TODO EN LA FAMILIA: EXAMINING THE RELATIONSHIPS AMONG MS IMPAIRMENTS, FAMILY NEEDS, AND CAREGIVER MENTAL HEALTH IN GUADALAJARA, MEXICO

Melody N. Mickens

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TODO EN LA FAMILIA: EXAMINING THE RELATIONSHIPS AMONG MS IMPAIRMENTS, FAMILY NEEDS, AND CAREGIVER MENTAL HEALTH IN GUADALAJARA, MEXICO

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

By: MELODY N. MICKENS
Bachelor of Arts, College of William and Mary, December 2007
Master of Science, Virginia Commonwealth University, December 2011

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

Virginia Commonwealth University
Richmond, Virginia
August 2014
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Abstract

TODO EN LA FAMILIA: EXAMINING THE RELATIONSHIPS AMONG MS IMPAIRMENTS, FAMILY NEEDS, AND CAREGIVER MENTAL HEALTH IN GUADALAJARA, MEXICO

By: Melody N. Mickens, M.S.

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

Virginia Commonwealth University, 2014

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

Individuals with multiple sclerosis (MS), especially those living in Latin America, often require assistance from family caregivers throughout the duration of disease. Previous findings suggest that family caregivers may experience positive and negative effects from providing care to individuals with MS, but few studies have examined the impact of MS caregiving on caregivers from Latin America. The current study examined the relationships between MS impairments (functional, neurological, cognitive, behavioral and emotional), unmet family needs (household, informational, financial, social support, health), and caregiver psychosocial functioning (satisfaction with life, anxiety, burden, and depression) in a sample of 81 MS caregivers from Guadalajara, Mexico. Canonical correlations revealed that behavioral impairments were associated with higher burden and decreased satisfaction with life, and that unmet financial, social support, and informational needs were associated with higher caregiver burden. A structural equation model demonstrated the meditational effect of unmet family needs on the relationship between MS impairments and caregiver mental health. These findings suggest that interventions for MS caregivers in Latin America should focus on reducing caregiver burden by addressing unmet family needs for
information, financial, and social support while teaching caregivers ways to manage the patient’s behavioral symptoms.
Multiple sclerosis (MS) is a chronic illness that eventually results in physical disability and cognitive impairments, which limit an individual’s ability to function independently (Dutta & Trapp, 2007). Approximately 2.5 million people have been diagnosed with MS worldwide (National MS Society, 2012), and research findings demonstrate that worldwide prevalence rates are increasing (Koch-Henriksen & Sørenson, 2010). As with other countries, researchers have observed that MS prevalence rates may be higher than previously reported in Latin American countries such as Mexico, where current prevalence rates vary by region and range from 7-30 cases per 100,000 people (De la Maza Flores & Arrambide García, 2006; Melcon et al., 2012; Velázquez-Quintana, Macías-Islas, Rivera-Omos & Lozano-Zárate, 2003).

MS is a neurological disorder that occurs when an auto-immune response destroys the myelin sheaths surrounding axons in the central nervous system (CNS; Dutta & Trapp, 2007). In individuals with MS, delayed communication among CNS neurons can affect multiple organ systems. Epidemiological data demonstrate that the onset of MS can vary, but the vast majority of individuals are diagnosed during early to middle adulthood, or between the ages of 20-40 (National MS Society, 2012). Four subtypes of MS have been identified: relapse remitting, secondary progressive, progressive-relapsing, and primary progressive. These types vary in symptom frequency and severity, such that individuals with relapse remitting forms may experience symptoms followed by a period of no symptoms, while those with progressive forms continuously experience symptoms that may increase in severity over time (Dutta & Trapp, 2007).
Although the duration and frequency of symptoms vary by subtype, eventually all individuals with MS experience symptoms that lead to long-term disability and a need for caregiver assistance (McKeown, Porter-Armstrong & Baxter, 2003; Buhse, 2008). Approximately 30% of individuals with MS depend on an informal caregiver for assistance with activities of daily living (ADLs) and medical care (Buchanan, Radin, Chakravorty & Tyry, 2010), and as the disease progresses, the need for informal care increases. Unlike formal caregivers who receive training in providing care and monetary compensation for their services, informal caregivers are often family members who voluntarily assist individuals with MS with a variety of activities such as toileting, bathing, shopping, household chores, transportation, managing finances, walking, and leisure activities (Carton, Loos, Pacolet, Versieck, & Vlietinck, 2000; Pakenham, 2007). Many individuals with MS who have physical and/or cognitive disabilities require assistance from informal caregivers because they cannot afford a formal caregiver or need continuous care in order to maintain their safety and a satisfactory quality of life (QOL; Aronson, Cleghorn, & Goldenberg, 1996). When compared to their non-caregiving counterparts, MS caregivers report significantly higher levels of depression (Buhse, 2008) and anxiety (Pakenham, 1998), as well as decreased social support (Akkus, 2011) and health related quality of life (HRQOL; McKeown et al., 2003).

In Latin America, where rates of MS are increasing but disparities still exist in its diagnosis and treatment (Carrá et al., 2011; Rivera, 2009), sociocultural values such as allocentrism, familism, and filial obligation (Ayalon & Huyck, 2001; Hinojosa, Zsembik, & Rittman, 2009; Zea, Quezada, & Belgrave, 1994) increase the likelihood that family members will serve as informal caregivers to individuals with MS. However, very few studies have examined MS caregiving in Latin America (Arango-Lasprilla, Premuda, Aguayo, Francis, Macias & Villaseñor, 2010; Lehan, Arango-Lasprilla, Macias, Aguayo & Villaseñor, 2012), and associations in this region among MS impairments, needs of
family members providing care, and caregiver mental health remain largely unknown. Because of this major gap in the research literature, there is a great need for research addressing the process of MS caregiving in Latin America, as well as the impact of MS impairments on family needs and caregiver mental health in this region. As a result, the goals of this study are to examine (a) the connections between MS impairments and unmet family needs in Guadalajara, Mexico, (b) the connections between MS impairments and caregiver mental health, (c) the connections between unmet family needs and caregiver mental health, and (d) the possible mediation of the relationship between MS impairments and caregiver mental health by unmet family needs.

This Introduction will begin with an overview of MS, its symptoms, clinical course, and treatment. Second, it will review the literature on the mental health of MS caregivers. Third, it will identify sociocultural factors that influence the process of caregiving in Latin America. Fourth, the Introduction will review previous research on the needs of MS family caregivers.

**Epidemiology, Pathophysiology, Clinical Course, Symptoms, and Treatment**

**Epidemiology.** MS is one of the most frequently diagnosed neurological disorders, as well as one of the most common causes of neurological impairment among adults (Dombovy, 2011). Worldwide prevalence rates vary from 1-150 cases of MS per 100,000 inhabitants, with higher rates in European countries, Australia, Canada and the United States (Koch-Henriksen & Sørensen, 2010; Koutsouraki, Costa & Baloyannis, 2010; Rosati, 2001). Emergent findings suggest that the incidence and prevalence of MS are increasing in Latin America (Carrá et al., 2011; Gonzalez & Sotelo, 1995; Ojeda et al., 2013). MS prevalence varies greatly across the region with some countries in Latin America reporting as few as .75 cases per 100,000 (Cristiano et al., 2012) and some regions of Mexico reporting prevalence rates as high as 30 cases per 100,000 (De la Maza Flores & Arrambide García, 2006). Although these rates vary greatly, Latin America has been characterized as a region with low to
medium MS prevalence when using Kurtzke’s (1975) classification of MS prevalence where low prevalence rates occur in countries with less than five cases of MS per 100,000 inhabitants and medium prevalence rates occur in countries with 5-10 cases of MS per 100,000 individuals (Ojeda et al., 2013).

Researchers believe that several factors have led to increased prevalence rates of MS among in Latin America. Technological advances, such as the increased use of magnetic resonance imaging (MRI), the consistent use of Poser and McDonald diagnosis criteria, and greater access to health care have improved diagnosis and management of the disease (Toro, Cárdenas, Fernando Martínez, Urrutia & Díaz, 2013). Additionally, collaborations with international organizations like the World Federation of Neurology have lead to the creation of the Latin American Committee on Treatment and Research in MS (LACTRIMS; Rivera, 2009), which has increased dissemination of research, and improved education about diagnosis and treatment of the disease among neurologists in Latin America (Medina & Munsat, 2010). As such, researchers assert that increasing prevalence rates in Latin America are largely due to improved diagnostic procedures and greater access to neurological care (Rivera & Landero, 2005).

Increased knowledge about the disease and research inquiry have improved the methodology used to collect prevalence and incidence data, as well as measure the influence of etiological factors such as the environment and genetics. At present, researchers also believe that MS prevalence rates vary worldwide and within Latin America because of a latitudinal gradient. The latitudinal gradient theory suggests that rates of MS increase the farther one moves north or south of the equator (Alonso & Hernán, 2008), and many studies have supported this theory (Koch-Henriksen & Sørensen, 2010; McGuigan, McCarthy, Quigley, Bannan, Hawkins & Hutchinson, 2004; Risco, Maldonado, Luna, Osada, Ruiz, Juarez & Vizcarra, 2011; Simpson, Blizzard, Otahal, Van der Mei & Taylor, 2011). In a recent review of MS prevalence rates in Latin American countries, Risco and colleagues (2011) assessed
10 studies of MS prevalence using samples from countries between Panama and Argentina. Their findings suggested that MS rates increased as latitude increased, and that the highest prevalence rate (21.5 cases per 100,000 inhabitants) was found in Argentina, one of Latin America’s southernmost countries (Risco et al., 2011). Despite the data in support of latitudinal gradient theory, many researchers are critical of the influence of latitude on the prevalence of MS globally (Koch-Henriksen & Sørensen, 2011; Pugliatti, Sotgiu, Solinas, Castiglia & Rosati, 2001; Rosati, 2001).

Moreover, further study of the latitudinal gradient hypothesis has revealed that latitudinal position may influence certain environmental factors that increase susceptibility to MS such as decreased exposure to sunlight and subsequent vitamin D deficiency (Beretich & Beretich, 2009; Munger, Levin, Hollis, Howard & Ascherio, 2006). Similarly, research suggests that genetic contributions influenced by migration and immigration patterns may explain the latitudinal gradient and its relationship to MS prevalence. In Latin America, there are four main ethnic groups: Africans, Native Americans, Europeans and Mestizos, as well as the presence of other ethnic groups such as Asians and Arabs (World Book Encyclopedia, 2013). While many of these ethnic groups are spread out throughout the region, areas of higher MS prevalence occur where there is a higher concentration of individuals with European origins (Risco et al., 2011). By contrast, lower MS prevalence rates have been reported in countries and areas with higher populations of individuals with Native American origin (Toro et al., 2013).

Many researchers attribute ethnic differences in MS prevalence to heterogeneous population genetics, and assert that individuals with Native American origins may experience protection from the absence of alleles associated with MS such as HLA-DRB1*1501, while many individuals of European origin may experience increased susceptibility due to the presence of this allele in their genetic composition (Esposito & De Jager, 2010; Schmidt, Williamson & Ashley-Koch, 2007). However, it is
important to note that there are few genetic studies that include samples from Latin America, and that some of these studies include small sample sizes, which limits their generalizability. Similarly, because of the long history of ethnic admixing, it is hard to isolate specific genetic contributions by ethnicity. Despite these limitations, findings from genetic studies conducted suggest lower MS prevalence among indigenous populations in Australia, Africa, Canada and Japan (Ascherio & Munger, 2007; Mirsattari et al., 2001; Rosati, 2001), and higher prevalence among populations of European descent (e.g. United Kingdom, France and Scotland; Rosati, 2001).

**Pathophysiology.** Although definitive etiological mechanisms are unknown, medical researchers assert that MS occurs when genetic and environmental factors (e.g., measles, mumps, rubella and Epstein-Barr infections, toxic chemical exposure, vitamin D deficiency) interact and cause an auto-immune reaction that leads to inflammation and demyelination of CNS neurons (Polman, Thompson, Murray, & McDonald, 2001). Demyelination of CNS neurons often leads to axonal injury and the formation of sclerotic plaques and lesions in the brain stem, ventricles, cerebellum, optic nerve, and spinal cord (Noseworthy & Hartung, 2006). As the disease progresses, the number of plaques and lesions within the brain and spinal cord increase, leading to neurodegeneration and loss of function in these affected areas (Compston & Coles, 2008). In addition to contributing to the proliferation of plaques and lesions, demyelination of CNS neurons disrupts conduction between axons and slows conduction of nerve impulses (Noseworthy & Hartung, 2006). Researchers believe that demyelination and its effect on nerve conduction are directly responsible for neurological symptoms such as loss of sensation, strength, and coordination, paroxysmal symptoms (e.g., spasms), neuralgia (e.g., nerve pain), and cognitive dysfunction (Lezak, Howieson, & Loring, 2004).

**MS diagnosis and disease course.** Individuals with MS often experience intermittent symptoms of the disease years before diagnosis. However, most individuals are diagnosed following a clinically
isolated syndrome, which has been described as an acute episode or attack of neurological symptoms that affects at least one, but often several sites and lasts for at least 24 hours (Compston & Coles, 2008). Data from clinic samples have demonstrated that 90% of MS patients initially present with fatigue, 20-50% of MS present with sensory symptoms (e.g., tingling, pain, burning in limbs), 49% present with visual symptoms (e.g., vision loss, optic neuritis, diplopia), 32-41% present with motor symptoms (e.g., muscle weakness, hyperreflexia, spasticity in legs and arms), 23% present with cerebellar symptoms (e.g., vertigo, tremor, loss of balance), 10% present with bowel and bladder symptoms (e.g., urgency, incontinence, constipation), and 4% present with cognitive impairments (e.g., attention deficits, slowed processing speed, executive dysfunction, impaired immediate recall and memory) (Felton, 2011; Mohr & Cox, 2001).

These acute symptoms may remit partially or fully, but often return repeatedly over the course of several months and years (Aminoff & Daroff, 2003). Following the first episode, returning symptoms and/or new symptoms are characterized as relapses. Over time, usually 10-20 years, repeated relapses eventually lead to physical disability, which may occur because of the proliferation of lesions as well as increased severity of neurological sequelae (Aminoff & Daroff, 2003). Chronic symptom onset frequently occurs among individuals over the age of 40, and is characterized as a gradual progression of symptoms with no period of remission (Aminoff & Daroff, 2003).

As noted above, four MS disease courses have been identified: relapsing-remitting (RRMS), secondary progressive (SPMS), primary progressive (PPMS), and progressive relapsing (PRMS). RRMS is one of the most common forms of MS, and nearly 80% of individuals with MS have a RR form of the disease (Compston & Coles, 2008; Noseworthy & Hartung, 2006). In RRMS, an individual experiences relapses, or acute symptom attacks that last several days or sometimes several weeks (Felton, 2011; Noseworthy & Hartung, 2006). During a relapse, the symptoms increase in intensity, as does the
patient’s level of neurologic deficit. After several days to three weeks, the symptoms plateau and then remit for several weeks or months (Felton, 2011; Noseworthy & Hartung, 2006). During the remission period, which may last three to six months or longer, symptoms may fully or partially remit, and the patient does not experience any additional symptoms until a subsequent relapse occurs. It is important to note that patients with RRMS experience periods of acute symptoms and then partial or full remission, but symptoms do not increase in severity during subsequent relapses (Noseworthy & Hartung, 2006).

Natural history studies of MS demonstrate that approximately 60-80% of patients with RRMS eventually develop SPMS, which is characterized by symptoms that progressively worsen without relapses or periods of remission (Chiaravalloti & DeLuca, 2008). Neurologists amend a patient’s diagnosis of RRMS to SPMS when the patient’s level of functioning during remissions gradually worsens and the patient no longer experiences periods of symptom remission. Because of the gradual progression of symptom severity, the patient’s level of functional disability increases over time, and once the patient is diagnosed with SPMS, he or she maintains this diagnosis until death (Lublin & Reingold, 1996).

Two progressive forms of MS, PPMS and PRMS are diagnosed at symptom onset (Chiaravalloti & DeLuca, 2008). PPMS involves a chronic disease course with no relapses or periods of remission (Lublin & Reingold, 1996). PPMS is often diagnosed among older patients with MS (e.g. those who begin experiencing symptoms after age 40) and is characterized as a consistent decline in functioning due to symptoms that persist and worsen over time. Approximately 15% of MS patients are diagnosed with the PPMS form of the disease. PRMS, while not as common, is described as acute symptom relapses without periods of remission (Lublin & Reingold, 1996). In addition to the lack of remission, symptoms increase in severity and the patient’s level of functioning gradually decreases (Chiaravalloti & DeLuca, 2008; Felton, 2011).
Despite its progressive nature and the incidence of neurological symptoms that produce physical disability and cognitive dysfunction, MS only slightly shortens one’s natural life expectancy by an average of 6-7 years (Sadovnick, Ebers, Wilson, & Paty, 1992; Weinshenker, 1995). In fact, natural history studies of the disease course demonstrate that many individuals live 30-40 years after diagnosis and die from complications of infections that affect the skin, lungs, and bladder (Compston & Coles, 2008). Suicide is also a common cause of death among individuals with MS (Sadovnick et al., 1992), and those with a progressive course and a co-morbid diagnosis of major depressive disorder have a greater probability of attempting and committing suicide (Feinstein, 2002).

**Symptoms.** Because demyelination of CNS neurons occurs in multiple areas of the brain and spinal cord, MS symptoms often affect numerous organ systems. For example, lesions and plaques in the cerebrum are associated with cognitive impairments (e.g., executive dysfunction, attention deficits), while lesions and plaques in the optic nerve are associated with visual impairments, and demyelination in the spinal cord is associated with muscle weakness, spasticity, stiffness, and neurogenic bowel and bladder dysfunction (Compston & Coles, 2008). While MS symptoms may vary in frequency and severity across the disease trajectory, individuals with MS often initially present with similar symptoms.

Across clinical courses, fatigue is one of the most commonly reported symptoms, as 80-90% of MS patients experience profound fatigue on a daily basis (Krupp, 2003). Moreover, MS-related fatigue distinguishes MS from other neurodegenerative disorders. MS-related fatigue tends to occur in the morning, even after restorative sleep, and increases during the day, especially with additional activities and changes in body temperature (Krupp, 2003). This symptom has been characterized as severely disabling because it restricts a patient’s ability engage in both physical and cognitive activities for more than several hours at time, and interferes with tasks that require sustained attention and focus (Lezak et al., 2004). Researchers believe that MS-related fatigue occurs because of delayed neuron conduction,
muscle loss/deconditioning, depression, immune reactions, increased cortical activation during movement, neuroendocrine changes, and neurological symptoms (e.g. urinary and bowel incontinence and muscle spasticity) that interrupt sleep cycles (Comi, Leocani, Rossi & Colombo, 2001; Krupp, 2003).

Depression has also been identified as a common co-morbid disorder and is believed to affect as many as 50% of MS patients at some point during the course of the disease (Siegert & Abernethy, 2005). Researchers attribute the high prevalence of depression to several factors including increased immune system reactivity (Arnett, Barwick, Beeney, 2008), medication side effects (National MS Society, 2011), role changes (National MS Society, 2011), and focal changes in the brain caused by demyelination (Bakshi et al., 2000; Berg et al., 2000; Chiaravalloti & DeLuca, 2008; Feinstein et al., 2004).

MS-related CNS changes not only lead to sensory and motor symptoms, but also cognitive changes that persist throughout the duration of the disease (Wallin, Wilken, & Kane, 2006). Cognitive impairments in individuals with MS have been associated with unemployment (Julian, Vella, Vollmer, Hadjimichael, & Mohr, 2008), as well as difficulties with medication adherence and with completion of ADLs (Bruce, Hancock, & Lynch, 2010; Wu, Minden, Hoaglin, Hadden & Frankel, 2007).

Approximately 40-70% of MS patients experience clinically significant cognitive impairments at some point (LaRocca & Kalb, 2006), with individuals who have longer disease durations (e.g., 10-15 years since symptom onset) and progressive courses of the diseases being at greater risk of experiencing cognitive impairments (Amato, Ponziani, Siracusa & Sorbi, 2001).

Cognitive impairments among MS patients affect at least one of three domains: memory, processing speed, or executive functioning (Chiaravalloti & DeLuca, 2008). Neuropsychological examination of MS-related memory impairment has revealed that approximately 40-65% of patients
experience clinically significant memory deficits that impact short- and long-term retention of new information, which are typically characterized as retrieval based memory deficits (Beatty, Goodkin, Beatty & Monson, 1989; Benedict and Bobholz, 2007; Grigsby, Ayarbe, Kravcisin & Busenbark, 1994; Lezak et al., 2004). While individuals with MS consistently demonstrate impairments on tasks that assess various aspects of memory, the heterogeneous presentation of memory deficits in MS is not consistent with a formal diagnosis of dementia (Chiaravalloti & DeLuca, 2008) and is not as clinically severe as that observed among individuals with dementia (Beatty et al., 1989; Fischer, 2001; Lezak et al., 2004). In addition, language skills (e.g., confrontation naming) and semantic memory are often intact and remain so throughout the duration of the disease (Lezak et al., 2004).

As with memory, processing speed and information processing abilities are often impaired when individuals with MS complete timed measures of visual and motor scanning and serial addition (DeLuca, Chelune, Tulsky, Lengenfelder, & Chiaravalloti, 2004; Diamond, DeLuca, Kim, & Kelley, 1997; Litvan, Grafman, Vendrell, & Martinez, 1988). Individuals with MS experience processing speed impairments due to slower cognitive processing of new information, regardless of the type of information or method of assessment (e.g. visual, auditory, or motor). Delayed processing speed also negatively impacts other cognitive processes such as the acquisition of new information (Demaree, DeLuca, Gaudino, & Diamond, 1999), working memory (Bergendal, Fredrikson & Almkvist, 2007; Lengenfelder et al., 2006), and attention (McCarthy, Beaumont, Thomson, Peacock, 2005).

In addition to memory and processing speed deficits, individuals with MS often experience impaired performance on measures of executive functioning that evaluate problem-solving skills, planning, abstract reasoning, and cognitive flexibility (Lezak et al., 2004). Many studies of executive functioning among MS patients include measures of timed verbal fluency and tasks such as card sorting tests, which require patients to organize information, incorporate feedback, and generate new strategies.
or alternative solutions (Chiaravalloti & DeLuca, 2008). Across samples, individuals with MS make an unusually high number of preservative errors, which demonstrates difficulty in generating new solutions, cognitive shifting, planning, and adapting to changes in task demands (Arnett et al., 1994; Drew, Tippet, Starkey & Isler, 2008).

A number of these cognitive problems have been linked to decreased energy and mood. For example, there is a positive relationship between patients’ reports of fatigue and impaired cognitive performance on tasks of sustained attention and working memory (Krupp & Elkins, 2000). While the etiological factors associated with depression in individuals with MS vary, those with depression sometimes perform within impaired ranges on measures of speed, attention, and working memory when compared to those without depression or to healthy controls (Arnett et al., 1999).

**Treatment.** Treatments for MS fulfill at least one of four purposes. They are designed to (a) modify (i.e., delay) the disease course, (b) treat relapses, (c) manage symptoms, and (d) improve overall function and patient safety (National MS Society, 2013). Disease modifying treatments such as interferon (beta-1a and beta-1b), glatiramer acetate, teriflunomide, natalizumab and mitoxantrone, have demonstrated efficacy in reducing the frequency of relapses and symptom severity among patients with RRMS and PRMS (Goodin et al., 2002; Rudick, 2004). These medications also delay the proliferation of sclerotic lesions, and possibly help to delay functional disability due to neurological sequelae (Rudick, 2004). Many of these drugs require intravenous, intramuscular, or subcutaneous administration by a trained health care professional, caregiver, or the patient (National MS Society, 2013). Associated side effects include flu-like symptoms, skin irritation at injection sites, possible liver damage, and increased risk of infection (National MS Society, 2013). At present, disease-modifying treatments are only efficacious in individuals with RRMS, SPMS and PRMS. There are no efficacious treatments that delay progression of MS in patients with PPMS (Goodin et al., 2002).
While disease-modifying treatments help delay relapse frequency, shorten relapse duration, and delay the spread of sclerotic plaques, they do not manage MS symptoms. Instead, individuals with MS must treat specific symptoms with additional medications and/or rehabilitation therapies such as physical therapy, occupational therapy, cognitive rehabilitation, and psychotherapy (National MS Society, 2013). Many individuals with MS receive high doses of intravenous corticosteroids to reduce the inflammation associated with relapses in RRMS, SPMS and PRMS (National MS Society, 2013). While helpful in managing symptoms, systemic corticosteroid use has been associated with changes in declarative and verbal memory, as well as increased symptoms of depression, hypomania, mania, and psychosis (Brown & Chandler, 2001). In addition to prescribing corticosteroids, health care professionals prescribe other medications as needed to manage symptoms such as bladder dysfunction (oxybutynin), pain (amitriptyline), fatigue (modafinil), anxiety, and depression (SSRIs) (National MS Society, 2013). Rehabilitation and occupational therapies help individuals with MS improve mobility, increase physical strength, and learn adaptive skills and strategies for coping with lifestyle changes. Similarly, psychotherapy has demonstrated efficacy in treating depression and anxiety, while limited findings support the use of cognitive rehabilitation for treating MS-related cognitive problems (Chiaravalloti & DeLuca, 2008).

**MS Caregiver Characteristics and Responsibilities**

Because of the unpredictable nature of MS, its impact on many aspects of daily functioning, and the resulting level of disability that individuals MS often experience, informal caregivers are a critical part of an MS patient’s treatment team. Approximately 30% of individuals with MS receive care from informal caregivers such as family members and/or close friends who volunteer to help the individual with MS without financial compensation (Buchanan et al., 2010). In part because of the higher prevalence of MS in women (Sellner et al., 2011), caregivers are more likely to be men in comparison to
other disease populations (Pinquart & Sörenson, 2011; Pöysti et al., 2012), although some global regions have a higher representation of women MS caregivers (e.g., Spain, Turkey, Iraq, Italy, Greece, and Mexico) where cultural norms ascribe the role of “caregiver” to women (Delgado & Tennstedt, 1997; DiGirolamo & Salgado de Snyder, 2008; Lutzky & Knight, 1994). Although many family members tend to be involved in MS caregiving, the majority of caregivers are spouses/romantic partners, or parents, adult children, other relatives or friends of the care recipient who live in the same house (Aronson, 1997; Buchanan & Huang, 2011; Corry & While, 2009; Liedström, Isaksson & Ahlstrom, 2010; McKeown, Porter-Armstrong & Baxter, 2004; Sato, Ricks & Watkins, 1996).

Given the wide range of years providing care and range of care recipient disability levels, caregivers’ involvement can vary greatly. For example, in one sample, 84% of caregivers reported providing personal care (e.g. help with bathing, dressing, feeding, toileting, etc.) on a daily basis, and 35% of those providing these services reported that they spent at least 90 minutes doing this daily (Cockerill & Warren, 1990). Other studies noted similar trends, with caregivers providing more assistance with personal care needs as care recipients’ disability levels increased (Carton et al., 2000; McKeown et al., 2003). Carton and colleagues (2000) observed that MS caregivers providing care to individuals with moderate to severe physical disabilities reported a range of 4.6-12 hours of daily care, as well as assistance with chores and homemaking activities (Carton et al., 2000). Other tasks frequently include administering medications, supervising bowel and bladder regimens, mobility assistance, and emotional care (Carton et al., 2000; O’Brien, 1993; Pakenham, 2007).

Psychosocial Functioning of MS Caregivers

Researchers have examined the following domains of psychosocial functioning in MS caregivers: social functioning, burden, strain, depression, anxiety, and positive affect. The following subsections will review the research on each of these psychosocial variables.
Social functioning. Social functioning is an individual’s ability to fulfill social roles (e.g., occupation, organization member), engage in social activities, and maintain a social network (Lazarus & Folkman, 1984). Cockerill and Warren (1990) found that caregiving “somewhat curtailed” MS caregivers’ ability to participate in recreational activities (49% of the sample), take vacations (42%), and attend social activities (41%). Aronson (1997), however, found that MS caregivers generally reported high satisfaction with family relationships (60% very satisfied) and friendships (68% very satisfied), but caregivers’ scores were significantly lower than those reported by healthy controls. Liedström and colleagues (2010) similarly found that MS caregivers rated their satisfaction with friends and family very highly, and content analysis of themes that emerged during qualitative interviews revealed that participants valued their friendships and relationships with family members and felt that it was important to maintain these relationships. Sato and colleagues (1996) found that MS caregivers were able to maintain relationships with friends (71% of the sample), family members (57%), and church members (24%), and many of the caregivers in their sample felt as though these relationships were a significant source of emotional support throughout the caregiving experience (Sato et al., 1996).

Occupational status has also been used as a measure of social functioning in MS caregiving populations. Hakim and colleagues (2000) found that 36% of their sample reported that their careers were affected by providing care to a relative with MS: 18% reported that they had left their job; 5% reported that they had reduced their hours from full-time to part-time; and 48% of those providing care to individuals with moderate to severe levels of physical disability reported changes to their occupational status as a result of providing care. Similarly, O’Brien (1993) found that 80% of caregivers reported that caregiving demands interfered with their ability to maintain a social life and fulfill work obligations.
**Caregiver burden.** Caregiver burden has been defined in several different ways. Zarit and colleagues (1980) proposed described burden as a feeling of discomfort that occurs during caregiving and in response to the tasks, time constraints, demands, and problems associated with providing care to the care recipient. Braithwaite (1996) expanded the definition to include the internal conflict that caregivers experience when caregiving demands inhibit caregivers’ abilities to meet personal needs. Building on this foundational definition, Kasuya and colleagues (2000) described burden as an emotional reaction to the physical, psychological, emotional, social, and financial difficulties that caregivers experience while providing care. Subjective measures of burden include emotional reactions to caregiving, estimates of the amount of time spent caregiving instead of engaging in necessary and meaningful activities, and the perceived costs of caregiving (Kasuya, Polgar-Bailey & Takeuchi, 2000). Objective measures of burden include tangible costs such as decreased physical energy, reduced social engagement outside of the relationship with the care recipient, financial problems, restricted free time, changes in scheduling due to caregiving, and negative health effects (Akkus, 2011; Hooyman, Gonyea & Montgomery, 1985; Jones, 1996).

Burden is highly prevalent among MS caregivers and has been conceptualized as both a component and cause of reduced mental health. Buchanan and Huang (2011) reported that 40.1% of their sample described caregiving as “burdensome” some of the time, another 11.4% reported caregiving as burdensome most of the time and 9.4% reported that caregiving was burdensome all of the time. In this sample, as well as others, higher burden has been associated with higher depression and distress (Buchanan & Huang, 2011; Buhse, 2008). In a study of Turkish MS caregivers, Akkus (2011) reported positive associations between caregiver burden and hopelessness, conflict in decision-making, leisure activity decline, and social isolation. Researchers have also identified the following care recipient illness factors as significant predictors of caregiver burden: disease severity (Coleman, Rath & Carey, 2001),
incontinence and pain (Knight, Devereux & Godfrey, 1997), mobility problems and need for assistance with walking (Myhr et al., 2001), increased dependence on the caregiver for ADLs (Aronson, Cleghorn, & Goldenberg, 1996; Finlayson & Cho, 2008), depression, neuropsychiatric symptoms, and cognitive impairments (Chipcase & Lincoln, 2001; Dunn, 2010; Figved, Myhr, Larsen, & Aarsland, 2007). These findings suggest that as the care recipient’s level of disability increases, his or her level of dependency on the caregiver increases, which increases daily caregiving tasks (Carton et al., 2000; O’Brien, Wineman, & Nelson, 1995) and the length of time the caregiver must provide care (Buchanan et al., 2010). Other factors associated with caregiver burden include caregiver variables such as low household income, unemployment, co-morbid health conditions, financial problems, female sex, limited social support, perceived uncertainty about the future, and conflicting roles such as parenting while caregiving (Akkus, 2011; Buchanan & Huang, 2011; Chipchase & Lincoln, 2001; Forbes, While, & Mathes, 2007; Good, Bower & Einsporn, 1995; O’Brien et al., 1995).

**Caregiver strain.** Extremely similar to—and often used interchangeably with—burden, caregiver strain is the physical and emotional stress that caregivers experience as a consequence of providing care (Hunt, 2003). Caregiver strain has also been referred to as the “felt difficulty in performing the caregiver role” (Archbold, Stewart, Greenlick & Harvath, 1990, p.376) and theorized to include three dimensions: exhaustion, emotional arousal, and goal discrepancy distress (England and Roberts, 1996). In one of the first studies to examine MS caregiver strain, O’Brien (1993) found that caregivers in her sample reported mean strain scores in the moderate range, 70% endorsed physical strain due to caregiving demands, and 70% reported financial strain. Another study found that 46% of caregivers reported caregiver strain, and the most frequently endorsed aspects of strain were changes in the caregiver’s daily schedule and financial strain (Chipcase & Lincoln, 2001). Chipchase and Lincoln (2001) identified the following care recipient factors as correlates of caregiver strain: disability,
cognitive impairment, changes in mood, and low quality of life, while the primary caregiver factor associated with strain was the caregiver’s mood.

Khan and colleagues (2007) observed that 42% of their sample experienced strain and found that caregivers reported similar types of strain to Chipchase and Lincoln (2001) with the addition of emotional adjustment, non-caregiving related demands, and disturbed sleep. These authors found that correlates of severe strain included problems with emotional adjustment and family adjustment to caregiving-related changes in routine. Correlates of extreme strain were personality and interpersonal changes in the care recipient and changes in personal plans due to caregiving role obligations. Additionally, caregivers reporting significant levels of strain had reduced social relationships and psychological well-being.

**Depression.** In comparison to social functioning and burden/strain, depression has received slightly more research attention in MS caregivers. When compared to a control group of healthy adults, Pakenham (2001) found that MS caregivers were not only more likely to report symptoms of depression, but that 30% of an MS caregiving sample reported clinically significant levels of mild depression. Lehan and colleagues (2012) similarly observed that 40% of MS caregivers in their sample from Mexico endorsed a clinically significant level of depression.

Depression in MS caregivers has been linked to a number of patient factors. In a study of Italian MS caregivers, Pozzilli and colleagues (2004) observed that declines in the care recipient’s mental health and social functioning, as well as increases in disability, over the course of one year were associated with increases in caregiver depression. Other care recipient factors such as disease duration, increased dependency, physical impairments, requiring over 20 hours of care each week, and unexpected psychological changes have been associated with caregiver depression (Covinsky et al., 2003; Haley, LaMonde, Han, Narramore & Schonwetter, 2001; Pinquart & Sörenson, 2003; Pozzilli et al., 2004).
Lehan and colleagues (2012) observed that stress associated with the following MS-related patient symptoms were associated with caregiver depression: patient depression, difficulty speaking, difficulty hearing, emotional changes, and disturbing others.

Also, depression in MS caregivers has been linked to caregiver and family factors. Alshubailli, Awadalla, Ohaeri, and Mabrouk (2007) found that caregiver depression was associated with lower QOL ratings in a sample of Kuwaiti MS caregivers as well as with negative family attitudes towards caregiving (e.g. sadness about the care recipient’s illness, disgust with the illness, and a focus on the exhaustive nature of caregiving). Caregivers’ experiences of burden/strain have also been strongly associated with depression (Buhse, 2008).

Anxiety. Only several studies have examined anxiety as a psychological outcome of MS caregiving which is particularly surprising given the often unpredictability of MS symptom onset and progression. This assertion finds support in Bogosian and colleagues’ (2009) qualitative study which identified constant worry about disease progression, worry about how the disease impacts caregivers’ lives, and worry about the patient’s wellbeing as common themes in MS caregivers’ self-reports. Other studies have found that caregivers endorse high anxiety and often attribute their anxiety to the fear that they might also receive a diagnosis of MS (Alshubailli et al., 2007), and rates of reported anxiety are especially high among MS caregivers who provided psycho-emotional support to the care recipient such as managing mood/personality changes, helping with memory problems, and assisting with fatigue (Pakenham, 2007). Argyriou and colleagues (2011) observed a higher rate of anxiety than depression among a Greek sample of MS caregivers, with 20% reporting moderate levels of anxiety and 3% reporting severe levels of anxiety. In addition to the high anxiety levels, these authors observed a negative correlation between anxiety and caregivers’ QOL scores. Finally, Mickens and colleagues
(2013) found that a sample of Mexican MS caregivers reported both higher state and trait anxiety than healthy age-matched controls.

**Positive psychological outcomes.** While much of the MS caregiving literature emphasizes the negative or adverse psychological consequences of caregiving, the literature has also demonstrated many positive effects of caregiving. Aronson (1997) found that MS caregivers reported more satisfaction with their family relationships and housing than their non-caregiving peers. Similarly, Liedström and colleagues (2010) found that caregivers reported higher satisfaction on dimensions of housing quality, relationships with partners, relationships with friends, and relationships with family. In this study, caregivers also reported the following positive outcomes as a result of MS caregiving: increased connectedness with partner, increased level of engagement with care, interest in learning about MS, participation in support networks, and improved relationships with friends who offer support (Liedström et al., 2010).

In another sample of MS caregivers, Buchanan and Huang (2011) found that lower burden was associated with stronger caregiver/care-recipient relationships among care-recipients with moderate to severe levels of physical disabilities. These authors posited that increased levels of dependency provided caregivers more opportunities for positive interactions that could strengthen the caregiver/care-recipient relationship. Additionally, 30% of MS caregivers report personal growth as an outcome associated with caregiving, and are able to attribute the following benefits to their role as a caregiver: increased interpersonal skills and identification of social supports; gained insight into MS and experience of having a chronic illness; appreciation of life, health, and physical abilities; and new qualities such as determination and self-sacrifice (Pakenham, 2005).

**The Role of Family in MS Caregiving**
As demonstrated in many of the studies reviewed, the vast majority of MS caregivers are often family members of the individual with MS. Researchers offer several reasons for this trend: physical proximity, reduced financial burden, limited access to formal care, emotional attachment to the care-recipient, the need to provide care for long periods of time, and cultural norms/beliefs about who is to provide care (Barraza-Llorén, Bertozzi, González-Pier & Gutiérrez, 2002; Dilworth-Anderson, Williams & Gibson, 2002; Pinquart & Sörenson, 2005; Schulz & Martire, 2004; Soskolne, Halevy-Levin & Ben-Yehuda, 2007). Regardless of the reason for providing care, family members often assume the role of primary caregiver. As such, MS caregiving not only affects the individual caregiver, but also the entire family system (Alshubaili, Ohaeri, Awadalla & Mabrouk, 2008; MS Society of Canada, 2008; National Alliance for Caregiving, 2012).

**Caregiving in Latino Communities**

In Latin America, family members are most likely to become caregivers of individuals with MS in part because of allocentric and collectivistic norms and values that emphasize interdependence within the community, advocate for the prosperity of the community over the well-being of the individual, and encourage the use of family systems for informal care of older adults and individuals with illnesses and disabilities (Hinojosa, Zsembik & Rittman, 2009; Oyserman, Coon & Kemmelmeier, 2002; Triandis, Bontempo, Villareal, Asai & Lucca, 1988). As in many other collectivistic cultures, family is an important part of Latino cultures, and the cultural value of *familismo* or familism often dictates family roles, obligations, and expectations (Zea et al., 1994). Familism has been described as solidarity and loyalty to one’s family that emphasizes the importance of protecting one’s family and fulfilling family needs before meeting the needs of the individual (Burgess & Locke, 1945; John, Resendiz & de Vargas, 1997; Madsen, 1969). Burgess and Locke (1945) have also described familism as a distinction between kin and others (e.g., non-relatives), and note that familism includes the collective use of individual
resources to encourage the prosperity and solidarity of the family. In Latino cultures, familism often manifests as a larger and intergenerational kin network that lives in close proximity, engages in frequent visitation and contact, and provides unconditional social, moral, and financial support during times of celebration and crisis (Burgess & Locke, 1945; Keefe, 1984). In addition to familism, other cultural values implicate family members, especially female family members as caregivers. While many of these cultural values occur within Latin America, they are especially prevalent in Mexico and in the family caregiving practices of family caregivers in Mexico.

Religiosity. Approximately 80-90% of individuals living in Mexico are Roman Catholic and regularly engage in religious practices (Santana & Santana, 2001). In Mexican culture, religion influences gender roles and provides a framework for social mores and norms. Within this religious context, illness and disability are perceived to be God’s Will with a prognosis that only God can control (Rehm, 1999). Because of the importance of God’s Will in the lives of individuals, many family members provide care to others out of an obligation to fulfill God’s Will and out of reverence for religious practices that include care of the sick and underserved (Rehm, 1999). Although religion is typically an individual experience, the widespread influence of the Roman Catholic Church in Mexico often extends beyond the individual and has become embedded in the national culture and cultural norms. As such, individuals may feel accountable at both an individual and a collective level to obey religious teachings and engage in religious practices such as caregiving.

Marianismo. In Mexico there is a strong emphasis on the Virgin Mary as a model of an ideal mother who is virginal, modest, faithful, pure, nurturing, obedient to God, and responsive to the needs of her family (Santana & Santana, 2001; Stevens, 1973). While the Virgin Mary is venerated as a saint throughout Roman Catholicism, the Virgin of Guadalupe, who is believed to be an apparition of the Virgin Mary that appeared to a man in Mexico, is revered throughout Mexico as a national symbol. Her
image has been integrated into religious art and cathedral architecture (Brading, 2001). Catholics living in Mexico and Latin America often celebrate her during festivals, through prayers, and with pilgrimages to La Basilica in Mexico City (Brading, 2001). Both her image and characteristic virtues of femininity, nurturing, purity, and devotion to family have become cultural totems and shaped expectations for women in Mexico. These expectations manifest as cultural practices that encourage sexual abstinence until marriage, marriage, devotion to and care of family members, religious obedience, self-sacrifice, and respect for a paternalistic family structure (Santana & Santana, 2001; Stevens, 1973). Because of her pervasive presence in Mexican culture, women often aspire to achieve standards inspired by the Virgin of Guadalupe, and in doing so, are more likely to comply with expectations of family caregiving.

**Family structure and social hierarchy.** Because of the strong emphasis on family and familism within Latin American cultures, values such as *machismo, respeto*, filial responsibility, and filial obligation are often associated with an increased tendency for family members to provide informal care to other family members within Latin American communities (Pinquart & Sörensen, 2005). Just as women have cultural expectations of femininity based on *marianismo*, *machismo* encourages men to be heads of households, family leaders, financial providers, and protectors of their families (Santana & Santana, 2001; Stevens, 1973). Given their importance to the financial stability and safety of the family, men are unlikely to assume caregiving roles and duties that include personal care, but they may contribute to the household finances and to health care decision making. In this regard, male family members often delegate caregiving duties to their wives, children, and/or other family members.

As authoritarians, the decisions of male family members are often revered and respected because of the cultural value of *respeto*. *Respeto* refers to the importance of respect for elders and other authority figures and for maintaining important interpersonal relationships within the family by complying with this hierarchical relationship (Santana & Santana, 2001). According to *respeto*, older family members
are always revered and cared for by younger generations. As such, *respeto* often results in filial responsibility and filial obligation, which manifest as caregiving that occurs when children provide care to their parents, siblings, or relatives that is instrumental (e.g., helping with household duties, contributing to finances) or emotional in nature (Jurkovic, Kuperminc, Perilla, Murphy, Ibañez, & Casey, 2004).

**Negative and Positive Outcomes of Caregiving in Latino Communities**

Because of the importance of familism in Latino communities (Zinn, 1982), family members who provide care to relatives with MS may be especially vulnerable to negative psychological outcomes because of the cultural obligation to assume the role of a caregiver, the strong cultural values of allocentrism, and the particularly strong emphasis on familism throughout Latino cultures (Losada et al., 2006). In a meta-analysis of general caregiving studies, Pinquart and Sörensen (2005) found that Latino caregivers reported higher depression, provided care for a greater number of years, completed a greater number of caregiving tasks, and endorsed stronger filial obligation beliefs than White caregivers.

When compared to other racial/ethnic groups, Latino caregivers often report limited use of formal support services (Dilworth-Anderson et al., 2002; Pinquart & Sörensen, 2005), larger informal social networks (Hinojosa et al., 2009), increased role strain (Cox & Monk, 1996), lower rates of institutionalization (Dilworth-Anderson et al., 2002), and higher rates of depression (Covinsky et al., 2003; Cox & Monk, 1990). While these studies did not explicitly assess the relationship between familism and these outcomes, researchers have inferred that within Latino caregiving networks, familism may be responsible for the increased use of informal support and the reluctance to use outside support (Aranda & Knight, 1997; Ayalon & Huyck, 2001; Cox & Monk, 1996; Clark & Huttlinger, 1998; Cromwell et al., 1996). Coon and colleagues (2004) found that higher endorsement of familism was associated with lower burden among Latino caregivers. One possible reason for these positive
outcomes is that caregiving promotes role fulfillment in many collectivistic societies where familism, reciprocity, and filial obligation are cultural norms regarding caregiving practices (Spitzer, Neufeld, Harrison, Hughes & Stewart, 2003; Wallhagen & Yamamoto-Mitani, 2006). Despite the increased use of informal support among Latino caregivers, many caregivers report that this support is not sufficient, or that with changing family roles, former sources of informal support may be unavailable, thus increasing their perceived burden and strain (Ayallon & Huyck, 2001; Cox & Monk, 1993; Polich & Gallagher-Thompson, 1997).

In spite of these negative outcomes, several positive outcomes have been associated with caregiving in Latino communities. Latino caregivers have reported higher role satisfaction and decreased desire to stop providing care when compared to caregivers from other racial/ethnic groups (Phillips, Torres de Ardon, Komnenich, Kileen & Rusinak, 2000). Similarly, when compared to other caregivers, Latino caregivers often have higher scores on measures of fulfillment (Evercare and National Alliance for Caregiving, 2008). Researchers attribute these outcomes to positive appraisals of caregiving and cultural values that characterize caregiving as an honorable act and one that strengthens social cohesion (Arévalo-Flechas, 2008; Epps, 2014; Becerra, Karno & Escobar, 1982). Also, many findings point to the importance of religious teachings and religious practices in the positive appraisal of caregiving and Latino caregivers’ coping strategies (Calderon & Tennstedt, 1998; Epps, 2014).

**Family Needs of MS Caregivers**

Because of the high likelihood that family members will provide care to individuals with MS (O’Hara et al., 2004), it is important to examine the needs that MS family caregivers have, however few studies have examined these needs worldwide. Cockerill and Warren (1990) found that family MS caregivers in Canada reported that they had increased needs for respite services (Cockerill & Warren, 1990). In a similar study of Canadian MS caregivers, Aronson and colleagues (1996) found that caregivers
endorsed important needs included obtaining information about MS, financial assistance, and procurement of medical equipment. Using a sample of MS caregivers from Australia, Kristjanson and colleagues (2005) found similar needs for medical equipment to assist with patient ADLs, financial assistance, and information about MS care and treatment from their health care providers.

Sato and colleagues (1996) developed a measure, the MS Needs Assessment (MSNA) to assess the needs of MS caregivers across four domains: physical (e.g., rest, nutrition), self-concept (e.g., perception of physical, personal and interpersonal self), interdependence (e.g., self sufficiency, access to others, receiving support from community organizations), and role function (performing various roles like housekeeper, companion, financial provider). Sato and colleagues (1996) administered this questionnaire to a sample of 21 MS caregivers in Idaho and found that participants reported the following needs as met: physical needs and self concept needs, but reported needing help with interdependence and role function needs. In one of the largest reviews of MS caregiver literature, Corry and While (2009) reported that the most commonly unmet family needs included access to emotional support (Benbow & Koopman, 2003; Courts, Newton & McNeal, 2005; Koopman, Benbow, Vandervoort, 2006); financial support (DeJubicibus & McCabe, 2005; Koopman et al., 2006; Sherman et al. 2007); information on MS care (Koopman et al., 2006; Kristjanson et al., 2005; Wollin, Yates & Kristjanson, 2006); respite care (Khan et al., 2007); feelings of productivity and mastery (Koopman et al., 2006); reassurance from health care providers (Koopman et al., 2006) and perceived interest in the well-being of the patient by treating providers (Koopman et al., 2006).

In the only study to examine family needs among MS caregivers living in Latin America, Arango-Lasprilla and colleagues (2010) used a modified version of Sato and colleague (1996)’s MSNA. Among this caregiver sample (N=43), fulfilled needs included self-concept and physical needs, while interdependence and role function needs were frequently reported as unmet. Moreover, Arango-Lasprilla and colleagues (2010) assessed the relationship between family needs and caregivers’ mental health. Positive correlations
emerged between interdependence, role function, and physical needs with caregiver depression and burden. Additionally, increased physical and interdependence needs were associated with reduced social support (Arango-Lasprilla et al., 2010).

**Statement of the Problem**

As demonstrated by this literature review, MS affects approximately 2.5 million individuals worldwide as well as the family members who assist them (National MS Society, 2012). Because MS is a chronic and progressive neurological disease typically diagnosed among 20-40 year old adults (National MS Society, 2012) nearly all individuals with MS will experience an increased need for long-term care, most likely from family members who provide care for an extended period of time (Aronson, 1997; Buhse, 2008; McKeown et al., 2003). As diagnostic procedures improve in Latin America (Medina & Munsat, 2010), prevalence and incidence rates of MS appear to be increasing, especially in Mexico (Alter & Olivares, 1970; Gonzalez & Sotelo, 1995).

Much like other regions of the world where individuals are diagnosed with MS, patients in Latin America frequently rely on the support of informal caregivers throughout the duration of their illness. Perhaps more so in Latin America, sociocultural values like familism, filial obligation and allocentrism often designate family members as caregivers, and many family members feel obligated to fulfill these expectations. However, there is a paucity of information on the effects of MS caregiving on the family, especially in Latin America where family caregiving is the norm.

Research has established that compared to non-caregivers, MS caregivers report higher levels of depression (Buhse, 2008), anxiety (Pakenham, 1998), and decreased social support (Akkus, 2011). Patient factors such as level of disability, cognitive impairments, behavioral changes, depression, incontinence, pain, mobility problems, and fatigue contribute to increased caregiver depression, strain, and burden (Aronson et al., 1996; Buhse, 2008; Chipcase & Lincoln, 2001; Dunn, 2010; Figved, et al.,
Although many of the findings on MS caregiver functioning emphasize the negative aspects of caregiving, the literature also demonstrates that MS caregivers report salubrious outcomes such as personal growth, role fulfillment, positive emotions, and satisfaction as a result of caregiving (Pakenham, 2005; Pinquart & Sörensen, 2005).

MS caregiving can be understood using Pearlin, Mullan, Semple and Skaff’s (1990) conceptual model of caregiver stress. This model identifies four primary domains of caregiving stress: (a) background and context of the caregiving situation (i.e., caregiver age, gender, ethnicity, socioeconomic status, relationship with the patient, and family and social network composition), (b) primary stressors (i.e., cognitive functioning of patient, behavioral changes, problematic behaviors of the patient, ADLs and instrumental ADLs, burnout, and relational deprivation), and secondary stressors (i.e., family conflict, conflict with occupational and social role fulfillment, economic strain, changes in self-concept, loss of self, role captivity, mastery, competence, and gain), (c) mediators of stress (i.e., coping strategies and social support), and (d) caregiver outcomes (i.e., mental health, physical health, and role changes). These aspects of caregiving often interact, and individually or collectively influence caregiver mental health (Pearlin et al., 1990).

Findings from studies of MS caregivers demonstrate that primary stressors (i.e., patient functioning) have been associated with adverse mental health outcomes such as higher depression and increased burden. Although these studies have examined aspects such as the patient’s cognitive functioning, psychological functioning, physical disability, and ADL impairments, few have examined unmet family needs within the context of these patient-related stressors. Within the framework of Pearlin and colleagues’ (1990) model, family needs (i.e., household needs, informational needs, financial needs, health needs and social support) are an extension of the background/context and
secondary stressor domains. Findings from a previous study demonstrate that unmet family needs are also a central determinant of caregiver adjustment, as they have been associated with increased burden and depression among MS caregivers (Arango-Lasprilla et al., 2010).

Given the often significant impairments documented in individuals with MS, the unknown levels of unmet family needs, and the generally poor mental health that MS caregivers report, many questions remain regarding the specific connections among these sets of variables, especially in Latin America. As such, the objective of the present study is to use parts of Pearlin et al.’s (1990) model to examine the relationships between MS impairments (primary stressor) and family needs (secondary stressor); family needs (secondary stressor) and caregiver mental health (outcome); and MS impairments (primary stressor) and caregiver mental health (outcome), possibly through unmet family needs (secondary stressor), in a sample of Mexican MS caregivers. The following hypotheses are proposed:

**Hypothesis 1:** MS impairments will be associated with higher unmet family needs. Specific associations may include (a) an increased need for household support, financial support, and information among caregivers whose care recipients report greater neurological impairments and greater functional impairments (Aronson, 1996; Carton et al., 2000; Cockerill & Warren, 1990; Kristjanson et al., 2005), and (b) an increased need for social support and information among caregivers of care recipients who report greater emotional and cognitive symptoms (Arango-Lasprilla et al., 2010; Benbow & Koopman, 2003; Cockerill & Warren, 1990; Hakim et al., 2000; Kersten et al., 2000; Koopman, Benbow & Vandervoort, 2008; Sato et al., 1996).

**Hypothesis 2:** MS impairments will be associated with reduced caregiver mental health. Specifically, as demonstrated by previous findings among MS caregivers, patient impairments in functional and emotional domains are hypothesized to have positive associations with caregiver’s scores on measures of depression, burden, and anxiety scores, but negative associations with satisfaction with
life scores (Aronson et al., 1996; Chipcase & Lincoln, 2001; Dunn, 2010; Figved, et al., 2007; Lehan et al., 2012).

Hypothesis 3: Unmet family needs will be associated with reduced caregiver mental health (depression, burden, anxiety, and satisfaction with life), as proposed by Pearlin and colleagues’ (1990) caregiver stress process model, and found in one prior MS caregiver study (Arango-Lasprilla et al., 2010) and in other neurological caregiver populations (Kreutzer et al., 2009; Marsh, Kersel, Havill & Sleigh, 2002; Murray, Maslany & Jeffery, 2006). In particular, unmet social support and health needs will be associated with reduced caregiver mental health (Arango-Lasprilla et al., 2010; Benbow & Koopman, 2003; Koopman, Benbow & Vandervoort, 2008).

Hypothesis 4: The relationship between MS impairments and caregiver mental health will be significantly mediated by unmet family needs. At present, no studies in the MS caregiver literature have examined this possible effect, but based on Pearlin et al.’s (1990) model, primary stressors (e.g., patient functioning) should be associated with reduced caregiver mental health outcomes. Similarly, secondary stressors such as family needs should be associated with both primary stressors (MS impairments) and negative caregiver mental health outcomes and could possibly account for the connection between these two sets of constructs.

Method

The present study is a secondary analysis of data that was collected as part of a larger exploratory study on the psychosocial functioning of individuals with MS and their caregivers (Arango-Lasprilla et al., 2010; Lehan et al., 2012). The larger study was a cross-sectional study of patients and caregivers receiving services at the Mexican Foundation for Multiple Sclerosis and the Department of Neurosciences at the University Center for Health Sciences, University of Guadalajara, Mexico.
Participants

Participants for the current secondary analysis \((N=81)\) were a convenience sample of self-identified MS caregivers recruited from The Mexican Foundation for Multiple Sclerosis and the Department of Neurosciences of the University Center for Health Sciences, University of Guadalajara, Mexico. In order to participate in the study, caregivers had to: (a) be the primary caregiver of an individual with a diagnosis of MS who was at least six months past the date of diagnosis, (b) have provided care to the person with MS for a minimum of six months, and (c) have had no history of a cognitive, serious psychiatric, or neurological disorder themselves. Initially 86 participants were approached, but after screening, five declined or did not meet study criteria. Data were collected from a final sample of 81 caregivers.

Demographic information for the caregiver sample is provided in Table 1. Caregivers were predominately female (66.7%) with a mean age of 43.37 years \((SD = 15.32)\). The majority of caregivers were parents of the individual with MS (45.7%). Caregivers reported that they had provided care for a mean of 52.31 months \((SD = 59.29)\) with an average of 70.96 \((SD = 60.66)\) hours of care per week. In addition to fulfilling caregiving duties, 49.4% of the sample reported outside employment. Reported household income ranged from less than minimum wage (i.e., less than $2,018.70 MXN monthly) to more than five times minimum wage (i.e., $10,093.50 MXN monthly). The mean household income was three to four times the monthly minimum wage (i.e., $6,056.10MXN-$8,074.80MXN, \(SD = 1.82\)).

As seen in Table 2, the majority of patients were female (69.1%) with a mean age of 33.25 \((SD = 10.78)\) years. Mean age at diagnosis was 28.17 years \((SD = 10.17)\), and the average age of symptom onset was 26.29 \((SD = 9.76)\) years. Caregivers identified three clinical courses of MS: relapse-remitting, secondary progressive and primary progressive. As with other samples of individuals with MS, the
majority of patients (79%) had relapse-remitting MS. Nearly 46% of patients reported employment outside of the home.

Table 1.

Characteristics of MS Caregivers (N=81)

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years, mean (SD)</td>
<td>43.37 (15.32)</td>
</tr>
<tr>
<td>Sex, %</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>66.7 %</td>
</tr>
<tr>
<td>Male</td>
<td>33.3 %</td>
</tr>
<tr>
<td>Years of education, mean (SD)</td>
<td>11.74 (4.42)</td>
</tr>
<tr>
<td>Marital status, %</td>
<td></td>
</tr>
<tr>
<td>Married or partnered</td>
<td>67.9 %</td>
</tr>
<tr>
<td>Single</td>
<td>23.5 %</td>
</tr>
<tr>
<td>Widowed</td>
<td>4.9 %</td>
</tr>
<tr>
<td>Divorced or separated</td>
<td>3.7 %</td>
</tr>
<tr>
<td>Relationship to individual with MS, %</td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>45.7 %</td>
</tr>
<tr>
<td>Spouse/romantic partner</td>
<td>32.1 %</td>
</tr>
<tr>
<td>Sibling</td>
<td>12.3 %</td>
</tr>
<tr>
<td>Child</td>
<td>6.2 %</td>
</tr>
<tr>
<td>Friend</td>
<td>1.2 %</td>
</tr>
<tr>
<td>Professional caregiver</td>
<td>1.2 %</td>
</tr>
<tr>
<td>Other</td>
<td>1.2 %</td>
</tr>
<tr>
<td>Duration of caregiving</td>
<td></td>
</tr>
<tr>
<td>Number of months, mean (SD)</td>
<td>52.31 (59.29)</td>
</tr>
<tr>
<td>Hours per week of care, mean (SD)</td>
<td>70.96 (60.66)</td>
</tr>
<tr>
<td>Current occupation, %</td>
<td></td>
</tr>
<tr>
<td>Homemaker</td>
<td>30.9 %</td>
</tr>
<tr>
<td>Full-time employment</td>
<td>25.9 %</td>
</tr>
<tr>
<td>Part-time employment</td>
<td>23.5 %</td>
</tr>
<tr>
<td>Student</td>
<td>8.6 %</td>
</tr>
<tr>
<td>Unemployed</td>
<td>4.9 %</td>
</tr>
<tr>
<td>Retired</td>
<td>3.7 %</td>
</tr>
<tr>
<td>Other</td>
<td>2.5 %</td>
</tr>
<tr>
<td>Monthly household income, %</td>
<td></td>
</tr>
<tr>
<td>Less than minimum wage</td>
<td>1.2</td>
</tr>
<tr>
<td>Minimum wage</td>
<td>7.4</td>
</tr>
<tr>
<td>1-2 times minimum wage</td>
<td>13.6</td>
</tr>
<tr>
<td>2-3 times minimum wage</td>
<td>12.3</td>
</tr>
<tr>
<td>3-4 times minimum wage</td>
<td>8.6</td>
</tr>
<tr>
<td>4-5 times minimum wage</td>
<td>13.6</td>
</tr>
<tr>
<td>More than 5 times minimum wage</td>
<td>43.2</td>
</tr>
</tbody>
</table>
Table 2.

**Characteristics of Individuals with MS as Reported By Caregivers (N=81)**

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years, mean (SD)</td>
<td>33.25 (10.78)</td>
</tr>
<tr>
<td>Sex, %</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>69.1 %</td>
</tr>
<tr>
<td>Male</td>
<td>30.9 %</td>
</tr>
<tr>
<td>Years of education, mean (SD)</td>
<td>13.34 (3.97)</td>
</tr>
<tr>
<td>Marital Status, %</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>49.4 %</td>
</tr>
<tr>
<td>Married or partnered</td>
<td>44.4 %</td>
</tr>
<tr>
<td>Divorced or separated</td>
<td>6.2 %</td>
</tr>
<tr>
<td>MS Clinical Course, %</td>
<td></td>
</tr>
<tr>
<td>Relapse Remitting</td>
<td>79.0 %</td>
</tr>
<tr>
<td>Secondary Progressive</td>
<td>19.8 %</td>
</tr>
<tr>
<td>Primary Progressive</td>
<td>1.2 %</td>
</tr>
<tr>
<td>Age of symptom onset, mean (SD)</td>
<td>26.29 (9.76)</td>
</tr>
<tr>
<td>Age at diagnosis, mean (SD)</td>
<td>28.17 (10.17)</td>
</tr>
<tr>
<td>Current occupation, %</td>
<td></td>
</tr>
<tr>
<td>Full-time employment</td>
<td>27.2 %</td>
</tr>
<tr>
<td>Homemaker</td>
<td>23.5 %</td>
</tr>
<tr>
<td>Part-time employment</td>
<td>18.5 %</td>
</tr>
<tr>
<td>Student</td>
<td>13.6 %</td>
</tr>
<tr>
<td>Unemployed</td>
<td>7.4 %</td>
</tr>
<tr>
<td>Receiving disability</td>
<td>8.6 %</td>
</tr>
<tr>
<td>Other</td>
<td>1.2 %</td>
</tr>
</tbody>
</table>

**Measures**

Eligible caregivers completed a battery of questionnaires in Spanish that assessed the following domains: demographic information, MS-related impairments (cognitive, emotional, functional, behavioral, and neurological), family needs (household, informational, financial, health, and social support), and mental health (anxiety, burden, depression, and satisfaction with life). Measures of depression, anxiety, caregiver burden, satisfaction with life, and caregiver needs had been previously
translated to Spanish and validated in Spanish speaking samples prior to their use in this study. Measures of these constructs were administered in Spanish and scored according to norms produced in Spanish speaking samples. The measure of MS Impairments was translated (forward and backward) into Spanish using methods published by Chapman and Carter (1979) and Guillemin and colleagues (1993). The original English questionnaire was translated into Spanish by a Spanish-speaking psychologist. The translated version was then back-translated into English by a bilingual psychologist who was blinded to the original, English version of the questionnaire. Both translations were compared by a monolingual psychologist from Mexico and a bilingual psychologist living in Spain. No discrepancies were identified. The final version was reviewed by the monolingual psychologist from Mexico.

**Demographic information.** Participants reported information on the following demographic variables: age, sex, educational level, marital status, relationship to the patient, total number of hours per week spent providing care, duration of caregiving in months, household income, and employment status. Household income in Mexico is calculated by monthly salary, where the monthly minimum wage is currently 2,018.70 pesos or approximately $155.40 USD per month (Schiaffino & Espiritu Santo, 2014). Participants’ responses indicated if their income was less than the minimum monthly salary or how much their income exceeded the minimum monthly salary. Caregivers also reported demographic information on patients including age, sex, education, employment status, MS clinical course, and disease duration.

**MS impairments.** Caregivers completed the MS Impairment Questionnaire (MS-IQ; Knight, Devereux & Godfrey, 1997), a 30-item checklist of common MS impairments. Assessed symptoms are grouped into five subscales: Cognitive, Emotional, Behavioral, Neurological, and Functional. Caregivers completed this measure by reporting “yes” for the specific symptoms that their care recipient experienced and “no” for the symptoms that the care recipient did not experience. Item scores are
summed (yes = 1, no = 0) so that subscale scores with higher values indicate domains with a larger number of impairments. For the purpose of this study, the original version of this questionnaire was forward translated into Spanish and then back translated into English using the methodology published by Chapman & Carter (1979). Psychometric properties were not reported by the measure’s authors.

**Anxiety.** Caregivers completed the Spielberger State-Trait Anxiety Inventory (STAI; Spielberger, 1983) as a measure of anxiety. The STAI is a 40-item self-report measure with a two-factor structure. The S-anxiety subscale measures anxiety as a temporary emotional state, while the T-anxiety subscale assesses anxiety as a fixed, personality trait. Both subscales include items that require respondents to rate their anxiety according to a 4-point Likert scale (1 = not at all to 4 = very much so; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983; Spielberger, 2010). Subscale scores range from 20 to 80, with higher scores indicating increased anxiety. Subscale scores greater than or equal to 30 indicate moderate levels of either state or trait anxiety, while subscale scores greater than or equal to 45 indicate severe levels of anxiety (Bunevicius et al., 2013; Spielberger, 1983). Both subscales can be combined to create a total scale which will be used in the current study. Total scale scores range from 40 to 160. The Spanish version of the STAI (Spielberger & Diaz-Guerrero, 1975) was used in this study, and has demonstrated very good construct validity and internal consistency in samples of male (state $\alpha = .93$, trait $\alpha = .96$) and female (state $\alpha = .88$, trait $\alpha = .82$) Spanish speakers (Novy, Nelson, Smith, Rogers & Rowzee, 1995; Virella, Arbona & Novy, 1994).

**Burden.** Caregivers completed the Zarit Burden Inventory (ZBI; Zarit, Reever & Bach-Peterson, 1980). The ZBI is one of the most commonly used measures of caregiver burden and assesses a caregiver’s stress level, role strain, financial strain, relationship changes, guilt, and personal strain in the context of providing care. Using a Likert-rating scale (0-never to 4-nearly always), caregivers rate their feelings about their current caregiving situation. Item scores are summed, and total scores range from 0-
88 with scores of 0-20 indicating little to no burden; scores of 21-40 suggesting mild to moderate burden; scores of 41-60 indicating moderate to severe burden; and scores from 61-88 suggesting severe burden (Karlikaya, Yukse, Varlipas & Tireli, 2005). The ZBI has been validated and used in numerous caregiver populations including TBI caregivers (Siegert, Jackson, Tennant, Turner-Stokes, 2010), dementia caregivers (Zarit et al., 1980) and Parkinson’s caregivers (Martínez-Martín et al., 2007). The Spanish version of the ZBI has demonstrated excellent construct validity and internal reliability (α = 0.92) in samples of Spanish speaking individuals (Martin et al., 1996).

**Depression.** Caregivers completed the Patient Health Questionnaire-9 (PHQ-9; Kroenke, Spitzer & Williams, 2001) as a measure of depressive symptoms. Caregivers completed the 9-item questionnaire by indicating how often they experienced symptoms of depression during a two-week period. Participants used a Likert rating scale (0-Not at all to 3-Nearly every day) to indicate symptom frequency. Item responses are summed, and total scores range from 0 to 27 with higher scores reflecting more severe symptoms of depression. Scores of 0-4 indicates no depression, 5-9 mild depression, 10-14 moderate depression, 15-19 moderately severe depression, and 20-27 severe depression. The PHQ-9 is frequently used in epidemiological studies and clinical settings. In the current study, the PHQ-9 was administered in Spanish. The Spanish version has demonstrated strong construct and criterion validity, as well as excellent internal consistency (α=.92) and convergent validity in Spanish-speaking validation samples (Diez-Quevado et al., 2001; Donlan & Lee, 2010; Wulsin, Somoza & Heck, 2002).

**Satisfaction with life.** Participants completed the Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985). The SWLS is a self-report measure of global life satisfaction comprised of five items. Respondents rate each item according to a 7-point Likert scale (1 = strongly disagree to 7 = strongly agree). Higher total scores represent higher life satisfaction with scores of 5-9 indicating extreme dissatisfaction, 10-14 dissatisfaction, 15-19 slight dissatisfaction, 20 neutral feelings,
21-25 slight dissatisfaction, 26-30 satisfaction, and 31-35 extreme satisfaction. (Pavot & Diener, 1993). Participants completed the Spanish version of the SWLS, which has high internal consistency (α = .88) and good construct validity in Spanish-speaking samples (Atienza, Pons, Balaguer, & García-Merita, 2000; Vázquez, Duque & Hervás, 2013).

**Family needs.** The Family Needs Assessment Tool (FNAT; Rivera, Perrin, Senra, de los Reyes, Olivera, Villaseñor et al., 2013) was created to assess the degree to which needs are met in family caregivers of individuals with neurological conditions in Latin America. The FNAT is comprised of 14 items and has five needs subscales: Household (two items), Informational (three items), Financial (three items), Health (four items), and Social Support (two items). Caregivers completed this assessment by using a 5-point Likert scale (1=strongly disagree to 5=strongly agree) to rate their endorsement of items assessing unmet family needs across the five domains. Higher scores indicate greater areas of unmet needs. Domain scores ranged from 2-10 for Household needs, 3-15 for Informational needs, 3-15 for Financial needs, 4-20 for Health needs, and 2-10 for Social Support needs.

The FNAT was created in Spanish using items from several family needs assessments that had been validated in samples of family caregivers who provided care to individuals with traumatic brain injury, spinal cord injuries, dementia, and MS (Rivera et al., 2013). During its validation, the scale was administered to a sample of 308 Spanish-speaking caregivers residing in Colombia and Mexico (Rivera et al., 2013). Psychometric properties from the validation study demonstrate adequate internal consistency for the overall score (α = .72) and for each of the subscale scores: Household needs (α = .66), Informational needs (α = .74), Financial needs (α = .79), Health needs (α = .57), and Social Support needs (α = .58).

**Procedure**
Prior to recruitment, the Institutional Review Board of the Mexican Foundation of Multiple Sclerosis reviewed and approved the study protocol. Staff at the Mexican Foundation for Multiple Sclerosis and the Department of Neurosciences of the University Center for Health Sciences, University of Guadalajara recruited prospective study participants from a neurology clinic using verbal and written advertisements. Interested participants contacted the research staff and were then screened for eligibility criteria. Eligible caregivers completed informed consent forms prior to data collection. During a 40-minute appointment at the Mexican Foundation for Multiple Sclerosis, a staff psychologist collected sociodemographic information and administered a battery of questionnaires to caregivers using a semi-structured interview format. Use of the semi-structured interview format helped to ensure that the participants understood the item content and did not skip any items. The full battery of questionnaires assessed MS impairments, burden, depression, anxiety, satisfaction with life and caregiver needs, caregivers completed questionnaires that assessed social support and health related quality of life. Findings from these additional measures have been previously studied and published (Arango-Lasprilla et al., 2010; Lehan et al., 2012), and will not be included in this study, which will focus on novel data and the currently proposed relationships between variables.

**Data Analysis**

**Preliminary analyses.** Prior to conducting statistical analyses to test the study’s hypotheses, frequencies and descriptive statistics were run to summarize MS impairments reported by caregivers, frequently reported unmet family needs, and clinically significant caregiver mental health problems. Correlation matrices were calculated to examine bivariate relationships between caregiver demographic variables (e.g., gender, age, duration of care, employment status, household income, educational level, marital status, and relationship to care recipient) and outcome variables, and bivariate relationships
between patient demographic variables (MS clinical course, duration of illness, age, gender, employment status and education level) and outcome variables.

**Hypothesis testing.** Three separate canonical correlation analyses were used to explore the relationships between (a) MS impairments and unmet family needs, (b) unmet family needs and caregiver mental health, and (c) MS impairments and caregiver mental health. A canonical correlation analysis (CCA) is a statistical test that extracts two conglomerations of shared variance (two canonical variates) from two groups of variables and then produces a correlation coefficient \( r \), indexing the strength and direction of the common variance between the canonical variates (Sherry & Henson, 2005). In a CCA, both variates are derived of shared variance from the manifest variables in each of the two sets. For example, in the present study, the variate “caregiver mental health” is comprised of shared variance from the following manifest variables: anxiety (STAI scores), depression (PHQ-9 scores), burden (ZBI scores), and satisfaction with life (SWLS). Unlike a Pearson correlation, which measures shared variance between two manifest variables, a CCA calculates the amount of variance shared between two variable sets (Sherry & Henson, 2005).

Each CCA produces several correlations comprised of unique variance with the first correlation being the largest and subsequent correlations reflecting progressively smaller amounts of unique, shared variance between the two variable sets. In a CCA, the number of correlations produced is equal to the number of variables in the smallest variable set. For example, in a canonical correlation examining the connections between caregiver mental health (comprised of four variables) and family needs (comprised of five variables), a CCA would produce four canonical correlations. However, only the first canonical correlation in each of the three CCAs will be interpreted because additional canonical correlations within the same analysis are often unreliable and increase statistical error. All CCA analyses were conducted using SPSS 21.0 (IBM Corp, 2010). Because there are little to no statistical programs that
calculate power or estimated sample size for a CCA (Tabachnick & Fidell, 2007), the author used the guidelines suggested by Mendoza and colleagues (1978), which assert that a sample size of at least 50-100 participants can identify significant and modest effects. CCAs were chosen over a series of multiple regressions because of the parsimony and comprehensiveness of CCAs. Thirteen multiple regressions would have had to be run in comparison to the three CCAs, and CCAs uniquely identify the strongest system of connections among two sets of variables. Multiple regressions only allow an investigation of the connections between several independent variables and one dependent variable at a time.

A structural equation model (SEM) was created with three latent variables: MS impairments, family needs, and caregiver mental health. MS impairments was comprised of shared variance from the five impairment variables: functional, cognitive, behavioral, emotional, and physical. Family needs were comprised of shared variance from the five types of family needs: household, informational, financial, health, and social needs. Caregiver mental health was comprised of shared variance from the four mental health variables: depression, burden, anxiety, and satisfaction with life. This SEM was conducted using AMOS 20 (Arbuckle, 2007). Because most traditional SEMs in rehabilitation research are run with at least 200 participants (Weston, Gore, Chan, & Catalano, 2008), and the sample size in the current study is 81 participants, estimates of model fit were omitted, as they would likely be inaccurate. Instead, the focus of this analysis was on the size and significance level of the standardized β weight for the indirect effect of MS impairments on caregiver mental health through family needs. Finally, for reference three correlation matrices were calculated to examine the bivariate correlations among MS impairments, family needs, and caregiver mental health.

Results

Summary of Outcome Variables
**MS Impairments.** Participants reported patient impairments in all five domains, as seen in Table 3. Of the neurological symptoms reported, more than 75% of participants reported tiring easily, while over half reported paralysis (69%), poor eyesight (62%), loss of sensation (54%), and clumsiness (52%). More than half of the sample reported the following emotional symptoms: depression (68%), easily upset (68%), irritability (58%), and mood changes (58%). Commonly reported functional and cognitive symptoms were difficulty walking (69%), doing things slowly (56%), forgetfulness (62%), and difficulty concentrating (53%). Less than 40% of participants reported behavioral symptoms, but endorsed acting impulsively (35%) as the most commonly observed behavioral symptom.

Table 3.

**Summary of MS Symptoms Reported by Caregivers (N=81)**

<table>
<thead>
<tr>
<th>Symptom Domain</th>
<th>Symptoms Endorsed</th>
<th>% Endorsing Symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurological</td>
<td>Tiring Easily</td>
<td>79%</td>
</tr>
<tr>
<td></td>
<td>Paralysis</td>
<td>69%</td>
</tr>
<tr>
<td></td>
<td>Poor Eyesight</td>
<td>62%</td>
</tr>
<tr>
<td></td>
<td>Loss of Sensation</td>
<td>54%</td>
</tr>
<tr>
<td></td>
<td>Clumsiness</td>
<td>52%</td>
</tr>
<tr>
<td></td>
<td>Pain</td>
<td>36%</td>
</tr>
<tr>
<td></td>
<td>Incontinence</td>
<td>27%</td>
</tr>
<tr>
<td></td>
<td>Seizures</td>
<td>14%</td>
</tr>
<tr>
<td>Emotional</td>
<td>Depression</td>
<td>68%</td>
</tr>
<tr>
<td></td>
<td>Easily Upset</td>
<td>68%</td>
</tr>
<tr>
<td></td>
<td>Irritability</td>
<td>58%</td>
</tr>
<tr>
<td></td>
<td>Mood Changes</td>
<td>58%</td>
</tr>
<tr>
<td></td>
<td>Anxiety</td>
<td>49%</td>
</tr>
<tr>
<td></td>
<td>Loss of Interest</td>
<td>33%</td>
</tr>
<tr>
<td>Functional</td>
<td>Difficulty Walking</td>
<td>69%</td>
</tr>
<tr>
<td></td>
<td>Doing Things Slowly</td>
<td>56%</td>
</tr>
<tr>
<td></td>
<td>Trouble Reading</td>
<td>33%</td>
</tr>
<tr>
<td></td>
<td>Difficulty Writing</td>
<td>32%</td>
</tr>
<tr>
<td></td>
<td>Difficulty Talking</td>
<td>27%</td>
</tr>
<tr>
<td></td>
<td>Difficulty Eating</td>
<td>22%</td>
</tr>
<tr>
<td></td>
<td>Difficulty Hearing</td>
<td>20%</td>
</tr>
</tbody>
</table>
Cognitive
  Forgetfulness                     62%
  Difficulty Concentrating         53%
  Difficulty Thinking              38%
  Poor Decision Making             30%
  Difficulty Learning              27%
  Denying Problems                 27%

Behavioral
  Acting Impulsively               35%
  Upsetting Other People          28%
  Not Being Reliable               12%

**Family Needs.** Caregivers’ item responses to the FNAT were ranked (identifying the top five) by the percentage of unmet (Table 4) and met (Table 5) need endorsement.

Table 4.

*Summary of Unmet Family Needs*

<table>
<thead>
<tr>
<th>Family Need</th>
<th>% Endorsed as Unmet</th>
<th>Domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>I need complete information</td>
<td>71.6 %</td>
<td>Information</td>
</tr>
<tr>
<td>I need specialized information about the patient.</td>
<td>70.3 %</td>
<td>Information</td>
</tr>
<tr>
<td>I get help from the community (reverse coded)</td>
<td>65.5 %</td>
<td>Social Support</td>
</tr>
<tr>
<td>I get support from my church (reverse coded)</td>
<td>61.7 %</td>
<td>Social Support</td>
</tr>
<tr>
<td>I need to discuss my feelings with someone who has been through the same experience</td>
<td>45.7 %</td>
<td>Information</td>
</tr>
</tbody>
</table>

As illustrated in Table 4, 60% of the needs identified were from the Informational domain, while the remaining needs were from the Social Support domain. In fact, all of the items from these two domains were present in the ranking of the five most highly endorsed unmet needs. Table 5 summarizes the
remaining items where a higher percentage of participants rated the need as met. Participants had the most met needs from the Health, Household, and Financial domains.

Table 5.

Summary of Met Family Needs

<table>
<thead>
<tr>
<th>Family Need</th>
<th>% Endorsed as Met</th>
<th>Domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel good about myself (reverse coded)</td>
<td>92.6 %</td>
<td>Health</td>
</tr>
<tr>
<td>I feel good about my personal appearance (reverse coded)</td>
<td>74.1 %</td>
<td>Health</td>
</tr>
<tr>
<td>I need help with preparing meals</td>
<td>60.5 %</td>
<td>Household</td>
</tr>
<tr>
<td>I need financial help</td>
<td>56.8 %</td>
<td>Financial</td>
</tr>
<tr>
<td>I can exercise regularly (reverse coded)</td>
<td>55.6 %</td>
<td>Health</td>
</tr>
</tbody>
</table>

Caregiver Mental Health. Using descriptive statistics and frequency distributions, caregiver mental health variables were examined by domain (e.g., depression, anxiety, burden, and satisfaction with life). Table 6 provides a summary of mean scores and percentages of participants with scores in clinical ranges.
Table 6.

Summary of Caregiver Mental Health Outcomes

<table>
<thead>
<tr>
<th>Variable</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHQ-9 Total Score, mean (SD)</td>
<td>5.92 (5.27)</td>
</tr>
<tr>
<td>Mild Depression (%)</td>
<td>26%</td>
</tr>
<tr>
<td>Moderate Depression (%)</td>
<td>16%</td>
</tr>
<tr>
<td>Moderate-Severe Depression (%)</td>
<td>3.7%</td>
</tr>
<tr>
<td>Severe Depression (%)</td>
<td>1.2%</td>
</tr>
<tr>
<td>STAI Total Score, mean (SD)</td>
<td>47.01 (21.40)</td>
</tr>
<tr>
<td>STAI-State, mean (SD)</td>
<td>22.67 (11.82)</td>
</tr>
<tr>
<td>STAI-Trait, mean (SD)</td>
<td>24.34 (10.97)</td>
</tr>
<tr>
<td>State Moderate Anxiety (%)</td>
<td>32%</td>
</tr>
<tr>
<td>State Severe Anxiety (%)</td>
<td>2.5%</td>
</tr>
<tr>
<td>Trait Moderate Anxiety (%)</td>
<td>31%</td>
</tr>
<tr>
<td>Trait Severe Anxiety (%)</td>
<td>3.7%</td>
</tr>
<tr>
<td>ZBI Total Score, mean (SD)</td>
<td>22.02 (14.72)</td>
</tr>
<tr>
<td>Mild to Moderate Burden (%)</td>
<td>29.6%</td>
</tr>
<tr>
<td>Moderate to Severe Burden (%)</td>
<td>12.3%</td>
</tr>
<tr>
<td>Severe Burden (%)</td>
<td>1.2%</td>
</tr>
<tr>
<td>SWLS Total Score, mean (SD)</td>
<td>23.43 (6.35)</td>
</tr>
<tr>
<td>Dissatisfaction (%)</td>
<td>26%</td>
</tr>
<tr>
<td>Neutral (%)</td>
<td>7%</td>
</tr>
<tr>
<td>Satisfaction (%)</td>
<td>67%</td>
</tr>
</tbody>
</table>

Total scores on the PHQ-9 ranged from 0-21 out of a possible maximum score of 27. The sample mean of 5.92 (SD = 5.27) indicated frequent endorsement of mild symptoms of depression. Nearly half of the sample reported clinically significant levels of depression, with 26% reporting mild symptoms, 16% reporting moderate symptoms, and 1.2% reporting severe symptoms of depression. This sample’s depression scores reflects similar trends among other groups of MS caregivers, where 48% of MS caregivers in Mexico reported minimal depression, and 40% reported clinically significant depression as assessed by the PHQ-9 (Lehan et al., 2012). By contrast, epidemiological data from Mexico suggest a lifetime prevalence of 7.2% for Major Depressive Disorder (Medina-Mora, Borges, Benjet, Lara, &
Berglund, 2007), which demonstrates that reported rates of depression in the current study are higher than those generally reported in the Mexican population.

Both total and subscale scores (e.g., State and Trait) of the STAI were reviewed. Participants’ total scores ranged from 11-93 out of a maximum score of 160. Nearly one third of participants reported clinically significant symptoms of State or Trait anxiety with 32% reporting moderate symptoms on the State subscale and 2.5% reporting severe symptoms on the State subscale of the measure. Responses on the Trait subscale demonstrated that 31% of participants reported moderate symptoms on the Trait subscale, while 3.7% reported severe symptoms. Although few studies have examined anxiety among MS caregivers, Argyriou and colleagues (2011) reported mean scores that reflected mild anxiety among their sample, while the scores in the current study demonstrated sub-clinical mean values for state and trait anxiety, even though one third of the sample endorsed moderate symptoms of anxiety. When comparing this sample’s scores to epidemiological lifetime prevalence data for anxiety in Mexico, participants in this sample reported higher than expected anxiety (i.e., 14.3% prevalence rate as reported by Medina-Mora et al., 2007).

Total scores on the ZBI ranged from 0 to 62 out of a maximum score of 88. The sample mean of 22.02 (SD = 14.72) indicated that on average, participants reported mild to moderate symptoms of burden. Further review of clinically significant scores revealed that 29.6% reported mild to moderate symptoms, 12.3% reported moderate to severe symptoms, and 1.2% reported severe symptoms of burden. Comparison with other studies of MS caregivers demonstrates that the current sample’s mean scores on the ZBI and reported percentages of MS caregivers experiencing mild, moderate, and severe burden is much lower than rates reported in other samples. For example, in another sample of MS caregivers, Akkus (2011) reported a mean ZBI score of 36.42 (SD = 18.41), while Buchanan and Huang
(2011) found that 40% of their sample described caregiving as burdensome some of the time and 11.4% reported that caregiving was burdensome all of the time.

Total scores on the SWLS ranged from 10 to 35 out of a maximum score of 35. The sample mean of 23.43 ($SD = 6.35$) indicated an overall feeling of slight dissatisfaction. Further examination revealed that 26% of participants reported some level of dissatisfaction with life, 7% felt neutral, and 67% reported some level of satisfaction with life.

**Bivariate Relationships between Demographic Variables and Outcome Variables**

A correlation matrix was calculated to examine the bivariate relationships between caregiver demographic variables (e.g., age, years of education, sex, marital status, hours of weekly care, duration of caregiving, current occupation, and income) and outcome variables (MS impairments, family needs, and caregiver mental health; Table 7). Results demonstrated significant relations between the following sets of MS impairments and caregiver demographic variables: greater functional impairments with increasing hours of weekly care ($r = .25, p < .05$), and greater behavioral impairments with unemployed caregivers ($r = -.25, p < .05$).

Table 7.

**Correlations Between Caregiver Demographics, MS Impairments, Family Needs and Mental Health Variables**

<table>
<thead>
<tr>
<th>Variables</th>
<th>CG Age</th>
<th>CG Education</th>
<th>CG Sex</th>
<th>CG Hrs/Wk</th>
<th>CG Duration</th>
<th>Income</th>
<th>Employment</th>
<th>Marital Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functional Sx</td>
<td>.11</td>
<td>-.07</td>
<td>.00</td>
<td>.25*</td>
<td>.08</td>
<td>-.03</td>
<td>-.13</td>
<td>-.15</td>
</tr>
<tr>
<td>Neurological Sx</td>
<td>-.14</td>
<td>-.03</td>
<td>-.01</td>
<td>.15</td>
<td>.04</td>
<td>-.04</td>
<td>-.11</td>
<td>-.17</td>
</tr>
<tr>
<td>Behavioral Sx</td>
<td>.08</td>
<td>-.04</td>
<td>.13</td>
<td>.15</td>
<td>.15</td>
<td>.11</td>
<td>-.25*</td>
<td>-.01</td>
</tr>
<tr>
<td>Emotional Sx</td>
<td>.05</td>
<td>-.05</td>
<td>.02</td>
<td>.10</td>
<td>.11</td>
<td>.14</td>
<td>.19</td>
<td></td>
</tr>
<tr>
<td>Cognitive Sx</td>
<td>-.12</td>
<td>-.09</td>
<td>-.02</td>
<td>-.04</td>
<td>-.15</td>
<td>-.03</td>
<td>.13</td>
<td>.09</td>
</tr>
<tr>
<td>Household</td>
<td>.01</td>
<td>-.11</td>
<td>.29**</td>
<td>.21</td>
<td>.16</td>
<td>-.12</td>
<td>-.25*</td>
<td>-.03</td>
</tr>
<tr>
<td>Informational</td>
<td>-.00</td>
<td>.07</td>
<td>-.06</td>
<td>-.10</td>
<td>-.10</td>
<td>.10</td>
<td>-.08</td>
<td>.05</td>
</tr>
<tr>
<td>Financial</td>
<td>.13</td>
<td>-.35**</td>
<td>.25*</td>
<td>.26*</td>
<td>.32**</td>
<td>-.32**</td>
<td>-.21</td>
<td>-.13</td>
</tr>
<tr>
<td>Health</td>
<td>.18</td>
<td>-.17</td>
<td>.27*</td>
<td>.20</td>
<td>.30**</td>
<td>-.00</td>
<td>-.08</td>
<td>.20</td>
</tr>
<tr>
<td>Social Support</td>
<td>.03</td>
<td>.02</td>
<td>.07</td>
<td>.32**</td>
<td>.11</td>
<td>-.10</td>
<td>-.10</td>
<td>.03</td>
</tr>
<tr>
<td>Sat. with Life</td>
<td>-.06</td>
<td>.10</td>
<td>-.16</td>
<td>-.11</td>
<td>-.05</td>
<td>.15</td>
<td>.25*</td>
<td>.04</td>
</tr>
</tbody>
</table>
Associations were identified between the following sets of family needs and caregiver demographics: greater household needs among female caregivers ($r = .29, p < .01$) and fewer household needs among employed caregivers ($r = -.25, p < .05$), fewer financial needs with increasing educational levels ($r = -.35, p < .01$) and increasing household income ($r = -.32, p < .01$), greater financial needs with female sex ($r = .25, p < .05$), increasing hours of weekly care ($r = .26, p < .05$) and increasing duration of care ($r = .32, p < .01$), greater health needs among female caregivers ($r = .27, p < .05$) and those with a longer duration of providing care ($r = .30, p < .01$), and greater social support needs with increasing hours of weekly care ($r = .32, p < .01$).

Significant relationships were identified between the following mental health variables and caregiver demographics: current employment associated with greater satisfaction with life ($r = .25, p < .05$) as well as decreased burden ($r = -.37, p < .001$) and depression ($r = -.36, p < .001$), increasing educational level and lower burden ($r = -.26, p < .05$), female sex and higher anxiety ($r = .37, p < .01$), burden ($r = .26, p < .05$), and depression ($r = .38, p < .01$), increasing hours of weekly care and higher burden ($r = .24, p < .05$) and depression ($r = .24, p < .05$), longer duration of caregiving and higher burden ($r = .25, p < .05$) and depression ($r = .31, p < .01$), and, lower burden ($r = -.34, p < .01$) and depression ($r = -.36, p < .01$).

A second correlation matrix was calculated to examine the bivariate relationships between patient demographic variables (e.g., sex, age, years of education age at diagnosis, age at symptom onset, time since diagnosis, MS type, occupation, and marital status) and outcome variables (MS impairments, family needs, and caregiver mental health; Table 8). The following significant relations were identified
between patient demographic variables and MS impairments: functional symptoms were associated with progressive MS types \((r = .35, p < .01)\), and behavioral symptoms were associated with younger patients \((r = -.27, p < .05)\), younger age at diagnosis \((r = -.31, p < .01)\), younger age of symptom onset \((r = -.27, p < .05)\), and patients without romantic partners or spouses \((r = -.38, p < .01)\).

Associations between the following patient demographic and family needs variables were identified: greater household needs were associated with progressive MS types \((r = .28, p < .05)\), greater financial needs were associated with younger age at diagnosis \((r = -.32, p < .01)\), younger age of symptom onset \((r = -.29, p < .01)\), progressive types \((r = .23, p < .01)\), unemployment \((r = -.36, p < .01)\) and marital status (e.g., single, \(r = -.22, p < .05\)). Greater health needs were associated with younger age at diagnosis \((r = -.30, p < .01)\) and younger age of symptom onset \((r = -.28, p < .05)\).

Significant relationships were identified between the following patient demographic and caregiver mental health variables: satisfaction with life was associated with female sex \((r = .24, p < .05)\), older patient age \((r = .25, p < .05)\), older age at diagnosis \((r = .27, p < .05)\), older age of symptom onset \((r = .23, p < .05)\), and partnered patients \((r = .36, p < .01)\). Caregiver anxiety was associated with providing care to male patients \((r = -.27, p < .05)\), younger patients \((r = -.29, p < .01)\), younger age at diagnosis \((r = -.26, p < .05)\), younger age of symptom onset \((r = -.23, p < .05)\), and marital status (e.g., single, \(r = -.27, p < .05\)). Burden was associated with progressive MS types \((r = .45, p < .01)\) and marital status (e.g., single, \(r = -.28, p < .05\)). Caregiver depression was associated with providing care to male patients \((r = -.35, p < .01)\), progressive MS types \((r = .33, p < .01)\), unemployment \((r = -.25, p < .05)\) and marital status (e.g. single; \(r = -.34, p < .01\)).

Table 8.

Correlations Between Patient Demographics, MS Impairments, Family Needs, and Caregiver Mental Health Variables
Variables | Sex | Age | Education | Age At Dx | Age of Sx Onset | Time Since Dx | MS Type | Employed | Marital Status
--- | --- | --- | --- | --- | --- | --- | --- | --- | ---
Functional Sx | -.15 | .22 | -.13 | .18 | .11 | .08 | .35** | -.17 | -.18
Neurological Sx | .11 | .06 | .04 | -.02 | -.06 | -.14 | .18 | -.02 | -.14
Behavioral Sx | -.15 | -.27* | -.07 | -.31** | -.27* | -.00 | .21 | -.19 | -.39**
Emotional Sx | -.17 | -.21 | .00 | -.21 | -.14 | .08 | .05 | .07 | -.22
Cognitive Sx | -.06 | -.02 | -.02 | -.08 | -.13 | -.07 | .22 | -.06 | -.14
Household | -.07 | -.02 | -.05 | -.05 | .04 | -.01 | .28* | -.18 | -.10
Informational | -.15 | -.07 | .01 | .05 | .08 | -.21 | -.10 | -.05 | -.19
Financial | -.04 | -.20 | -.13 | -.32** | -.29** | .13 | .23* | -.36** | -.22*
Health | -.05 | -.18 | .10 | -.30** | -.28* | .17 | .08 | -.10 | -.17
Social Support | .08 | .04 | .10 | -.02 | -.03 | .08 | .07 | .01 | -.16
Sat. with Life | .24* | .25* | .04 | .27* | .23* | .00 | -.13 | .06 | .36**
Anxiety | -.27* | -.29** | .00 | -.26* | -.23* | -.11 | .13 | -.05 | -.27*
Burden | -.13 | -.06 | .04 | -.20 | -.18 | .17 | .45** | -.19 | -.28*
Depression | -.22* | -.15 | -.12 | -.21 | -.19 | .07 | .33** | -.25* | -.34**

Abbreviations: sat., satisfaction; sx., symptoms; dx., diagnosis

Note. * denotes p < .05, ** p < .01

Hypothesis Testing

Three canonical correlation analyses (CCAs) were conducted to test each of the first three hypotheses. The first CCA examined which MS impairments (neurological, functional, behavioral, cognitive, and emotional) were associated with higher unmet family needs (financial, informational, household, social support, and health). In this analysis, the first canonical correlation was not statistically significant, \( r = .38, \lambda = .71, \chi^2 (25) = 24.64, p = .48 \), and neither were the other four canonical correlations. As such, the canonical loadings for this analysis will not be interpreted, and Hypothesis 1 was not supported, although the non-significant correlation coefficient between the two variable sets was medium-sized.

The second CCA examined whether MS impairments (neurological, functional, behavioral, cognitive, and emotional) were associated with reduced caregiver mental health (depression, anxiety, burden, and satisfaction with life). The first canonical correlation for this hypothesis was statistically significant, \( r = .69 \) (48% overlapping variance), \( \lambda = .43, \chi^2 (20) = 62.84, p < .001 \), which is considered a
large effect. None of the other three canonical correlations were statistically significant. Standardized canonical coefficients were calculated to compare the relative contributions of the variables within each variable set to the overall canonical correlation. As seen in Figure 1, the standardized coefficients for the MS impairments associated with caregiver mental health variables demonstrated that only behavioral symptoms (-.67) loaded at or above the conventional cutoff of .40. Among the caregiver mental health variables, satisfaction with life (.73) and burden (-.52) were the highest loadings, and the only two to exceed the cutoff of .40. These associations suggest that when patients experience behavioral symptoms, caregivers report higher burden and decreased satisfaction with life. As a result, Hypothesis 2 was supported.

Figure 1. Canonical Correlation between MS Impairments and Caregiver Mental Health.

The third CCA examined whether unmet family needs (financial, household, social support, informational, and health) were associated with caregiver mental health variables (depression, anxiety, burden, and satisfaction with life). The first canonical correlation for this analysis was statistically significant, \( r = .54 \) (29% overlapping variance), \( \lambda = .56, \chi^2 (20) = 42.88, p < .01 \), which is considered a large effect. Standardized coefficients were calculated to identify the relative contribution of the individual variables within each variable set to the overall canonical correlation. As seen in Figure 2, the standardized coefficients for the unmet family needs that loaded highly and exceeded the cutoff of .40 were Financial (-.83), Social Support (-.41), and Information (-.40) needs. Burden (-.82) emerged as the only mental health variable to load above the cut-off of .40. This pattern of associations indicates that
unmet financial, social support, and informational needs were associated with higher caregiver burden. As a result, Hypothesis 3 found support.

Hypothesis 4: Two structural equation models (SEMs) were created to examine whether unmet family needs mediated the relationship between MS impairments and caregiver mental health. Both models included three latent variables: MS impairments, family needs, and caregiver mental health. MS impairments was comprised of the following five manifest variables: neurological, cognitive, functional, behavioral, and emotional symptoms. Family needs was created using the five manifest variables of financial, informational, household, health, and social support needs. Caregiver mental health was created using four manifest variables of depression (PHQ-9), anxiety (Total STAI), burden (ZBI), and satisfaction with life (SWLS). The first SEM examined correlations (e.g., bidirectional paths) between each of the latent variables as opposed to directional paths. In this model, only one statistically significant correlation emerged between MS impairments and caregiver mental health at $r = -0.64 (p < 0.01)$. The bivariate relationships between MS impairments and family needs ($r = 0.34, p = 0.39$) and family needs and caregiver mental health ($r = -0.55, p = 0.37$) were not statistically significant. Although two of these correlations were not statistically significant, all three were in the expected direction and were at least medium-sized.

In the second SEM (Figure 3), MS impairments were specified to lead directly to caregiver mental health, as well as to have an indirect effect on caregiver mental health through family needs. In
this model, MS impairments was significantly associated with caregiver mental health ($\beta = -0.51, p = 0.003$). MS impairments was not significantly associated with family needs ($\beta = 0.34, p = 0.39$), nor was family needs associated with caregiver mental health ($\beta = -0.38, p = 0.39$). However, again all three directional paths were in the hypothesized direction. The indirect effect of MS impairments on caregiver mental health through family needs was statistically significant ($\beta = 0.13, p = 0.008$), suggesting the presence of an indirect (or mediational) effect and supporting Hypothesis 4.

![Figure 3. SEM of the Mediation of Family Needs on the Relationship between MS Impairments and Caregiver Mental Health](image)

Figure 3. SEM of the Mediation of Family Needs on the Relationship between MS Impairments and Caregiver Mental Health
Discussion

The present study was designed to examine the caregiving experiences of MS caregivers living in Guadalajara, Mexico with a specific emphasis on identifying possible relationships among MS impairments, family needs, and caregiver mental health. Using Pearlin and colleagues’ (1990) model of caregiver stress as a conceptual framework, the following study aims were proposed: to assess the general and specific relationships between (a) MS impairments (primary stressor) and family needs (secondary stressor), (b) family needs (secondary stressor) and caregiver mental health (outcome), and (c) family needs (secondary stressor) and caregiver mental health (outcome); as well as (d) to examine the meditational effect of family needs (secondary stressor) on the relationship between MS impairments (primary stressor) and caregiver mental health (outcome). The findings in this regard generally support the use of Pearlin and colleagues’ (1990) model and identify additional areas for intervention and subsequent research. The discussion will summarize these findings, draw connections between the findings and the previous literature, and address clinical implications, strengths, and limitations of the current study.

Hypothesis 1: MS impairments and unmet family needs

The first hypothesis predicted a relationship between MS impairments and unmet family needs, and specifically, that neurological and functional impairments would be associated with unmet household, financial, and informational needs. The first canonical correlation analysis (CCA) demonstrated a medium-sized, but non-significant effect between MS impairments and unmet family needs. As such, Hypothesis 1 was not supported by the CCA, and associations between specific impairments and specific unmet needs were not examined using canonical loadings. Although Hypothesis 1 was not supported using the CCA, bivariate correlations identified relationships between specific MS impairments and family needs that were not hypothesized. Significant positive correlations...
emerged between emotional impairments and informational needs, behavioral impairments and household needs, and behavioral impairments and financial needs.

Caregivers who provided care to individuals with emotional symptoms (e.g., depression, easily upset, irritability, mood changes, anxiety, and loss of interest) tended to experience a greater need for information (e.g., complete information about the patient, specific information about MS, and support from someone else with MS caregiving experience). In the previous literature, relationships have somewhat similarly emerged between family needs for information and higher pain, fatigue (Aronson et al., 1996; Pakenham, 2007), and functional impairments (Carton et al., 2000; Chipchase & Lincoln, 2001; Kristjanson et al., 2005; Pakenham, 2007) in individuals with MS, as well as between increased family needs for emotional support and emotional, functional, and neurological MS symptoms (Pakenham, 2007). Despite these similar findings, no studies have identified a specific relationship between emotional symptoms and informational family needs.

Several explanations may account for this relationship. First, the informational needs assessed in this sample include a need for education about the disease and advice/support from an individual who has had similar experiences, and this finding suggests that this need is especially prevalent when the patient has emotional problems. Caregivers likely need informational support from people with experience managing the emotional symptoms MS and/or relevant training. During the past decade, numerous organizations have highlighted the burden of mental illness and treatment gaps in Latin America. Compared to different global regions, Latin America has fewer mental health providers, minimal insurance coverage for mental health care, and health care providers (e.g., primary care physicians, nurses, neurologists) with inadequate training in the assessment, diagnosis, and treatment of mental health disorders (Alarcón, 2003; Caldas de Almeida & Horvitz-Lennon, 2010; Kohn, Levav, de Almeida, Vincente, Andrade, Caraveo-Anduaga et al., 2005; Rodriguez, 2010). The current findings
suggest a need for providers in Guadalajara, Mexico to have knowledge of psychological and psychiatric treatment in addition to knowledge about the physical components of MS, and to share this knowledge with caregivers.

Second, much of the MS research conducted in Latin America and used to inform health care providers has focused on identifying MS epidemiology with a strong emphasis on the diagnosis and treatment of neurological symptoms of the disease. As such, many patients and their families may characterize MS as a disease with solely physical symptoms that lead to physical disability because they may not know about or understand the emotional symptoms that can accompany the physical symptoms. Limited knowledge about the frequency and impact of emotional symptoms of MS may increase caregivers’ feelings of helplessness and may tax their coping resources because emotional symptoms may be unexpected and negatively impact the interpersonal relationship between the caregiver and the patient. Because of the strong cultural emphasis on positive interpersonal relationships and supportive family relationships in Latin America (Villarreal, Blozis, & Widaman, 2005), emotional symptoms that disrupt the caregiver-care recipient relationship and other familial relationships may be particularly overwhelming, thus creating a greater need for caregivers to find ways to manage these symptoms.

Third, cultural stigma and shame regarding mental health may actually contribute to increased family informational needs when individuals with MS display these symptoms. Among many families in Latin America, mental illness may be minimized or described to others as nervios, which is a more innocuous term describing a reaction to situational stress and preventing the perception of locura or severe mental illness with symptoms of psychosis (Applewhite, Garcia Biggs, & Herrera, 2009; Guernaccia, Martinez, & Acosta, 2005). At the individual level, the internalized stigma associated with mental illness has lead to increased shame and humiliation about emotional symptoms, which manifests as self-imposed isolation, increased use of family caregiving, and reduced mental health services
utilization in Latin America (Acuña & Bolis, 2005). Similarly, the cultural value of ponerse de su parte encourages individuals to rely on the support of family or their own emotional resources when coping with mental health problems, as opposed to formal providers (Guernaccia, Martínez, & Acosta, 2005; Ortega & Alegria, 2002). Because of the tendency for individuals with emotional symptoms to use family members for support instead of seeking professional care, informational needs likely arise given the unpredictability of MS symptoms and the need for treatments such as psychotropic medications and psychotherapy to manage the emotional symptoms of MS.

In addition to this relationship, caregivers who provided care to individuals with behavioral symptoms (e.g., impulsivity, upsetting others, not being reliable) needed greater assistance with household tasks and with meeting financial obligations. Across studies of caregivers of individuals with neurological conditions, behavioral symptoms have emerged as some of the most distressing and difficult symptoms for caregivers to manage because they are frontal deficits that are difficult to treat, require constant monitoring, and can lead to dangerous outcomes for the patient (Figved et al., 2007; Gaugler, Wall, Kane, Menk, Sarsour, Johnston et al., 2010; Koskinen, 1998; Rymer, Salloway, Norton, Malloy, Correia & Monast, 2002). Behavioral symptoms may occur in MS and personality and social behavioral changes may confuse, frighten, and embarrass caregivers, and may result in care confined to the home and increased social isolation. Because of the increased amount of time spent with the patient at home, caregivers may have less time and energy to complete household chores while continuously monitoring the patient. Similarly, the amount of time needed to provide continuous care to a patient with behavioral symptoms restricts the amount of hours available for employment, which may explain the relationship between behavioral symptoms and unmet financial needs.

Previous research has yet to identify a relationship between the presence of behavioral symptoms in individuals with MS and increased family needs. Although there is limited knowledge about the
relationship between behavioral impairments and family needs, previous findings have established a consistent relationship between MS caregiving and greater needs for household support and financial assistance as the patient’s physical disability and functional impairments increase (Carton et al., 2000, DeJubicibus & McCabe, 2005; Koopman et al., 2006; Sherman et al. 2007). As such, the findings of this study introduce a new potential area of clinical intervention and assessment for health care providers, especially among this sample of caregivers from Mexico.

**Hypothesis 2: MS impairments and caregiver mental health**

The second hypothesis predicted a broad relationship between MS impairments and reduced caregiver mental health and more specifically that functional and emotional impairments would be associated with increased caregiver depression, burden, and anxiety, but decreased satisfaction with life. A second CCA yielded a large-sized correlation coefficient between MS impairments and caregiver mental health variables, strongly supporting the second hypothesis. Canonical loadings revealed that caregivers of individuals with higher behavioral symptoms were more likely to report higher burden and decreased satisfaction with life. One of the study’s strongest findings was the relationship between increased MS impairments and reduced caregiver mental health. While several specific symptoms have been associated with increased burden among MS caregivers, numerous findings have supported the association between increased functional disability and increased burden (Aronson et al.,1996; Finlayson & Cho, 2008; Myhr et al., 2001), and the presence of behavioral and psychiatric symptoms and increased burden (Chipcase & Lincoln, 2001; Dunn, 2010; Figved et al., 2007). In this sample, 43% of caregivers reported burden, and the most frequently endorsed patient symptom domains included neurological, emotional, functional, and cognitive symptoms, respectively. Even though behavioral symptoms were the least endorsed in this sample, caregivers who observed these symptoms in patients were more likely to experience increased burden.
In the second CCA, decreased caregiver satisfaction with life was also shown to be strongly associated with patient behavioral symptoms. The findings from this study are consistent with the previous MS caregiver literature, where lower caregiver satisfaction with life was associated with functional impairments (Khan et al., 2007), cognitive and behavioral symptoms (Figved et al., 2007; Khan et al., 2007), and progressive types of MS, which are more likely to have behavioral symptoms (Noseworthy & Hartung, 2006).

One explanation for these findings is the well-established relationship between decreased patient functioning and increased need for assistance from caregivers (Aronson, 1997; Buchanan & Huang, 2011; Carton et al., 2000; Figved et al., 2007; Khan et al., 2007; Pakenham, 2007). As MS patients experience greater symptoms, and especially behavioral symptoms that impair their ability to function independently, they need additional caregiving to complete ADLs, take medications, and achieve a satisfactory quality of life. This increased need for a caregiver means that caregivers have less time to engage in activities outside of caregiving that would otherwise improve caregivers’ quality of life. Similarly, as the patient’s behavioral functioning declines, caregivers may experience a change in the interpersonal relationship that they once had with the patient because the patient is less able to engage meaningfully with the caregiver, and the interactions between the caregiver and patient may revolve around meeting the patient’s medical and functional needs. Finally, increased behavioral symptoms have been strongly associated with increased burden among MS caregivers (Chipcase & Lincoln, 2001; Dunn, 2010; Figved et al., 2007; Khan et al., 2007), which has in turn, been associated with decreased life satisfaction (Cockerill & Warren, 1990; O’Brien, 1993).

**Hypothesis 3: Unmet family needs and caregiver mental health**

The third hypothesis predicted a relationship between unmet family needs and reduced caregiver mental health such that unmet social support and unmet health needs would be associated with caregiver
burden, depression, anxiety, and decreased satisfaction with life. The third CCA was significant and demonstrated a large-sized correlation between unmet family needs and caregiver mental health variables. Specific associations emerged between unmet financial, social support, and informational needs with burden. As a result, Hypothesis 3 found general support for the hypothesized relationship between the two variable sets and more specific support regarding social support needs and burden.

The findings of the association between unmet financial, social support, and informational needs with increased caregiver burden offer support for Pearlin and colleagues’ (1990) model of caregiver stress, which proposed a relationship between secondary stressors (e.g., family needs) and caregiver outcomes (e.g., mental health variables). Also, this is one of the few times the association between unmet family needs and MS caregiver mental health has emerged in the research literature, highlighting the need to further examine the connections among these variables in the context of MS, as this is a potentially important area for clinical intervention generally overlooked in the literature. Other studies of MS caregivers have identified a relationship between higher financial needs with caregiver burden (Chipcase & Lincoln, 2001; DeJubicibus & McCabe, 2005), between unmet social support and physical health needs with caregiver depression and decreased satisfaction with life (Arango-Lasprilla et al., 2010), and between increased informational needs with caregiver burden (Courts et al., 2005; Gulick, 1995).

Across diverse samples of caregivers, financial difficulties have consistently emerged as a significant correlate of increased burden. As expected, caregivers with lower incomes or increasing financial constraints have fewer options for healthcare and may struggle to afford medication and medical equipment that the patient needs to manage symptoms and maintain functional independence. Although treatment type and cost of treatment was not directly assessed in this sample, current research collected in Mexico suggests that individuals with MS typically pay at least $17,334 MXN annually for
monthly medical visits and prescription refills, as well as an additional $48,329.46 MXN for hospitalization and rehabilitation costs associated with treating relapses (Macías-Islas, Soria-Cedillo, Velazquez-Quintana, Rivera, Baca-Muro, Lemus-Carmona & Chiquete, 2013). While the costs of MS medications and some medical procedures are typically subsidized by the Mexican Social Security Institute, and the annual costs of care would consume most of the income of the households included in the current sample (i.e., annual cost of MS care = $65,663.46 MXN, and on average, caregivers reported household incomes of three to four times the monthly minimum wage or $72,673.20 MXN to $96,897.60MXN annually). Based on reported household income, medical costs would constitute 67-90% of household income, and caregivers in this sample would likely experience financial strain while trying to cover these costs.

Caregivers with limited financial resources may experience increased burden because of the guilt and disappointment that they feel when they are unable to provide a family member with the medical supplies, care, and support that they need because they cannot afford it. Also, unmet financial needs may be observed among caregivers with high burden because the construct of burden includes an assessment of the impact of caregiving on one’s financial state (Kasuya et al., 2000). As such, the specific domains of financial needs and financial aspects of burden may have overlapped, accounting for some of the shared variance identified in this analysis.

Caregivers with unmet social support needs were likely to experience burden as well. Burden describes an emotional reaction to the demands of caregiving and the effect of caregiving on the caregiver’s physical, social, and emotional functioning (Kasuya et al., 2000). As such, many measures of burden include an assessment of the negative impact of caregiving on social engagement. Given this overlap in measurement, it is similarly expected that unmet social support needs would be associated with burden. And previous findings in the MS literature demonstrate this finding, such that MS
caregivers experiencing burden also report social isolation and limited social support (Akkus, 2011; Chipchase & Lincoln, 2001; Hakim et al., 2000).

Several explanations may account for this pattern. First, MS caregivers may have limited time for social activities because of the disease’s unpredictable symptom cycle and the varying needs of the patient. In one study, Cockerill and Warren (1990) found that caregivers had difficulty with fulfilling social obligations, especially those that required planning (e.g., trips away) because of changes in the patient’s level of functioning. Second, as observed by McKeown and colleagues (2003), caregivers’ social relationships often decreased throughout the duration of the patient’s disease, which lead to fewer available sources of social support over time. As opportunities for social engagement decrease and sources of social support lessen, MS caregivers may become frustrated, overwhelmed, and sad because of the lack of social support available to them. Third, across different studies, there has been some support for the role of perceived social support as a moderator of burden and depression among caregivers (Ergh, Rapport, Coleman, & Hanks, 2002; Oh, 2009; Thielemann & Conner, 2009). These findings suggest that social support is an important coping mechanism that can decrease burden by helping caregivers with completing practical tasks (e.g., household chores), providing emotional support, and by giving caregivers an opportunity to socialize outside of the caregiving relationship and fulfill other important roles like friend or community organization member. When caregivers report unmet social support needs, they may experience higher burden because they do not have the additional emotional or practical support that could alleviate some of burden.

Many MS caregivers report informational needs; however, few researchers have identified the relationship between informational needs and burden, as in this study. Several explanations may account for this relationship in the current study. A large percentage of participants were mothers who had likely had prior caregiver experience as parents. However, the needs of individuals with MS require a different
skill set that the caregiver would need to learn and practice and the skills may also change over time. Similarly, MS caregivers are assisting adults with neurological, cognitive, emotional, functional, and behavioral symptoms that are all managed differently and can occur at varying frequency and intensity throughout the course of the disease. The informational needs of MS caregivers may consist of facts about the disease and symptom management in addition to practical information about how to find neurologists, community support, and how to prepare for the patient’s future. When MS caregivers have unmet informational needs, they may experience burden because they are overwhelmed with tasks and demands that they do not know how to solve or address.

**Hypothesis 4: Mediation model.** The fourth hypothesis predicted that the relationship between MS impairments and caregiver mental health would be significantly mediated by unmet family needs. Two structural equation models were calculated and used to examine unmet family needs as a possible mediator of the relationship between MS impairments and caregiver mental health variables. A significant, bivariate relationship was identified between MS impairments and caregiver mental health suggesting that as MS symptoms occur, caregivers experience declines in mental health. Non-significant relationships were identified between MS impairments and family needs, and between family needs and caregiver mental health. Despite these non-significant—but in the hypothesized direction—relationships, family needs mediated the relationship between MS impairments and caregiver mental health, supporting Hypothesis 4.

This statistically significant indirect effect of MS impairments on caregiver mental health through unmet family needs is the first time this finding has emerged in the research literature. One possible interpretation of this finding is that as the patient’s health worsens and symptoms occur across different domains, the family may need additional support or may have new needs that it did not have when the patient’s health was more stable. When these needs are unmet, the family has fewer coping
resources to draw upon, increasing the amount of distress that caregivers experience. In addition to fewer coping sources, the family has fewer means to support their family member, which may increase feelings of guilt and disappointment. Previous research on caregivers of individuals with moderate to severe impairments has consistently identified increased needs for social, informational, and financial support, as well as increased burden, strain, and depression (Carton et al., 2000; Chipchase & Lincoln, 2001; Corry & While, 2009; Kristjanson et al., 2005; Pakenham, 2007).

Another possible explanation can be garnered from cultural norms and expectations regarding the family and how family members cope with illness and disability. In Latin America, as well as other collectivistic cultures, nearly everyone in the nuclear and extended family is affected by one family member’s illness. As demonstrated by the meditational model, the patient’s MS symptoms (individual level) not only impact the individual (caregiver’s mental health), but they in turn also impact the family’s functioning and ability to meet its own needs (unmet family needs). As the family’s functioning requires additional assistance from others outside of the family, the individual members may feel saddened by the “illness” in their family, and disappointed by their inability to care for and heal their own family members without seeking outside assistance.

**Exploratory Covariate Analyses**

Because the CCAs and SEMs could not easily control for demographic variables, correlation matrices were created to examine whether caregiver and patient demographics were associated with the primary outcome variables of MS impairments, family needs, and caregiver mental health.

**Covariates of MS Impairments.** Greater hours of weekly care were associated with more functional symptoms in individuals with MS. These findings support the well-documented relationship between increased MS symptoms and increased need for caregiver support, which other researchers attribute to an increase in the number daily caregiving tasks and hours of care (Aronson, 1997;
Buchanan & Huang, 2011; Carton et al., 2000; Khan et al., 2007). Caregiver unemployment was associated with more behavioral symptoms in individuals with MS. While this specific finding has not been identified in previous studies, Hakim and colleagues (2000) reported a decrease in caregiver employment as patients’ symptoms increased in number and severity. This study’s finding suggests that caregivers of individuals with behavioral symptoms of MS may be unable to maintain employment while providing care possibly because of the increased care duties associated with managing behavioral symptoms.

Patient age, age at symptom onset, age of diagnosis, and marital status (e.g. partnered) were negatively associated with behavioral symptoms, which suggests that younger patients, patients who were younger at symptom onset and diagnosis, and single patients were more likely to experience behavioral symptoms. Current epidemiological data suggest that neurobehavioral symptoms can occur at any time during the disease’s progression and that some individuals present with symptoms of impulsivity and disinhibition along with commonly reported neurological symptoms (Lima, Simioni, Bruggimann, Ruffieux, Dudler, Felley et al., 2007; Lopez-Meza, Corona-Vazquez, Ruano-Calderon & Ramirez-Bermudez; Polittle, Huffman, & Stern, 2008). Individuals with progressive types of MS were more likely to experience functional symptoms. This finding supports previously identified relationships between progressive MS types, increasing symptom severity, and greater functional disability (Composton & Coles, 2008; Noseworthy & Hartung, 2006).

**Covariates of Unmet Family Needs.** As compared to males, female caregivers were more likely to report greater unmet household, financial, and health needs. Fulfillment of household duties is a culturally sanctioned practice for women in Latin America, as well as an important part of complying with gender roles that emphasize self-sacrifice and putting the needs of the family before one’s own (Stevens, 1973). Female caregivers may be more likely to report greater household and financial needs
because they are more aware of specific household needs and the effect of the patient’s care needs on the family’s finances. In the same way, female caregivers may have endorsed greater unmet health needs because of cultural expectations that encourage self-sacrifice or because caregiving demands limit female caregivers’ abilities to provide care for others and themselves simultaneously. In other samples of MS caregivers, female caregivers have reported decreased physical functioning and poorer general health when compared to male counterparts (Corry & While, 2009; Pakenham, 2001; Patti et al., 2007). Together these findings indicate the need to target female caregivers, as they may be particularly vulnerable to the negative effects of MS caregiving in terms of increased family needs.

Increasing hours of weekly care and a longer duration of caregiving was also associated with increased financial needs. When caregivers provide care for increasing periods of time, they may have less time to devote to paid employment which would increase the need for financial support. Also, caregivers with a greater number of weekly hours providing care and those who have been providing care for longer periods of time often care for individuals with greater impairments and higher medical care costs (National MS Society, 2012). Increasing care needs across the disease’s duration may also explain the relationship between greater health needs and longer duration of caregiving, because as caregivers continuously provide care, they may have less time to meet their own needs and may experience increasing health problems over time (Argyriou et al., 2011; Aronson, 1997; Giordano et al., 2012; McKeown et al., 2003). Similarly, caregivers who provide care for a greater number of hours each week may have increased needs for social support because in other samples, caregivers have reported reduced access to social support as the patient’s symptoms increase as well as less time to access available resources (Corry & While, 2009; McKeown et al., 2003).

Caregivers of individuals with progressive types of MS were more likely to report unmet household needs. Progressive types of MS include symptoms that progressively worsen in clinical
severity and decrease functional ability (Noseworthy & Hartung, 2006). As the patient’s functional ability decreases or symptom severity increases, the patient may need continuous assistance to complete ADLs and caregivers may have less time to complete household tasks. Caregivers of younger patients, patients with a younger age at diagnosis and symptom onset, patients with progressive types, unemployed patients and single patients reported greater financial needs. While a specific relationship between care recipient age and family needs has not previously been established in the literature, this finding may reflect the established relationship between greater symptom severity and increased need for financial assistance (Corry & While, 2009; DeJubicibus & McCabe, 2005; Koopman et al., 2006; Kristjanson et al., 2005).

Caregivers of younger patients and patients with a younger age at diagnosis and onset reported greater health needs. While this specific relationship between caregiver health needs and care recipient age has not been identified in the current literature, it appears that younger patients in this sample presented with more behavioral symptoms, which may have required more care. As caregivers in this sample provided more care to manage behavioral symptoms, they may have had less time to meet their own physical health needs.

**Covariates of Caregiver Mental Health.** Caregivers reported higher satisfaction with life when they were employed. Although this association has not yet been identified by previous MS research, the general literature has robustly found that employment is associated with mental health benefits (Eichorn, 2012; Erdogan, Bauer, Truxillo & Mansfield, 2012; Grün, Hauser, & Rhein, 2010; James & Spiro, 2006). Caregivers in this sample also reported higher life satisfaction when providing care for older patients and those with an older age at diagnosis and symptom onset. Caregivers may experience greater satisfaction with life when providing care to older patients because research has shown that caregiving in Latino communities is congruent with cultural norms regarding the care of older family members, as
well as those who are sick and have disabilities (Villarreal et al., 2005). Additionally, caregivers who provided care to partnered patients had greater life satisfaction, which may be due to caregivers being married to those patients and the well-established relationship between marriage and life satisfaction (Luhmann, Lucas, Eid, & Diener, 2013; Williams, 2003).

Caregiver female sex was associated with greater anxiety, depression, and burden in this sample, and this has generally been found in other samples of MS caregivers (Corry & While, 2009). This finding may reflect increased cultural expectations for female caregivers, as well as increasing concern about the patient’s declining health by women (Dunn, 2010; Sherman, 2007; Salgado de Synder, Diaz-Perez & Ojeda, 2000). The majority of caregivers in this sample were female, and as demonstrated in the literature and in the findings in this study, being female has been associated with increased caregiving burden as well as depression (Akkus, 2011; Buchanan & Huang, 2011; Chipchase & Lincoln, 2001; Forbes, While, & Mathes, 2007; Good, Bower & Einsporn, 1995; O’Brien et al., 1995). The high prevalence of caregiver burden among women is a particularly important finding within Latin American cultures, as women are expected to fulfill the role obligations of a caregiver to other family members and to comply with marianismo (i.e., cultural norms encouraging purity, nurturing, and virtues modeled by the Virgin Mary) thus, making them more vulnerable to feelings of burden and role strain.

Increased hours of weekly care, greater duration of care, and providing care for patients with progressive MS type was associated with higher burden, suggesting that within this sample, the longer caregivers provided care, the more burden they experienced, likely as caregiving tasks consumed more of their time. Across the literature, as patient impairment increases, the need for caregiving increases, and the amount of the caregiver’s time and energy devoted to caregiving increases (Buchanan et al., 2010). Also, patients with progressive types of MS typically have greater impairments and require additional care (Noseworthy & Hartung, 2006).
Providing care to single/unpartnered patients was associated with higher caregiver anxiety and burden. Although this relationship has not previously been demonstrated in the MS caregiver literature, in the current sample, younger and single/unpartnered patients were more likely to experience behavioral symptoms and as such, their caregivers may experience increased anxiety and burden because of the additional care needs associated with managing behavioral symptoms (Chipcase & Lincoln, 2001; Dunn, 2010; Figved et al., 2007). Similarly, providing care to male patients was associated with higher caregiver anxiety and depression, which may be accounted for by greater disease severity among male patients with MS (Houtchens, Lublin, Miller, & Khoury, 2012) and the established relationship between lower caregiver mental health outcomes among patients with more severe symptoms of MS (Bogosian et al., 2009; Buchanan & Huang, 2011; Pozzilli et al., 2004).

**Clinical Implications**

One of the overarching goals of this study was to identify specific needs and intervention targets for MS caregivers living in Latin America. The current findings highlight critical areas of intervention and practical solutions for some of the concerns and difficulties reported by this group of caregivers.

**Information for caregivers.** A large number of participants reported unmet informational needs, which were associated with increased behavioral and emotional symptoms in patients. In the present study, caregivers reported how much they needed “specialized information about the patient,” “complete information,” and “to share [their] feelings with someone who has been in the same situation.” The caregivers in this sample may benefit from general education about MS (e.g., disease course, symptom types, and treatments), as well as specific information about behavioral and emotional symptoms (i.e., psychoeducation, resource identification, and symptom management strategies). Additionally, the caregivers may have had informational needs that were not assessed. As such, a focus group or follow
up survey to assess the type of information that caregivers need is a feasible way to meet the needs of the caregivers in this sample.

**Financial and household assistance.** Unmet financial and household needs were associated with increased burden, depression, anxiety, and decreased satisfaction with life. Interventions designed to help caregiver determine how to meet these needs could help alleviate the negative mental health outcomes that caregivers in this sample experience. Addressing these needs may include education about resources in the community (e.g., grants, supplemental income, and respite care services) that are available to families in the region or education about how to delegate household tasks. Addressing these needs may also require education about when to seek support outside of the family (e.g., respite care), and ways to overcome cultural barriers to accepting and accessing care outside of a kinship network. Finally, families and this community may need community advocacy to promote systems-level changes that increase access to low-cost health care and insurance, or increase public funding for caregivers.

**Mental health screening of caregivers.** In the current study, over 40% of caregivers reported burden, 30% reported moderate symptoms of anxiety, and 46% reported symptoms of depression. Although these rates are comparable to those from other MS caregiver studies (Arango-Lasprilla et al., 2010; Chipchase & Lincoln, 2001; Khan et al., 2007), they demonstrate a greater need for emotional support within the community from which this sample was drawn. Moreover, additional findings from this study suggest that the caregivers who experienced burden were more likely to experience co-morbid symptoms of depression and anxiety, and that their symptoms of burden were more likely to be associated with unmet needs for social support, financial assistance, and physical health/personal care.

These findings suggest the need for health care providers to continuously assess the mental health functioning of caregivers in the community and to provide them with access to services that can include emotional support (e.g., support groups, volunteer organizations, nursing care, spiritual/religious leaders,
and communities) throughout the disease’s duration. Because unmet family needs were identified as a mediator of the relationship between MS impairments and caregiver mental health, health care providers may also want to assess the mental health of other family members in the household and target interventions towards the family system, as family functioning and the overall health of the family unit are important parts of Mexican and Latin American cultures. Finally, the high prevalence of mental health issues in this sample indicates the potential for a multi-family group intervention that informs caregivers about the effects of caregiving tasks on individuals and families. Such an intervention may help bring together families within the community and could help normalize the feelings of burden, disappointment, guilt, and fear that caregivers experience but may be too guarded to share with others.

**Support for caregivers of individuals with cognitive and behavioral symptoms.** Caregivers of individuals with cognitive and behavioral symptoms of MS tended to have the highest mental health problems. Appropriate interventions could include a family-systems program with education, emotional support, and problem-solving training, as well as referrals to community resources and health care providers (e.g., psychiatrists, psychologists, and social workers) for medical and psychological treatment when patients are specifically experiencing cognitive and behavioral symptoms.

**Assessment of family needs.** Unmet family needs play an important role in the established relationship between MS symptoms and caregiver mental health. However, few researchers have examined the needs of family members providing care to an individual with MS in Latin America. As such, researchers need to find comprehensive ways to assess the needs of caregivers at both the individual and the family levels and to continue to assess these needs throughout the trajectory of the patient’s illness. Such information can help health care providers connect family members with specific resources and can alleviate the burden and strain that caregivers may feel when their needs are unmet. At this time, the research literature could benefit from more precise measures of family needs that include
the assessment of all family members in the household and assesses many of the needs that were not included in the FNAT (e.g., respite care, specific medications, and spiritual advice) used in the present study.

**Limitations and Future Research**

The findings of this study should be viewed in light of several limitations, which can be considered potential areas for future research.

**Secondary analysis of an existing database.** While secondary analysis of a previously collected data set has numerous advantages, there are several disadvantages that could have limited the findings identified in the current study. First, a previously collected data set is designed and created with the original researcher’s research questions in mind. The current data set was collected for exploratory purposes as the original researcher wanted to identify the psychosocial outcomes of MS caregivers, the prevalence of MS impairments, and the types of family needs endorsed by caregivers. By adopting the existing data set, the current author was restricted by the types of variables that had been previously collected and had to propose relationships among the variables available. Similarly, when one uses an existing data set, important variables such as cultural values (e.g., filial obligation, religiosity, mariansimo, machismo, and familismo) that were not originally collected cannot be retroactively collected or added to the current data set. As such, the author had to infer the cultural influence on relationships identified between key variables.

Second, when an author does not collect her own data, she must rely on the other researchers and staff members to describe the data collection methods and forms of measurement. Similarly, by using a previously collected data set, the current researcher had no contact with the sample and no ability to follow up with the sample. As a result, the participants in the current sample may not receive the tangible benefits (e.g., interventions, access to resources) that could come from these findings.
**Model of caregiver stress.** Several theoretical models exist that attempt to explain the relationship among caregiving variables, patient variables, and caregiver outcomes. Of these models, Pearlin and colleagues’ (1990) model was chosen because it contained many of the variables collected in the current data set and it proposed relationships among these variables that had yet to be studied in the MS caregiver literature. Although the use of this model in the current study provided a theoretical basis for the proposed relationships, this model, which was designed to describe the stress process that dementia caregivers experience, overlooked the influence of other variables (e.g., caregiver cultural variables, caregiver mental health before assuming the caregiving role, caregiver physical health, and MS disease type and severity), as well as bidirectional relationships among these variables. As such, the current study and interpretation of the findings highlight the possible need for future research using Pearlin and colleagues’ model to consider (a) the inclusion of filial piety, familism, family dynamics, gender roles, household income, spirituality/religious beliefs, and the inclusion of mental health functioning and physical health functioning among the caregiver/care recipient background variables, (b) the inclusion of disease-specific symptoms such as cognitive, emotional, neurological, functional and behavioral symptoms among primary stressors, (c) a pathway that demonstrates the bidirectional relationship between caregiver/care recipient background variables and caregiver outcomes, as well as the bidirectional relationships between caregiver/care recipient background variables, primary stressors (e.g., patient’s functioning), and secondary stressors (e.g., family conflicts, unmet needs), and (d) the inclusion of positive caregiving outcomes such as resilience, role fulfillment, and satisfaction with life. Given the strong cultural influences (i.e., gender roles, familism, filial responsibility, religiousity) that influence caregiving, a model that incorporates these elements is necessary to fully understand underlying mechanisms that may account for reported distress or possible lack of distress among caregivers.
**Self-Efficacy.** Pearlin and colleagues’ (1990) model of caregiver stress includes global mastery and self-esteem as secondary intrapsychic strains that can lead to psychological distress among caregivers. In other studies of caregivers, lower self-efficacy and lack of perceived mastery of caregiving related skills has been associated with increased depression (Gilliam & Steffen, 2006) while higher self-efficacy and perceived mastery has been associated with lower reported strain (Keefe et al, 2003) and depression (Aneshensel, Pearlin, Mullan, Zarit & Whitlatch, 1995). Although the model used to conceptualize the relationships assessed in this study included mastery, the measures collected from participants did not asses for self-efficacy or mastery. As such, some of the relationships, for example, the relationship between behavioral symptoms and increased caregiver burden and greater needs for information could be explained by the caregiver’s level of perceived self-efficacy. Additionally, self-efficacy may moderate the relationships between family needs and caregiver mental health and possibly the relationship between MS impairments and family needs. Including a measure of caregiving related self-efficacy or skills mastery could account for this possible relationship and potentially provide a specific outcome for intervention among caregivers as perceived self-efficacy may vary according to MS symptom type, length of providing care, and previous caregiving experiences (i.e., parenting, etc).

**Family Needs Assessment Tool (FNAT).** Unmet family needs was one of the most important constructs assessed in the current study. At present, there are few empirically validated MS-specific needs assessments and other than that used in the current study, none with normative data collected in Latin America. As such, the FNAT was used in the current study because the measure had been validated in a sample of caregivers of individuals with neurological conditions in Latin America (Rivera et al., 2013). Despite this strength, this measure’s limitations include first-person measurement of family needs and a limited assessment of additional possible family needs which may or may not be MS-specific.
Because the items ask what needs each specific caregiver has, the scale may actually assess the caregiver’s individual needs instead of the family unit’s needs. By changing the stem from “I need” to “we need” in future studies, the scale would assess not only what one person needs, but what the caregiver perceives the family needs. Similarly, in order to truly assess family needs, administration of the measure should include reports from all family members in the family unit/household of the individual receiving care. As the measure is currently written and administered, the results only offer the perspective of one reporter, but attribute this variance to the perspectives of others within the family unit. By including multiple reporters, researchers can then differentiate between variance observed within-reporters (unique reporter variance) and across reporters (e.g., shared variance; Burk & Laursen, 2010).

Another way to improve the measure is to increase the comprehensiveness and specificity of the constructs being assessed. Although the items in the current measure come from an aggregate of items from needs assessments of caregivers of individuals with MS and other neurological disorders, the current measure does not include items that assess potentially important aspects such as the need for respite care, the specific types of information that caregivers need, assistance with obtaining medical equipment, and the need for holistic or non-traditional medical practices that may be common and useful in Latin America. Including these items may come from additional focus groups and surveys with MS caregivers in other communities, especially communities of individuals who are hard to reach or do not regularly access medical care. As such, the current body of literature could greatly benefit from an MS-specific measure of family needs that has been developed using a Spanish-speaking sample and has been empirically validated in similar samples.

**MS Impairments Questionnaire.** The current study used the MS Impairments Questionnaire, a 30-item checklist of MS symptoms developed by Knight and colleagues (1997) to assess the types of
symptoms that patients experience. Although this questionnaire assesses the general clusters of symptoms shown to be common in individuals with MS, the measure itself has not gone through extensive psychometric evaluation. Additionally, several of the items comprising this questionnaire are vague and may not translate well into Spanish (e.g., “being unreliable”). Because of the importance of accurate assessment of MS symptoms, this measure should undergo further revision and evaluation in an attempt to assess additional symptoms of MS, as some of the common symptoms such as sexual dysfunction, attention problems, and heat sensitivity were omitted. A revised version should also include a factor analysis of items, as well as measure of disease severity or disability since the presence of a symptom does not necessarily indicate its functional impact or severity. Finally, as with the FNAT, a measure of MS symptoms should include multiple raters and/or a review of medical records to support self-reported and caregiver-reported data. Relying on the caregiver’s perspective may overlook symptoms that the caregiver is unaware of (e.g., sexual dysfunction) and result an incomplete assessment of patient functioning.

**Methodological flaws in data collection.** Many of this study’s additional limitations stem from the methodology used to recruit the study’s sample and assess the primary variables. In the present study, participants were recruited from a single medical clinic in a major urban area in Mexico as well as through the local MS Society affiliate in Guadalajara, Mexico. As such, the findings of this study have limited generalizability because this sample may have better resources for accessing medical care and meeting other family needs. The findings in this sample may overlook or underestimate the true needs and psychosocial functioning of caregivers who do not have adequate resources and thus, cannot acquire medical care for their loved ones and are not as well connected with community-based organizations. Similarly, the demographic characteristics of this sample are unique because the vast majority of caregivers were mothers. In many other caregiver samples from various global regions, MS caregivers
are mostly men (because of the disproportionate number of women with MS) and spouses or partners of the care recipient. As such, the findings from this study are highly specific to female caregivers and maternal caregivers of adult children with MS, which means the psychosocial outcomes and relationships among MS impairments, family needs, and caregiver mental health variables may not occur in samples of male and/or spousal caregivers.

In addition to limitations imposed by sampling methods and the sample’s characteristics, the researcher’s use of oral interviews for data collection may have limited participants’ responses and influenced the validity of the measures because these measures had been validated for self-report and not with an interviewer. The interview format via a staff psychologist and graduate student was intended to reduce missing data and confusion due to reading difficulties. However, as noted by other researchers, interviews that ask personal and highly subjective questions may increase the likelihood of error due to social desirability bias (Lavrakas, 2008). Because of the internalization of culturally embedded values such as *familismo* and *simpatía* within Mexican culture, family members in the current study may have been less likely to endorse feelings of burden or acknowledge unmet family needs in the presence of another individual who could judge them. Similarly, acknowledging unmet family needs or feelings of burden may create internal conflict in caregivers, as they may feel disloyal to their family and their obligations to keep family discord private. In the same way, cultural values that stigmatize individuals with mental illness may prevent caregivers from reporting feelings of sadness, anxiety, and dissatisfaction with life. The current reports may underestimate the psychosocial functioning and family needs of the caregivers included in this sample.

**Common methods variance.** Because the current study used a single reporter, there is no way to assess for common methods variance or error resulting from a rater’s tendency to over-endorse similar phenomena (Kamakura, 2010), for example increased family needs among participants who also endorse
high levels of depression. When common methods variance occurs, observed relationships may be exaggerated. Future researchers should account for the effect of common methods variance by including multiple reporters, more objective reporting methods, and multiple measures of similar constructs (Kamakura, 2010).

**Cultural equivalence of measures.** The present study included several measures that were developed and studied using normative samples of English-speaking individuals living in the United States. Although only one measure was translated for the purposes of this study (MS Impairments Questionnaire) and Spanish versions with normative data were available for the other measures (e.g., FNAT, STAI, ZBI, PHQ-9, SWLS), one limitation of the current study is the possibility that the constructs assessed may not be truly culturally equivalent. When measures assess different constructs or lack linguistic and cultural accuracy, researchers are unable to generalize findings (Reuland, Cherrington, Watkins, Bradford, Blanco & Gaynes, 2009) or they may over or underestimate or overestimate the prevalence of mental health problems such as depression, anxiety, and caregiver burden. Using culturally appropriate measures that have been *created and validated* in the same language and in the same culture as the study sample is one way to promote cross-cultural equivalence of measures and reduce cultural invariance.

Fortunately, many findings in the current literature support the construct validity of the Spanish versions of the PHQ-9, STAI, ZBI, and SWLS (Atienza et al., 2000; Huang, Chung, Kroenke, Delucchi & Spitzer, 2006; Martin et al., 1996; Vázquez et al., 2013; Wulsin et al., 2002). As a result, the findings of this study are not as vulnerable to the threat of cultural invariance. However, there is limited support for the use of these measures, as well as the MS Impairments Questionnaire and the FNAT, in samples of caregivers from Mexico where specific cultural practices and views (e.g., *marianismo*, internalized stigma of mental illness, *ponerse de su parte*) could potentially influence self-reported symptoms of
anxiety, depression, and caregiver burden as well as a caregiver’s willingness to disclose unmet family needs and the prevalence of their family member’s symptoms. Given these potential threats to cultural equivalence, revisions of these measures could include the collection of additional normative samples, as well as focus groups to identify culturally relevant aspects that are pertinent to assessing these constructs.

**Method of data analysis.** The research questions required CCAs that would assess the proposed relationships among latent variables (e.g., MS impairments, family needs, and caregiver mental health), as well as Pearson correlations to assess relationships among directly-measured variables (e.g., specific MS impairments, specific family needs, and various aspects of mental health). There were several advantages to using CCAs to assess the proposed hypotheses. First, unlike multiple regression analyses, a CCA can evaluate the relationships between *a set* of independent variables and *a set* of dependent variables. Second, a CCA has several correlations included in the analysis, but only the first, and most robust value is used and reported. This analysis identifies the strongest pattern of connections among the variables in the two variable sets. Third, this test is more parsimonious and less prone to the effects of type-I error than a series of 13 multiple regressions, which would have been the alternative analysis.

Despite these advantages and the overall appropriateness of a CCA for examining the hypothesized relationships, a CCA cannot control for the effects of covariates. In the present study, several patient and caregiver demographic variables were correlated with MS impairments, family needs, and caregiver mental health variables. However, these covariates could not be entered into the CCA, and as such, their overall effects on the identified relationships could not be isolated or controlled for. Although a series of 13 multiple regressions would have lacked parsimony and increased the likelihood of type-I error, this approach could control for the effects of demographic covariates on the relationships between MS impairments and family needs, MS impairments and caregiver mental health,
and family needs and caregiver mental health. In this way, the CCA’s greatest limitation for the present study is its inability to account for the possible effects of covariates. However, a series of Pearson correlations permitted inferences regarding possible covariates that could have contributed to the primary findings.

**Limited generalizability of findings.** As with any study, the findings of the current study may not generalize to other samples of MS caregivers, even within Latin America. However, the current sample had several unique characteristics that pose a challenge for generalizing these findings to international samples of MS caregivers. Specifically, unlike many samples of MS caregivers, caregivers for the current study were predominately women who were mothers of the care recipients. Because of the strong cultural values of familism and the stigma associated with mental illness, caregivers within this sample may have under-reported symptoms of burden, depression, and anxiety. Given the desire to fulfill cultural roles, Latina women, especially mothers, may not perceive caregiving as burdensome or they may be reluctant to disclose feelings of strain, anxiety, and sadness. By contrast, in other countries where male spouses or romantic partners typically fulfill MS caregiving roles, perceptions of burden may be stronger, as caregiving is a new skill set for them.

Additionally, the reported household incomes of the families in this sample may be higher than other caregivers who do not receive subsidized care and who are not employed while providing care. This study’s participants were recruited from an urban university medical center and a local chapter of the MS foundation. As such, this sample’s utilization of care and access to resources may be greater than most caregivers, especially those living in rural areas.

**Areas of future inquiry.** Using this study’s findings and limitations, future researchers could focus on several aspects of the relationships between MS impairments, unmet family needs, and caregiver psychosocial functioning. For example, improving Pearlin and colleagues’ (1990) theoretical
model could entail collecting data on missing cultural variables (i.e., familism, filial responsibility, gender role identity/beliefs, religiosity) and identifying the relationships between these variables, primary stressors, secondary stressors, and caregiver outcomes. Because of the strong association between role fulfillment and positive outcomes, another study could investigate positive outcomes associated with caregiving (resiliency, personal growth, mastery, benefit-finding and meaning making) so that positive outcomes can be included in the model. Improving the psychometric properties of the FNAT and MS-IQ or even adding additional symptoms to the MS-IQ could provide better measurement of the family needs questionnaire. Additionally, re-wording the FNAT to reflect family needs versus caregiver needs and collecting data from multiple family members could help to better capture a family unit’s unmet needs. Finally, information needs and behavioral symptoms emerged as two areas of clinical focus. Future studies could examine the types of information that family members need, how this need changes throughout the course of the disease, and the best ways to provide this information (i.e., through support groups, websites, etc). Based on the negative outcomes associated with behavioral symptoms, additional information on specific types of behaviors, strategies used to manage these behaviors, and stigma associated with disability and mental illness could help inform future interventions for caregivers.

Conclusions

This study provided empirical support for the relationship between greater MS impairments and unmet family needs, as well as between greater MS impairments and decreased mental health among family caregivers of individuals with MS in Guadalajara, Mexico. It also suggested that the relationship between MS impairments and caregiver mental health is mediated by unmet family needs. These findings suggest that MS symptoms may affect both the individual caregiver and the family unit. As a result, MS rehabilitation interventions, especially in Mexico and other Latin American countries, should
comprehensively assess and target the patient’s functioning, the family’s unmet needs, and the
caregiver’s mental health functioning. Doing so—if supported by future research—could improve
services for a population that has faced marginalization and a dearth of care within traditional
rehabilitation settings.
List of References
List of References


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Appendix A

MS Impairments Questionnaire (MS-IQ)

Below is a list of symptoms that individuals with MS often experience. Please check “yes” for the symptoms that the individual you provide care has recently experienced or “no” for the symptoms that he or she has not experienced recently.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Paralysis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Difficulty walking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Tiring easily</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Loss of sensation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Difficulty concentrating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Incontinence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Depression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Difficulty thinking clearly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Easily upset</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Clumsiness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Irritability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Forgetfulness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Doing things slowly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Anxiety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Loss of interest</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Poor eyesight</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Trouble reading</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Mood changes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Difficulty writing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Difficulty learning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Difficulty talking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. Difficulty eating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. Poor decision making</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. Difficulty hearing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. Denying problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. Acting impulsively</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. Upsetting other people</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. Not reliable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. Seizures</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix B

Spielberger State-Trait Anxiety Inventory (STAI)

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to indicate how you feel right now, that is at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Moderately so</th>
<th>Very much so</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel calm</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I feel secure</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. I am tense</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I feel strained</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I feel at ease</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. I feel upset</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. I am presently worrying over possible misfortunes</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I feel satisfied</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. I feel frightened</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. I feel comfortable</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. I feel self-confident</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. I feel nervous</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. I am jittery</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. I feel indecisive</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. I am relaxed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. I feel content</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. I am worried</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. I feel confused</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. I feel steady</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. I feel pleasant</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Spielberger State-Trait Anxiety Inventory (STAI)

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to indicate how you generally feel. There are no right or wrong answers. Do not speed too much time on any one statement but give the answer which seems to best describe how you generally feel.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Almost never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. I feel pleasant</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>22. I feel nervous and restless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>23. I feel satisfied with myself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>24. I wish I could be as happy as others seem</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>25. I feel like a failure</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>26. I feel rested</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>27. I am “calm, cool and collected”</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>28. I feel that difficulties are piling up so that I cannot overcome them</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>29. I worry too much over something that really doesn’t matter</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>30. I am happy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>31. I have disturbing thoughts</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>32. I lack self-confidence</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>33. I feel secure</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>34. I make decisions easily</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>35. I feel inadequate</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>36. I am content</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>37. Some unimportant thought runs through my mind and bothers me</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>38. I take disappointments so keenly that I can’t put them out of my mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>39. I am a steady person.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>40. I get in a state of tension or turmoil as I think over my recent concerns and interests</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Appendix C

Zarit Burden Inventory (ZBI)

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

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you feel that your relative asks for more help than he/she needs?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Do you feel embarrassed over your relative’s behavior?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Do you feel angry when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Are you afraid what the future holds for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. Do you feel your relative is dependent on you?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Do you feel strained when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. Do you feel your health has suffered because of your involvement with your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. Do you feel that you don’t have as much privacy as you would like because of your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. Do you feel that your social life has suffered because you are caring for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Question</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>13. Do you feel uncomfortable about having friends over because of your relative?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Do you feel that you don’t have enough money to take care of your relative in addition to the rest of your expenses?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Do you feel that you will be unable to take care of your relative much longer?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Do you feel you have lost control of your life since your relative’s illness?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Do you wish you could leave the care of your relative to someone else?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Do you feel uncertain about what to do about your relative?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Do you feel you should be doing more for your relative?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Do you feel you could do a better job in caring for your relative?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Overall, how burdened do you feel in caring for your relative?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix D

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.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Little interest or pleasure in doing things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>b. Feeling down, depressed, or hopeless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>c. Trouble falling asleep, staying asleep, or sleeping too much</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>d. Feeling tired or having little energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>e. Poor appetite or overeating</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>f. Feeling bad about yourself, feeling that you are a failure, or feeling that you have let yourself or your family down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>g. Trouble concentrating on things such as reading the newspaper or watching television</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>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</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>i. Thinking that you would be better off dead or that you want to hurt yourself in some way</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

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?

<table>
<thead>
<tr>
<th></th>
<th>Not Difficult At All</th>
<th>Somewhat Difficult</th>
<th>Very Difficult</th>
<th>Extremely Difficult</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Appendix E

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 F

Family Needs Assessment Tool

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.

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

Melody Nichole Mickens was born on November 7, 1984 in Richmond Virginia, and is an American citizen. She graduated from St. Catherine’s School in Richmond, Virginia in 2003. She received her Bachelor of Arts in Psychology from The College of William and Mary in Williamsburg, Virginia in 2007. She received a Master of Science in Psychology from Virginia Commonwealth University in 2011.