic status, do not have discretionary income to fund expensive rehabilitation that is not covered by private health insurance. Survivors may require long-term services due to supervision needs, however, these types of services are not always available. Brain injury rehabilitation professionals discussed the lack of Medicaid waiver programs in their states; programs that would provide the level of care required for many survivors of brain injuries. These inequities ultimately impact treatment outcomes and quality of life of survivors of brain injuries. Continued advocacy for the development of programs to fund treatment for the extensive continuum of care required after brain injury is imperative. Additionally, education and training needs to be provided to healthcare and mental health professionals to increase survivors’ access to specialty care, such as psychiatry and substance abuse treatment.
Implications for Future Research

There is limited research on this topic: two previous studies utilizing mixed methods research (Wittig et al., 2003; Saban et al., 2013) and one quantitative study (Gosseries et al., 2012). There was an additional qualitative study exploring risk assessment and management in providing community-based rehabilitation to survivors of brain injuries. There continues to be a gap in the literature to examine not only how work-related stress impacts brain injury rehabilitation professionals, but also how this impacts survivors of brain injuries, their families and treatment outcomes. Further research is warranted to quantify the stressors brain injury rehabilitation professionals face and what activities and programs are effective in reducing stress levels. Future research to explore the experience of brain injury rehabilitation professionals working with children and adolescents may be helpful to better understand this topic. Future research is warranted to explore supervisory relationships and styles. Exploring the perspective of other rehabilitation professionals who provide services to other types of debilitating and chronic disabilities is also warranted.

Limitations

Due to the nature of qualitative research methods and the small sample size of 17 participants, there are limitations to this study. Participants were predominantly female, 15 females and two males. The sample size was predominantly Caucasian and female. Although this is un-researched, this does reflect the known demographic characteristics of brain injury rehabilitation professionals. This may or may not be an accurate reflection of this population. To this researcher’s knowledge, there is no research available on the ethnicity and cultural backgrounds of brain injury rehabilitation professionals. Participants resided in three major geographic areas of the United States of America. This does not account for potential regional
differences due to culture of the geographic area, organizational structures and funding sources. Brain injury rehabilitation professionals who reside and practice outside of the United States of America may have a different experience. Brain injury rehabilitation professionals who chose to participate in this research study are more likely to have more effective and positive coping strategies to manage work-related stress. The findings describe the nature of relationships with supervisors and survivors of brain injuries. However, neither supervisors nor survivors were interviewed. Qualitative research also relies on the knowledge and expertise of the researcher to conduct the interviews and interpret the results (Padgett, 2008).

**Conclusion**

This research study sought to understand and explore the experience of work-related stress in brain injury rehabilitation professionals. Brain injury rehabilitation professionals face significant challenges due to *limited funding and resources* that do not allow for the continuum of care that is required to provide rehabilitation services to survivors of brain injuries. The findings identified working in *brain injury rehabilitation is difficult* due to the complex nature of brain injury and the slow and difficult rehabilitation process. *Emotional experience* of brain injury rehabilitation professionals explored the close relationships developed with survivors during the rehabilitation process and exposure to *sad stories* increases the risk for work-related stress. *Organizational factors* such as heavy workloads, time constraints, and poor communication were contributing factors in the development of work-related stress. Brain injury rehabilitation professionals experience the effects of work-related stress in both their work environments and in their personal lives, and therefore engage in *stress management* strategies in both their work environments and in their personal lives. Brain injury rehabilitation professionals rely on *support provided in work environment* by their coworkers and supervisors to cope with
the difficulties of working in brain injury rehabilitation as well as effectively managing their stress levels. In addition, this study sought to identify a more apt term to operationalize the work-related stress experienced by brain injury rehabilitation professionals. The term compassion fatigue appears to be the most relevant term to effectively describe the nature of work-related stress experienced by brain injury rehabilitation professionals. Brain injury rehabilitation professionals continue to persevere to promote meaningful change and recovery in the lives of survivors of brain injuries despite facing adversity due to inadequate funding, lack of understanding, the perplexity and mystery that is the human brain, and the complex consequences of brain injury.
References


and burnout among staff caregivers in nursing homes and acute geriatric wards.


 sector rehabilitation professionals (Doctoral dissertation, University of George, 1994).

_Dissertation Abstracts International, 52, 5005._


Appendices
Appendix A. IRB Approval

University of Pennsylvania
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INSTITUTIONAL REVIEW BOARD
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PRINCIPAL INVESTIGATOR : Andrea M Doyle
TITLE : Factors Contributing to Work-related Stress in Brain Injury Professionals
SPONSORING AGENCY : No Sponsor Number
PROTOCOL # : 821983
REVIEW BOARD : IRB #8

Dear Dr. Doyle:

The documents noted below, for the above-referenced protocol, were reviewed using the expedited procedure set forth in 45 CFR 46.110 and approved on 1/11/2016.

- HS-ERA Modification (confirmation code bjhhaaeb ), submitted 12/21/15
- Revised Informed Consent Form, dated 01/11/15
- CITI Training Report of Completion for Gillian Murray, passed on 12/20/15
- Recruitment Flyer, uploaded 12/20/15
- Internet Recruitment Ad Language, uploaded 12/20/15

If you have any questions about the information in this letter, please contact the IRB administrative staff. Contact information is available at our website: http://www.upenn.edu/IRB/directory

Thank you for your cooperation.

Sincerely,

IRB Administrator
Appendix B. Interview Guide

**Facesheet Information**

Age

Gender

Educational Background/CBIS

Years working in the field

What type of brain injury rehabilitation services do you provide?

Case management  Counseling  Job coaching  Skills training in home/community

Facilitating Groups

Do you have a loved one who has a TBI?

**Purpose of study**

I am studying what it’s like for professionals to work in brain injury rehabilitation. I will be asking about your experiences working with clients and their families, as well as what it’s like for you to work with other professionals and your experiences of supervision.

**Career Experience**

What is it like for you to work in brain injury rehabilitation?

  - What are the positives?
  - What are the negatives?

Do you work on an interdisciplinary team?

  - What is that like for you?

What is it like working with your supervisors?

What do you find to be the most difficult aspect of working in brain injury rehabilitation?

What do you find to be the least difficult aspect in working in brain injury rehabilitation?
**Work-related Stress**

What about working in brain injury rehabilitation do you find stressful?

In what circumstances do you start feeling stress?

What about working with clients is stressful?
  
  Cognitive impairments?
  
  Behavioral changes?
  
  Sad stories?

What about working with families is stressful?

What about administrative duties such as documentation is stressful?

What about working with funding sources is stressful?

What about working with limited funding?

  What is it like for you when you can’t help a client due to lack of funding or funding constraints?

Have you ever found yourself to become overwhelmed?

  Have you ever experienced emotional exhaustion or distancing yourself from clients to cope?
  
  What are signs/symptoms that you are experiencing this?
  
  Tell me what that is like for you.

What do you do to reduce your level of stress when experiencing work-related stress?

  What do you find helpful in reducing your stress levels?
  
  What do you find unhelpful in reducing your stress levels?

What do you think about breaks?
Do you get a break daily?
Is this helpful/unhelpful?
How do you think this affects/does not affect your stress levels?

How does your level of stress affect you at work?
  Work with clients?
  Working with co-workers?
  Working with supervisors?

How does your level of stress affect your personal life outside of work?

If one of your co-workers is experiencing stress, does that affect the rehabilitation environment?
  Does that affect interactions with clients?
  Their families?
  Interactions with co-workers?
  Interactions with supervisors?

Why do you think professionals in brain injury rehab experience high rates of work related stress?
  What about working in brain injury rehab causes high levels of stress?
  What have you noticed in your co-workers?
  Are there high turnover rates at your agency?
    If so, why do you think that is?
    If not, why do you think that is?

**Supervision, Support and Training**

What clinical supervision do you receive?
What is it like for you?

What is most helpful?

What is not so helpful?

What issues do you wish you could get better or more frequent supervision for?

What informal supervision do you receive from supervisors and/or co-workers?

What is that like for you?

Is it helpful/unhelpful?

Do you feel that you can openly share your thoughts and feelings with your supervisor?

What formal training or education do you receive?

How is this helpful/unhelpful?

What does your agency do to reduce staff stress and burnout?

What do you find helpful?

What do you find unhelpful?

Do you think it is effective in reducing staff stress?

Why/Why not

How do you think your agency can better help to reduce staff stress and burnout?

**Debriefing questions**

Is there anything that I didn’t ask that I should have asked?

Is there anything you think I should know that would help me better understand this topic?

What advice would you have for other brain injury professionals to minimize burnout?

What advice would you give to administrators and clinical supervisors?
Title of the Research Study: Factors Contributing to Work-Related Stress in Brain Injury Professionals
Protocol Number: 821983
Principal Investigator: (name, address, phone and email) Dr. Andrea Doyle, Ph.D., SSW-
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Co-investigator: (name, address, phone and email) Gillian Murray, MSW, LSW, CBIS, SSW-
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2035

You are being asked to take part in a research study. This is not a form of treatment or therapy.
It is not supposed to detect a disease or find something wrong. Your participation is voluntary
which means you can choose whether or not to participate. If you decide to participate or not to
participate there will be no loss of benefits to which you are otherwise entitled. Before you make
a decision you will need to know the purpose of the study, the possible risks and benefits of
being in the study and what you will have to do if decide to participate. The research team is
going to talk with you about the study and give you this consent document to read. You do not
have to make a decision now; you can take the consent document home and share it with
friends, family doctor and family.

If you do not understand what you are reading, do not sign it. Please ask the researcher to
explain anything you do not understand, including any language contained in this form. If you
decide to participate, you will be asked to sign this form and a copy will be given to you. Keep
this form, in it you will find contact information and answers to questions about the study. You
may ask to have this form read to you.

What is the purpose of the study?
The purpose of the study is to learn more about:

• How brain injury professionals experience work-related stress
• How professionals cope or reduce stress
• What about working in brain injury rehabilitation is difficult.

This study is being conducted as part of a dissertation at the University of Pennsylvania School
of Social Policy and Practice.
Why was I asked to participate in the study?
You are being asked to join this study because:
• You have at least two consecutive years of full-time experience working in the brain injury rehabilitation field in an outpatient or community-based setting
• You provide direct clinical care to individuals with traumatic brain injuries or acquired brain injuries
• You have at least a Bachelor’s Degree in a Human Services field, such as social work, psychology, nursing, disability services, vocational rehabilitation, recreational therapy, health care administration, rehabilitation counseling, education, or counseling

How long will I be in the study? How many other people will be in the study?
The study will take place over a period of 15 months. This means we will ask you to spend 1 day participating in this study. Each session will last approximately 45 minutes to 2 hours. There will be approximately 12 to 15 participants from the United States of America in this study.

Where will the study take place?
You will be asked to come to a private office space, located at the brain injury rehabilitation program where you work OR participate in a video interview on ______ at ______ pm or am.

What will I be asked to do?
You will meet in-person one time with the interviewer either in person or during a video interview. You will be asked a series of questions about working in the brain injury rehabilitation field. The interview will be audio-recorded and will be sent for transcription.

What are the risks?
There is minimal risk to participate in this study. Subjects may experience minor discomfort that you may experience in every day life, such as becoming sad or upset.

If you do experience distress as a result of participation, you will be provided resources including the names and numbers for agencies or individuals for emotional support and counseling.

How will I benefit from the study?
There is no direct benefit to you. However, your participation could help us understand why brain injury rehabilitation is difficult, what makes working in brain injury rehabilitation stressful, and how to better support staff and to prevent stress among brain injury rehabilitation professionals. In the future, this may help brain injury rehabilitation professionals to receive better coping strategies and trainings to reduce the stress of working in brain injury rehabilitation.

What other choices do I have?
Your alternative to being in the study is to not be in the study.
What happens if I do not choose to join the research study?

You may choose to join the study or you may choose not to join the study. Your participation is voluntary.

There is no penalty if you choose not to participate in the research study. You will lose no benefits or advantages that are now coming to you, or would come to you in the future. Your employer will not be upset with your decision. Your decision to not participate in this study will not affect your employment status.

When is the study over? Can I leave the study before it ends?

The study is expected to end after all participants have completed all visits and all the information has been collected. The study may be stopped without your consent for the following reasons:

- The PI feels it is best for your safety and/or health-you will be informed of the reasons why.
- You have not followed the study instructions
- The PI, the sponsor or the Office of Regulatory Affairs at the University of Pennsylvania can stop the study anytime

You have the right to drop out of the research study at anytime during your participation. There is no penalty or loss of benefits to which you are otherwise entitled if you decide to do so. Withdrawal will not interfere with your employer or employment status.

If you no longer wish to be in the research study, please contact Gillian Murray, MSW, LSW, CBIS, at 516-503-2035 and take the following steps:

- State that you no longer wish to be involved in the study and that you would like to withdraw the data collected during your interview. There will be no consequences of your decision to withdraw from the study. Your decision to withdraw from the study will not affect your employment status.

How will confidentiality be maintained and my privacy be protected?

We will do our best to make sure that the personal information obtained during the course of this research study will be kept private. However, we cannot guarantee total privacy. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

- Subjects will be assigned a numeric code. Any private information that could be used to identify the subject will be removed by blackening out or whitening out this information.
- A listing containing the assigned codes and corresponding subject’s identifiable information will be maintained in a password protected word document. Only Gillian Murray will have access to this document.
- Transcriptions of the interviews will be labeled only with the assigned numeric codes. Any printed transcriptions will be stored in a locked file cabinet. All transcriptions will be stored for a maximum of 5 years. After 5 years, they will be destroyed.
• The audio recordings will be labeled with only the assigned numeric code. Recordings will be stored on a password protected hard drive. All recordings will be stored for a maximum of 5 years. After 5 years, they will be destroyed.
• The University of Pennsylvania IRB will also have access to the records.

What happens if I am injured from being in the study?
Not applicable for the purpose of this study

Will I have to pay for anything?

• You will not have to pay for anything to be involved in the study. You will be interviewed at your site of employment or during a video interview.

Will I be paid for being in this study?
☐ If participating in a face to face interview, you will be provided with a $10 Visa gift card and a mug for your participation in the study.
☐ If participating in a video interview, you will be provided with a $15 Amazon gift card that will be emailed to you for your participation in the study.

Who can I call with questions, complaints or if I’m concerned about my rights as a research subject?
If you have questions, concerns or complaints regarding your participation in this research study or if you have any questions about your rights as a research subject, you should speak with the Principal Investigator listed on page one of this form. If a member of the research team cannot be reached or you want to talk to someone other than those working on the study, you may contact the Office of Regulatory Affairs with any question, concerns or complaints at the University of Pennsylvania by calling (215) 898-2614.

If you have any questions or there is something you do not understand, please ask. You will receive a copy of this consent document.

☐ I agree to take part in this research study
☐ I do not agree to take part in this research study

Date
Date
### Theme: Brain Injury Rehabilitation is Difficult

<table>
<thead>
<tr>
<th>Codes</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Slow progress</td>
<td>The recovery process is slow and long. Survivors may require several years of rehabilitation, and others may require a lifetime of care. Survivors of brain injuries experience gradual improvement over time. Due to cognitive impairments, it is necessary to implement interventions repeatedly. Ex: being a broken record, doing the same thing over and over, baby steps, see little changes, stuck in a rut, stuck in the mud, back to square one, day in and day out, a lot of start back from scratch, frustrated by lack of progress, it takes time, it’s not brief intervention.</td>
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<tr>
<td>Increased responsibility of professionals</td>
<td>Participants do not take a neutral role in the recovery process. Due to the reduced autonomy among survivors of brain injuries, participants take more responsibility such as advocacy and providing guidance and direction in decision-making. Ex: other people make decisions for clients, clients can’t always advocate, take responsibility myself, more of a parental role, more emotional and not engaged role, remain neutral or promote better decisions, bringing things to client in hospital, we are their family.</td>
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### Theme: Unpredictable

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<td>Brain injuries manifest differently in each and every person. This makes it challenging to plan therapeutic interventions, as each survivor may respond differently. Survivors also act in unpredictable ways due to the cognitive and behavioral deficits of brain injury. Participants explored the unpredictability experienced when conducting home visits. Ex: each person different, each person unique, slowly head for crisis, have an alternative plan, think about everything, being on your toes, plan for everything, don’t know what you’re walking into, if there’s flying cockroaches or honeybees we have to continue at a different time.</td>
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### Theme: Can’t fix it

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<td>Brain injury is a long term and chronic disability due to the persistent and permanent cognitive, emotional, and physical sequelae. Although some survivors improve, many continue to experience permanent residual effects throughout their lives. Ex: people aren’t getting better, can’t fix it, permanent effects, permanent life consequences, have to talk about it even though can’t fix it, help people deal with not getting better, learning to live with limitations, there is no solution to brain injury, you’re taking a glass that broke and putting the pieces back together, never going to be 100%, it’s a forever thing – there is no end, we can’t put humpty dumpty back together, can’t heal the brain injury and no repairing brain tissue.</td>
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### Theme: Challenging to collaborate with survivors

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<td>The collaboration between clients and participants to develop and implement strategies in the achievement of rehabilitation goals. Educating survivors about their brain injuries and subsequent deficits. Collaboration versus refusal and resistance is explored. Participants also explored survivors’ goals are very functional in nature. Ex: being able to understand and appreciate their injury, develop strategies so they can be successful, doing real-life functional tasks, goals are really functional, don’t like telling people what to do, educating in the moment, figure out a way to do the things you like to do, focusing on goals that is important to them, identify strengths and weaknesses, more likely to follow through if they had something to do with the decision, nicer way to work when collaborative, can’t battle someone who doesn’t want to give up, if they let me I can build them up.</td>
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### Theme: So much to learn

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<td>There is so much that is not known about the human brain and the consequences of sustaining a brain injury. There is a never-ending learning curve to understand the nature of brain injury and the best practices to be utilized in providing rehabilitation to survivors. Ex: always reassessing to do better, have to think, I can’t do this in my sleep, I could never go to sleep for 5 years and still not feel knowledgeable, not where we need to be, there’s always new things to learn, trying to understand and master something that’s so little understood.</td>
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<tr>
<td>Emotional Experience</td>
<td>Anosognosia</td>
<td>The challenges of working with clients with lack of insight or awareness after a brain injury. This was identified as the most stressful cognitive deficit to treat. There are very few interventions found to be effective in increasing awareness after brain injury. Participants explore topics such as how to help survivors who do not think they have a problem, how to work with survivors whose goals are unrealistic given their level of functioning, and blaming brain injury professionals for not being allowed to do a certain activity. Ex: brain injury itself interferes with awareness, awareness can disqualify people from treatment, can’t force them to work on something they don’t see as a problem, client doesn’t see his deficits so doesn’t want help, you really do have a problem, working with people who have goals that aren’t realistic, very few strategies to teach awareness, when awareness isn’t there of how deficits impact their functioning, if you can’t break through awareness you can’t help them, hard to be attacked and not walk away and give up on person, hardest ones when they direct or blame you</td>
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<td>Building rapport and relationships</td>
<td></td>
<td>Participants explore emotionally investing in survivors of brain injuries during the rehabilitation process. Building rapport and close relationships with survivors. Due to the slow recovery process, participants explore the long-term relationships with survivors, often lasting years. Participants also explore having to give bad news to survivors. The use of humor to help survivors cope. Ex: challenging to develop rapport with clients to engage them and work on goals, I’d be the worst client, can’t imagine how frustrating, we feel for them, give them permission to be angry, when I first left a family conference and just cried, I know I’m going to have to tell someone bad news, worry about providing that news, joking around to help them out, share jokes, try to foster fun and silliness, what happened is so serious</td>
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<tr>
<td>Sad stories/ Empathy</td>
<td></td>
<td>Participants explore the effects of hearing or reading the details of how a survivor sustained a brain injury. Participants explore relating to survivor experiences and living more cautiously to avoid sustaining a brain injury themselves. The experience of participants to understanding survivors’ experiences of living life after a brain injury. The recovery and rehabilitation process is very difficult for survivors, and survivors often struggle, experience frustration, and grieve the loss of self. Ex: as they build their awareness they start to feel bad about themselves, being there through the process of realization, setting them up for depression grief and loss, affects the way I live and how I am as a parent, be thankful you can run, cuts you up, difficult to bear witness and not become disillusioned by humanity, everybody has a sad story, gotten better at compartmentalizing, have to emotionally shut down, it’s just our norm, keeping a therapist point of view</td>
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<td>Family challenges</td>
<td></td>
<td>Families often have a lack of understanding of the nature of brain injury and have unrealistic expectations. Participants explore supportive families versus families who lack follow through or hinder the rehabilitation process. Participants also explore the toll and role changes in families. Ex: challenging when families don’t understand, if there’s no carryover outside the program it’s not going to be successful, inability to see reality gets in the way of loved one gaining more independence, lack of awareness and lack of patience, nagging to get something done, family has to go through acceptance and understanding, help family get past expectations, when family interferes with process and become a hindrance, family reinforcing unsafe and negative behaviors</td>
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<tr>
<td>Limited Funding and Resources</td>
<td>Lack of funding for brain injury rehabilitation</td>
<td>There are limited funding sources and resources available to provide survivors with brain injuries with treatment. Many survivors with brain injuries require supervision and assistance with activities of daily living. In some states, there is no funding to provide this type of care. The healthcare system does not provide for the continuum of care required after an individual sustains a traumatic brain injury.</td>
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<td>Ex: doesn’t see brain injury as a chronic thing, individuals with brain injury are the underdog, can’t see a lot of people after brain injury, cognitive therapy is not covered, cognitive therapy is what person needs, don’t have resources, don’t see work reintegration and assessment as medically necessary, nobody knows what they’re going to deny,</td>
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<td>Lack of providers who will treat survivors of brain injuries</td>
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<td>It is difficult to access healthcare providers who will provide care for survivors of brain injuries.</td>
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<td>Ex: have to jump through hoops to get my clients seen, challenge to find specialists who treat population, because there’s only one doctor he can turn down anybody he wants to turn down, don’t have psychotherapists who take insurance or understand brain injuries,</td>
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<tr>
<td>Working around the system</td>
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<td>Participants discuss getting creative to make the funding that is available work for survivors. Participants discussing being accessible by phone, sending emails, providing home programs, and training family members to do therapeutic interventions.</td>
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<td>Ex: be persistent in trying to find resources, doing the best you can with what you have to work with, always try to find a different avenue but that’s hard, be more flexible with health insurance and providers, you just need to buy people time, do a couple of weeks of home therapy and then outpatient, gave my phone number as resource for families, get creative about sending emails and providing a home program, get creative and do a tele-health model</td>
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<tr>
<td>Impact of funding on treatment outcomes and professionals</td>
<td></td>
<td>Treatment outcomes for survivors of brain injuries are negatively impacted by lack of funding. Brain injury professionals are frustrated and demotivated by lack of funding.</td>
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<td>Ex: frustrating and saps drive and motivation, funding issues are demotivating, eye opening and frustrating to see the shortcomings of the systems we work within, clients don’t improve as quickly as they could be, agency tries to keep stress from funding as low as possible, anxiety provoking because problems might get worse, become less ambitious about what you can achieve, detracts from quality of care, disappointed because support not available, frustrating when I know I can’t do something about it</td>
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<td>Stress</td>
<td>Management</td>
<td>Coping strategies utilized in the work environment to minimize the effects of stress in performing their job responsibilities. Participants explored topics such as problem solving with coworkers, complaining not being helpful, prioritizing tasks, and taking a short break. Emotional distancing can be both positive and negative. Ex: kill steam in office, change what I’m working on, choose to prioritize, bite my tongue, breathe, mental reboot, ask for help, getting it out, lock themselves in office, gotten good at breathing, have to think, write a list, need mental reboots, talk about stressors more, work closely with coworker if stressed, mini sessions to problem solve, consult with people who know more than I do, being organized and planning deadlines, complaining isn’t helpful</td>
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<tr>
<td>Stress</td>
<td>reduction</td>
<td>Participants engage in a variety of activities in their personal lives to reduce their stress levels. Participants explored topics such as exercises, social activities with family and friends, and blacking out or forcing themselves to not think about work. Talking about work with friends and family who don’t understand brain injury is not helpful. Ex: take your time off, black everything out from day, climbing is practice in mindfulness, complaining about work is not helpful, do fun things with husband, do stuff that’s nothing to do with here, turn my brain off for a time, do things to feel grounded and stay physically active and healthy, find a friend with a baby or puppy, get daily exercise, have a bottle of wine ready at all times, practice yoga, things I can get lost in, can’t talk to people outside of work because everything confidential, work life balance</td>
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<tr>
<td>Effects</td>
<td>stress at work</td>
<td>Participants explored how their stress levels impacted job performance, interactions with co-workers and supervisors, and interactions with brain injury survivors and their families. Participants discussed limiting interactions when stressed to avoid being rude or brusque with coworkers. Ex: ct know when I’m frustrated, less clear to family about expectations, more brusque with family, be rude without realizing, less efficient thinking, giving less feedback, less passion, more quiet</td>
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<tr>
<td>Effects</td>
<td>stress in personal life</td>
<td>The way in which work-related stress impacts the personal lives and personal relationships of participants. Irritability and self-isolation impact social relationships. Physiological symptoms include headaches, muscle tension, sleep disturbance, and fatigue. Participants also explored not taking work home. Ex: lay in bed for days, not wanting to cook or be on computer at home after day with clients, I’m not in the mood to talk, more sensitive to things than I would normally be, put my kids on back burner, stomach problems, I won’t make plans, shouldn’t plan things until I have time to recover, quick to react, head pounding, I eat my emotions, just want to sleep, short tempered, cut myself off socially, crankier at home, get short and irritable, thinking about clients outside of work, have no patience, wake up in middle of night, shoulders and back get tight,</td>
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<td>Resiliency</td>
<td></td>
<td>The capacity of participants to maintain positive attitudes and effectively utilize coping strategies while handling stressful and difficult situations in their work environments. Ex: you have to accept there’s only so much you can do, all I can do is offer support, deal day by day, doing the best I can, don’t take it personally, good at keeping expectations realistic, have to deal, have to have a thick skin, have to go with the flow, having a goal oriented mindset, it’s the nature of the beast, it’s just the way things are, learning to let it roll off, people who can’t let go struggle a lot, remember they have a brain injury, you just can’t fix everything</td>
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<tr>
<td>Support Provided in Work Environment</td>
<td>Experience of supervision</td>
<td>The experience and benefits of seeking supervision and support from supervisors. Supervisory styles as well as formal versus informal supervision is explored.</td>
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<td>Ex: be more connected to what’s going on, be validated more for our concerns, being able to go and talk about different perspectives, another set of eyes and ears, address clinical issue or what needs to be taken care of, have different styles and personalities so had to figure that out, biggest fear is supervisor won’t be the same discipline, can ask any question under the sun, doesn’t understand my role, don’t have the confidence to initiate those kinds of conversations myself, feel really supported, appreciate not being micromanaged, I can share my thoughts but they’re not always well received, I don’t feel I need my supervisor to micromanage me at this point, I don’t have your attention, no one fights for what you need, we’re not always heard</td>
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<tr>
<td>Cohesion and relationships with coworkers</td>
<td>Participants explore topics such as team cohesiveness and relationships with co-workers. Having an opportunity to bounce ideas off of coworkers as well as seek different perspectives are benefits of working on an interdisciplinary team. The use of humor to cope.</td>
<td>Ex: can’t have this job and not have a sense of humor, black humor, being silly to cope, culture of keeping humor in things, silly sense of humor on team, a lot of laughter, working together to achieve one goal, conduit for information, everyone has an important piece of the puzzle, everyone’s got each other’s backs, have a unified front, don’t ever feel alone</td>
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<tr>
<td>Opportunities for education</td>
<td>Educational opportunities provided by the employer as well as external opportunities such as Continuing Education requirements to maintain licensure. This also includes attendance at conferences. These opportunities were helpful in informing the clinical practice of participants.</td>
<td>Ex: ACBIS lectures, continuing education for license and boards, encouraged to attend workshops to improve our work, improves knowledge to inform practice, how to adapt to brain injury population, range of things at agency, find out what others are doing and latest research, value staying connected to peers, trainings helpful if directed toward TBI, outside speaker who doesn’t understand brain injury less helpful</td>
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<tr>
<td>Stress Reduction by Employer</td>
<td>Services and opportunities offered to participants by their employer to reduce stress levels. This includes formal EAP programs, acknowledging employee stress levels, and acts of appreciation, such as providing free lunch or coffee to participants. Participants provided advice to employers to be more effective in reducing staff stress levels.</td>
<td>Ex: acknowledging that everyone is busy and works hard, checking in with staff, employee health programs like massages for low cost, foster positive culture, gym for employees, half hour yoga during lunch, newsletter with wellness tips, offer exercise classes, reward cards, should be paying more, random acts of kindness</td>
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<td>Organizational Factors</td>
<td>Administrative duties</td>
<td>Non-clinical duties such as documentation, scheduling, follow-up phone calls, increasing caseloads, and billing. Participants explore having to deal with changes in documentation methods and billing due to the constantly changing documentation requirements of funding sources. Some participants found documentation to be helpful while others found the amount of documentation to be stressful. When having to focus on challenging clinical issues, the addition of administrative duties becomes overwhelming. Ex: can’t help clients reach goals when doing other administrative stuff, annoying to figure out changes in documentation, changes with billing frustrating, documentation assists in remembering, don’t have a secretary, get overwhelmed when it piles up, volume of paperwork, amount of documentation required by insurance is ridiculous, any change in systems is stressful, documentation and deadlines, feels like a marathon, overwhelming when team struggling with clients having challenging issues, never-ending to-do list is stressful</td>
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<td>Scheduled breaks</td>
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<td>The ability to take a scheduled lunch break or other scheduled breaks during the workday. Participants explored frustrations in regards to lunch meetings. Participants expressed mixed opinions on whether or not a break would be helpful. Ex: break would be helpful, don’t have time to think, give us a mental reboot, help refocus, mentally forget what’s going on, moment to ignore what’s happening, I don’t take breaks even though I could, eat at desk or in car, help me reduce stress or step away to give new perspective, get away from office and desk, might be more upset that day is longer than taking break, guilty of working through lunch, work through lunch to leave earlier, I’d worry about the stuff I had to do and then be here later, give breaks and not lunchtime meetings, lunch meetings are my pet peeve, breaks are precious, have a cancellation is like Christmas coming early</td>
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<td>Communication</td>
<td></td>
<td>Frustration with the lack of communication from supervisors and administration when making changes that impact participants and the treatment provided to survivors. Participants also expressed frustration when supervisors did not communicate in a timely manner the need for additional administrative tasks to be completed. Ex: changes with no communication difficult, communication getting lost, don’t know the result, I wish I knew more about what’s going on, if I’d known earlier, information about changes, don’t always know what’s going on, if I understood I could help, more apt to do it if I understood, not being told by manager, should have been part of that conversation, communication is the key, decisions being made that had effect down in the trenches</td>
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<td>Time</td>
<td></td>
<td>The lack of time available to perform non-clinical job responsibilities, such as documentation, scheduling, and follow-up phone calls. The impact of productivity requirements. Due to consecutive scheduling of clients, participants may be unable to go to the restroom, eat, or drink throughout their work day Ex: have to be here late, planning eats up a lot of your potential free time, breaking point of having so much going on, coming in early and leaving late to get stuff done, don’t have time to think, don’t have time to mingle with coworkers, not enough time in day, haven’t had time to go to bathroom</td>
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## Appendix E. CITI Training

### Initial Certification

**COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI)**

**HUMAN RESEARCH CURRICULUM COMPLETION REPORT**

Printed on 08/16/2014

**LEARNER**
Gillian Murray (ID: 2743543)

**DEPARTMENT**
Moss Rehab Research Institute

**PHONE**
215-456-9901 x69043

**EMAIL**
murraygi@einstein.edu

**INSTITUTION**
Albert Einstein Healthcare Network - Philadelphia

**EXPIRATION DATE**
03/25/2014

**HUMAN RESEARCH PROTECTION COURSE**
Any Human Subject Research conducted within Albert Einstein Healthcare Network Philadelphia regardless of funding source.

**COURSE/STAGE**
Initial/1

**PASSED ON**
03/25/2012

**REFERENCE ID**
7590523

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<td>Research and HIPAA Privacy Protections</td>
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<td>Vulnerable Subjects - Research Involving Workers/Employees</td>
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For this Completion Report to be valid, the learner listed above must be affiliated with a CITI Program participating institution or be a paid Independent Learner. Falsified information and unauthorized use of the CITI Program course site is unethical, and may be considered research misconduct by your institution.

Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Program Course Coordinator
CITI Training Renewal 2014

COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI)
HUMAN RESEARCH CURRICULUM COMPLETION REPORT
Printed on 08/16/2014

LEARNER: Gillian Murray (ID: 2743543)
DEPARTMENT: Moss Rehab Research Institute
PHONE: 215 456 9901 x69043
EMAIL: murraygi@einstein.edu
INSTITUTION: Albert Einstein Healthcare Network - Philadelphia
EXPIRATION DATE: 02/04/2016

HUMAN RESEARCH PROTECTION COURSE: Any Human Subject Research conducted within Albert Einstein Healthcare Network Philadelphia regardless of funding source.

COURSE/STAGE: Refresher Course/2
PASSED ON: 02/04/2014
REFERENCE ID: 12273569

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Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Program Course Coordinator
CITI Training Renewal 2015

COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)
COURSEWORK REQUIREMENTS REPORT*

* NOTE: Scores on this Requirements Report reflect quiz completions at the time all requirements for the course were met. See list below for details. See separate Transcript Report for more recent quiz scores, including those on optional (supplemental) course elements.

- Name: Gillian Murray (ID: 2743543)
- Email: murrayg@einstein.edu
- Institution Affiliation: Albert Einstein Healthcare Network - Philadelphia (ID: 821)
- Institution Unit: Moss Rehab Research Institute
- Phone: 215-456-9901 x69043

- Curriculum Group: Human Research
- Course Learner Group: Human Research Protection Course
- Stage: Stage 3 - Refresher Course
- Description: Any Human Subject Research conducted within Albert Einstein Healthcare Network Philadelphia regardless of funding source.

- Report ID: 18172138
- Completion Date: 12/20/2015
- Expiration Date: 12/19/2017
- Minimum Passing: 80
- Reported Score*: 97

**REQUIRED AND ELECTIVE MODULES ONLY**

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For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

CITI Program
Email: citisupport@miami.edu
Phone: 305-243-7510
Web: https://www.citiprogram.org
Appendix F. Recruitment Flyer

Research Study
University of Pennsylvania
School of Social Work Policy & Practice
3701 Locust Walk, Philadelphia, PA 19104-6214

This study conducts interviews with brain injury professionals to explore what about brain injury rehabilitation is difficult, why brain injury professionals are at risk for work-related stress and burnout, and what would be helpful to reduce this risk.

Who is Eligible?
- Brain injury rehabilitation professionals such as social workers, case managers, brain injury therapists, vocational rehabilitation therapists/counselors, and neuropsychologists
- Provide direct clinical care to individuals with traumatic brain injury or acquired brain injury
- Have at least two years of experience and are currently working in an outpatient community based rehabilitation program
- Have at least a Bachelor’s Degree in a Human Services field, such as social work, psychology, nursing, disability services, vocational rehabilitation, recreational therapy, health care administration, rehabilitation counseling, education, or counseling

What will you be asked to do?
- Participate in an interview for approximately 1-2 hours

Compensation
- You will receive a gift card for your participation in the study.

If you have any questions or are interested in participating in this study, please contact:

Gillian Murray, MSW, LSW, CBIS at (516) 503-2035
or Email: murraygi@sp2.upenn.edu
Appendix G. Article Published in ACBIS Newsletter

Work-Related Stress in Brain Injury Professionals

Treatment after brain injury involves management of physical, cognitive, emotional, and behavioral symptoms. In addition, mood disorders, depression, and substance abuse after brain injury further complicate treatment interventions and outcomes. Recovery is difficult for individuals with brain injuries, their families, and rehabilitation professionals. The recovery process is long and providers typically have limited time to provide needed care and to accomplish rehabilitation goals due to limited funding sources.

Work-related stress is a concern for brain injury professionals: several research studies concluded the daily stress and emotional exhaustion experienced by brain injury rehabilitation professionals leads to burnout. Saban et al. (2013) conducted a study in 2013 investigating burnout in healthcare professionals treating Veterans with TBI and discussed that “the intense emotional and demanding work of caring for those with TBI can also take its toll on professional healthcare providers” (p. 307-308). It was concluded that there are higher levels of emotional exhaustion experienced by those workers who spent more than 50% of their time treating TBI as compared to workers who spent less than 50% of their time treating TBI (Saban et al., 2013). In a study conducted by Mooney et al. (2009), providers of community based rehabilitation to individuals with TBI reported frequent home visits, increased hours spent driving to client homes, and working in an isolated setting as risks for stress and burnout.

Although it is known that the daily stress and emotional exhaustion experienced by brain injury rehabilitation professionals leads to an increased risk for burnout, there have been very few studies researching this issue. There has not been any research conducted to investigate what brain injury rehabilitation professionals would find helpful and effective in decreasing work-
related stress. The need for further knowledge about the impact of staff burnout on brain injury rehabilitation professionals leads to the need for further research on this topic.

Brain injury rehabilitation professionals are currently being recruited for a research study investigating what about brain injury rehabilitation is difficult, why brain injury professionals are at risk for work-related stress, and what would be helpful to reduce this risk. Brain injury professionals are eligible to participate should the following criteria be met: (1) have at least two years of experience working in an outpatient community based brain injury rehabilitation setting; (2) provide direct clinical care to individuals with traumatic brain injury (TBI) or acquired brain injury (ABI); (3) possess at least a Bachelors Degree in Psychology, Social Work, Disability Services, Vocational Rehabilitation, Nursing, or Counseling; and (4) be a Certified Brain Injury Specialist or Therapist through the Academy of Certified Brain Injury Specialists.

Participants will be interviewed and asked questions about what makes working in brain injury rehabilitation difficult, what is stressful about working in the brain injury rehabilitation field, and what would be helpful to reduce this risk. Interviews will last approximately one to two hours. Interviews will be recorded and all information discussed and audio recordings will be strictly confidential. Participants will receive a small gift as compensation for their time.

It is hoped that this research will lead to a better understanding of what about working in the brain injury rehabilitation field is difficult, why brain injury rehabilitation professionals are at risk for work-related stress, and what recommendations can be made to brain injury rehabilitation professionals and brain injury rehabilitation providers to reduce this risk. It is also hoped that a more apt term to operationalize the work-related stress experienced by brain injury professionals will emerge and be identified. If you have questions about this study, or are
interested in participating, please contact Gillian Murray, MSW, LSW, CBIS at murraygi@sp2.upenn.edu.

References