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FAMILY NEEDS, CAREGIVER BURDEN, AND MENTAL HEALTH: CAREGIVERS OF INDIVIDUALS WITH VARIOUS NEUROLOGICAL CONDITIONS FROM COLOMBIA AND MEXICO

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science at Virginia Commonwealth University

> Megan Elizabeth Sutter Bachelor of Arts, University of South Florida St. Petersburg, May 2011

> > Director: Paul B. Perrin, Ph.D. Assistant Professor of Psychology Department of Psychology

Virginia Commonwealth University Richmond, Virginia September 2014

Acknowledgements

There are several people who I would like to acknowledge and thank for their contributions to my thesis. First and foremost, I would like to thank my committee members, Paul B. Perrin, Ph.D., Juan Carlos Arango Lasprilla, Ph.D., and Robin Everhart, Ph.D. for their guidance throughout this thesis. I am grateful for the time they committed to conceptualizing the project and editing that helped me improve my thesis immensely. I would like to express my gratitude to Juan Carlos Arango Lasprilla for generously allowing me to use his dataset for this thesis, and my advisor Dr. Paul Perrin for his continued dedication to my professional development. Finally, I would like to thank my family and friends for their unwavering support throughout all stages of my thesis.

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Abstract

FAMILY NEEDS, CAREGIVER BURDEN, AND MENTAL HEALTH:

CAREGIVERS OF INDIVIDUALS WITH VARIOUS NEUROLOGICAL CONDITIONS

FROM COLOMBIA AND MEXICO

By Megan Elizabeth Sutter

A Thesis submitted in partial fulfillment of the requirements for the degree of Master of Science at Virginia Commonwealth University.

Virginia Commonwealth University, 2014

Major Director: Paul B. Perrin Assistant Professor, Department of Psychology

This cross-sectional study examined differences in family needs (informational, social, financial, health, and household support), caregiver mental health (depression, satisfaction with life, vitality, social functioning, and emotional role limitations), and caregiver burden (personal life, guilt, and psychological) among caregivers of individuals with traumatic brain injury, spinal cord injury, multiple sclerosis, and dementia from cities in Colombia and Mexico (N = 343). The study also examined the connections among family needs, caregiver mental health, and caregiver burden in the combined sample of caregivers of individuals with neurological conditions. Many significant differences were identified among groups, and implications are discussed. Family needs, caregiver mental health, and burden were all robustly associated with each other, with financial and social support needs, depression, and burden-personal life and guilt emerging as particularly important. Clinicians should focus on helping caregivers meet financial and social support needs in order to positively influence caregiver burden and mental health.

Family needs, caregiver burden, and mental health:

Caregivers of individuals with various neurological conditions from Colombia and Mexico

Neurological conditions are disorders that affect the central and peripheral nervous systems and that ultimately impair individuals' physical and cognitive abilities, limiting their functional independence (WHO, 2006). Neurological conditions represent 12% of total deaths globally, and prevalence rates are on the rise (WHO 2006). The etiologies of neurological conditions vary widely. Some conditions fall under the neuropsychiatric category such as multiple sclerosis and Alzheimer's disease and other dementias, whereas other conditions are due to traumatic injuries resulting in neurological sequelae such as traumatic brain injury and spinal cord injury (WHO, 2006).

The severity and frequency of each condition vary; however, most individuals with a neurological condition will need a caregiver for some part of their recovery or as their condition worsens. Informal caregivers are individuals who do not receive training or financial compensation for their assistance, and are often family members of the individual with the neurological condition (Zucchella et al., 2012; Buchanan et al., 2010). Informal caregivers assist with various daily activities such as bathing, grooming, providing transportation, preparing meals, performing chores, and managing behavioral or safety issues associated with the conditions (AA, 2012; Carton, Loos, Pacolet, Versieck, & Vlietinck, 2000). Caregivers of individuals with neurological conditions often report increased levels of depression (Rodakowski, Skidmore, Rogers, & Schultz, 2012), anxiety (Mahoney, Regan, Katona, & Livingston, 2005), poor life satisfaction (Arango-Lasprilla et al., 2010a), reduced social functioning, low energy (Lee, 2008; Marsh, Kersel, Havill, & Sleigh, 2002), reduced quality of life (Norup, Siert, & Lykke Mortensen, 2010), high caregiver burden (Marsh et al., 2002; Post,

Bloeme, & de Witte, 2005), and report many unmet family needs (Kolakowsky-Hayner, Miner, & Kreutzer, 2001; Robison, Shugrue, Porter, Fortinsky, & Curry, 2012; Arango-Lasprilla et al., 2010b; Arango-Lasprilla et al., 2010c).

Cultural values in Latin America increase the likelihood that family members in that region will provide care for individuals with neurological conditions. Values that are more salient in Latin American cultures such as familism, allocentrism (Zea, Quezada, & Belgrave, 1994), and respeto (Neary & Mahoney, 2005) reflect the collectivism in the region that make caregiving a valued cultural role. Despite the vast research literature on caregiving for individuals with neurological conditions, this research area is only beginning to be examined in Latin America. The current study begins to address these gaps in the research literature. The aims of the current study are to examine (a) the connections between unmet family needs and caregiver burden, (b) the connections between caregiver burden and mental health, (c) the connections between unmet family needs and caregiver mental health, (d) the differences among family needs by neurological condition, (e) the differences among caregiver burden by neurological condition, and (f) the differences in caregiver mental health by neurological condition.

This thesis will be based in part on Pearlin's Stress Process Model of Caregiving which posits that the caregiving background and context (e.g., socioeconomic status, program availability, and family variables) influence the objective and subjective primary stressors into other life domains, such as increasing amounts of caregiving duties and feelings of exhaustion (Pearlin, Mullan, Semple, & Skaff, 1990). According to this model, the accumulation of primary and secondary stressors (i.e., burden) ultimately increases caregivers' physical and mental health problems (Pearlin et al., 1990). The current study conceptualizes unmet family needs as

important caregiving context variables that may influence caregiver burden, and ultimately, caregiver mental health.

The following Introduction will first present a review of various neurological conditions (i.e., dementia, multiple sclerosis, traumatic brain injury, and spinal cord injury), the epidemiology, symptoms, and impairments of each condition. Second, it will discuss caregiving characteristics and duties. Third, it will review psychosocial functioning of caregivers of individuals with neurological conditions. Fourth, it will discuss common needs of caregivers across the various conditions. Finally, it will present sociocultural factors that affect caregiving in Latin America.

Epidemiology

According to the World Health Organization (WHO), hundreds of millions of people worldwide are affected by neurological disorders of the central and peripheral nervous systems (WHO, 2006). The majority of neurological conditions are chronic and a primary cause of disability across the world (WHO, 2004), and the comprise 12% of total deaths globally (WHO 2006b). Neurological conditions represent 6.3% of the burden of disease globally, and are projected to increase to 6.8% by 2030 (WHO, 2006). To put this in context of other major causes of death, HIV/AIDS and cancer each contribute approximately 5% to the global burden of disease (WHO, 2006). The loss of healthy years of individuals with neurological conditions is increasing, with a projected loss increase of 12% from 2005 to 2030 (WHO, 2006). From a public health perspective, the epidemiological evidence and burden of neurological conditions globally indicate the need for greater allocation of resources to these populations (WHO, 2006).

Dementia. It was estimated that in 2010, 35.6 million people were living with dementia, and this number is expected to increase twofold every 20 years (Prince et al., 2013). In Latin

America, the prevalence of dementia (8.5%) is higher than other world regions, such as the United States (6.5%), Western Europe (6.9%), and Eastern Asia (4.2%; Prince et al., 2013).

Notably, the increase of older adults in Latin America and the Caribbean is expected to grow from 50,228 individuals aged 60 and over in 2005 to an estimated 186,721 in 2050 (CELADE, 2008). The increase in this demographic is thought to be due in part to the rise in life expectancy in Latin America, which has increased from 51.8 to 73.4 years over the past 60 years (CELADE, 2008). Nevertheless, life expectancy is increasing at varying degrees based on the level of development in various countries. For example, Costa Rica, Brazil, and Colombia are more developed nations, and have life expectancies of 78.8, 72.4, and 72.8 years, respectively. Conversely, less developed countries, such as Haiti and Bolivia have lower life expectancies of 60.6 and 65.5 years, respectively (CELADE, 2008). Nonetheless, this increase is quite evident in advancing countries such as Mexico and Colombia, where from 1990 to 2010 the life expectancy has increased 4.2 and 4.6 years for males; and 3.5 and 3.1 years for females, respectively (Salomon et al., 2012).

Multiple Sclerosis. Another common neurological conditions among adults is multiple sclerosis (MS) (Dombovy, 2011). Higher prevalence rates of MS are observed in developed global regions such as Europe, Canada, and the United States with prevalence rates ranging from 60 to greater than 100 cases per 100,000 residents (Koch-Henriksen & Sorensen, 2010; Pugliatti, Sotgiu, & Rosati, 2002; Rosati, 2001). A review of incidence and prevalence of MS in Latin America and the Caribbean reported a range of 0.83 to 21.5 prevalence rates per 100,000 individuals annually (Cristiano et al., 2012). Importantly, there has been an increase in incidence rates of MS in Mexico based on referrals to tertiary neurological facilities (Velazquez, Macias, Rivera, &

Lozano, 2003; Corona, Rodriguez, Otero, & Stopp, 1996; Aguilar et al., 1985). Although Latin America was once considered low risk for MS, there is growing support for its increased prevalence in this region (Corona & Roman, 2006). Research has indicated some risk factors for increases in MS in Mexico, such as decreases in breastfeeding, increased rates of varicella and childhood eczema (Tartas, Ordonez, Rios, & Sotelo, 2002).

Spinal Cord Injury. Spinal cord injury (SCI) is an acquired neurological condition that affects an estimated 10.4 to 83 million people per year globally, with prevalence rates at approximately 223 to 755 cases per million worldwide (Wyndaele & Wyndaele, 2006). SCI can affect individuals who are often young and healthy, with an average of 33 years of age at the time of injury (Wyndaele & Wyndaele, 2006). Unfortunately, there is a dearth of epidemiological data for SCI in developing countries such as Mexico and Colombia (Ackery, Tator, & Krassioukov, 2004). It is reported that violence is a leading cause of SCI in developing nations, where prognoses for individuals with SCI can be worse due to lack of rehabilitation infrastructure (Ackery, Tator, & Krassioukov, 2004).

Traumatic Brain Injury. More than 10 million people experience a traumatic brain injury (TBI) globally each year (Hyder, Wunderlich, Puvanachandra, Gururaj & Kobusingye, 2007). Among those affected by TBI, children from age 0 to 4 have the highest combined emergency department visits, hospitalizations, and deaths; individuals aged 5 to 19 have the highest likelihood of sustaining a TBI compared to other age groups; and those 75 years and older have the highest incidence of hospitalizations for TBI (Langlois, Ruthland-Brown, & Thomas, 2004). In Latin America and the Caribbean, there are increased incidence rates of TBI of nearly 150 cases per 100,000 inhabitants, which is higher compared to the worldwide rate of 106 per 100,000 (Hyder et al., 2007).

Symptoms and Impairments

Dementia. Dementia is not a disease, but rather a cluster of symptoms associated with disorders that affect the brain (NINDS, 2014a). Diseases that can cause dementia are Alzheimer's disease (AD), vascular dementia, Lewy body dementia, frontotemporal dementia, Huntington's disease, and Creutzfeldt-Jakob disease, with the most common being AD (NINDS, 2014a; AA, 2012). AD is a persistent neurodegenerative disease distinguished by a slow and gradual decline in cognitive functioning (Serrano-Aguilar, Lopez-Bastida, & Yanes-Lopez, 2006). The second most common cause of dementia is vascular dementia (AS, 2011), which is caused by damage to the vessels that supply blood to the brain, and can originate from multiple strokes or injury to the vessels supplying blood to the brain (NINDS, 2014b)

The hallmark of dementia symptomatology is a marked deterioration of cognitive ability and functional skills (AA, 2012). Cognitive symptoms include memory loss, deficits in communication, mood and personality changes (e.g., apathy and depression), and poor judgment. Functional changes such as problems with bathing, eating, dressing, and toileting occur as well. As the disease advances, symptoms become more severe (AA, 2012). This includes the entire loss of functional daily activities (e.g., walking and swallowing), capacity for communication, and inability to identify loved ones. Ultimately, individuals with dementia become bedridden, leaving them prone to serious infections such as pneumonia, eventually leading to mortality (AA, 2012).

Multiple Sclerosis. Multiple sclerosis (MS) is a chronic neurological disorder caused by an autoimmune reaction that damages the myelin sheaths around axons of neurons in the central nervous system (Dutta & Trapp, 2007). Depending on the course of the condition, MS symptom occurrence and severity will vary (Dutta & Trapp, 2007). Common symptoms are fatigue

(Krupp, 2003), cognitive impairments, and sensory/motor problems (Wallin, Wilken, & Kane, 2006). These symptoms are considered severely debilitating due to the reduction in ability to participate in functional and cognitive activities (Lezak et al., 2004). Cognitive impairments include deficits in memory, processing speed, or executive functioning (Chiaravalloti & DeLuca, 2008); however, the severity of memory symptoms is not as problematic as individuals with dementia (Lezak et al., 2004).

Spinal Cord Injury. Spinal cord injury (SCI) is caused by any trauma or damage to the spinal cord (NINDS, 2013a). The most common causes of SCI are preventable such as car accidents and violence; however, some cancers can cause damage to the spinal cord (NINDS, 2013a). After the initial injury, a set of biological events are triggered that destroy neurons, myelin sheaths on axons, and increase the inflammatory immune response (NINDS, 2013a). As long as weeks after the primary injury, secondary injuries can cause even more damage to the spinal cord surrounding the initial injury site (NINDS, 2013a). SCIs are characterized as complete or incomplete (NINDS, 2013b), such that an incomplete injury allows some messages from the brain pass down the spinal cord, allowing the maintenance of some sensory and motor function below the injury site (NINDS, 2013b). Complete injuries occur when there is a complete lack of sensory and motor function below the injury site (NINDS, 2013b). There are many medical complications that accompany SCI such as chronic pain, bladder and bowel dysfunction, and increased vulnerability to heart and respiratory complications (NINDS, 2013b).

Traumatic Brain Injury. Traumatic brain injury (TBI) is caused by impact to or penetration of the head disrupting normal brain functioning (Faul, Xu, Wald, Coronado, 2010). TBI-related impairments depend of the injury severity, and range from acute mental status change post-mild TBI to coma or amnesia post-severe TBI (Faul et al., 2010). Individuals with

TBI face long lasting, and sometimes permanent physical, cognitive, behavioral, and emotional impairments (Corrigan & Hammond, 2013). Cognitive deficits associated with TBI include, for example, problems concentrating and difficulty with memory (Lundin, Boussard, Edman, & Borg, 2006). Somatic symptoms can occurs such as headaches, nausea, and blurry vision (Lundin et al., 2006; AA, 2014). In addition, affective symptoms (e.g., restlessness, irritability) and motor problems affect individuals with TBI (Lundin et al., 2006). Recovery from TBI is possible, and ranges from several weeks to many years, varying by injury severity. Individuals with mild TBI have reported lack of symptoms after 3 months post-TBI (Lannsjo, af Geijerstam, Johansson, Bring, & Borg, 2009). Although, for most individuals it may take more than six years to fully recover (Huang, Ho & Yang, 2010).

Caregiver Characteristics and Duties

Due to the often-pervasive symptoms and impairments associated with neurological disorders, a large portion of caregiving responsibilities falls onto unpaid family caregivers (Anderson, Parmenter, & Mok, 2002). Although the negative effects of neurological disorders originate with the patient, the caregiver and family are all affected (Henderson, Alexander, & Mayka, 1989). Many caregivers are family members, where 70% of dementia caregivers (Zucchella eta l., 2012) and 30% of MS caregivers (Buchanan et al., 2010) are unpaid informal family caregivers. Caregivers of individuals with dementia, TBI, or SCI are typically women (Turró-Garriga, et al., 2013; Oreta & Sterzo, 2013; Sequeira, 2013; Marsh et al., 2002; Arango-Lasprilla et al., 2010a). However, with a higher prevalence of MS among women (Sellner et al., 2011), MS caregivers are more likely to be men (Pinquart & Sörenson, 2011). Many different family members care for individuals with neurological conditions, although caregivers tend to be spouses, parents, or adult children (Buchanan & Huang, 2011; Corry & While, 2009; Turró-

Garriga, et al., 2013; Oreta & Sterzo, 2013). Unpaid caregivers assist with many daily activities such as toileting, bathing, grooming, providing transportation, preparing meals, performing chores, and managing behavioral or safety issues associated with the conditions (AA, 2012; Carton et al., 2000).

Psychosocial Functioning of Caregivers of Individuals with Neurological Conditions

Caregivers of individuals with neurological disorders experience many changes in their lives after becoming a caregiver, and report high levels of psychological distress, in part due to the obligations that accompany their role (Bartolo et al., 2010). TBI caregivers report having less time to take care of themselves, changes in sleep patterns, more financial problems, and more changes in relationships after six months of caregiving (Marsh et al., 2002). In a sample of MS caregivers, 42% of caregivers reported strain on emotional adjustment, demands on time, changes in personal plans, and disrupted sleep (Khan, Pallant, & Brand, 2007). Additionally, SCI caregivers have reported feeling overwhelmed with their caretaking responsibilities (Arango-Lasprilla et al., 2010a). Many facets of psychosocial functioning have been examined such as caregiver burden, depression, social functioning, and quality of life. The following subsections will review the literature of caregivers of individuals with various neurological conditions in these areas.

Caregiver Burden. Caregiver burden is the reaction to stressors that accumulate from caregiving duties, time restrictions, and difficulties in providing care (Zarit et al., 1980). Within the context of the caregiver-patient relationship, caregivers' health, psychological well-being, finances, and social life often are restricted (Zarit et al., 1980). Burden is a common predictor of physical and psychological well-being of both the caregiver and care-recipient (e.g., Khan, Pallant, & Brand, 2007; Pozzilli et al., 2004; Fisher & Lieberman, 1994). In general, caregivers

often report experiencing high levels of burden (Pinquart & Sorensen, 2003). Increased caregiving obligations often result in a loss of free time, friendships, and social isolation (Rodriguez et al., 2003). In a study of dementia caregivers, a third of participants reported increased objective burden (i.e., time dependency), and a quarter reported high developmental burden such as feeling left out of normal life experiences (Zucchella et al., 2012). Forty percent of MS caregivers in one study reported caregiving as burdensome at least some of the time, and 20.8% described it as burdensome most of the time or all of the time (Buchanan & Huang, 2011). Among SCI caregivers, perceived burden of care has been reported as high in 24.8% of partners of individuals with more severe disabilities and 3.9% in partners of individuals with minor disabilities (Post, Bloeme, & de Witte, 2005). Caregivers of individuals with TBI also have been shown to have high levels of burden (Marsh et al., 2002; Vangel, Rapport, & Hanks, 2011).

Many care-recipient factors are associated with caregiver burden. Among individuals with various chronic neurological conditions and their caregivers, caregiver burden has been negatively associated with patient functional independence, quality of life (Bartolo et al., 2010), and cognitive functioning (Thommessen et al., 2002). Caregiver strain has also been correlated with poor quality of life in individuals with MS (Khan et al., 2007). Among SCI caregivers, perceived burden is higher for those with greater disabilities and more care-recipient psychological problems (Post et al., 2005). Additionally, behavioral and psychological symptoms of dementia (i.e., memory-related problems, disruption, depression) (Cheng, Ip, & Kwok, 2013), greater dementia severity (Mioshi et al., 2013; Bruvik, Ulstein, Ranhoff, & Engedal, 2013; Turró-Garriga, et al., 2013), higher degree of anosognosia (i.e., lack of awareness of deficits), reduced ADLs, and younger age of the care-recipient (Etters, Goodall, & Harrison, 2008) have predicted increased burden among dementia caregivers. Likewise, disease severity and dependence on the caregiver for ADLs are also associated with increased MS caregiver burden (Coleman, Rath & Carey, 2001; Aronson, Cleghorn, & Goldenberg, 1996; Finlayson & Cho, 2008). Finally, fewer behavioral and emotional changes among individuals with TBI have been related to lower caregiver burden (Knight, Devereux, & Godfrey, 1998; Hanks, Rapport, & Vangel, 2007).

Caregiver factors associated with caregiver burden have also been well documented. Among caregivers of individuals with various chronic neurological conditions, caregiver burden has been positively associated with caregiver depression (Bartolo et al., 2010). Among dementia caregivers, strain is associated with more caregiver depressive and anxiety symptoms (Fisher & Lieberman, 1994). Also among dementia caregivers from the Netherlands with reduced social functioning, poor health status, perception of threat within the role of caregiving, and reduced perceived instrumental support experienced more burden (Van Den Wijngaart, Vernooij-Dassen, & Felling, 2007). The provision of support for activities of daily living, caregiver age, and caregiver gender have predicted higher burden among SCI caregivers (Post et al., 2005). Caregiver external locus of control orientation, hours per day spent caregiving, (Bruvik et al., 2013), and closer kinship ties (Etters et al., 2008) have predicted increased burden among dementia caregivers. And better family functioning has been related to lower caregiver burden among TBI caregivers (Knight et al., 1998; Hanks et al., 2007).

Mental Health. Caregivers of individuals with neurological conditions often experience reduced mental health. Dementia caregivers have reported increased depressive and anxiety symptoms (Burgener, 1999; Mahoney et al., 2005). Nearly 30% of dementia caregivers in one sample had physician-diagnosed depression, and dementia caregivers without depression had significantly lower ratings of personal sacrifice and burden (Strong & Mast, 2013). Similarly,

30% of MS caregivers in one study reported mild clinical depression (Pakenham, 2001). Among MS caregivers from Mexico, 40% have reported clinical levels of depression (Lehan et al., 2012), and a quarter of MS caregivers have reported feeling dissatisfied with their lives (Arango-Lasprilla et al., 2010b). Approximately 40% of SCI caregivers have reported clinically significant depressive symptoms (Rodakowski et al., 2012; Arango-Lasprilla et al., 2010a), and almost half of one sample of SCI caregivers reported being dissatisfied with their lives (Arango-Lasprilla et al., 2010a). Epstein-Lubow and colleagues (2012) identified that 63.4% of their sample of dementia caregivers of a hospitalized patient had clinical levels of depression, and 43.2% of dementia caregivers in their sample from an outpatient care setting did. Compared to non-caregivers, mental health of dementia caregivers has been quantified as 22% lower (Gusi et al., 2009), MS caregivers have been more likely to report depressive symptoms (Pakenham, 2001), and SCI caregivers have reported greater depressive affect and somatic depression (Weitzenkamp et al., 1997). Rivera, Elliott, Berry, Grant, & Oswald (2007) reported approximately half of their sample of TBI caregivers met criteria for significant depressive symptoms, and Gervasio & Kreutzer (1997) found 40% of their sample of TBI caregivers to be above the clinical level on a measure of depression.

Many other mental health problems among caregivers of individuals with neurological conditions have been recognized. Dementia caregivers have reported reduced social functioning, emotional role limitations, and energy outcomes compared to a non-caregiving sample (Lee, 2008). TBI caregivers have experienced clinically significant anxiety symptoms and poor social adjustment six months post-TBI (Marsh et al., 2002). Moreover, TBI caregivers have shown significantly lower quality of life than the general population in a Danish sample (Norup et al., 2010). Additionally, older caregivers of various conditions have reported greater fatigue, reduced

energy, and more sleep problems compared to controls (Teel & Press, 1999). When compared with non-caregivers, spousal SCI caregivers have reported more physical and emotional stress, burnout, fatigue, anger, and resentment (Weitzenkamp et al., 1997).

Caregivers with poor mental health are at risk for many negative outcomes for both themselves and their care-recipient. Increased depression among dementia caregivers is associated with a greater likelihood of suicidal ideation (O'Dwyer, Moyle, Zimmer-Gembeck, & De Leo, 2013). O'Dwyer and colleagues (2013) found that 26% of their sample of dementia caregivers have contemplated suicide more than one time in the past year. SCI caregiver depression is associated with more negative social interactions and reduced social integration (Rodakowski et al., 2012). Caregivers who engage in more pleasant events and experience lower perceived activity restriction have a lower arterial pressure as well as systolic and diastolic blood pressure versus caregivers without those characteristics (Chattillion et al., 2013). And lower levels of caregiver satisfaction with life have been associated with reduced likelihood of carerecipient outpatient visits to primary and mental health care, which suggests low life satisfaction may be a barrier to outpatient care for individuals with dementia (Thorpe, Van Houtven, & Sleath, 2009).

Care-recipient factors are known to contribute to poor caregiver mental health. Among dementia caregivers from Brazil, caregiver depression and health-related quality of life has been associated with their care-recipients' quality of life and dementia severity (Pinto et al., 2009). Neuropsychiatric symptom severity, and functional and cognitive impairments have been associated with dementia caregiver quality of life (Black et al., 2011). Additionally, there has been a relationship between care-recipient problem behavior and personal care dependency, and dementia caregiver depression (Bass et al., 2012). Psychiatric symptoms and cognitive

impairment in individuals with multiple sclerosis have been associated with increased caregiver distress and reduced quality of life (Figved, Myhr, Larsen, & Aarsland, 2007). Furthermore, physical, emotional, and health status of the individual with MS has been associated with depression among MS caregivers (Pozzilli et al., 2004). Caregiving for a hospitalized individual with dementia is related to greater depression severity (Epstein-Lubow et al., 2012). Additionally, the negative affects of TBI symptoms on family members other than the primary caregiver can increase caregiver depression (Harris, Codfrey, Partridge, & Knight, 2001). Finally, initial care-recipient agitation and aggression has predicted future caregiver depression up to 12 years, after controlling for behavioral and psychological symptoms of the individuals with dementia (Ornstein et al., 2013).

Caregiver characteristics also contribute to their own mental health. Dementia caregivers with more education, larger social support networks, better health, and greater use of problemfocused coping tend to have lower levels of depression (Piercy et al., 2013). Further, depression has been linked to dementia caregivers' quality of life (Cucciare, Gray, Azar, Jimenez, & Gallagher-Thompson, 2009; Black et al., 2012), self-rated health, burden (Black et al., 2012), sleep quality, and perceived stress (Simpson & Carter, 2013a; Simpson & Carter, 2013b). Additionally, dementia caregivers' sleep disturbance has been related to their own fatigue (Chiu et al., 2013) and to caregiver physical and emotional role limitations (Lee, 2008).

Family Needs

In addition to psychosocial functioning, family needs has emerged in the literature as an important construct in the lives of caregivers of individuals with neurological disorders and care-recipients. Caregivers of individuals with frontotemporal dementia from Germany have reported unmet needs for information, education, psychosocial support from educated staff, and financial

support (Diehl-Schmid et al., 2013). Informal dementia caregivers from Singapore perceived unmet needs for emotional and social support in order to overcome the psychological and physical burden of caregiving, informational support, financial support, and accessible and suitable facilities (Vaingankar et al., 2013). MS caregivers have reported increased needs for respite services (Cockerill & Warren, 1990), information about MS, financial support, and obtaining medical equipment (Aronson et al., 1996; Kristjanson et al., 2005). Unmet family needs reported by individuals with TBI have included health information, involvement with care, instrumental support, professional support (Kolakowsky-Hayner et al., 2001), life planning, community integration, behavioral support, and emotional support (Rotondi et al., 2007). Unmet needs reported by dementia caregivers include difficulty obtaining employment, transportation obstacles, limited supportive housing choices (Robison, Shugrue, Porter, Fortinsky, & Curry, 2012), daytime activities, help with psychological distress (Miranda-Castillo et al., 2010), and support for social engagement (Górska et al., 2013).

Unmet family needs can exacerbate caregiver mental health problems as well as burden (Arango-Lasprilla et al., 2010a). Among Colombian SCI caregivers, informational, emotional, economic, physical, sleep, and psychological needs have been positively associated with depression and burden, and greater household, physical, sleep, economic, and psychological needs have been associated with less satisfaction with life and social support (Arango-Lasprilla et al., 2010a). Additionally, MS caregivers from Mexico with more physical, daily care, and interdependence needs (e.g., general support from social networks) have reported higher levels of depression (Arango-Lasprilla et al., 2010b). Unmet needs in individuals with dementia are associated with caregiver anxiety (Miranda-Castillo et al., 2010), more emotional strain (Li, Chadiha, & Morrow-Howell, 2005), and reduced quality of life (Black et al., 2011).

Care-recipient qualities and caregiver demographics also are associated with more unmet needs. Parents of depressed individuals with TBI report more unmet needs (Serio, Kreutzer, & Gervasio, 1995), and spousal TBI caregivers report more unmet needs when their partner exhibits problematic behaviors (e.g., hitting, pushing, cursing; Serio et al., 1995). Greater behavioral and psychological symptoms and reduced community involvement among individuals with dementia are related to more unmet needs (Miranda-Castillo et al., 2010). Caregiver and patient non-White race, reduced income, and patient ADL impairments are also associated with greater unmet needs (Black et al., 2013). Additionally, more unmet needs (i.e., 2 or more) has predicted nursing home placement and death of the person with dementia (Gaugler, Kane, Kane, & Newcomer, 2005).

Caregiving in Latino Communities

Many cultural values in Latin America have been identified that may increase the likelihood of family members providing care for individuals with neurological conditions. Values that are more salient in Latin American cultures such as familism, allocentrism (Zea et al., 1994) and respeto (Neary & Mahoney, 2005) reflect the collectivism in this region that makes caregiving a valued cultural role. For example, Latinos display a strong sense of familial obligation to care for older adults, which has been associated with an aversion to nursing home placement as well as to increasing burden (Mahoney, Cloutterbuck, Neary, & Zhan, 2005). Latino caregivers often see caregiving as a mechanism for passing along cultural values (Neary & Mahoney, 2005). While some family needs are comparable to families in the United States (e.g., need for health information), a sample of Colombian TBI caregivers have reported more unmet needs such as emotional support, instrumental support, and professional support (Arango-Lasprilla et al., 2010c). With strong cultural values, family caregivers may appraise caregiving

tasks differently than caregivers from more individualistic cultures, which may in turn affect their levels of burden and mental health.

Objectives

The purpose of the current study is to build upon the current literature of mental health, burden, and family needs in caregivers of individuals with neurological disorders in Latin America. Unmet family needs have been identified in some Latin American countries, and have been shown to be associated with increased psychological distress (Arango-Lasprilla et al., 2010a; Arango-Lasprilla et al., 2010b; Arango-Lasprilla et al., 2010c). Additionally, it is established that caregiver burden exacerbates caregiver psychological distress (Bartolo et al., 2010).

Hypotheses

Hypothesis 1. Caregiver mental health (depression, satisfaction with life, vitality, social functioning, and emotional role limitations) will significantly vary among the care-recipients' neurological disorder type. Although the research literature has not compared these four conditions on caregiver mental health, some studies have compared differences among dementia, Parkinson's and stroke caregivers. Dementia caregivers are expected to have worse mental health compared to others, based on a study by Hooker, Monahan, Bowman, Frazier, & Shifren (1998) that found caregivers of individuals with AD to have poorer mental health compared to Parkinson's caregivers. Specifically, dementia caregivers are expected to have higher depression (Wright et al., 1999).

Hypothesis 2. Levels of family needs (informational, social, financial, health, and household support) will significantly vary among the care- recipients' neurological disorder type. Dementia caregivers have reported less time for leisure activities, spending less time with other

family members, and employment problems compared to non-dementia caregivers (Ory, Hoffman, Yee, Tennstedt, & Schultz, 1999). Therefore, it is predicted that dementia caregivers will express more social support, financial, and household support needs than the other caregivers.

Hypothesis 3. Levels of caregiver burden (effect on the social and personal life, psychological burden and feelings of guilt) will significantly vary among the care- recipients' neurological disorder type. Dementia caregivers will report the highest levels of caregiver burden. As compared to non-dementia caregivers, dementia caregivers report more strain and more hours per week spent caregiving (Ory et al., 1999).

Hypothesis 4. More unmet family needs will be associated with decreased caregiver mental health. Based on the caregiver stress process model by Pearlin and colleagues' (1990), reduced resources are associated with poor mental health outcomes for caregivers. In addition, reduced caregiver mental health was found to be associated with unmet needs by Arango-Lasprilla and colleagues (2010b) and Marsh and others (2002). Specifically, more unmet social support and health needs will be associated with poor caregiver mental health (Arango-Lasprilla et al., 2010b; Doyle et al., 2013).

Hypothesis 5. Unmet family needs will be associated with increased caregiver burden. Family needs have been strongly associated with TBI caregiver burden (Leibach et al., 2014). Particularly, more household needs and informational needs will be associated with increased burden (Leibach et al., 2014; Doyle et al., 2013).

Hypothesis 6. Increased caregiver burden will be associated with reduced caregiver mental health. As discussed previously, depression (Bartolo et al., 2010), anxiety (Fisher &

Lieberman, 1994), and poor social functioning (Van Den Wijngaart et al., 2007) have all been associated with increased caregiver burden.

Method

Participants

Participants (N = 343) were primary caregivers of individuals with spinal cord injury (SCI; n = 40), dementia (n = 102), traumatic brain injury (TBI; n = 120), and multiple sclerosis (MS; n = 81) from Guadalajara, Mexico, as well as Neiva, Bogota, and Barranquilla, Colombia. Participant inclusion and exclusion criteria were as follows: (a) participants were the primary caregiver of the person with a neurological condition; (b) were at least 18 years old; (c) had been providing care to the person with the neurological condition for at least three months; (d) and had no personal history of neurological problems. All caregivers provided care to a patient who had a confirmed diagnosis of dementia, SCI, MS, or TBI via medical record reviews.

For a summary of participant demographics, see Table 1. Caregivers had an average age of 48.50 (SD = 15.76), and an average education of 8.87 years (SD = 4.83). The majority of caregivers were female (81.9%).

Measures

Caregivers completed a sequence of surveys which evaluated the following constructs: sociodemographics, family needs (household, informational, financial, health, and social support), and psychosocial functioning (burden, depression, satisfaction with life, mental healthrelated quality of life). All measures were previously translated to Spanish and validated in Spanish-speaking populations.

Family Needs. The Spanish Family Needs Assessment Tool (FNAT) is a 14-item measure of family needs of Spanish-speaking caregivers with responses ranging from 1 (strongly

disagree) to 5 (strongly agree) and higher scores indicate more need (Rivera, Perrin, Senra, & Arango-Lasprilla, 2013). The scale was created and validated among a sample of caregivers of individuals with neurological conditions in Latin America, and demonstrates adequate overall internal consistency ($\alpha = .72$). Subscales assessed household, informational, financial, health (related to independence), and social support needs. Examples of questions from the subscales (translated here into English) are as follows: household, "I need help with housework," informational, "I need to discuss my feelings with someone who has gone through the same experiences," financial, "I need financial help," health, "I can regularly exercise," and social support, "I get support from my church" (Rivera et al., 2013).

Depression. The Patient Health Questionnaire-9 (PHQ-9), a nine-item module of the Patient Health Questionnaire, was used to measure caregiver depression (Kroenke, Spitzer, & Williams, 2001). Respondents were asked to indicate how often they had been bothered by each item on a 4-point Likert-type scale, with response options ranging from 0 (not at all) to 3 (nearly every day). Response scores are totaled and range from 0 to 27, with higher scores reflecting higher levels of depression (Kroenke et al., 2001). A score of 0 to 4 indicates no depression, 5 to 9 mild depression, 10 to 14 moderate depression, 15 to 19 moderately severe depression, and 20 to 27 severe depression. The Spanish version utilized in this study (Wulsin, Somoza, & Heck, 2002), has demonstrated good criterion, construct validity, (Diez-Quevado, Rangil, Sanchez-Planell, Kroenke, & Spitzer, 2001) and convergent validity, as well as excellent internal consistency ($\alpha = .92$) in assessing depression in Spanish speakers (Donlan & Lee, 2010).

Satisfaction with Life. The Satisfaction with Life Scale (SWLS) is a 5-item self-report scale used to measure global satisfaction with life (Pavot & Diener, 1993). Individuals respond to items such as "I am satisfied with life" with item responses ranging from 1 (strongly disagree) to

7 (strongly agree). Total score ranges from 5 to 35, where higher scores indicate higher life satisfaction. The SWLS has demonstrated good construct validity (Pavot & Diener, 1993), and good internal consistency ($\alpha = .82$) in a sample of Colombian dementia caregivers with the Spanish version of this scale (Arango-Lasprilla, Moreno, Rogers, & Francis, 2009).

Mental Health-Related Quality of Life. The Short Form-36 (SF-36) is a self-report health questionnaire used to assess health-related quality of life (Stewart & Ware, 1992). This scale consists of 36 items, with possible responses ranging from 0-100, and higher scores indicating better health-related quality of life. Eight subscales examine different health-related quality of life dimensions: physical functioning, role limitations due to emotional problems, role limitations due to physical problems, bodily pain, vitality, social functioning, emotional wellbeing, and general health (Stewart & Ware, 1992).

For the purposes of the current study, three dimensions tapping mental health-related quality of life will be used to represent the aspects of mental health relating to energy (vitality), social functioning, and impairment due to poor emotional functioning (role-emotional). The subscale of vitality taps levels of participants' energy by presenting the stem, "How much during the past 4 weeks" to which participants rate each item (e.g., "did you have a lot of energy") from 1 (all of the time) to 6 (none of the time) (Stewart & Ware, 1992). To assess social functioning, participants responded from 1 (all of the time) to 5 (none of the time) to items such as, "During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (e.g., visiting friends, relatives)?" (Stewart & Ware, 1992). Finally, to assess role limitations due to emotional problems (role-emotional), participants were presented with the stem, "During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as

feeling depressed or anxious)?" Participants respond to items such as, "Didn't do work or other activities as carefully as usual" with either 1 (yes) or 2 (no) (Stewart & Ware, 1992)."

The Spanish version of the SF-36 has demonstrated acceptable to excellent internal consistency, with subscale Cronbach's alphas ranging from .70 to .90 (Ayuso-Mateos et al., 1999), and has been utilized in a sample of caregivers of individuals with dementia from Mexico (Arango-Lasprilla et al., 2010b). Concurrent validity has been supported with correlations between the Spanish version of the SF-36 and a valid and reliable Spanish measure of general mental health (Ayuso-Mateos et al., 1999). Construct validity has been demonstrated via lower scores on the Spanish version of the SF-36 in participants who reported experiencing long-term illness or a medical consultation in the month prior to completing the SF-36 (Ayuso-Mateos et al., 1999).

Caregiver Burden. The Zarit Burden Interview (ZBI) was used to measure caregiver burden (Zarit, Reever, & Bach-Peterson, 1980). It is a 22-item, self-report questionnaire that evaluates the caregiver's health condition, psychological well-being, finances, and social life in the context of the caregiver-patient relationship. Responses are on a 5-point Likert-type scale ranging from 0 (never) to 4 (nearly always), and item scores are summed to obtain a total score that ranges from 0 to 88. Participants respond to the stem "Do you feel..." with items such as, "strained when you are around your relative?" and, "you could do a better job in caring for your relative?" (Zarit et al., 1980). Higher scores indicate greater levels of caregiver burden. The following categories have been developed to identify little to severe caregiver burden: 0-20 indicates little or no burden, 21-40 reflects mild to moderate burden, 41-60 moderate to severe burden, and 60-88 severe levels of burden (Zarit et al., 1980). The Spanish version of the ZBI

utilized in this study has demonstrated good construct validity and internal reliability ($\alpha = .92$) (Martin et al., 2006).

Procedure

Participants were recruited from Neiva, Bogota, and Barranquilla, Colombia, and Guadalajara, Mexico. Potential participants were contacted either in-person or by telephone, screened for eligibility, and informed about the purpose of the study. Caregivers who consented to participate and met the criteria for the study were asked to fill out several questionnaires, either during a home-visit by research assistants or filled out paper-and-pencil questionnaires. Questionnaires consisted of scales measuring their levels of burden, depression, satisfaction with life, health related-quality of life, and family needs. All caregivers completed a survey of sociodemographic information as well as history of medical and/or neurological problems. Procedures were approved through the ethics committees of Surcolombiana University in Neiva, the Central Police Hospital in Bogota, the Universidad del Norte in Barranquilla, the Hospital Civil Fray Antonio Alcade in Guadalajara, and the Mexican Foundation for Multiple Sclerosis in Guadalajara.

Recruitment. Individuals with SCI were identified using a database from the Foundation for the Integral Development of People with Disabilities in Colombia. From this database, a list of individuals with SCI and their caregivers were identified in Neiva, Colombia. Dementia caregivers from Bogota, Colombia were recruited from the Memory Clinic of the Central Police Hospital where a research assistant approached and screened potential participants for eligibility. Individuals with TBI from Barranquilla, Colombia were identified from the Clinica Cervantes Hospital in Barranquilla and from the Hospital Civil Fray Antonio Alcade in Guadalajara, Mexico. Caregivers of individuals with MS from Guadalajara, Mexico were recruited from the

Mexican Foundation for Multiple Sclerosis and the Department of Neurosciences of the University Center for Health Sciences, University of Guadalajara, Mexico.

Data Analysis Plan

Preliminary analyses. To determine whether caregivers of individuals with dementia, TBI, SCI, and MS differ significantly on demographic variables, a sequence of analyses of variance (ANOVAs) and chi-square tests were conducted with the neurological groups (dementia vs. TBI vs. SCI vs. MS) as the independent variable, and demographic variables as the dependent variables. ANOVAs were conducted for education level, age, and hours per week spent caregiving, and a chi-square will be conducted for gender. For the analyses in which there are significant differences in demographics between neurological groups, the demographic variables were added as covariates in the subsequent analyses (multivariate analyses of covariance [MANCOVA] only) to control for the differences.

Hypothesis testing. First, three MANCOVAs were used to examine whether (1) unmet family needs and (2) caregiver burden and mental health variables differ by neurological group. Second, a series or canonical correlation analyses will be used to test the connections between (a) unmet family needs and caregiver mental health; (b) unmet family needs and caregiver burden; and (c) caregiver burden and mental health.

Multivariate Analyses of Covariance. A MANCOVA is a statistical test that compares two or more groups on a series of continuous dependent variables simultaneously, effectively controlling for family-wise error. To test the first two hypotheses, two MANCOVAs was run to examine differences between neurological groups on caregiver burden and mental health variables, as well as family needs. The independent variable was neurological group (dementia vs. TBI vs. SCI vs. MS), and the first set of dependent variables was caregiver burden (effect on

the social and personal life, psychological burden and feelings of guilt). The second set of dependent variables was caregiver mental health (depression, satisfaction with life, vitality, roleemotional, and social functioning). And the final set of dependent variables was family needs (financial, household, health, informational, and social support needs).

In the MANCOVAs, demographic variables previously shown to differ among caregiver groups were added as covariates. Given an overall omnibus effect of neurological group, Holm– Bonferroni-corrected ANOVAs (Holm, 1979) were conducted to distinguish the particular significant effect where the independent variable is neurological group and the dependent variables are (a) caregiver burden, (b) caregiver mental health, and (c) family needs. Then, posthoc Holm–Bonferroni-corrected multiple comparison tests determined the exact location of the individual differences among neurological groups on each dependent variable.

Hypothesis 1. Levels of caregiver mental health (depression, satisfaction with life, vitality, social functioning, and role-emotional) will significantly vary among the care-receiver's neurological disorder type. To test these differences, a MANCOVA and follow-up ANCOVAs and multiple comparison tests was computed between neurological disorders. Compared to other caregivers, dementia caregivers were expected to have worse mental health (Hooker et al., 1998). AD caregivers have reported more depression than stroke caregivers, and therefore, dementia caregivers were expected to have higher depression (Wright et al., 1999).

Hypothesis 2. Levels of family needs will significantly vary among the care-receiver's neurological disorder type. The same method described above was used to compute differences between neurological disorders. Dementia caregivers have reported more problems with employment, as well as spending less time on leisure activities and other family members (Ory et

al., 1999). Thus, dementia caregivers were expected to express more social support, financial, and household support needs than the other caregivers.

Hypothesis 3. Levels of caregiver burden (effect on the social and personal life, psychological burden and feelings of guilt) will significantly vary among the care-receiver's neurological disorder type. To test these differences, a MANCOVA and follow-up ANCOVAs and multiple comparison tests were computed between neurological disorders. When dementia caregivers have been compared to non-dementia caregivers, they report more strain and more hours per week spent caregiving (Ory et al., 1999). Therefore, dementia caregivers are expected report the highest levels of caregiver burden.

Canonical correlations. To examine hypotheses 3, 4, and 5, three separate canonical correlation analyses (CCA) were performed. CCA is a statistical test that extracts the shared variance between two sets of variables (i.e., two canonical variates). Standardized canonical loadings from each variable on its canonical variate are used to identify the strength of that variable's contribution to the canonical variate, and as a result to the overall correlation between the two sets of variables (Sherry & Henson, 2005). CCA generates a number of canonical correlations equivalent to the number of variables in the smallest variable set, and each canonical correlation controls for the shared variance from the preceding correlations. The first canonical correlation is the largest. Successive canonical correlations indicate gradually smaller amounts of unique shared variance between the two variables sets, and often indicate associations between error variance of the two variable sets; therefore, only the first canonical correlations are reported for each analysis. The CCAs will be conducted using SPSS 22.0 (IBM, 2014).

Hypothesis 4. More unmet family needs will be associated with decreased caregiver mental health (Figure 1). A CCA was computed between the two variables sets (family needs

and caregiver mental health). Family needs is comprised of shared variance of five observed variables (financial, household, health, informational, and social support needs). Caregiver mental health is comprised of the shared variance among five observed variables (depression, satisfaction with life, social functioning, vitality, and role-emotional).



Figure 1. Conceptual model of proposed CCA of the relationship between family needs and caregiver (CG) mental health.

Hypothesis 5. Unmet family needs will be associated with increased caregiver burden. CCA was conducted in the same manner as above using the same five family needs variables and the three dimensions of caregiver burden (effect on the social and personal life, psychological burden and feelings of guilt; Figure 2).



Figure 2. Conceptual model of proposed CCA of the relationship between family needs and caregiver (CG) burden.

Hypothesis 6. Increased caregiver burden will be associated with reduced caregiver mental health. A CCA was conducted using the same five mental health variables and the three facets of caregiver burden (Figure 3).



Figure 3. Conceptual model of proposed CCA of the relationship between caregiver (CG) burden and mental health.
Characteristics of Caregivers.

Demographic Variable	Value
Place of residence, n (%)	
Neiva, Colombia	40 (11.7)
Bogota, Colombia	102 (29.7)
Barranquilla, Colombia	30 (8.7)
Guadalajara, Mexico	171 (49.8)
Neurological disorder, n (%)	
TBI	120 (34.9)
SCI	40 (11.7)
MS	81 (23.6)
Dementia	102 (29.7)
Sex, <i>n</i> (%)	
Male	62 (18.1)
Female	281 (81.9)
Age, years, $M(SD)$	48.50 (15.76)
Education, years, $M(SD)$	8.87 (4.83)

Note. TBI = Traumatic brain injury; SCI = Spinal cord injury; MS = Multiple sclerosis.

Results

Preliminary analyses

Descriptive Statistics. The means and standard deviations for all study variables appear in Table 3. Based on the cutoffs established by the authors of the Patient Health Questionnaire-9 (PHQ-9; Kroenke et al., 2001), over half the caregivers in this sample (56.7%) were experiencing clinically significant levels of depression, of whom 29.2% reported mild depression, 18.9% moderate depression, 6.8% moderately severe depression, and 1.8% severe depression. However, 43.4% did not have clinically significant depression symptoms. Using the categories set by the authors of the Zarit Burden Interview (ZBI; Zarit et al., 1980), over half of the caregivers experienced burden (62.8%), where 5.1% reported experiencing severe burden, 23.6% indicated moderate to severe burden, and 34.1% reported mild to moderate burden. Approximately onethird of caregivers reported experiencing little or no burden (38.7%). Based on the classification scheme for the Satisfaction with Life Scale (SWLS; Pavot & Diener, 1995), over one-third of caregivers were dissatisfied with life to some degree with 14.0% of caregivers were classified as being extremely dissatisfied with life, 14.5% as dissatisfied, 9.9% as slightly dissatisfied, 3.8% were neutral, 13.6% as slightly satisfied, 36.4% as satisfied, and 7.6% as extremely satisfied.

Normality Assumptions. Normality assumptions were checked prior to running the primary analyses. The mental health, burden, and family needs subscales met the criteria for skewness and kurtosis of an absolute value of 2.0. Mahalanobis distance had a value of 12.26, suggesting there were no multivariate outliers. Tolerance and VIF values were used to assess multicollinearity. Tolerance values ranged from .74 to .91, and VIF values ranged from 1.10 to 1.35, indicating the absence of multicollinearity. Additionally, no multicollinearity was observed

Bivariate Correlations, Means, and Standard Deviations for Scores on the ZBI Subscales, PHQ-9, SWLS, SF-36 Subscales, and Family Needs Subscales

	1	2	3	4	5	6	7	8	9	10	11	12	13
1. ZBI-Personal Life	-												
2. ZBI-Psychological	.81***	-											
3. ZBI-Guilt	.44***	.46***	-										
4. PHQ-9	.43***	.45***	.38***	-									
5. SWLS	22***	19***	42***	46***	-								
6. Social Functioning	43***	39***	21***	52***	.34***	-							
7. Vitality	37***	36***	34***	58***	.49***	.56***	-						
8. Role-Emotion	28***	28***	22***	44***	.33***	.60***	.53***	-					
9. Household Needs	.38***	.32***	.14**	.29***	-0.05	22***	15**	16**	-				
10. Informational Needs	.21***	.20***	.29***	.20***	17**	14*	23***	15**	0.08	-			
11. Financial Needs	.25***	.23***	.49***	.42***	54***	25***	35***	21***	.20***	.29***	-		
12. Health Needs	.31***	.30***	.27***	.31***	37***	28***	41***	25***	.13*	.17**	.36***	_	
13. Social Support Needs	0.06	0.07	.20***	.18**	44***	13*	29***	-0.10	15**	-0.08	.23***	.24***	-
М	5.58	5.25	6.30	6.65	21.55	72.14	55.21	58.75	5.25	11.58	9.55	10.62	7.55
SD	5.74	4.70	3.78	5.23	8.75	21.91	19.38	44.20	2.25	2.47	3.29	2.83	2.06

Note. ZBI = Zarit Burden Inventory; PHQ-9 = Patient Health Questionnaire; SWLS = Satisfaction with Life Scale; SF-36 = Short Form 36. *p < .05, *p < .01, *p < .001.

at the .70 level by examining bivariate correlations (Table 3). Appropriate and normal distribution of residual scatterplots was observed.

Tests of Covariates. To determine whether caregivers of individuals with dementia, TBI, SCI, and MS differed significantly on demographic variables, a sequence of analyses of variance (ANOVAs) and chi-square tests was conducted with type of neurological group (dementia, TBI, SCI, or MS) as the independent variable, and demographic variables as the dependent variables. ANOVAs were conducted for years of education, age, and hours per week spent caregiving, and a chi-square was conducted for gender.

The ANOVAs for hours per week spent caregiving, age, and years of education were all significantly different by neurological group [F(3, 339) = 57.70, p < .001; F(3, 339) = 23.45, p < .001; and F(3, 339) = 19.77, p < .001, respectively]. Post-hoc Bonferroni-corrected multiple comparison tests indicated the exact location of the differences among neurological groups and continuous demographic variables (i.e., education, age, and hours per week spent caregiving; Table 4). Dementia caregivers were significantly older and reported significantly more hours per week spent caregiving than all other caregivers. For education, MS caregivers had significantly higher education compared to all other caregivers, and dementia caregivers had significantly fewer hours per week spent caregiver than SCI and dementia caregivers.

The chi-square test for gender was also significant, $\chi^2(3) = 20.01$, p < .001. Post-hoc chisquare tests were conducted between each pair of neurological group and gender (Table 5). TBI caregivers had significantly more women than men compared to MS and dementia caregivers, and MS caregivers had more men than SCI and dementia caregivers, on average. Therefore, all demographic variables were used as covariates in the subsequent MANCOVAs.

Means, Standard Deviations, and Mean Differences of Continuous Caregiver Demographics by

Neu	rolog	gical	Group
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			1	2	3
	М	SD	Ν	Iean Differen	ce
1. TBI					
Education	6.81	4.07			
Age	44.88	13.99	—		
Hours/Week CG	54.08	35.91			
2. SCI					
Education	8.53	4.41	1.72		
Age	44.28	16.39	-6.1	_	
Hours/Week CG	80.83	46.30	26.75*		
3. MS					
Education	11.74	4.42	4.93***	3.22**	
Age	43.37	15.32	-1.51	91	_
Hours/Week CG	69.01	55.90	14.94	-11.81	
4. Dementia					
Education	9.14	4.975	2.33**	.61	-2.60**
Age	58.49	13.27	13.61***	14.22***	15.12***
Hours/Week CG	135.25	53.27	81.17***	54.42***	66.23***

Note. TBI = Traumatic Brain Injury; SCI = Spinal Cord Injury; MS = Multiple Sclerosis; CG = Caregiving. A negative mean difference indicates that the respective neurological condition in the first column is greater than the respective neurological group in the first row. *p < .05, ** p < .01, *** p < .001.

p-values were adjusted using Bonferroni's correction (alpha = $1 - 0.95^{1/N}$).

Chi-Square Tests of Neurological Groups and Gender

		1	2	3
	n		χ^2	
1. TBI				
Man	11	—		
Woman	109			
2. SCI		.37		
Man	5		_	
Woman	35			
3. MS		18.42***	5.98*	
Man	27			_
Woman	54			
4. Dementia		4.22*	.77	5.12*
Man	19			
Woman	83			

Note. TBI = Traumatic brain injury; SCI = Spinal cord injury; MS = Multiple sclerosis *p < .05, ***p < .001.

Multivariate Analyses of Covariance (MANCOVAs)

Differences in Caregiver Mental Health. A MANCOVA was used to examine the first hypothesis that the levels of caregiver mental health (depression, SWL, role-emotional, vitality, and social functioning) would significantly vary by the care-receiver's neurological disorder type.

The caregiver mental health variables were entered as dependent variables into the first MANCOVA, and a statistically significant Box-M test for homogeneity of the variancecovariance matrices across design cells, Box-M = 114.10, F(45, 92371.74) = 2.45, p < .001, with three significant Levene's tests (ps < .021) and two non-significant Leven's test for vitality and social functioning (ps > .262) provided multivariate and univariate support for the heterogeneity of variance, suggesting that a more conservative estimate of the *F*-statistic should be used, such as Pillai's Trace. The overall omnibus MANCOVA revealed a statistically significant effect for neurological group, Pillai's Trace = .293, F(15, 993) = 7.17, p < .001, $\eta^2 =$.098. As a result, five follow-up univariate analyses of covariance (ANCOVAs), controlling for demographic differences, were run to identify the location of the significant differences of mental health among neurological groups. In each of these ANCOVAs, the independent variable was neurological condition, and the dependent variables were each of the five caregiver mental health variables in the omnibus MANCOVA. The Holm-Bonferonni correction was utilized to control for family-wise error. As such, the alpha levels were .05, .025, .017, .013, and .01, respectively. Depression, SWL, role-emotional, vitality, and social functioning all indicated statistically significant differences among neurological groups [F(3, 335) = 10.95, p < .001, $\eta^2 = .09$; F(3, 335) = 25.31, p < .001, $\eta^2 = .19$; F(3, 333) = 6.92, p < .001, $\eta^2 = .06$; F(3, 333) = 18.22, p < .001, $\eta^2 = .14$; and F(3, 333) = 6.62, p < .001, $\eta^2 = .06$, respectively].

A follow-up series of Holm-Bonferroni-corrected ANCOVAs were conducted to determine the exact location of the differences of caregiver mental health among neurological groups. The alpha levels for the 30 comparisons between groups are presented in Table 6. Means and standard deviations of mental health variables by neurological group are presented in Table 7, and the effect size as well as statistic significance of each comparison among mental health variables are presented in Table 8.

TBI caregivers had significantly higher scores of depression and lower scores on role limitations due to emotional problems compared to all other caregiving groups. TBI caregivers also had lower scores of social functioning and vitality compared to SCI and dementia caregivers. TBI caregivers reported the lowest SWL scores, followed by SCI caregivers, MS caregivers, and finally dementia caregivers. The remaining comparisons were not significantly different.

Table 5

No. of	a
Comparisons	u
1	0.0500
2	0.0250
3	0.0167
4	0.0125
5	0.0100
6	0.0083
7	0.0071
8	0.0063
9	0.0056
10	0.0050
11	0.0045
12	0.0042
13	0.0038
14	0.0036
15	0.0033
16	0.0031
17	0.0029
18	0.0028
19	0.0026
20	0.0025
21	0.0024
22	0.0023
23	0.0022
24	0.0021
25	0.0020
26	0.0019
27	0.0019
28	0.0018
29	0.0017
30	0.0017

Holm-Bonferroni Alpha Levels

Note. Alpha = $1 - 0.95^{1/a}$ ^aNumber of comparisons.

	TRI	SCI	MS	Dementia
	IDI	SCI	WIS	Dementia
Variable	M(SD)	M(SD)	M(SD)	M(SD)
CG Mental Health				
PHQ-9	8.73 _{abc} (5.32)	$6.15_{a}(5.53)$	5.93 _{bd} (5.27)	4.97 _{cd} (4.12)
SWLS	15.44 _{ab} (8.26)	$20.43_{\rm c}$ (9.45)	22.60 _{ad} (6.81)	28.32 _{bcd} (3.98)
Role-Emotional	43.61 _{abc} (41.40)	72.50 _a (39.14)	69.96 _b (39.30)	62.33 _c (48.24)
Vitality	45.63 _{ab} (17.79)	66.50 _{ac} (18.99)	58.02 _c (19.66)	59.90 _b (16.22)
Social Functioning	65.83 _{ab} (20.35)	81.56 _a (22.11)	75.62 (20.63)	73.13 _b (22.78)
Family Needs				
Informational	11.80 (2.40)	12.18 (2.84)	10.74 (3.42)	11.76 (0.87)
Household	5.17 (2.37)	5.30 (2.34)	4.90 (2.47)	5.60 (1.84)
Financial	11.53 _{ab} (2.70)	10.85 _c (3.87)	8.26 _a (3.45)	7.75 _{bc} (1.69)
Health	11.68 _{ab} (3.17)	9.40 _{ac} (2.51)	9.09 _{bd} (2.94)	11.09 _{cd} (1.42)
Social support	8.58 _{abc} (1.83)	$7.18_{a}(2.12)$	7.47 _{bd} (2.54)	6.53 _{cd} (1.12)
CG Burden				
ZBI-Personal Life	6.78 _{ab} (5.03)	$3.55_{a}(4.32)$	2.74 _b (3.72)	7.24 (7.13)
ZBI-Psychological	5.58 (4.10)	3.93 (3.83)	3.90 (3.93)	6.44 (5.77)
ZBI-Guilt	8.17 _a (3.13)	6.15 (4.03)	5.42 (3.83)	$4.86_{a}(3.46)$

Note. Means within a row sharing the same subscript letter were significantly different. TBI = Traumatic brain injury; SCI = Spinal cord injury; MS = Multiple sclerosis; CG = Caregiver; ZBI = Zarit Burden Inventory; PHQ-9 = Patient Health Questionnaire; SWLS = Satisfaction with Life Scale.

	1	2	3
		Partial η^2	
1. TBI	_		
2. SCI			
PHQ-9	.05**		
SWLS	.03		
Role-Emotional	.08***	—	
Vitality	.17***		
Social Functioning	.10***		
3. MS			
PHQ-9	.04**	.01	
SWLS	.07***	.00	
Role-Emotional	.06**	.01	—
Vitality	.03	.10**	
Social Functioning	.02	.05	
4. Dementia			
PHQ-9	.13***	.03	.07***
SWLS	.23***	.12***	.15***
Role-Emotional	.06***	.00	.00
Vitality	.13***	.00	.04
Social Functioning	.04**	.00	.02

Effect Sizes among Caregiver Mental Health and Neurological Groups

Note. TBI = Traumatic Brain Injury; SCI = Spinal Cord Injury; MS = Multiple Sclerosis; CG = Caregiving; PHQ-9 = Patient Health Questionnaire; SWLS = Satisfaction with Life Scale. ** p < .01, *** p < .001.

p-values were adjusted using Holm-Bonferroni's correction (alpha = $1 - 0.95^{1/a}$). ^aNumber of comparisons.

Differences in Family Needs. A MANCOVA was used in the same manner as above to

examine the second hypothesis that the levels of family needs (informational, social, financial,

health, and household support) would significantly vary by the care-receiver's neurological

disorder type.

The family needs variables were entered as dependent variables into the second

MANCOVA, and a statistically significant Box-M test for homogeneity of the variance-

covariance matrices across design cells, Box-M = 401.82, F(45, 92225.52) = 8.64, p < .001, with five significant Levene's tests (ps < .036) provided evidence for the heterogeneity of variance as with caregiver mental health; thus the more conservative estimate of the *F*-statistic, Pillai's Trace, was used. The overall omnibus MANCOVA revealed a statistically significant effect for neurological group, Pillai's Trace = .383, F(15, 999) = 9.75, p < .001, $\eta^2 = .128$. Five follow-up univariate analyses of covariance (ANCOVAs), in the same manner as the previous analysis, were run to identify the location of the significant differences of family needs among neurological groups. Informational, financial, health, and social support needs indicated statistically significant differences among neurological groups [F(3, 335) = 3.47, p = .016, $\eta^2 = .03$; F(3, 335) = 20.32, p < .001, $\eta^2 = .15$; F(3, 335) = 11.83, p < .001, $\eta^2 = .10$; and F(3, 335) = 16.74, p < .001, $\eta^2 = .13$, respectively].

A follow-up series of Holm-Bonferroni-corrected ANCOVAs were conducted to determine individual differences among caregiver mental health and the four neurological groups. Means and standard deviations of family needs variables by neurological group are presented in Table 7; and the effect size as well as statistical significance of each comparison among family needs variables are presented in Table 9.

TBI caregivers reported significantly more social support needs than all other caregivers, more financial needs than MS and dementia caregivers, and more health needs than SCI and MS caregivers. Additionally, SCI caregivers reported more financial needs and less health needs than dementia caregivers. Finally, MS caregivers reported more social support needs and less health needs than dementia caregivers. The remaining comparisons were not significantly different.

Effect Sizes amon	g Family	Needs and N	leurological	Groups
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	1	2	3
		Partial η^2	
1. TBI	_		
2. SCI			
Household	.00		
Informational	.00		
Financial	.00	—	
Health	.06**		
Social Support	.07**		
3. MS			
Household	.01	.04	
Informational	.00	.00	
Financial	.08***	.04	—
Health	.04**	.00	
Social Support	.04**	.00	
4. Dementia			
Household	.01	.01	.04
Informational	.00	.01	.00
Financial	.24***	.16***	.04
Health	.00	.11***	.06**
Social Support	.14***	.02	.07***

Note. TBI = Traumatic Brain Injury; SCI = Spinal Cord Injury; MS = Multiple Sclerosis; CG = Caregiving. ** *p* < .01, *** *p* < .001.

p-values were adjusted using Holm-Bonferroni's correction (alpha = $1 - 0.95^{1/a}$). ^aNumber of comparisons.

Differences in Caregiver Burden. A third MANCOVA was used to examine the third

hypothesis that the levels of caregiver burden (effect on the social and personal life,

psychological burden and feelings of guilt) would significantly vary by the care-receiver's

neurological disorder type.

The three caregiver burden variables were entered as dependent variables into the

MANCOVA, and a statistically significant Box-M test for homogeneity of the variance-

covariance matrices across design cells, Box-M = 75.01, F(18, 119280.82) = 4.09, p < .001,

with two significant Levene's tests (ps < .001) and one non-significant Leven's test for guilt (p = .061) provided multivariate and univariate support for the heterogeneity of variance, suggesting that a more conservative estimate of the F-statistic should be used, such as Pillai's Trace. The overall omnibus MANCOVA revealed a statistically significant effect for neurological group, Pillai's Trace = .170, F(9, 1005) = 6.70, p < .001, $\eta 2 = .057$. As a result, three follow-up univariate analyses of covariance (ANCOVAs), controlling for demographic differences, were run to identify the location of the significant differences in caregiver burden among neurological group, and the dependent variables were each of the three caregiver burden variables in the omnibus MANCOVA. The Holm-Bonferonni correction was utilized to control for family-wise error. As such, the alpha levels were .05, .025, and .017, respectively. Guilt and personal life showed statistically significant differences among neurological groups. The results of these ANCOVAs

A follow-up series of Holm-Bonferroni-corrected ANCOVAs were conducted to determine individual differences among caregiver burden and the four neurological groups. Means and standard deviations of burden variables by neurological group are presented in Table 7. TBI caregivers reported more burden in personal life compared to SCI and MS caregivers, as well as more guilt related burden than dementia caregivers. The remaining comparisons were not significantly different.

	1	2	3
]	Partial η^2	
1. TBI	—		
2. SCI			
ZBI-Personal Life	.09***		
ZBI-Psychological	.03	-	
ZBI-Guilt	.03		
3. MS			
ZBI-Personal Life	.09***	.00	
ZBI-Psychological	.01	.01	_
ZBI-Guilt	.03	.00	
4. Dementia			
ZBI-Personal Life	.01	.02	.04
ZBI-Psychological	.01	.01	.00
ZBI-Guilt	.09***	.03	.01

Effect Sizes among Caregiver Burden and Neurological Groups

Note. TBI = Traumatic Brain Injury; SCI = Spinal Cord Injury; MS = Multiple Sclerosis; CG = Caregiving; ZBI = Zarit Burden Inventory. *** p < .001. p-values were adjusted using Holm-Bonferroni's correction (alpha = 1 - 0.95^{1/a}).

^aNumber of comparisons.

Canonical Correlations

Family Needs and Caregiver Mental Health. The first canonical correlation was .68

(46.8% overlapping variance), $\lambda = .45$, $\chi^2(25) = 268.67$, p < .001. Standardized canonical coefficients were used to examine the relative contribution of each variable to the overall canonical correlations. In the first canonical correlation, the standardized canonical coefficients for the family needs variables showed that financial needs loaded most highly (-.546), followed by social support (-.463), health (-.299), informational (.165), and household needs (-.105). Because the coefficients reflecting financial and social support needs were above the conventional cutoff of .40, these will be focused on for interpretation. For the caregiver mental health variables, satisfaction with life loaded most highly (.717), followed by vitality (.306),

depression (.213), role limitations due to emotional problems (-.083), and social functioning (-.009). This pattern of shared variance suggests that caregivers experience higher satisfaction with life when they had reduced financial and social support needs.

Family Needs and Caregiver Burden. The second canonical correlation was .56 (31.4% overlapping variance), $\lambda = .59$, $\chi^2(15) = 178.34$, p < .001. In the first canonical correlation, the standardized canonical coefficients for the family needs variables showed that financial needs once again loaded most highly (-.516), followed by household (-.360), informational (-.313), health (-.288), and social support needs (-.192). Because the coefficient reflecting financial needs was above the conventional cutoff of .40, this will be focused on for interpretation. For the caregiver burden variables (guilt, psychological, and personal life), burden–personal life loaded most highly (-.718), followed by burden–guilt (-.440), and finally burden–psychological (-.009). This pattern of shared variance suggests that caregivers experience more guilt and report more consequences in their everyday social and personal life, privacy, and friendships when they had more financial needs.

Caregiver Burden and Mental Health. The third canonical correlation was .54 (29.2% overlapping variance), $\lambda = .61$, $\chi^2(15) = 166.38$, p < .001. In the first canonical correlation, the standardized canonical coefficients for the caregiver mental health variables showed that depression loaded most highly (.568), followed by social functioning (.268), vitality (.233), satisfaction with life (.165), and role limitations-emotional (-.012). For the caregiver burden variables, burden–personal life loaded most highly (-.433), followed by burden–guilt (-.436), and finally burden–psychological (-.321). This pattern of shared variance suggests that caregivers experience more depression when they report more guilt as well as increased consequences in their everyday social and personal life, privacy and friendships.

Discussion

The present study examined differences in family needs (informational, social, financial, health, and household support), caregiver mental health (depression, satisfaction with life [SWL], vitality, social functioning, and emotional role limitations), and caregiver burden (personal life, guilt, and psychological) among caregivers of individuals with traumatic brain injury (TBI), spinal cord injury (SCI), multiple sclerosis (MS), and dementia from cities in Colombia and Mexico. The study also assessed the patterns of shared variance among family needs, caregiver mental health, and caregiver burden in the combined sample of caregivers of individuals with neurological conditions.

Differences in Variables by Neurological Condition

Mental Health. As hypothesized, caregiver mental health significantly varied by the care-recipients' neurological disorder type. It was also hypothesized that dementia caregivers would have worse mental health compared to others, and more specifically, that dementia caregivers would report higher depression. In the opposite direction of what was expected, dementia caregivers had the highest SWL in comparison to all other caregivers. This was in direct contrast to previous research that has found dementia caregivers to experience the most significant mental health problems out of various types of caregivers (Pinquart & Sorensen, 2003). Additionally, Latino dementia caregivers in the US in particular have been shown to have high rates of mental health problems (Strong & Mast, 2013; Epstein-Lubow et al., 2012).

One reason why the findings from the current study in particular may have diverged from those in previous studies is that Latino communities have culturally informed roles for caring for elders (*respeto;* Neary & Mahoney, 2005); thus, family members who provide care for a parent or older relative with dementia may see this role as an opportunity for passing along and

behaving in accordance with cherished cultural values. Moreover, caring for family can be gratifying, meaningful, and in some cases can actually increase life satisfaction among caregivers (Grant et al., 1993; Nolan et al., 1992). Given this and the cultural value of *respeto*, dementia caregivers in Latin America in the current study may have cultivated meaning within their caregiving role, resulting in increased SWL.

Instead of what was hypothesized, TBI caregivers generally had the lowest mental health, with worse depression and role-limitations due to emotional problems compared to all other caregivers. Additionally, TBI caregivers had lower SWL than MS and dementia caregivers, as well as lower social functioning and vitality than SCI and dementia caregivers. TBI caregivers also reported worse mental health on the majority of indices in comparison to SCI caregivers. This pattern of findings for TBI caregivers may be due to impairments associated with the respective conditions. TBI is often accompanied with behavioral and affective changes, such as emotional outbursts and irritability (Lundin et al., 2006), whereas SCI for example often involves physical disability within the care-recipient (NINDS, 2013b). As a result, the burden of care may be especially high for TBI caregivers as they have to deal with behavioral impairments, affecting their ability to interact socially within their community. Indeed, TBI caregivers often struggle with integrating their family members back into the community after injury (Rotondi et al., 2007) and face stigma with regards to the care-recipients' behavioral problems (Simpson, Mohr, & Redman, 2000), which may result in reduced social functioning more generally.

In contrast to previous findings that Alzheimer caregivers reported more depression than stroke caregivers (Wright et al., 1999), MS and dementia caregivers in the current study had better mental health than TBI caregivers. The progression of the neurological conditions may affect the caregivers' ability to adjust psychologically to their new role as caregivers, as TBI and

the resulting impairments occur suddenly, whereas the impairments of dementia and MS increase over time, often years. This sudden vs. longer term progression may influence the appraisal of caregiving roles and the speed with which caregivers must adjust to their new roles, which may influence caregiver mental health. TBI more often occurs among younger individuals (Faul et al., 2010), whereas dementia and MS are acquired developmentally later in life (AA, 2012; Dutta & Trapp, 2007). While caregivers of dementia and MS may have time to anticipate their role as caregivers, TBI caregivers have to quickly adjust to their new roles. The differences in impairments may also partially explain why MS caregivers had lower vitality than SCI caregivers. This may be due to the fact that MS can have cognitive and behavioral impairments, especially in the advanced stages, which may result in greater care responsibilities, and lower vitality in MS caregivers than SCI caregivers. However, further research is needed to better understand the mechanisms underpinning these differences.

Finally, MS caregivers reported significantly greater depression symptoms than dementia caregivers. This is surprising in light of previous research, which has found that depression symptoms are particularly prevalent in both dementia (Strong & Mast, 2013) and MS caregivers (Pakenham, 2001). This finding is in the opposite direction of what was predicted, but as with the finding mentioned above of the highest satisfaction with life in dementia caregivers, the cultural value of *respeto* may be operating with this depression comparison as well, such that dementia caregivers may be deriving particular meaning from their caregiving role, resulting in decreased depression.

Family Needs. Caregiver family needs also significantly varied by neurological disorder type. It was hypothesized that dementia caregivers would report more unmet social support, financial, and household support needs than other caregivers. However, as with the mental health

comparisons, TBI caregivers reported the most unmet social support needs compared to all other caregivers, more unmet financial needs than MS and dementia caregivers, and more unmet health needs than SCI and MS caregivers. Because individuals with TBI tend to be male and of working age (Faul et al., 2010), it is likely that the individual with TBI had been a primary income earner in the household relative to other family members due to the patriarchal structure of Latino cultures (Cravey, 1998). On the other hand, MS and dementia occur in older or middle-aged adults, as previously stated, and thus there may be less pressure on caregivers to shift their role to financial provider. Despite reporting the least number of hours per week spent caregiver, TBI caregivers reported more unmet health needs compared to SCI and MS caregivers. This finding is also surprising, because TBI, SCI, and MS caregivers alike have reported needs for respite care (Degeneffe, 2001; Ellenbogen, Meade, Jackson, & Barrett, 2006; Cockerill & Warren, 1990). Future research is needed to more thoroughly tease out the reasons behind this finding.

Additionally, SCI caregivers reported more unmet financial needs than dementia caregivers, which is contrary to the hypothesis. Compared to non-dementia caregivers, dementia caregivers have reported less time for leisure activities and more employment problems (Ory et al., 1999). However, as with TBI, individuals with SCI are younger and more likely men (Wyndaele & Wyndaele, 2006), and thus more likely had been a primary financial provider in their family. This may have put a greater burden on caregivers to adjust to a reduced income and result in more unmet financial needs.

MS caregivers reported more unmet social support needs than dementia caregivers which can possibly be viewed through the lens of gender roles in Latino cultures. Because MS is more common among women than men, there is typically a greater proportion of male caregivers in

this caregiving group in comparison to other neurological conditions. *Machismo* is a culturally embedded value of masculinity in Latin America and has been related to Latino men's health behaviors (Panitz, McConchie, Sauber, & Fonseco, 1983) and poorer coping (Nicholas, 2000). In the US, male MS caregivers have reported reduced social support versus female caregivers (Good, Bower, & Einsporn, 1995). Because of the high proportion of male MS caregivers in the current sample in comparison to that in other neurological conditions, the MS caregivers may have reported higher social support needs because of the reduced social support that male caregivers have been shown to have (Good, Bower, & Einsporn, 1995). It is important to note however, that the analyses controlled for gender, but not gender-role conformity, which could have influenced the current pattern of differences.

Finally, dementia caregivers reported more unmet health needs compared to MS and SCI caregivers. As measured in this study, health needs refer in part to general and physical independence of the caregiver. Research has found dementia caregivers to have limited daytime and leisure activities (Górska et al., 2013; Ory et al., 1999), which may be due to the time-consuming nature providing care for an individual with severe memory loss, personality changes, and extreme functional decline (AA, 2012). Compared to MS and SCI, these symptoms and impairments are typically much more extreme, and may result in caregivers feeling less able to function on their own and take care of their health needs. Unmet needs in individuals with dementia have also been associated with caregiver anxiety (Miranda-Castillo et al., 2010) and reduced quality of life (Black et al., 2011), which may interfere with dementia caregivers' ability to feel capable and self-sufficient.

Caregiver Burden. The third hypothesis was partially supported such that caregiver burden varied by the care-receiver's neurological disorder type. It was hypothesized that

dementia caregivers would have highest levels of burden compared to other caregivers.

Dementia and TBI caregivers reported the highest burden in the personal life domain compared to MS and SCI caregivers. Burden – personal life refers to restrictions on caregivers' social and personal life, their privacy, and friendships due to their role as caregivers (Ankri et al., 2005). Previous research has found that social impairments in individuals with TBI have the strongest connection of any other type of impairment to increased caregiver burden (Nonterah et al., 2013). Because social impairments are such a prominent feature of TBI and dementia in comparison to MS or SCI, it is logical that TBI and dementia caregivers might experience high burden to their personal lives, likely as the social deficits in care-receivers increase.

TBI caregivers also had more guilt-related burden than dementia caregivers which includes guilt related to monetary support, time, and quality of caring (Ankri et al., 2005). Those with more financial needs, as was the case in the current study with TBI caregivers, may have higher guilt-related burden as they may feel like they would be able to provide better care if they had more money. To mirror the discussion of dementia caregivers and mental health, *respeto* may be playing a role in buffering effects of burden – guilt for dementia caregivers, whereas this cultural value may apply less to caring for individuals with TBI given the inherent differences in injury/disease etiology and patient characteristics that have been previously discussed. In addition, dementia patients may not be aware of their own deficits, while TBI patients are more aware. As a result, TBI patients might have more mental health problems, which then create more burden in caregivers. Due to the progressive lack of awareness among dementia patients, the patients may create less mental health problems, depending on their level of severity, which may reduce burden in caregivers; however Etters and others (2008) did find anosognosia to be

related to increased burden. Therefore, there needs to be further research to explain this difference.

Canonical Correlations

Family Needs and Caregiver Mental Health. Similar to previous findings (Arango-Lasprilla et al., 2010b; Marsh et al. 2002), the first canonical correlation analysis (CCA) found that more unmet family needs were strongly related to worse mental health. Hypothesis 4 was partially supported such that caregivers with more unmet financial and social support needs tended to have reduced satisfaction with life. Research has shown that caregivers have had more financial problems and changes in their relationships after six months of caregiving (Marsh et al., 2002), as well as time demands and changes in personal plans (Khan, Pallant, & Brand, 2007). Given the significant changes in the lives of caregivers, especially in financial and social domains, it is important to determine the best method to target these needs.

Satisfaction with life emerged as the key variable associated with unmet financial and social support needs among caregivers. Engagement in activities has been associated with improved satisfaction with life among dementia caregivers (Wakui, Saito, Agree, & Kai, 2012), which is known to protect against stressors (Lundh, 1999). Yet, there are still high rates of caregivers reportedly feeling dissatisfied with their lives (Arango-Lasprilla et al., 2010a; Arango-Lasprilla et al., 2010b; Argimon, Limon, Vila, & Cabezas, 2004). Moreover, caregivers frequently report unmet financial and social support needs (Vaingankar et al., 2013; Aronson et al., 1996; Kristjanson et al., 2005; Górska et al., 2013). One way to strengthen satisfaction with life could be to help caregivers identify financial resources to supplement their family income, and to help caregivers garner support from other family members and their social networks. If

this is achieved, life satisfaction may be improved, which, in turn, may serve as a buffer for negative life stressors.

Research has shown that caregivers who engage in more pleasurable activities and experience lower perceived activity restriction have a lower arterial pressure as well as systolic and diastolic blood pressure compared to caregivers without those experiences (Chattillion et al., 2013). As such, increased social engagement may improve caregiver life satisfaction and, importantly, have physical health benefits. Additionally, improved dementia caregiver satisfaction with life has been associated with increased likelihood of care-recipient outpatient visits to primary and mental health care (Thorpe et al., 2009), suggesting caregiver life satisfaction has implications not only for their own mental and physical health, but also on their family member with a neurological condition.

Family Needs and Caregiver Burden. The second CCA found more unmet family needs were robustly associated with increased caregiver burden, as hypothesized. These findings are consistent with previous research that has found unmet family needs to exacerbate caregiver burden (Arango-Lasprilla et al., 2010a) and increase emotional strain (Li, Chadiha, & Morrow-Howell, 2005). More unmet needs have been reported when behavioral problems in the care-recipient surface (Serio et al., 1995; Miranda-Castillo et al., 2010), which may result in a higher burden of care.

Unmet financial needs among caregivers can have tangible effects on their ability to provide quality care for their family members. Dementia caregivers have reported difficulties obtaining employment, transportation obstacles, and limited supportive housing choices (Robison et al., 2012), which can affect feelings of burden. TBI caregivers have expressed reduced time to take care of themselves, changes in sleep patterns, and more financial problems

after six months of caregiving (Marsh et al., 2002). Given the strong influence of cultural values surrounding caregiving that has been linked to increase burden (Mahoney et al., 2005), it is possible that caregivers feel that they should be able to take care of their family in spite of their own well-being. Guilt may arise in light of financial difficulties, as caregivers are unable to provide stability for their family members. Restriction on their personal life may be influenced by time limitations accompanying their caregiving role, but also through their inability to afford social activities. By targeting financial needs of caregivers, it may be possible to reduce feelings of burden on personal life and feelings of guilt related to the provision of care.

Caregiver Burden and Mental Health. Similar to other findings (Bartolo et al., 2010), the third CCA demonstrated that caregiver burden and mental health were robustly associated with one another. Partially supporting the final hypothesis, depression was positively associated with personal life and guilt-related burden. Depression emerged as the most important factor relating to personal life and guilt-related burden. The link between caregiver depression and burden has been well document among caregiving samples, as for example among dementia caregivers, strain has been associated with more caregiver depressive and anxiety symptoms (Fisher & Lieberman, 1994).

This is of importance because between one-third and two-thirds of neurological caregiving samples have reported clinically significant levels of depression (Pakenham, 2001; Lehan et al., 2012; Rodakowski et al., 2012; Arango-Lasprilla et al., 2010a; Epstein-Lubow et al., 2012; Berry, Grant, & Oswald, 2007). Even more concerning is that increased depression among dementia caregivers has been associated with higher rates of suicidal ideation (O'Dwyer et al., 2013). Among SCI caregivers, depression has been associated with more negative social

interactions and reduced social integration (Rodakowski et al., 2012), which can be contributing to feelings of burden on caregivers' personal lives in the current sample.

As caregiving obligations increase, caregivers experience loss of free time, friendships, and social isolation (Rodriguez et al., 2003). Burden of care is even higher among those caring for individuals with more severe symptoms/disabilities (Post et al., 2005; Cheng et al., 2013; Mioshi et al., 2013; Bruvik et al., 2013; Turró-Garriga, et al., 2013; Coleman et al., 2001; Aronson et al., 1996; Finlayson & Cho, 2008). So, as more time is spent caring for family members with neurological conditions, especially more demanding tasks, burden on caregivers' time increases, and their social and personal lives tend to suffer. The association between leisure activities and caregiver depression has been moderated by feelings of guilt among caregiving daughters (Romero-Moreno et al., 2014). Thus, as caregivers' personal lives are impeded upon, depression may increase, which could be exacerbated even further with the addition of feelings of guilt. Assisting caregivers to find approaches to focus on their personal lives and feelings of guilt may be a way to reduce depression if supported in future research.

Taken together, these findings suggest that attention should be focused on supplementing financial and social support needs for family caregivers of individuals with neurological conditions. Financial needs are associated with caregiver life satisfaction as well as burden on caregivers' personal life and feelings of guilt, which are linked to increased depression. Social support needs are also linked to caregiver satisfaction with life. These findings are of particular importance as psychological distress has been shown to affect quality of care provided to the care-recipient (Smith, Williamson, Miller & Schulz, 2011; Cooper et al., 2010).

Clinical Implications

Given these findings in conjunction with previous research, there are many implications for interventions and allocation of resources among communities in Latin America. Despite what was originally expected, TBI caregivers consistently demonstrated the greatest mental health problems, the most unmet family needs, and more guilt-related burden. As previously noted, TBI symptoms involve behavioral and affective changes along with physical problems (Lundin et al., 2006). Clinicians can sensitize TBI caregivers to the changes that accompany the injury as early as possible in the rehabilitation process, preparing them for some of these possible impairments. Community integration of individuals with TBI is one major long-term problem with which caregivers have to contend (Rotondi et al., 2007). Clinicians should be sensitive to the abrupt role changes that family TBI caregivers face, and be prepared to refer them to support groups, and respite care when appropriate. Given the burden of care and high levels of unmet needs TBI caregivers demonstrate, it is especially important that resources be available in rehabilitation clinics that serve individuals with TBI.

For caregivers of individuals with neurological conditions more broadly, clinicians should target caregiver financial and social support needs, which if shown in future research, could have a positive effect on caregiver mental health and burden. Interventions that help increase caregivers' participation in daily social activities and garner support from social networks may have the potential to improve caregiver mental health. For example, a group cognitive-behavioral intervention for dementia caregivers in Latin America has shown evidence in improving caregiver depression and satisfaction with life, with the added benefit of improving social support given the group format (Arango-Lasprilla et al., 2014). The Resources for Enhancing Alzheimer's Caregiver Health (REACH), a well-researched intervention for dementia

caregivers, may be a model to aspire to for all caregivers of individuals with neurological disorders if the appropriate adaptations are undertaken (Belle et al., 2006). REACH facilitates information delivery, didactic instruction, role-playing, problem solving, skills training, stress management techniques, and telephone support (Belle et al., 2006). REACH has been shown to improve caregiver quality of life and reduce depression (Belle et al., 2006). Financial needs may be targeted through interventions where families are taught basic finance management skills in which they can strategize about how to obtain more income for the family given their current resources.

Several studies have presented various interventions utilizing systemic family therapy the goals of which are to repair non-cohesive relationships, as well as accepting and adapting to the new roles for the family members and individuals with TBI (Yeates et al., 2007). Case studies aimed to identify families' own resources and their ability to cope with brain injury trauma through improving communication skills (Chenail et al., 1992; Laroi, 2001); re-establishing and redistributing family roles to restore cohesion (Laroi, 2001), meet family needs, and reduce burden (Maitz & Zachs, 1995); and reducing blame to increase understanding of family needs, cohesion and empathy (Yeates et al., 2010). Zimostrad (1989) utilized a bi-dimensional approach using family systems and behavioral interventions to positively influence familial interactions as well as assist in behavioral change.

Systemic family interventions among individuals with TBI have reported improvements for patients during and after therapy such as better family cohesion and reduced conflict and psychological distress (Perlesz & O'Loughlan, 1998) and increased knowledge about impairments (Wahrborg & Borenstein, 1989) through various methods such as providing a place for the families to discuss the affect of impairments on the family; exploring roles, relationships

(Nichols, Varchevker, Pring, 1996) and communication patterns (Söderström et al., 1992); decision making (Söderström et al., 1992); and reflections, validation, reframing and normalizing (Kreutzer et al., 2009). Family interventions have been shown to improve healthy adjustment and reduce burden and strain among family caregivers up to 24 month (Perlesz & O'Loughlan, 1998). Future research should adapt existing family systems interventions to address financial and social support needs, which, in light of the current findings, may positively affect caregiver mental health and burden.

There are also public policy implications based on the salient financial needs of the caregivers in the present study. These findings provide support for the implication of a social security program for individuals with neurological conditions, physical disabilities, and their caregivers. Publicly funded rehabilitation or adult day care facilities would allow individuals with neurological conditions to get assistance with their conditions, as well as allow their caregivers to work to earn an income, which may reduce their financial burden, and may ultimately increase the quality of care provided to the care-recipient.

Limitations and Future Directions

The present study has several limitations to be taken into consideration for interpretation of the findings, and as a result, directions for future research. The first limitation was the use of convenience sampling from clinics and universities that likely affects representativeness of the sample and the ability to generalize findings. As a result, this group may have had unique resources in comparisons to caregivers of individuals with neurological conditions who do not have access to these same resources. The current sample reflects only a small portion of the population of caregivers of individuals with neurological conditions in Latin America. However, the current study included caregivers from urban and rural regions, resulting in a more diverse

sample than other studies recruiting from only one site. Future studies should replicate the methods in this study to determine further the generalizability of the findings.

A second limitation is the confounding of certain neurological conditions by city and country. SCI caregivers were recruited from rural Neiva, Colombia, dementia caregivers from Bogota, Colombia, and MS caregivers from Guadalajara Mexico. TBI caregivers were recruited from Barranquilla, Colombia and Guadalajara Mexico. Thus, comparisons of TBI caregivers to other groups will be more accurately attributed to their care-recipients' neurological conditions as opposed to their city. To make more accurate comparisons across neurological conditions, future studies should equally sample each condition in the respective cities of interest. Third, the SCI caregivers in the current sample are from a rural area, and as a result, many are in poverty. For dementia and TBI caregivers, financial problems may not be as important compared to SCI caregivers. Future studies should further delineate the differences between caregivers based on their physical and socioeconomic environments.

Fourth, the family needs scale that was used in the present study was created based on family needs in the United States. There may me other needs that were not originally identified in the scale's creation that are unique to these global regions. In the future, focus groups should be conducted with caregivers of individuals with neurological conditions in Latin America to determine if there are additional needs not tapped by the FNAT, which was developed solely from the range of needs identified in the United States.

Fifth, the cross-sectional nature of the study design limits the ability to make causal statements. Future research can more directly test the influence of family needs on caregiver burden and mental health by assessing these variables longitudinally to provide stronger causal evidence. As timing of disease/injury diagnoses varies between the conditions, this would be an

important factor to consider for future studies. Finally, demographics were not controlled for in the canonical correlations, and disease/injury characteristics were not controlled for in either set of analyses. It is possible that care-recipient factors influence caregiver perception of family needs, caregiver mental health and burden, and future studies should take care-recipient variables into consideration.

Conclusion

The current study examined differences in family needs, caregiver mental health, and caregiver burden among caregivers of individuals with traumatic brain injury, spinal cord injury, multiple sclerosis, and dementia from cities in Colombia and Mexico. The study also examined the connections among family needs, caregiver mental health, and caregiver burden in the combined sample of caregivers of individuals with neurological conditions. Many significant differences were identified among caregiving groups, with the most prominent and pervasive differences being that TBI caregivers generally had more unmet family needs, and worse mental health and burden than other caregivers on most measures. Among all caregivers, family needs, caregiver mental health, and burden were all robustly associated with each other. Specifically, financial and social support needs were associated with life satisfaction, financial needs with burden-personal life and guilt, and burden-personal life and guilt with depression. The current findings may inform the allocation of resources in rehabilitation clinics in Colombia and Mexico. Clinicians should focus on caregivers meet financial and social support needs in order to positively influence caregiver burden and mental health.

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Appendix A

Zarit Burden Inventory (ZBI)

Please circle the number for the response that best describes how you feel.

	Never	Rarely	Sometimes	Quite	Nearly
				Frequently	Always
1. Do you feel that your	0	1	2	3	4
relative asks for more help than					
he/she needs?					
2. Do you feel that because of	0	1	2	3	4
the time you spend with your					
relative that you don't have					
enough time for yourself?					
3. Do you feel stressed	0	1	2	3	4
between caring for your					
relative and trying to meet					
other responsibilities for your					
family or work?					
4. Do you feel embarrassed	0	1	2	3	4
over your relative's behavior?					
5. Do you feel angry when you	0	1	2	3	4
are around your relative?					
6. Do you feel that your	0	1	2	3	4
relative currently affects your					
relationships with other family					
members or friends in a					
negative way?					
7. Are you afraid what the	0	1	2	3	4
future holds for your relative?					
8. Do you feel your relative is	0	1	2	3	4
dependent on you?					
9. Do you feel strained when	0	1	2	3	4
you are around your relative?					
10. Do you feel your health has	0	1	2	3	4
suffered because of your					
involvement with your					
relative?					
11. Do you feel that you don't	0	1	2	3	4
have as much privacy as you					
would like because of your					
relative?					
12. Do you feel that your social	0	1	2	3	4
life has suffered because you					
are caring for your relative?					

13. Do you feel uncomfortable	0	1	2	3	4
about having friends over					
because of your relative?					
14. Do you feel that your	0	1	2	3	4
relative seems to expect you to					
take care of him/her as if you					
were the only one he/she could					
depend on?					
15. Do you feel that you don't	0	1	2	3	4
have enough money to take					
care of your relative in addition					
to the rest of your expenses?					
16. Do you feel that you will	0	1	2	3	4
be unable to take care of your					
relative much longer?					
17. Do you feel you have lost	0	1	2	3	4
control of your life since your					
relative's illness?					
18. Do you wish you could	0	1	2	3	4
leave the care of your relative					
to someone else?					
19. Do you feel uncertain about	0	1	2	3	4
what to do about your relative?					
20. Do you feel you should be	0	1	2	3	4
doing more for your relative?					
21. Do you feel you could do a	0	1	2	3	4
better job in caring for your					
relative?					
22. Overall, how burdened do	0	1	2	3	4
you feel in caring for your					
relative?					

Appendix B

Patient Health Questionnaire-9 (PHQ-9)

1. Over the last 2 weeks, how often have you been bothered by any of the following problems? Read each item carefully, and circle your response.

	Not	Several	More	Nearly
	at all	days	than	every
			half the	day
			days	
	0	1	2	3
a. Little interest or pleasure in doing things	0	1	2	3
b. Feeling down, depressed, or hopeless	0	1	2	3
c. Trouble falling asleep, staying asleep, or sleeping too much	0	1	2	3
d. Feeling tired or having little energy	0	1	2	3
e. Poor appetite or overeating	0	1	2	3
f. Feeling bad about yourself, feeling that you are a failure, or feeling that you have let yourself or your family down	0	1	2	3
g. Trouble concentrating on things such as reading the newspaper or watching television	0	1	2	3
h. Moving or speaking so slowly that other people could have noticed. Or being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
i. Thinking that you would be better off dead or that you want to hurt yourself in some way	0	1	2	3

2. If you checked off any problem on this questionnaire so far, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not Difficult At All	Somewhat Difficult	Very Difficult	Extremely Difficult
0	1	2	3

Appendix C

Satisfaction With Life Scale (SWLS)

Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate number in the line preceding that item. Please be open and honest in your responding.

1 = Strongly Disagree

2 = Disagree

3 = Slightly Disagree

4 = Neither Agree or Disagree

5 = Slightly Agree

6 = Agree

7 = Strongly Agree

1. In most ways my life is close to my ideal.

_____2. The conditions of my life are excellent.

_____3. I am satisfied with life.

_____4. So far I have gotten the important things I want in life.

5. If I could live my life over, I would change almost nothing

Appendix D

Family Needs Assessment Tool (FNAT)

Below is a list of needs that family members who provide care to individuals often have. Please read over each question and then circle one of the responses to indicate how much you agree or disagree that this is a need for you and your family.

	Strongly	Disagree	Neutral	Agree	Strongly
	disagree				agree
1. I need help with the house	1	2	3	4	5
work					
2. I need help with preparing	1	2	3	4	5
meals					
3. I need specialized information	1	2	3	4	5
about the patient.					
4. I need complete information	1	2	3	4	5
5. I need to discuss my feelings	1	2	3	4	5
with someone who has been					
through the same experience					
6. I need financial help	1	2	3	4	5
7. I need help with meeting	1	2	3	4	5
economic needs					
8. I have enough money	1	2	3	4	5
9. I feel good about myself	1	2	3	4	5
10. I can exercise regularly	1	2	3	4	5
11. I am self-sufficient and do	1	2	3	4	5
not need help					
12. I feel good about my	1	2	3	4	5
personal appearance					
13. I get support from my church	1	2	3	4	5
14. I get help from community	1	2	3	4	5
organizations.					

Appendix E

Short Form 36 (SF-36)

Please answer every question. Some questions may look like others, but each one is different. Please take the time to read and answer each question carefully by filling in the bubble that best represents your response.

- 1. In general, would you say your health is:
 - 1. Excellent
 - 2. Very Good
 - 3. Good
 - 4. Fair
 - 5. Poor
- 2. Compared to on year ago, how would you rate your health in general now?
 - 1. Much better now than a year ago
 - 2. Somewhat better now than a year ago
 - 3. About the same as one year ago
 - 4. Somewhat worse now than one year ago
 - 5. Much worse now than one year ago

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

		Yes, limited a lot.	Yes, limited a little.	No, not limited at all.
3.	Vigorous activities, such as running,			
	lifting heavy objects, participating in strenuous sports.	1	2	3
4.	Moderate activities, such as moving a			
	table, pushing a vacuum cleaner,	1	2	3
	bowling, or playing golf?			
5.	Lifting or carrying groceries.	1	2	3
6.	Climbing several flights of stairs	1	2	3
7.	Climbing one flight of stairs.	1	2	3
8.	Bending, kneeling or stooping.	1	2	3
9.	Walking more than one mile.	1	2	3

10. Walking several blocks.	1	2	3
11. Walking one block.	1	2	3
12. Bathing or dressing yourself.	1	2	3

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? Please circle either Yes or No.

13. Cut down the amount of time you spent on work or other activities?

1. Yes 2. No

14. Accomplished less than you would like?

1. Yes 2. No

15. Were limited in the kind of work or other activities.

1. Yes 2. No

16. Had difficulty performing the work or other activities (for example, it took extra time).

1. Yes 2. No

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

17. Cut down the amount of time you spent on work or other activities?

1. Yes 2. No

18. Accomplished less than you would like.

1. Yes 2. No

19. Didn't do work or other activities as carefully as usual.

1. Yes 2. No

- 20. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?
 - 1. Not at all
 - 2. Slightly
 - 3. Moderately
 - 4. Quite a bit
 - 5. Extremely

21. How much bodily pain have you had during the past 4 weeks?

- 1. Not at all
- 2. Slightly
- 3. Moderately
- 4. Quite a bit
- 5. Extremely
- 22. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?
 - 1. Not at all
 - 2. Slightly
 - 3. Moderately
 - 4. Quite a bit
 - 5. Extremely

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. <u>How much of the time during the past 4 weeks:</u>

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
23. did you feel full of pep?	0	1	2	3	4	5
24. have you been a very nervous person?	0	1	2	3	4	5
25. have you felt so down in the dumps nothing could cheer you up?	0	1	2	3	4	5
26. have you felt calm and peaceful?	0	1	2	3	4	5
27. did you have a lot of energy?	0	1	2	3	4	5
28. have you felt downhearted and blue?	0	1	2	3	4	5
29. did you feel worn out?	0	1	2	3	4	5
30. have you been a happy person?	0	1	2	3	4	5
31. did you feel tired?	0	1	2	3	4	5

32. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with you social activities (like visiting friends, relatives, etc.)?

- 1. All of the time
- 2. Most of the time
- 3. Some of the time
- 4. A little of the time
- 5. None of the time

How TRUE or FALSE is each of the following statements for you?

	Definitely False	Mostly False	Don't know	Mostly True	Definitely True
33. I seem to get sick a little easier than other people.	0	1	2	3	4
34. I am as healthy as anybody I know.	0	1	2	3	4
35. I expect my health to get worse.	0	1	2	3	4
36. My health is excellent.	0	1	2	3	4

Megan Elizabeth Sutter was born on July 9, 1989 in St. Petersburg, Florida. She attended St. Petersburg Collegiate High School, and obtained her high school diploma in 2007. She received her Bachelor of Arts in Psychology from the University of South Florida St. Petersburg in May of 2011.