THE INFLUENCE OF DEMOGRAPHIC FACTORS, RESILIENCE, AND OTHER PSYCHOLOGICAL FACTORS IN PREDICTING CAREGIVER BURDEN IN TRAUMA ICU POPULATIONS

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DEDICATION

I would like to thank the members of my Dissertation Committee for their time and participation in this project. I would also like to thank my parents (Suresh and Shaku), husband (Heetesh), siblings (Mukesh and Sheetal), son (Nilan), extended family, and friends for their unwavering support, encouragement, love, and guidance. Your presence has been invaluable and immensely appreciated and I will be eternally grateful for everything you have done to help me get through the last four years of this program. Lastly, to my 2020 doctoral cohort, I could not have asked to be part of a better cohort. You provided humor and support while we spent endless hours in a classroom our first year, during which I also planned my destination wedding! You kept me grounded as our schedules became even busier our second and third year and cheered me on toward the finish line during fourth year, in the midst of the COVID-19 pandemic. Outside of the program, you helped me celebrate my wedding and the birth of my son and I feel so fortunate to have shared these milestones and so much more with you all. Thank you for everything.

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Although only a small number of studies specifically focus on caregivers of ICU patients, findings suggest that these caregivers can experience a substantial burden. Although negative psychological states, including depression and posttraumatic stress disorder (PTSD), are gaining attention in the literature following the injury of a family member, less attention has been paid to the role that potentially protective psychological factors, such as resilience, may have in one's response to injury or critical illness in a family member. The purpose of this study is to examine the role of specific demographics factors and resilience in predicting

caregiver burden, depression, and PTSD symptoms in caregivers of trauma patients. Eligible individuals were identified based on their family member's medical diagnosis through the trauma service admission list at Baylor University Medical Center (BUMC), a Level I trauma center and part of the Baylor Scott & White Healthcare system. Participants (aged 18-82, N=91, 73.6% female) completed brief self-report measures assessing depression, PTSD and resilience at baseline, and completed brief self-report measures assessing depression, PTSD, and caregiver burden at three-month follow-up. Regression analyses were used to determine the association between resilience and each outcome (caregiver burden, depression, and PTSD). Results illustrated significant associations between resilience and depression and PTSD separately. Exploratory analyses were conducted to determine the role of demographic factors in predicting caregiver burden, depression, and PTSD over time. A series of linear and logistic regressions were conducted to evaluate the intersectionality of the demographic factors and each outcome. Findings suggest that higher levels of resilience may significantly be associated with lower rates of depression and PTSD. Additionally, the interaction of several demographic factors may significantly be associated with higher rates of depression and PTSD. Current study findings suggest that certain demographic factors are associated with higher levels of depression and PTSD in caregivers. Although further exploration is warranted before drawing firm conclusions, this novel information may be used to direct future research, educate caregivers, clinicians and researchers, and inform the development of interventions specific to this population.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF APPENDICES

CHAPTER ONE
Introduction

According to the Centers for Disease Control and Prevention (2017), injuries are the leading cause of death for children and adults between the ages of 1 and 44 years, which is greater than cancer, HIV, or the flu. Each year, 214,000 individuals die from traumatic injuries, equaling approximately one death every three minutes (Centers for Disease Control and Prevention, 2017). The total cost of traumatic injury in the United States in 2013 was approximately $671 billion; the costs associated with fatal injuries was $214 billion, while nonfatal injuries accounted for over $457 billion (Centers for Disease Control and Prevention, 2017). In the United States, approximately five million people are admitted to an intensive care unit (ICU) each year for traumatic injury or critical illness (SCCM, 2014).

The Society of Critical Care and Medicine (2017) define family members as "individuals who provide support and with whom the patient has a significant relationship." The ICU environment can be anxiety provoking and emotionally distressing for both patients and their family members. After a critical illness, patients face challenges in their lives, including mental, cognitive, and/or physical impairments (Oeyen et al., 2010). Patients who survive a critical illness are dependent on both professional and nonprofessional caregivers, and family members are often essential through all phases of the ICU stay and recovery. In the ICU, patients are often subjected to unfamiliar and sometimes painful medical procedures, have significant communication barriers, and display changes in cognition and behavior. While witnessing these experiences, family members often have to simultaneously cope with the external demands of managing occupational and household responsibilities,

navigating complex insurance and financial decisions, and maintaining the needs of other family members, such as children and elderly. In the ICU setting, balancing time with the hospitalized family member and coping with outside demands is often done with minimal sleep and is accompanied by a general lack of regard for one's own sense of health and well-being.

Previous research has shown that individuals who have a family member admitted to the ICU can develop adverse psychological outcomes, including symptoms of depression, posttraumatic stress, anxiety, and complicated grief (Belayachi et al., 2013; Davidson, Jones, & Bienvenu, 2012). Baumhover and May (2013) provide an important conceptual model to describe this vulnerability that ICU family members experience. In this model, the role of both antecedents (i.e., family system disruption, helplessness) and defining attributes (i.e., exposure to burden due to lack of sleep and other factors, lack of protection), as well as the subsequent consequences are described and can provide a useful framework in which to consider the perspective of the family member.

The existing literature describes family members as having a generally positive effect on the patient's psychological state and provision of crucial support that may improve patient outcomes; however, more information is needed to better understand the psychological impact of being in a caregiver role (Alfheim et al., 2018). Consequences for family members, according to the Baumhover and May (2013) model, can be positive, such as increased resilience, but also could result in a wide range of negative psychological symptoms. Having a loved one in the ICU places profound demands on physical and mental energy in family caregivers. Some patients regain their former level of health, but many do not. Thus,

caregiving demands may continue or escalate following ICU discharge, placing caregivers at risk for negative psychological consequences.

It is not surprising, then, that having a family member admitted to the ICU after an injury or illness can take a significant emotional toll. Although only a small number of studies specifically focus on caregivers of ICU patients, findings suggest that these caregivers can experience a substantial burden. Although negative psychological states, including depression and posttraumatic stress disorder (PTSD), are gaining attention in the literature following the injury of a family member, less attention has been paid to the role that potentially protective psychological factors, such as resilience, may have in one's response to injury or critical illness in a family member.

The purpose of this study is to examine the role of specific demographics factors and resilience in predicting caregiver burden, depression, and PTSD symptoms in caregivers of trauma patients.

CHAPTER TWO
Review of the Literature

Historically, the single measure of interest for measuring quality in trauma care has been patient hospital survival. However, research examining the impact of caring for a family member following a critical illness or injury is on the rise in the literature. Previous research has identified the development of adverse psychological outcomes, such as depression, posttraumatic stress, and complicated grief in individuals who have a loved one admitted to an intensive care unit (ICU; Davidson et al., 2012). Further, these symptoms may continue after discharge from the ICU. For example, family members have reported psychological distress from caregiving provided during the recovery phase of a relative's injury (Johansson, Fridlund & Hildingh, 2002), and these symptoms may continue unchecked, since the majority of support and resources are directed at the patients, not their caregivers, during recovery (Davidson et al., 2012). The primary focus of clinical research on caregivers of individuals with a critical illness or injury has been to describe the consequences of being a caregiver or to identify the risk factors associated with being a caregiver. However, few studies have provided an understanding of how positive outcomes are achieved by caregivers.

TRAUMA

There exists today a wide consensus among theorists on a specific definition of trauma. Judith Herman is considered to be one of the pioneering clinicians in the field of

trauma. Herman describes a traumatic event as an event that "overwhelms the ordinary adaptations to human life and generally involves threats to life or bodily integrity, or a close personal encounter with violence and death" (Herman, 1992). A more neurologically based definition includes a traumatic event that produces an excess of external stimuli and a corresponding excess of excitation in the brain that the brain is unable to fully process resulting in various mechanisms, such as psychological numbing or repression of typical emotional responses (Suleiman, 2008).

Trauma biology is an area of burgeoning research, with the promise of more complex and explanatory findings yet to come. Although a thorough presentation on the biological aspects of trauma is beyond the scope of this study, what is currently known is that exposure to trauma leads to a cascade of biological changes and stress responses. These biological alterations are highly associated with posttraumatic stress disorder (PTSD), and other mental illnesses, including substance use disorders (Center for Substance Abuse Treatment, 2014). These include changes in limbic system functioning, hypothalamic-pituitary-adrenal axis (HPA) changes with variable cortisol levels, and neurotransmitter-related dysregulation of arousal and endogenous opioid systems (Center for Substance Abuse Treatment, 2014). Furthermore, trauma-induced changes in neutrophil biology have been linked to the development of such posttraumatic complications such as multiple organ failure and acute respiratory distress syndrome (Hazeldine, Hampson, & Lord, 2014). It is important to note that individuals react physiologically and psychology to all types of stressors in different ways.

The Substance Abuse and Mental Health Services Administration (2019) describes individual trauma as resulting from "an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life-threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being." Trauma, including one-time, multiple, or long-lasting repetitive events, affects individuals in different ways. Some individuals may clearly display criteria associated with PTSD, but many more individuals will exhibit resilient responses or brief subclinical symptoms or consequences that fall outside of diagnostic criteria (Center for Substance Abuse Treatment, 2014). The impact of trauma can be subtle, insidious, or outright destructive. How an event affects an individual depends on many factors, including characteristics of the individual, the type and characteristics of the event(s), developmental processes, the meaning of the trauma, and sociocultural factors (van der Kolk, McFarlane, & Weisaeth, 1996). Initial reactions to trauma can include exhaustion, confusion, sadness, anxiety, agitation, numbness, dissociation, confusion, physical arousal, and blunted affect (Center for Substance Abuse Treatment, 2014). Most responses are considered typical in that they affect most survivors and are socially acceptable, psychologically effective, and self-limited. Indicators of more severe responses include continuous distress without periods of relative calm or rest, severe dissociation symptoms, and intense intrusive recollections that continue despite a return to safety (Center for Substance Abuse Treatment, 2014).

Traumatic stress tends to evoke two emotional extremes: feeling either too much (overwhelmed) or too little (numb) emotion (van der Kolk, McFarlane, & Weisaeth, 1996). Emotional reactions to trauma can vary greatly and are significantly influenced by the

individual's sociocultural history. Beyond the initial emotional reactions during the event, those most likely to surface include anger, fear, sadness, and shame (Center for Substance Abuse Treatment, 2014; van der Kolk, McFarlane, & Weisaeth, 1996). According to van der Kolk and colleagues (1996), individuals may encounter difficulty in identifying any of these feelings for various reasons, such as lack experience with or prior exposure to emotional expression in their family or community. Some individuals may associate strong feelings with the past trauma, thus believing that emotional expression is too dangerous or will lead to feeling out of control. Still others might deny that they have any feelings associated with their traumatic experiences and define their reactions as numbness or lack of emotions (Center for Substance Abuse Treatment, 2014; van der Kolk, McFarlane, & Weisaeth, 1996).

Some trauma survivors have difficulty regulating emotions such as anger, anxiety, sadness, and shame—this is more so when the trauma occurred at a young age (van der Kolk, McFarlane, & Weisaeth, 1996). In individuals who are older and functioning well prior to the trauma, such emotional dysregulation is usually short lived and represents an immediate reaction to the trauma, rather than an ongoing pattern (van der Kolk, McFarlane, & Weisaeth, 1996). Efforts toward emotional regulation can include engagement in high-risk or self-injurious behaviors, disordered eating, compulsive behaviors such as gambling or overworking, and repression or denial of emotions; however, not all behaviors associated with self-regulation are considered negative (Center for Substance Abuse Treatment, 2014; van der Kolk, McFarlane, & Weisaeth, 1996). In fact, some individuals find creative, healthy, and industrious ways to manage strong affect generated by trauma, such as renewed

commitment to physical activity or creating an organization to support survivors of a particular trauma (Center for Substance Abuse Treatment, 2014).

STRESS

Before the concept of resilience is discussed, it is important to understand the concept of stress. Stress was observed by Hans Selye in 1935 as a syndrome occurring in laboratory rats. In the modern world, stress has become a universal explanation for human behavior in industrial society (Viner, 1999). Selye's discovery arose out of widespread interest in the stability of bodily systems in physiology in the 1930s (Viner, 1999). Stress has more recently been defined as a perceived threat to an individual's homeostasis (Horner, 2017). The threat to homeostasis can be physical, psychological, emotional, or both. Biologically, periods of stress are accompanied by increased activation of the hypothalamus-pituitary-adrenal (HPA) axis and increased production of cortisol (Petrini et al., 2019). The initial responses of the brain, body, and behavior are protective and hormones, cytokines and other mediators, such as neurotransmitters, are used to survive and adapt to the challenge (Petrini et al., 2019). However, repeated stressful experiences have deleterious effects, in part because the very same mechanisms that help to protect in the short-term are either mismanaged or overused (Petrini et al., 2019). Exposure to severe or chronic stress (toxic stress) has been associated with both physical and psychological negative health consequences, such as depression, anxiety, and cardiovascular disease (Banny et al., 2013). However, exposure to mild or moderate stress is much less likely to result in negative health consequences and may

actually be beneficial to development (Rutter, 2013). While trauma includes a precipitating event that can dramatically alter and change the way individuals perceive themselves and their world, stress, on the other hand, is a reaction to less dramatic events that are still perceived as threatening.

The term stress is often used to refer both to stressors and to stress responses. It is a process that consists of stressors (i.e. challenging events), mediators (i.e. constructs that help to evaluate the nature of a threat and the emotional and behavioral responses elicited by threats) and the stress response (i.e. physical and emotional responses elicited by a stressor; Petrini et al., 2019). Stress is somewhat subjective both in the measurement of severity and experience; the way in which individuals perceive and interpret stressors may vary greatly (Bowes & Jaffee, 2013). This variance may be a function of an individual's previous exposures to stress (Cicchetti & Rogosch, 2009). Exposure to low or controlled levels of stress may potentially benefit an individual both physiologically and psychologically (Lazarus, 1966).

Key elements that help determine whether a stressor is associated with severe symptoms or recovery include appraisal of the experience, potential consequences of the experience, and the choice of coping strategies used by the individual to either change the stressful experience or modify his/her emotional response (Lazarus, 1966). Lazarus (1966) defined stress as a relationship between the person and the environment that is appraised as personally significant and as taxing or exceeding resources for coping. This definition became the foundation for Lazarus and Folkman's transactional model of stress and coping theory which emphasizes appraisal to evaluate harm, threat and challenges, resulting in the

process of coping with stressful events (Lazarus, 1966; Lazarus and Folkman, 1984). The level of stress experienced in the form of thoughts, feelings, emotions and behaviors, as a result of external stressors, depends on appraisals of the situation which involves a judgement about whether internal or external demands exceed resources and ability to cope when demands exceed resources (Lazarus and Folkman, 1984). The transactional model explained coping as a phenomenon that involves both cognitive and behavioral responses that individuals use in an attempt to manage internal and/or external stressors perceived to exceed their personal resources (Lazarus and Folkman, 1984). The influence of Lazarus and Folkman's transactional theory of coping remains the cornerstone of psychological stress and coping research across multiple fields (Biggs, Brough, & Drummond, 2017).

The stress/resilience phenomena can be explained using three models: the cumulative stress model, the match/mismatch model, and the three-hit model (Daskalakis et al., 2013; Gluckman et al., 2009; McEwen, 1998). The cumulative stress model (McEwen, 1998) states that the accumulation of stressors throughout a lifetime enhances the development of psychopathology in at-risk individuals. The match/mismatch model takes into account the concept of epigenetic changes (Gluckman et al., 2009). Gluckman and colleagues (2009) posited that early-life exposure to stressors can induce epigenetic changes to match an organism to its environment and decrease the risk of disease. A mismatch between the phenotypic outcome of the epigenetic changes and the ability to cope with current environmental stressors is thought to increase the risk of disease (Gluckman et al., 2009). The major difference between these two models is that the cumulative stress model asserts that cumulative stress or adversity never has any advantageous effect; rather, it progressively

increases disease risk (Gluckman et al., 2009; McEwen, 1998). The cumulative stress model does not allow for adaptation/ epigenetic changes that can be protective for the individual (McEwen, 1998). The match/mismatch model includes the concept of adaptation to early life stressors (even significant cumulative stressors) for certain individuals; thus, it includes the concept of resilience (Gluckman et al., 2009). The three-hit concept of vulnerability and resilience (Daskalakis et al., 2013) attempts to reconcile the differences in these two models. The three-hit model includes the concept of environmental interventions affecting vulnerability or resilience outcomes (Daskalakis et al., 2013). The three-hit model considers the following: the interaction of genetic factors (Hit 1) with early life experiences (Hit 2) causes altered endocrine regulations and epigenetic changes during brain development, which programs gene expression patterns relevant for an evolving phenotype (Daskalakis et al., 2013). When exposed to one type of later-life environment (Hit 3), the programmed phenotype may become more compromised and a higher risk of psychiatric symptoms may arise (vulnerability), but when exposed to another type of later-life environment the same phenotype will result in resilience (Daskalakis et al., 2013).

Brief exposures to stress with opportunities to return to baseline can be positive and result in growth (Cicchetti & Rogosch, 2009). These exposures can better prepare the individual for stress exposure later in life and results in only a mild elevation of stress hormones, helping individuals learn to self-regulate (Cicchetti & Rogosch, 2009). A supportive caregiver facilitates stress exposure that results in positive growth for the individual. There is also tolerable stress, defined as serious but temporary stress exposure.

Stress hormone levels are elevated, but with buffering from genetics and supportive relationships the individual recovers (Cicchetti & Rogosch, 2009).

Caregiving can produce also secondary stress, such as in work and familiar or social relationships (Hornor, 2015; Petrini et al., 2019). Caregiving may generate chronic or toxic stress in situations such as long-lasting care, severe illness or disability of the individual being cared for, lack of the necessary informal and formal support and high levels of unpredictability, uncontrollability and vigilance. (Hornor, 2015; Petrini et al., 2019). This results in chronic activation of the stress response, which results in consistently high levels of stress hormones. When this occurs in the absence of protective relationships and protective genetics, lifelong physical and psychological consequences can occur for the individual (Hornor, 2015; Petrini et al., 2019).

Several studies have reported that some physiological abnormalities are associated with caregiving chronic stress (Damjanovic et al., 2007; Epel and Blackburn, 2004; Picard et al., 2018). A milestone study by Epel and Blackburn (2004) showed that perceived life stress and the number of years, spent as a caregiver, were significantly associated with determinants of accelerated cell aging (i.e. higher oxidative stress, shorter telomere length and lower telomerase activity), in peripheral blood mononuclear cells (PMBC) from healthy premenopausal women. In particular, caregiving mothers with the highest levels of perceived stress have shorter telomeres, on average by the equivalent of at least one decade of additional aging, as compared to mothers who were not caregivers or reported low amounts of stress (Epel and Blackburn, 2004). Accordingly, Damjanovic and colleagues (2007) demonstrated that chronic stress is associated with altered T-cell function, accelerated

immune cell aging and excessive telomere loss not compensated by telomerase activity, in PMBC of caregivers of Alzheimer patients. More recent data by Picard and colleagues (2018) demonstrated that an association exists between daily mood, chronic caregiving stress and mitochondrial functional capacity, suggesting that mitochondrial health may represent a step in the pathway between psychological stress and health outcomes.

RESILIENCE

Developmental psychologist Emmy Werner was one of the first individuals to use the term resilience in the 1970s in an important, longitudinal, 32-year study (Werner & Smith, 2001). Werner traced the development of 700 infants born in 1955 in Kauai, Hawaii until they turned 40. One third of the children faced ordeals, including poverty, domestic conflict, and parental drug abuse; however, by the end of the study, only one in six suffered from substance abuse, mental health issues, or had criminal records (Werner & Smith, 2001). Werner found that some high-risk youths displayed resilience and recovered from their unstable and difficult childhood circumstances (Werner, 1993, 2013). She discovered several protective factors that encouraged positive change, including higher education, education and vocational skills acquired during service in the armed forces, marriage to a stable partner, conversion to a religion that demanded active participation in a 'community of faith,' and recovery from a life-threatening illness or accident (Werner & Smith, 2001). In the 1980s, researchers began to analyze responses to adversity when a 1989 study emerged involving parents who had schizophrenia who may not have given an adequate amount of comfort as a

caregiver to their child, thereby impacting their child's likelihood of following maladaptive paths through life (Masten, 1989). Other children, as Masten (1989) found with the "Project Competence" studies of stress resistance in Minnesota, however, were capable of overcoming adversity, and this led researchers to explore the "process" of resilience.

Resilience is a dynamic concept that is increasingly being used to describe and explain the complexities of individual and group responses to traumatic and challenging situations (Bowes & Jaffe, 2013). The broader, systems framework definition of resilience is the capacity of a dynamic system to withstand or recover from significant challenges that threaten its stability, viability, or development (Sapienza & Masten, 2011). Rutter (2006) used the term resilience to refer to the finding that some individuals have a relatively good psychological outcome despite suffering risk experiences that would be expected to result in serious sequelae. Resilience, at its essence, is an interactive concept to describe the combination of serious risk experiences and a relatively positive psychological outcome despite those experiences (Rutter, 2006). Resiliency can also be defined as protective or positive processes that reduce maladaptive outcomes under conditions of risk (Greenberg, 2006). Greenberg (2006) identified three broad categories of protective factors have been identified: individual (temperament and intelligence/cognitive ability), the quality of a child's relationships, and broader environmental factors (safe neighborhoods, quality schools, and regulatory activities; Greenberg, 2006).

The American Psychological Association (APA) refers to resilience as the process of adapting well in the face of adversity, trauma, tragedy, threats, or significant stress or, more specifically, as a dynamic process in which psychological, social, environmental, and

biological factors interact to enable an individual to regain his or her mental health despite exposure to adversity (American Psychological Association, 2010; Hayas, Arroyabe & Calvete, 2015). Resilience has also been described as one's capacity, following an exposure to an isolated and highly disruptive event (i.e., death, life threatening experience), to maintain stable and healthy levels of psychological function (Bonanno, 2004).

From a biological standpoint, resilience has also been described as a combination of neurobiological (i.e., serotonin, norepinephrine, neuropeptide Y, dopamine) and psychological factors (i.e., positive emotions and optimism, humor, cognitive flexibility, acceptance, religion/spirituality, altruism, social support, coping style, and stress inoculation; Southwick, Vythilingam & Charney, 2005). Accordingly, it is proposed that individuals who possess a greater number of these attributes are more likely to adapt to disruptive events such as severe injury, loss of a loved one, or traumatic events. In contrast, individuals who have fewer of those attributes are less likely to successfully adapt to these disruptive events and adversity (White, Driver & Warren, 2010). Despite the increasing use of the term resilience, there is no universal definition of resilience adopted in the research literature. Most definitions of resilience include the overcoming of stress or adversity or a relative resistance to environmental factors (Bowes & Jaffe, 2013).

As noted, resilience is a multidimensional construct that explains why individuals facing consequences of adversity and stress can have a positive outcome by adjusting to experiences that are perceived as threatening (Rutter, 2012). It is an inference based on evidence that some individuals have a better outcome than others who have experienced a comparable level of adversity; moreover, the negative experience may have either a

sensitizing effect or a strengthening effect in relation to the response to later stress or adversity (Rutter, 2012). It has been conceptualized as both an inherited trait that remains relatively stable despite life circumstances, as well as a state-like variable comprised of behaviors, thoughts, and actions that can be taught and enhanced (Miller, 1988; Waaktaar and Torgersen, 2011; White, Driver & Warren, 2010; Luthar, Cicchetti & Becker., 2000).

Resilience is defined as an ability to recover from or adjust easily to misfortune or change and has been studied in conjunction with the vulnerability model in psychiatry (Zubin and Spring, 1977). It is conceptualized as brevity in the breakdown of coping strategies and is juxtaposed with high vulnerability to a psychotic episode following repeated failures to adapt (Zubin and Spring, 1977). The two major components of vulnerability are inborn and acquired, that is, genetics and the influence of traumas. An individual's vulnerability to any illness determines the ease and frequency with which challenges to his stability will catapult him into a psychotic episode (Zubin and Spring, 1977). A resilient individual regains equilibrium after a temporary period of distress. In a vulnerable person, a temporary breakdown in adaptation may lead to the manifestation of more fundamental problems (Zubin and Spring, 1977).

Resilience can develop from repeated brief exposures to negative life experiences as long as circumstances allow the individual to successfully cope with the experience (Rutter, 2012). Decades of research reveal evolving definitions of resilience to trauma. Early scholars categorized it as an internal construct, relating to traits such as self-esteem and goal-orientation (Block and Block, 1980; Rutter, 1985). Groundbreaking work by Werner et al. (1971) challenged this notion by demonstrating that among children who endured multiple

traumas, one third were thriving in adulthood due largely to external supports. Werner's results pointed to the value of situational and contextual factors in facilitating resilience.

Studies have found that positive social relationships and adequate ego strength increase the likelihood of resilience (Horner, 2017; Kadner, 1989; Rutter, 2013; Zubin and Spring, 1977). There are also personality and cognitive factors that tend to be present in resilient individuals. Certain mental features, such as planning (Clausen, 1993), self-reflection, determination, self-confidence (Hauser, Allen, & Golden, 2006), and self-control (Moffitt, et al., 2011) tend to be present in resilient individuals. Resilient individuals possess a propensity to plan regarding all of life's key decisions (Horner, 2017). The act of planning can be more important than the skill of planning. Self-reflection allows an individual to determine what has or has not worked for them in the past. Resilient individuals also possess a sense of determination to meet life's challenges and develop self-confidence in being able to meet these challenges with success (Horner, 2017). Additionally, a sense of self-control in childhood is associated with overall better physical, psychological, and social outcomes (Moffitt et al., 2011). Resilience is conceptualized as an aggregate of specific psychosocial resources, namely ego strength, social intimacy, and resourcefulness, that promote coping efficacy (Kadner, 1989).

Psychodynamically, the ego-resiliency construct refers to a personality that is able to adapt and sufficiently express emotional impulses, whereas an ego-brittle personality tends to perseverate and becomes fragile and disorganized when faced with stress (Letzring, Block, & Funder, 2005; Nelson, 1994). When resilience has been conceived as a trait, it has been suggested that it represents a constellation of characteristics that enable individuals to adapt

to the circumstances they encounter (Connor and Davidson, 2003). This notion was first alluded to by Block and Block (1980) who used the term ego resilience to describe a set of traits reflecting general resourcefulness, strength of character, and flexibility of functioning in response to varying environmental demands. Individuals with high levels of ego resilience were characterized by high levels of energy, a sense of optimism, curiosity, and the ability to detach and conceptualize problems (Block & Block, 1980). These characteristics have been referred to as protective factors, which Rutter (1985) defined as "influences that modify, ameliorate, or alter a person's response to some environmental hazard that predisposes to a maladaptive outcome." Various self-report measures and other studies have demonstrated that personalities of ego-resilient individuals exhibit a few main components, such as confident optimism, productive and autonomous activity, interpersonal warmth and insight, and skilled expressiveness (Klohnen, 1996). Based on reviews immediately following treatment and one year later, psychodynamic approaches resulted in stable reductions in symptoms, both specific and general (Friedberg and Malefakis, 2018; Sachsse, Vogel, & Leichsenring, 2006).

Psychological resilience refers to a dynamic process that takes shape as a change allowing one to find a new balance and evolve positively (Grinker and Spiegal, 1963). While psychological resilience has been conceptualized as an inherited trait, it has also been conceived as a process that changes over time. Luthar and Cicchetti (2000) referred to psychological resilience as a dynamic process encompassing positive adaptation within the context of significant adversity. Psychological resilience has also been described as the "ability to adapt to changing situations and recover from negative emotions while being

affected by the external environment, thus creating a dynamic balance" (Block and Kremen, 1996). During this process of change, the individual develops new skills and a renewed feeling of personal efficacy and self-enhancement (Block and Kremen, 1996). This circular mechanism helps to implement the resilience process and its development as a whole (Block and Kremen, 1996; Sisto et al., 2019). The process of conceptualizing resilience recognizes that the effects of protective factors will vary contextually (from situation to situation) and temporally (throughout a situation and across an individual's lifespan; Fletcher and Sarkar, 2013). Thus, although an individual may react positively to adversity at one point in his or her life, it does not mean that the person will react in the same way to stressors at other points in his or her life (Davydov et al., 2010; Fletcher and Sarkar, 2013; Rutter, 2006; Vanderbilt-Adriance and Shaw, 2008). Furthermore, psychological resilience is defined as the role of mental processes and behavior in promoting personal assets and protecting an individual from the potential negative effect of stressors (Sisto et al., 2019).

RESILIENCE AND POSTTRAUMATIC GROWTH

Early studies on resilience focused on understanding why only some individuals can react to adversity in a positive way by transforming them into opportunities for growth and new adaptation (Fletcher and Sarkar, 2013). After the Second World War, researchers began to investigate how people overcome traumatic events which cause psychological distress (Sisto et al., 2019). Issues concerning the possibility of transforming a destabilizing event into an area of personal growth, and the ability to integrate resources and vulnerability, or

suffering and courage started to become primary subjects of research aimed at providing a better understanding of the processes of resilience (Sisto et al., 2019). In particular, case studies of soldiers with PTSD, as well as other forms of pathologies which have been diagnosed as results of traumatic events experienced in war, provided descriptions of individual characteristics of war veterans, highlighting at the same time that a significant number of subjects were able to effectively process the traumatic events experienced (Luther and Cicchetti, 2000; Sisto et al., 2019). Later, research involving the analysis of risk and protective factors for mental health began to focus on the context of developmental psychology with the aim of exploring the different life trajectories of those subjects that had experienced trauma (Sisto et al., 2019). This has led to the idea that resilience is much more than the ability to continue developing one's skills despite adversity or to resist trauma by protecting oneself from the influence of external circumstances (Luther and Cicchetti, 2000; Sisto et al., 2019). It expresses the ability to react positively despite difficulties, turning them into opportunities for growth.

It is worth noting that resilience is distinct from its related construct of posttraumatic growth which refers to one's ability to thrive and improve, particularly in interpersonal relationships, after exposure to trauma (Tedeschi and Calhoun, 2004). Resilience focuses on one's ability to return to previous levels of functioning (Masten et al., 1990) whereas posttraumatic growth is defined as a collection of positive changes following a traumatic event (Walsh et al., 2018). In the development of posttraumatic growth, a traumatic event acts as a catalyst for the individual to re-evaluate their worldview which can often result in distress but also various forms of positive growth (Tedeschi and Calhoun, 1996).

Quantitative research in the area of posttraumatic growth has revealed that, after a traumatic event, life changes often occur in five domains: personal strength; social relationships; appreciation for life; identification of new possibilities; and changes to spirituality (Tedeschi and Calhoun, 1996, 2004). Duan and colleagues (2015) examined the relationship between trait resilience and virtues in the context of trauma in individuals who suffered from personal traumatic experiences and found that resilience was positively associated with posttraumatic growth. However, other studies have found high levels of resilience associated with the lowest posttraumatic growth scores (Levine et al., 2009). Tedeschi and Calhoun (1996) posited that those who are most resilient may experience posttraumatic growth to a lesser extent as the traumatic experience may be less challenging to them and thus may not act as a catalyst for meaning making (Bonanno et al., 2004) and the extensive cognitive processing associated with growth. Given that cognitive processing is an essential element in the model of posttraumatic growth, it has been argued that, perhaps, resilience may not facilitate posttraumatic growth (Westphal and Bonanno, 2007). Resilience is a target of interest for posttraumatic growth research as it has been cited as a key component which can manipulate the level of cognitive processing engaged in by an individual following a trauma (Calhoun and Tedeschi, 2006). Resilience has been hypothesized to play a role in posttraumatic growth as traumatic experiences may be less traumatic to resilience individuals (Bonanno et al., 2004). However, conflicting research findings exist in the literature with regard to the relationship between posttraumatic growth and resilience (Bonanno et al., 2004).

DETERMINANTS OF RESILIENCE AND PROTECTIVE FACTORS

Research indicates that approximately 70% of adults globally (Benjet et al., 2016) and 89.7% of adults in the United States (Kilpatrick et al., 2013) experience at least one traumatic event during their lifetimes. The negative consequences of trauma exposure are well documented, including psychological (Turner and Lloyd, 1995) and somatic symptoms (Chester and Holtan, 1992). Despite this data, the prevalence of PTSD in United States population is only 6.8% (Gradus, 2013), and is similarly low worldwide (Kessler et al., 2017). While rates may reflect underreporting, it is also likely that many are able to display the resilience necessary to avoid developing significant PTSD symptoms (Bonanno et al., 2011).

Recent studies have focused on helping to identify and study specific factors that are determinants of resilience (Friedberg and Malefakis, 2018). By conducting detailed analyses of interviews with resilient individuals, Southwick and Charney (2012) identified ten "resilience factors" or coping mechanisms for dealing with trauma or severe stress. These include: an optimistic but realistic outlook, sought and accepted social support, sturdy role models as well as an inner, moral compass, religious or spiritual practices, and acceptance of what could not be changed (Southwick and Charney, 2012). In addition, other features found included attending to health and well-being such as physical fitness, mental sharpness, and emotional strength, actively solving problems while looking for meaning and opportunity, and even humor (Southwick and Charney, 2012). Finally, Southwick and Chaney (2012)

concluded that resilient individuals tend to take responsibility for their emotional well-being and use the traumatic experience as a basis for personal growth.

Numerous protective factors have been identified in the resilience research literature, including hardiness (Bonanno, 2004), positive emotions (Tugade and Fredrickson, 2004), extraversion (Campbell-Sills, Cohan, & Stein, 2006), self-efficacy (Gu and Day, 2007), spirituality (Bogar and Hulse-Killacky, 2006), self-esteem (Kidd and Shahar, 2008), and positive affect (Zautra, Johnson, & Davis, 2005). The identification of these protective factors supports Rutter's (1987) view that psychological resilience is the "positive role of individual differences in people's response to stress and adversity." Research has also established positive links between psychological resilience and well-being (Li et al., 2017). He and colleagues (2013) contended that psychological resilience partially mediated the relationship between dispositional optimism and well-being, where dispositional optimism acted as a protective factor by increasing the ability of an individual to recover from frustrations. Moreover, higher psychological resilience predicted greater happiness, lower depression, and greater satisfaction with life in older adults (i.e., greater psychological well-being; Tomás et al., 2012; Smith and Hollinger-Smith, 2014). When individuals possess high psychological resilience, they are able to cope with stressful events and deal with negative emotions (Campbell-Sills et al., 2006), resulting in a high level of well-being. It has been demonstrated that psychological resilience is negatively correlated with neuroticism (Morales et al., 2018). There is evidence that people with high neuroticism possess more vulnerable emotions and poor coping styles (Ormel et al., 2012). In contrast, people low in neuroticism

are characterized by emotional stability and the ability to cope with stress (Ormel et al., 2012).

Research has also examined the role of resilience on individuals who sustain a traumatic injury (Quale & Schanke, 2010; White, Driver & Warren, 2010). Changes in resilience and indicators of adjustment (i.e., satisfaction with life, depressive symptomatology, spirituality, functional independence) were identified in a sample of individuals during inpatient rehabilitation after a spinal cord injury (SCI; White Driver & Warren, 2010). Findings suggested resilience to be a common response to an acquired severe injury, with significant correlations between resilience, satisfaction with life, spirituality, posttraumatic stress, and anxiety and depressive symptoms (White Driver & Warren, 2010).

CAREGIVER BURDEN

Caring for loved ones is associated with several benefits, including personal satisfaction in relieving another's discomfort, feeling useful and needed, and finding more meaning in life. Caregiving is also associated with significant physical, psychological, and financial burden for care providers (Haley et al., 2010; Kelly, Reinhard & Brooks-Danso, 2008; Reinhard et al., 2015; Roth, Fredman & Haley, 2015; Schulz and Beach, 1999; Swartz and Collins, 2019). Past research has examined negative outcomes for families of patients with critical illness, including impact on quality of life, as well as functional and psychological outcomes (e.g., depression, posttraumatic stress disorder; Davidson et al., 2012), both at the time of patient discharge and longitudinally (Bekes, 2006; Jones et al.,

2004; Johansson, Fridlund & Hildingh, 2004; Anderson et al., 2008). This negative impact on family members has been referred to in the literature as caregiver burden.

Caregiver burden has been defined as "the extent to which caregivers perceive their emotional or physical health, social life and financial status are suffering as a result of caring for their relative" (Faison et al., 1999). Although it is frequently measured as a unidimensional construct, there is a growing consensus that burden is multidimensional (Ankr et al., 2005; Bédard et al., 2001; Hebert, Bravo, & Preville, 2000; Knight, Fox, & Chou, 2000; O'Rourke and Tuokko, 2003). Caregiver burden has been conceptualized as a two-dimensional phenomenon with both objective and subjective components (Foster and Chaboyer, 2003). A review by Braithwaite (1993) described objective burden as the extent of disruption to the caregiver's life and subjective burden as the caregiver's attitude and feelings toward the caregiver experience. Caregiver burden has also been studied as both a predictor and an outcome variable (Pinquart and Sorensen, 2007; Schulz and Martire, 2004). The burden of caregiving responsibilities has been shown to influence the quality of the relationship between caregivers and care receivers, caregiver health, and the decision to institutionalize the care receiver (Pinquart and Sorensen, 2007; Schulz and Martire, 2004).

Caring for individuals with physical disabilities and chronic illness may present long-standing periods of stress that puts informal caregivers at increased risk of reduced well-being and enhanced morbidity and mortality (Schulz and Sherwood, 2008). Stressors associated with caregiving situations are often persistent, uncontrollable, and unpredictable, and one-third of all caregivers describe a high burden of care (Swartz and Collins, 2019). In contrast with professional caregivers, informal caregivers provide care for a person without

being compensated or specifically trained (Swartz and Collins, 2019). This group of caregivers is steadily increasing as a consequence of a high burden of chronic disease in the aging population and an extended life expectancy for persons living with chronic disabling conditions (Schulz and Sherwood, 2008), in addition to shorter hospital stays and limited hospital discharge planning (Swartz and Collins, 2019). Eighty percent of adults requiring long-term care live at home in the community, and unpaid family caregivers provide 90% of their care (Fineberg, 2008). These caregivers fill an important role for the family and provided a substantial cost savings of an estimated $470 billion nationwide in 2013 (Reinhard et al., 2015). Family caregivers serve as a critical extension of the U.S. health care system and supporting this "invisible and isolated army" has emerged as a national public health priority (Reinhard et al., 2015).

The adverse effects that caregiving has on the caregiver's health status have been demonstrated in a number of studies. High levels of caregiver burden has been documented in caregivers of hemodialysis patients, which resulted in a negative effect caregiver quality of life (Jafari et al., 2018). A study conducted by Besser and Galvin (2018) examined caregiver burden in patients with frontotemporal degeneration (FTD) and found increased neuropsychiatric symptoms were associated with overall caregiver burden and greater role, personal, and performance strain. Financial costs of caregiving and experiencing a caregiving crisis in the past year was also associated with higher overall burden and role strain (Besser and Galvin, 2018). A study examining predominately female caregivers of family members who were physically dependent and/or memory impaired, found that caregivers with the highest degree of subjective burden neglected their own health and well-being and

participated in fewer health-promoting behaviors (i.e., diet, exercise, social support; Sisk, 2000). In this study, subjective burden related to the caregivers' perceived stress, nervousness, and lack of control related to the caregiving situation (Sisk, 2000).

Caregiving also impacts the caregiver's psychological functioning. Overall, studies have shown that caregivers of individuals with chronic illness experience a significant level of caregiver burden resulting in complications such as depression and may result in reduced care provision and deteriorating conditions for the family member with the chronic illness (Belasco and Sesso, 2002; Jafari et al., 2018). The deterioration of the individual's health conditions can in turn increase caregiver burden and result in a vicious cycle which may lead to a gradual exhaustion of the caregivers (Jafari et al., 2018). With regard to the ICU and hospitalization, caregivers experience high levels of stress, anxiety, and depression within the first 3 to 5 days of the ICU admission (McAdam et al., 2010) Additionally, a caregiver's lack of preparedness to face crisis, unfamiliar hospital environment, lack of knowledge, lack of timely communication, apprehension regarding the prognosis of the family member's condition, and financial burden are associated with psychological distress (Kanmani et al., 2019; Raju et al., 2016). A study by Scholten and colleagues (2018) examined caregiver burden, mental health and life satisfaction among caregivers of individuals with a SCI five years after discharge from inpatient rehabilitation. Findings showed that high levels of perceived burden was strongly associated with worse mental health and life satisfaction (Scholten et al., 2018).

RESILIENCE IN CAREGIVERS

Caregiver stress has been described as a consequence of a process comprising a number of interrelated conditions, including the socioeconomic characteristics and resources of caregivers and the primary and secondary stressors to which they are exposed (Pearlin et al., 1990). Primary stressors are hardships and problems anchored directly in caregiving (Pearlin et al., 1990). Secondary stressors fall into two categories: the strains experienced in roles and activities outside of caregiving, and intrapsychic strains, involving the diminishment of self-concepts (Pearlin et al., 1990). Using this model of caregiving allows the potential development of interventions for coping and social support at multiple points along the stress process.

Caregivers' resilience can be a protective factor against burden in caregivers of individuals with cancer, dementia, and stem cell transplantation (Li et al., 2018; Luo, Zhang & Liu, 2019; Ruisoto et al., 2019). A descriptive cross-sectional survey conducted by Luo and colleagues (2019) explored resilience, social support, coping style, and posttraumatic growth in hematopoietic stem cell transplantation caregivers. Analyses from this study revealed that posttraumatic growth was positively associated with resilience, social support, and positive coping style (Luo, Zhang & Liu, 2019). These findings are consistent with resilience theories that propose people with high resilience are more likely to display positive adaptation and positive affect when faced with significant adversity (Simpson & Jones, 2012).

Simpson and Jones (2012) assessed resilience in a sample of 61 family caregivers of persons with severe traumatic brain injury (TBI) or SCI by investigating the relationship between resilience and affective state. Correlational analyses found that for both types of caregivers, higher levels of the resilience factors of personal competence and self/life acceptance resulted in a higher positive and a lower negative affect on the caregiver and the caregiver burden. A study by Elliott and colleagues (2014) examined resilience in the initial year of caregiving for a family member with a traumatic spinal cord injury (SCI), conceptualizing caregiving from the Pearlin model (Pearlin et al., 1990) and the resilience process model (Bonanno, 2004). Results over time revealed three groups of caregivers: chronic (experienced high levels of depression and anxiety), recovery (experienced a high level of distress during hospitalization that subsided following their return to the community), and resilient (experienced less distress and better adjustment; Elliott et al., 2014). The chronic group reported more anxiety, negative affect, and ill health than the other two groups throughout the year (Elliott et al., 2014). The resilient group was best characterized by their enduring levels of positive affect and supportive social networks (Elliott et al., 2014). Overall, Elliott and colleagues (2014) concluded that a large percentage of caregivers are resilient in the initial year of caregiving; however, those who have problems adapting tend to exhibit significant distress shortly after the traumatic event. Results indicated the need for early detection of, and psychological interventions for, caregivers who have difficulty adjusting, as their distress is unlikely to abate untreated over the year (Elliott et al., 2014).

In another study of SCI caregivers, expectations of recovery were assessed across four primary domains including pain severity, level of engagement in social/recreational activities, sleep quality, and ability to return to work/school in caregivers at three- and six-months post-injury as part of a prospective, longitudinal observation study (Agtarap et al. 2018). Unmet caregiver expectations were measured as caregivers' forecasts, with percentage of future recovery compared to percentage of later perceived actual recovery (Agtarap et al. 2018). Unmet caregiver expectations were present at three- and six-months post-injury for the four primary domains, suggesting that unmet caregiver expectations for recovery could pose a risk for caregiver recovery and adjustment (Agtarap et al., 2018). Across the four SCI recovery domains, 75% of caregivers had unmet expectations for engagement in social activity, 50% had unmet expectations for pain decrease, and 42% had unmet expectations for sleep improvement and resuming work at the three-month follow-up (Agtarap et al. 2018). The rates of unmet expectations for recovery were similar at the six-month follow-up. Additionally, these results merit further investigation into their link with caregiver mental health.

Anderson and colleagues (2019) approached family caregivers supporting relatives with traumatic brain injury (TBI) from six rehabilitation units from New South Wales and Queensland and found that resilience had a direct effect on positive affect in caregivers and also played a protective role in relation to positive mental health. Resilience, in combination with other psychological attributes, was also associated with reduced morbidity among family caregivers after a severe TBI (Anderson, Daher & Simpson, 2019). In a study examining caregiver burden, resilience, and satisfaction among caregivers supporting

relatives and loved ones with a traumatic SCI, Castellano-Tejedor and Lusilla-Palacios (2017) concluded that more resilient and satisfied caregivers experienced lower burden related to uncertainty about the future, and less insecurity with caregiving and dependence of the injured patient.

Overall, existing research underlies the importance of resilience among family members and caregivers supporting patients through chronic illness and injury; however, there is limited information on resilience on caregivers in trauma ICU populations available in the literature.

POSTINTENSIVE CARE SYNDROME-FAMILY (PICS-F)

Research suggests having a family member or close friend experience a traumatic injury can result in reduced participation of necessary care-giving functions, such as decision-making and assistance with activities of daily living, after their loved one is released from the hospital, which may result in detrimental physical and mental health consequences for both the injured individual and caregiver (Davidson et al., 2012). These adverse psychological outcomes may be present four or more years after discharge from the ICU (Davidson et al., 2012).

A study by Livingston and colleagues (2009) concluded that ICU survivors continued to demonstrate significant functional impairments more than three years after sustaining their initial injury. In addition to the negative impact on the patient, this also creates a potential scenario in which a family member or friend may shift into a chronic caregiving role, which

is associated with a variety of negative consequences (Livingston et al., 2009). For example, those unable to manage a caregiver role effectively can impact a patient's physical health, resulting in possible readmission to the hospital for secondary complications (Johansson, Fridlund & Hildingh, 2002).

Individuals who have a family member admitted to the ICU can develop adverse psychological outcomes including symptoms of depression, anxiety, posttraumatic stress, and complicated grief (Davidson, Jones, & Bienvenu, 2012; Warren et al., 2015). In 2010, the Society for Critical Care Medicine (SCCM) created a task force to examine these issues and coined the term "postintensive care syndrome-family" (PICS-F) to better describe these symptoms in family members of ICU patients (SCCM, 2010). A novel study by Warren and colleagues (2015) identified psychological differences of family members in the ICU based on whether or not the injured individual experienced a TBI. Using the constellation of symptoms under PICS-F, the results of the study suggested that family members in the TBI group endorsed more symptoms of depression and posttraumatic stress at 3 months compared to the non-TBI group (Warren et al., 2015). This study also demonstrated the need for early psychological interventions to reduce the potential negative consequences of having a family member in the ICU, as families who experience symptoms consistent with PICS-F may have increased difficulty if placed in a caregiving role post hospitalization (Warren et al., 2015).

In a systematic review of psychosocial outcomes in informal caregivers, Haines and colleagues (2015) demonstrated that the most commonly investigated and reported outcomes across 14 studies was depression, with the reported incidence of 22.8% to 31.9%. A critical review of PICS-F by Davidson and colleagues (2012) indicated the rates of generalized

anxiety disorder ranged from 21–56%, rates of posttraumatic stress disorder (PTSD) ranged from 13%–56%, and of the presence of depression ranged from 8%–42%. A recent literature review by van Beusekom and colleagues (2016) noted that, during an ICU or hospital stay, 42% to 80% of caregivers experience anxiety, 16% to 90% experience depression, and 57% experience posttraumatic stress and these symptoms can persist for months after discharge from the ICU. This is especially concerning given that these symptoms may continue long after ICU discharge (van Beusekom et al., 2016). For example, Jones et al. (2004) found up to 49% of relatives exhibited high posttraumatic stress-related symptoms 6 months after ICU discharge. Several studies have described PTSD symptoms in ICU family members of adult patients following ICU discharge (Anderson et al., 2008; Bekes, 2006; Jones et al., 2004; Miranda et al., 2011). Symptoms of PTSD have been reported in 35% to approximately 50% of family caregivers during an ICU stay and symptoms of PTSD have been reported in more than one third of family members 6 months after ICU discharge (Anderson et al., 2008; Bekes, 2006; Jones et al., 2004; Miranda et al., 2011). Research has shown that despite patients' functional autonomy and health related quality of life improving 6 months after discharge, caregivers' burden was still high and similar to that observed at baseline but tended to involve a higher percentage of caregivers requiring urgent psychological help 6 months after discharge compared to baseline (Comini et al., 2016). The current research indicates that PICS-F may negatively impact a family member's ability to provide caregiving for those relatives who are discharged to a home setting (Schmidt & Azoulay, 2012). Despite this, there is limited information on caregiver burden or posttraumatic stress disorders in caregivers available in the literature.

SOCIAL DETERMINANTS OF HEALTH IN CAREGIVERS

The multidimensionality of burden means that any global measure of burden may not adequately reflect the individual domains of burden, and therefore, such measures may fail to reveal significant levels of distress for many caregivers (Savundranayagam, Montgomery & Kosloski, 2011). Therefore, in addition to demonstrating that a burden measure is multidimensional, it is also necessary to show that the individual domains matter uniquely. Caregiving can be considered as a social determinant of heath inequalities. In the last two decades, many studies on the relationship between psycho-physical health and caregiving have been reported (Petrini et al., 2019); however, literature focused on social determinants of health with caregiver burden in trauma populations is sparse. A meta-analysis by Pinquart and Sorensen (2003) showed that, among family caregivers, a number of predictive factors are related to a worse physical health such as: severity of behavior problems and cognitive impairment of the care recipient, intensity of care provided, co-residence, kind of kinship, higher burden and depression, higher age, lower socio-economic status and scarce levels of informal support.

Social problems for caregivers have also been described in the literature, including social isolation, job loss, disputes over disability, and insurance claims (McPeake et al., 2016). Griffiths and colleagues (2013) reported that family members provided 80% of the care needed at 6 months post-discharge for critical care survivors. Although it has been suggested that social support in any form may reduce the adverse consequences of stressful

events (Schwarz and Roberts, 2000), the extant literature regarding the effects of social support on caregiver burden is inconclusive. However, research suggests that factors such as female gender (Johnson et al., 2001; McAdam et al., 2010; Pochard et al., 2005), younger age (Alfheim et al., 2018; Cameron et al., 2016; Neundorfer, 1991; Pochard et al., 2005), being an ethnic or cultural minority (McAdam et al., 2010), prior psychiatric disorders (Alfheim et al., 2018; Lefkowitz, Baxt, & Evans, 2010; Jepson et al., 1999), and being either a spouse (McAdam et al., 2010; Pochard et al., 2005; Alfheim et al., 2018) or a child of the ICU patient (Bekes, 2006; Cameron et al., 2016) may place individuals at higher risk for developing PICS-F. Existing research suggests that the physical health of the caregiver is compromised when caregivers were psychologically distressed (Pinquart and Sorensen, 2007; Schulz and Beach, 1999; Schulz and Martire, 2004; Schulz et al., 1995).

Pinquart and Sorensen (2003) reported that gender differences in depression and physical health among caregivers are indeed larger than those found in the general adult population, being in part explained by gender differences in caregiving stressors. In particular, higher levels of stressors and lower levels of social resources, among females versus males, accounted for elevated gender differences. Caregiver literature has consistently shown that female caregivers are more burdened than male caregivers (Marks, Lambert, & Choi, 2002; McDonnell and Ryan, 2013; Penning and Wu, 2016; Pinquart and Sorensen, 2006; Swinkels et al., 2019; Yee and Schulz, 2000). Explanations of gender differences in caregiver burden may follow two lines of reasoning. The first argues that women and men live in different structural contexts and the unequal distributions of rewards, privileges, opportunities, and responsibilities leads to different kinds and intensities of stressors to which

people are exposed (Pearlin et al., 1990). The unequal distribution of opportunities and responsibilities may push women into the caregiver role more often than men and thus hamper their functioning in other fields (work, health). Since women provide more hours of care and experience, more negative effects of caregiving may also explain why they experience a higher caregiver burden (Pinquart and Sorensen, 2006; Yee and Schulz, 2000). Psychological and physical health differences have been found between caregivers and non-caregivers and the most significant were observed in specific caregiver groups, such as those for dementia or mental illness or disability patients (Petrini et al., 2019). Several findings again suggest that women suffer a greater burden of care compared to men, also in the presence of the same pathological condition of the care recipient (Petrini et al., 2019; Pinquart and Sorensen, 2003). Moreover, women have a greater perception and react differently to psychological distress than men, most likely due to societal expectations, type of support received, and perceived inequalities in the division of tasks in the home (Petrini et al., 2019).

Culture, which includes an individual's social, political, interpersonal and familial contexts, and acts as a lens through which people view their world (Triandis, 1972), should also be considered when discussing resilience. Cultural values and beliefs impact both an individual's interpretation of a traumatic event as well as his/her reaction to it (Kalmanowitz and Ho, 2017). Much of the research on resilience is steeped in a Western-centric value system that emphasizes individual qualities and fails to identify important protective factors that may relate to culture (Ungar, 2017). Regarding specific dimensions of culture, research points to the protective impact of spiritual or religious beliefs (Pargament et al., 2011) as well

as strong affiliation with ethnic identity (Han et al., 2016). For example, recent research by Veronese and colleagues (2017) pointed to the protective impact of spirituality and sense of meaning amongst trauma exposed Palestinian aid workers in the Gaza Strip. In fact, the researchers demonstrated that participants with the highest levels of trauma exposure could experience resilience through spiritual and religious affiliations.

A pilot study by Raghavan and Sandanapitchai (2019) explored reactions to trauma and psychological resilience in an international sample of trauma-exposed participants. The final sample included 200 trauma exposed adults from nineteen different countries worldwide, with a majority hailing from the United States, India, Sri Lanka, and the Philippines. Results indicated high levels of trauma exposure and posttraumatic symptoms, along with high levels of reported resilience, with significant differences between groups. Specifically, participants who identified as Asian or South Asian scored significantly higher on resilience scores, affiliation with ethnic identity, and use of positive spiritual coping than other groups (Raghavan and Sandanapitchai, 2019). These findings are consistent with resilience literature in specific cultural groups that points to use of religious or spiritual coping (Reinert et al., 2015), as well as pride in ethnic identity (Moscardino et al., 2007).

The 2009 California Health Interview Survey (CHIS) dataset identified 591 Asian, 989 Hispanic, and 6357 White, non-Hispanic caregivers of older adults to examine caregiver characteristics, caregiving situations, and practice patterns (i.e., respite care use, hours and length of caregiving) by racial/ethnic groups and immigrant generations (Miyawaki, 2016). The caregiving patterns of White, non-Hispanic caregivers showed less caregiving involvement in later generations; whereas, Asian and Hispanic caregivers use respite care

less and spent more hours caregiving per week (Miyawaki, 2016). These findings suggest the importance of considering the cultural values of each racial/ethnic group when working with racially and ethnically diverse populations of family caregivers. Similar to Hispanic caregivers, Asian caregivers tend to use more informal than formal support within their family members (Ho et al. 2003; Jones et al. 2002) because of their cultural beliefs and/or taboos to use outside formal services (Han et al. 2008; Jones et al. 2002; Kong et al. 2010; Lai 2007, 2010; Zhan 2004). For Asian caregivers, caregiving is an expected stage in their lives (Ho et al. 2003) and viewed as a cultural, lifelong reciprocal obligation for aging parents (Jones et al. 2002; Tang 2011).

Culturally, gendered behavior expectations can produce various tensions and expectations within families, especially with female caregivers who must also raise their own families and work outside the home (Flores et al., 2009; Maldonado, 2017; Simpson, 2010; Williams et al., 2014). Several studies have found that female Hispanic caregivers expressed tension as they cared for family members while trying to maintain their own sense of self (Flores et al., 2009; Simpson, 2010; Williams et al., 2014). Of note, female Hispanic caregivers who were younger reported higher incidences of depressive symptoms, more burdens and demands related to finances, work, and lack of family support when compared with older female Hispanic caregivers (Magana & Ghosh, 2010).

Regarding level of kinship, Savundranayagam and colleagues (2011) assessed whether the dimensions of burden were the same for caregiving spouses and adult children of persons with chronic illnesses and the role on self-rated health. For both spouses and adult children, stress burden was associated with lower levels of self-rated health compared to

other informal caregivers. This finding corroborates previous studies showing that caregiving has detrimental effects on the health of spouses and adult children caregivers (Pinquart and Sorensen, 2007; Schulz and Martire, 2004; Schulz et al., 1995).

Current literature highlights the impact of standardized education to help alleviate caregiver burden and improve health outcomes for both the patient and caregiver; however, there is a limited body of evidence examining the impact of education and income level on caregiver burden. A recent study by Ugur and Erci (2019) examined the effects of education of caregivers on caregiver burden and quality of life when providing home care for stroke patients. Results found recovery in the general psychological status of caregivers and the levels of caregiver fatigue were decreased due to the effect of education and consultation provided to caregivers (Ugur and Erci, 2019). Similarly, a study by Creedle and colleagues (2012) examined the impact of education on caregiver burden and health outcomes in inpatient oncology units and found that standardized patient education helped improve caregivers' overall well-being.

A cross-sectional study conducted in Spain by García-Mochón and colleagues (2019) analyzed and compared burden, severe burden, and satisfaction among caregivers providing care to a dependent person living in the same or another home in relation to health-related quality of life, type and duration of caregiving, perceived social support, and use of social and health care services. Results showed that secondary or third-level education, performance of ungratifying tasks (changing diapers), negative coping with caregiving, and more years providing care were associated with greater burden (García-Mochón et al., 2019). Variables with protective effect were better perceived health of the person being cared for,

better caregiver health-related quality of life, and high perceived social support. Consistent with the literature, women were 75% more likely to experience severe burden compared with male caregivers (García-Mochón et al., 2019; Petrini et al., 2019; Pinquart and Sorensen, 2003). Burden was reduced by high perceived social support in the case of women and by high caregiver health-related quality of life in the case of men. The main determinant of caregiving satisfaction for both men and women was perceived social support. Higher income and education level were also associated with greater burden following adjustment for social support and other variables. This could be related to opportunity costs in terms of lost time and earnings and with the psychological and emotional dimensions of burden (García-Mochón et al., 2019). In many cases, having to divide one's time between caregiving responsibilities, paid employment, and pursuit of leisure activities places an additional burden on caregivers, causing greater emotional stress (García-Mochón et al., 2019; Mudrazija, 2019; Oliva-Moreno et al., 2019).

THE CURRENT STUDY

Prior research of the lived experiences of caregivers has mainly been explored during the time of hospitalization. Few studies have examined this population in the months following hospital discharge, resulting in limited understanding of the impact of caregiving during this time. In addition, the vast majority of the literature examining caregiver burden focuses on those caring for the elderly or terminally ill, those with a chronic illness, those who have had a cardiovascular accident (CVA) or have some form of dementia. However,

few studies have examined caregiver burden in patients who have sustained a critical illness or injury requiring admission to the ICU, yet these individuals often experience complex and diverse health problems.

Further, there is a paucity of research on the role of positive psychological factors (i.e. resilience) in this population. A better understanding of long-term psychological and quality of life outcomes after the traumatic injury of a family member or friend may ultimately assist in developing interventions that can be used with families at the time of the trauma. The aim of the present study was to examine the role of specific demographic factors and resilience in predicting caregiver burden, depression, and PTSD outcomes in caregivers of trauma patients.

The first aim of the study was to examine the role of resilience in predicting caregiver burden and other psychological factors (depression and PTSD) to determine how resilience impacts caregiver burden, depression, and PTSD outcomes over time. The second aim of the study was to examine the influence of specific demographic factors in predicting caregiver burden and other psychological factors (depression and PTSD) at three months to determine how stratifying various groups (i.e., age, gender, race/ethnicity, marital status, education, income) predicts caregiver burden, depression, and PTSD outcomes over time.

CHAPTER THREE
Methodology

The study was conducted at Baylor University Medical Center (BUMC), a Level I trauma center and part of the Baylor Scott & White Healthcare system. The research protocol, including all recruitment materials, was approved by the BUMC Institutional Review Board (IRB). Data protection plans were approved by BUMC IRB. Participants were assigned numerical codes with dates of the interviews, and data was recorded in de-identified form. Data was stored in a locked filing cabinet within a locked office that could only be accessed by members of the study team.

PARTICIPANTS

Participants in the current analysis constituted a subgroup of a larger longitudinal dataset examining mental health among caregivers of patients admitted to the trauma/critical care ICU of BUMC, an urban Level I trauma center in the southwestern United States. For the purposes of this study, family members were defined according to the Institute of Patient and Family Centered Care as "two or more persons who are related in any way-biologically, legally, or emotionally" (Institute for Patient- and Family-Centered Care, 2015). Participants for the study included close adult (18 or older) family members and friends of adult patients (≥ 18 years of age) admitted into the ICU on the trauma service at BUMC, who anticipated some level of involvement in the care or support (i.e., emotional, financial, social) of the patient after discharge. Participants for the present study were screened between 3/26/2013

and 7/28/2015. The 91 participants in this study were chosen as they had completed both a baseline and 3-month follow-up (Appendix A).

Inclusion criteria included a patient admission of at least 48 hours, with the patient currently admitted to the ICU and expected to survive more than 96 hours at 48 hours after admission, current age of ≥ 18 years (both patient and participant), and the participant's ability to provide at least two forms of contact information for follow up at 3, 6 and 12 months. Exclusion criteria included an inability to understand written or spoken English, less than 8th grade reading level, and an inability to provide at least two forms of contact information for follow-up.

MEASURES

Connor-Davidson Resilience Scale (CD-RISC) 10 Item

The CD-RISC 10 (Appendix B) consists of 10 items, using a 5-point Likert-type scale ranging from 0 (not true at all) to 4 (true nearly all of the time), which has been developed and tested as (i) a measure of degree of resilience; (ii) a predictor of outcome to treatment with medication or psychotherapy, stress management and resilience-building; (iii) a marker of progress during treatment; (iv) a marker of biological (i.e. physical) changes in the brain. The scale demonstrates sound psychometric properties in general populations with good internal consistency (Cronbach's alpha = .85) and test-retest reliability (r = .92; Campbell-Sills & Stein, 2007). The scale exhibits validity relative to other measures of stress and hardiness and reflects different levels of resilience in populations that are thought to be

differential, among other ways, by their degree of resilience (e.g., general populations versus patients with anxiety disorders; Connor and Davidson, 2003). The scale also has promise as a method to screen people for high, intermediate, and low resilience. To examine nonlinear associations, 1+ standard deviation (SD) over the sample mean was considered high resilience and 1+ SD below the sample mean was considered low resilience. Accordingly, scores between these 2 values were considered intermediate resilience. Other studies have used similar distribution when using the CD-RISC 10 (Scali et al., 2012).

The Patient Health Questionnaire 8 (PHQ-8)

The PHQ-8 (Appendix C) is a brief, validated, self-report measure of major depressive disorder for population-based studies and clinical populations (Kroenke & Spitzer, 2002; Kroenke et al., 2009). Several large studies have confirmed the validity and reliability of the PHQ-8 as both a diagnostic and severity measure for depressive disorders in large clinical studies (Kroenke et al., 2009; Shin et al., 2019). The PHQ-8 is derived from the PHQ-9 by removing the last question regarding suicide ideation. The PHQ-8 consists of 8 items that are statements about an individual's affective state (e.g., "Little interest or pleasure in doing things," "Feeling down, depressed, or hopeless"), with response choices ranging from 0 (not at all) to 3 (nearly every day). A cut off score of equal or greater than 10 was considered as the cutoff diagnostic value for a positive screen for clinically relevant depressive symptoms for the PHQ-8 (Shin et al., 2019). While this cutoff score is the same as the standard cutoff used for the PHQ-9 to indicate a likely depressive episode, the sensitivity

and specificity of this cutoff for the PHQ-8 is very similar and therefore was considered appropriate to use.

Primary Care Posttraumatic Stress Disorder Screen (PC-PTSD)

The PC-PTSD (Appendix D) is a four-item screen designed for use in medical settings and is the current screening instrument used in the Veterans Affairs (VA) system to screen for PTSD. This is considered a psychometrically sounds screen for determining the presence and absence of PTSD in the VA setting and has also been used in the civilian primary care population (Freedy et al., 2010). With a cutoff score of 3, the PC-PTSD has shown 85% diagnostic efficiency, 78% sensitivity, and 87% specificity (Prins et al., 2003).

PTSD Checklist, Civilian Version (PCL-C)

The PCL-C (Appendix E) was developed by Frank Weathers and colleagues at the National Center for PTSD in 1993 (Norris & Hamblen, 2003). The PCL-C is a well-established self-report measure of PTSD symptoms with sound reliability and validity (Wilkins, Lang & Norman, 2011). The scale consists of 17 questions that correspond to DSM-IV criteria for PTSD. The decision was made to use the PCL-C due to the study already being underway while the DSM-5 was published. The PCL-C is widely used in mental health settings to quantify PTSD symptoms and anchors items to “stressful experiences” (Lang et al., 2012). Respondents are asked how often they have been bothered

by each symptom in the past month (e.g., “Repeated, disturbing memories, thoughts, or images of a stressful experience from the past,” “Feeling distant or cut off from other people”), on a 5-point Likert-type scale ranging from 0 (not at all) to 5 (extremely). For the PCL-C, the questions are worded generically to refer to "stressful experiences in the past." A cut off score of equal or greater than 34 was considered as the cutoff diagnostic value for a positive screen for posttraumatic stress symptoms (Lang et al., 2012).

Caregiver Burden Scale (CBS)

The CBS (Appendix F) is a 22-item scale that assesses subjectively experienced burden by caregivers to chronically disabled persons. This instrument has now been used among caregivers to patients with different diagnoses such as dementia, stroke, Parkinson, fracture, and multiple disabled elderly, who also live in different care settings. The CBS has satisfactory internal consistency (Cronbach’s alpha = .87) and test-retest reliability with kappa values in the range of 0.89-1.0 in community-based populations (Elmståhl, Malmberg, & Annerstedt, 1996). The CBS comprises five factors: general strain, isolation, disappointment, emotional involvement and environment (e.g., “Do you feel tired and worn out,” “Do you think you have to shoulder too much responsibility for your relative’s welfare”). Responses use a Likert-type scale ranging from 1 (not at all) to 4 (often). A total burden index comprises the mean of all the 22 items (range = 0 to 80) and a higher score indicates a higher burden.

Demographic Questionnaire

The demographic questionnaire (Appendix G) was researcher-created and included self-report information about the participant (i.e., age, gender, ethnicity, marital status, educational level, pre-morbid economic status, relation to patient, distance from hospital, and contact information).

PROCEDURE

Eligible individuals were identified based on their family member's medical diagnosis through the trauma service admission list, as well as from bi-weekly trauma ICU rounds and communication with ICU staff (i.e., nurses and physicians) familiar with the people who were close to the patient. After the ICU patient was admitted for greater than 48 hours and, at that point, expected to survive for more than 96 hours, eligible participants were approached in a private area or the ICU waiting room to explain the informed consent process. Participants were informed that the participation in the study was voluntary and had no bearing on their family member's medical treatment; that, if they chose to participate, their responses would be de-identified; that there were no benefits or greater-than-minimal risks associated with participations; and that they may withdraw from the study at any time. After informed consent was obtained, the participant was enrolled into the study.

Baseline measures of caregivers (*Demographic Questionnaire; Patient Health Questionnaire, PHQ-8; Primary Care Post-traumatic Stress Disorder Screen, PC-PTSD; Connor-Davidson Resilience Scale, CD-RISC)* were collected during initial inpatient hospital

admission following traumatic injury. Three-month follow-ups were conducted within a 4-week window around the participants' follow-up due date (e.g., 2 weeks before due date to 2 weeks after). Reminder postcards or e-mails based on participants' preference during hospitalization were sent 1 week before the 4-week window opening. Participants were contacted over the telephone using the contact information provided by the patient at baseline, with a maximum number of 12 attempts to successfully contact the patient.

Measures administered during these 3-month follow-up calls included: PHQ-8, PC-PTSD, PCL-C (if positive on PC-PTSD), and CBS. At baseline, participants, regardless of their responses, were provided with a list of community mental health referrals including counseling, substance abuse resources, and local support groups. This list was provided again if requested by the participant at the 3-month follow-up time.

CHAPTER FOUR
Statistical Analyses

PRELIMINARY ANALYSES

SAS version 9.4 was used for all analysis. All continuous variables were assessed for normality, linearity, and outliers. The three continuous variables included in the analysis (age, CD-RISC total, and CBS total) were evaluated for normality using a combination of visual inspection of the histograms, Q-Q plots, and Kolmogorov-Smirnov tests. All diagnostic measures agreed that age follows a normal distribution. Both CD-RISC total and CBS total showed some deviations from normality. However, these deviation were not extreme and in combination with a sample size near 100 these measures were not transformed. Previous literature has shown that regression models are robust to violations of this assumption with adequate sample size (Schmidt & Finan, 2018). There were also no outliers found in the data.

PLANNED ANALYSES

Aim 1: To examine the role of resilience in predicting caregiver burden and other psychological factors (depression and PTSD).

Regression analysis was used to determine the association between resilience and each outcome (caregiver burden, depression, and PTSD). For caregiver burden, general linear regression was used with CBS score at 3 months. For depression and PTSD outcomes, logistic regressions were used and included both baseline and 3-month outcomes. To assess

how resilience impacts scores over time, the logistic regression models included both CD-RISC score as well as the interaction between CD-RISC and time. Additionally, the dependency in the outcomes over time from the same participant were accounted for using a random patient effect in the model. All models were assessed with and without adjustment for demographic factors including age, sex, race, ethnicity, marital status, educational level, employment status, and history of psychological disorder. The model for CBS included a single variable for prior psychological disorders, whereas the models for depression and PTSD included a variable for prior history of the respective disorder and prior history of any other disorders.

Aim 2: To examine the influence of demographics factors (age, gender, race/ethnicity, marital status, education, income) in predicting caregiver burden and other psychological variables (depression and PTSD) at three months.

Analysis for Aim 2 was largely exploratory in nature to determine potential associations between the demographic and socioeconomic indicators and each outcome (caregiver burden, PTSD, and depression). Initially, univariate analysis was conducted using t-tests or chi-square tests. To evaluate intersectionality of the factors, the associations between the interactions of the indicators and each outcome were evaluated. Interactions were assessed using a series of linear (for caregiver burden) and logistic (for PTSD and depression) regression models. Individual factors and interactions that were significant at the 0.10 level were then included in the final multiple regression model for each outcome. In the final model, an interaction or individual factor was considered significant if the p-value was less than 0.05.

CHAPTER FIVE
Results

DEMOGRAPHICS

Table 1 lists demographic information for the study sample. The 91 participants included 67 females and 24 males. Of the participants, 65.9% were White, 26.4% were Black, 4.4% were Asian, 1.1% were American Indian or Alaska Native, 2.2% classified themselves as "Other," and 20.9% classified themselves as being of Hispanic ethnicity. Ages of participants ranged from 18 to 82 years (M = 49.2; SD = 13.9) and 57 (62.6%) of the participants reported being married. Regarding relationship to the patient, 28 participants reported being a parent, 26 participants reported being a spouse, 16 participants reported being a child, 5 participants reported being a sibling, 3 participants reported being a friend, and 13 participants reported "Other." Of the participants, 52 (57.1%) reported a post-secondary education and 52 (57.1%) reported current employment. Thirty-three participants (36.3%) reported earning an annual household income less than $50,000, 36 participants (39.6%) reported earning an annual income greater than $50,000, while 22 participants (24.2%) declined to answer. Regarding pre-morbid psychological disorders, 23 participants (25.3%) reported depression, 7 participants (7.7%) reported posttraumatic stress disorder, while 16 participants (17.6%) reported at least one other psychological disorder (i.e., bipolar/manic depression, panic disorder, generalized anxiety disorder, obsessive compulsive disorder, schizophrenia, any phobia).

Table 2 lists descriptive statistics for the psychosocial measures at baseline and 3 months. The overall mean CD-RISC score reported by participants was 32.7 (*SD* = 5.6). Using distributions established in the literature, 1+ SD over the sample mean was considered high resilience and 1+ SD below the sample mean was considered low resilience. Accordingly, scores between these 2 values were considered intermediate resilience. At baseline, of the 91 participants included, 17 participants reported high resilience, 59 participants reported intermediate resilience, and 15 participants reported low resilience. Regarding caregiver burden, a total burden index comprises the mean of all the 22 items (range = 0 to 80) and a higher score indicates a higher burden. Overall, scores ranged from 22 to 76, with a mean of 41 (*SD* = 14.7). Regarding the PHQ-8, a cut-off score of 10 was used to indicate statistically significant presence of depressive symptoms. Overall, 36 participants (39.6%) reported the presence of statistically significant depressive symptoms at baseline, while 20 participants (22%) reported the presence of statistically significant depressive symptoms at 3 months. A PC-PTSD cut-off score of 3 was used a screen to determine the presence and absence of posttraumatic stress symptoms in the sample. At baseline, 23 participants (25.3%) screened positive for the presence of posttraumatic stress symptoms. At 3 months, 16 participants (17.6%) screened positive for the presence of posttraumatic stress symptoms and were subsequently administered the PCL-C. A cut off score of equal or greater than 34 on the PCL-C was considered as the cutoff diagnostic value for a positive screen for posttraumatic stress symptoms. Out of these 16 participants, 11 participants (12.1%) screened positive for posttraumatic stress symptoms at 3 months.

RESULTS OF HYPOTHESIS-TESTING

Hypothesis 1: Individuals with higher resilience will have fewer negative psychological outcomes and report less caregiver burden over time compared with individuals with lower resilience.

Regression analyses were used to determine the association between resilience and each outcome (caregiver burden, depression, and PTSD). To assess how resilience impacted scores over time, the logistic regression models included both the CD-RISC score as well as the interaction between CD-RISC and time. All models were also assessed with and without adjustment for demographic factors including age, sex, race, ethnicity, marital status, educational level, employment status, and history of psychological disorder. A summary of each outcome variable (caregiver burden, depression, and PTSD) in relation to resilience is reported in Table 3. A weak, negative correlation (r = -0.17) was found between resilience and caregiver burden. However, Figure 1 indicates no statistically significant findings regarding resilience and caregiver burden at 3 months. Figures 2 and 3 illustrate the distribution of scores for resilience at baseline by self-reported depressive symptoms at baseline and 3 months and posttraumatic stress symptoms at baseline and 3 months, respectively.

Regression analyses and statistics used to determine the association between resilience and each outcome (caregiver burden, depression, and PTSD) are reported in Table 4. There was no significant association between resilience and caregiver burden in either or unadjusted (p = .105) or adjusted analysis (p = .39). In the unadjusted model higher resilience was associated with lower odds of depression (OR = 0.92; *95% CI* = 0.87, 0.99; p = 0.016)

and lower odds of PTSD (*OR* =0.91; *95% CI* = .84, 1.00; *p* = 0.043); however, neither were significant once the models were adjusted for demographic factors (age, sex, race, ethnicity, marital status, educational level, employment status, and pre-morbid psychological disorders). In summary, Table 4 does not reflect any significant associations between resilience and caregiver burden; however, it does illustrate significant associations between resilience and depression and PTSD separately.

Of note, time did remain significant across adjusted and unadjusted models for both depression (adjusted *p* = .003, unadjusted *p* = .002) and PTSD (adjusted *p* = .005, unadjusted *p* = .005) and showed that the odds of both outcomes were lower at 3 months than at baseline. There was not a significant interaction found between time and resilience with respect to either depression (*p* = 0.524) or PTSD (*p* = 0.425) models. Therefore, the significant reduction in depression and posttraumatic stress symptoms occurred at approximately the same rate across CD-RISC total scores. Thus, the Hypothesis for Aim 1 was not supported.

Hypothesis 2: Demographic factors will play an influential role in predicting caregiver burden and other psychological variables (depression and PTSD) over time.

Due to the exploratory nature for Aim 2, attributable to the small sample size and limited generalizability, the first step was to determine to the most useful way to categorize race and ethnicity. Several combined race/ethnicity variables were evaluated: four options (White, Black, Hispanic, Other); a White versus Other race variable combined with Hispanic versus Non-Hispanic; a White (Non-Hispanic) versus Other variable. Combining race/ethnicity variables in this way has previously been utilized in a different subgroup of

caregivers of a larger longitudinal data set due to limited generalizability and small sample size (Kearns et al., 2017). The combinations described above are shown in Table 5. A race/ethnicity variable with four category options produced low counts for multiple groups for the depression and PTSD outcomes. Dichotomizing race into White versus Other found no significant differences; however, Hispanic ethnicity was a significant factor ($p = .029$). Of note, all participants who identified as Hispanic also identified as "White." Some studies have reported that non-Hispanic White caregivers compared to minority counterparts use more formal caregiver services (Dilworth-Anderson et al. 2002; Scharlach et al. 2006) while other earlier studies reported a higher level of service use by caregivers of color (Cox 1996; Schoenberg et al. 1998). Hispanic family caregivers tend to use fewer caregiving services (Crist and Speaks 2011; Dilworth-Anderson et al. 2002; Scharlach et al. 2006) and rely more on family/kin help (Navaie-Waliser et al. 2001; Pinquart and Sörensen 2005) compared to White, non-Hispanic counterparts. This may be due to their lack of awareness of caregiver services, fewer financial resources (Pinquart and Sörensen 2005), structural barriers such as language and limited availability of culturally-appropriate services (Dilworth-Anderson et al. 2002; Scharlach et al. 2006). Hispanic cultural values and beliefs about caregiving appear to affect their caregiving practices and attitudes. Hispanic caregivers compared to their White, non-Hispanic counterparts tend to support and endorse filial responsibility, which refers to the sense of obligation adult children feel regarding assisting their aging parents (Blieszner and Hamon 1992). Due to the preliminary findings described above and highlighted in Table 5, as well as a review of the current literature, the determination was made to use a White (non-Hispanic) versus Other variable in the remainder of the analyses as a way to reduce the

number of variables due to the small sample size, while also being able to capture potential cultural differences.

Next, all demographic and socioeconomic factors, regardless of significance, were included and analyzed together in multiple linear (for caregiver burden) and logistic (for PTSD and depression) regression models. As mentioned above, only the White (non-Hispanic) variable was used to identify race/ethnicity. Regression variables and statistics for the linear regression for caregiver burden are reported in Table 6. Due to 24% of the participants missing income, the income variable was not included in the combined model with all other demographic characteristics. To determine the significance of income when accounting for all other variables, a separate model was run that only included the 61 participants with reported income, while also adjusting for the other demographic characteristics. When evaluating demographic characteristics in the univariate analysis, marital status was significantly correlated with caregiver burden (p = .049); however, this finding did not hold true in the multiple regression (*OR* = 5.81; *95% CI* = -0.1, 11.71; p = .054). When controlling for all factors simultaneously in the multiple regression, both employment status (*OR* = -6.91; *95% CI* = -12.37, -.01; p = .049) and income (*OR* = -9.66; *95% CI* = -17.81, -1.51; p = .020) were significantly associated with caregiver burden. Higher caregiver burden scores were found in participants who were not employed (M = 44.6; SD = 16.4) and had a lower income (M = 45.7; SD = 15.9). In summary, Table 6 reflects significant correlations between caregiver burden and several demographic factors (marital status, employment status, income).

A series of linear regressions were conducted to evaluate the intersectionality of the demographic factors and caregiver burden. Regression variables and statistics for these linear regressions are reported in Table 7. Interactions that had p-values less than 0.10 were included. Interactions significant at the 0.05 level included age and income (p = .040). An increase in age combined with income greater than $50,000 had a weak, negative correlation (r = -.12) with caregiver burden; whereas, an increase in age combined with a lower income had a positive correlation (r = .08) with caregiver burden. Race/ethnicity had significant interactions with several factors, namely, gender (p = .039), marital status (p = .033), education (p = .015), and employment (p = .047).

Since Aim 2 is exploratory in nature, a final model that controlled for all interactions simultaneously was unable to be run due to the small sample size and the number of significant interactions. Regarding the interaction between race/ethnicity and gender, the linear regression revealed that White, Non-Hispanic women (n = 30) reported the highest average caregiver burden (M = 47.1; SD = 16.4), while male participants from a non-White group (n = 13) reported the lowest average caregiver burden (M = 36.9; SD = 10.0). Regarding the interaction between race/ethnicity and marital status, White, Non-Hispanic participants who were married (n = 30) reported the highest average caregiver burden (M = 44.9; SD = 15.7), while participants from a non-White group who were not married (n = 23) reported the lowest average caregiver burden (M = 33.7; SD = 10.1). Regarding the interaction between race/ethnicity and education, White, Non-Hispanic participants with a post-secondary education (n = 30) reported the highest average caregiver burden (M = 47.8; SD = 15.4), while White, Non-Hispanic participants without a post-secondary education (n =

11) reported the lowest average caregiver burden (*M* = 36.1; *SD* = 13.9). Regarding the interaction between race/ethnicity and employment, White, Non-Hispanic participants who were not employed (*n* = 22) had the highest average caregiver burden (*M* = 47.8; *SD* = 18.0), while participants from a minority group who were employed (*n* = 33) had the lowest average caregiver burden (*M* = 36.7; *SD* = 13.1). Additionally, significant interactions were found between marital status and employment (*p* = .031), as well as between employment and education (*p* = .016). Regarding marital status and employment, married participants who were not employed (*n* = 24) had the highest average caregiver burden (*M* = 46.3; *SD* = 17.2), while unmarried participants who were employed (*n* = 19) had the lowest average caregiver burden (*M* = 33.3; *SD* = 10.5). Regarding employment and education, participants with a post-secondary education who were not employed (*n* = 20) had the highest average caregiver burden (*M* = 49.6; *SD* = 17.4), while participants without a post-secondary education who were employed (*n* = 20) had the lowest average caregiver burden (*M* = 35.9; *SD* = 10.8). Due to the small sample size and the number of significant interactions, a final model that controlled for all interactions simultaneously was unable to be run. In summary, Table 7 reflects significant interactions between age and income, marital status and employment, and education and employment, as well as significant interactions between race/ethnicity and several other demographic factors (gender, marital status, education, employment) on caregiver burden.

Regression variables and statistics for the logistic regression for depression are reported in Table 8. When evaluating demographic characteristics in the univariate analysis, race/ethnicity was significantly correlated with depression (*p* = .042); however, this finding

did not hold true in the multiple regression (*OR* = 2.54; *95% CI* = 0.77, 8.32; *p* = .125). Gender was found to be significantly correlated with depression (*p* = .014) in the univariate analysis and remained significant in the multiple regression (*OR* = 0.12; *95% CI* = 0.01, .96; *p* = .046), with females reporting higher rates of depressive symptoms.

A series of logistic regressions were conducted to evaluate the intersectionality of the demographic factors and depression. Regression variables and statistics for these logistic regressions are reported in Table 9. Interactions that had p-values less than 0.10 were included. Interactions significant at the 0.05 level all included gender. Gender demonstrated significant interactions with several factors, namely age (*p* = .033), race/ethnicity (*p* = .002), marital status (*p* = .027), education (*p* = .019), and employment (*p* = .029). Regarding the interaction between gender and age, 19 out of 67 women were identified to have higher rates of depression, with an average age of 46.4 (*SD* = 11.9) for those 19 women who reported higher rates of depression compared to an average age of 50.3 (*SD* = 14.8) for those who did not. Overall, findings revealed that higher rates of depression were found in younger women who were White, Non-Hispanic, married, had a post-secondary education, and who were not employed. There was insufficient data to further interpret findings on how men varied across other variables as only 1 male participant scoring above the PHQ-8 cutoff was identified. Due to the small sample size and the number of significant interactions, a final model that controlled for all interactions simultaneously was unable to be run. In summary, Table 9 reflects significant interactions between gender and several demographic factors (age, race/ethnicity, marital status, education, employment) on depression.

Regression variables and statistics for the logistic regression for PTSD are reported in Table 10. When evaluating demographic characteristics, there were no significant associations with PTSD in the univariate analysis or the multiple regression model.

A series of logistic regressions were conducted to evaluate the intersectionality of the demographic factors and PTSD. Regression variables and statistics for these logistic regressions are reported in Table 11. Interactions that had p-values less than 0.10 were included. Interactions significant at the 0.05 level included the interaction between gender and race/ethnicity (p = .021) and the interaction between race/ethnicity and employment status (p = .038). Regarding the interaction between gender and race/ethnicity, findings showed that higher rates of PTSD symptoms were found in White, Non-Hispanic women. Regarding race/ethnicity and employment status, findings showed that higher rates of PTSD symptoms were found in White non-Hispanic participants who were not employed. Thus, the Hypothesis for Aim 2 was partially supported. Specifically, significant associations were found between gender and race/ethnicity, and also between race/ethnicity and employment on PTSD.

CHAPTER SIX
Discussion

Although previous studies have examined caregiver burden in various populations (e.g., elderly, terminally ill, chronic illness, dementia, CVA), with a chronic illness, few studies have examined caregiver burden in patients who have sustained a critical illness or injury requiring admission to the ICU. The purpose of this study is to examine the role of specific demographics factors and resilience in predicting caregiver burden, depression, and PTSD symptoms in caregivers of trauma patients. The current study is one of the first to examine the influence of specific demographic factors and resilience in predicting caregiver burden, depression, and PTSD outcomes specifically in caregivers of trauma patients.

HYPOTHESIS 1

Resilience and Psychological Outcomes (Depression, PTSD)

The current study found that there were no significant associations between resilience and each outcome (caregiver burden, depression, and PTSD) over time. Overall, the present study reflected a smaller percentage of individuals reporting intermediate or high levels of resilience, in comparison to a recent national online survey conducted through researchers at the Ohio State University, using the 14-item Resilience Scale (RS14; Melnyk, 2020). Previous research has shown that individuals who possess higher psychological resilience are able to cope with stressful events, resulting in a high level of well-being and lower

depression (Campbell-Sills et al., 2006; Tomás et al., 2012; Smith and Hollinger-Smith, 2014). Previous findings have also suggested resilience to be a common response to a stressful or traumatic experience (Campbell-Sills et al., 2006), with significant correlations between resilience, satisfaction with life, spirituality, posttraumatic stress, and anxiety and depressive symptoms (White, Driver & Warren, 2010). Fifty-nine participants and 17 participants in this study reported intermediate resilience and high resilience at baseline, respectively. Previous research has shown that higher levels of resilience are associated with older age and female sex (Dias et al., 2015). The majority of the current sample was female, with an age range from 18 to 82 years, so it is possible that individuals who reported high and intermediate resilience at baseline were older and female. Additionally, if caregivers are unaware of the potential challenges (i.e., finances, caregiver burden, mental and physical well-being) involved with caregiving, post-hospitalization, or are waiting to receive more information on their loved one's prognosis, their reported resilience score may just be a snapshot of their current, perceived level of resilience captured at baseline. Another possible explanation for the higher/intermediate resilience scores could be perceived social support associated with hospitalization (i.e., family and friends visiting the hospital, hospital staff). Studies have shown that caregivers who report more social support are also more likely to report higher levels of resilience (Elliott et al., 2014, Pinquart and Sorensen, 2003). Previous studies have shown that a large percentage of caregivers are resilient in the initial year of caregiving; however, those who have problems adapting tend to exhibit significant distress after the traumatic event (Castellano-Tejedor and Lusilla-Palacios, 2017; Elliott et al., 2014). Resilience was not re-assessed during the 3-month follow-up call, so it is possible that

resilience scores may have changed over time, as a result of discharging from the hospital and caregiving at home.

The current study found that higher resilience was associated with lower odds of depressive symptoms and posttraumatic stress; however, neither association was statistically significant after being adjusted for demographic factors (age, sex, race, ethnicity, marital status, educational level, employment status, and pre-morbid psychological disorders). This finding suggests that demographic factors did not appear to be associated with fewer negative psychological outcomes in individuals with higher resilience. Additionally, there was not a significant interaction found between time and resilience with respect to either depression or posttraumatic stress. Overall, previous studies have shown that perceived burden in caregivers was strongly associated with worse mental health and life satisfaction (Belasco and Sesso, 2002; Jafari et al., 2018; Scholten et al., 2018). Findings of the present study are not consistent with resilience theories that propose people with high resilience are more likely to display positive adaptation and positive affect when faced with significant adversity (Simpson & Jones, 2012). Furthermore, previous studies have shown resilience to be positively associated with positive affect in caregivers and posttraumatic growth, and also play a protective role in relation to mental health (Anderson, Daher & Simpson, 2019; Levine et al., 2009). Conversely, previous research has shown that caregivers with significant levels of caregiver burden reported negative psychological outcomes, such as depression, anxiety, and posttraumatic stress (Davidson, Jones, & Bienvenu, 2012; Elliott et al., 2014; Warren et al., 2015). It is possible that sample size of the current study could have impacted the lack of significant findings in this area.

Resilience and Caregiver Burden

The present study found a weak, negative correlation between resilience and caregiver burden. Previous studies have shown that higher levels of resilience in caregivers resulted in lower caregiver burden (Castellano-Tejedor and Lusilla-Palacios, 2017; Simpson and Jones, 2012). Although this finding in the current study was not statistically significant, previous research has highlighted resilience as a potential protective factor for caregiver burden (Castellano-Tejedor and Lusilla-Palacios, 2017; Simpson and Jones, 2012). However, previous studies have not examined resilience specifically in caregivers in trauma populations, so it is possible that the current hypothesis does not hold true in trauma populations. Another possible explanation for the lack of significant findings in the current study is the relatively small sample size (n = 91) and therefore a sheer lack of power. Other possible explanations for the lack of significant findings could be attributed to methodological limitations, which are discussed in further detail below.

The current study findings regarding the associations between resilience and each outcome (caregiver burden, depression, and PTSD) were not found to be statistically significant. However, the clinical implications, when compared to previous studies, demonstrate the need for early psychological interventions in family members who may experience increased difficulty if placed in a caregiving role post- hospitalization (Davidson, Jones, & Bienvenu, 2012; Warren et al., 2015).

HYPOTHESIS 2

Several studies have examined the relationship between psychological and physical health and caregiving; however, literature focused on social determinants of health with caregiver burden in trauma populations is limited. Despite the small sample size and limited generalizability, the current study aimed to examine the influence of demographic factors in predicting caregiver burden, depression, and PTSD over time. Additionally, the intersectionality of demographic factors were evaluated to determine any associations between individual factors and each outcome (caregiver burden, depression, PTSD).

Caregiver Burden

Current research suggests a number of predictive factors related to perceived caregiver burden. The current study found that being married was correlated with caregiver burden, but more importantly, unemployment and low income were significantly associated with caregiver burden. It is reasonable to expect that individuals who may be struggling financially, unable to gain employment, or forced to give up employment may report high levels of caregiver burden from the additional responsibilities of caregiving for a family member with a chronic illness. A previous study found that unpaid family caregivers provide 90% of the care for adults requiring long-term care (Fineberg, 2008). That said, recent studies found that higher income and education level were associated with greater caregiver burden, related to lost time and earnings (García-Mochón et al., 2019; Mudrazija, 2019; Oliva-Moreno et al., 2019).

The current study expands upon previous research as it also examines the intersectionality of demographic factors in predicting caregiver burden, depression, and PTSD in trauma populations. Findings of the present study suggest that caregiver burden was higher among older individuals with lower income, individuals who are married but unemployed, and those have a post-secondary education but are unemployed. These findings seem consistent with previous studies showing that caregiving has detrimental effects on spouses (vs friends acquaintances or other relatives), older individuals (generally above the age of 50), and those with lower socioeconomic status (i.e., age, education, employment; Pinquart and Sorensen, 2003; Pinquart and Sorensen, 2007; Schulz and Martire, 2004; Schulz et al., 1995). The present study also found that interactions involving race/ethnicity played an influential role in predicting caregiver burden. Higher caregiver burden was found in White, Non-Hispanic women, and White, Non-Hispanic individuals who were married, had a post-secondary education, and were unemployed. The current study's findings imply that in trauma populations, White, Non-Hispanic individuals may be more at risk for reporting high levels of caregiver burden compared to Non-White individuals. Indeed, prior research points to the protective impact of ethnic minority identity affiliation post-trauma (Han et al., 2016; Moscardino et al., 2007; Raghavan and Sandanapitchai, 2019). Additionally, familism, gender roles, and the influence of folklore and faith on caregiving are cornerstones of Hispanic values and culture (Crist et al., 2009; Del Gaudio et al., 2013; Flores et al., 2009; Kreling et al., 2010; Lucke et al., 2013; Rabinowitz et al., 2009; Saunders, 2013; Siefert et al., 2008). Familism ideology refers to the cultural valuing of the family over individual interest that guide family relationships. While familism is not unique to the Hispanic culture,

it is often regarded as the most significant common cultural denominator among Hispanics of various national origins, and the value most likely to remain unchanged despite migration and increased acculturation (Marin & VanOss Marin, 1991; Velasquez, Arellano, & McNeill, 2004). Familism with its cultural expectation for children to care for their parents operates in tension with a larger society that values a more individualistic culture (Maldonado, 2017). Another possibility for the current study findings may be related to current caregiver statistics, as reported by the Family Caregiver Alliance (FCA; 2015). The FCA (2015) found that 62% of adult caregivers in the U.S. identified their race/ethnicity as White, Non-Hispanic, which may explain why these individuals are more at risk for reporting higher levels of caregiver burden. Among the U.S. adult population, approximately one-fifth of the White, Non-Hispanic population are in need of caregiving (Cultural Diversity and Caregiving, 2011). According to the 2009 US Census 75.8% of the Baby Boomer Generation (born between 1946 and 1964) identified as White, Non-Hispanic (Frey, 2010), so it is conceivable that the majority of adult caregivers also identify similarly.

Depression

The current study found that interactions involving gender played an influential role in predicting depression in caregivers. Higher rates of depression were found in women who were younger, identified as White, Non-Hispanic, had a post-secondary education, married, and unemployed. There is considerable research that caregivers who are female are more burdened than male caregivers (Marks, Lambert, & Choi, 2002; McDonnell and Ryan, 2013;

Penning and Wu, 2016; Pinquart and Sorensen, 2006; Swinkels et al., 2019; Yee and Schulz, 2000), and findings of the present study seem consistent with this prior research. It is possible that perceived unequal distribution of responsibilities in the home may push women into a caregiving role more than men and may explain why they experience a higher degree of burden. The FCA (2015) reported that 75% of caregivers are female and may spend as much as 50% more time providing care to a family member than males. Previous research has shown that other demographic factors, such as being a spouse and higher age may place caregivers at higher risk for developing symptoms associated with depression compared to the general population (McAdam et al., 2010; Pinquart and Sorensen, 2003; Pochard et al., 2005; Alfheim et al., 2018). The current study also expands on this previous research, as it is the first to examine the potential interactions of demographic factors in predicting depression in trauma populations. Findings of the present study suggest that the hospital staff needs to recognize that female caregivers with certain demographic factors (i.e., married, younger, post-secondary education, unemployed) may be at greater risk for developing depression when caring for others in a trauma populations. By identifying caregivers who are at a higher risk for developing depression, hospital staff may be able to provide community referrals for treatment, in addition to providing psychoeducation and resources on depression (i.e., recognizing the signs and symptoms of depressions, how to reach out for help).

PTSD

The current study found that there were no significant associations between

demographic characteristics and PTSD; however, significant associations were found when examining the intersectionality of a few demographic factors. Overall, the present study found that interactions involving race/ethnicity played an influential role in predicting PTSD in caregivers. Higher rates of PTSD were found in White, Non-Hispanic women, and White, Non-Hispanic individuals who were unemployed. As stated earlier, previous findings have found that a majority of caregivers are female and White, Non-Hispanic (Caregiver Statistics, 2019), so it is possible that findings from the current study could be attributed to these demographic factors. Notably, of the current study participants, 73.5% were female and 65.9% identified as White. Another possible explanation for the current study findings could be the presence of pre-morbid psychological disorders. In the current study, 23 participants (25.3%) reported depression, 7 participants (7.7%) reported posttraumatic stress disorder, while 16 participants (17.6%) reported at least one other psychological disorder (i.e., bipolar/manic depression, panic disorder, generalized anxiety disorder, obsessive compulsive disorder, schizophrenia, any phobia). Previous research suggests that prior psychiatric disorders may place individuals at higher risk for developing symptoms of depression and PTSD (Alfheim et al., 2018; Lefkowitz, Baxt, & Evans, 2010; Jepson et al., 1999). Given that 46 participants (50.5%) reported a pre-morbid psychological disorder, it is possible that the injury of a family member was a precipitating event, leading to additional psychological comorbidities and symptoms.

The current study's findings imply that in trauma populations, certain demographic factors, such as gender and race/ethnicity may be significant risk factors for reporting high caregiver burden, and symptoms of depression and PTSD. Specifically, the current study

indicates the need to identify individuals who may be at high risk for reporting caregiver burden and/or developing symptoms of depression and PTSD, in an effort to provide as much support and guidance during the initial hospital stay. This information could inform interventions during hospitalization, with a specific focus on recognizing symptoms of depression and PTSD, as well as resources and strategies to help minimize caregiver burden.

Limitations

A number of limitations to the current study merit discussion. First, a relatively small sample size was used in this study. A larger sample size is needed to confirm findings before firm conclusions can be drawn. Due to the small sample size, race/ethnicity was combined as a two-category outcome in order to reduce the number of variables, while being able to capture potential cultural differences. Nevertheless, this outcome produced low counts for multiple groups for depression and PTSD, resulting in exploratory analyses to determine potential associations between demographic characteristics and caregiver burden, depression, and PTSD. Second, the results of the study may have limited generalizability, as the majority of the sample was White (65.9%), female (73.6%), employed (57.1%) with a post-secondary education (57.1%), and the entire sample consisted of only English-speaking participants. Despite the limited generalizability of the current study, compared to national caregiver demographics, 62% of adult caregivers in the U.S. identify their race/ethnicity as White and 75% of caregivers are female (FCA, 2015).

Another limitation of the present study is the lack of an SES variable. However, proxy variables, such as education, employment status, and income were collected and should be considered in future studies as a way to assess for SES. For this study, adding a measure that included a socioeconomic status variable, such as the Hollingshead Four Factor index method (1975) was beyond the scope of the study design and was not added to the protocol. It should also be noted that participants were not administered the CD-RISC during the 3-month follow-up call. Since the present study did not capture resilience scores at 3-months, no inferences could be made regarding resilience and caregiver burden outcomes over time.

Additionally, potential confounding variables may have influenced data collection. Since the current study consented participants in a hospital setting, it was not always feasible to approach and consent participants in a timely manner due to the nature of the trauma ICU (i.e., visitor hours, trauma ICU rounds), as well as the participants' schedules. Participants were also lost to follow-up due to not being able to be successfully contacted within the 4-week window despite 12 attempts. Several reasons for this included no longer having a working number or having a voicemail that was full or not set up.

Another potential limitation of the study is related to the lack of a standard definition of resilience in the literature. Although many definitions have been proposed in several contexts, an essential understanding of the concept is still lacking up to now. This negatively affects comparisons among research results and makes objective measurement difficult. Having a more conceptual unification of the term in the literature will contribute to improving the accuracy of research on this topic by suggesting future paths of investigation

aimed at deeply exploring the issues surrounding the promotion of resilience resources. Since much of the research on resilience is so steeped in a Western-centric value system that emphasizes individual qualities that it fails to identify important protective factors that may relate to culture, it may be of interest for future definitions of resilience to also incorporate culture. The present study sought to address the multiple definitions of resilience present in the literature by using a well-validated measure (CD-RISC) to assess resilience.

Despite the fact that caregiver burden is preponderantly used as an indicator of the caregiving experience, much disagreement remains on what the term entails and how it should be utilized. The vagueness derived from the various caregiver burden definitions in the literature limits the term's relevance to policy-making and clinical practice. Additionally, much of the literature on caregiver burden is not theoretically framed, which reduces the conceptual clarity of the term. Quantitative measures are largely used to investigate caregiver burden, which can sometimes fail to capture contextual features that are relevant to caregiving outcomes (e.g., culture).

Future Directions

Although adding a socioeconomic status variable was beyond the scope of the current study design, it may be of interest to include a measure that calculates socioeconomic status in future studies, especially as this may capture additional demographic information that could contribute to resilience more so than other demographic variables. Future research studies should also aim to recruit a large sample of participants with more demographic

diversity (i.e., gender, ethnicity, SES) to increase generalizability. Further, larger samples can help parse apart differences between different forms and readiness for caregiving, such as financial or daily physical caregiving, differences in education, differences in caregiver experiences by sex, experience or available resources and assistance, and other expectations beyond time involvement and improvement. Additionally, developing, validating, and utilizing Spanish-language versions of all measures would allow for a larger and more culturally varied sample of participants.

Findings from the present study suggest that less caregiver burden was reported in men who identified as a minority, were unmarried, employed, had less than a post-secondary education, and reported a higher income (> $50,000). It is possible that the protective impact of spiritual or religious beliefs and strong affiliation with ethnic identity, as well as financial security, perceived gender roles, and independence in romantic relationships allows individuals to feel less burdened when exposed to high levels of trauma. Future studies should aim to investigate these potential protective factors to better understand how to effectively assist caregivers who are at greater risk for developing caregiver burden.

Future research on caregiver burden would also benefit from integrating qualitative and quantitative approaches into mixed method designs in order to gain a holistic understanding of the concept. Including caregiver assessments in the current study might also provide an additional valuable perspective and could be used to compare to self-reported caregiver burden. Assessments can be performed by a physician, social worker, or other health care team member during hospitalization to gather information about a caregiver's situation and identify needs and resources.

If future studies confirm the findings from the current study and/or identify other factors that predict caregiver burden through the analysis of larger and more diverse samples, the next step could involve designing interventions specific to those at higher risk of caregiver burden. There are a number of factors that need to be considered prior to discharging a former ICU patient to the care of a family member. It is therefore important that discharge planning begin as early as possible, so that the most appropriate plan of care can be developed from ICU admission, throughout hospitalization and discharge into the community. Considerations when discharge planning include the caregiver's physical and psychological status; the type and amount of care required, which may include the need for formal support services; the caregiver's age, gender, health, financial and employment status; and the type and availability of informal support. In addition, the education and information required, particularly if technology is involved in patient management, should be identified and appropriate education programs implemented. By assessing each patient's situation individually and systematically, health care team members can instigate interventions that will be proactive, ongoing and aimed at minimizing the problems associated with caregiving for both the patient and caregiver.

Future studies could also look at existing interventions for caregivers in other settings (i.e., community caregivers, outpatient rehabilitation) in an effort to tailor those interventions for caregiving in trauma ICU populations. Clinicians and researchers could consider incorporating web-based interventions for caregivers during and after a patient's hospital visit, possibly tailoring the interventions to promote resilience, reduce caregiver stress, and

identify potential psychological factors. No web-based interventions have been designed specifically for caregivers in the trauma ICU population.

Lastly, future studies should expand on research regarding caregiving in COVID-19 populations by examining reported caregiver burden and adverse psychological outcomes in order to tailor interventions as initial studies have found an increase in time spent caregiving within this population (Greenberg, Wallick & Brown, 2020). It is known that coping style, cognitive evaluation, and social support are all mediators of stress (Sun et al., 2020). Studies have shown that psychological adaptation and social support play an intermediary role in psychological rehabilitation under outbreak stress (Sun et al., 2020). Many studies have shown that epidemic outbreaks can cause psychological trauma for caregivers (Kang et al., 2020; Su et al., 2020; Xiang et al., 2020). The severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2; COVID-19) is a newly discovered ribonucleic acid coronavirus isolated and identified from patients with unexplained pneumonia in Wuhan, China (Sun et al., 2020). Since the first case of unexplained pneumonia in Wuhan in December 2019, 52 countries in the world have confirmed cases by February 2020 (Sun et al., 2020). As a result of the COVID-19 pandemic, many caregivers may now find themselves providing even more care than previously (Greenberg, Wallick & Brown, 2020). The COVID-19 outbreak amplifies the daily challenges caregivers face as a result of the varied and evolving restrictions and mandates put in place to keep communities safe. For caregivers, these orders could precipitate feelings of loneliness, intensify social isolation, and increase levels of caregiver stress as a result of social-distancing efforts (Greenberg, Wallick & Brown, 2020). Decreases in structure and routine and the closure of services and facilities that caregivers routinely use

for respite care affect both caregivers and persons with chronic conditions (Greenberg, Wallick & Brown, 2020).

Given the current climate, researchers might tailor modules and narratives through a virtual learning platform so that it can be delivered easily in a hospital setting. Creating short vignettes tailored to focus on caregiver burden and resilience could allow family members and caregivers to complete modules during a hospital visit, ideally facilitated by a psychologist or social worker.

Conclusion

The present study in one of the first to examine the influence of specific demographic factors and resilience in predicting caregiver burden, depression, and PTSD outcomes specifically in caregivers of trauma patients. Findings suggest that higher levels of resilience may significantly be associated with lower rates of depression and PTSD. Additionally, the interaction of several demographic factors may significantly be associated with higher rates of depression and PTSD. Although more research is warranted, the current study represents a significant step toward understanding the potential influence of demographic factors and resilience in predicting caregiver burden, depression, and PTSD in trauma ICU populations. Since present findings suggest that certain demographic factors are associated with higher levels of depression and PTSD in caregivers, this novel information may be used to direct future research, educate caregivers, clinicians and researchers, and inform the development of interventions specific to this population.

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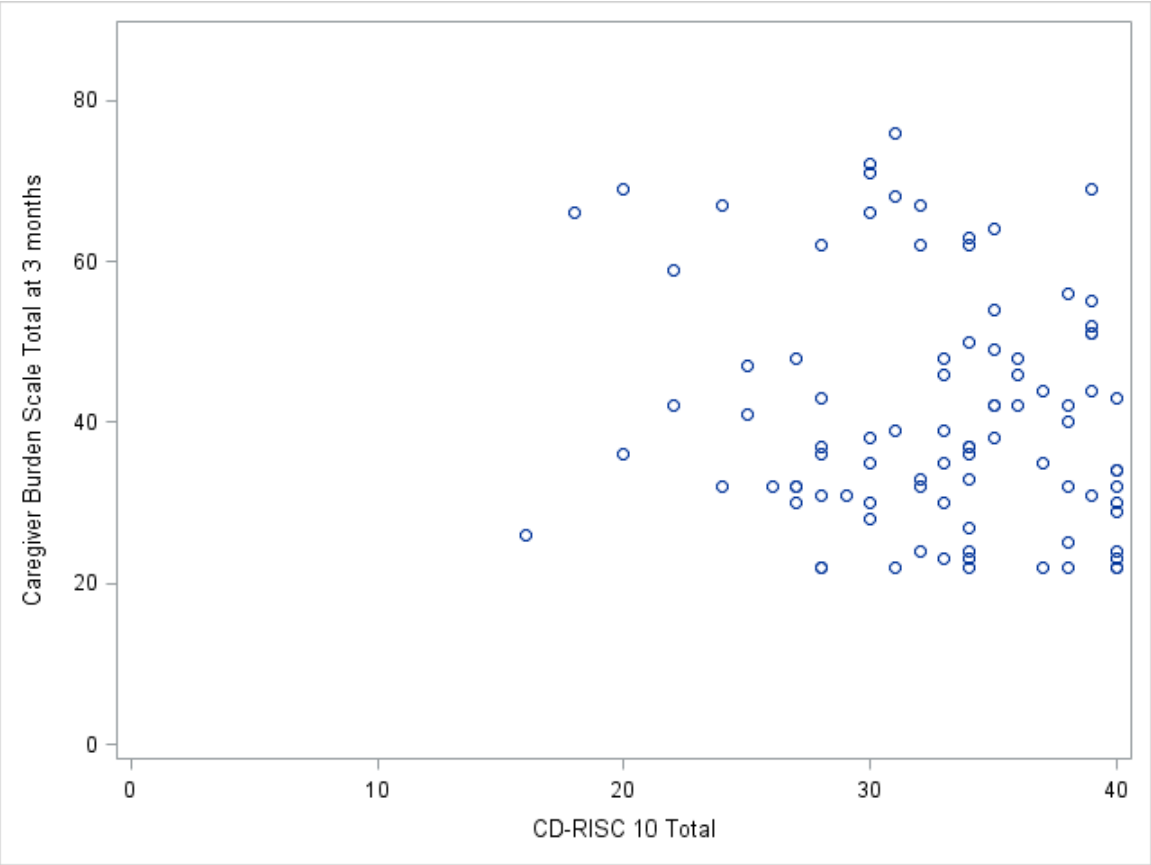


Figure 1: *CD-RISC Total at Baseline by Caregiver Burden Scale Total at 3 Months*

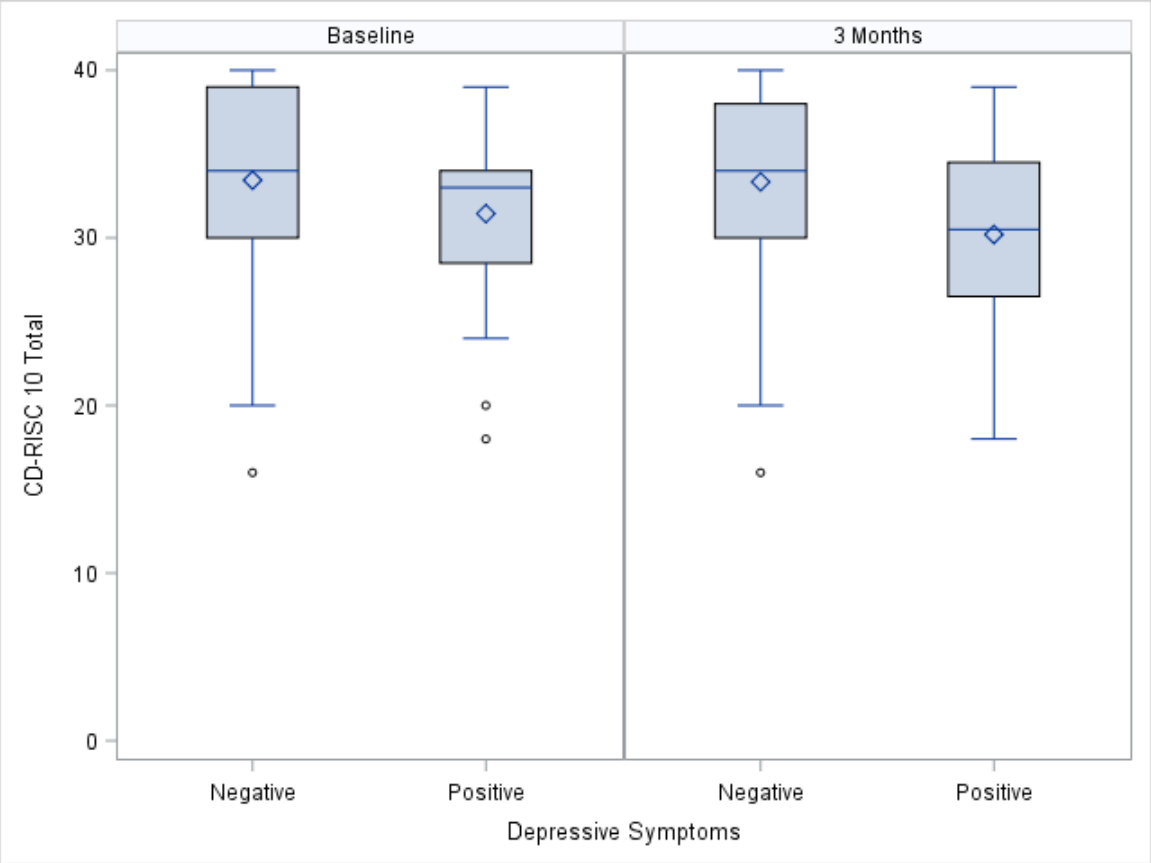


Figure 2: *Box Plots of CD-RISC Totals at Baseline by PHQ-8 Results at Baseline and 3 Months*

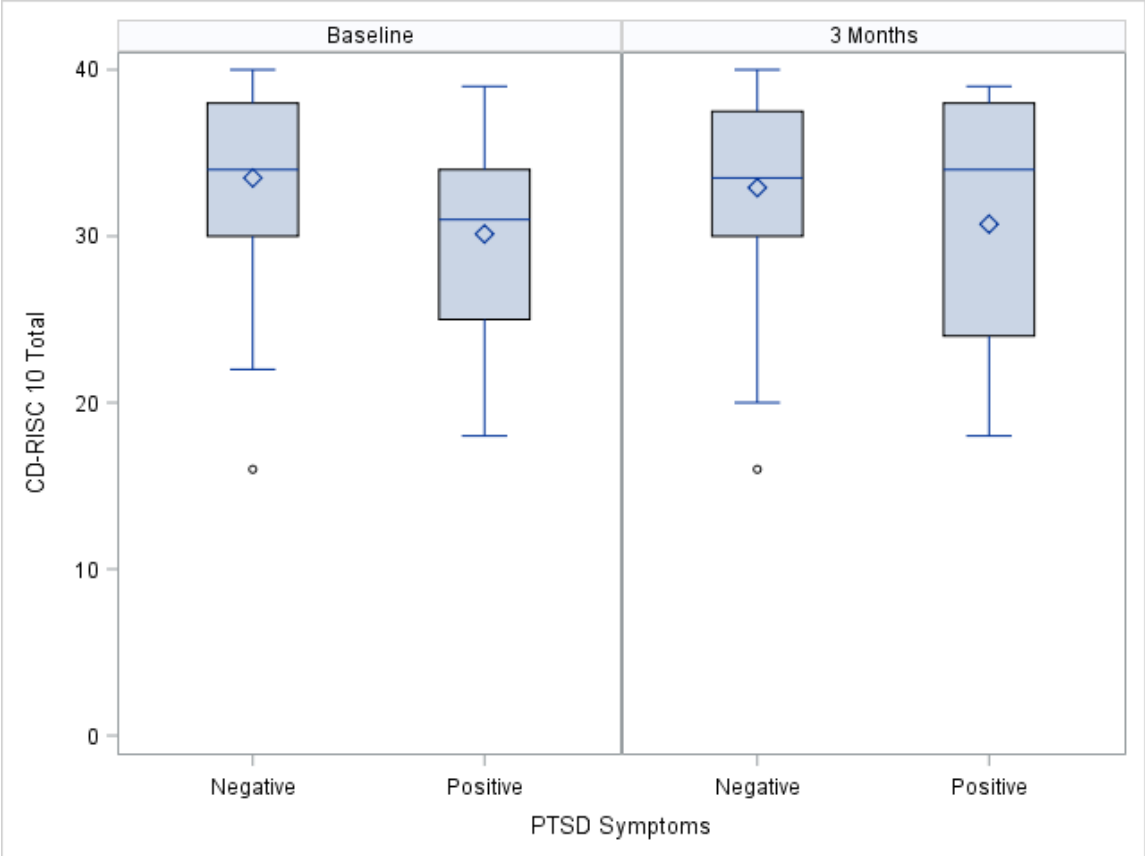


Figure 3: *Box Plots of CD-RISC Totals at Baseline by PC-PTSD/PCL-C Results at Baseline and 3 Months*

Table 1

Demographic Statistics for Participants

Variable	**N=91**
Age	49.2 ± 13.9
Gender - Male	24 (26.4%)
Race	
Caucasian/White	60 (65.9%)
African American/Black	24 (26.4%)
Asian	4 (4.4%)
American Indian or Alaska Native	1 (1.1%)
Other	2 (2.2%)
Hispanic Ethnicity	19 (20.9%)
Married	57 (62.6%)
Relationship to Patient	
Parent	28 (30.8%)
Spouse	16 (17.6%)
Child	26 (28.6%)
Sibling	3 (3.3%)
Friend	5 (5.5%)
Other	13 (14.3%)
Post-Secondary Education	52 (57.1%)
Employed	52 (57.1%)
Income	
< 50,000	33 (36.3%)
> 50,000	36 (39.6%)
Unknown	22 (24.2%)
Pre-Morbid Psychological Disorder	
Depression	23 (25.3%)
Posttraumatic Stress Disorder	7 (7.7%)
Other	16 (17.6%)

Table 2

Descriptive Statistics of Psychosocial Measures at Baseline and 3 Months

	Baseline	**3 Months**
CD-RISC		-
Mean ± SD	32.7 ± 5.6	
Median (Q1, Q3)	34 (29 - 38)	
Range	16 - 40	
Low	15 (16.5%)	
Intermediate	59 (64.8%)	
High	17 (18.7.%)	
Caregiver Burden Scale	-	
Mean ± SD		41.0 ± 14.7
Median (Q1, Q3)		37 (30 - 50)
Range		22 - 76
PHQ-8 positive[a]	36 (39.6%)	20 (22%)
PC-PTSD positive[b]	23 (25.3%)	16 (17.6%)
PCL-C positive[c]	-	11 (12.1%)

[a]PHQ-8 positive ≥ 10
[b]PC-PTSD positive ≥ 3
[c]PCL-C positive ≥ 34

Table 3

Summary of CD-RISC Total Score by Outcome

	Summary of Outcome	**Relation to CD-RISC Total**
	mean ± SD	*correlation*
Caregiver Burden Scale Total	41 ± 14.7	-0.17
	n (%)	*mean ± SD*
PHQ-8 baseline		
Positive[a]	36 (39.6%)	31.4 ± 5.2
Negative	55 (60.4%)	33.4 ± 5.8
PHQ-8 3 months		
Positive[a]	20 (22.0%)	30.2 ± 5.9
Negative	71 (78%)	33.3 ± 5.4
PC-PTSD baseline		
Positive[b]	23 (25.3%)	30.1 ± 6.2
Negative	68 (74.7%)	33.5 ± 5.2
PCL-C 3 months		
Positive[c]	11 (12.1%)	30.7 ± 7.6
Negative	80 (87.9%)	32.9 ± 5.3

[a]PHQ-8 positive ≥ 10
[b]PC-PTSD positive ≥ 3
[c]PCL-C positive ≥ 3

Table 4

Regression Results

Outcome	**Unadjusted Model**		**Adjusted Model[a]**	
	Beta (95% CI)	*p-value*	*Beta (95% CI)*	*p-value*
Caregiver Burden				
CD-RISC	-0.44 (-0.97, 0.09)	0.105	-0.23 (-0.76, 0.3)	0.39
	Odds Ratio (95% CI)	*p-value*	*Odds Ratio (95% CI)*	*p-value*
Depression[b]				
CD-RISC	0.92 (0.87, 0.99)	0.016*	0.95 (0.88, 1.03)	0.191
Time (3 month vs. Baseline)	0.41 (0.24, 0.72)	0.002*	0.33 (0.16, 0.68)	0.003*
PTSD[b]				
CD-RISC	0.91 (0.84, 1.00)	0.043*	0.94 (0.86, 1.02)	0.149
Time (3 month vs. Baseline)	0.39 (0.20, 0.75)	0.005*	0.31 (0.14, 0.70)	0.005*

[a]Models adjusted for age, sex, race, ethnicity, marital status, educational level, employment status, and history of psychological disorder
[b]There was not a significant interaction between CD-RISC total and time with respect to either depression or PTSD ($p_{depression} = 0.524$; $p_{PTSD} = 0.425$), thus the interaction term was removed from the models
*$p < .05$

Table 5

Evaluating Race and Ethnicity Combinations

Variable	CBS Total	p-value	PHQ-8 Negative	PHQ-8 Positive	p-value	PTSD Negative	PTSD Positive	p-value
Race/Ethnicity		0.088			0.168			0.127
White (n=41)	44.7 ± 15.8		28 (68.3%)	13 (31.7%)		33 (80.5%)	8 (19.5%)	
Black (n=24)	40.5 ± 13.3		20 (83.3%)	4 (16.7%)		21 (87.5%)	3 (12.5%)	
Hispanic (n=19)	36.7 ± 14.5		16 (84.2%)	3 (15.8%)		19 (100%)	0 (0%)	
Other (n=7)	32.6 ± 7.6		7 (100%)	0 (0%)		33 (80.5%)	8 (19.5%)	
White Race		0.291			0.133			0.612
No (n=31)	38.7 ± 12.6		27 (87.1%)	4 (12.9%)		28 (90.3%)	3 (9.7%)	
Yes (n=60)	42.2 ± 15.7		44 (73.3%)	16 (26.7%)		52 (86.7%)	8 (13.3%)	
Hispanic Ethnicity		0.029*			0.464			0.069
No (n=72)	42.1 ± 14.7		55 (76.4%)	17 (23.6%)		61 (84.7%)	11 (15.3%)	
Yes (n=19)	36.7 ± 14.5		16 (84.2%)	3 (15.8%)		19 (100%)	0 (0%)	
White, Non-Hispanic		0.158			0.042*			0.060
No (n=50)	38.0 ± 13.2		43 (86%)	7 (14.0%)		47 (94%)	3 (6.0%)	
Yes (n=41)	44.7 ± 15.8		28 (68.3%)	13 (31.7%)		33 (80.5%)	8 (19.5%)	

*$p < .05$

Table 6

Relationship of Socioeconomic Factors to Caregiver Burden

Variable	**n**	**CBS (3 months)**	**Univariate p-value**	**Beta (95% CI)**	**Multiple Regression p-value**
		correlation			
Age		0.03	0.783	-0.09 (-0.3, 0.13)	0.423
		mean ± sd			
Gender			0.100		0.276
Female	67	42.3 ± 15.8		(reference)	
Male	24	37.4 ± 10.9		-3.63 (-10.16, 2.9)	
White, Non-Hispanic			0.158		0.276
No	50	38.0 ± 13.2		(reference)	
Yes	41	44.7 ± 15.8		3.4 (-2.71, 9.51)	
Married			0.049*		0.054
No	34	37.1 ± 13.3		(reference)	
Yes	57	43.3 ± 15.1		5.81 (-0.1, 11.71)	
Post-Secondary Edu			0.054		0.113
No	39	37.6 ± 12.4		(reference)	
Yes	52	43.6 ± 15.9		4.86 (-1.14, 10.86)	
Employment Status			0.051		0.049*
Not Employed	39	44.6 ± 16.4		(reference)	
Employed	52	38.3 ± 12.8		-6.19 (-12.37, -0.01)	
Income			0.056		0.020*
< 50,000	33	45.7 ± 15.9		(reference)	
> 50,000	36	38.6 ± 14.1		-9.66 (-17.81, -1.51)	

*$p < .05$

Table 7

Interactions between Demographic Factors on Caregiver Burden

Variable 1	Variable 2	n	CBS	p-value
			Correlation	
Age	**Income >$50,000**			0.040*
	No	33	0.08	
	Yes	36	-0.12	
Gender	**White, Non-Hispanic**		*Mean ± SD*	0.039*
Female	No	37	38.4 ± 14.3	
	Yes	30	47.1 ± 16.4	
Male	No	13	36.9 ± 10.0	
	Yes	11	38.0 ± 12.3	
Gender	**Married**			0.066**
Female	No	27	37.6 ± 14.0	
	Yes	40	45.5 ± 16.2	
Male	No	7	35.1 ± 10.8	
	Yes	17	38.3 ± 11.1	
White, Non-Hispanic	**Married**			0.033*
No	No	23	33.7 ± 10.1	
	Yes	27	41.6 ± 14.6	
Yes	No	11	44.0 ± 16.8	
	Yes	30	44.9 ± 15.7	
White, Non-Hispanic	**Post-Secondary Edu**			0.015*
No	No	28	38.1 ± 12.0	
	Yes	22	37.7 ± 14.9	
Yes	No	11	36.1 ± 13.9	

	Yes	30	47.8 ± 15.4	
White, Non-Hispanic	**Employment**			0.047*
No	No	17	40.5 ± 13.5	
	Yes	33	36.7 ± 13.1	
Yes	No	22	47.8 ± 18.0	
	Yes	19	41.1 ± 12.2	
Married	**Post-Secondary Edu**			0.067**
No	No	17	34.6 ± 11.5	
	Yes	17	39.5 ± 14.9	
Yes	No	22	39.9 ± 12.9	
	Yes	35	45.5 ± 16.2	
Married	**Employment**			0.031*
No	No	15	41.8 ± 15.3	
	Yes	19	33.3 ± 10.5	
Yes	No	24	46.3 ± 17.2	
	Yes	33	41.2 ± 13.3	
Married	**Income >$50,000**			0.072**
No	No	15	40.3 ± 15.8	
	Yes	7	32.6 ± 11.8	
Yes	No	18	50.2 ± 15	
	Yes	29	40.1 ± 14.5	
Employment	**Post-Secondary Edu**			0.016*
No	No	19	39.4 ± 13.9	
	Yes	20	49.6 ± 17.4	
Yes	No	20	35.9 ± 10.8	
	Yes	32	39.8 ± 13.9	

*$p < .05$
**$p < .10$

Table 8

Relationship of Demographic Factors to Depression

Variable	n	PHQ-8 Negative	PHQ-8 Positive	Univariate p-value	Odds Ratio (95% CI)	Multiple Regression p-value
Age		49.8 ± 14.4	47.0 ± 11.9	0.432	0.97 (0.94, 1.01)	0.205
Gender				0.014*		0.046*
Female	67	48 (71.6%)	19 (28.4%)		(reference)	
Male	25	23 (95.8%)	1 (4.2%)		0.12 (0.01, 0.96)	
White, Non-Hispanic				0.042*		0.125
No	50	43 (86%)	7 (14.0%)		(reference)	
Yes	41	28 (68.3%)	13 (31.7%)		2.54 (0.77, 8.32)	
Married				0.441		0.444
No	34	28 (82.4%)	6 (17.6%)		(reference)	
Yes	57	43 (75.4%)	14 (24.6%)		1.59 (0.49, 5.22)	
Post-Secondary Edu				0.188		0.457
No	39	33 (84.6%)	6 (15.4%)		(reference)	
Yes	52	38 (73.1%)	14 (26.9%)		1.59 (0.47, 5.41)	
Employment Status				0.214		0.467
Not Employed	39	28 (71.8%)	11 (28.2%)		(reference)	
Employed	52	43 (82.7%)	9 (17.3%)		0.65 (0.2, 2.08)	
Income[a]				0.099		0.118
< 50,000	33	23 (69.7%)	10 (30.3%)		(reference)	
> 50,000	36	31 (86.1%)	5 (13.9%)		0.26 (0.05, 1.41)	

[a]A separate model was run that only included the 61 participants with reported income, while adjusting for the other demographic factors

*p <.05

Table 9

Interactions between Demographic Factors on Depression

Variable 1	Variable 2	n	PHQ-8 Positive	p-value
Age	**Gender**			0.033*
	Female	67 (19 positive)	46.4 ± 11.9	
	Male	24 (1 positive)	59 ± 0	
Age	**Income >$50,000**			0.087**
	No	33 (10 positive)	43.6 ± 11.0	
	Yes	36 (5 positive)	45.6 ± 14.7	
Gender	**White, Non-Hispanic**			0.002*
Female	No	37	6 (16.2%)	
	Yes	30	13 (43.3%)	
Male	No	13	1 (7.7%)	
	Yes	11	0 (0%)	
Gender	**Married**			0.027*
Female	No	27	6 (22.2%)	
	Yes	40	13 (32.5%)	
Male	No	7	0 (0%)	
	Yes	17	1 (5.9%)	
Gender	**Post-Secondary Edu**			0.019*
Female	No	27	6 (22.2%)	
	Yes	40	13 (32.5%)	
Male	No	12	0 (0%)	
	Yes	12	1 (8.3%)	
Gender	**Employment**			0.029*
Female	No	33	11 (33.3%)	

	Yes	34	8 (23.5%)	
Male	No	6	0 (0%)	
	Yes	18	1 (5.6%)	
Gender	**Income >$50,000**			0.053**
Female	No	23	9 (39.1%)	
	Yes	27	5 (18.5%)	
Male	No	10	1 (10%)	
	Yes	9	0 (0%)	
Post-Secondary Edu	**Income >$50,000**			0.064**
No	No	16	4 (25%)	
	Yes	8	0 (0%)	
Yes	No	17	6 (35.3%)	
	Yes	28	5 (17.9%)	

*p <.05
**p <.10

Table 10

Relationship of Demographic Factors to PTSD

Variable	n	PTSD Negative	PTSD Positive	Univariate p-value	Odds Ratio (95% CI)	Multiple Regression p-value
Age		49.3 ± 14.0	48.1 ± 13.8	0.786	0.99 (0.94, 1.04)	0.695
Gender				0.165		0.207
Female	67	57 (85.1%)	10 (14.9%)		(reference)	
Male	24	23 (95.8%)	1 (4.2%)		0.24 (0.03, 2.2)	
White Non-Hispanic				0.060		0.050
No	50	47 (94%)	3 (6.0%)		(reference)	
Yes	41	33 (80.5%)	8 (19.5%)		5.28 (1, 27.92)	
Married				0.554		0.341
No	34	29 (85.3%)	5 (14.7%)		(reference)	
Yes	57	51 (89.5%)	6 (10.5%)		0.5 (0.12, 2.09)	
Post-Secondary Edu				0.643		0.723
No	39	35 (89.7%)	4 (10.3%)		(reference)	
Yes	52	45 (86.5%)	7 (13.5%)		0.76 (0.16, 3.51)	
Employment Status				0.404		0.849
Not employed	39	33 (84.6%)	6 (15.4%)		(reference)	
Employed	52	47 (90.4%)	5 (9.6%)		0.87 (0.21, 3.65)	
Income[a]				0.140		0.281
< 50,000	33	27 (81.8%)	6 (18.2%)		(reference)	
> 50,000	36	34 (94.4%)	2 (5.6%)		0.28 (0.03, 2.82)	

[a]A separate model was run that only included the 61 participants with reported income, while adjusting for the other demographic factors

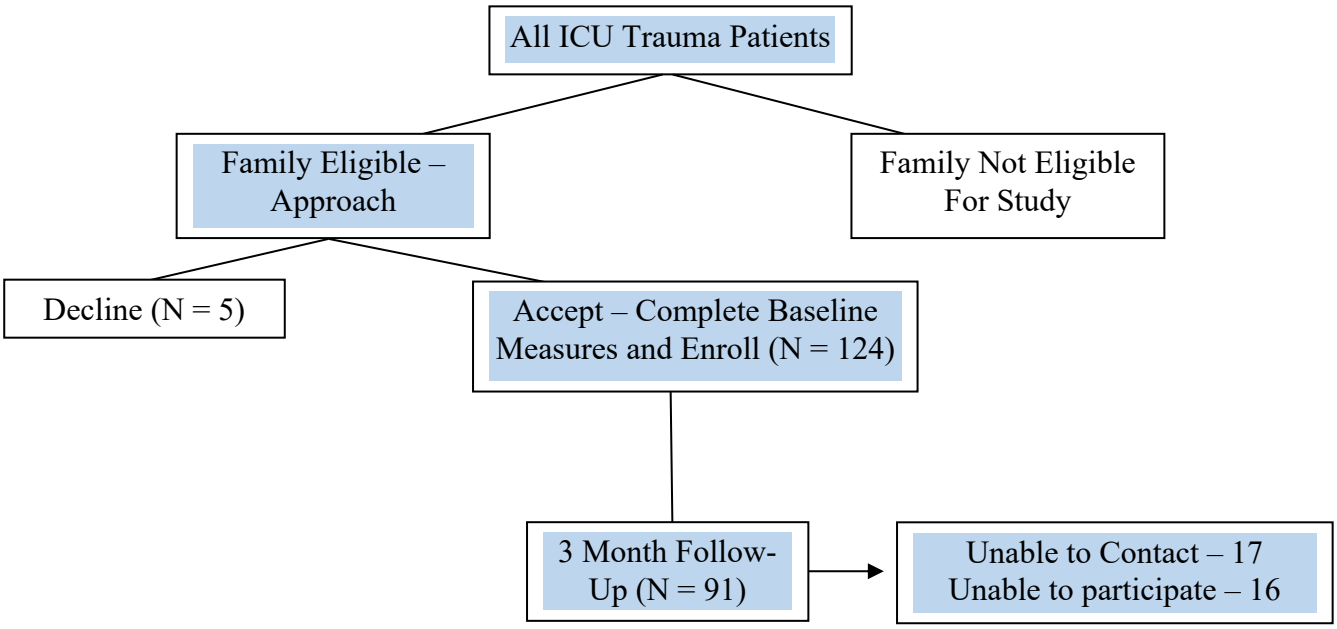
Table 11

Interactions between Demographic Factors on PTSD

Variable 1	Variable 2	n	PTSD Positive	p-value
Age	**Income >$50,000**			0.073**
	No	33 (19 positive)	52.5 ± 14.5	
	Yes	36 (2 positive)	42.0 ± 26.9	
Gender	**White, Non-Hispanic**			0.021*
Female	No	37	2 (5.4%)	
	Yes	30	8 (26.7%)	
Male	No	13	1 (7.7%)	
	Yes	11	0 (0%)	
White, Non-Hispanic	**Married**			0.085**
No	No	23	1 (4.3%)	
	Yes	27	2 (7.4%)	
Yes	No	11	4 (36.4%)	
	Yes	30	4 (13.3%)	
White, Non-Hispanic	**Employment**			0.038*
No	No	17	0 (0%)	
	Yes	33	3 (9.1%)	
Yes	No	22	6 (27.3%)	
	Yes	19	2 (10.5%)	
White, Non-Hispanic	**Income >$50,000**			0.066**
No	No	18	1 (5.6%)	
	Yes	17	0 (0%)	
Yes	No	15	5 (33.3%)	
	Yes	19	2 (10.5%)	

*$p < .05$
**$p < .10$

APPENDIX A
CONSORT Flow Chart of Consent Process and Treatment Schedule



APPENDIX B
Connor-Davidson Resilience Scale (CD-RISC) 10 Item

Connor-Davidson Resilience Scale 10
(CD-RISC 10)

initials ☐☐☐ ***date*** ☐☐ / ☐☐ / ☐☐ ***visit*** ☐☐ ***age*** ☐☐

marital status O married O separated O widowed O never married O divorced O refused

gender O male O female

race or ethnic origin O White, not Hispanic origin O black, not Hispanic origin O Hispanic
O Asian O Native American or Alaskan native O other O unsure

---

*Please indicate how much you agree with the following statements as they apply to you over the last **month**.*
If a particular situation has not occurred recently, answer according to how you think you would have felt.

---

	not true at all	**rarely true**	**some times true**	**often true**	**true nearly all the time**
1. I am able to adapt when changes occur.	O 0	O 1	O 2	O 3	O 4
2. I can deal with whatever comes my way.	O 0	O 1	O 2	O 3	O 4
3. I try to see the humorous side of things when I am faced with problems.	O 0	O 1	O 2	O 3	O 4
4. Having to cope with stress can make me stronger.	O 0	O 1	O 2	O 3	O 4
5. I tend to bounce back after illness, injury, or other hardships.	O 0	O 1	O 2	O 3	O 4
6. I believe I can achieve my goals, even if there are obstacles.	O 0	O 1	O 2	O 3	O 4
7. Under pressure, I stay focused and think clearly.	O 0	O 1	O 2	O 3	O 4
8. I am not easily discouraged by failure.	O 0	O 1	O 2	O 3	O 4
9. I think of myself as a strong person when dealing with life's challenges and difficulties.	O 0	O 1	O 2	O 3	O 4
10. I am able to handle unpleasant or painful feelings like sadness, fear and anger.	O 0	O 1	O 2	O 3	O 4

We acknowledge contributions as works made for hire by Laura Campbell-Sills, Ph.D. and Murray Stein, M.D.

09-2011

APPENDIX C
The Patient Health Questionnaire 8 (PHQ-8)

Over the **last 2 weeks**, how often have you been bothered by any of the following problems?
*(circle **one** number on each line)*

How often during the past 2 weeks were you bothered by...	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3

Scoring

If two consecutive numbers are circled, score the higher (more distress) number. If the numbers are not consecutive, do not score the item. Score is the sum of the 8 items. If more than 1 item missing, set the value of the scale to missing. A score of 10 or greater is considered major depression, 20 or more is severe major depression.

APPENDIX D
Primary Care Posttraumatic Stress Disorder Screen (PC-PTSD)

Primary Care PTSD Screen (PC-PTSD)

Description

The PC-PTSD is a 4-item screen that was designed for use in primary care and other medical settings and is currently used to screen for PTSD in veterans at the VA. The screen includes an introductory sentence to cue respondents to traumatic events. The authors suggest that in most circumstances the results of the PC-PTSD should be considered "positive" if a patient answers "yes" to any 3 items. Those screening positive should then be assessed with a structured interview for PTSD. The screen does not include a list of potentially traumatic events.

Scale

Instructions:

In your life, have you ever had any experience that was so frightening, horrible, or upsetting that, in the past month, you:

1. Have had nightmares about it or thought about it when you did not want to?

   YES / NO

2. Tried hard not to think about it or went out of your way to avoid situations that reminded you of it?

   YES / NO

3. Were constantly on guard, watchful, or easily startled?

   YES / NO

4. Felt numb or detached from others, activities, or your surroundings?

   YES / NO

Current research suggests that the results of the PC-PTSD should be considered "positive" if a patient answers "yes" to any three items.

APPENDIX E
PTSD Checklist, Civilian Version (PCL-C)

Client's Name: _____

Instruction to patient: Below is a list of problems and complaints that veterans sometimes have in response to stressful life experiences. Please read each one carefully, put an "X" in the box to indicate how much you have been bothered by that problem *in the last month*.

No.	Response	Not at all (1)	A little bit (2)	Moderately (3)	Quite a bit (4)	Extremely (5)
1.	Repeated, disturbing *memories, thoughts, or images* of a stressful experience from the past?					
2.	Repeated, disturbing *dreams* of a stressful experience from the past?					
3.	Suddenly *acting* or *feeling* as if a stressful experience *were happening* again (as if you were reliving it)?					
4.	Feeling *very upset* when *something reminded* you of a stressful experience from the past?					
5.	Having *physical reactions* (e.g., heart pounding, trouble breathing, or sweating) when *something reminded* you of a stressful experience from the past?					
6.	Avoid *thinking about* or *talking about* a stressful experience from the past or avoid *having feelings* related to it?					
7.	Avoid *activities* or *situations* because they *remind you* of a stressful experience from the past?					
8.	Trouble *remembering important parts* of a stressful experience from the past?					
9.	Loss of *interest in things that you used to enjoy?*					
10.	Feeling *distant* or *cut* off from other people?					
11.	Feeling *emotionally numb* or being unable to have loving feelings for those close to you?					
12.	Feeling as if your *future* will somehow be *cut short*?					
13.	Trouble *falling* or *staying asleep*?					
14.	Feeling *irritable* or having *angry outbursts*?					
15.	Having *difficulty concentrating*?					
16.	Being *"super alert"* or watchful on guard?					
17.	Feeling *jumpy* or easily startled?					

PCL-M for DSM-IV (11/1/94) Weathers, Litz, Huska, & Keane National Center for PTSD - Behavioral Science Division

APPENDIX F
Caregiver Burden Scale (CBS)

Questions

Please, place a tick in the appropriate box.

No 1. Do you feel tired and worn out?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 2. Do you feel lonely and isolated because of your relative´s problem?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 3. Do you think you have to shoulder too much responsibility for your relative´s welfare?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 4. Do you sometimes feel as if you would like to run away from the entire situation you find yourself in?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 5. Do you find yourself facing purely practical problems in the care of your relative that you think are difficult to solve?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 6. Do you ever feel offended and angry with your relative?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 7. Do you think your own health has suffered because you have been taking care of your relative?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 8. Has your social life, e.g., with family and friends, been lessened?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 9. Does the physical environment make it troublesome for you taking care of your relative?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 10. Do you feel tied down by your relative´s problem?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 11. Do you feel embarrassed by your relative´s behaviour?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 12. Has your relative´s problem prevented you from doing what you had planned to do in this phase of your life?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 13. Do you find it physically trying to take care of your relative?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 14. Do you think you spend so much time with your relative that the time for yourself is insufficient?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 15. Do you worry about not taking care of your relative in the proper way?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 16. Are you sometimes ashamed of your relative´s behaviour?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 17. Is there anything in the neighbourhood of your relative´s home making it troublesome for you to take care of your relative?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 18. Have you experienced economic sacrifice because you have been taking care of your relative?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 19. Do you find it mentally trying to take care of your relative?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 20. Do you feel that life has treated you unfairly?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 21. Had you expected that life would be different than it is at your age?

☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

No 22. Do you avoid inviting friends and acquaintances home because of your relative´s problem?
☐ Not at all1
☐ Seldom2
☐ Sometimes3
☐ Often4

APPENDIX G
Demographic Questionnaire

Treatment Arm:	FLOAT DEMOGRAPHIC DATA	
Participant ID#:	Date Consented:	Examiner Initials:

DOB: _____

Gender:
0. Female
1. Male

What is your racial background?
1. Caucasian/White
2. African American /Black
3. American Indian or Alaska Native
4. Asian
5. Native Hawaiian or Pacific Islander
9.

Are you of Hispanic/Latino Origin?
0. Not of Hispanic Origin
1. Hispanic Origin (includes Mexican, Cuban, Puerto Rican, Latin American, Spanish)
9.

What is your marital status?
1. Never married
2. Married
3. Divorced
4. Separated
5. Widowed
6. Other: _____
9.

What is the highest grade/degree you completed in school?
1. 8th Grade or Less
2. 9th – 12th Grade
3. High School Diploma
4. Associate's Degree
5. Bachelor's Degree
6. Master's Degree
7. Doctoral Degree
8. Professional Degree
9.

Are you currently working?
0. No
1. Yes

What is your job?
_____

What is your current household income in U.S. dollars (pre-injury)?
1. < $25,000
2. $25,000 - $49,000
3. $50,000 - $74,000
4. Above $75,000
9.

What distance do you travel to and from the hospital each day? _____(city, miles)

What is your relation to the patient? _____

Were you present at the time of the event?_____

How much time do you anticipate spending in the care-giving role for your patient? _____%

Have you ever participated in a therapy session? _____

Have you ever spent time in the ICU (e.g., patient, family member, friend, employee)?
_____

Pre-Morbid Psychological Conditions

I am going to read a list of psychological conditions. Please tell me if you have been diagnosed with, or treated for, any of the following: (Responses can include yes, no, or unknown)

CONDITION:	NO / YES / UNKNOWN		
a. Depression:	0	1	3
b. Bipolar Disorder or manic depression:	0	1	3
c. Panic Disorder:	0	1	3
d. Generalized anxiety disorder:	0	1	3
e. Posttraumatic stress disorder:	0	1	3
f. Obsessive compulsive disorder or OCD:	0	1	3
g. Any phobia *(if yes, which kind?):*	0	1	3
h. Schizophrenia, schizoaffective disorder, or any psychotic disorder:	0	1	3

(if yes to psychotic d/o, what kind?) _____

i. Other: _____

CONTACT INFORMATION

Participant Phone #: _____ Email: _____

Address: _____

Alternate Contact # 1: _____

Relation: _____

Alternate Contact # 2: _____

Relation: _____

Measure	**Assessment**
ICU Waiting Room Experience	BA - - -
Experience and Understanding of the ICU	BA - - -
CEDS-R	BA, 3. 6. 12
GAD-7	BA, 3 6 12
CD-RISC	BA - - 12
PSQI	BA, 3, 6, 12
SPS	BA - - 12
PC-PTSD	BA, 3, 6, 12
PCL-C*	- 3, 6, 12 (* if + on PC-PTSD)
SPSI-R	BA, 3, 6, 12
AUDIT-C	BA, 3, 6, 12
Expectancies - OV	BA, 3, 6, 12
PTGI	- - - 12
Caregiver Burden	- 3, 6, 12
ICG-R (*only if patient is deceased at follow-up)	- 3, 6, 12

Patient Characteristics

DOB: _____ **DOI: _____** **Age at Injury: _____**

GCS:_____ **ISS: _____**

Etiology of injury (ICD-9 Ecode): _____

Primary ICU Diagnosis:_____

# of Days Spent on Vent: _____ **# of Days Spent in ICU: _____**

Date of ICU admission:_____ **Total Length of Stay:_____**

Dispo:

1. **Home**
2. **Rehab**
3. **SNF**
4. **LTAC**
5. **Hospice**
6. **Expired**
9. **_____**

Does patient have insurance?

0. None
1. Public (Medicare/Medicaid)
2. Private (Aetna, BCBS, etc.)

Is patient noted as homeless?

0. **No**
1 **Yes**
2. **Not indicated on chart**

Does the patient have a contact person (friend or family) listed in the chart?

0. **No**
1. **Yes**

According to nursing documentation, has anyone been to visit the patient in the first 24 hours after admission?

0. **No**
1. **Yes**

According to nursing documentation, has anyone been to visit the patient in the first 72 hours after admission?

0. **No**
1. **Yes**

Does patient have a TBI?

0. **No**
1. **Yes**

Patient Name:

MRN/V#:

Trauma #: