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HOW THE ILLNESS EXPERIENCE PREDICTS KEY PSYCHOSOCIAL OUTCOMES IN VETERANS WITH BRAIN INJURY

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We hereby approve this thesis

For

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for the Department of

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And

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_____May 5, 2017______
Student's Date of Defense

Dedicated to all the veterans of United States armed forces who have sustained brain injuries. Thank you for your service.

Acknowledgement

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HOW THE ILLNESS EXPERIENCE PREDICTS KEY PSYCHOSOCIAL OUTCOMES IN VETERANS WITH BRAIN INJURY

CARMEN M. TYLER

ABSTRACT

The object of this thesis was to examine the illness experience of veterans who have suffered either a stroke or traumatic brain injury. Predictors of key psychosocial outcomes were identified by looking at the illness experience through the veterans' perspective via self-report measures. Results confirmed relationships between the stressors role captivity, low self-esteem, decreased socialization, and dyad relationship strain and the outcome of depression and between the stressors physical strain and emotional strain and the outcome social/recreational participation for this population. More importantly, role captivity, social/recreational strain, and self-esteem uniquely predicted depression, and both physical and emotional strain uniquely predicted social/recreational strain in veterans with brain injury. Not only has this study demonstrated how the illness experience predicts key psychosocial outcomes in VBIs, it has also illustrated that self-reports from VBIs are reliable and valid indicators of their illness experiences and should be seriously considered when constructing treatment goals and plans.

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CHAPTER I

INTRODUCTION

Over 2,000,000 Americans will suffer a brain injury—“an insult to the brain which causes damage” (Brain Injury Alliance New Jersey, 2015)—this year (Aarabi & Simard, 2009; Ghajar, 2000; Go et al., 2014). Brain damage may be caused by an external force like a fall, a blast, or a blow to the head, as in the case of traumatic brain injuries, or it may occur internally as in the case of strokes (Brain Injury Association, 2011). Traumatic brain injuries (TBIs) are the leading cause of death and disability in young people (Ghajar, 2000), and stroke is the third most common cause of death in the U.S. and a leading cause of disability both in this country and worldwide (Perrin, Heesacker, Stidham, Rittman, & Gonzalez-Rothi, 2008; Foulkes, Wolf, Price, Mohr, & Hier, 1988). For the purpose of this paper, stroke and traumatic brain injury will be collectively referred to as brain injury.

Veterans, Stroke, and Traumatic Brain Injury

Unfortunately, brain injuries are something that both our younger and older veterans have in common. The number of brain injuries sustained by the general population of the United States per year is quite high, but our servicemen and women and veterans have been especially susceptible to suffering these injuries (Wiederhold, 2011). Many older veterans are facing the debilitating repercussions of strokes, and numerous younger veterans have sustained traumatic brain injuries as a result of their service in the Middle East. After age 55, stroke risk doubles each decade (Stroke Association, 2012), and as our Vietnam-era veterans have now reached older adulthood, the number of veterans admitted to Veterans Administration (VA) facilities for first-time ischemic strokes has reached approximately 6,000 per year (VA Office of Research and Development, 2014). Improvised explosive devices (IEDs) and traditional munitions used in the recent Middle Eastern conflicts have caused traumatic brain injuries in many of our military members. From Operation Iraqi Freedom alone, as many as 320,000 military servicemen and veterans may have traumatic brain injuries (Aarabi & Simard, 2009). Both stroke and TBI may have devastating long-term effects, not only physiologically, but also psychosocially.

Although their etiologies may differ, both traumatic brain injury and stroke can cause massive insults to the brain and monumental aftereffects. The survivor must cope not only with the healing process from the physical damage to the brain itself but also with the repercussions of impairment of control mechanisms for various affected physiological, psychological, socioemotional, and cognitive functions. Depending on the part of the brain involved and the severity of the injury, sequelae can be momentary or lifelong and may affect a single or multiple domains. For example, survivors may experience effects ranging from a minutes-long period of disorientation to coma and/or transient difficulty with short-term memory and anterograde amnesia to long-term retrograde amnesia.

Not only are the objective consequences of brain injury highly individualized, the subjective perceptions and appraisals of their meaning are also unique to the individual. Characteristics such as age, race, and health history as well as each veteran’s personal resources and the content of care they are receiving from their family and friends provide a context in which the veteran with a brain injury (VBI) constructs his/her appraisals and perceptions of what occurs during the course of the illness (Pierret, 2003). These variations may potentially result in more or less effective methods of managing and coping with their brain injury. For instance, veterans who experience a brain injury while in their twenties may feel a different degree of social/recreational role strain than veterans whose brain injury occurs while they are in their eighties because of differing expectations.

The Illness Experience

The "illness experience" here encompasses the cumulative effects of a brain injury from the subjective perspective of the person who is living with and managing their symptoms. It is more than the physical injury itself. The illness experience includes how people think of and feel about their illness, themselves, and their relationships (Pierret, 2003) as they recognize and cope with the changes that come with a brain injury. The illness experience incorporates the altered physiological, psychological, and social functions brought about by the brain injury and also the VBI's appraisals of what these alterations mean for them. Perceptions that are built from the veteran's own personal characteristics and experiences combine with family, medical, and social expectations to add up to what constitutes that individual's illness experience.

Although the course of the illness caused by a brain injury may be roughly estimated by medical experts, what each individual brings to the experience is unique, with a great amount of inter-individual variation. For example, experiencing a stroke at a young age may have different physical, social, and emotional implications and results than experiencing a stroke at an older age, such as returning to the workforce or caring for children. Relatively few studies have examined the illness experience of stroke or TBI from the viewpoint of the individual who has sustained the injury.

Instead, most of what we know about the aftereffects of stroke and TBI comes from the observations of formal and informal care providers. However, proxy reports may not be as accurate as first-hand accounts due to their under- and over-estimations of the abilities of the VBI (Williams & Dahl, 2002).

Additionally, the illness experiences of veterans may be more complex because of polytrauma (serious damage sustained to more than one body part or organ at the same time (“What is polytrauma?” 2015)) or other comorbidities associated with military service. In fact, Risdall and Menon (2011) called post-concussive symptoms, post-traumatic stress disorder, and chronic pain the “polytrauma clinical triad” which often accompanies traumatic brain injuries.

Some studies have looked at the illness experience in general, but most are concerned with broader societal, cultural, or public health implications. While the value of studying these macro-level effects cannot be denied, they shed no light on how the illness experience affects the individual. Even those studies which have examined the illness experience on an individual level have typically examined only one specific illness such as cancer, arthritis, or heart disease, so their findings may or may not be generalizable to brain injuries such as stroke and TBI (Pierret, 2003; Thorne, et al., 2002).

An example of what may be discovered by examining the illness experience of individuals is the national (Ireland) survey of stroke survivors and the systematic literature review done by Walsh, Galvin, Macey, McCormack, and Horgan (2013). They identified four major obstacles to recovery for stroke patients in the first year post-stroke. The first set of obstacles are the primary effects of the stroke, like cognitive, functional, behavioral, and physical changes. The second group of obstacles are social changes, such as being unable to fulfill previously held roles. The third obstacle comprises personal factors, such as feeling dependent. The fourth obstacle includes relationship dynamics with professionals involved in their treatment, perhaps manifesting as feelings of not being in control or loss of status.

Walsh et al. (2013) found that stroke survivors cited physical deficits caused by the stroke as the most significant factors keeping them from reintegration into the workplace and community (e.g., 50% of their 196 participants needed help with personal care, ~66% required assistance with household tasks, and 83% had mobility problems), but emotional strains were also highly problematic (77% reported emotional problems), particularly perceived stigmatization. Survey respondents also noted that being dependent and requiring assistance had brought about troubling changes in their personal relationships (42% said their relationships were affected by the stroke). Likewise, Rachpukdee, Howteerakul, Suwannapong, and Tang-aroonsin (2012) found that predictors of poor quality of life post-stroke included being dependent, having severe cognitive impairment, being single, and being unemployed.

These findings demonstrate that it is not purely primary effects of a brain injury that are important in the illness experience of individuals, nor is it necessarily a single factor, whether it be physiological, psychological, social, or emotional, which leads to negative outcomes from a brain injury. Rather, it is likely a combination of factors that may hinder recovery. For example, it may not be only a primary effect of the brain injury such as a physical decrement by itself that is responsible for a negative psychosocial outcome like depression. Instead, it may only be that when that stressful primary effect is combined with the VBI’s assessment of the situation that the negative psychosocial outcome occurs.

Examining how individuals cope and manage with the aftereffects of a brain injury along with discovering key variables that may alter these relationships, such as role captivity (a feeling of being trapped in a position not of one’s own choosing), may facilitate our comprehension of individuals’ illness experiences. Additionally, understanding how individuals with brain injury experience their illness may serve to inform development of intervention protocols that address the negative psychosocial implications of living with a brain injury. One under-utilized, but potentially key, method for examining these issues is the inclusion of first-hand input from brain-injured survivors. Traditionally, treatment of brain injuries has been accomplished by using a general medical model, but as person-centered care continues to develop (Verbrugge & Jette, 1994), care plan input has included more people who are closer to the survivor and the individuals themselves (Barry & Edgman-Levitan, 2012).

Including individuals with brain injury in the research process, rather than obtaining data via proxy measures, may provide a more accurate and valid assessment of their illness experience. By examining the illness experience from the perspective of the individual we may be able to better understand how their brain injury impacts a wide range of psychosocial issues and how best to intervene on their behalf. The current study examined the illness experience of brain-injured veterans using the Stress Process Model for Veterans with Brain Injuries, based on the Stress Process Model for Individuals with Dementia (Judge, Menne, & Whitlatch, 2010), as a framework and guide.

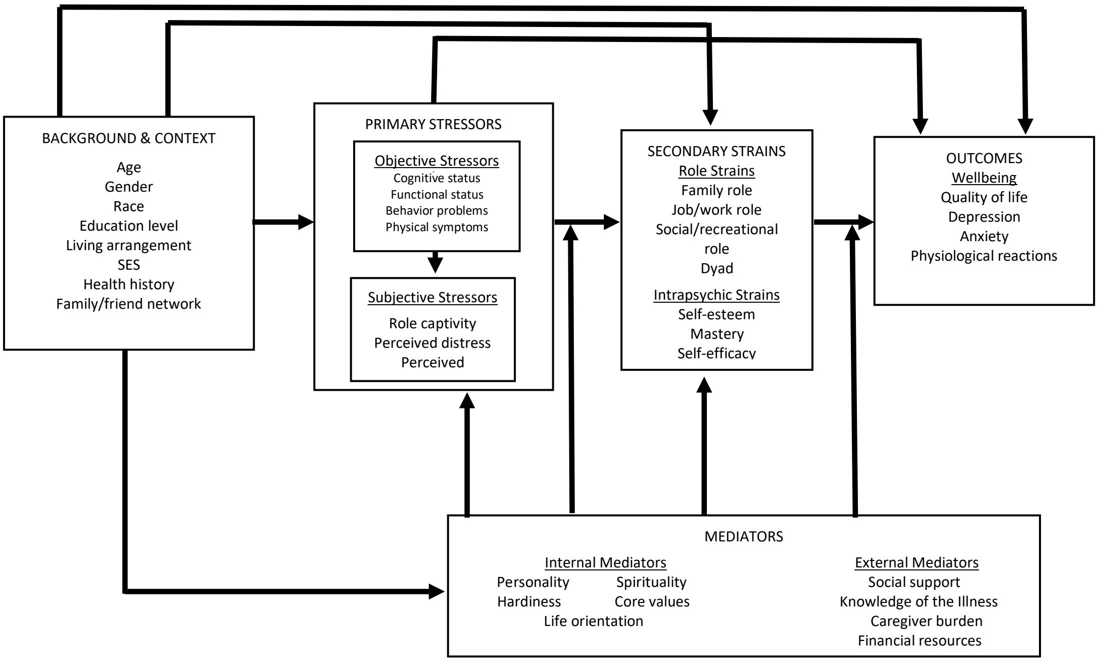

Figure 1. Stress Process Model for Veterans with Brain Injuries—based on the Stress Process Model for Individuals with Dementia (Judge et al., 2010).

The Stress Process Model as a Theoretical Framework

As noted above, the illness experience of a person with a brain injury can be quite complex, with influences from demographic characteristics, objective symptoms, and subjective appraisals. Few studies have examined the experience of stroke and TBI from the survivor's perspective, and even fewer have used a theoretical model as a framework for examining psychosocial outcomes for veterans with brain injuries. In order to examine the illness experience of brain injured individuals it is important to have a conceptual model that represents both the objective and subjective aspects of their experience.

For this purpose, this study employed the Stress Process Model for Veterans with Brain Injuries as a model to explore the illness experience of VBIs. This model served as a guide for examination of the relationships between stressors, strains, or other factors which may contribute to psychosocial outcomes and highlighted areas amenable to intervention.

The domains (Background and Context, Stressors, Strains, Mediators, and Outcomes) of the SPM for VBIs, like the Judge et al. model (2010), are interrelated, and their relationships demonstrate linear processes by which an individual experiences the stressors of a chronic health condition. The SPM was adopted for use because it represents how the sudden involuntary changes that come about with stroke and TBI are not static but fluid and progressive (in that one characteristic or stressor may directly or indirectly influence the development of a secondary stressor or outcome). It should also be noted that the terms “primary” and “secondary” do not describe ranks of importance but depict the sequence of appearance in the illness experience.

Using the SPM for VBIs and based on the literature to date, the next section will discuss in further detail the domains and constructs of the SPM for VBIs pertinent to this study as they relate to the illness experience: background and context; primary subjective stressors such as role captivity and perceived distress; secondary strains comprising social/recreational and dyad relationship roles and self-esteem; and the outcome of depression.

Background and context. The background and context domain is made up of the individual’s traits and environmental factors which are not likely to change as a result of the brain injury. It includes personal characteristics such as gender, age, and race and also includes pertinent personal historical factors like education level, socioeconomic status, and health history. Background and context attributes may be important influences in the stress process in any or every subsequent domain and were used as covariates in this study.

Primary stressors. The primary stressors are the basic symptoms or lasting effects of the brain injury most closely tied to the neurologic insult and the appraisals of the individual regarding these symptoms and effects. Primary stressors affect outcomes directly and indirectly through secondary strains and their mediators. These primary stressors are divided into two categories, primary objective stressors and primary subjective stressors, but for the purposes of this study only two primary subjective stressors were examined.

Primary subjective stressors. Primary subjective stressors are those stressors which result from the individual's interpretation or appraisal of the significance of the impact of the primary objective stressors (i.e., cognitive, functional, behavioral, and physical stressors) in his/her life. Primary subjective stressors reflect an individual's perceived experience of the disability that results from their primary objective stressors. Examples include individuals feeling trapped, distressed, and/or dependent because of their brain injury. Individuals with the same primary objective stressors may appraise or perceive these objective stressors differently and subsequently experience different primary subjective stressors. For example, one person may feel overwhelmingly confined or captive in the role they have had thrust upon them by the brain injury while someone else experiencing the same primary objective stressor may feel distress or embarrassment regarding their condition.

Role captivity. Role captivity is a primary subjective stressor and reflects an individual's feeling of detachment and/or being trapped in a role forced upon them by the brain injury. Chamberlain (2006) found that individuals who had experienced a traumatic brain injury often felt unnoticed and trapped. Not only does the VBI have to reconcile himself/herself to new cognitive, emotional, and functional challenges, he/she must also determine how they feel about having someone (usually a family member) provide assistance for tasks which were previously performed independently.

There is very little in the literature regarding the illness experiences of individuals who suddenly find themselves in a position where they have lost abilities they once had and how they feel about and deal with the situation. This is certainly true with regard to the construct of role captivity per se. However, several research studies have described the defining components of role captivity in the context of brain injuries. These components included feelings of helplessness and loss of independence, loss of control (Hafsteinsdottir & Grypdonck, 1997), loss of confidence, loss of freedom, loss of abilities, and changed ways of interacting (Salter et al., 2008) as well as feelings of uselessness (Sisson, 1998).

One area where researchers have started exploring the illness experience from the perspective of the individual with the illness is dementia research. Like individuals with dementia, those with brain injuries may also experience changes such as feelings of role captivity and problems with self-esteem. In one such study regarding individuals with dementia, Dawson, Powers, Krestar, Yarry, and Judge (2012) found that individuals who experienced more feelings of role captivity had more symptoms of depression. These results highlight the link between role captivity and symptoms of depression in individuals with dementia. Research is needed to examine whether this relationship exists for survivors of brain injuries.

Research from caregivers may shed additional light on aspects of role captivity. Aneshensel, Pearlin, and Schuler (1993) found that for caregivers of Alzheimer patients, those most likely to develop a sense of role captivity were adult children caring for parents, Caucasians, or those caring for younger patients. They noted that contributing to feelings of role captivity were factors such as the amount of debility in doing everyday functions, decline in relationship, and behavioral problems. In Alspaugh, Stephens, Townsend, Zarit, and Greene's (1999) longitudinal study on stressors as predictors of depression in caregivers, they found that feelings of role captivity were important predictors of the risk of developing clinical depression over a one-year time span. Similarly, in their study of caregiver–care receiver relationships, Lawrence, Tennstedt, and Assman (1998) found that caregiver depression was predicted by caregivers' feelings of role captivity.

Both the dementia research and caregiver research have linked the feeling of role captivity with symptoms of depression. Since depression is such a common outcome for VBIs, possible connections between role captivity and depression were investigated in this study.

Perceived distress. Perceived distress is a primary subjective stressor and is the awareness of unpleasant emotions regarding some aspect of the illness experience. An important element includes the idea of appraisal—what the VBI thinks about the illness experience and the belief he/she constructs about it (whether consciously or unconsciously).

Regret and grief about feeling a loss of control or independence are common for individuals with brain injuries (Salter, Hellings, Foley, & Teasell, 2008). VBIs may feel distressed about cognitive deficits such as memory loss or about how long and how well rehabilitation and recovery are going (Chamberlain, 2006; Sisson, 1998). Other commonly reported distressing emotions are grouchiness (Williams & Dahl, 2002; Williams & Evans, 2003), irritability (Sisson, 1998), fear (Hafsteinsdottir & Grypdonck, 1997; Khan, Bagueley, & Cameron, 2003), frustration (O'Connell et al., 2001; Salter et al., 2008; Sisson, 1998), anger (Khan et al., 2003; Salter et al., 2008; Sisson, 1998), and apathy (Salmond et al., 2006).

Many VBIs also struggle with trying to make sense of feelings of shame, loss of status, and stigma (Pierret, 2003). TBI survivors report feeling stigmatized (Lefebvre, Cloutier, & Levert, 2008) and believe that others view them as powerless, developmentally disabled, or mentally ill (Nochi, 1998). Stroke survivors also report feeling easily frustrated and irritated and slow at thinking or acting and afraid they will not be able to return to activities they once enjoyed (Sisson, 1998). In fact, Salmond et al. (2006) found that 80% of subarachnoid hemorrhage survivors experience irritability, apathy, and depression.

By interpreting and appraising changes in cognitive, functional, behavioral, or physical status in terms of prior abilities, brain-injured individuals may feel regret and grief (Chamberlain, 2006). Some survivors have found that not only are emotional problems bothersome throughout the first year post injury, but they actually may increase over time (Godwin et al., 2013; Williams & Evans, 2003). Ownsworth et al. (2011) found that physical and cognitive deficits caused by traumatic brain injuries contribute to development of depression because of perceptions of functional deficits when the survivor attempts to reengage in their former lifestyle. The importance of perception regarding the overall influence of an illness was also demonstrated in Stuitbergen, Phillips, Voelmeck, and Browder’s (2006) study of a group of women with fibromyalgia. They found that better physical health scores were associated with those who deemed the fibromyalgia symptoms to be more controllable, and better mental health scores were associated with those who had less emotional distress regarding the illness.

If VBIs make negative appraisals about their condition, they may also be setting themselves up for secondary strains and adverse rehabilitation and functional outcomes (Williams & Dahl, 2002; Williams & Evans, 2003; Sisson, 1998).

Perceived distress could contribute to secondary strains or influence outcomes of wellbeing. For instance, if a veteran has functional changes (primary objective stressor) about which he/she feels distress (e.g., being dismissed by others) or embarrassment (e.g., feeling misunderstood) (primary subjective stressors), it may cause him/her to disengage from social roles (secondary role strain) (Murray & Harrison, 2004) he/she held pre-injury. They may believe that they would be a burden on others so they decrease social participation (Salter et al., 2008). It is important to understand how the role of perceived distress impacts the illness experience of VBIs.

Secondary strains. Secondary strains stem from the cumulative effect of the primary objective and subjective stressors and are divided into role strains and intrapsychic strains. As illustrated by the SPM for VBIs, secondary strains can directly impact well-being outcomes and can be impacted by mediators.

Role strains. Role strains reflect the impact or changes in an individual's life roles due to their brain injury. Roles include the wide range of positions we assume in our daily lives, such as family, work, leisure, and social roles. The role of receiving care due to the brain injury is also included since the original dynamics between individuals may change when they take on the role of care provider or care receiver. These role changes necessitated because of a sudden inability to drive, work, participate in childcare activities, or function independently may be considerable, long-lasting, and very disruptive. It is also important to note that role strains may come about because of the influence of subjective stressors as well.

Social/recreational role. Social/recreational role strain is a secondary role strain and is the protracted post-injury stress that comes about as a result of the inability of the VBI to take part in activities or events (non-work) that involve people and places outside the family and home as he/she did pre-injury. This change in roles may be because of cognitive, functional, behavioral, or physical ramifications of the brain injury or from reluctance to participate because of perceived distress such as embarrassment or emotional or physical unease.

Reduced social participation is problematic because research has shown that physical recovery and overall quality of life is better with continued engagement in social roles (Rachpukdee et al., 2012; Salter et al., 2008). Reduction in social participation may be by personal choice or as a function of the environment. For example, divorce or separation contributes to the collapse of the VBI’s social network and goes a long way toward keeping the veteran socially isolated (Lefebvre et al., 2008).

Even with a social network in place, some VBIs choose to self-isolate. There are potentially many reasons for this. Some feel that they do not want to be a burden on others (Salter et al., 2008). Some veterans may be aware of distressing or embarrassing changes in themselves in impulsivity, self-centeredness, disinhibition, social skills, apathy (Khan et al., 2003) and speed (Nochi, 1998), and they may then constrain their social participation to include only those within the immediate social circle. On the other hand, if the veteran has experienced changes in behavior that he/she is unaware of, this may result in puzzlement and frustration because of people’s reactions, and the VBI may subsequently avoid social involvement. Other brain injury survivors feel isolated because they have a hard time explaining how they feel post-stroke (Salter et al., 2008). But by self-limiting engagement in social activities, VBIs may be limiting their social network and potential sources of support.

Many survivors of brain injury cite yet other reasons for narrowing social roles and interactions, such as primary effects from the injury which impair their motivation or ability to be with others. Examples are feeling weak or fatigued, having trouble communicating or concentrating, loss of interest in previously enjoyed activities, fear of others' reactions to them, and decreased access or opportunities to participate in social activities (Khan et al., 2003; Walsh et al., 2013).

Whatever the reason, social/recreational role changes are widespread among brain-injured individuals (Hafsteinsdottir & Grypdonck, 1997). One study found that in the first year after stroke, survivors had less social participation (Godwin et al., 2013), and in the Walsh et al. (2013) study, over 60% of stroke survivors said their leisure activity engagement had changed. Although physical symptoms, functional limitations, and cognitive debilities may make involvement in group activities more difficult (Walsh et al., 2013), it is important that survivors re-engage and become socially integrated. In a study with survivors of TBI, rates of post-TBI depression were significantly inversely related to sense of belonging (Bay, Hagerty, Williams, Kirsch, & Gillespie, 2002). Likewise, in a three-year follow-up study of individuals who had suffered a stroke, researchers found that although rates of depression varied over time, being socially isolated (living alone or having few non-family contacts) was a key determinant in developing depression. In fact, if survivors were depressed one year or later post stroke, deficiency in the number of their social contacts became the most important predictor of developing depression (Astrom, Adolfsson, & Asplund, 1993).

Dyad relationship role. Dyad relationship role strain is a secondary role strain and is the prolonged stress in the caregiver–care receiver partnership brought about as a result of the brain injury. In addition to the veteran who has experienced the brain injury, caregivers, most often family members, have also been thrust into new caregiving roles and may experience varying degrees of difficulty adapting to and coping with these changes.

There is little in the existing literature regarding the effects of dyadic relationship role strains on the brain injury survivor. However, the caregiving literature has several studies which look at the relationship between partners in the caregiving dyad, so we may glean some understanding from looking at these studies and note avenues for future research regarding the care receiver.

One example of dyadic relationship strain can be found when caregivers and care receivers disagree about level of care needed and provided. For example, in the Lyons, Zarit, Sayer, and Whitlatch (2002) study (exploring caregiving across many illness/conditional domains), they found that caregivers felt they received less support and cooperation and had more difficulties with caregiving than the care receivers did. What is more, they found that the more difficult the caregiving situation, the more the caregivers and care receivers differed in their appraisals of caregiving need and provision.

Perceptions of relationship quality are also very important when looking at dyad relationship role strains. Yates, Tennstedt, and Chang (1999) found that depression was significantly linked to caregiver–care receiver relationship quality. They found that caregivers who judged their relationship with the care receiver to be of poor quality had higher rates of depression. Adams, McClendon, and Smyth (2008) had similar results in their study, with worse relationship quality being linked to a higher risk of developing depression. The greater the perceived caregiver relationship strain, the more difficult the caregiving situation became, so caregiving difficulty and appraisal incongruity between care partners were both significantly predicted by caregiver relationship strain. Therefore it is not surprising that Lyons et al. (2002) were able to link not only caregiver depression but poor general health to relationship strain. The importance of relationship quality was also found to be consistent over time in the Archbold, Stewart, Greenlick, and Harvath (1990) study. They interviewed caregivers at six weeks post care receiver hospital discharge and at nine months post discharge and found at both time periods that the dyad relationship quality predicted caregiver role strain.

As much of the caregiving done for brain-injured survivors is done by family members, it is important to look specifically at relationship dynamics between family care partners as well. Family members are usually unprepared for the extent to which cognitive, emotional, and behavioral changes occur in their loved one (Sisson, 1998). A study which specifically looked at the quality of the family caregiver–care receiver relationship and its effects found that relationship quality was a mediator between problem behaviors and role captivity and depression. The authors interpreted this to mean that the relationship suffers because problem behaviors increase feelings of role captivity and depression in the caregiver. They also found that higher quality relationships were significantly linked to lowered levels of depression (in the caregiver) (Lawrence, Tennstedt, & Assman, 1998).

In addition to the general strains of role changes within the family, those who are married may find themselves in a sudden transition from an intimate, mutual partnership to a caregiving/receiving situation where the caregiving spouse becomes more dominant (Radcliffe, Lowton, & Morgan, 2013). Spousal dyadic relationship changes may be further complicated by deficits in communication, physical functionality, and behavior changes that reduce intimacy and mutuality between spouses (Khan et al., 2003; Walsh et al., 2013; Williams & Dahl, 2002). In their survey of stroke survivors, Walsh et al. (2013) reported that 67% of stroke survivors felt their romantic relationship had been at least somewhat affected (42% said significantly) by their stroke. With both members of the dyad suddenly plunged into new roles as caregiver and care receiver while dealing with all the above changes, conflict within the dyad as adjustments are made should not be unexpected. If the brain-injured veteran's main caregiver is the spouse, this can result in increased tension in the dyadic relationship, as the subjective stressors being felt by the survivor may result in resentment, anger, and frustration toward the caregiving spouse. Positive correlations in stress have been found in spousal caregiving partners. Brain-injured survivors who appraised their relationship with their spouse as being good also had less stress (Ostwald, Turner, Bernal, Cron, & Godwin, 2009).

Research has shown that the relationship of the caregiver and care receiver is very pertinent in a caregiving situation, as the perception of the quality of the relationship affects both members of the care dyad. If there is strain in the relationship, the caregiver may feel role strain/burden/captivity and may develop depression. This in turn may affect the quality of care the caregiver is able to provide, thereby affecting the quality of life of the care receiver as well. Stress patterns within the dyad are also correlated. What is not known is how dyadic role strain affects the brain injury survivor and if patterns of psychosocial outcomes in the caregiver can also be applied to the care recipient.

Intrapsychic strains. Intrapsychic strains are defined as the personal characteristics, internal emotions, and internal appraisals of one's self that may change or be altered due to the brain injury or as a result of going through the post-injury illness experience. Examples of intrapsychic strains include insults to an individual's self-esteem, feelings of mastery (control), and self-efficacy.

Self-esteem. Self-esteem is a secondary intrapsychic strain and is the degree of satisfaction a person has in his self-worth after judging his competence against a previously constructed standard, gleaned from past experience and the feedback of important others (Guindon, 2002). As such, this construct may be subject to environmental influences and circumstances and therefore changeable depending on the individual's assessment at the time.

Studies of both stroke and TBI survivors found that low self-esteem is very common throughout the brain-injury illness experience, from as little as 72 hours post injury to up to six years post injury. (Hafsteinsdottir & Grypdonck, 1997; Khan et al., 2003). Survivors often find themselves overwhelmed by the sudden drastic changes brought about by the brain injury (O'Connell et al., 2001; Salter et al., 2008) like substantial changes in emotions (Murray & Harrison, 2004), personality, abilities, activities (O'Connell et al., 2001), roles, and social relationships (Khan et al., 2003). These changes may be due to appraisals (Williams & Dahl, 2002), lack of personal environmental control (Salter et al., 2008), and/or changes in their social interactions (Nochi, 1998). For example, Lefebvre et al. (2008) found that being unable to return to work reduces self-esteem. Physical and cognitive deficits (Murray & Harrison, 2004) could also be responsible for changes in their self-perception. While survivors sort out these issues, they are especially sensitive to how others perceive them and the labels people apply to them (Nochi, 1998). They report feeling useless (Sisson, 1998), misunderstood, and being labeled as abnormal. These changes in self-esteem, although resultant from the brain injury, are not commonly measured or documented, nor is the potential impact of these changes on other domains, such as depressive symptomology.

Although decreased self-esteem is pervasive in survivors of brain injuries, few studies have linked the many possible causes to important psychosocial outcomes like depression. This is in spite of the abundance of literature supporting the relationship between low self-esteem and depression in general.

Outcomes. Outcomes are the conditions which result from the influences and interactions of the constructs and characteristics included in the background and context, primary stressors, secondary strains, and mediators domains.

Wellbeing. The culmination of the stress process for veterans with brain injuries results in the well-being domain and includes psychological outcomes such as quality of life, depression, and anxiety, and physiological reactions such as hypertension or sleep disturbances (Judge et al., 2010). Wellbeing can be defined to include feelings of happiness, contentment, goal fulfillment, and engagement. But wellbeing encompasses more than just feeling good or satisfied. Wellbeing has been found to be important in overall health outcomes, with studies showing that positive wellbeing seems to be protective in the development of coronary artery disease, risk of stroke, and even mortality (Dockray & Steptoe, 2010). This study limited examination to the outcome of wellbeing depression.

Depression. Depression is a well-being outcome and is a condition of prolonged sadness, despondency, and dejection that is severe enough to impact daily function. It often includes feelings of apathy and hopelessness and affects the way a person feels, thinks, and behaves. It is frequently co-morbid with other medical conditions and is implicated in detrimental physical states such as high levels of inflammatory activity and cortisol, and in increasing the risk of developing diseases such as heart disease and diabetes. In older adults especially, depression has been linked to increased mortality risks (Young & Vitaliano, 2007). According to the *DSM-5* (2013), not only is developing depression subsequent to stressful life events (including illnesses that are long-lasting and cause disability such as brain injuries) known to be a common occurrence, almost all major disorders carry with them a risk of depression development (Depressive Disorders, 2013).

In the relatively few studies that have examined psychosocial outcomes of stroke and TBI, depression has been found to be one of the most common neurobehavioral changes reported (Hafsteinsdottir & Grypdonck,1997; Khan et al., 2003; Salmond et al., 2006). For TBI survivors, depressive symptomology increases with the level of injury severity (Satz et al., 1998) and with the realization of how functionality may be impacted (Ownsworth et al., 2011; Williams & Evans, 2003). Likewise, in stroke survivors, depression has been shown to increase over time. At one week post stroke, survivors reported feeling sad and depressed, especially concerned about the change in their mental state. At one month post stroke, survivors reported increased depression. At three months post stroke, individuals had increased depression, mostly about the amount of time needed for recovery. At six months post stroke, women had increased depression because they didn’t like who they had become (Sisson, 1998).

As noted above, depression in brain-injured veterans can be multifactorial and multidimensional in origin. Contributors to depression may include primary objective stressors such as physiological deficits caused directly by the brain injury (e.g., changes in neurotransmitter production and function) as well as primary subjective stressors such as realization/perception of cognitive and functional limitations (Williams & Evans, 2003) and the perceived captivity in the role of a brain-injury survivor. Those primary symptoms and subjective appraisals then influence the development of secondary strains such as lowered self-esteem and social participation, and role changes (Sisson, 1998; MacMillan, Hart, Martelli, & Zasler, 2002; Khan et al., 2003). The above secondary strains can then contribute to development of depression, an outcome of wellbeing (Adams, McClendon, & Smyth, 2008; Astrom, Adolfsson, & Asplund, 1993; Sowislo & Orth, 2013).

Hypotheses

Using the SPM for VBIs, this study examined the extent to which hypothesized constructs are significantly related to each other. Next, the study examined whether a set of hypothesized constructs significantly predicted selected study outcomes. As modeled in the SPM for VBIs, stresses and strains may follow a linear pattern (from the Background and Context domain to the Outcomes of Wellbeing domain) such that constructs in the earlier domains may contribute to the development of stressors and strains in any of the subsequent domains. Thus, study outcomes may include constructs other than those found in the Outcomes of Wellbeing domain. Therefore, this study not only examined factors contributing to the outcome of depression but also explored connections suggested by the literature between primary subjective stressor elements perceived distress and role captivity and the study outcome of social/recreational role strain.

H1: The primary subjective stressor role captivity will be significantly and positively correlated with symptoms of depression; VBIs who self-report more role captivity will have greater symptoms of depression.

H2: The secondary role strains social/recreational strain and dyad relationship strain will be significantly and positively correlated with symptoms of depression; VBIs who self-report more social/recreational strain and dyad relationship strain will have greater symptoms of depression.

H3: The secondary intrapsychic strain self-esteem will be significantly and negatively correlated with symptoms of depression; VBIs who self-report less self-esteem will have more symptoms of depression.

H4: Role captivity, social/recreational strain, dyad relationship strain, and self-esteem, as well as covariates age and spousal relationship, will be significant predictors of the psychosocial well-being outcome depression.

H5: The primary subjective stressors perceived distress and role captivity will be significantly and positively correlated with the study outcome of social/recreational role strain; VBIs who self-report more perceived distress and/or role captivity will experience more social/recreational strain.

H6: Perceived distress and role captivity, as well as covariates age and spousal relationship, will be significant predictors of the study outcome social/recreational strain.

CHAPTER II

METHOD

Analysis of self-report data collected from veterans with a diagnosis of stroke or traumatic brain injury regarding their perception of the illness experience was done to look specifically at how the illness experience predicted certain psychosocial outcomes. For the purposes of this study, secondary analysis was performed with baseline data collected from 61 veterans who participated in the larger ANSWERS-VA research project.

Participants

Veterans who were patients of either the Michael E. DeBakey Veterans Affairs Medical Center in Houston, Texas or the Richard L. Roudebush VA Medical Center in Indianapolis, Indiana and had a diagnosis of stroke (within the past three years) or traumatic brain injury (after 9/11/2001) and their caregivers were eligible for recruitment into the larger ANSWERS-VA study. Potential participants in ANSWERS-VA were found by search of the computerized patient record system (CPRS) via ICD-9 codes and by referral from specialty clinics within the above medical centers. Once potential participants were identified, they were approached either in person or by letter and invited to participate in the study.

Inclusion/exclusion criteria. VBIs must have been community-dwelling, had Mini-Mental State Examination (MMSE) scores of 4 or above, been over the age of

18, fluent in English, and able to hear and speak over a telephone. Stroke survivors must have experienced either a hemorrhagic (ICD-9 codes: 430, 431, 432.1, and 852.4) or ischemic (ICD-9 codes: 433.01, 433.11, 433.21, 433.31, 433.81, 433.91, 434.01, 434.11, 434.91, and 436) stroke (rather than a transient ischemic attack). Veterans with TBIs were identified by using ICD-9 codes: 800.xx, 801.xx, 802.xx, 804.xx, 850.xx-854.xx, 905.0, 907.0, 950.1-950.3, 959.01, 310.2, and V15.52. Lastly, VBIs could not be prisoners or under house arrest, have a terminal illness, a history of hospitalization due to alcohol or drug abuse, or a history of severe mental illness.

Procedure

As this study used data from the larger ANSWERS-VA intervention study, it focused only on Time 1 data collected from participating veterans and background information on those veterans obtained by chart abstraction. Following receipt of written informed consent by both partners of the caregiving dyad, trained research personnel reviewed the informed consent by phone and then conducted the baseline (Time 1) interview by telephone or in person. The Time 1 interview took approximately one hour to complete. After written informed consent was obtained, participants were mailed the appropriate study materials as well as a gift card.

Measures

Data for this study comprised Time 1 information collected via chart abstraction and telephone or in-person interviews after written informed consent was received. Trained interviewers collected data by filling out questionnaires with responses obtained through their interviews. In addition to demographic questionnaires and information collected via chart abstraction, the following measures were used: Relationship Strain, Emotional and Physical Strain (EPS), Social

Participation (SP), Self-esteem, and the Patient Health Questionnaire Depression Scale (PHQ-9).

As this study used data from the larger interdisciplinary ANSWERS-VA study, some of the measures are similar to those typically seen in the psychological literature (e.g., the measure for Self-esteem was the Rosenberg Self-esteem Scale (Rosenberg, 1965)), while others may be less familiar, like the PHQ-9 Depression Scale. However, these instruments are widely used and may be considered psychometrically comparable. For example, along with the Beck Depression Inventory-II (BDI-II) and the Hospital Anxiety and Depression Scale, the PHQ-9 has been recommended as an excellent measure of depression in primary care settings by the United Kingdom's National Health Service agency, the National Institute for Health and Care Excellence (NICE). Scores on the PHQ-9 and the Beck Depression Inventory (BDI) are highly correlated (r = 0.73) (Smarr & Keefer, 2011). Details regarding the instruments used in this study and their psychometric properties are given below.

The Relationship Strain questionnaire comprises 9 questions regarding the caregiver–veteran relationship (e.g., "I felt resentful toward him/her," "I felt angry toward him/her") which elucidate the concepts of dyad relationship strain and role captivity. Answers choices are: Strongly agree, Agree, Disagree, or Strongly disagree. As most care receivers and caregivers are related and are new to this caregiving relationship, it is important to measure how this adds or subtracts to the stress of the illness experience. This questionnaire was previously used with individuals with dementia and in this study was used to measure the secondary strain of dyad relationship role strain (six items with a Cronbach's alpha of .81) and the primary subjective stressor of perceived role captivity (three items with a Cronbach's alpha of

.64). Factor analysis showed all items loading at .40 or higher (Dawson, et al., 2012). As this measure was not previously used with a population of brain-injured veterans, reliability tests were again conducted. Dyad relationship strain had a Cronbach's alpha of .88 and role captivity had a Cronbach's alpha of .78.

The Social Participation questionnaire consists of six questions in which the brain-injured veteran rated his participation in activities such as attending church or going out to dinner after the brain injury as happening: More often, Same, Less often, Never did this. Responses to these questions measure how the veteran's social roles may have changed as a result of the brain injury. According to the SPM for VBIs, changes in social roles are an example of role strains that may develop secondarily (secondary strains) to the primary stressors of the brain injury. This construct is important because research has shown that low levels of participation in social activities is associated with increased health risks (Cornwell & Waite, 2009). This questionnaire was used to measure social participation/the secondary strain social/recreational role strain (so lower levels of participation indicate more social/recreational strain) and was adapted from the Bass, Noelker, and Rechlin (1996) questionnaire with factor loadings of .80 to .71 and a Cronbach's alpha of .85. However, Cronbach's alpha for this population measured .58, but with the elimination of the item "I had personal time to myself," reliability (alpha) increased to .66.

The EPS questionnaire consists of eight questions regarding the perceived distress of a brain injury and focuses on the following areas: general emotional (four questions) and physical (four questions) status post the brain injury (e.g., "I feel irritable more often," "I seemed to get sick more often"). Response choices are: Strongly agree, Agree, Disagree, and Strongly disagree. The EPS questionnaire was adapted from a caregiving study. Items had Cronbach's alphas ranging from .78 to .61

and factors loaded separately from other caregiving consequences at .40 or higher (Bass, et al., 1996; Judge, Yarry, Looman, & Bass, 2012). Reliability measures with this population yielded a Cronbach’s alpha of .84 when both emotional and physical items were taken together. When separated into emotional strain and physical strain, Cronbach’s alphas were each .77.

The Self-esteem questionnaire has 10 statements regarding self-esteem (e.g., “I have a number of good qualities,” “I feel useless sometimes”). The Self-esteem questionnaire is answered by choosing one of the following for each statement: Strongly agree, Agree, Disagree, Strongly disagree. This instrument was used to measure the secondary intrapsychic strain of self-esteem. Factor loadings were .40 or higher and alpha was in the .73 to .87 range (Judge et al., 2012). With this population of brain-injured veterans, alpha was .91.

The PHQ-9 questionnaire asks veterans to rate on a 0-3 scale (0=Not at all, 1=Several days, 2=More than half the days, 3=Nearly every day) how they often they have been bothered in the prior two weeks by the nine statements presented (e.g., “Poor appetite or overeating,” “Feeling down, depressed, or hopeless”). The PHQ-9 has shown that for scores ≥10 it has a sensitivity of 88% and specificity of 88% for major depressive disorder (Kroenke, Spitzer, & Williams, 2001). The PHQ-9 questionnaire was used to measure the outcome of wellbeing of depression for this study, and for this population alpha was .83.

CHAPTER III

RESULTS

Data Analysis

Correlation coefficients were used to evaluate hypotheses 1, 2, and 3, which examined the relationships between each of the following variables and depression: role captivity, social/recreational role strain, dyad relationship role strain, and self-esteem. Correlation was also used to examine hypothesis 5—how perceived distress and role captivity were related to social/recreational role strain.

Multiple linear regression was used to examine hypothesis 4 to understand the unique contribution of each of the model's variables on development of depression. Multiple linear regression was also used to examine hypothesis 6 regarding the development of social/recreational role strains in VBIs. For each of the multiple regression equations, the background and context variables age and spousal relationship were included as covariates (hypotheses 4 and 6).

Depression

Hypotheses 1, 2, 3, and 5 were examined using Pearson product-moment correlations. Hypotheses 4 and 6 were examined using multiple regression. For hypothesis 1, a significant positive correlation between role captivity and depression was found ($r = 0.46$, $p < .01$), indicating that more role captivity experienced by the VBI was related to more symptoms of depression experienced.

Partial support for hypothesis 2 was found. A non-significant relationship between social/recreational strain and symptoms of depression was found ($r = -0.19$, $p = 0.13$), whereas a significant positive relationship was found between dyad relationship strain and depression ($r = 0.58$, $p < 0.01$). Results indicated greater dyad relationship strain was related to more symptoms of depression experienced by VBIs.

Support for hypothesis 3 was found with a significant negative correlation between self-esteem and depression ($r = -0.61$, $p < 0.001$), indicating less self-esteem reported by VBIs was related to more depressive symptoms experienced.

For hypothesis 4, multiple regression analysis examined the unique predictive contribution to the dependent variable depression of each of the following independent variables: role captivity, social/recreational strain, dyad relationship strain, and self-esteem. Age and spousal relationship were included in the analysis as covariates. Overall, the model significantly predicted depression ($F(6, 52)=18.35$, $p < 0.01$), accounting for 64% of the total variance in depression.

Table 1

Regression Predicting Psychosocial Outcomes Depression and Social/Recreational Strain

SPM Construct	Depression		Social/Recreational Strain	
Variables	β	Significance	β	Significance
Background and Context				
Age	-.406	<.001	-.072	.618
Relationship status	.142	.097	.110	.418
Primary Subjective Stressors				
Role captivity	.254	.012	-.024	.871
Perceived distress (aggregate)			-.290	.060
Perceived distress Physical strain			-.729	<.001
Perceived distress Emotional strain			.453	.024
Secondary Role Strains				
Social/recreational participation	-.182	.032		
Dyad relationship strain	.191	.122		
Secondary Intrapsychic Strains				
Self-Esteem	-.259	.029		

Results found that self-esteem ($\beta = -0.26$, $p = 0.03$), role captivity ($\beta = 0.25$, $p = 0.01$), social/recreational strain ($\beta = -0.18$, $p = 0.03$), and covariate age ($\beta = -0.41$, $p < 0.01$) were unique and significant predictors of the outcome depression. These results indicate that younger VBIs with lower self-esteem, VBIs with greater role captivity, and VBIs with more social/recreational strain experienced more symptoms of depression.

Social/Recreational Role Strain

Support was not found for hypothesis 5, indicating a non-significant relationship between perceived distress and social/recreational strain ($r = -0.23$, $p = 0.07$) and a non-significant relationship between role captivity and social/recreational strain ($r = -0.14$, $p = 0.28$).

For hypothesis 6, multiple regression analysis was used to examine the unique contributions of the independent variables perceived distress and role captivity to the dependent variable social/recreational strain. The covariates age and spousal relationship also were included. Non-significant results were found for the model ($F(4, 54) = 1.34$, $p = 0.27$), indicating perceived distress and role captivity did not account for significant variance in depressive symptomology.

Exploratory Analysis

When the Pearson Correlation was run to test the correlation of perceived distress and role captivity with social/recreational role strain (hypothesis 5), it was found that neither role captivity nor perceived distress was significantly correlated with social/recreational role strain. However, the correlation between perceived distress and social/recreational role strain approached significance ($p = 0.07$) and in the regression model perceived distress predicted social/recreational role strain at a significance level of $p = 0.06$.

The instrument used to measure perceived distress, Emotional and Physical Strain, factored well into its two components in dementia and caregiving literature (e.g., Bass et al., 1996; Dawson et al., 2012), but since both emotional strain and physical strain contribute to perceived distress, the measure was initially used as a total unit for this study. With emotional and physical strain combined, the instrument has good reliability (Cronbach's alpha of 0.84), but when used separately they have also demonstrated good reliability (alphas of 0.77 each). With the analysis results and documentation in the literature for dividing the measure into its component parts in mind, the decision was made to perform additional analyses with the components separated to see if more precision could be obtained in the analysis.

Physical strain was significantly negatively correlated with social/recreational strain at $r = -0.37$, $p < 0.01$, indicating that as physical strain decreased, social/recreational strain (measured by social participation) decreased. The regression model with independent variables emotional strain, physical strain, role captivity, relationship status, and covariate age significantly predicted social/recreational strain, $R^2 = 25.2$, adjusted $R^2 = 18.1$, $F(5, 53)=3.57$, $p < .01$ and accounted for 18.1% of the total variance in social/recreational strain. Only physical strain ($\beta = -0.73$, $p < 0.01$) and emotional strain ($\beta = 0.45$, $p = 0.02$) were found to uniquely and significantly predict social/recreational strain.

CHAPTER IV

DISCUSSION

Advances in medical knowledge and practice are greatly responsible for the number of brain-injury survivors we have today, but as much as is known about the physics and physiology of brain injuries, relatively little is known about the brain injury experience from the perspective of the survivor. Rehabilitation after a brain injury depends to a large degree on patient efforts, so understanding the phenomenology of the illness experience from the survivor's perspective can have important implications for the recovery process and outcomes.

This study furthered our understanding of how the illness experience influences the ways VBIs cope and manage. Survivors of brain injuries may face negative consequences in physical, emotional, and social realms, and it is therefore important to consider both objective and subjective aspects of the illness experience. For VBIs, polytrauma is often a factor that must be taken into consideration when deciding how best to help (Risdall & Menon, 2011). Although stroke survivors cited physical symptoms as being most important in prohibiting them from re-involvement in their communities (Walsh et al., 2013), negative appraisals can also adversely affect rehabilitation and function (e.g., Sisson, 1998).

In this sample, 45.5% of the VBIs reported scores of 10 or above, the diagnostic cutoff score for depression on the PHQ-9, and twenty-six VBIs reported being on medication for depression. Findings from this study showed that VBIs who experienced greater amounts of role captivity, perceived distress, and dyad relationship strain experienced more symptoms of depression. Another finding of this study was that as self-esteem decreased in VBIs, depression symptoms increased. While noting these relationships provides valuable new insights regarding depression in the VBI population, what may be even more important is how this study found that lower self-esteem, feelings of role captivity, and social/recreational strain were predictors of depression in VBIs. Similarly, this study also showed that while perceived distress as an aggregate measure did not significantly predict social/recreational strain, when separated into its elements, physical strain and emotional strain, both were predictors of social/recreational strain (physical strain positively and emotional strain negatively). Establishing that the above-mentioned stressors can predict development of depression and social/recreational strain is an important step in understanding potential areas for targeting in intervention design.

Analyses supported hypothesis 1, with the subjective stressor role captivity having a significant and moderate positive correlation with symptoms of depression. This would indicate that VBIs who self-report experiencing more role captivity have a greater number of depression symptoms. This is consistent with studies which have shown that survivors of brain injury often experience role captivity components such as loss of control and loss of freedom (Hafsteindottir & Grypdonck, 1997; Salter et al., 2008) and the significantly strong relationship between feeling little control over one's circumstances and increased depressive symptoms (Benassi, Sweeney, & Dufour, 1988). While research with dementia patients has demonstrated that there is a relationship between increased feelings of role captivity and increased symptoms of depression (Dawson et al., 2012), this study confirms that this relationship also holds true for veterans who have experienced brain injury. By confirming this relationship, we can now explore which specific aspects of role captivity are most related to depression and design ways to intervene on those elements before depression develops. As the illness experience is highly individualized, pinpointing important pathways like the relationship between role captivity and depression allows us to narrow the focus of our interventions when tailoring them for VBIs.

Hypothesis 2, positing that social/recreational strain and dyad relationship strain will be found to be significantly and positively correlated with symptoms of depression, was only partially supported. Dyad relationship strain showed a significant and large positive relationship to depression, signifying that VBIs experiencing dyad relationship strain had more symptoms of depression. In this study, 74% of the VBIs surveyed had caregivers that were spouses/significant others. Marriage is a protective social relationship with regard to psychological health (including development of depression) (Pearlin & Johnson, 1977), so it stands to reason that disturbance of that relationship would have negative psychosocial consequences. The significant and large relationship between dyad relationship strain and depression in VBIs demonstrated in this study informs us that practices which strengthen the dyadic relationship should be included when constructing interventions for this population.

Contrary to hypothesis 2, however, analysis showed that with this population, social/recreational strain did not have a statistically significant relationship with depression. This is in contrast with literature supporting a lack of social connectedness and social withdrawal being linked to depression (Williams & Galliher, 2006). It may be that this measure of social participation did not adequately capture the facet of social connectedness for this population. VBIs may attempt to meet their social needs in different ways or with other groups or activities. More emphasis should be given to researching the activities or groups veterans find most relevant. Postdeployment social support and unit support were found to be linked to depression in the Pietrzak et al. (2010) study, suggesting that postdeployment contact with other veterans from the same unit may be an important aspect of social connectedness for veterans.

Support for hypothesis 3, examining the relationship between self-esteem and depression, was found with correlation analysis. There was a large significant negative relationship between self-esteem and symptoms of depression in veterans with brain injury. As self-esteem decreased, depression symptoms increased. This is consistent with literature which shows links between low self-esteem and symptoms of depression (Battle, 1978). With documentation in the literature for the widespread issues of both low self-esteem and depression in VBIs, it is important that we note the position of low self-esteem on the route to development of depression as denoted in the SPM for VBIs. This study provides the link between these two pervasive psychosocial constructs in VBIs and can inform future interventions.

Hypothesis 4 proposed that role captivity, social/recreational strain, dyad relationship strain, and self-esteem, along with covariates age and spousal relationship, would significantly predict symptoms of depression. This model significantly predicted depression and showed a large effect size (Cohen, 1988). The utility of the Stress Process Model in guiding hypothesis formation regarding veterans with brain injury was supported by the results of this study in that stressors from two different domains (primary stressors and secondary strains) combined in a linear fashion to predict an outcome of wellbeing.

In this model, self-esteem levels uniquely predicted depression over and above all other independent variables. This is an especially important discovery, due to the widespread occurrence of low self-esteem in VBIs (Hafsteinsdottir & Grypdonck, 1997; Khan et al., 2003) and the well-established links between low self-esteem and depression in other populations. This study demonstrated the importance of improving self-esteem in VBIs as a way to avert or lessen development of depression.

Similar to findings in studies done with caregivers for individuals with dementia (Alspaugh et al., 1999; Lawrence, et al., 1998), role captivity was found to predict depression in veterans with brain injuries as well. Veterans who feel trapped by the consequences of their brain injury are more likely to experience depression. The link between perceptions of role captivity and depression revealed in this study further emphasizes the importance of taking into account self-appraisals when designing ways to lessen depression in VBIs.

Although bivariate correlation examination of social/recreational strain and depression was not significant, social/recreational strain was included in the regression model because of the possible relationship suggested by the Stress Process Model, the fact that VBIs constitute a new population for testing this model, and also by the literature which does suggest a relationship between these two variables. Social/recreational strain did significantly predict depression over and above dyad relationship strain and relationship status, so VBIs with increased social/recreational strain also had increased depression. This is consistent with findings that link lower perceived social support with more depressive symptoms (Oxman & Hull, 2001) and fewer social contacts predicting development of depression (Astrom, et al., 1993).

Dyad relationship strain was not uniquely predictive of depression. Although bivariate correlational analysis did show a significant correlation between these two variables, it may be that the part that dyad relationship strain plays in depression is related to how it affects other variables like self-esteem and role captivity more than its individual role in contributing to depressive symptoms.

The covariate age was significantly uniquely predictive of depression in this model. In fact, age was the factor which was most predictive of depression, with older VBIs (age 65 or older, n = 27) less likely to experience depression than younger VBIs (n = 32). This is in concordance with literature which has found that in general, older adults experience less major depression than younger adults until about age 85. In this study of veterans with brain injuries, as age increases, depressive symptoms decrease.

Hypotheses 5 and 6 were not supported. There was no statistically significant correlation between perceived distress or role captivity and social/recreational strain. However, it should be noted that the correlation between perceived distress and social/recreational strain was close to being statistically significant (p = .07). Perceived distress, role captivity, age, and spousal relationship as a model did not significantly predict social/recreational strain. This was an unexpected result because of the evidence in the brain injury literature regarding the commonly experienced components of role captivity such as declines of confidence and changes in interpersonal interactions (Salter et al., 2008). Feeling distressed about functional changes has also been noted to inhibit participation in former social activities by survivors of brain injury (Murray & Harrison, 2004).

It was initially hypothesized that the overall construct of perceived distress would be important both because of the support in the literature for its influence and since the Stress Process Model includes the construct of perceived distress as a subjective primary stressor. Because the results of the initial correlational analysis showed a relationship between perceived distress and social/recreational strain that approached statistical significance, and because in the dementia literature this measure was successfully used by separating it into its components (e.g., Dawson et al., 2012) it was decided that a closer look at the measure was warranted to discover potential differential impact. As noted previously, the measure for perceived distress factors well into two components, physical strain and emotional strain, and therefore an exploratory analysis was run with the components separated.

When the regression model was analyzed again with physical strain and emotional strain separated, these two variables were found to uniquely predict social/recreational strain while the other variables in the model did not. Physical strain also predicted social/recreational strain above emotional strain. VBIs experiencing less physical strain have less social/recreational strain. Emotional strain, however, did not increase social/recreational strain. As emotional strain increased, social/recreational strain decreased. A possible explanation of this phenomenon could be that social/recreational strain was measured by social participation, and as VBIs experience more emotional strain, they may actually increase attendance at venues where they can receive emotional support, especially by seeking out the company of other veterans (Elder & Clipp, 1988). This could be accomplished by being among fellow veterans while receiving medical care at the VA, by attending VA-endorsed therapy groups, or by meeting with other veterans at formal or informal gathering places such as VFW or American Legion halls.

Examination of components involved in the illness experience and their interrelatedness sheds light on contributors to psychosocial outcomes often faced by VBIs such as depression and social/recreational strain. This, in turn, can inform us about avenues for intervention regarding these outcomes. By early attention to what we now know are contributors to these outcomes, these negative experiences may be lessened or avoided altogether.

With data collected from veterans themselves, reliance on proxy reports from informal and/or formal caregivers can be lessened and avenues for prospective interventions can be determined with patient-informed treatment plans. Proxy reports, while valuable, are in themselves very subjective and have been found to be a frequent area of disagreement between caregivers and care receivers (Williams & Dahl, 2002; Dahlberg et al., 2006). As a result of this disagreement, interpersonal relationships and self-concept of the TBI may be negatively affected (Perrin et al., 2008; Williams & Dahl, 2002; Nochi, 1998). Consideration of the VBI's insights may illuminate key areas in need of focused attention. It is therefore crucial to include information regarding the illness experience garnered from the VBI in addition to proxy commentaries when designing interventions and forming treatment plans.

Not only does this study show the importance of including VBI perceptions of the illness experience when considering treatment options, the fact that these VBIs were able to understand and report details of how they cope and manage in their illness experiences is a vital new piece of information. The reliability analyses done for the measures with this population demonstrate how VBIs can and should contribute meaningfully to their own recovery and rehabilitation after a brain injury.

Clearly, this study has demonstrated that the illness experience of brain-injured veterans is not purely a result of objective physiological injury, but it also consists of subjective appraisals of the post-injury processes of coping and healing. While immediate and ongoing medical interventions are vital for surviving brain injuries, psychological and environmental interventions are no less crucial in their contributions to superior outcomes in life after a brain injury. This study has demonstrated that there are multiple constructs which influence the illness experience of VBIs, that those constructs represent possible avenues for intervention which could appreciably contribute to the improved health of these veterans, and that VBIs themselves are capable of making impactful contributions to informing their treatment plans.

Limitations and Future Research: One limitation of this study was that participants were all male. Because of the very small number of female veterans who met ANSWERS-VA study qualifications, only male veterans were included in this study. As the great majority of veterans are male, this study can still be thought of as being representative of the majority of VBIs. Extension of this study's results to the general population, however, should include conducting research with females with brain injuries as participants.

It should be noted that the time from injury and severity of injury differed greatly between participants. These differences may be important when measuring constructs in primary and secondary stressors domains. For example, participants who experience more dependence on caregivers may feel more role captivity and/or social/recreational strain than those VBIs who are have more independent functioning. Although in future studies participants would ideally have similar dates and severity of injury, this would require a substantially larger pool of VBIs to draw from than was available at the two VA medical centers involved in the ANSWERS-VA study.

The SPM for VBIs, while very useful for demonstrating some of the relationships between constructs and domains involved in the illness experience, is unidirectional. As such, it does not allow for examination of the potential influences of constructs in subsequent domains on those in preceding domains. In future studies, bidirectionality of construct influences should be examined (Hammen, 2005).

Other constructs found in the SPM for VBIs, such as mediators, should be included in future studies. Mediators have the effect of positively or negatively impacting the stress process and, as illustrated by the model, have direct and indirect effects in impacting wellbeing outcomes. The effects of mediators explain how people with similar circumstances can experience vastly different outcomes. Intervening on one or more of the resources represented in the mediators domain has the potential to substantially change outcomes of wellbeing like depression.

Much research is being done on caregivers and the ramifications of caregiving on psychosocial outcomes. This research should be extended to include care receivers to see if the effects of dyadic role strains emerge in the same patterns as they do with caregivers.

Future studies should emphasize the importance of including the individual VBI’s perspective of the illness experience so that the focus can be on not only surviving but actually thriving. By exploring, monitoring, and intervening upon the veteran’s appraisals and judgments regarding coping with a brain injury, negative psychosocial outcomes may be lessened or avoided altogether.

CHAPTER V

CONCLUDING REMARKS

Improving the quality of life of brain-injured veterans by understanding the pathways which lead to the psychosocial consequences of their illness experience may provide benefits not only for individual brain-injured veterans, but also for civilian brain-injury survivors and our society in general (e.g., avoiding or shortening the symptoms of negative psychosocial outcomes, influencing public policy regarding caregiving, etc.).

The VA healthcare system is the largest integrated healthcare system in the U.S. (Health Care, 2015) and as such provides unparalleled opportunities for research and dissemination of new treatment protocols. However, given the challenges of overwhelmed VA facilities in meeting the health needs of area veterans, streamlining treatment processes by empowering VBIs to make decisions about what constitutes success for them and then focusing on patient-determined goals may lead to increased psychosocial health outcomes and more efficient rehabilitation processes. With survivor input, interventions can be tailored specifically to the needs of VBIs.

This study confirms that the relationships between feelings of role captivity and depression, low self-esteem and depression, decreased socialization and depression, and dyad relationship strain and depression hold true for VBIs. In addition to confirming these links, we now know that interventions which include ways to strengthen the dyadic relationship, improve self-esteem, maintain social participation, and decrease perceptions of role captivity will be important in averting or lessening development of depression in this population. This study has also shown that social/recreational participation can be improved by intervening on physical and emotional strains. Not only has this study demonstrated how the illness experience predicts key psychosocial outcomes in VBIs, it has also illustrated that self-reports from VBIs are reliable and valid indicators of their illness experiences and should be seriously considered when constructing treatment goals and plans.

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APPENDICES

Appendix A

Veteran Chart Abstraction

Subject ID ___________________________________

Demographics

What is the Veteran's age? ___________________________________
(do not enter if 90 or older)

Has the Veteran suffered a stroke?
___ Yes
___ No

In what year did it occur? ___________________________________
(enter year only-most recent if multiple strokes)

14. Has the Veteran suffered a traumatic brain injury (TBI)?
☐ Yes
☐ No

In what year did it occur? ___________________________________
(enter year only-most recent if multiple tbis)

Is the Veteran’s caregiver a spouse/significant other?

☐ Yes
☐ No

Appendix B

Social Participation

"These next questions are about things you may have done recently. After I read each activity, please tell me whether you did these things more often, the same, or less often. Recently, because of my brain injury, I more often, less often, or did not change how often I:"

a. participated in church or religious activities.

___ More often (yes)
___ Same
___ Less often (no)
___ Never did this

b. engaged in volunteer activities.

___ More often (yes)
___ Same
___ Less often (no)
___ Never did this

c. participated in group activities.

___ More often (yes)
___ Same
___ Less often (no)
___ Never did this

d. visited with friends or family.

___ More often (yes)
___ Same
___ Less often (no)
___ Never did this

e. went out to dinner, a movie, or a show.

___ More often (yes)
___ Same
___ Less often (no)
___ Never did this

Appendix C

Emotional and Physical Strain (EPS)

"After I read each of the following statements, please tell me if you strongly agree, agree, disagree, or strongly disagree. Because of my brain injury:"

a. I was under more stress, strain, or pressure.

☐ Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

b. I was more nervous or bothered by nerves than before.

☐ Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

c. I felt irritable more often.

☐ Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

d. I was more downhearted, blue, or sad.

☐ Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

e. I felt my physical health was worse than before.

☐ Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

f. I was bothered more by aches and pains.

☐ Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

g. I seemed to get sick more often.

☐ Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

h. I had less pep or energy.

☐ Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

Appendix D

Relationship strain/Role captivity

"Now I'd like to talk about how your brain injury has affected your relationship with (CAREGIVER) recently. After I read each statement, please tell me if you strongly agree, agree, disagree, or strongly disagree. Because of my brain injury:"

a. I felt that he/she tried to manipulate me.
☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

b. I felt that my relationship with him/her was strained.
☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

c. I felt resentful toward him/her.
☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

d. I felt angry toward him/her
☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

e. I did not feel appreciated for what I do.
☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

f. I wished I was free to lead my own life.
☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

g. I did not feel close to him/her.

☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

h. I felt trapped having to depend on (CAREGIVER).

☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

i. I wished I could run away from this situation.

☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

==

Appendix E

Self-esteem

“After I read each statement, please tell me if you strongly agree, agree, disagree, or strongly disagree with each statement.”

a. I am a worthwhile person.

☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

b. I have a number of good qualities.

☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

c. I feel that I am a failure.

☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

d. I do things as well as other people.

☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

e. I do not have much to be proud of.

☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

f. I have a positive attitude.

☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

g. I am satisfied with myself.
☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

h. I wish I could have more respect for myself.
☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

i. I feel useless sometimes.
☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

j. I think I am no good at all.
☐Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree

Appendix F

Patient Health Questionnaire Depression Scale (PHQ-9)

"This set of questions looks over the past 2 weeks. How often have you been bothered by any of the following problems? Please select a number, from 0-not at all, 1-several days, 2-more than half the days, or 3-nearly everyday."

1. Little interest or pleasure in doing things	☐ 0 Not at all ☐ 1 Several days ☐ 2 More than half the days ☐ 3 Nearly every day
2. Feeling down, depressed, or hopeless	☐ 0 Not at all ☐ 1 Several days ☐ 2 More than half the days ☐ 3 Nearly every day
3. Trouble falling or staying asleep, or sleeping too much	☐ 0 Not at all ☐ 1 Several days ☐ 2 More than half the days ☐ 3 Nearly every day
4. Feeling tired or having little energy	☐ 0 Not at all ☐ 1 Several days ☐ 2 More than half the days ☐ 3 Nearly every day
5. Poor appetite or overeating	☐ 0 Not at all ☐ 1 Several days ☐ 2 More than half the days ☐ 3 Nearly every day
6. Feeling bad about yourself or that you are a failure or have let yourself or your family down	☐ 0 Not at all ☐ 1 Several days ☐ 2 More than half the days ☐ 3 Nearly every day
7. Trouble concentrating on things, such as reading The newspaper or watching television	☐ 0 Not at all ☐ 1 Several days ☐ 2 More than half the days ☐ 3 Nearly every day
8. Moving or speaking so slowly that other people could have noticed. Or the opposite being so fidgety or restless that you have been moving around a lot	☐ 0 Not at all ☐ 1 Several days ☐ 2 More than half the days ☐ 3 Nearly every day
9. Thoughts that you would be better off dead or of hurting yourself in some way	☐ 0 Not at all ☐ 1 Several days ☐ 2 More than half the days ☐ 3 Nearly every day