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THE ROLE OF POSITIVE EMOTIONS IN HEALTH-RELATED OUTCOMES FOR  
CAREGIVERS OF VETERANS WITH TRAUMATIC BRAIN INJURY

A dissertation submitted in partial fulfillment of the requirements for the degree of  
Doctor of Philosophy at Virginia Commonwealth University

by:

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## **Acknowledgements**

I would like to thank the many individuals who provided me with the support and guidance necessary to complete this dissertation. First, I would like to thank my graduate advisor, Steve Danish, for his ongoing and enthusiastic support of my ideas—wherever they might lead—throughout graduate school. I am grateful for being included in your projects and being supported in pursuing my own research. Your encouragement to both accept challenges and acknowledge strengths has been vital to my professional development and is truly appreciated.

Thank you to my committee members, Eric Benotsch, Sherry Ceperich, Jean Corcoran, and Jennifer Lumpkin, for providing advice and support. Special thanks goes to Scott McDonald for his assistance and recommendations about statistical procedures and results. Thank you also to the McGuire VAMC Writers' Task Force for providing helpful feedback.

I also want to thank Joan Griffin, Agnes Jensen, and the entire Family and Caregiver Experience Survey (FACES) study team for allowing me to pursue this project, guiding me through the VA process, and offering encouragement along the way.

## Table of Contents

	Page
Acknowledgements . . . . .	ii
List of Tables . . . . .	v
List of Figures . . . . .	vii
Abstract . . . . .	viii
Introduction . . . . .	1
Incidence, Prevalence, and Etiology of TBI . . . . .	1
TBI Severity . . . . .	2
Effects of TBI . . . . .	4
Caregivers . . . . .	5
TBI and Veterans . . . . .	8
Statement of Purpose . . . . .	9
Literature Review . . . . .	10
Depression and Anxiety and Caregiving . . . . .	11
Burden . . . . .	13
Negative Physical Effects of Caregiving . . . . .	15
Positive Emotions and Caregiving: Finding Meaning Through the Caregiving Process . .	18
Positive Aspects of Caregiving . . . . .	21
Preparedness and Self-Efficacy for Caregiving . . . . .	24
Effects of Race/Ethnicity and Caregiving . . . . .	26
Kinship Status . . . . .	28
Effects of Caregiver Variables on Care Recipient . . . . .	29
Research Hypotheses . . . . .	33
Method . . . . .	35
Participants . . . . .	35
Design . . . . .	37
Measures . . . . .	38
Results . . . . .	43
Discussion . . . . .	64
Summary of Results . . . . .	63

Limitations .....	71
Recommendations for Future Research .....	75
List of References .....	79
Appendices .....	88
A    Demographic Data .....	88
B    Key Behavior Change Inventory—Modified .....	90
C    Pearlin’s Personal Gain & Spirituality Scale—Modified .....	94
D    Preparedness for Caregiving Scale—Modified .....	95
E    PROMIS Anxiety—Short Form .....	96
F    PROMIS Depression—Short Form .....	97
G    PROMIS Physical Functioning—Short Form .....	98
H    PROMIS Global Item—Subjective Health .....	99
I    Zarit Burden Interview—Short Form .....	100
Vita .....	102

## List of Tables

	Page
Table 1. Frequencies of Demographic Characteristics of Participants . . . . .	36
Table 2. Descriptive Demographic Characteristics of Participants. . . . .	37
Table 3. Overall Means, Standard Deviations, and Intercorrelations of Study Variables . . . . .	45
Table 4. Hierarchical Regression Analysis Summary for Variables Associated with Perceived Physical Functioning . . . . .	46
Table 5. Hierarchical Regression Analysis Summary for Variables Associated with Subjective Health . . . . .	47
Table 6. Hierarchical Regression Analysis Summary for Variables Associated with Caregiver Depression . . . . .	48
Table 7. Mediation of the Effect of Personal Gain on Depression Through Perceived Burden . . . . .	51
Table 8. Hierarchical Regression Analysis Summary for Variables Associated with Caregiver Anxiety. . . . .	53
Table 9. Mediation of the Effect of Personal Gain on Anxiety Through Perceived Burden. . . . .	54
Table 10. Hierarchical Regression Analysis Summary for Variables Associated with Perceived Care Recipient Communication. . . . .	56
Table 11. Hierarchical Regression Analysis Summary for Variables Associated with Perceived Care Recipient Emotional Behavior . . . . .	57
Table 12. Multivariate and Univariate Analyses of Covariance for Perceived Caregiver Health . . . . .	59
Table 13. Mean Scores and Standard Deviations for Measures of Perceived Caregiver Health by Racial Group . . . . .	60
Table 14. Multivariate and Univariate Analyses of Covariance for Caregiver Impact . . . . .	60

Table 15.	Mean Scores and Standard Deviations for Measures of Caregiver Impact by Racial Group . . . . .	61
Table 16.	Multivariate and Univariate Analyses of Covariance for Kinship Differences . . . . .	62
Table 17.	Mean Scores and Standard Deviations for Measures of Caregiver Depression, Anxiety, and Subjective Burden by Kinship Group . . . . .	63

**List of Figures**

	Page
Figure 1. Total Effect . . . . .	49
Figure 2. Simple Mediation Model. . . . .	50
Figure 3. Proposed Mediation Model for Hypothesis 2 (a) . . . . .	67



## **Abstract**

### **THE ROLE OF POSITIVE EMOTIONS IN HEALTH-RELATED OUTCOMES FOR CAREGIVERS OF VETERANS WITH TRAUMATIC BRAIN INJURY**

By Suzzette M. Chopin, M.A., M.S., M.B.A.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2012.

Major Director: Steven J. Danish, Director, Life Skills Center and F.R.E.E 4 Vets Program  
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The purpose of this study was to examine the relationship between both self-efficacy for caregiving and personal gain and several variables related to well-being in caregivers ( $N = 70$ ) of veterans who sustained a traumatic brain injury (TBI). Specifically, the relationship between self-efficacy for caregiving and perceived physical health and the relationship between personal gain related to caregiving and depression and anxiety was examined. The relationship between caregiver personal gain and perceived care recipient behavior was also examined. Exploratory analyses considered kinship and racial/ethnic differences. This was a secondary analysis of pilot data collected at four Polytrauma Rehabilitation Centers (PRC) of the United States Department of Veterans Affairs. It was a cross-sectional, pen and paper-based survey study mailed to caregivers of non-OEF/OIF veterans who were treated at a PRC for TBI between 2001 and 2008.

Results suggest that self-efficacy for caregiving is not associated with subjective health or physical functioning in the caregiver. There was also no direct effect of personal gain associated with caregiving on depression or anxiety. However, perceived burden was found to mediate the

relationship between personal gain associated with caregiving and both depression and anxiety. No significant differences were found between Caucasian and non-Caucasian caregivers in number of hours spent providing care, perceived burden, or subjective health. Non-Caucasian caregivers reported significantly higher levels of physical functioning. No differences were found between parental and non-parental caregivers on measures of depression, anxiety, or perceived burden.

These findings suggest that interventions for caregivers should focus on helping them find meaning in caregiving and articulate ways in which they have benefitted from caregiving. By helping caregivers highlight the benefits of caregiving, perceived burden may be decreased, which in turn may result in lower depression and anxiety levels.

## The Role of Positive Emotions in Health-Related Outcomes for Caregivers of Veterans with Traumatic Brain Injury

This introduction provides information about traumatic brain injury (TBI), including incidence, prevalence, etiology, and short- and long-term consequences. It includes a discussion of the care required by those who sustain a TBI and a discussion of TBI patients and their caregivers specifically within the context of the Department of Veterans Affairs' (VA) facilities. Finally, a statement of purpose for the proposed study is included.

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

Traumatic brain injury is any type of injury to the brain and is the most common type of brain damage in young adults. It can occur with either an open (penetrating) or closed head wound (Lezak, Howieson, Loring, Hannay, & Fischer, 2004). The Centers for Disease Control and Prevention (CDC) estimates that 1.7 million people sustain a TBI annually, of which approximately 275,000 visit a hospital. Further, one-third of all injury-related deaths in the U.S. involve a TBI (CDC, 2010). Of those with a TBI who visit a hospital, approximately 43 percent experience ongoing effects and disability (Corrigan, Selaissie, & Orman, 2010).

TBI has a bimodal age distribution, with peaks under the age of 10 and over the age of 74 (Corrigan, Selaissie, & Orman, 2010). The leading cause of TBI in all age groups is falls, with motor vehicle accidents being the leading cause of TBI-related death (CDC, 2010). With the exception of those over the age of 65, males have the highest rate of TBI in every age group (CDC, 2010). For those over 65, the number of women with a TBI is greater than the number of men due to the greater number of elderly females (Lezak et al., 2004). Low SES is associated with increased likelihood of a TBI (Corrigan et al., 2010). African-Americans are at higher risk for TBI than Caucasians and, along with Hispanics, are less likely than to return to their previous level of functioning after one year, even controlling for injury severity (Arango-Lasprilla &

Kreutzer, 2010). Adult members of minority groups are also less likely to receive care from a rehabilitation center and, in general, receive fewer services than their Caucasian counterparts, again even when controlling for injury severity (Arango-Lasprilla & Kreutzer, 2010). Many people with a TBI, and especially Service Members who sustain a TBI while deployed, sustain additional physical injuries, which are known as polytrauma injuries (National Institutes of Health [NIH], 2010). Polytrauma compounds the effects of the TBI, and the type and duration of care needed increases in complexity.

### **TBI Severity**

TBIs are rated as mild (mTBI), moderate, or severe. Diagnostic criteria for determining TBI severity are variable, though there are some generally established measures. The Glasgow Coma Scale (GCS) measures the patient's abilities in terms of eye opening, verbal, and motor skills (Merck, 2010). The GCS, measured as early as possible after injury, is often used in combination with a measure of the patient's posttraumatic amnesia (PTA), the length of time a patient remains confused and unable to form new memories after injury. Even with the use of these indices, it can be difficult to precisely determine the severity of a patient's TBI due to issues such as when the GCS was measured, results from additional scans, whether the patient was under the influence of a substance, and when PTA is subjectively determined to resolve (Lezak et al., 2004).

The majority of TBIs—approximately 80 to 85 percent—are classified as mild (Merck, 2010). Approximately 8 to 10 percent of all TBIs are considered moderate, with the remaining falling into the severe range (Lezak et al., 2004). The American College of Rehabilitation Medicine (ACRM) defines mild TBI as one in which the patient experiences trauma to the brain, and also experiences at least one of the following symptoms: loss of consciousness for no more than 30 minutes, loss of memory, altered mental status, and neurological deficits (McCrea,

2008). Additionally, the GCS after 30 minutes should be 13-15 and PTA should last no longer than 24 hours (McCrea, 2008).

Some researchers believe that the individual with mTBI may still suffer effects such as problems with memory, concentration, headaches, and cognitive difficulties (Helmick, Parkinson, Chandler, & Warden, 2007). However, evidence indicates that mTBI is not associated with long-term dysfunction in thinking or socialization (Hoge, Goldberg, & Castro, 2009). For those who report ongoing symptoms, these symptoms often are similar to those associated with depression, anxiety, and PTSD, which makes distinguishing mTBI symptoms from psychiatric conditions difficult, especially when the TBI was sustained in a traumatic event (Kennedy et al., 2007). In fact, there is some debate as to whether it is even appropriate to consider mTBI on the same spectrum of injury as moderate and severe TBI (Hoge, Goldberg, & Castro, 2009), as mTBI is usually undetectable on imaging, symptoms often fully resolve, and other factors such as psychological history and litigation potential are the predictors associated with long-term disability (Hoge, Goldberg, & Castro, 2009; McCrea, 2008). In terms of neurophysiology, mTBI is not associated with irreversible cellular changes, moderate TBI is associated with delayed but reversible cellular changes, and severe TBI is associated with delayed and perhaps irreversible cellular changes, including cell death (McCrea, 2008).

More severe TBI is associated with reduced likelihood of return to work as well as with more significant personality and behavioral changes (Lezak et al., 2004). Individuals who sustain a penetrating heady injury are also more likely to suffer longer-term consequences (Defense and Veterans Brain Injury Center, 2010). Moderate and severe TBI are detected via imaging and result in neurological impairment; prognosis for long-term recovery is predicted by injury characteristics and severity (Hoge, Goldberg, & Castro, 2009). When TBI results in observable changes on imaging studies, the TBI is classified as complicated, though the diagnostic utility of

imaging techniques is highly variable and it is not known whether all detectable changes and any associated functional impairments will persist in the individual in the long term (McCrea, 2008).

### **Effects of TBI**

The short- and long-term effects of TBI depend on severity, location, patient age, and patient personality (Lezak et al., 2004). Immediately after a TBI, patients are at increased risk of problems such as infections, nerve injuries, and seizures (NIH, 2010). Mild to moderate TBIs are associated with cognitive impairments such as memory, concentration, and executive functioning difficulties (NIH, 2010). Delays in processing speed are also common and can lead patients to become easily overwhelmed by distracting stimuli, leading to confusion and frustration. These effects in turn may cause the patient to avoid highly stimulating situations, which can contribute to feelings of social isolation (Lezak et al., 2004). Individuals with TBI are four times more likely to be at risk of self-harm or suicide; this risk increases to six times for those with comorbid depression. Individuals with mTBI tend to experience rapid recovery (i.e. within hours) and up to 90 percent of individuals with mTBI experience nearly complete symptom resolution within 10 days, with headache emerging as the symptom most likely to persist (McCrea, 2008). Extremely rare exceptions to this trajectory include when an individual (often an athlete) experiences a second TBI prior to symptom resolution of the first TBI; in these cases, permanent effects or even death is possible (McCrea, 2008). Further, there is some evidence that repeated mTBI (three or more) may be associated with long-term effects (McCrea, 2008).

Impairment associated with TBI can be confined to specific domains if the injury is to a localized portion of the brain, or may be noticeable across different domains, especially if the frontal lobe is damaged (Lezak et al., 2004). Long-term effects of mTBI are usually rare, but vary from patient to patient, and may include ongoing attentional difficulties, depression, and anxiety. For patients with moderate TBI, problems with executive functioning, impulsivity, and

flattening of affect are common (Lezak et al., 2004). Although less than 10 percent of patients sustain a severe TBI, long-term effects can be highly debilitating and include problems with executive functioning as well as disturbances in personality (Lezak et al., 2004). Major depressive disorder is found in 26 to 36 percent of those with moderate to severe TBI and is the most common psychiatric diagnosis in this group (Seel, Macciocchi, & Kreutzer, 2010). However, due to overlapping symptoms between moderate/severe TBI and MDD, accurate diagnosis can be challenging (Seel, Macciocchi, & Kreutzer, 2010). Individuals with moderate to severe TBI and MDD are also at greater risk of developing anxiety, aggression, pain, and apathetic syndrome, a constellation of symptoms such as anhedonia and lack of energy (Seel, Macciocchi, & Kreutzer, 2010). Severity of TBI and/or repeated head injury may also be associated with an increased risk of developing dementia later in life (McCrea, 2008).

Individuals with severe TBI are unlikely to return to their previous employment in a full-time capacity and require the most significant amount of care. Further, African-Americans who sustain TBI are significantly less likely to find employment than Caucasians, even after five years, as are those patients who are older and more seriously injured (Gary, Arango-Lasprilla, Ketchum, Kreutzer, Copolillo, Novack, & Jha, 2009).

## **Caregivers**

It is estimated that 52 million people in the United States serve as caregivers for someone with an illness or disease (Family Caregiver Alliance, 2010). Caregivers include spouses, parents, adult children, and family friends who provide care to those with brain disorders, cancer, HIV, and a multitude of other conditions. Although TBI can occur to anyone at any age, TBI patients tend to be male, and caregivers of people with TBI tend to be female (Wells, Dywan, & Dumas, 2005). Approximately 60 to 75 percent of caregivers are female, and female caregivers tend to assist more with activities of daily living such as bathing and grooming, while male

caregivers tend to assist with tasks such as financial and health care management (Family Caregiver Alliance, 2010). The majority of caregivers of both sexes are between the ages of 35 and 64 (Family Caregiver Alliance, 2010), indicating that many are managing their own families and careers while simultaneously serving as an informal caregiver. The demographics are different for caregivers of veterans. The National Alliance for Caregiving (NAC), a nonprofit group made up of many caregiving organizations that is focused on policy and communications about caregiving, based on a 2010 survey study it conducted of caregivers of veterans, found that 96 percent of caregivers were women, 70 were spousal caregivers, and that they were three times more likely to live in the same house as their care recipient compared to caregivers of non-veterans (2010). Further, veteran care recipients tend to be young; the NAC reports that 41 percent are under the age of 54 (2010).

The costs of caregiving are high, not only for families, but also for society. Direct and indirect costs associated with caregiving for TBI total nearly \$50 billion annually; individual lifetime costs can reach \$4 million for those with severe TBI (Family Caregiver Alliance, 2010). For those who require acute rehabilitation, the costs can exceed \$1,000 per day (Family Caregiver Alliance, 2010). Clearly the patient is unable to fully participate in society, but the caregiver is also affected because of the time demands and costs associated with caregiving.

In terms of race/ethnicity, approximately 20% of African-Americans and Caucasians, 18% of Asians, and 16% of Hispanics are involved in caregiving to some extent. Among all caregivers, approximately half spend eight hours a week or less caregiving, while 20 percent spend up to 40 hours per week (Family Caregiver Alliance, 2010). The type and duration of caregiving depends on the nature of the injury.

Caregivers for a loved one with a moderate or severe TBI face unique challenges in that the individual may have not only physical but also psychological and behavioral changes. Most



improvement after a TBI occurs in the two years after the injury, though with emerging therapies and medications, subtle improvements may be possible for many years (Lezak et al., 2004). Further, overall lifespan may be normal, thus potentially putting the caregiver in that role for many years. Effects on the caregiver may depend on whether the caregiver is a parent, with a history of caring for the patient, or spouse, who may have increased difficulty adjusting to his or her new role (Degeneffe, 2001). Degeneffe (2001) notes that a primary challenge to research with caregivers of people with TBI is the variability of both the etiology of and the severity of the TBI, making comparisons difficult. Although other illnesses such as cancer may include caregivers of patients with different types and/or severity of disease, caregivers of patients with TBI face not only physical but also behavioral challenges. Dealing with behavioral or psychological issues in a care recipient is generally more stressful for caregivers than managing physical challenges alone (Kreutzer, Gervasio, & Camplair, 1994).

People with a moderate to severe TBI may exhibit cognitive and behavioral changes for many years or even decades after injury; the accompanying personality changes tend to affect caregivers more than physical disabilities (Knight, Devereux, & Godfrey, 1998). Most patients with mTBI are unlikely to require a caregiver unless there are other accompanying injuries or PTSD. In that case, caregivers may make small changes to adapt to their loved one's problems with memory and concentration; for those with moderate to severe TBI, more significant caregiving may be required, such as assisting with managing the household and/or activities of daily living such as dressing and grooming (DVBIC, 2010). Given the number of people living with TBI and the potential for family members to be long-term caregivers, there is surprisingly little research about effective family-based interventions (Kreutzer, Stejskal, Ketchum, Marwitz, Taylor, & Menzel, 2009). One study with 53 families caring for a TBI patient focused on providing a five session manualized treatment known as the Brain Injury Family Intervention

(BIFI), which included both psychoeducational and cognitive behavioral components (Kreutzer et al., 2009). Results indicated that participants in the program reported an increased number of needs being met and fewer perceived barriers to resources, benefits which remained at a three month follow-up (Kreutzer et al., 2009). Another recent study with 76 caregivers and TBI patients provided additional support for the effectiveness for the BIFI and found that caregivers rated the most important thing they learned from the intervention to be the importance of asking for help and self-care (Kreutzer, Stejskal, Godwin, Powell, & Arano-Lasprilla, 2010.)

### **TBI and Veterans**

With less hand-to-hand combat and improved protective devices compared to earlier generations, today's veterans are more likely to survive events that would have proved fatal in previous conflicts (Côté, Syam, Vogel, & Cowper, 2007). Due to improved body armor, seven out of every eight injured soldier survive, compared to only five out of every eight in Vietnam (Department of Veterans Affairs, 2006). Ongoing physical problems and PTSD are associated with mTBI for veterans of OIF who are likely to have lost consciousness during a traumatic event (Hoge et al., 2008). However, combat-related injuries are not the sole cause of TBI in veterans. Veterans are susceptible to incurring a TBI after their service has ended in the same ways as the general population. These TBI patients—and their families—are still a part of the VA system. Because of the bi-modal distribution of TBIs, it is likely that veterans from Korea, Vietnam, and eventually the first Gulf War will sustain TBIs as they age and seek care from the VA. Further, many OEF/OIF are injured after deployment in auto or motorcycle accidents.

VA admits nearly 12,000 patients with TBI annually; of those, 9,300 are estimated to suffer from a severe TBI (Côté et al., 2007). Average inpatient stays for TBI patients at VA facilities range from 13 to 26 days at an average cost of \$16,000 to \$29,000, depending on severity (Côté et al., 2007). These numbers are based on data through 2006 and include

information from the Polytrauma Rehabilitation Centers (PRCs). Although significant attention has focused recently on TBIs in veterans from OEF/OIF, as troop withdrawals continue, the number of TBIs in that population is likely to decrease. However, the VA serves a large number of veterans with TBI from sources such as accidents and falls. As the veteran population ages, VAs will continue to treat veterans with TBIs and aid their caregiver family members. The NAC reports that 11 percent of caregivers are themselves veterans and that 17 percent of those caregivers' care recipients are veterans (2010).

With TBI known as the signature injury of OEF/OIF, in 2005 VA implemented the Polytrauma System of Care (PSC), "a national, multitiered system of rehabilitation care designed to address the specialized rehabilitation needs of polytrauma patients while simultaneously addressing the broad geographic distribution of patients and the potential life-long treatment needs" (Collins & Kennedy, 2008, p. 993-994). The PSC aims to integrate treatment across disciplines and provide services to both the patient and the family; services are provided in many VAs, but there are four Polytrauma Rehabilitation Centers (Minneapolis, Palo Alto, Richmond, and Tampa) that provide the highest level of care to both patients and their families as they embark on the recovery process (Collins & Kennedy, 2008). PRCs are unique in that they involve family members in the patient's recovery from the beginning, with the entire treatment team focused not only on the patient, but also on his or her caregivers as well (Griffin, Friedemann-Sanchez, Hall, Phelan, & van Ryan, 2009). PRCs use online, collaborative Family Care Maps (FCM) to encourage communication between the family and the treatment team (Griffin et al, 2009).

### **Statement of Purpose**

Significant research exists on the effects of caregiving in populations such as dementia patients. However, there are fewer studies on caregivers of patients who sustain a TBI. Such

patients may exhibit cognitive, personality, and behavioral changes, and may or may not have an accompanying physical disability. Due to the large number of younger people who sustain TBIs, the caregiver may be in that role for many years, possibly decades. Thus, while some research from the dementia caregiving population may be generalizable to caregivers of people with TBI, it is important to understand the unique situation of the TBI caregiver. Further, research on caregivers of people with TBI has by and large focused on the negative consequences associated with caregiving. Far fewer studies have considered why some caregivers suffer negative effects but others manage quite well.

Understanding why some caregivers manage the caregiving role well can help psychologists and others develop interventions for caregivers to aid them in succeeding in the caregiving role and minimizing the negative effects of caregiving. The proposed study focuses broadly on positive outcomes, both physical and mental, experienced by caregivers of people with TBI. The author will also consider what effect, if any, positive caregiver emotions have on the care recipient's functioning. Finally, between group differences will be considered to determine how kinship status and race/ethnicity affect caregivers of individuals with TBI. Thus, this project is significant because it investigates the relationship between positive emotions associated with caregiving and physical and psychological outcomes in caregivers of TBI patients. Understanding these relationships can help provide directions for future interventions and lead to future research on evaluating interventions. This study also adds to the small research base on caregivers of people with TBI.

## **Literature Review**

This literature review will consider the main constructs that are relevant to the proposed study. First, the negative psychological and physical health effects associated with caregiving will be considered. Second, the role of positive emotions during the caregiving process will be

reviewed, along with positive aspects of caregiving and self-efficacy for caregiving. Differences based on race/ethnicity and kinship status will also be considered. Finally, the effects of caregiver variables on care recipient outcomes will be reviewed. Where relevant, studies from other caregiving populations will be included. For example, more studies with larger sample sizes have been conducted with dementia caregivers, and although the results may not be completely generalizable to caregivers of people with TBI, investigators can benefit from an understanding of that literature. This is especially true because dementia patient caregivers, like caregivers of people with TBI, face similar challenges associated with providing care for someone whose personality and behavior may have changed. Whereas the increasing number of dementia patients and caregivers has led to growth in the number and quality of empirical studies on that population, literature on caregivers of people with TBI remains relatively small in comparison, even as this population increases.

Just 15 years ago, Chwalisz (1996) noted the lack of theory related to caregivers of people with TBI and the fact that different measures were often used to operationalize the concept of burden, which made it difficult to understand the caregiving process. Since then, studies on caregivers of people with TBI have considered negative effects associated with caregiving, and have more recently begun to consider variables associated with alleviating burden and/or promoting better caregiver outcomes. The concepts and studies most relevant to the proposed study are reviewed.

### **Depression and anxiety and caregiving.**

The negative psychological consequences of caring for a loved one who sustains a TBI are well-documented and focus primarily on symptoms of depression and anxiety. For example, a survey study of caregivers ( $N = 62$ ) of TBI patients whose primary cause of TBI (70 percent) was a motor vehicle accident found that 23 percent of caregivers reported clinically significant

levels of depression and 32 percent reported clinically significant levels of anxiety as measured by the Brief Symptom Inventory (BSI) (Kreutzer, Gervasio, & Camplair, 1994). These rates are higher than would be expected in a non-caregiving population. For example, the point prevalence rate of Major Depressive Disorder in the community is 2 to 9 percent, depending on gender; for Generalized Anxiety Disorder the one-year prevalence rate is 3 percent (American Psychiatric Association, 2000). A more recent study of caregivers of people with TBI ( $N = 273$ ) found that the percentage of caregivers reporting clinically significant levels of depression and anxiety (as measured by the BSI) were 19 and 17.9, respectively (Kreutzer et al., 2009). The authors note that depression levels in their study were lower than in other studies, and suggest that this difference is because they prospectively followed a cohort of caregivers rather than recruited them from clinical lists of individuals seeking assistance. Thus, the levels of depression they found might be expected to be similar to those in the currently proposed study, which does not rely on a current clinical population for its sample.

Another study of caregivers ( $N = 60$ ) of TBI patients found that nearly half were at risk of depression, as measured by the Centers for Epidemiologic Studies—Depression scale (CES-D) (Rivera, Elliot, Berry, Grant, & Oswald, 2007). The study also found that caregivers with less adaptive problem-solving styles such as impulsive or avoidant behaviors were more likely to report depressive symptoms. These results suggest an association between problem-solving ability and depression, and offer support for the idea that better problem-solving, or feeling more equipped to face the challenges associated with caregiving, may be related to better psychological outcomes. A survey study of caregivers of severe TBI patients ( $N = 69$ ) and their care recipients one year post-injury found that 32 percent of caregivers reported clinically significant levels of depression (measured by the Beck Depression Inventory) and 35 percent reported clinically significant levels of anxiety (measured by the Trait Anxiety Inventory from

the State-Trait Anxiety Inventory (Marsh, Kersel, Havill, & Sleight, 1998). These results suggest that the psychological toll of providing care to a loved one is high. For caregivers who had a pre-existing medical or mental health issue, the caregiving role may be even more taxing. In a survey study of caregivers ( $N = 114$ ) of patients with TBI, caregivers who reported a history of serious medical illness or a psychiatric diagnosis prior to becoming a caregiver reported significantly higher levels of distress one year after becoming a caregiver, even after controlling for demographic variables and injury severity of the care recipient (Davis et al., 2009).

Caregivers are in the position of providing care to a person who may not only have a physical disability, but may also be unable to manage his or her own finances or hold a job. Caregivers may assist in instrumental activities of daily living (IADLs) such as managing finances or medical care, or may need to provide assistance with activities of daily living (ADLs), which are basic tasks such as grooming, dressing, and toileting. Additionally, the personality changes sometimes associated with TBI exacerbate the challenges faced by caregivers. This may be especially true for spousal caregivers, who, unlike parents, are unaccustomed to being in the caregiver role for the TBI patient.

### **Burden.**

The demands of caregiving can affect caregivers' time, finances, and physical and emotional health. Caregivers have their own individual, subjective experience of how much their caregiving role is negatively affecting their lives—or how much burden they are experiencing. Lawton, Kleban, Moss, Rovine, and Glicksman (1989) argued that caregiver burden was part of a broader concept of appraisal. Hanks, Rapport, and Vangel (2007) suggested that when burden is considered as part of the appraisal process, it allows for the possibility of a positive caregiving experience, depending on how much subjective burden the individual feels. Caregivers who report higher levels of burden are likely to suffer from more of the negative effects of caregiving.

Studies of caregiver burden grew out of the literature on caregivers of older adults (Zarit, Orr, & Zarit, 1985), then expanded to include caregivers of HIV patients, and cancer and other physical illnesses (Knight, Devereux, & Godfrey, 1998). Although all caregivers likely share some of the same frustrations and experiences, caregiver burden may be different for a caregiver of a TBI patient as compared to a dementia patient. One difference is that a dementia patient is likely to be older, and thus his or her illness may be seen as more natural or expected as well as time-limited, whereas TBI can occur unexpectedly and at any age. Family members may not be prepared for the caregiving tasks associated with caring for a loved one with a TBI.

Depression and burden are frequently reported among caregivers of people with TBI. A study of caregivers of moderate to severe TBI patients at least six months post injury ( $N = 180$ ) included surveys, structured interviews, and neuropsychological evaluation. Results indicated that those caregivers who reported the highest levels of burden also reported higher levels of depression. Sixty-four percent of caregivers who reported the most burden met the cutoff score indicative of depression. Among caregivers who reported the least amount of burden, only 14 percent met the cutoff criterion for depression (Machamer, Temkin, & Dikmen, 2002).

Subjective burden was also found to be associated with emotional distress in another survey study of caregivers of people with TBI ( $N = 69$ ) (Sander, High, Hannay, & Sherer, 1997).

However, although that study used the General Health Questionnaire to assess emotional distress, it also used a single item measure asking caregivers about stress levels to assess burden. The authors argued that stress is a major factor underlying burden because of its relationship to appraisal, but they cite no empirical evidence for these assertions, and it remains unclear whether a single item can truly capture a caregiver's perceived burden. Regardless, the results of these studies as a whole suggest that caregivers of TBI patients who feel more burdened are also more likely to report symptoms of depression. A survey study of caregivers of TBI patients ( $N = 121$ )



indicated that in addition to being concerned about their loved one's ability to travel, manage their own finances, and be left alone, caregivers reported extremely high levels of stress associated with caregiving (Kreutzer et al, 2009). The authors suggest that caregiver stress may be driven, in part, by the amount of care and level of functioning of the care recipient.

Results from other caregiving populations lend support to the idea that burden's effects for caregivers are far-reaching. A longitudinal study of older caregivers ( $n = 392$ ) and non-caregivers ( $n = 427$ ) found that caregivers who reported caregiver strain, similar to burden, had a 63 percent higher risk of mortality at four-year follow up compared to non-caregivers or caregivers who did not report strain, even after controlling for demographics and physical health status (Schultz & Beach, 1999). This study reinforces the notion that caregiving burden can also affect caregiver health, a topic which will be discussed in the next section. In another caregiving population, a survey study of caregivers of liver transplant patients ( $N = 24$ ) found a correlation between higher perceived overload, similar to burden, and depression (Cohen, Katz, & Baruch, 2007). Part of the caregiver's subjective assessment of burden is related to his or her perception of the situation and whether he or she is capable of meeting the demands of caregiving. Caregivers who feel confident in their abilities may be less likely to experience negative psychological effects associated with caregiving. This concept will be further explored in the section on preparedness for caregiving.

### **Negative physical effects of caregiving.**

Caregivers face physical and psychological challenges that may contribute to negative physical health effects. Caring for a loved one with a TBI can be very time-consuming, and may leave caregivers with little time to devote to their own health needs. From a theoretical perspective, researchers in the field of psychoneuroimmunology (PNI) have proposed a model for understanding how the chronic stress of caregiving may contribute to poor physical health.

Working within the biopsychosocial framework, Lutgendorf and Costanzo (2003) argue that psychosocial processes such as depression, anxiety, religion, meaning, benefit finding, and stress reactivity are part of a complex process in which these factors interact with genetics and health behaviors to increase or decrease an individual's disease risk. They also believe that the "effects of life stress are filtered through psychosocial processes and health behaviors in their resultant effects on downstream mechanisms" (p. 226), which includes immune functioning and onset/severity of disease processes. In their model, religiosity and meaning-making serve as protective factors. They cite several studies of older adults in which meaning-making in the face of stressful events is associated with better immune system responses.

In one six year longitudinal study of older adults, spousal caregivers ( $n = 119$ ) of dementia patients had significantly increased levels of interleukin-6, a proinflammatory cytokine associated with increased morbidity and mortality, compared to non-caregivers ( $n = 106$ ) (Kiecolt-Glaser et al., 2003). This finding highlights the effects of chronic stress on the body, and may be of particular importance to older adults, whose physical capabilities are already reduced due to age. These findings may not, however, be generalizable to younger caregivers, and it remains to be seen what physiological effects may occur if one serves as a caregiver at a younger age and/or is in a caregiving role for a prolonged period of time in middle age. Caregiving, especially for TBI patients whose conditions are generally stable after the initial recovery period, is a chronic stressor. Physical and mental health effects associated with chronic stressors underscore the connection between physical and mental health that is central to the biopsychosocial model. As part of the year 2000 national Behavior Risk Factor Surveillance System survey conducted by the CDC, 184,450 people were surveyed; of those, 16 percent identified themselves as caregivers. When asked to rate their physical health, caregivers under 55 were 36 percent more likely to rate their health as "fair" or "poor" compared to non-caregivers.

Older caregivers were slightly less likely to rate their health similarly, though they did report experiencing fewer healthy days than their non-caregiver counterparts (Neugaard, Andreson, McKune, & Jamoom, 2008).

Pinquart and Sorensen (2007) have categorized health-related caregiving challenges into four broad areas: (1) physical effects due to having to lift or otherwise assist care recipients, (2) reduced time to exercise and decline in diet, (3) physiological effects associated with chronic, long-term stress, and (4) physiological effects that increase caregiver risk of cardiovascular disease and hypertension. Their large meta-analysis ( $N = 176$  studies) of caregiver physical health considered studies published between 1986 and 2002; 48 percent focused on dementia caregivers, 34 percent focused on dementia and other types of caregivers, and 18 percent focused on older adult caregivers. Thus, although their sample did not focus on caregivers of people with TBI, the large sample size, combined with the lack of a comparable meta-analysis of caregivers of people with TBI, is relevant to the current study. The authors considered the relationships among physical health, burden, and depression. Their results indicated that impaired physical health was associated with increasing age, non-spousal kinship status, living with the care recipient, care recipients with higher levels of behavioral and cognitive issues, fewer caregiving tasks, longer time spent caregiving, lower education, lower income, less social support, and higher levels of both burden and depression. They did not find a relationship between health and number of hours spent caregiving, though number of hours was associated with burden and depression (Pinquart & Sorensen, 2007). The authors concluded that caregiving stress does affect physical health, though perhaps not to the same extent as it affects psychological health. It is worth noting, and the authors do so, that physical symptoms are often associated with depression, and thus it is not surprising that individuals reporting clinically significant levels of depression would also report a range of physical complaints.

A previously mentioned study that found half of the caregivers of people with TBI reported symptoms of depression also concluded that those individuals were significantly more likely to report experiencing physical symptoms such as backache or stiffness the previous week (Rivera et al., 2007). This suggests that there is a relationship between depression and physical complaints, though the cross-sectional nature of the study makes it impossible to determine causality in either direction. Similar results have been found in other caregiving populations; the previously mentioned study of caregivers of liver transplant patients (Cohen, Colantonio, & Vernich, 2007) found a correlation between higher levels of overload and subjective health.

Previous studies support the idea that caregivers are more likely to experience negative mental and physical health than non-caregivers. However, not all caregivers suffer from depression, anxiety, or poor health. Caregivers who have confidence in their ability to meet the demands of caregiving may be less likely to exhibit symptoms of depression and anxiety and more likely to engage in positive health practices. It may also be the case that finding meaning through caregiving mitigates its negative effects as a chronic stressor thus resulting in a reduced inflammatory response and allostatic load that would ultimately be associated with poor physical health outcomes.

### **Positive emotions and caregiving: Finding meaning through the caregiving process.**

Whereas the negative effects of caregiving are well-documented, some caregivers manage the process quite well, and some even report an increase in positive emotions associated with the caregiving role. Even caregivers who experience negative effects associated with their caregiving role can report positive emotions during the caregiving process (Folkman & Moskowitz, 2000). There has been a shift in the literature that coincides with the emergence of positive psychology in which caregiving researchers seek to understand the role of positive emotions in the coping process, and what implications such findings would have for caregivers

and care recipients. As a result, researchers are seeking to develop interventions aimed at improving caregivers' well-being.

Few empirical studies exist that consider the role of positive emotions in the caregiving process, but there is a sound theoretical foundation for considering these relationships. In the late 1990s, Folkman revised her stress and coping model to include the role of positive emotions (Folkman, 1997). Much of Folkman's ideas for these revisions grew out of her work with HIV caregivers in the 1980s and 1990s and the discovery that positive appraisal was associated with enhanced well-being of the caregiver (Folkman & Moskowitz, 2000). The original stress and coping model explained coping in terms of one's cognitive appraisal of the situation and problem- and emotion-focused coping, but failed to account for coping in the face of an undesired event (Folkman, 2008). The revised model posits that there is a third type of coping associated with such a situation—meaning-focused coping. This type of coping occurs when an unexpected or undesirable outcome occurs and it generates positive emotions and enables the individual to persevere; religious/spiritual beliefs, as well as individual values and life goals are critical to this process (Folkman, 2008).

An intervention study with Alzheimer's caregivers based on Folkman's revised model of stress and coping provides support for the idea that personal mastery and positive emotions, and specifically finding positive aspects of caregiving, can benefit caregivers. The study focused on ways to modify the home environment to increase caregiver mastery (Hilgeman, Allen, DeCoster, & Burgio, 2007). Self-report measures included demographics, activities of daily living for the care recipient, mental status of the care recipient, caregiver health and health behaviors, caregiver anxiety, social support, depression, positive aspects of caregiving, religiosity, and social activities. Measures were completed at baseline, 6 months, and 12 months. Findings indicated that African-Americans reported more positive aspects of caregiving (PAC)

than Caucasians; decreases in caregiver burden over time were associated with increased PAC, and higher PAC was associated with lower levels of depression as well as with less upset related to providing care. The intervention was most effective for caregivers who were initially low in PAC. A potential explanation for this finding is that this variable, PAC, is not trait-based, but rather is open to development and augmentation, an idea which has important implications for caregivers and for potential interventions. If caregivers can be taught to find positive aspects of caregiving, the development of such skills may aid in alleviating negative effects associated with caregiving.

A recent study of caregivers ( $N = 73$ ) for patients with dementia, cancer, and other disorders found that time spent helping was associated with greater positive affect, particularly among spouses who considered themselves highly interdependent with their care recipient (Poulin et al., 2010). The authors hypothesized that these results suggest that helping a loved one can be beneficial because of the feelings of altruism and love the caregiver feels when helping. One major strength of this study was its use of palm pilots that beeped at random intervals and prompted caregivers to respond to questions. Many studies of caregivers are retrospective, and thus this innovative design made this study of particular note.

Fredrickson's "broaden and build" model has also emerged as a way of understanding the role of positive emotions and psychological well-being. Fredrickson argues that "an emotion begins with an individual's assessment of the personal meaning of some antecedent event. This appraisal process may be either conscious or unconscious ..." (Fredrickson, 2001, pg. 218). In this definition it is easy to see the connection to Folkman's meaning-focused coping as well as the connection between emotions and cognitions. Fredrickson agrees with existing theory that suggests that positive emotions and affect encourage individuals to engage with their environments. Her theory expands the role of positive emotions; she argues that positive

emotions such as joy or love encourage individuals to seek out new experiences and become more creative—they broaden our usual set of behaviors or thoughts. With this enhanced way of thinking, we develop “enduring personal resources, which function as reserves to be drawn on later to manage future threats” (Fredrickson, 2001, pg. 220). Finally, she discusses the implications of this model within the context of the undoing hypothesis, in which she argues that positive emotions can, essentially, undo negative emotions and ultimately improve both psychological and physical health.

Within the military context, the Resiliency Model of Family Stress, Adaptation, and Adjustment is based on stress and coping theory and incorporates the family response (Griffin et al, 2009). Griffin and colleagues describe resiliency in the face of adversity within a family systems model in that the individual is part of the family unit that must recover from an injury.

### **Positive aspects of caregiving.**

Although this is a relatively new—and exciting area—for caregiving research, especially among caregivers of people with TBI, some studies do exist that lend empirical support to the above mentioned theories. For caregivers of TBI patients, strong family functioning pre-injury is associated with better adjustment to caregiving (Degeneffe, 2001). However, the concept of family functioning is intertwined with other variables such as SES. A New Zealand study surveyed caregivers ( $N = 52$ ) whose care recipients had sustained a TBI an average of six years previously, mostly in car accidents. They found that 60 percent of caregivers reported that they enjoyed caregiving and 50 percent reported that the work was rewarding and provided them with feelings of accomplishment (Knight, Devereux, & Godfrey, 1998). Similar results were found in a later study of caregivers of people with TBI. Machamer, Temkin, and Dikmen’s (2002) previously mentioned study of caregivers of people with TBI included a modified version of the Zarit Burden Interview (Zarit, Reever, Bach-Peterson, 1980) that included additional questions

aimed at assessing positive aspects of caregiving. In that study, 60 percent of caregivers reported more positive than negative aspects of caregiving; 92 percent reported that they felt pleasure associated with their caregiving role.

Building on these studies, a more recent study of caregivers of people with TBI ( $N = 72$ ) assessed both negative and positive aspects of caregiving. (Wells, Dywan, & Dumas, 2005). In that survey study, the care recipient had sustained a TBI in a motor vehicle accident, was at least one year post-injury, and averaged 10 years post-injury. Caregivers reported more positive emotions than negative emotions related to the caregiving experience, and caregivers who felt better equipped for caregiving also reported more positive feelings about caregiving. Caregivers who had higher self-efficacy for managing caregiving-related problems reported lower levels of depression, anxiety, and somatic complaints (Wells, Dywan, & Dumas, 2005). The authors noted that the Machamer, Temkin, and Dikmen study (2002) was one of the first to ask caregivers about their positive experiences, and suggest that the assumption that caregiving is generally a negative experience may be due to the fact that researchers had previously neglected to ask caregivers about their positive experiences.

These results suggest that it is important to ask caregivers about their positive emotions related to caregiving and that the lack of studies on this population regarding positive emotional outcomes may be due to researchers previously not assessing these types of emotions. Thus, whereas previous research has documented the negative effects of caregiving, it is possible that we have yet to fully understand the caregiving experience because we have failed to appreciate the full range of emotions experienced by caregivers of people with TBI.

Chronister and Chan (2006) support the conclusions by Wells et al. (2005) and also believe that one of the reasons positive emotions are ignored is that there is no recognition of the role of positive emotions in the caregiving process. Furthermore, they argue that although



general theories of caregiving stress and coping as well as specific models of stress and coping for dementia caregivers exist, TBI researchers have yet to develop a specific model of coping relevant to caregivers of people with TBI. The majority of TBI research, they contend, has focused on associations among variables. They developed and tested a stress process model based on 108 caregivers of severe TBI patients. In their final model, quality of life was associated with burden and mastery. Specifically, burden was the best predictor of quality of life for caregivers who reported the highest levels of burden and the lowest overall quality of life. Mastery, part of caregiver appraisal, was associated with increased quality of life, suggesting that caregivers who feel better equipped to handle the demands of caregiving are less likely to experience pervasive negative emotions or psychological distress. Researchers in other caregiving populations have found similar results.

A Canadian study involving caregivers of older adults ( $N = 289$ ) found that 73 percent reported at least one positive aspect of caregiving and nearly seven percent reported more than one (Cohen, Colantonio, & Vernich, 2002). Higher levels of positive emotions related to caregiving were associated with less burden, less depression and with higher levels of self-reported physical health as measured by two questions. Although this study is not specific to the TBI caregiving population, it is relevant because its findings offer empirical support for the idea that caregivers do find meaning and positivity through caregiving in a large sample. Similarly, a study of liver transplant caregivers found that caregivers with a higher sense of personal gain related to their caregiving role reported lower levels of depression (Cohen, Katz, & Baruch, 2007).

Some caregivers not only avoid negative mental and physical health consequences, but also exhibit strength, positivity, and resilience (Cohen, Colantonio, & Vernich, 2002). Resilience in caregivers is often considered to be the caregiver's ability to endure the burdens of caregiving

without experiencing depressive symptoms, and is hypothesized to relate to constructs such as self-efficacy, locus of control, and (inversely with ) neuroticism (Gaugler, Kane, & Newcomer, 2007). Research has also considered the effects of caregivers' recognition of the positive aspects of caregiving (PAC), or the benefits and satisfaction associated with providing care (Hilgeman et al., 2007). In a longitudinal study of in-home family caregivers ( $N = 243$ ), caregivers who reported higher levels of PAC experienced less depression, less behavioral bother, and less daily burden (Hilgeman et al., 2007). These results suggest that positively appraising the caregiving situation can benefit the mental health of the caregiver. In a series of studies with older adults, researchers found that positive emotions are critically important during times of stress, that resilient individuals report more positive emotions, and that individuals low in resilience exhibit difficulty regulating negative emotions and tend to be more reactive to stress in their everyday lives (Ong et al., 2006).

Thus empirical research supports the idea that positivity is associated with resilience and closely tied to a more adaptive way of responding to daily stressors. These findings are of particular interest for caregivers, who face the same daily stressors as most people but are also dealing with the stress associated with caregiving. When faced with the task of providing care to a family member and the prospect that such care will only increase over time as the care recipient's health declines, a caregiver's positive emotions may serve as important buffer against negative outcomes during the caregiving process.

### **Preparedness and self-efficacy for caregiving.**

Within the caregiving literature, several different constructs are discussed in terms of positivity, such as preparedness for caregiving, self-efficacy for caregiving, resilience, and positive emotions. These constructs represent different concepts; however, the measures used in

the current study do not necessarily neatly map onto only one, and thus a broad discussion of these constructs and the literature incorporating them follows.

Preparedness for caregiving is “how ready caregivers believe they are for the tasks and stresses of caregiving” (Schumacher, Stewart, & Archbold, 1998, p. 66). It is related to one’s perceptions about the role of the caregiver and an individual’s self-perception relative to his or her readiness for this task (Schumacher, Stewart, & Archbold, 1998). Preparedness is closely related to self-efficacy in that both constructs concern an individual’s beliefs about his or her abilities. In the current study, the measure used is called preparedness for caregiving; however, due to modifications by the study team, preparedness was subsumed under “self-efficacy” and thus that concept will be reviewed.

The concept of self-efficacy is rooted in Albert Bandura’s social cognitive theory. Recently, Bandura (2007) has re-emphasized that self-efficacy is a domain-specific construct, and is not to be confused with actual ability. That is, “it is concerned not with what one *has* but with belief in what one *can do* with whatever resources one can muster. The operative nature of perceived self-efficacy is an integral feature of the procedure used to access people’s efficacy beliefs” (Bandura, 2007, p. 646). Self-efficacy’s predictive power has been documented across domains as varied as personal empowerment (Ozer & Bandura, 1990), career choice (Lent & Hackett, 1987), job satisfaction and performance (Judge & Bono, 2001) and leadership (Hoyt, Murphy, Halverson, & Watson, 2003).

Archbold, Stewart, Greenlick, and Harvath (1990) argue that caregiver preparedness should be assessed relative to the general domain of caregiving, and not be task-specific. In their study of caregivers ( $N = 78$ ) of older adults, preparedness for caregiving was found to predict caregiver role strain, a concept similar to burden. Similar results were found in a survey study of caregivers of people with TBI ( $N = 52$ ) whose care recipient had been injured an average of six

years previously. In that study, caregivers who had more confidence in their abilities to handle caregiving responsibilities reported lower levels of burden than those caregivers whose reported lower confidence in their caregiving abilities (Knight, Devereux, & Godfrey, 1998). In that study, injury severity was not associated with caregiver's confidence, suggesting that caregiver appraisal can mediate the effects of stressors on depression (Harris, Godfrey, Partridge, & Knight, 2001).

In a study of in-home family caregivers of dementia patients, increased self-efficacy in two domains related to caregiving was associated with better caregiver health (Rabinowitz et al., 2007). Thus a caregiver's self-efficacy for caregiving is tied to his or her perceived ability to manage upcoming challenges. Caregivers with low self-efficacy for caregiving are likely to feel overwhelmed and unable to meet the challenges associated with caregiving, whereas those with high self-efficacy for caregiving should, theoretically, view the caregiving situation as one to which they will adapt and successfully manage.

### **Effects of race/ethnicity and caregiving.**

Studies on racial/ethnic differences in caregivers of people with TBI have produced mixed results. For example, one such study ( $N = 256$ ) at 1, 2, and 5 years post-injury found that African-American caregivers were more likely to be friends or family members as opposed to spouses; African-American care recipients were more disabled than their Caucasian counterparts and this difference was not due to injury severity. The authors do not hypothesize as to why African-American care recipients were more disabled, but note that TBI etiology differed significantly between groups, with one-third of the African-American care recipients having been injured in a violent attack compared with only 3% of the Caucasian care recipients. Further, African-American caregivers reported spending more time engaged in caregiving activities and reported higher levels of depression (Hart et al., 2007). The authors suggest that African-

Americans may be at increased risk of negative emotional effects from caregiving and tend not to take full advantage of services available to them. There is also some evidence that minorities' marriages are more adversely affected by TBI (Arango-Lasprilla & Kreutzer, 2010). Other studies, however, have failed to find significant differences among caregivers of different races/ethnicities.

In a study using structured interviews of community residents in Chicago ( $N = 5,924$ ), 16 percent reported serving as caregivers; African-Americans were 30 percent more likely to be caregivers than Caucasians. Among caregivers, African-Americans reported spending 13 hours more per week engaged in caregiving (McCann et al., 2000). In another study, focused on Alzheimer's disease caregivers, African-American caregivers ( $n = 121$ ) reported more positive aspects of caregiving than Caucasians ( $n = 122$ ) and less depression (measured by the CES-D) and behavioral bother, a concept the authors compare to burden (Hilgeman et al., 2007). Taken together, these studies suggest that although African-American caregivers spend more time caregiving, they also report less subjective burden and more positive emotions associated with the caregiving experience.

A study that considered racial differences compared African-American ( $n = 24$ ) and Caucasian ( $n = 21$ ) caregivers of TBI patients with a moderate to severe TBI who had been an inpatient or received rehabilitation services and were at least one year post-injury (Nabors, Seacat, & Rosenthal, 2002). The majority of the patients had sustained a TBI in a motor vehicle accident, and the research was conducted using both self-report surveys and structured interviews via telephone. No statistically significant differences between the two groups were found in terms of perceived level of support or burden; however, only 30 percent of African-American caregivers reported that their needs were being met, compared to 60 percent of their Caucasian counterparts. Another study used structured interviews and surveys with caregivers of

people with TBI ( $N = 195$ ) in which 75 percent were Caucasian and the remainder were African-American and Hispanic (Sander et al., 2007). Results indicated that race/ethnicity was not a significant predictor of caregiver depression, anxiety, perceived burden, or caregiver satisfaction when controlling for the effects of age, education, and kinship status. This large, recent study offers support for the idea that between group differences may not exist in caregivers of people with TBI, despite findings from studies on other types of caregivers.

It is important to try to understand the unique experiences of caregivers. If differences do exist between different racial/ethnic groups, researchers and clinicians may be able to tailor interventions that target the caregivers with whom they are working. This is also an important research question because it has the potential to inform our understanding of health disparities. African-American caregivers are at higher risk for obesity, high blood pressure, heart disease, stroke, and kidney disease compared to their Caucasian counterparts (Long et al., 2004), and thus finding ways to alleviate caregiver stress may directly affect the long-term health of African-American caregivers. Thus until this question has more support in either direction, it is important that caregiver researchers continue to seek to explore what differences, if any, do exist.

### **Kinship status.**

Kinship status refers to whether the caregiver is a spouse, parent, or other family member. Findings regarding differences among these groups are also mixed. For example, no differences in depression or anxiety based on kinship status were found in one study of caregivers of people with TBI, though the authors suggest that the relatively small sample size (51 spouses and 17 parents) may have affected their results (Wells, Dywan, & Dumas, 2005). A recent study of caregivers of people with TBI ( $N = 273$ ) also found no such differences (Kreutzer et al., 2009). However, other studies have found support for the idea that important differences between parental and non-parental caregivers exist.

A study of caregivers of TBI patients ( $N = 62$ ) found that parents were less likely than spouses to report depressive symptoms or distressed family functioning (Kreutzer, Gervasio, & Camplair, 1994). In one of the largest studies to focus primarily on kinship differences, caregivers ( $N = 116$ ) of TBI outpatients at least 10 months post-injury completed several measures (Gervasio & Kreutzer, 1997). The study included spousal caregivers ( $n = 69$ ) and parental caregivers ( $n = 47$ ) and found that spouses were significantly more likely to report psychological distress than parents, though levels of perceived stress did not differ between the two groups. The authors hypothesize that having a large sample, with caregivers who had been in their roles for an average of two years, may have contributed to their significant findings as compared to other, smaller studies. They suggest that time since injury may be important because it is only after caregivers have been their role for some time would significant differences emerge based on kinship status. Further, the large meta-analysis discussed previously (Pinquart & Sorensen, 2007) did find that spousal caregivers generally report higher levels of burden and depression. The authors suggest that this finding may be due to the role conflict experienced by spouses, who perhaps never envisioned themselves providing such care for a spouse, whereas parental caregivers have a history of caregiving for their child.

### **Effects of caregiver variables on care recipient.**

Although few studies consider how caregiver characteristics might affect care recipient outcomes, or caregiver perceptions of care recipient outcomes, this remains an important research question. By pinpointing caregiver traits associated with better care recipient outcomes, it may be possible to develop interventions that can promote not only caregiver well-being, but also care recipient well-being.

One study of caregivers of TBI patients in the Netherlands included surveys of the caregivers ( $N = 51$ ) as well as surveys and interviews with the care recipients to understand what

effect caregiver coping style had on the care recipient (Van Baalen et al., 2007). Results indicated that even when controlling for care recipient age, passive coping such as avoiding others or worrying about the past on the part of the caregiver was associated with restrictions in activities on the part of the care recipient. These findings suggest that passive coping by the caregiver may have negative consequences for the care recipient, and the authors believe that interventions aimed at encouraging active coping—which they define as immediate attention to issues and problem-solving behaviors—would not only result in reduction of stress for the caregiver, but would also have positive consequences such as increased functionality for the care recipient. The authors do note the limitations imposed by the small sample, and thus replication of their findings would provide additional support for their conclusions.

No other comparable studies with caregivers of people with TBI were found. However, similar work has been done with dementia patient caregivers. For example, a study of French, Spanish, and Italian Alzheimer's Disease patients and their caregivers ( $N = 224$ ) found that higher caregiver burden, measured by the Zarit Burden Interview at baseline, was associated with the development of feeding problems in the care recipient one year later (Rivieère et al., 2002). This study is important because the relationship between caregiver burden and care recipient feeding behavior was not significant at baseline, when burden was measured, which suggests that the caregiver was affecting the care recipient, rather than the converse.

Another study (Gaugler, Kane, & Newcomer, 2007) of caregiver burden and care recipient outcomes considered Alzheimer's disease caregivers ( $N = 1,979$ ). Burden was measured with a seven-item version of the Zarit Burden Interview (Bedard, Molloy, Squire, Dubois, Lever, & O'Donnell, 2001). Nurses and social-workers conducted in-home interviews every six months for three years. Caregivers were dichotomized into two categories: high resilience, defined by having high care demands and low burden; and low resilience, defined by having low care



demands and high burden. High burden was defined as those participants scoring in the upper quartile on burden. Additionally, the nurses and social workers gave the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) to the care recipients and participants completed a survey on what resources they had used within the previous six months. Results indicated that high baseline resilience was associated with fewer institutionalizations, fewer cases lost to follow up, and more frequent care recipient mortality. There were also racial/ethnic differences, with Caucasian caregivers more likely to fall into the low resilience group. The authors' hypotheses were partially supported, as increased mortality of the care recipient was found in the high resilience group, a finding the authors suggest may be due to preparation on the part of the caregiver for the death of their care recipient. Alternatively, due to the operationalization of the term "resilience," the authors hypothesize that because the "high resilience" group was defined by those reporting high care demands, that the associated care recipients were further progressed in the disease process. Regardless of the explanation, this study provides support for the idea that caregiver variables, in this case, resilience, can affect care recipient outcomes.

A large study of dementia caregivers ( $N = 5,788$ ), in which interviewers met with caregivers in their homes found that even when controlling for patient age, sex, dementia severity and functional status, caregiver characteristics such as age, education, subjective burden, depression level, and hours spent providing care were associated with increased neuropsychiatric symptoms of depression in their care recipient (Sink et al., 2006). The authors note that the direction of this relationship cannot be established by their or other cross-sectional studies, but that it should not be assumed that care recipient symptoms are causing caregiver symptoms, as is often the case. They believe that the relationship between the members of the dyad is critical and that caregiver variables can affect care recipient outcomes. This study is especially relevant to

the current study because care recipient outcomes were measured by a survey the caregivers completed that asked them about key behaviors in their care recipients.

It is possible that the reason there is a dearth of studies along these lines is that it is very difficult to determine the direction of any relationship that is found. First, caregiving studies are largely correlational in nature, and thus causality cannot be inferred. Perhaps the care recipient's reduced activity or increased depression leads to poor coping or feelings of increased burden in their caregivers. However, because random assignment and true experimental design would be impossible to employ to test these hypotheses, replication, particularly in different caregiver/care recipient populations is an important way to garner additional support for these ideas. If indeed certain caregiver characteristics—besides demographic variables that are unable to be changed—are associated with improved care recipient outcomes, then interventions to improve caregiver psychological health would benefit not only the caregiver, but also the care recipient.

Based on a review of the literature of caregiving and positive emotions, it appears that study of positive aspects of caregiving and personal growth associated with the caregiver role originated with HIV caregivers and Folkman's recognition of the need to revise the original stress and coping theory. As our lifespans have increased and more people are diagnosed with dementia, many more people are finding themselves serving as caregivers. Dementia caregiving research has followed Folkman's model and has begun to focus on the role of positive emotions. Although the TBI caregiving literature is not as large as the dementia caregiving literature, it is important to understand the role of positive emotions in these caregivers too, especially as they are likely to represent a different population from HIV or dementia caregivers. The first step in this process is documenting the existence of relationships among positive emotions and positive outcomes in TBI patient caregivers.

### **Research hypotheses.**

*Hypothesis 1 (a) and (b).* Caregivers who report increased self-efficacy for caregiving will report both (a) better perceived physical functioning and (b) better subjective physical health even when controlling for the effects of age and education level.

*Hypothesis 2 (a) and (b).* Folkman's revised stress and coping model (Folkman, 1997) suggests that individuals who are able to find meaning in stressful events are likely to experience more positive emotions. She recommends that researchers studying stress include measures of positive emotions and continue to elucidate the role of meaning-focused coping in stressful situations (Folkman, 2008). Thus, hypotheses 2 (a) and (b) will focus on positive growth associated with caregiving and are as follows: Personal gain will be inversely associated with (a) depression and (b) anxiety in caregivers, even when controlling for age and education level. The relationship between personal gain and both depression and anxiety will be partially mediated by perceived burden. Burden will serve as a mediator rather than the predictor variable for two reasons. First, previous research already strongly suggests that burden is associated with depression (Cohen, Katz, & Baruch, 2007; Machamer, Temkin, & Dikmen, 2002; Sander, High, Hannay, & Shere, 1997) and further documenting that relationship is unlikely to add much to our understanding of the correlates of caregiver depression. However, understanding the full spectrum of caregiver emotions, including positive feelings, is an area that has been underexplored among TBI researchers. Thus, the second reason for considering the relationship among the variables in the proposed way is to determine whether having a sense of personal gain associated with caregiving may affect the relationship between burden and depression. Implications of this relationship would include focusing on helping caregivers recognize positive aspects of caregiving and how those aspects reduce their sense of burden.

**Hypothesis 3.** Based on previous research suggesting an association between caregiver characteristics and care recipient outcomes, this hypothesis will consider such a relationship within the context of positive growth on the part of the caregiver and positive outcomes for the care recipient as perceived by the caregiver. That is, caregivers who report higher levels of personal gain and spirituality will report care recipients who are better emotionally adjusted (as perceived by the caregiver) even when controlling for caregiver age and education level.

**Hypothesis 4 (a) and (b).** Some previous research suggests that racial differences exist in caregiving populations, whereas other studies have failed to find such differences. This hypothesis will be exploratory in nature. Due to the small sample size, participant race will be dichotomized into two groups: Caucasian and non-Caucasian. Hypothesis 4 (a) focuses on perceived caregiver health and posits that non-Caucasian caregivers will report lower levels of physical functioning as well as subjective health than their Caucasian counterparts. Hypothesis 4 (b) focuses on caregiver impact and posits that non-Caucasian caregivers will report providing more hours of care but lower subjective burden.

**Hypothesis 5 (a) and (b).** Studies on differences in depression, anxiety, and burden based on kinship status have yielded mixed results, with some finding no significant differences based on the caregiver's relationship to the care recipient. However, one of the largest studies on caregivers of TBI patients that focused on kinship differences did find that parental caregivers reported less psychological distress than non-parental caregivers (Gervasio & Kreutzer, 1997). These findings were echoed by a large meta-analysis of studies on caregiving that included caregivers of many different types of patients and found that parental caregivers reported less depression and burden (Pinquart & Sorensen, 2007) did find that spousal caregivers generally report higher levels of burden and depression. Thus this hypothesis is exploratory in nature and

posits that parental caregivers will report less depression, anxiety, and burden than non-parental caregivers, even after controlling for education level.

## **Method**

### **Participants**

Surveys were mailed in February 2009 to the designated next of kin or contact person of veterans who were treated in an inpatient rehabilitation unit between 2001 and 2008 at one of four Department of Veterans Affairs Medical Center sites designated as Polytrauma Rehabilitation Centers (PRCs) (Minneapolis, Palo Alto, Richmond, or Tampa). IRB approval was obtained at all four sites. The Virginia Commonwealth University's IRB has approved the secondary analysis of this data set.

Inclusion criteria related to the care recipient included:

- Patient was not a veteran of Operation Enduring Freedom/Operation Iraqi Freedom (OEF/OIF). The reason for this is that the current study was a pilot (Griffin et al., 2012) for a larger study that focused on OEF/OIF caregivers;
- Patient had been discharged for at least three months;
- Patient had been diagnosed with a traumatic brain injury; specifically, the veteran had received inpatient care for a TBI at a PRC between 2001 and 2008; and
- Patient age at the time the study began was 50 or younger.

Prospective participants received a \$20 incentive; individuals could keep the incentive whether or not they returned the survey. The overall response rate to the survey was 61% and the total number of responses received was 75. Five surveys were received after the survey close-out date and therefore were not included in analysis. Sample size for the current study is thus  $N = 70$ . Demographic data are summarized in Tables 1 and 2.

Table 1.

*Frequencies of Demographic Characteristics of Participants (N = 70)*

Characteristic	<i>n</i>	%
Male caregiver	7	10
Male care recipient	65	92.86
Marital status of caregiver		
Married	46	66.67
Divorced	13	18.84
Separated	2	2.90
Widowed	4	5.80
Never married	3	4.35
Living with a partner	1	1.45
Education level of caregiver		
Some high school/high school/GED/trade school	26	37.68
Some college/associates degree	28	40.58
College or higher	15	21.74
Days per week of caregiving		
Less than once a week	16	24.24
One day a week	3	4.55
2 days a week	2	3.03
3 days a week	1	1.52
4 days a week	1	1.52
5 days a week	3	4.55
6 days a week	4	6.06
7 days a week	36	54.55
Amount of care provided		
Less than half of care recipient needs	18	25.7
Half of care recipient needs	5	7.1
Most of care recipient needs	12	17.1

All of care recipient needs	29	41.4
Race		
Caucasian	56	82.35
Non-Caucasian	12	17.65
Kinship status of caregiver		
Mother	17	27.87
Father	1	1.64
Wife	15	24.59
Husband	7	11.48
Girlfriend (romantic partner)	3	4.92
Daughter	1	1.64
Son	11	18.03
Sister	2	3.28
Brother	2	3.28
Other	2	3.28

*Note.* Columns may not sum to 70 due to missing data

Table 2

*Descriptive Demographic Characteristics of Participants (N = 70)*

Characteristic	<i>M</i>	<i>SD</i>
Caregiver age in years	53.28	13.18
Care recipient age in years	40.86	6.55
Months caregiver had been providing care at time of survey	69.61	57.39

## Design

This study was a non-experimental survey design employing well-validated pen and paper self-report measures. It was developed as a pilot study for a larger Family and Caregiver

Experience Survey (FACES). The study was a multi-site collaboration among the four VA polytrauma sites mentioned above. Deidentified data related to the study hypotheses were provided to me by the FACES Minneapolis team. Data not related to the current study's hypotheses was not provided.

## **Measures**

Participants were asked information about themselves, their families, and their care recipient using several measures. The entire survey was 33 pages long. For this study, only the following measures were be used:

**Demographic data.** (Appendix A). Participants were asked to provide information on the following: relationship to care recipient, length of time caregiving, amount of time spent caregiving, marital status, age, gender, race/ethnicity, education level, and when and how the care recipient was injured. These questions were integrated throughout the survey. Participants were asked to check a box indicating their level of education, so in the analyses, this variable was dummy coded with three levels: some high school/high school/GED/trade school; some college/associates degree, and college or higher. The first group served as the reference group.

**Key Behavior Change Inventory—modified** (Kolitz, Vanderploeg, & Curtiss, 2003). (Appendix B). The original Key Behavior Change Inventory assesses behavioral changes in a patient who sustains a TBI by asking the caregiver to rate how much a series of statements applies to their care recipient. It consists of 64 questions that load onto eight subscales: inattention, impulsivity, unawareness of problems, apathy, interpersonal difficulties, communication problems, somatic difficulties, and emotional adjustment. Items are rated on a four-point Likert-type scale with *1 = Not True* through *4 = Very True*. Positively-worded items are reversed scored, and subscales are summed such that higher scores indicate higher levels of behavioral problems. For this study, 35 questions, comprising six subscales and omitting the



apathy and somatic difficulties scales, were used in order to reduce the overall number of questions participants would have to answer. In deciding which questions to retain, the FACES research team considered the factor structure and scale properties and selected the questions with the greatest item-scale correlations, combined with the greatest internal consistency (S. Phelan, personal communication, August 19, 2010). The current study uses the Communication Problems and Emotional Adjustment subscales. Sample items from the Communication Problems subscale include asking the caregiver to rate how much the care recipient “says things that don’t make sense” and “listens carefully and responds normally when talking with others.” Sample items from the Emotional Adjustment subscales include asking the caregiver to rate how much the care recipient “is positive about the future” and “copes poorly with stress.” Cronbach’s alpha for the subscales has been reported to range from .82 to .91 (Kolitz, Vanderploeg, & Curtiss, 2003). In the current study, Cronbach’s alpha was .88 for the Emotional Behavior subscale and .80 for the Communication subscale.

**Pearlin’s Personal Gain and Spirituality Scale—modified** (Pearlin, Mullan, Semple, & Skaff, 1990). (Appendix C). A modified version of Pearlin’s et al. Personal Gain Scale was used. The original scale is a 4-item measure assessing what kind of positive changes an individual believes he or she has experienced as a direct result of caregiving. Participants are asked to rate how much they have experienced these changes on a four-point Likert scale. The FACES pilot study modified this scale to include a question assessing increases in faith or spirituality and expanded the answer choice to a five-point Likert-type scale, with answer choices ranging from *1 = Disagree A Lot* to *5 = Agree A Lot*. Participants were instructed to rate how much they agreed with a series of statements as a result of caregiving. Sample statements include “become more aware of your inner strengths” and “grown as a person.” Higher scores indicate that the participant believes he or she has experienced more positive growth as a result of caregiving.

Cronbach's alpha for the original four-question scale has been reported to be .76 (Pearlin et al., 1990). Cronbach's alpha is not available for the modified scale's use in other studies. In the current study, Cronbach's alpha was .89.

**Preparedness for Caregiving Scale—modified** (Archbold, Stewart, Greenlick, & Harvath, 1990). (Appendix D). A modified version of the Preparedness for Caregiving Scale was used. The original scale is a three-item scale measuring how prepared one feels for the physical, emotional, and emergency-related needs of caregiving. For FACES, this scale was reduced to two items (physical and emotional needs) and modified by replacing the word “prepared” with “confidence” in order to assess caregiver's self-efficacy for caregiving in general, thus in the current study, this scale will be used to measure self-efficacy for caregiving. The original, unmodified, scale has Cronbach's alpha reported to range from .88 to .92 (Schumacher, Stewart, & Archbold, 1998). This was the first time the modified scale was used, and Cronbach's alpha was .57.

**PROMIS Anxiety—Short Form** (PROMIS Health Organization and PROMIS Cooperative Group, 2008). (Appendix E). The Patient-Reported Outcomes Measurement System (PROMIS) anxiety short form assesses an individual's subjective experience of anxiety symptoms such as fear and arousal. It was developed by NIH as part of its comprehensive research efforts to encourage research and collaboration across the United States. The PROMIS anxiety short form is a seven-item measure on which participants are asked to rate how often they have experienced certain symptoms over the past seven days. Each item is rated on a five-point Likert-type scale ranging from *1 = None of the Time* to *5 = All of the Time*. Sample items include, “I felt fearful” and “I felt nervous.” Scoring is based on an algorithm developed by NIH in which raw scores are converted to T-scores. Higher T-scores indicate higher levels of anxiety. The possible range is 46.4; in the current study, the range was 43.2. Cronbach's alpha has been

reported to be .93 for this measure (NIH, 2010). In the current study, Cronbach's alpha was also .93.

**PROMIS Depression—Short Form** (PROMIS Health Organization and PROMIS Cooperative Group, 2008). (Appendix F). The Patient-Reported Outcomes Measurement System (PROMIS) depression short form assesses an individual's subjective experience of depressive symptoms. It was developed by NIH as part of its comprehensive research efforts to encourage research and collaboration across the United States. The PROMIS depression short form is an eight-item measure on which participants are asked to rate how often they have experienced certain symptoms over the past seven days. Each item is rated on a five-point Likert-type scale ranging from *1 = None of the Time* to *5 = All of the Time*. Sample items include, "I felt worthless" and "I felt unhappy." Scoring is based on an algorithm developed by NIH in which raw scores are converted to T-scores. Higher T-scores indicate higher levels of depression. The possible range is 44; in the current study the range was 33.3. Cronbach's alpha has been reported to be .95 for this measure (NIH, 2010). In the current study, Cronbach's alpha was .92.

**Promis Physical Functioning—Short Form** (PROMIS Health Organization and PROMIS Cooperative Group, 2008). (Appendix G). This measure assesses both the extent to which an individual's health limits him or her in daily activities and whether he or she can engage in normal self care. It was developed by NIH as part of its comprehensive research efforts to encourage research and collaboration across the United States. The PROMIS Physical Functioning—Short Form is a 10-item measure on which participants rate themselves on a Likert-type scale ranging from 1 to 5. For the first five questions, participants were asked to what extent their health limits their abilities to do things such as do vigorous activity or climb stairs. Response choices ranged from *1 = Not at All* to *5 = Cannot Do*. For the last five questions, participants were asked if they were able to do activities such as yard work or shampoo their

hair. Response choices ranged from *1 = Without Any Difficulty* to *5 = Unable To Do*. Scoring is based on an algorithm developed by NIH in which raw scores are converted to T-scores.

According to the NIH scoring system, higher T-scores indicate less impaired physical functioning. Thus, in the current study, scores were first converted to match NIH protocol, then the NIH algorithm was used to generate a T-score. Cronbach's alpha was not available for this measure, but NIH states that all Promis measures "meet scientific standards of reliability" (nihpromis.org, 2010). In the current study, Cronbach's alpha was .89.

**Promis Global Item—Subjective Health** (PROMIS Health Organization and PROMIS Cooperative Group, 2008). (Appendix H). To measure subjective health, a single-item was used from the PROMIS measure of global health in which participants were asked to rate their health on Likert-type scale from *1 = Excellent* to *5 = Poor*. Higher scores indicate lower ratings of perceived health. Note that in the original NIH measure, this scoring is reversed, with higher scores indicate higher ratings of subjective health.

**Zarit Burden Interview—Short Form** (Bédard et al., 2001). (Appendix I). The ZBI Short Form is a 12-item adaptation of the original 22-item Zarit Burden Interview (Zarit, Orr, & Zarit, 1985), designed to measure subjective burden associated with caregiving. The original measure has been widely used in caregiver studies, and the short form was created to reduce participant completion time while maintaining adequate internal consistency and allowing for comparisons across studies. Correlations between the original and short forms range from .92 to .97. On the ZBI Short Form, participants rated items on a 5-point Likert-type scale ranging from *1 = Never* to *5 = Nearly Always*. Examples of items include: "Because of the times I spend with my care recipient, I don't have enough time for myself" and "I feel strained when I am around my care recipient." Responses are summed, with higher scores indicating higher levels of

subjective burden. Cronbach's alpha of .88 has been reported for the short form of this measure (Bédard et al., 2001). In the current study, Cronbach's alpha was also .88.

## **Results**

The purpose of this study was to understand associations among physical and psychological measures of health and wellness in caregivers of veterans with traumatic brain injury. Scores on variables of interest were first assessed for missing data, normality, linearity, independence, and the presence of outliers.

Normality was assessed by reviewing the residuals scatterplot and the probability plot of residuals. Additionally, tests for normality using skewness or kurtosis absolute values above one showed that all variables were acceptable. I assessed for linearity by reviewing the residuals scatterplot and by creating scatterplots using the dependent and independent variables and plotting the regression line (Field, 2009). No curvilinear relationships were detected.

I assessed for univariate outliers by converting scores for all continuous variables to standardized values. No univariate outliers were detected, based on Tabachnick and Fidell's (2007) suggested cutoff of z-scores with an absolute value of 3.29, or  $p < .001$ . No multivariate outliers were found using Tabachnick and Fidell's (2007) recommended use of a  $p < .001$  criterion.

Independent variables and covariates were assessed for multicollinearity and singularity by examining the correlations among the independent variables and covariates. Using Tabachnick and Fidell's (2007) guidelines, no correlations greater than .70 were found; tolerance and VIF levels were also within Tabachnick and Fidell's (2007) recommended ranges. Note that for individual analyses, listwise deletion was used because NIH advises that Promis measures can only be accurately scored if a participant answers every item. The bootstrapping mediation macro also uses listwise deletion because "it would be inappropriate to piece together a causal

model using tests of significance when the analyses for different paths are based on different subsets of the data” (afhayes.com, 2011). That is why sample sizes are different for different analyses.

In addition to the assumption testing previously discussed, regression-specific assumption testing was conducted for the variables in hypotheses 1-3. I assessed for homoscedasticity by reviewing the residuals scatterplot. No violations of were found. The assumption of independent errors was tested in each hypothesis by reviewing the Durbin-Watson statistic, and per Field’s (2009) guidelines, this assumption was met. Means, standard deviations, and correlations among study variables are provided in Table 3.

Table 3.

*Overall Means, Standard Deviations, and Intercorrelations of Study Variables (N = 41)*

Variable	<i>M</i>	<i>SD</i>	1	2	3	4	5	6	7	8	9	10	11
1. Anxiety	49.34	8.34	–										
2. Caregiver age in years	52.15	13.81	-.22	–									
3. Care recipient communication score (caregiver rated)	2.26	.68	.22	-.17	–								
4. Care recipient emotional behavior score (caregiver rated)	2.41	.75	.30	.00	.65**	–							
5. Depression	49.26	8.04	.79**	-.16	.28	.36*	–						
6. Personal gain score	4.30	.70	-.22	-.00	.21	-.14	-.29	–					
7. Physical functioning	50.06	9.75	-.16	-.51**	-.10	-.17	-.32*	.11	–				
8. Self-efficacy for caregiving score	3.78	.89	-.42**	.08	-.13	-.44**	-.29	.53**	.05	–			
9. Subjective health	2.85	1.13	.27	.12	.19	.42**	.53**	-.30	-.59**	-.26	–		
10. Weekly hours spent caregiving	38.73	48.12	.05	.16	.11	-.21	-.01	.32*	-.17	.28	-.10	–	
11. Zarit burden score	1.22	.73	.72**	-.05	.27	.53**	.78**	-.29	-.26	-.42**	.45**	.04	–

*Note.* The overall *N* presented in this table is low due to the use of listwise deletion. That is also why some means may differ slightly from those presented in hypothesis-specific results.

\* $p < .05$ . \*\* $p < .01$

*Hypothesis 1(a): Caregivers who report increased self-efficacy for caregiving will report significantly better perceived physical functioning even when controlling for the effects of age and education level.*

Hierarchical multiple regression was used to determine whether increased self-efficacy for caregiving is associated with better perceived physical functioning after controlling for the effects of age and education level. Table 4 displays the results of the analysis for Hypothesis 1(a). Age and education level were entered at Step 1, explaining 11.3% of the variance in perceived physical functioning. After self-efficacy for caregiving was entered at Step 2, the total variance explained by the model as a whole remained 11.3%,  $F(4, 55) = 1.76, p = .15$ . The predictor variable of interest, self-efficacy for caregiving, did not explain any additional variance in perceived physical functioning, after controlling for caregiver age and education,  $R^2$  change = .00,  $F$  change (1, 55) = 0.00,  $p = .99$ . In the final model, only the control variable caregiver age was significant, (beta = -.278,  $p = .04$ ). Thus, Hypothesis 1(a) was not supported.

Table 4

*Hierarchical Regression Analysis Summary for Variables Associated with Perceived Physical Functioning (N = 60)*

Step and predictor variable	<i>B</i>	<i>SE B</i>	$\beta$	$R^2$	$\Delta R^2$
Step 1:				0.11	
Caregiver education level:	0.9	2.72	0.05		
Some college					
Caregiver education level:	-3.01	3.38	-0.12		
College and higher					
Caregiver age	-0.20	0.09	-0.28*		
Step 2:				0.11	0.00



Self-efficacy for caregiving	-0.01	1.31	0.001
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\*  $p < .05$

*Hypothesis 1(b): Caregivers who report increased self-efficacy for caregiving will report significantly better subjective physical health even when controlling for the effects of age and education level.*

Hierarchical multiple regression was used to determine whether increased self-efficacy for caregiving is associated with better subjective physical health after controlling for the effects of age and education level. Table 5 displays the results of the analysis for Hypothesis 1(b).

Table 5

*Hierarchical Regression Analysis Summary for Variables Associated with Subjective Health (N = 63)*

Step and predictor variable	<i>B</i>	<i>SE B</i>	$\beta$	$R^2$	$\Delta R^2$
Step 1:				0.02	
Caregiver education level:	0.14	0.30	0.07		
Some college					
Caregiver education level:	0.43	0.36	0.17		
College and higher					
Caregiver age	0.00	0.01	0.01		
Step 2:				0.04	0.02
Self-efficacy for caregiving	-0.16	0.14	-0.15		

---

Age and education level were entered at Step 1, explaining 2.3% of the variance in subjective physical health. After self-efficacy for caregiving was entered at Step 2, the total variance explained by the model as a whole was 4.2%,  $F(4, 58) = .64$ ,  $p = .64$ . The predictor variable of interest, self-efficacy for caregiving, explained an additional 2% of the variance in

subjective physical health, after controlling for caregiver age and education,  $R^2$  change = .02,  $F$  change (1, 58) = 1.18,  $p = .28$ . None of the predictor variables were statistically significant. Thus, Hypothesis 1(b) was not supported.

*Hypothesis 2 (a): Personal gain will be inversely associated with depression in caregivers, even when controlling for age and education level. The relationship between personal gain and depression will be partially mediated by perceived burden.*

First, the direct effects of personal gain on depression, while controlling for age and education level, was tested via hierarchical regression. Hierarchical multiple regression was used to determine whether increased personal gain is associated with less depression after controlling for the effects of age and education level. Table 6 displays the results of the hierarchical regression analysis for Hypothesis 2 (a).

Table 6

*Hierarchical Regression Analysis Summary for Variables Associated with Caregiver Depression (N = 59)*

Step and predictor variable	<i>B</i>	<i>SE B</i>	$\beta$	$R^2$	$\Delta R^2$
Step 1:				0.07	
Caregiver education level:	2.83	2.26	0.18		
Some college					
Caregiver education level:	3.75	2.70	0.20		
College and higher					
Caregiver age	-0.11	0.08	-0.19		
Step 2:				0.09	0.01
Personal gain and	-1.16	1.29	-0.12		
spirituality					

Age and education level were entered at Step 1, explaining 7.2% of the variance in depression. After personal gain was entered at Step 2, the total variance explained by the model as a whole was 8.6%,  $F(4, 54) = 1.27, p = .29$ . The predictor variable of interest, personal gain, explained an additional 1.4% of the variance in depression, after controlling for caregiver age and education,  $R^2 \text{ change} = .01, F \text{ change}(1, 54) = .81, p = .37$ . None of the predictor variables were statistically significant.

To test the second part of the hypothesis, that perceived burden mediates the relationship between personal gain and depression, I bootstrapped the indirect effects of personal gain on depression, using the Preacher and Hayes INDIRECT script version of their SPSS macro. Bootstrapping was used because it is the mediation method with the most power. Given the small sample size, traditional mediation methods would have been inappropriate. Further, as Hayes (2009) notes, the Baron and Kenny method for detecting mediation not only lacks power, but also requires a number of steps, which increases the likelihood of error. For the mediation analyses, a simple mediation model (Hayes, 2009) was proposed. Following are two figures from Hayes (2009), the first depicting the total effect and the second depicting a simple mediation model.



*Figure 1. Total Effect.*

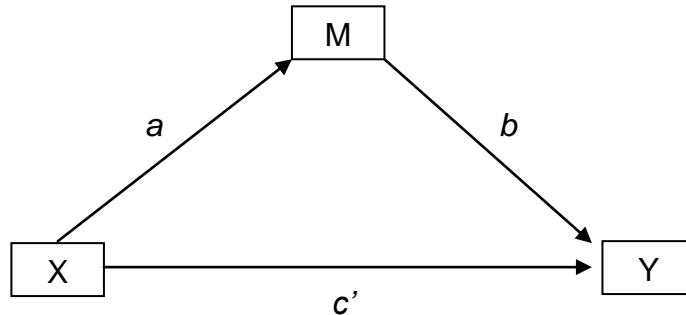


Figure 2. Simple Mediation Model.

Hayes explains a simple mediation model succinctly. I have bolded the especially relevant sentence that will help explain the current study's results:

“In this model,  $a$  is the coefficient for  $X$  in a model predicting  $M$  from  $X$ , and  $b$  and  $c'$  are the coefficients in a model predicting  $Y$  from both  $M$  and  $X$ , respectively. In the language of path analysis,  $c'$  quantifies the *direct effect* of  $X$ , whereas the product of  $a$  and  $b$  quantifies the *indirect effect* of  $X$  on  $Y$  through  $M$ . If all three variables are observed, then  $c = c' + ab$  (in latent variable models or models of dichotomous outcomes, this will not always be true). Simple algebra shows that the indirect effect,  $ab$ , is just the difference between the total and direct effect of  $X$ :  $ab = c - c'$ . **The indirect effect is interpreted as the amount by which two cases who differ by one unit on  $X$  are expected to differ on  $Y$  through  $X$ 's effect on  $M$ , which in turn affects  $Y$ .** The direct effect is interpreted as the part of the effect of  $X$  on  $Y$  that is independent of the pathway through  $M$ ” (Hayes, 2009, p. 409).

In the mediation model, the predictor variable ( $X$ ) was personal gain, the mediator variable ( $M$ ) was perceived burden, and the outcome variable ( $Y$ ) was depression. Age and education were used as covariates. Basic results for total, direct, and indirect effects are provided in Table 7.

Table 7

*Mediation of the Effect of Personal Gain on Depression Through Perceived Burden*

Effect	Point Estimate	Product of Coefficients		Bootstrapping	
		SE	p	BCa 95% CI	
				Lower	Upper
Personal gain to Zarit burden ( <i>a</i> )	-0.2963	0.1178	0.0149		
Zarit burden to depression ( <i>b</i> )	7.8439	1.0736	0.0000		
Personal gain to depression ( <i>c</i> )	-1.5112	1.2980	0.2495		
Direct effect of personal gain on depression ( <i>c'</i> )	0.8132	0.9739	0.4076		
Partial effect of control variables on DV					
Caregiver education: Some college	0.5480	1.9436	0.7791		
Caregiver education: College and higher	0.8024	1.6231	0.6231		
Caregiver age	-0.0947	0.0565	0.0996		
Indirect effect: Zarit burden ( <i>axb</i> )	-2.3245	1.0684		-4.9873	-0.5484

Note—BCa, bias corrected and accelerated; 1,000 bootstrap samples

Analysis revealed that the indirect effect of personal gain on depression through subjective burden, while controlling for age and education, is not zero by a 95% bias corrected and accelerated bootstrap confidence intervals based on 1000 bootstrap resamples (-4.9873 to -.5484, with a point estimate of -2.3245), as are the paths from  $X$  to  $M$  ( $a = -0.2963, p = .0149$ ) and  $M$  to  $Y$  controlling for  $X$  ( $b = 7.8439, p = .0000$ ). Interpreting bootstrapping results relies on the usage of confidence intervals rather than  $p$  values (Shrout & Bolger, 2002). As opposed to the Baron and Kenny method, bootstrapping does not rely on significant  $a$  and  $b$  paths; the indirect effect(s) is the focus (Preacher & Hayes, 2008). Bias corrected and accelerated confidence intervals are used because the distribution is usually asymmetrical, whereas regular confidence intervals are symmetrical (Giesbrecht, Miller, & Muller, 2010).

These results are consistent with the hypothesis that personal gain reduces subjective burden, which in turn reduces depression. Thus, hypothesis 2 (a) was partially supported.

*Hypothesis 2 (b): Personal gain will be inversely associated with anxiety in caregivers, even when controlling for age and education level. The relationship between personal gain and anxiety will be partially mediated by burden.*

First, the direct effects of personal gain on anxiety, while controlling for age and education level, was tested via hierarchical regression. Hierarchical multiple regression was used to determine whether increased personal gain is associated with less anxiety after controlling for the effects of age and education level. Table 8 displays the results of the hierarchical regression analysis for Hypothesis 2 (b).

Table 8

*Hierarchical Regression Analysis Summary for Variables Associated with Caregiver Anxiety (N = 62)*

Step and predictor variable	<i>B</i>	<i>SE B</i>	$\beta$	$R^2$	$\Delta R^2$
Step 1:				0.18	
Caregiver education level:	6.80	2.46	0.371*		
Some college					
Caregiver education level:	3.84	3.04	0.17		
College and higher					
Caregiver age	-0.16	0.09	-0.22		
Step 2:				0.18	0.00
Personal gain and	-0.56	1.43	-0.05		
spirituality					

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\*  $p < .05$ .

Age and education level were entered at Step 1, explaining 18.1% of the variance in anxiety. After personal gain was entered at Step 2, the total variance explained by the model as a whole was 18.3%,  $F(4, 57) = 3.19$ ,  $p = .02$ . The predictor variable of interest, personal gain, explained an additional 0.2% of the variance in anxiety, after controlling for caregiver age and education,  $R^2 \text{ change} = .002$ ,  $F \text{ change}(1, 57) = .16$ ,  $p = .70$ . In the final model, only one control measure was statistically significant, with education level of some college recording a higher beta value ( $\beta = .37$ ,  $p = .008$ ) than years of education with college or more ( $\beta = .17$ ,  $p = .21$ ), caregiver age ( $\beta = -.22$ ,  $p = .09$ ), or personal gain ( $\beta = -.05$ ,  $p = .70$ ). Thus, the predictor variable of interest, personal gain, did not have a significant relationship to the dependent variable, anxiety.

To test the second part of the hypothesis, that perceived burden mediates the relationship between personal gain and anxiety, I bootstrapped the indirect effects of personal gain on anxiety, using the Preacher and Hayes INDIRECT script version of their SPSS macro. In the mediation model, the predictor variable ( $X$ ) was personal gain, the mediator variable ( $M$ ) was perceived burden, and the outcome variable ( $Y$ ) was anxiety. Age and education were used as covariates. Basic results for total, direct, and indirect effects are provided in Table 9.

Table 9

*Mediation of the Effect of Personal Gain on Anxiety through Perceived Burden*

Effect	Point Estimate	Product of Coefficients		Bootstrapping	
		<i>SE</i>	<i>p</i>	BCa 95% CI	
				Lower	Upper
Personal gain to Zarit	-0.2908	0.1188	0.0175		
burden ( $a$ )					
Zarit burden to anxiety ( $b$ )	7.9458	1.2413	0.0000		
Personal gain to anxiety ( $c$ )	-0.8609	1.4450	0.5537		
Direct effect of personal	1.4500	1.1613	0.2171		
gain on anxiety ( $c'$ )					

Partial effect of control variables on DV

Caregiver education: Some	0.6648	2.3660	0.7798		
college					
Caregiver education:	4.4862	1.9229	0.0233		
College and higher					
Caregiver age	-0.1448	0.0683	0.0385		
Indirect effect: Zarit burden ( $axb$ )	-2.3109	0.9533		-4.6531	-0.7118

Note—BCa, bias corrected and accelerated; 1,000 bootstrap samples



Analysis revealed that the indirect effect of personal gain on anxiety through subjective burden, while controlling for age and education, is not zero by a 95% bias corrected and accelerated bootstrap confidence intervals based on 1000 bootstrap resamples (-4.6531 to -0.7118., with a point estimate of -2.3109), as are the paths from  $X$  to  $M$  ( $a = -0.2908, p = .0175$ ) and  $M$  to  $Y$  controlling for  $X$  ( $b = 7.9458, p = .0000$ ). These results are consistent with the hypothesis that personal gain reduces subjective burden, which in turn reduces anxiety. Thus, hypothesis 2 (b) was partially supported.

*Hypothesis 3: Caregivers who report higher levels of personal gain and spirituality will report care recipients who are significantly better emotionally adjusted (as perceived by the caregiver) even when controlling for caregiver age and education level.*

For this hypothesis, two hierarchical regressions were run. In each, age and education level were entered at Step 1 in order to control for their effects. Score on the personal gain and spirituality measure is the predictor variable of interest and was entered in Step 2 of each analysis.

In the first analysis, the criterion variable was score on the communication subscale of the Key Behavior Change Inventory. Hierarchical multiple regression was used to determine whether increased personal gain is associated with better communication behaviors by the care recipient as perceived by the caregiver after controlling for the effects of caregiver age and education level. Table 10 displays the results of the hierarchical analysis.

Table 10

*Hierarchical Regression Analysis Summary for Variables Associated with Perceived Care Recipient Communication (N = 60)*

Step and predictor variable		<i>B</i>	<i>SE B</i>	$\beta$	$R^2$	$\Delta R^2$
Step 1:					0.02	
	Caregiver education level: Some college	0.07	0.19	0.06		
	Caregiver education level: College and higher	0.01	0.25	0.00		
	Caregiver age	-0.01	0.01	-		
				0.11		
Step 2:					0.05	0.03
	Personal gain and spirituality	0.15	0.12	0.16		

Age and education level were entered at Step 1, explaining 2.2% of the variance in communication behaviors. After personal gain was entered at Step 2, the total variance explained by the model as a whole was 4.6%,  $F(4, 55) = .67$ ,  $p = .62$ . The predictor variable of interest, personal gain, explained an additional 2.5% of the variance in communication behaviors, after controlling for caregiver age and education,  $R^2 \text{ change} = .025$ ,  $F \text{ change}(1, 55) = 1.41$ ,  $p = .24$ . In the final model, none of the predictor variables were statistically significant.

In the second analysis, the criterion variable was score on the emotional behavior subscale of the Key Behavior Change Inventory. Hierarchical multiple regression was used to determine whether increased personal gain is associated with better care recipient emotional behavior as perceived by the caregiver after controlling for the effects of caregiver age and education level. Table 11 displays the results of the hierarchical analysis.

Table 11

*Hierarchical Regression Analysis Summary for Variables Associated with Perceived Care Recipient Emotional Behavior (N = 59)*

Step and predictor variable	<i>B</i>	<i>SE B</i>	$\beta$	$R^2$	$\Delta R^2$
Step 1:				0.02	
Caregiver education level: Some college	0.00	0.23	0.00		
Caregiver education level: College and higher	-0.19	0.29	-0.10		
Caregiver age	0.00	0.01	-0.05		
Step 2:				0.02	0.01
Personal gain and spirituality	-0.08	0.13	-0.09		

Age and education level were entered at Step 1, explaining 1.5% of the variance in emotional behavior. After personal gain was entered at Step 2, the total variance explained by the model as a whole was 2.1%,  $F(4, 54) = .30, p = .88$ . The predictor variable of interest, personal gain, explained an additional 0.7% of the variance in care recipient emotional behaviors as perceived by the caregiver, after controlling for caregiver age and education,  $R^2$  squared change = .007,  $F$  change (1, 54) = .38,  $p = .54$ . In the final model, none of the predictor variables were statistically significant. Thus, Hypothesis 3 was not supported.

*Hypothesis 4 (a) and (b). Non-Caucasian caregivers will report providing more hours of care and poorer perceived physical health, but lower levels of subjective burden than their Caucasian counterparts even when controlling for age and education level. Hypothesis 4 (a) will focus on perceived caregiver health and hypothesis 4 (b) will focus on caregiver impact. Due to the small sample size, participant race will be dichotomized into two groups: Caucasian and non-Caucasian.*

*Additional Assumption Testing.*

In addition to the assumption testing previously discussed, MANCOVA-specific assumption testing was conducted. For both Hypotheses 4 (a) and (b), there was no violation of

the assumption of homogeneity of regression slopes for age or education; thus the relationship between the dependent variables and the covariates is the same for both Caucasian and non-Caucasian caregivers (Field, 2009).

For both Hypotheses 4 (a) and (b), testing to check for homogeneity of variance-covariance matrices via Box's M revealed no violations. For hypothesis 4 (a), Levene's test was used to assess for homogeneity of variance and no violations were found. For physical functioning, the variances were equal for both groups,  $F(1, 58) = .265, p = .61$ . For subjective health, the variances were also equal for both groups,  $F(1, 58) = .987, p = .325$ . For hypothesis 4 (b): Levene's test was used to assess for homogeneity of variance and no violations were found. Variances were equal for Caucasian and non-Caucasian caregivers for both subjective burden,  $F(1, 52) = 3.71, p = .06$ , and for number of hours spent caregiving per week,  $F(1, 52) = .72, p = .41$ .

#### *Hypothesis 4 (a) and (b) main analyses.*

For hypothesis 4 (a), a one-way multivariate analysis of covariance (MANCOVA) was conducted. Racial group was dichotomized into Caucasian ( $n = 48$ ) or non-Caucasian ( $n = 11$ ) and served as the independent variable. A separate question asked participants whether they were Latino/Hispanic; the four participants who answered affirmatively indicated in the subsequent question that their race was White. Thus those four participants were placed in the Caucasian group. The two dependent variables were score on the PROMIS physical functioning measure and score on the PROMIS global item—subjective health measure. Age and education level served as covariates. Results are summarized in Table 12.

Table 12

*Multivariate and Univariate Analyses of Covariance for Perceived Caregiver Health*

Source	Multivariate			Univariate					
	$F^a$	$P$	$\eta^2$	Physical functioning			Global Item		
Caregiver education level: Some college	0.58	0.56	0.02	0.15	0.70	0.00	0.37	0.55	0.01
Caregiver education level: College and higher	0.44	0.65	0.02	0.73	0.40	0.01	0.68	0.41	0.01
Caregiver age	2.57	0.09	0.09	3.39	0.07	0.06	0.00	0.98	0.00
Race	2.77	0.07	0.10	5.64	0.02	0.10	1.91	0.17	0.03

Note. Multivariate F ratios were generated from Wilks' Lambda.

<sup>a</sup>Multivariate  $df = 2, 48$ . <sup>b</sup>Univariate  $df = 1, 54$ .

Results indicated that neither covariate had a statistically significant effect on the set of criterion variables,  $p > .05$ . There was also no statistically significant difference between Caucasian and non-Caucasian caregivers on the combined dependent variables,  $F(2, 53) = 2.77$ ,  $p = .07$ ; Wilks' Lambda = .91; partial eta squared = .095. When the results for the dependent variables were considered separately, the only difference to reach statistical significance, using a Bonferroni adjusted alpha level of .025, was physical functioning,  $F(1, 54) = 5.64$ ,  $p = .021$ , partial eta squared = .095. An inspection of the mean scores indicated that non-Caucasian caregivers reported significantly higher levels of physical functioning ( $M = 55.29$ ,  $SD = 8.82$ ) than Caucasian caregivers ( $M = 47.58$ ,  $SD = 8.89$ ). Although a significant difference in perceived physical functioning was detected, it was reported to be higher in the non-Caucasian group, a finding that is opposite from the study hypothesis. Means and standard deviations are reported in Table 13.

Table 13

*Mean Scores and Standard Deviations for Measures of Perceived Caregiver Health by Racial Group*

Group	Subjective Health		Perceived Physical Functioning	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Caucasian	3.00	0.99	47.58	8.89
Non-Caucasian	2.55	1.04	55.29	8.82

For hypothesis 4 (b), a one-way multivariate analysis of covariance (MANCOVA) was be conducted. Racial group was dichotomized into Caucasian ( $n = 45$ ) or non-Caucasian ( $n = 9$ ) and served as the independent variable. Age and education level served as covariates. The two dependent variables were number of hours per week spent caregiving and score on the Zarit Burden Interview. Results are summarized in Table 14.

Table 14

*Multivariate and Univariate Analyses of Covariance for Caregiver Impact*

Source	Multivariate			Univariate					
				Hours per week spent caregiving			Subjective burden		
	<i>F<sup>a</sup></i>	<i>P</i>	$\eta^2$	<i>F<sup>b</sup></i>	<i>p</i>	$\eta^2$	<i>F<sup>b</sup></i>	<i>p</i>	$\eta^2$
Caregiver education level: Some college	1.41	0.26	0.06	0.35	0.56	0.01	2.50	0.12	0.05
Caregiver education level: College and higher	1.64	0.21	0.06	2.78	0.10	0.05	0.54	0.47	0.00
Caregiver age	0.00	0.99	0.00	0.02	0.89	0.00	0.00	0.96	0.00
Race	0.73	0.49	0.03	0.25	0.62	0.01	1.22	0.27	0.02

Note. Multivariate F ratios were generated from Wilks' Lambda.

<sup>a</sup>Multivariate  $df = 2,48$ . <sup>b</sup>Univariate  $df = 1,49$ .

Results indicated that neither covariate had a statistically significant effect on the set of criterion variables,  $p > .05$ . There was also no statistically significant difference between Caucasian and non-Caucasian caregivers on the combined dependent variables,  $F(2, 48) = 0.73$ ,  $p = .49$  Wilks' Lambda = .97; partial eta squared = .03. When the results for the dependent variables were considered separately, no statistically significant results were found. However, Caucasian caregivers did report spending more hours providing care ( $M = 57.43$ ,  $SD = 63.03$ ) than non-Caucasian caregivers ( $M = 46.61$ ,  $SD = 57.68$ ), though the difference was not statistically significant. Further, Caucasians also reported higher levels of perceived burden ( $M = 1.26$ ,  $SD = .66$ ) than non-Caucasians ( $M = .98$ ,  $SD = .91$ ), though again this difference was not statistically significant. Means and standard deviations are reported in Table 15. Thus, hypothesis 4 (b) was not supported.

Table 15

*Mean Scores and Standard Deviations for Measures of Caregiver Impact by Racial Group*

Group	Hours Per Week Caregiving		Zarit Burden	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Caucasian	57.43	63.03	1.25	0.66
Non-Caucasian	46.61	57.68	0.98	0.91

*Hypothesis 5: Parental caregivers ( $n = 14$ ) will report significantly less depression, anxiety, and subjective burden than non-parental caregivers ( $n = 37$ ), even after controlling for education level.* A one-way between-groups multivariate analysis of covariance (MANCOVA) was conducted, with depression, anxiety, and Zarit burden scores serving as the dependent variables. Education level served as a covariate. Results are summarized in Table 16.

Table 16.

*Multivariate and Univariate Analyses of Covariance for Kinship Differences*

Source	Multivariate			Depression			Univariate Anxiety			Zarit Burden		
	$F^a$	$p$	$\eta^2$	$F^b$	$p$	$\eta^2$	$F^b$	$p$	$\eta^2$	$F^b$	$p$	$\eta^2$
Caregiver education level: Some college	1.80	0.16	0.11	1.94	0.17	0.04	5.30	0.03*	0.10	2.23	0.14	0.05
Caregiver education level: College and higher	0.64	0.60	0.04	1.55	0.22	0.03	1.17	0.29	0.02	1.87	0.18	0.04
Kinship	0.87	0.47	0.06	0.51	0.48	0.01	0.02	0.88	0.00	0.24	0.63	0.01

Note. \*  $p < .05$ . Multivariate F ratios were generated from Wilks' Lambda.

<sup>a</sup>Multivariate  $df = 3, 45$ . <sup>b</sup>Univariate  $df = 1, 51$ .



For hypothesis 5, there were no violations of the assumption of homogeneity of regression slopes for age or education; thus, the relationship between the dependent variables and the covariates is the same in for both parental and non-parental caregivers (Field, 2009). There were also no violations in homogeneity of variance. Specifically, variances were equal for parental and non-parental caregivers for subjective burden,  $F(1, 49) = .45, p = .51$ , for depression,  $F(1, 49) = .08, p = .78$ , and for anxiety,  $F(1, 49) = .32, p = .58$ .

Testing to check for homogeneity of variance-covariance matrices via Box's M revealed no violations. Results indicated that the covariate did not have a statistically significant effect on the set of criterion variables,  $p > .05$ . There was also no statistically significant difference between parental and non-parental caregivers on the combined dependent variables,  $F(3, 45) = 0.87, p = .47$  Wilks' Lambda = .47; partial eta squared = .06. When the results for the dependent variables were considered separately, using a Bonferroni adjusted alpha level of .025, no statistically significant differences were found. Hypothesis 5 was not supported. Means and standard deviations are reported in Table 17.

Table 17

*Mean Scores and Standard Deviations for Measures of Caregiver Depression, Anxiety, and Subjective Burden by Kinship Group*

Group	Depression		Anxiety		Zarit Burden	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Parental	47.88	7.55	47.67	8.84	1.24	0.72
Non-Parental	50.16	7.84	49.27	8.43	1.18	0.74

Due to the small sample size, all non-parental caregivers were combined into a group, which included girlfriends, siblings, and other family members. As a check to determine whether different caregiver relationships may have yielded different results, a one-way between-groups

multivariate analysis of covariance (MANCOVA) was conducted, with only parental caregivers ( $n = 14$ ) and spousal caregivers ( $n = 19$ ) and with depression, anxiety, and Zarit burden scores serving as the dependent variables and education level serving as the covariate. No statistically significant difference between parental and spousal caregivers was detected ( $p > .05$ ).

## **Discussion**

The present study considered personal gain, self-efficacy for caregiving, racial group, and kinship status and both positive and negative mental and physical outcomes in caregivers ( $N = 70$ ) of veterans with traumatic brain injury.

## **Summary of Results**

Results in the study were mixed, with most hypotheses not supported. For hypotheses 1(a) and 1(b), self-efficacy for caregiving was not found to be associated with perceived physical functioning or of subjective health. This finding is inconsistent with previous research with dementia caregivers that found that self-efficacy for obtaining respite and for controlling upsetting thoughts was associated with better health outcomes (Rabinowitz et al., 2007). In that study, researchers argue that having a sense of control over the caregiving process may be associated with both better health-related behaviors and with better physiological outcomes. However, a third domain of self-efficacy for caregiving, self-efficacy for responding to disturbing behaviors, was not associated with health risk behavior. The authors hypothesized that this finding suggests that health outcomes are more related to the caregiver's general beliefs about the effects of caregiving on his or her health than to self-efficacy for specific caregiving tasks. They suggest that interventions focused on reducing caregiver stress would be more beneficial than ones designed to teach caregivers how to manage caregiver behavior. That explanation is relevant to the current study because the caregiving measure used in the current

study assessed beliefs about managing the care recipient's physical and emotional needs. Different results may have been obtained if caregivers had been asked about their self-efficacy for managing their own stress related to caregiving. It could be that health outcomes are more related to the caregivers' beliefs about their ability to manage the stress associated with caregiving than to their confidence in their caregiving ability. Finally, Rabinowitz et al.'s (2007) study included over 250 caregivers and thus benefitted from a much larger sample size.

Results in the current study do not support the literature suggesting that chronic stress is associated with increased wear and tear on the body (Kiecolt-Glaser et al., 2003) and that caregivers are more likely to rate their subjective health as worse than non-caregivers (Neugaard, Andreson, McKune, & Jamoom, 2008). In addition to the small sample size of this study, it is also possible that caregivers in the current study viewed their own health and/or limitations in a more positive light than caregivers in previous research or as an objective observer or medical professional might. The current study focused on perceived physical functioning and subjective health, which were both self-reported. Objective assessment and/or validation of the caregiver's health status may have yielded different results.

In the current study, neither depression nor anxiety was associated with personal gain. These results are inconsistent with Folkman's revised stress and coping model (Folkman, 2008). This model introduced the concept of meaning-focused coping in the face of undesirable circumstances. Current results also do not support previous work with caregivers. For example, one study of Alzheimer's disease caregivers found that those who reported more positive aspects of caregiving were found to have lower levels of depression (Hilgeman, Allen, DeCoster, & Burgio, 2007). Positive aspects of caregiving is a similar construct to personal gain related to caregiving, but similar results were not found. Reasons for this could include the current study's

small sample size compared to the other study's sample of 243 caregivers. Further, the other study assessed its variables multiple times over a one-year period, whereas the current study offers only a snapshot of caregiver emotions/behaviors at a single point in time. Longitudinal studies are more likely to take into account the process of caregiving as well as a caregiver's variations in emotions over time. Further, caregivers in the current study reported much lower levels of clinically significant ( $T \geq 60$ ) depression and anxiety than caregivers in previous studies: 6.6 percent and 14.8 percent respectively. It may be the case that caregivers in the current study underreported their negative emotions or, they may in fact have lower levels of depression/anxiety.

One way in which these results are consistent with previous work with caregivers is that caregivers in the current study generally reported high levels of personal gain and spirituality. The mean score on this measure was 4.3 ( $SD = 0.70$ ) out of a potential 5; higher scores indicate higher levels of personal gain and spirituality. This scale specifically asks caregivers to rate their level of agreement with statements regarding growth "as a result of caregiving." Thus, overall, caregivers were reporting that they agreed that they had experienced personal growth as a result of their caregiver role. Prior studies with TBI caregivers found similar results, with caregivers reporting positive aspects of caregiving and positive emotions related to caregiving (Knight, Devereux, & Godfrey, 1998; Machamer, Temkin, and Dikmen, 2002; and Wells, Dywan, & Dumas, 2005).

Some of the most interesting results of the current study came from the mediation analyses. Specifically, for the hypotheses in the current study, results suggest that there is no total effect of personal gain on depression or on anxiety. However, Hayes (2009) stresses that it is not necessary to find a significant total effect in order to justify testing for a significant indirect

effect. In fact, he believes that a significant indirect effect in such circumstances is still considered mediation, and that not assessing for such a relationship could lead one to miss important information about the relationship between the IV and the DV (Hayes, 2009).

Results suggest the presence of an indirect effect without a direct effect of personal gain on depression. That means, for hypothesis 2 (a), as personal gain increases, depression will decline through an associated decrease in perceived burden. For hypothesis 2 (b), a similar relationship exists between personal gain, perceived burden, and anxiety. A visual depiction of the relationship in hypothesis 2 (a) follows; the relationship among variables in hypothesis 2 (b) is the same, with anxiety serving as variable Y in that model:

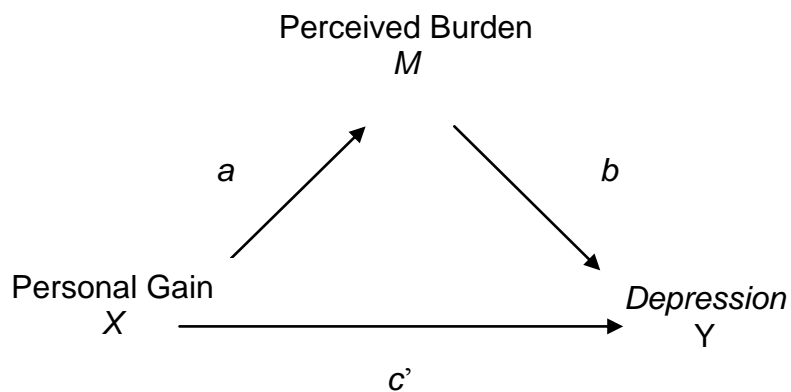


Figure 3. Proposed Mediation Model for Hypothesis 2 (a).

No support was found for a total effect of personal gain on depression or on anxiety because the  $c$  paths were non-significant. There were also no direct effects found due to the non-significant  $c'$  paths. The direct effect in hypothesis 2 (a) is the effect of personal gain on depression without the effects of perceived burden (Hayes, 2009) and in 2 (b) the direct effect is the effect of personal gain on anxiety without the effects of perceived burden. However, personal gain does have a significant effect on perceived burden and perceived burden has a significant

effect on both depression and anxiety. Support for the proposed mediation models, or indirect effect, was found because the confidence intervals (CIs) excluded zero. Results suggest that personal gain reduces subjective burden, which in turn reduces depression as well as anxiety. These results also provide support for using a bootstrap analysis to test indirect effects. Hayes (2009) notes that using the causal steps approach may lead researchers to abandon testing for indirect effects in the absence of total effects, as was the case in this study. Further, the small sample size of this study makes it unlikely that the indirect effect would have been detected using older mediation methods, which traditionally require large sample sizes.

Study results suggest that perceived burden is affected by changes in personal gain and that those changes in perceived burden are associated with changes in depression and anxiety beyond any effects achieved solely by changes in personal gain (Shrout & Bolger, 2002). That is, personal gain has an indirect effect on both depression and on anxiety through the mediator, perceived burden. Shrout and Bolger (2002) argue that it is important to shift focus away from emphasizing that the *c* path (or total effect) be significant, especially in research that considers processes that unfold over long periods of time, what they term “distal processes” (Shrout & Bolger, 2002, p. 430). They recommend using bootstrapping techniques to test indirect effects in small samples and for research on nuanced changes that may progress slowly. Caregiving is certainly such a process, and the use of more advanced analysis techniques permits researchers to test for effects that may have previously gone undetected.

In this study, results suggest that caregiver depression and anxiety will decrease as personal gain increases and influences perceived caregiver burden. However, merely attempting to modify caregiver personal gain may not result in an effect on depression or anxiety. The implications of these results are that interventions should focus on helping caregivers increase

their sense of personal gain and show them how that in turn can result in decreased perceived burden. In the current study, the measure on personal gain specifically asks caregivers whether they have grown in strength, faith, and knowledge as a result of caregiving. The measure of subjective burden also focuses on the caregiving role and negative effects associated with it. Thus the implications of the mediation model are that interventions may want to focus on increasing the caregiver's awareness of how he or she has grown as a person because of the caregiving role. Doing so may ultimately lead to decreases in caregiver depression and anxiety because personal gain related to caregiving influences the subjective experience of caregiver burden. These results also support previous research. For example, a study of Alzheimer's disease caregivers found that, over time, decreasing subjective burden was associated with increased reported positive aspects of caregiving (Hilgeman, Allen, DeCoster, & Burgio, 2007). Positive aspects of caregiving is similar to the personal gain scale in the current study because both focus on positive emotions specifically related to the caregiving role. Further, a large meta-analysis of caregiving studies found that positive emotions related to caregiving were associated with less caregiver depression and burden (Pinquart & Sorensen, 2003). Helping caregivers articulate the benefits associated with caregiving may highlight the positive aspects and lead to a reduced sense of burden, which is in turn associated with less depression and anxiety. These results also support a recent study on family caregivers of TBI patients which found support for a five session manualized treatment focusing on family needs after TBI (Kreutzer et al., 2009). The authors of that study point out that focusing on educating family members and building problem-solving skills benefits the entire family, all of whom play a role in supporting the TBI patient in his or her recovery (Kreutzer et al., 2009).

This study also considered whether race or kinship status differences exist in TBI caregivers. Non-Caucasian caregivers reported significantly better perceived physical functioning than Caucasian caregivers. Although it was not statistically significant, the mean difference in subjective health also indicated that non-Caucasians reported better perceived health. The consistency between these results is intriguing and is contrary to what was hypothesized. This finding is also inconsistent with extant research on caregiver health and health disparities. It could be the case that the 11 non-Caucasian caregivers in this study are truly in better health than their non-Caucasian counterparts or it could be that the two caregiver groups are not representative samples. Most caregiver research, especially with TBI caregivers, focused on racial or ethnic differences considers African-American or Hispanic caregivers compared to Caucasians. Because of the small sample size in the current study, race was dichotomized and though 10 of the non-Caucasian caregivers were African-American, it would be inappropriate to draw general conclusions about non-Caucasian caregivers based on the experiences of this small group of individuals. Finally, there is another possible explanation. Previous research with Alzheimer's caregivers has found that African-Americans report more positive aspects of caregiving (Hilgeman et al., 2007), so perhaps African-Americans are more likely to perceive their health as better than their Caucasian counterparts. Future research that includes objective and subjective assessments of health would aid in determining whether this is the case.

It should be noted that although there was a significant difference between the two groups, the physical functioning measure generates a T-score and both groups' mean T-scores were within the average range. Thus, whereas non-Caucasian caregivers reported better perceived physical functioning than their Caucasian counterparts, the significant difference is



relative. That is, neither group reported perceived physical functioning that is outside of the average range.

No significant differences were found in caregiver impact between the Caucasian and non-Caucasian groups. These results are consistent with those of two studies on TBI caregivers, one of which found no difference in terms of perceived burden (Nabors, Seacat, & Rosenthal, 2002), and the other which found no differences in burden when controlling for age and education. Previous research on racial differences in caregivers has produced mixed findings as to whether such differences exist. Given the extremely small sample sizes in the current study, the fact that a significant difference was detected for at least one outcome between the groups is striking and provides support for the idea that these differences should be explored in future work.

Finally, this study considered whether kinship status was associated with differences in depression, anxiety, and subjective burden. No differences were found. The literature in this area is generally mixed, with some studies finding that parents of TBI patients report less depression and burden than spouses (Gervasio & Kreutzer, 1997; Kreutzer, Gervasio, & Camplair, 1994; Pinquart & Sorenson, 2007); other studies have failed to detect such differences (Kreutzer et al., 2009; Wells, Dyway, & Dumas, 2005). Current study results support the idea that there are no differences; however, the two samples sizes were very small, with only 14 parental caregivers and 37 non-parental caregivers, and thus the study may have been underpowered.

### **Limitations**

Findings from the current study may have been limited due to the small overall sample and especially the analyses considering between-group differences. However, as revealed by the literature review, this sample size is comparable to the many other studies on caregivers of TBI

patients. For between-group analyses, small group sizes may result in non-significant findings when, in fact, differences do exist. Unequal sample sizes are generally not problematic in multivariate analyses (Tabachnick & Fidell, 2007). However, given the large differences in sample sizes combined with the relatively small numbers of cases in some between group comparisons, sample size is likely an important limitation of the current study. Future work that includes a large overall sample size as well as large numbers of different races/ethnicities and kinship relationships would address this limitation and provide important information about group differences, if any do exist.

Kinship status and race were dichotomized in such a way to maximize the number of cases in each group. However, such dichotomization results in a loss of variability. To truly understand racial and ethnic differences in caregivers, research is needed that contains sufficient participants of multiple groups so that results can be compared across the groups. Such work should also consider the effects of culture, religiosity, and SES. As the number of multi-racial individuals increases, these other variables may well prove more important than race/ethnicity, which may currently be serving as a proxy for another, more influential variable when differences are detected.

The high reported levels of personal gain may also have been a limitation. Although caregivers may have been accurately reporting their feelings, it is also possible that this high mean was the result of social desirability. Also the non-significant results in hypothesis 2(a) and (b) could have been affected by the high levels of personal gain but average levels of depression and anxiety reported. Whereas the mean was high and the range restricted for personal gain, the mean was average and the range normal for depression and anxiety.

The current study is part of a larger pilot study for which the questionnaire packet was quite long (more than 30 pages). Participants were caregivers and taking the time to complete the lengthy survey may have been overly burdensome. The response rate for the survey was 61%, but it may be that caregivers who took the time to complete the survey were qualitatively different from those who did not. Also, I did not have access to all of the data, only to the variables which were considered in the original hypotheses.

This study uses a cross-sectional, correlational design, and thus causality cannot be inferred. Further, the data may be explained by other relationships. Inferences about care recipients were based on caregiver reports, which may be inaccurate. However, this is a relatively common practice and clinicians often rely on such reports in assessing the patient, particularly when cognitive deficits are present (Sink et al., 2006). Further, such reports reflect the perception of the caregiver, who is the main focus of this study. In the current study, all data were not provided and thus I was limited in the relationships I could explore, which is another potential limitation.

All data were collected via self-report measures, which may increase common source method variance. However, such research is common in social and behavioral sciences. Suggested remedies for common source variance due to self-report measures include obtaining information from separate sources, distributing measures at different time points, or ensuring that scales have different rating systems (Podsakoff et al., 2003). In this study, the scales did have different rating systems.

As noted by the study authors in the main study (Griffin et al., 2012), it is also possible that the person completing the packet was not the most appropriate person to do so. Packets were mailed to the designated next of kin according to the computer medical record; however, this

person may not have actually completed the survey and/or may not actually be the primary or sole caregiver.

As noted above, the current study relies on measures which are essentially checklists, and as Coyne and Racioppo (2000) point out, such a design fails to appreciate a process that unfolds over time. As with coping, caregiving is an ongoing process that can last weeks, years, or decades, and the current study is a snapshot of caregiver emotions and beliefs at a certain point in time. Further, this snapshot is of caregivers at different points in the rehabilitation process spanning eight years, some much more recently than others. To truly understand the caregiving process over time, it would be best to track caregivers who began providing care at the same time, as caregiver feelings and beliefs may change over time. The current study provided only a single assessment of caregiver emotions and beliefs. The lack of data about caregiver emotions over time, as previously discussed, is an important limitation in all studies with caregivers that are not longitudinal.

Subjective health was measured with a single item. Though this item is widely used, validity would be improved by also measuring caregiver health in objective ways, e.g. by study personnel assessing health markers such as BMI, blood pressure, cholesterol, physical fitness, etc. However, the use of a single-item measure of subjective health is widespread (Cohen et al., 2007; Schulz, O'Brien, & Bookwala, 1995). Of the 176 caregiving studies in Pinquart and Sorensen's metanalysis (2007), 116 used single-item measures to assess caregiver physical health. Thus, there is precedent for using such a measure when assessing caregiver health.

The modified Preparedness for Caregiving Scale, used to measure self-efficacy for caregiving, had Cronbach's alpha of .57, which is lower than recommended (Heppner, Wampold, & Kivlighan, 2008) and could have potentially affected results. It is possible that the

scale's brevity (two items) is largely responsible for its low reliability coefficient. Also, this scale was modified to assess for self-efficacy rather than preparedness; although these concepts are related, they are not the same, and it is unknown what effect the modification may have had on the results and/or reliability. It is recommended that this scale be normed for use on a caregiving population and, if necessary, lengthened to increase its reliability.

### **Recommendations for Future Research**

It is recommended that future studies on TBI caregivers consider both physical and mental health outcomes broadly. In addition to physical functioning and subjective health, for example, objective assessment of sleep, alcohol and smoking behaviors should be included. In addition to providing researchers with a more complete picture of caregiver health, including such information will help to balance the more subjective nature of the measures used in the current study. Future research might also consider whether TBI etiology is associated with caregiver mental health. It is also recommended that self-report measures not be used as the exclusive assessment of caregiver health. Having study personnel conduct BMI assessments, blood pressure screenings, etc. would increase the validity of the health risk assessment ratings.

Future research should focus not only on self-efficacy for caregiving and specific caregiving tasks, but also on self-efficacy for managing caregiving stress. Caregivers may feel more confident in their abilities to care for their loved one than in their ability to care for themselves, and that could have a direct effect on health outcomes. This idea was supported by a recent study that provided additional support for the Brain Injury Family Intervention, in which caregivers of TBI patients reported that the most helpful part of the intervention was learning to ask for help and recognizing the need for self-care (Kreutzer et al., 2010).

It is also recommended that future research with caregivers be longitudinal, with multiple assessments. Such a design would be more likely to take into account the fact that caregiving is a process and that caregivers are likely to have emotions that fluctuate over time. This is especially true for caregivers of TBI patients. Such caregivers may be facing the prospect of providing decades of care, so it is important to focus on ways to understand the caregiving experience over time. The process aspect of caregiving is particularly relevant to these results, as the measures of anxiety and depression ask caregivers to consider their feelings over the past 7 days. In this respect, the current study and much of the caregiving literature shares the problem noted by Coyne and Racioppo (2000) that exists in the coping literature: an overreliance on checklists. As those authors note, checklists fail to provide data about process and also potentially confound individual traits and coping—or, in this case, caregiving. As previously discussed, preparedness should be considered (and measured) separately from self-efficacy using appropriate measures.

Although there is a line of research focused on negative effects of caregiving for TBI patients, investigators have only recently begun considering how to develop effective family-based interventions (Kreutzer, Marwitz, Godwin, Arango-Lasprilla, 2010). Kreutzer and colleagues (2010) point out that caregivers must take time for self-care, as it will benefit not only themselves but also their care recipient. They emphasize the importance of valuing each family member, building a strong therapeutic alliance, and providing information about expected sequelae of TBI. Interventions that include such education may be able to build caregivers' sense of personal gain because they will be more knowledgeable about the tasks they might be expected to complete. It is also recommended that interventions assess positive emotions and outcomes as well as negative thoughts, and that future research focus on ways to build caregiver strengths and not only on decreasing depression, anxiety, and burden.

Despite these limitations, the current study makes an important contribution to the literature on caregivers of TBI patients. With more than a million people in the United States sustaining a serious TBI each year, the number of people involved in caregiving is high. As lifespans become longer and baby boomers aging, the number of caregivers may be expected to increase. In 2011, APA released an online Caregiver Briefcase aimed at providing information about caregiving to professionals and resources to caregivers. However, that site fails to provide any TBI-specific resources for caregivers, and includes a link to an online forum focused broadly on neurological disorders. Whereas caregivers of those with Alzheimer's disease, cancer, stroke, and other conditions have specific resources, caregivers for TBI patients are not specifically mentioned in the APA briefcase. VA has recently released an online, multi-module resource for caregivers, [www.caregiver.va.gov](http://www.caregiver.va.gov), with special information about benefits and resources for post-9/11 veterans and their caregivers. There are numerous policy implications associated with an aging population, and the costs—both financial and emotional—of caregiving are among them. Also, the Defense and Veterans Brain Injury Center (DVBIC), provides information to service members and their families about TBI. On the DVBIC web site, a four-module caregiver curriculum is available to any user. The online program offers education about the nature of TBI, caregiver advice, and information about navigating benefits available to Veterans.

There is some tax relief available to caregivers who provide more than fifty percent financial support for a family member care recipient living with the caregiver or elsewhere or for a non-family member care recipient living with the caregiver (Tergesen, 2011). Depending on the individual's tax situation, medical expenses for the care recipient may also be deductible; also, single filers may be eligible to change their filing status to head of household, which would increase their standard deduction (Tergesen, 2011). This last point is an important one, as most

caregivers are women, and for those who are single, this could result in several thousands of dollars in tax savings. It is important that legislative and tax-policy not only recognize the costs of caregiving but also that any benefits to caregivers are publicized. The National Alliance for Caregiving (NAC) released a report in 2010 on a previously mentioned study it did on caregivers of veterans and included seven recommendations. Five of these related to improving communication to caregivers about the resources that are available to them. The other two focused on respite care and improving caregiver-health care provider communication.

As Hanks, Rapport, and Vangel (2007) note, results studies on positive emotions have important implications for developing interventions because “caregivers’ cognitions and emotions about caregiving may be more easily modified than factors such as the TBI survivor’s neurobehavioral disturbances” (p. 44). Thus if researchers can understand how feelings of subjective burden mediate the relationship between personal gain associated with caregiving and both depression and anxiety, the next step would be developing interventions aimed at teaching caregivers how to focus on feelings of positive gain in order to reduce negative psychological health outcomes.



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## Appendix A

### Demographic Data

1. What is your relationship to the person you are helping (your care recipient)?

☐ Husband                      ☐ Wife                      ☐ Boyfriend (romantic partner)

☐ Girlfriend (romantic partner)      ☐ Son                      ☐ Daughter      ☐ Mother

☐ Father                      ☐ Sister                      ☐ Brother                      ☐ Friend

☐ Other Family Member. Please specify: \_\_\_\_\_

☐ Other relationship. Please specify: \_\_\_\_\_

2. What was the month and year that you first started doing things to help your care recipient due to his or her injury? Please give us your best estimate.

\_\_\_\_\_ of 200

Month

3. In a typical week, on how many days do you provide care or help your care recipient as a result of his or her injuries? *Choose only one.*

☐ Less than once a week    ☐ 1 day a week                      ☐ 2 days a week    ☐ 3 days a week

☐ 4 days a week    ☐ 5 days a week    ☐ 6 days a week    ☐ 7 days a week (everyday)

4. Are you currently married, separated, divorced, widowed, or never married?

*Choose only one.*

☐ Married    ☐ Divorced    ☐ Living with a partner    ☐ Separated  
☐ Widowed    ☐ Never married

5. What year were you born?        19\_\_\_\_

6. Are you male or female? ☐ Male        ☐ Female

7. Are you of Latino/Hispanic origin?        ☐ Yes        ☐ No        ☐ Unsure

8. Which of the following best describes you? *Choose all that apply.*

☐ American Indian or Alaskan Native    ☐ Asian        ☐ Black or African American

☐ Native Hawaiian        ☐ Other Pacific Islander        ☐ White

☐ Other. Please specify: \_\_\_\_\_

9. What is the highest grade of school you have completed? *Choose only one.*

☐ Less than high school    ☐ Some high school

☐ Graduated from High School/received GED

☐ Vocational, business, or trade school

☐ Some college    ☐ Associates degree    ☐ College degree (BA/BS)

☐ Master's or Doctoral Degree (JD, MD, PhD) or other post-graduate training

## Appendix B

### Key Behavior Change Inventory—modified

The following is a series of statements that can apply to people. We would like to know how well each of these statements describes your care recipient. Think of this person and then read each statement carefully. Then decide how well that statement fits the individual right now.

	Not True	Slightly True	Mostly True	Very True
1. Says things that don't make sense.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Talks too much.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Talks too loudly or softly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Listens carefully and responds normally when talking with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Talks in a way that makes sense (it is easy to follow his/her train of thought).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Sticks to the topic when talking to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is positive about the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Seems to feel worthless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is moody and irritable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Copes poorly with stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Not True	Slightly True	Mostly True	Very True
11. Adjusts well to life's difficulties.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Seems happy most of the time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Says or does the first thing that comes to mind.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Plans things out ahead of time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Acts unpredictably.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Is too hasty in his/her actions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Often acts without thinking.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Cannot wait patiently.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Carefully thinks things through.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Gets confused easily.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Has trouble with details.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Concentrates easily on what he/she is doing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Not True	Slightly True	Mostly True	Very True
23. Is attentive and sharp.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Has trouble following directions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Gets into arguments easily.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Does things without thinking about other people's feelings.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Is polite in social situations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Cares about other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Is sensitive to other people's feelings and needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Is self-centered.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Gets along well with other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Can recognize when he/she is beginning to get upset.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Not True	Slightly True	Mostly True	Very True
33. Thinks he/she can do things they really can't.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Recognizes when others are having trouble following what he/she is saying.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Knows his/her limitations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Appendix C

### Pearlin's Personal Gain & Spirituality Scale—modified

How much do you agree or disagree with the following statements?

As a result of caregiving, do you feel that you have ...	Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
a. become aware of your inner strengths?	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. become more self-confident?	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. grown as a person?	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. learned to do things that you didn't do before?	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. strengthened your faith or spirituality?	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



## Appendix D

### Preparedness for Caregiving Scale—modified

Some people feel very confident in their ability to provide care while others do not. Please think about all that you provide for your care recipient as a result of his or her injuries.

How confident are you that you can...

	<u>Not at all</u> <u>confident</u>	<u>A little</u> <u>confident</u>	<u>Somewhat</u> <u>confident</u>	<u>Very</u> <u>confident</u>	<u>Extremely</u> <u>confident</u>
a. Take care of your care recipient's physical needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Take care of your care recipient's emotional needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Appendix E

### PROMIS Anxiety—Short Form

<u>In the past 7 days ...</u>	<u>None of the Time</u>	<u>A Little of the Time</u>	<u>Some of the Time</u>	<u>Most of the Time</u>	<u>All of Time</u>
a. I felt fearful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I felt anxious.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I felt worried.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I found it hard to focus on anything other than my anxiety.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I felt nervous.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I felt uneasy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I felt tense.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Appendix F

### PROMIS Depression—Short Form

<u>In the past 7 days ...</u>	<u>None of the Time</u>	<u>A Little of the Time</u>	<u>Some of the Time</u>	<u>Most of the Time</u>	<u>All of Time</u>
h. I felt worthless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. I felt I had nothing to look forward to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. I felt helpless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. I felt sad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. I felt like a failure.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. I felt depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. I felt unhappy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. I felt hopeless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Appendix G**  
Promis Physical Functioning—Short Form

Does your health now limit you in ...	Not at all	Very Little	Somewhat	Quite A Lot	Cannot Do
a. Doing vigorous activities, such as running, lifting heavy objects, or participating in strenuous sports?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Walking more than a mile?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Climbing one flight of stairs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Lifting or carrying groceries?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Bending, kneeling, or stooping?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are you able to ...	Without Any Difficulty	With A Little Difficulty	With Some Difficulty	With Much Difficulty	Unable To Do
a. Do chores such as vacuuming or yard work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Dress yourself, including tying shoelaces and doing buttons?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Shampoo your hair?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Wash and dry your body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Get on and off the toilet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## **Appendix H**

### Promis Global Item—Subjective Health

In general, how would you say your health is now?

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

## Appendix I

### Zarit Burden Interview—Short Form

Next, we would like to know more about your feelings toward providing care. Below is a list of questions about the caregiving experience. Please check the response that best describes how you feel now.

How often do you feel the following?	Never	Rarely	Sometimes	Often	Nearly Always
a. Because of the time I spend with my care recipient I don't have enough time for myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I feel stressed between caring for my care recipient and trying to meet other responsibilities for my family or work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I feel angry when I am around my care recipient.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I feel that my care recipient affects my relationship with family members or friends in a negative way	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I feel strained when I am around my care recipient.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. My health has suffered because of my involvement with my care recipient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I don't have as much privacy as I would like because of my care recipient.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. My social life has suffered because I am caring for my care recipient.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. I have lost control of my life since my care recipient's injury.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. I feel uncertain about what to do about my care recipient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- k. I feel I should be doing more  
for my care recipient ☐ ☐ ☐ ☐ ☐
- l. I feel I could do a better job in caring  
for my care recipient ☐ ☐ ☐ ☐ ☐

## Vita

Suzzette M. Chopin was born October 6, 1976 in Nederville, Texas, and is an American citizen. She graduated from Duchesne Academy of the Sacred Heart in 1994. She received her Bachelor and Master of Arts in English from The George Washington University, Washington, D.C., in 1998 and 2000, respectively. She received her Master of Business Administration from the University of New Orleans in 2007 and her Master of Science in psychology from Virginia Commonwealth University in 2009. She was a graduate research assistant at Virginia Commonwealth University from 2007 to 2012.