Protective psychosocial factors and trauma in multiple sclerosis spousal/partner caregivers: intersecting roles and interactional influences

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Protective Psychosocial Factors and Trauma in Multiple Sclerosis Spousal/Partner Caregivers:
Intersecting Roles and Interactional Influences

By

Alison J. Rivers

A Dissertation
Submitted to the University at Albany, State University of New York
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Department of Psychology
Fall 2016
Protective Psychosocial Factors and Trauma in Multiple Sclerosis Spousal/Partner Caregivers:  
Intersecting Roles and Interactional Influences

By

Alison J. Rivers

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Dedication

To my husband, Jerry, who has lovingly, patiently, and enthusiastically supported me throughout my graduate education. He reminds me every day to bring my imagination and dreams to fruition and for this, and countless other virtues, I am lucky to be his partner.

To my parents, John and Marilyn, who have taught me to work hard, be grateful, and to capture every possible opportunity. These lessons, among so many more, have helped me to become the person I am and these lessons will continue to influence my life.

To the Multiple sclerosis spousal and partner caregivers who completed my studies. It is my hope that my work can pay even the smallest tribute to your tireless efforts as caregivers.
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Abstract

Multiple sclerosis (MS) is a debilitating, unpredictable, chronic illness for which many diagnosed individuals are cared for by their spouses or partners (e.g., McKeown, Porter-Armstrong, & Baxter, 2003). These MS spousal/partner caregivers are especially vulnerable to the deleterious outcomes of caregiving (e.g., Buhse, 2008; Corry & While, 2009). The present research examined hypothesized protective psychosocial factors and the impact of trauma in these unique caregivers through two cross-sectional studies (n=93 and n=62). Findings from Study One demonstrate that lower caregiver burden and higher dyadic adjustment were associated with improved caregiver mental health outcomes (Chapter 1). Study One also shows that reducing caregiver burden, increasing received social support, and giving social support by engaging in MS-related volunteer work were associated with improved caregiver outcomes (Chapter 2). Findings furthermore demonstrate that higher levels of altruism buffered against the negative effects of caregiver burden on general mental and physical health. Altruism also protected against negative effects of caregiver burden on satisfaction with life, but this effect was only detectable at low levels of caregiver burden. Study Two demonstrates that MS spousal/partner caregivers are at higher risk for PTSD and subclinical posttraumatic stress symptoms than other caregivers and than the general population (Chapter 3). Results suggest that MS spousal/partner caregivers should be screened for PTSD and that prevention and intervention efforts should target reducing caregiver burden, increasing dyadic adjustment, increasing received social support, and encouraging caregivers to engage in MS-related volunteer activities.

Keywords: Multiple sclerosis, spousal/partner caregivers, dyadic adjustment, social support, altruism, posttraumatic stress
General Introduction

The present studies examined protective psychosocial factors and trauma in the spousal or partner caregivers of individuals diagnosed with MS. Multiple sclerosis is a chronic, disabling disease that affects about 2.3 million people across the world (National Multiple Sclerosis Society, 2015). There are several factors that influence incidence of MS, including genetics, gender, age, race, ethnicity, geography, infectious triggers, and stress (National Multiple Sclerosis Society, 2015). The disease is about two to three times as likely in women as in men. It is typically diagnosed between the ages of twenty and fifty years old, is most often diagnosed in late twenties to early thirties, and also occurs, though less frequently, in children and adolescents. While the evidence is mixed, data have historically shown that MS is most common in Caucasians, but also occurs in African Americans, Asians, and Latinos (National Multiple Sclerosis Society, 2015; Rosati, 2001). Some recent data find that MS is more common in African American/black individuals (incidence of 10.20) than Caucasian/white (incidence of 6.9), Hispanic (incidence of 2.9), or Asian individuals (incidence of 1.4; Langer-Gould, Brara, Beaber, & Zhang, 2013). The data also show that race and ethnicity do not predict incidence on their own, but rather, these factors interact with gender and geography, to predict incidence of MS (Langer-Gould et al., 2013; Rosati, 2001).

Multiple sclerosis is an autoimmune disease in which it is believed that the myelin sheath around the axons in the central nervous system is attacked (Mohr & Cox, 2001). Lesions or plaques form, which can adversely affect any function that the central nervous system performs. Symptoms include, but are not limited to, emotional changes, depression, anxiety, anger, cognitive difficulties, loss of vision, loss of hearing, loss of function or feeling in limbs, loss of balance, loss of bowel and/or bladder control, fatigue, and pain. Stress may exacerbate
symptoms and may play a role in the initial onset of symptoms. Sometimes diagnosis can take several years due to ambiguous symptoms that seem to come and go.

While there are several common courses and severities of MS, symptoms are unpredictable and can change drastically from one day to another (National Multiple Sclerosis Society, 2015). Medications that help to alter the course of the disease have been available since about 1990 (Buhse, 2008) and are constantly changing. Medications help to reduce relapses and severity of some symptoms, but thus far, medications cannot cure MS and patients are left with debilitating idiosyncratic symptoms that persist for decades.

The Role of MS Spousal Caregivers

Due to the unpredictable nature of symptoms, individuals with MS often need a caregiver who is flexibly available to help manage their symptoms and to provide assistance with activities of daily living (e.g., McKeown et al., 2003). Symptoms may range widely from emotional lability to bladder and bowel incontinence. Assistance needed for activities of daily living may also vary from household chores to transfers from bed to chair and toileting. As the disease progresses, individuals with MS may need more constant caregiver support (National Multiple Sclerosis Society, 2015).

Data suggest that individuals with MS are most often cared for by family members (O’Hara, De Souza, & Ide, 2004). Family members often act as caregivers because patients live for decades with these unpredictable care needs. It is often not cost effective to pay caregivers to be available for highly fluctuating care needs, especially over long periods of time. Family or informal caregivers can flexibly provide the level and types of care that their loved ones may require and typically do not receive paid compensation (Aronson, 1997; Corry & While, 2009). In a large cross-sectional study, Aronson and colleagues found that of people with MS who
reported having a primary caregiver, 65% of caregivers were spouses, and 75% of those spousal
caregivers lived with the person for whom they cared (Aronson, Cleghorn, & Goldenberg, 1996;
Aronson, 1997).

While it is common for many people with chronic illnesses to be cared for by a spouse, MS spousal caregivers are unique in comparison to other spousal caregivers. Multiple sclerosis caregivers are more likely to be younger, have children, be students, and be in the early stages of career development than family caregivers of those with Alzheimer's disease or stroke (Mohr & Cox, 2001). This is because individuals diagnosed with MS are often younger than those diagnosed with Alzheimer's disease or stroke. Furthermore, MS spousal caregivers are likely to be male, given the higher disease prevalence in females and the commonality of heterosexual relationships and marriages. This gender difference is in contrast to other spousal caregiver populations, which are often primarily female. These considerations, combined with the unpredictable nature of MS, make MS spousal caregivers a uniquely vulnerable group of caregivers who are highly susceptible to experience negative consequences because of their role (e.g., McKeown et al., 2003).

Caregiving Duties

We are just beginning to understand the many different duties that MS caregivers take on for their family members. Empirical research studying caregiving duties across various types of caregivers has increased exponentially since about the early 1980s. While initial studies focused primarily on Alzheimer's disease, dementia, or HIV/AIDS caregivers, research has increasingly expanded to look at MS caregivers. This research base on MS caregivers is still relatively small; however, it does include studies from across the globe including research conducted in Australia (e.g., Pakenham, 2005), Italy (Patti et al., 2007), Kuwait (Alshubaili, Ohaeri, Awadalla, &
Mabrouk, 2008), Spain (Rivera-Navarro et al., 2009), and Turkey (Akkus, 2011). Research has revealed that MS caregivers perform household tasks including cleaning and management of finances; personal care tasks including bathing, dressing, and toileting; and tasks associated with physical movement including transportation and lifting the patient (e.g., from chair to bed; e.g., McKeown et al., 2003; O'Brien, 1993b). Multiple sclerosis caregivers may also help to administer medications and provide ongoing emotional support, especially for patients with MS-associated labile mood. While caregivers for patients with many different chronic illnesses often perform these types of tasks, MS caregivers face the unique challenge that MS is highly unpredictable. Patients can wake up from one day to the next with wildly different symptoms and functional abilities and therefore, different care needs. Research has begun to examine the stress and strain that caregiving duties can cause caregivers. This concept is referred to as caregiver burden.

**General Caregiver Burden**

Zarit and colleagues (1980) were some of the first researchers to study the concept of caregiver burden. They defined caregiver burden as the stress or strain that results from the necessary caring tasks or associated limitations that cause discomfort for the caregiver. Caregiver burden has further been defined as a "multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience" (Buhse, 2008, p. 27). Caregiver burden involves both objective and subjective forms of burden (Pinquart & Sorensen, 2003). Objective burden refers to practical consequences of caring for someone, including increased risk of physical injury, lack of sleep, and more. Subjective burden is focused on the caregivers’ own internal experiences of caregiving, including their emotional responses.
Caregiver burden is associated with a wide range of adverse psychosocial and physical consequences for multiple different types of caregivers including caregivers for patients with dementia (e.g., Etters, Goodall, & Harrison, 2008) and breast cancer (e.g., Grunfeld et al., 2004). Interestingly, caregiver burden not only directly impacts caregivers, often negatively, but caregiver burden can even affect the care receivers. For example, in a sample of spousal caregivers of individuals with dementia, Zarit and colleagues (1986) found that the decision to place a partner with dementia in a nursing home was associated more with perceived caregiver burden than with objective factors such as the severity of the illness.

**Multiple sclerosis caregiver burden.** To date, findings from research on caregiver burden in MS caregivers are mixed. Some investigators speculate that caregiver burden in MS caregivers is similar to caregiver burden in other caregivers (Knight, Devereux, and Godfrey, 1997). However, several other studies show that MS caregivers may face more pronounced adverse consequences compared to other caregiver populations. Multiple sclerosis caregivers are shown to have reduced psychological well-being (McKeown et al., 2003), reduced positive mood (Corry & While, 2009), increased depression and anxiety (Corry & While, 2009), decreased quality of life (Aronson, 1997; Corry & While, 2009; Figved, Myhr, Larsen, & Aarsland, 2007; Pozzilli et al., 2004), sexual and relationship problems (Corry & While, 2009), and physical health deficits (Corry & While, 2009; McKeown et al., 2003) in comparison to caregivers of individuals with other chronic illnesses and non-caregivers due to the unique symptoms of MS. Caregivers of individuals with MS are also shown to have increased psychosocial needs, including the need for improved communication with others and the ability to access support and information (Corry & While, 2009).
Additionally, some research demonstrates the impact of caregiver burden on individuals with MS. In a sample of MS caregivers from a randomized trial, Pozzilli and colleagues (2004) found that caregiver depression was associated with the physical and emotional health status of the care receiver such that as care receiver health worsened, caregiver depression increased.

Therefore, research suggests that MS caregivers may face unique and severe mental health repercussions in comparison to other chronic illness caregivers. However, the available research is mixed and there is even less research on MS spousal/partner caregiver burden.

**Multiple sclerosis spousal or partner caregiver burden.** Research has started to narrow in on the unique caregiver burden that spouses may experience. For example, Buhse (2008) found that spousal caregivers of individuals with a variety of different diseases might be up to six times more likely to experience depression and anxiety than other family caregivers. Spouses seem especially susceptible to caregiver burden because they face a compounding effect of needing to handle the direct care that they provide their partners while simultaneously handling the everyday stressors inherent for partners. Also unlike burden for other family caregivers, a meta-analysis showed that spousal caregiver burden was directly related to the physical impairments and behavior problems of the care receiver (Pinquart & Sorensen, 2003). It is possible the spousal caregivers are especially impacted by the physical limitations and behavior problems of their partners because they are unable to escape these difficulties whether they are acting as caregivers or as spouses/partners.

Data thus suggest that MS spousal/partner caregivers face worse caregiver burden than other MS caregivers (e.g., Corry & While, 2009). Multiple sclerosis spousal caregivers have also been shown to feel several senses of loss, including a loss of personal identity, loss of relationship and sexual relationship, and a loss of income and financial stability (Buhse, 2008;
Corry & While, 2009). They have also been shown to experience severe anxiety and distress, especially in the early phases after diagnosis (Corry & While, 2009).

Several research studies have highlighted that MS spousal caregiver burden is impacted by physical symptoms or physical disability of the care receiver (Aronson, 1997; Corry & While, 2009; O'Brien, 1993a; O'Brien, Wineman, & Nealon, 1995; Pakenham, 2001). Multiple sclerosis caregiver burden has been shown to worsen or increase if the caregiver perceives that the patient's personality has changed (Buhse, 2008), if caregiving interferes with family obligations or normal activities (Buhse, 2008; O'Brien, 1993b), if caregiving changes personal or financial plans (Buhse, 2008; O'Brien, 1993b), or if there is financial distress (Corry & While, 2009). Furthermore, MS caregiver distress and poor quality of life have been shown to increase due to depression (Corry & While, 2009), cognitive (Corry & While, 2009), and neuropsychiatric symptoms (Figved et al., 2007) in the care receiver over and above the effects of physical disability. Additionally, research has shown that one of the most difficult MS symptoms for a caregiver to understand and cope with is the debilitating fatigue that MS causes (Buhse, 2008), likely because it limits opportunities for these spouses/partners to spend quality time with one another.

**Synthesis**

In summary, the available literature demonstrates that MS spousal/partner caregivers are a unique population in comparison to other studied populations of caregivers because they are often faced with handling unpredictable yet chronic symptoms that last for decades and start at relatively young ages (e.g., National Multiple Sclerosis Society, 2015). Due to the relatively early age of onset, MS spousal/partner caregivers must frequently balance caregiving with maintaining a relationship, raising a family, keeping up a home, completing their education, and
working (e.g., McKeown et al., 2003; Mohr & Cox, 2001). As a result, MS spousal/partner caregivers are known to be susceptible to significant caregiver burden and impaired mental and physical health (e.g., Corry & While, 2009). While some research has started to investigate factors that may influence the experience of caregiver burden in MS spousal/partner caregivers, there is little available empirical data to inform prevention and treatment interventions designed to improve outcomes in this population. There are even fewer studies that examine possible protective factors for these caregivers.

The present studies sought to expand upon the currently available research through two cross-sectional investigations of MS spousal/partner caregivers summarized into three chapters. These studies were designed after identifying gaps in the current literature and by conducting in-depth qualitative pilot interviews with one husband and wife dyad in which the wife was diagnosed with MS and her husband was her primary caregiver (Anonymous Personal Interview, 2011). The present study conceptualizes that MS spousal/partner caregivers are faced with needing to act in multiple roles across different levels of influence (Bronfenbrenner, 1977). Multiple sclerosis spousal/partner caregivers must balance their needs as individuals and their roles in the microsystem as spouses/partners and as caregivers. Their ability to balance these roles is influenced by their exosystem (including availability of social support), macrosystem (such as societal and cultural expectations regarding the roles they take on), and chronosystem (such as past and future experiences). Chapter One examined dyadic adjustment as a possible protective factor against MS spousal/partner caregiver burden and therefore focuses on MS spousal/partner caregivers' microsystems. Chapter Two examined both giving and receiving social support as possible protective factors and therefore focuses on exosystems. Finally, Chapter Three aimed to understand MS spousal/partner caregivers’ experience of MS and their
caregiving duties as especially stressful by examining posttraumatic stress disorder (PTSD), subclinical posttraumatic stress symptoms, and anticipatory grief. Chapter Three views PTSD as the effects of past trauma and anticipatory grief as the effects of future trauma, and therefore, focuses on MS spousal/partner caregivers' chronosystems.
Chapter One

Psychosocial Predictors of Mental and Physical Health in Multiple Sclerosis

Spousal/Partner Caregivers: The Role of Dyadic Adjustment

Abstract

The spousal or partner caregivers of individuals diagnosed with MS are a largely understudied population of caregivers who are susceptible to a host of mental and physical health deficits, likely because of uniquely stressful caregiver burden associated with MS (e.g., Corry & While, 2009). The present study sought to build upon the current literature on psychosocial predictors of caregiver burden by examining dyadic adjustment as a possible moderator in the relationship between caregiver burden and negative physical and mental health outcomes for MS spousal/partner caregivers. Participants (n=93, 55.8% male, mean age=49.07 years old, SD=13.35) completed self-report measures assessing dyadic adjustment and a range of physical and mental health outcomes. Dyadic adjustment did not interact significantly with caregiver burden to predict caregiver health outcomes as initially hypothesized. However, hierarchical multiple regression analyses indicated that lower caregiver burden was correlated with reduced depression and mental health problems, while higher dyadic adjustment was correlated with improved mental health and satisfaction with life. Caregiver burden and dyadic adjustment were unrelated to physical health problems. Results also demonstrate gender differences such that dyadic adjustment was significantly negatively correlated with caregiver burden in males. Findings suggest that reducing caregiver burden and increasing dyadic adjustment through prevention and intervention efforts may improve caregivers' mental health.

Keywords: Multiple sclerosis, spousal caregivers, partner caregivers, dyadic adjustment, caregiver burden
Introduction

The present study investigated dyadic adjustment as a possible protective factor in a unique population of caregivers, the spousal or partner caregivers of individuals diagnosed with Multiple sclerosis (MS). Multiple sclerosis is a chronic, debilitating autoimmune disease that affects 2.3 million people and is about two to three times more common in women than in men (National Multiple Sclerosis Society, 2015). Onset can be early and symptoms are generally unpredictable and can change every day. Therefore, individuals with MS often need a caregiver who is flexibly available to help manage their symptoms and to provide assistance with activities of daily living (e.g., McKeown et al., 2003). Data suggests that individuals with MS are most often cared for by family members (O’Hara et al., 2004). It has been estimated that of people with MS who reported having a primary caregiver, 65% of caregivers were spouses, and 75% of those spousal caregivers lived with the person for whom they cared (Aronson et al., 1996; Aronson, 1997).

Caregivers of individuals with MS are shown to have reduced psychological well-being (McKeown et al., 2003), reduced positive mood (Corry & While, 2009), increased depression and anxiety (Corry & While, 2009), decreased quality of life (Aronson, 1997; Corry & While, 2009; Figved et al., 2007; Pozzilli et al., 2004), sexual and relationship problems (Corry & While, 2009), and physical health deficits (Corry & While, 2009; McKeown et al., 2003) in comparison to caregivers of other chronic illnesses and non-caregivers. These differences are likely attributable to the unique symptom presentation of MS. This stress or strain that results from caregiving tasks is defined as caregiver burden (Zarit, Reever, & Bach-Peterson, 1980).

To date, there is little research that specifically examines caregiver burden in MS spousal/partner caregivers. Available literature has shown that MS spousal caregivers
experience severe anxiety and distress in the early phases after diagnosis (Corry & While, 2009) and feel several senses of loss including a loss of personal identity, loss of relationship including sexual relationship, and a loss of income and financial stability (Buhse, 2008; Corry & While, 2009). Research has additionally shown that a variety of factors influence objective and subjective caregiver burden. The present study sought to further explore caregiver burden in this uniquely vulnerable population and narrowed in on the possible ways that caregiver burden may interact with a potential protective factor, dyadic adjustment.

**Dyadic Adjustment**

Dyadic adjustment is defined as the quality of a marriage or a romantic relationship as perceived by each member of the dyad (Spanier, 1976). There is a plethora of research exploring dyadic adjustment in multiple different populations. More recently, research has started to investigate dyadic adjustment in couples in which one partner has MS. Impaired dyadic adjustment, including low marital satisfaction, has been shown to increase MS spousal caregiver burden and adversely impact general outcomes for couples in which one partner has MS.

Research has shown that divorce rates are high in couples in which one partner has MS, and that divorce and separation rates increase with disease severity (Hammond, McLeod, Macaskill, & English, 1996). Hammond and colleagues also found that men with MS with severe disability were four times more likely to be divorced or separated than men with a low level of disability severity. Hammond and colleagues additionally found that women with MS with severe disability were twice as likely to be divorced or separated, compared to women with a low level of disability severity. These results indicate that couples in which one partner has MS experience high divorce rates and that MS severity and patient gender exert an influence on relationship status and risk of separation. Pakenham (2005) found that as caregiver age
increased, their level of distress increased and dyadic adjustment decreased. This also indicates that age may influence dyadic adjustment in the context of MS. Furthermore, Perrone and colleagues (2006) found that MS spousal caregivers had lower levels of overall marital satisfaction, lower satisfaction with communication, and lower satisfaction with physical intimacy than a normative group. This research demonstrates that MS can negatively affect relationship status and relationship quality and points to patient disability level, gender, and age as important factors that interact with dyadic adjustment.

Factors pertaining to dyadic adjustment have also been shown to positively affect MS spousal caregiver burden and general outcomes for couples in which one partner has MS. For example, research has found that increased dyadic adjustment (measured using multiple different definitions and terms) can be associated with decreased caregiver burden, suggesting a possible protective effect. For example, Perrone and colleagues (2006) found that marital satisfaction was negatively correlated with caregiver burden in MS spousal caregivers. Research has even shown that dyadic adjustment may increase because of MS. Perrone and colleagues (2006) also found that MS spousal caregivers on average had more love for their spouses than a normative group. In a different study, marital loyalty was found to be associated with continued commitment to being a caregiver (Boeije, Duijnstee, & Grypdonck, 2003). Through qualitative and quantitative research, Pakenham (2005) found that caregivers of individuals with MS experience insights into illness and hardship, companionship gains, personal growth (e.g., increased patience), stronger relationships, more appreciation for life, physical health benefits, and changes in life priorities.

Pakenham has also shown that dyadic adjustment sometimes improves in spousal MS caregivers. For example, congruence of certain coping strategies (or the degree to which
caregiver and care receiver coping strategies complement one another) has been shown to increase adjustment to MS and dyadic adjustment in spousal caregiver-patient dyads (Pakenham, 1998). However, similar results have also been seen in couples with dissimilar coping strategies, likely because partners with different coping strategies create a broader repertoire of coping strategies (Pakenham, 1998). Pakenham's research shows that couples facing MS together can strengthen their relationships, particularly through helping one another to cope instead of isolating apart from one another. Taken together, the research shows that high quality relationships can get better when a stressor such as MS is experienced while pre-existing problems in a relationship can be exacerbated by the stress of MS.

**Synthesis and Hypotheses**

In conclusion, the currently available research demonstrates that dyadic adjustment and MS can interact in a variety of different, meaningful ways ranging from poor marital satisfaction and high divorce rates because of MS to increased dyadic adjustment because of MS. The research also shows that dyadic adjustment does not occur in a vacuum and the context of patient disability level, caregiver age, and gender are all factors to consider when examining dyadic adjustment in MS spousal/partner caregivers.

Given the current literature, we sought to replicate the finding that dyadic adjustment is inversely associated with caregiver burden specifically in a sample of spousal/partner MS caregivers. We hypothesized that higher dyadic adjustment would be associated with lower caregiver burden. We also sought to expand upon the current literature by examining dyadic adjustment as a possible buffer against the adverse effects of caregiver burden. We hypothesized that dyadic adjustment would moderate the relationship between caregiver burden and physical and mental health outcomes in MS spousal/partner caregivers (see Figure 1 for hypothesized
moderation model). We sought to explore the impact of caregiver burden and dyadic adjustment on a wider range of both physical and mental health outcomes for MS spousal/partner caregivers than some previous studies have investigated. We hypothesized that increased dyadic adjustment would be associated with improved physical and mental health outcomes.

**Methods**

All methods were reviewed and approved by the local Institutional Review Board. All participants were informed of the nature and purpose of the research and consented prior to participation.

**Participants**

Participants were recruited using a variety of means, including through collaborators at the National Multiple Sclerosis Society Upstate New York Chapter, by posting flyers at local neurologist offices, posting advertisements on MS and caregiver related websites and social media pages, and through word of mouth. All participants responded that they provided care for their spouse/partner diagnosed with MS. Participants completed self-report surveys online (n=88), via paper-and-pencil copies (n=4), or via telephone (n=1). Participants were offered the opportunity to enter a raffle for one of eight $25 gift cards in exchange for time spent completing the survey.

One hundred seventy three individuals accessed the survey and 93 completed the survey (53.8% completion rate). A priori power analyses (using G*Power 3.1.9.2) indicated a required sample size of at least 86 participants for sufficient power (1-β≥0.80) to detect a medium-sized effect in linear regression analysis. Participants qualified to take the survey based on their answers to inclusion criteria questions which were: participants were 18 years old or older, could
read, write, and understand English, were currently caring for their significant other who was diagnosed with MS, the individual they cared for was their spouse or partner, the individual they cared for was diagnosed with MS by a health care professional, and they did not receive any financial payment for the care they provided. Twenty-six individuals accessed the survey online but did not meet inclusion criteria. Another 26 individuals qualified to complete the survey based on the online inclusion questions, but did not provide consent and were therefore not given the opportunity to complete the survey. Another eight individuals provided consent to take the online survey, but did not answer any survey questions. Thus, the final sample size was 93 participants. Mean age of participants who completed the survey was 49.07 years old ($SD=13.35$, range=23-72 years) and a vast majority of participants self-identified as Caucasian (95.7%, $n=89$) and Non-Hispanic (96.7%, $n=87$). Just over half of respondents were male (55.8%, $n=53$). There was no significant difference between completers and non-completers in regards to mean age ($t(104)=0.86$, $p=0.39$, Cohen's $d=0.26$), gender ($\chi^2(1, 113)=2.42$, $p=0.12$, $\Phi=-0.15$), or ethnicity (Hispanic versus Non-Hispanic; $\chi^2(1, 108)=0.66$, $p=0.42$, $\Phi=-0.08$). There was a significant difference between completers and non-completers in regards to race ($\chi^2(4, 111)=12.05$, $p<0.05$, $\Phi=0.33$). Several racial differences were noted. Eighty-eight completers identified as White/Caucasian compared to 16 non-completers. Two completers identified as Black/African-American compared to zero non-completers. One completer identified as Native American compared to zero non-completers and zero completers identified as mixed race compared to two non-completers. All surveys were completed between February 1, 2012 and November 12, 2014.
Measures

Participants completed the following widely used and well-validated self-report measures (also, see Appendix B):

**Dyadic Adjustment Scale.** The Dyadic Adjustment Scale is a 32 item self-report measure designed to assess the quality of marriage and other non-married cohabitating dyads (Spanier, 1976). The concept of quality of marriage or marital adjustment has been researched since at least the 1920s and the DAS is one of the most popular and widely used measures to date. The scale yields a total and four different subscale scores, quantifying "dyadic satisfaction" (i.e., satisfaction in the relationship), "dyadic consensus" (i.e., agreement on family and household related decisions and behavioral conventions), "dyadic cohesion" (i.e., shared interests and activities), and "affectional expression" (i.e., demonstrations of affections, often physical). Responses to questions vary from yes/no answers to Likert-type ratings. According to validation samples, the DAS is valid and reliable. Cronbach's alphas in our sample were 0.92 for the total score (excellent internal consistency), 0.91 dyadic consensus subscale score (excellent internal consistency), 0.71 affectional expression subscale score (acceptable internal consistency), 0.50 dyadic satisfaction subscale score (poor internal consistency), and 0.86 dyadic cohesion subscale score (good internal consistency). The use of the four subscales has been criticized based on results of confirmatory factor analyses which support using the total, and not subscale scores (Kazak, Jarmas, & Snitzer, 1988; Sharpley & Cross, 1982; Spanier & Thompson, 1982). Given this criticism in the existing literature and evidence for somewhat variable internal consistency of subscales in our sample, we only used the total dyadic adjustment score in the analyses presented here. The DAS has previously been used in the similar population of cancer caregivers (Toseland, Blanchard, & McCallion, 1995).
**Caregiver Burden Inventory.** The Caregiver Burden Inventory is a 24 item self-report measure that assesses caregivers' needs or caregiving strain (Novak & Guest, 1989). It loads onto five different factors, measuring “time-dependence burden” (i.e., burden due to restrictions on caregivers' time), “developmental burden” (i.e., feeling 'off-time' in their development from peers), “physical burden” (i.e., chronic fatigue and damage to physical health), “social burden” (i.e., feeling role conflict), and “emotional burden” (i.e., negative feelings towards care receivers). Cronbach's alphas for our sample suggested good to excellent internal consistency (total score 0.96, time-dependence burden 0.91, developmental burden 0.95, physical burden 0.88, social burden 0.86, and emotional burden 0.93), which is consistent with prior findings from validation samples.

**Patient Health Questionnaire.** The Patient Health Questionnaire (PHQ-9) is a brief self-report measure of depression severity (Kroenke, Spitzer, & Williams, 2001). It assesses all nine criteria for major depressive disorder from the *Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV-TR)* (American Psychiatric Association, 2000) on a scale of zero ("not at all") to three ("nearly every day"). It is designed for use in the general population and was normed based on a large sample from primary care and obstetrics-gynecology clinics. It was found to be a valid and reliable measure of depression severity (Cronbach's $\alpha=0.89$ in prior samples). PHQ-9 scores of five, 10, 15, and 20 represent thresholds of mild, moderate, moderately severe, and severe depression, respectively. We included the PHQ-9 in the present study because prior research suggests that the assessment of caregiver burden is impacted by depression and we sought to differentiate the two variables (Caserta, Lund, & Wright, 1996). Cronbach's alpha for our sample was 0.91, suggesting excellent internal consistency of the scale.
**Short Form Health Survey.** The 12-item Short Form Health Survey is a measure of general physical and mental health. This short self-report measure was developed as an alternative to the longer 36-item version because the two subscales of physical health and mental health were found to account for 80% to 85% of the variance on the 36-item version (Ware Jr, Kosinski, & Keller, 1996). Short Form Health Survey scoring is proprietary. We only have access to subscale and total scores and we are unable to compute reliability estimates within our sample. However, prior research suggests that the 12-item version of the measure is valid and reliable (test-retest reliability of physical health component=0.89; mental health component=0.76). The SF-12 was included here to quantify mental and physical health as they are impacted by caregiver burden and dyadic adjustment.

**Satisfaction with Life Scale.** The Satisfaction with Life Scale is a widely used brief measure designed to capture life satisfaction, defined as a cognitive judgmental process (Diener, Emmons, Larsen, & Griffin, 1985). The SWLS was included in the present study to examine the hypothesized protective effects of dyadic adjustment against an adverse impact of caregiver burden on life satisfaction. The scale consists of five items that load onto a single factor. Respondents answer each item using a seven-point Likert scale ranging from one ("Strongly Disagree") to seven ("Strongly Agree"). Therefore, possible total scores range from five to 35. Questions include items such as "So far I have gotten the important things I want in life." The scale has previously demonstrated good internal consistency and reliability. Cronbach's alpha for our sample was 0.93, suggesting excellent internal consistency.

**Barthel Index of Activities of Daily Living.** The Barthel Index of Activities of Daily Living is designed to quantify caregivers’ assessment of a patient’s level of physical disability or functionality (Mahoney & Barthel, 1965). It was included here to control for the impact of
patient disability level of variables of interest, including caregiver burden and dyadic adjustment. Participants responded to 10 questions covering patient’s need for assistance with feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers, mobility, and stairs. Higher scores indicate more independent patient functioning. The Barthel Index is widely used, valid, reliable, and sensitive to change (Collin, Wade, Davies, & Horne, 1988). Cronbach's alpha for our sample was 0.93, suggesting excellent internal consistency.

**Statistical Analyses**

Prior to analysis, the data were examined for any outliers. No extraneous data points were identified. Only cases with complete responses on key variables of interest (defined as Caregiver Burden Inventory and Dyadic Adjustment Scale) were included in the analyses. Violations of assumptions were examined prior to analysis to ensure that the statistical analyses could be appropriately completed. Violations of assumptions were evaluated by examining skewness and kurtosis, visual inspection of plots of the variables (quantile-quantile plots, histograms, and boxplots), and tests of normality. We expected that some of our variables would be skewed given that literature shows that our population experiences disproportionately high levels of distress and mental and physical health impairments. Assessment of skewness and kurtosis indicated that none of the variables were severely skewed (e.g., all variables were within skew and kurtosis values of about negative 1.5 to 1.5). We did not apply any transformations in order to ease interpretation and to preserve the naturally expected distribution of the data.1

1 The following variables violated the Kolmogorov-Smirnov and Shapiro-Wilk tests of normality: Barthel Index of Activities of Daily Living, Patient Health Questionnaire, Satisfaction with Life Scale, and Short Form Health Survey Physical Component. The following variables violated only one of the tests of normality: Caregiver Burden Inventory (violated Shapiro-Wilk) and Short Form Health Survey Mental Health Component (violated Shapiro-Wilk). The Dyadic Adjustment Scale did not violate either test of normality. We created natural log, log base ten, and square root transformations for all variables that violated at least one test of normality (after
Other similar studies in the same population also did not appear to transform variables before executing comparable statistical analyses (e.g., Pakenham, 2005; Perrone, Gordon, & Tschopp, 2006). All data preparations and statistical analyses were completed using Statistical Package for the Social Sciences (SPSS) Version 21.0.

Study variables as predictors of patient disability level (as measured by the Barthel Index of Activities of Daily Living) and caregiver age were examined using Pearson's correlation coefficients and linear regression (for measures with multiple subscales). Differences in study variables by gender were examined using independent samples t-tests and multivariate analysis of variance (for measures with multiple subscales). Partial correlations controlling for gender were used to examine relationships among all variables and to test our hypothesis that dyadic adjustment would be inversely associated with caregiver burden. Hierarchical multiple regression models and the SPSS macro PROCESS (“Model 1”) were used to test the hypothesis that dyadic adjustment (as measured by the Dyadic Adjustment Scale) moderates the relationship between caregiver burden (Caregiver Burden Inventory) and caregiver outcomes including depression (Patient Health Questionnaire), general mental health (Short Form Health Survey Mental Health Component), general physical health (Short Form Health Survey Physical Health Component), and satisfaction with life (Satisfaction with Life Scale).

Given that literature shows that patient disability level, age, and gender can impact our variables and the significant effects that we found these factors to have on our variables, we appropriately adding constants as needed). None of the transformations improved results on tests of normality and most transformations made skew and kurtosis worse. The only transformation that made both tests of normality non-significant was the square root transformation of the Caregiver Burden Inventory. This transformation only slightly improved skewness and kurtosis and the original Caregiver Burden Inventory only violated one test of normality. Additionally, the transformed Caregiver Burden Inventory behaved similarly to the non-transformed version in our linear regression analyses.
initially included patient disability level, age, and gender in step one of our hierarchical multiple regression models and as covariates in moderation analyses, but subsequently removed them if found to be non-significant. All variables were standardized prior to regression analysis in order to reduce potentially problematic multicollinearity (Rosenthal & Rosnow, 2008).

Results

Table 1 summarizes information on caregivers' education and employment. Most commonly, participants reported that they completed some college (24.2%, \( n = 23 \)) or had bachelor's degrees (24.2%, \( n = 23 \)). Most participants worked full time (55.8%, \( n = 53 \)).

Regarding their relationships, 100% of our participants reported that they lived with their spouse/partner whom they cared for (\( n = 94 \), 1 non-responder), 90.3% were legally married (\( n = 84 \)) and 97.8% were in heterosexual relationships (\( n = 91 \)). Participants reported that they had been in their relationships on average for 22.88 years (\( SD = 14.25 \), range=1-52 years) and married on average for 21.84 years (\( SD = 14.22 \), range=1-49 years). On average, participants had 2.48 children (\( SD = 1.34 \), range=1-6 children) and reported that their spouses/partners were 47.64 years old (\( SD = 12.58 \), range=22-70 years old).

Table 2 provides information on income and medical expenses. Most commonly, 21.7% (\( n = 20 \)) of our sample reported annual estimated household incomes before taxes of $100,000 or more. When asked to estimate what they spend per year on out-of-pocket medical costs, 31.6% (\( n = 30 \)) reported that they spent $5001 or more. The majority of our sample reported that they shared finances with their spouse/partner (95.7%, \( n = 90 \)). This study did not assess medical insurance coverage.

The majority of participants reported that their spouse/partner had Relapsing-Remitting MS (59.1%, \( n = 55 \); Table 3). On average, participants reported that their spouses/partners were
diagnosed 10.97 years ago ($SD=9.88$, range=0-47 years). On average, participants had been providing care for 8.94 years ($SD=9.19$, range=0-52 years) and, according to caregiver self-report, provided 57.24% ($SD=33.10$, range=5-100%) of all care. There were no significant gender differences in percentage of care provided ($X^2(18, 100)=12.91$, $p=0.80$, $\Phi=0.36$).

Participants reported that they fulfilled a wide range of caregiving duties including: toileting (15.8%, $n=15$), transportation (62.1%, $n=59$), bathing (22.1%, $n=21$), feeding (14.7%, $n=14$), help with medications (61.1%, $n=58$), personal care (28.4%, $n=27$), transferring or transitioning (28.4%, $n=27$), household chores (78.9%, $n=75$), emotional support (90.5%, $n=86$), and help with making family or household decisions (82.1%, $n=78$).

The average Barthel Index patient disability level score in our sample was $76.65$ ($SD=29.23$, range=0-100). The total score was significantly and inversely correlated with years since diagnosis ($r=-0.50$, $p<0.001$). There was a significant effect of type or course of MS on total patient disability level ($F(4, 90)=10.58$, $p<0.001$). Post-hoc Tukey analysis indicated that those diagnosed with Relapsing-Remitting MS ($M=88.40$, $SD=18.93$) were on average significantly higher functioning than those diagnosed with Secondary-Progressive MS ($M=52.11$, $SD=33.92$; post-hoc $p<0.001$). Those diagnosed with Relapsing-Remitting MS were also significantly better functioning than patients with Progressive-Relapsing MS ($M=40.00$, $SD=14.14$; post-hoc $p=0.05$).

Participants reported that 21.5% ($n=20$) of patients receive some care from other people for an average total of 18.48 hours per week ($SD=24.19$, range=0-80 hours). Among those participants who did receive help from other people, 35.0% ($n=7$) received help from family members, 35.0% ($n=7$) from friends, and 60.0% ($n=12$) from home health care aides, and 10.0%
(n=2) from home respite care workers. Furthermore, 33.0% (n=30) of participants reported that they wanted additional help, but could not afford to pay for additional care.

Table 4 contains the means and standard deviations for all study variables. Of note, on average, our sample was mildly depressed (M=6.45, SD=6.26; Kroenke et al., 2001). Our sample reported slightly less satisfaction with life than normative samples (M=20.90, SD=8.53, compared to M of 23.5 and SD of 6.43; Diener et al., 1985).

Table 5 summarizes findings from analyses examining the relationships between study variables and patient disability level. Patient disability was significantly inversely correlated with total caregiver burden (r=-0.55, p<0.001) and depression (r=-0.27, p<0.05). Patient disability was significantly positively correlated with satisfaction with life (r=0.23, p<0.05) and general physical health (r=0.32, p<0.01). Patient disability accounted for 67% of the variance in caregiver burden subscale scores (F(5, 70)=28.49, R²=0.67, p<0.001), with time-dependence (β=-0.83, t(76)=-9.14, p<0.001) and social caregiver burden subscale scores emerging as significant predictors (β=0.44, t=3.43, p<0.01).

Table 6 contains findings from analyses examining associations between age and all study variables. Increased age was significantly correlated with greater total caregiver burden (r=0.25, p<0.05), lower dyadic adjustment (r=-0.30, p<0.05), and decreased satisfaction with life (r=-0.29, p<0.05). Age accounted for 16% of the variance in caregiver burden subscale scores (F(5, 73)=2.69, R²=0.16, p<0.05), with time-dependence caregiver burden subscale emerging as the single significant predictor in the model (β=0.32, t(79)=2.23, p<0.05).

The effect of gender on all study variables is summarized in Table 7. Results indicated significant gender differences such that total caregiver burden (t=-2.24(77), p=0.03, Cohen's d=0.51) and depression (t=-2.49(87), p=0.02, Cohen's d=0.52) were significantly higher in
women. There was no significant multivariate main effect of gender on combined Caregiver Burden Inventory subscale scores \( F(5, 73)=1.49, \) Wilks' \( \lambda=0.91, \) \( p=0.20, \) \( \eta^2_p=0.09 \).

Partial correlations among all variables controlling for gender are included in Table 8. The strength of all significant correlations ranged between moderate and strong. Of particular note, we observed that dyadic adjustment was significantly negatively correlated with caregiver burden \( (r=-0.49, p<0.001) \) such that as dyadic adjustment increased, caregiver burden decreased. Because of our particular interest in the relationship between dyadic adjustment and caregiver burden, and the significant effect of gender on total caregiver burden score (see Table 7), we also assessed this relationship separately in each gender. We found that inverse correlation between dyadic adjustment and caregiver burden was significant in males \( (r=-0.71, p<0.001) \) and not significant in females \( (r=-0.39, p=0.06) \).

**Caregiver Burden and Dyadic Adjustment Regression Analyses**

First, we examined the impact of caregiver burden and dyadic adjustment on depression in our sample of MS spousal/partner caregivers (Table 9). In the first step of hierarchical multiple regression, patient disability level accounted for a significant amount of the variance in depression \( R^2=0.14, p<0.01; F(1, 56)=8.91, p<0.01 \), and was therefore retained as a covariate in subsequent steps. In the second step, the addition of caregiver burden and dyadic adjustment accounted for 30% more of the variance in depression after controlling for patient disability level \( R^2 \text{ Change}=0.30, p<0.001; F(3, 54)=13.89, p<0.001 \). Caregiver burden was a significant predictor of caregiver depression \( (\beta=0.76, t=4.91, p<0.001) \) while dyadic adjustment was not \( (\beta=0.16, t=1.21, p=0.23) \). In the third step, the addition of the interaction term of caregiver burden and dyadic adjustment did not account for a significantly greater proportion of the variance in depression than the step that contained caregiver burden and dyadic adjustment as
independent predictors ($R^2$ Change=0.00, $p=0.92$; $F(4, 53)=10.23, p<0.001$). Therefore, moderation was not observed.

Next, we examined the impact of caregiver burden and dyadic adjustment on general mental health, as quantified by the SF-12 (Table 9). None of the hypothesized covariates emerged as significant and were therefore removed. In the first step, caregiver burden and dyadic adjustment accounted for 37% of the variance in general mental health ($R^2=0.37, p<0.001; F(2, 58)=17.16, p=0.00$). Caregiver burden ($\beta=-0.37, t=-3.08, p<0.01$) and dyadic adjustment ($\beta=0.34, t=2.84, p<0.05$) were each significant predictors of general mental health. In the second step, the addition of the interaction term of caregiver burden and dyadic adjustment did not account for a significantly greater proportion of the variance in general mental health than the step that contained caregiver burden and dyadic adjustment as independent predictors ($R^2$ Change=0.00, $p=0.89$; $F(3, 57)=11.25, p<0.001$). Therefore, moderation was not observed.

Next, we examined the impact of caregiver burden and dyadic adjustment on general physical health, as measured by the SF-12 (Table 9). None of the hypothesized covariates emerged as significant and were therefore removed. In the first step, caregiver burden and dyadic adjustment did not account for a significant amount of the variance in general physical health ($R^2=0.05, p=0.24; F(2, 58)=1.47, p=0.24$). Neither caregiver burden ($\beta=-0.20, t=-1.39, p=0.17$) nor dyadic adjustment ($\beta=-0.23, t=-1.55, p=0.13$) were significant predictors of general physical health. The addition of the interaction term of caregiver burden and dyadic adjustment in the second step also did not account for a significant amount of the variance in general physical health ($R^2$ Change=0.02, $p=0.24$; $F(3, 57)=1.46, p=0.24$). Moderation was not observed.
Then, we examined the impact of caregiver burden and dyadic adjustment on satisfaction with life (Table 9). None of the hypothesized covariates emerged as significant and were therefore removed. In the first step, caregiver burden and dyadic adjustment accounted for 50% of the variance in satisfaction with life ($R^2=0.50$, $p<0.001$; $F(2, 58)=29.39$, $p<0.001$). Caregiver burden ($\beta=-0.25$, $t=-2.30$, $p<0.05$) and dyadic adjustment ($\beta=0.55$, $t=5.03$, $p<0.001$) were each significant predictors of satisfaction with life. In the second step, the addition of the interaction term of caregiver burden and dyadic adjustment did not account for a significantly greater proportion of the variance in satisfaction with life than the step that contained caregiver burden and dyadic adjustment as independent predictors ($R^2$ Change=$0.00$, $p=0.54$; $F(3, 57)=19.52$, $p=0.00$). Therefore, moderation was not observed.

Preliminary analyses indicated that two caregiver burden subscales, developmental caregiver burden and emotional caregiver burden were significantly associated with dyadic adjustment. Therefore, we repeated our analyses with these subscales scores and the corresponding interactions with dyadic adjustment (as opposed to Caregiver Burden Inventory total scores). We did not identify any models in which moderation occurred.

**Discussion**

The present study sought to expand upon current literature that demonstrates that dyadic adjustment and MS can interact in a variety of different ways to affect outcomes in MS spousal/partner caregivers (e.g., Pakenham, 1998; Pakenham, 2005; Perrone et al., 2006). Our results replicated findings from similar previous research (Perrone et al., 2006) suggesting that dyadic adjustment (or marital satisfaction in Perrone's research) was negatively correlated with caregiver burden such that as dyadic adjustment increases, caregiver burden decreases. However, we expanded on the currently available literature by observing important
gender differences. We only found this effect in males, which suggests that male caregivers may benefit the most from interventions to improve dyadic adjustment.

We also hypothesized that dyadic adjustment would moderate the relationship between caregiver burden and caregiver outcomes. Dyadic adjustment did not interact significantly with the relationship between caregiver burden and outcomes in any of our models as initially hypothesized. Results indicated that lower caregiver burden and higher dyadic adjustment were associated with positive outcomes for MS spousal/partner caregivers after controlling for significant effects of patient disability level, caregiver age, and caregiver gender. Lower caregiver burden was associated with reduced depression, improved general mental health, and improved satisfaction with life. Higher dyadic adjustment was associated with improved general mental health and improved satisfaction with life. Neither caregiver burden nor dyadic adjustment had a significant impact on caregivers' general physical health. Therefore, our results suggest that higher dyadic adjustment and lower caregiver burden are each independently associated with improved mental health outcomes in MS spousal/partner caregivers. Our results additionally suggest that the positive effect of higher dyadic adjustment on caregiver burden may only be present in males.

Limitations

The present study was not without limitations. First, this study relied on self-report measures, which may be subject to recall bias, and was cross-sectional. Second, the sample was potentially biased because it was composed of self-selecting caregivers who were willing and able to complete a relatively long survey, and who therefore might have been higher functioning than MS spousal/partner caregivers who did not participate. Enough data were not available to assess whether completers had lower overall caregiver burden than non-completers, as one may
hypothesize. Furthermore, while multiple survey completion methods were available, the vast majority of participants completed surveys online, and therefore these individuals had access to the internet and may have had a higher socioeconomic status than non-completers. This assumption was supported by the relatively high levels of income reported by the majority of respondents in the present study. The sample was also potentially biased in terms of other participant demographics. Of those participants who answered what state they were from, all were from the Northeast (35 participants were from New York, one from New Jersey, and 12 from Connecticut). Additionally, 98.63% of our sample was Caucasian and 97.14% was non-Hispanic; however, given that some research indicates that rates of MS may be higher in Caucasian individuals (e.g., National Multiple Sclerosis Society, 2015), findings may nevertheless generalize to the vast majority of MS spousal/partner caregivers.

Clinical Implications

Taken together, results suggest that reducing caregiver burden and increasing dyadic adjustment through prevention and intervention efforts may improve caregivers' mental health. Results additionally suggest that gender should be taken into consideration when designing and implementing such efforts because men may benefit more from increasing dyadic adjustment than women. Therefore, interventions should be designed to provide targeted support to MS caregivers and their spouses/partners on their marriages/relationships. Occasionally, the National MS Society offers workshops on relationships. Efforts such as these should be offered routinely and the content should lend from empirically supported couple therapy work (e.g., Gurman, 2008).
Chapter Two

Giving and Receiving Social Support in Multiple Sclerosis Spousal/Partner Caregivers

Abstract

While some research has investigated the positive impact of receipt of social support in MS spousal or partner caregivers (e.g., Knight et al., 1997; Pakenham, 2001), there is no known research that has investigated how these caregivers may benefit from giving social support. The present study sought to investigate how both giving and receiving social support may influence caregiver burden and other health outcomes in MS spousal/partner caregivers. Participants (n=93, 55.8% male, mean age=49.07 years old, SD=13.35) completed self-report measures assessing perceived social support, involvement in volunteer work, altruism, and several outcomes. Perceived social support did not interact significantly with caregiver burden to predict health outcomes as initially hypothesized. However, analyses indicated that higher receipt of social support and lower caregiver burden were associated with reduced depression and improved general mental health and satisfaction with life. Additionally, giving social support by engaging in MS-related volunteer work was significantly positively associated with altruism and satisfaction with life. Finally, moderation analyses indicated that high altruism buffered against the negative effects of caregiver burden on general mental and physical health. Altruism also protected against the impact of caregiver burden on satisfaction with life; however, this effect was only present at low and moderate levels of caregiver burden. Findings have implications for interventions targeting MS caregivers who may benefit from receiving social support and from volunteering for MS-related activities.

Keywords: Multiple sclerosis, spousal caregivers, partner caregivers, social support, altruism, volunteer work
Introduction

In the present study, we examined psychosocial correlates of giving and receiving social support in the spousal or partner caregivers of individuals with MS. Multiple sclerosis spousal/partner caregivers are uniquely susceptible to the deleterious impacts of caregiver burden (e.g., Buhse, 2008; Corry & While, 2009). Due to unpredictable and debilitating symptoms, individuals with MS often need a caregiver who is flexibly available to help manage their symptoms and to provide assistance with activities of daily living (e.g., McKeown et al., 2003). Individuals with MS are most often cared for by family members (O’Hara et al., 2004). In a sample of people with MS who reported having a primary caregiver, 65% of caregivers were spouses, and 75% of those spousal caregivers lived with the person for whom they cared (Aronson et al., 1996; Aronson, 1997). Therefore, the most common caregivers for individuals with MS are spouses/partners. Due to the relatively early onset of the disease (National Multiple Sclerosis Society, 2015) and the constantly shifting symptoms, these caregivers may face caregiving challenges for decades with little reprieve. Therefore, it is important to examine possible protective factors that may help shield these uniquely vulnerable caregivers against the adverse effects of the chronic stress associated with providing care for their partner.

Receiving Social Support

The perceived receipt of social support is one protective factor that the standing literature has consistently identified as buffering effectively against the chronic stress of caregiving. The concept of social support has been studied extensively since about the 1970s. Social support is defined as the resources that individuals gain from their interpersonal relationships (Cohen & Hoberman, 1983). Types of social support can include emotional, informational, and instrumental support. Receiving social support has been repeatedly documented to be a buffer
against negative mental health consequences from life stress, such as depression (e.g., seminal research by Cohen & Hoberman, 1983). Social support has also been shown to be aide recovery from illness, to support the immune system, and has even been shown to predict first-time acute myocardial infarction with lack of social support being associated with earlier acute myocardial infarction (e.g., reviews by Cohen & Syme, 1985; Langford, Bowsher, Maloney, & Lillis, 1997; Reblin & Uchino, 2008). The receipt of social support has also been shown to be influenced by a variety of different factors, including age. For example, Lang and Cartensen (1994) found that the size of social networks decreased with increased age; however, the number of close relationships did not significantly differ between individuals of varying ages. Similarly, van Tilburg (1998) found that networks of friends decreased with advanced age, while networks of close relationships with family members increased.

There are seemingly limitless ways to experience the benefits of social support, and therefore, social support has also been studied using a multitude of different conceptualizations and measurements. As Cohen and Syme caution, the ways in which social support is "perceived, mobilized, given, and taken" must be viewed within a context in order to understand it (Cohen & Syme, 1985, p. 9). The present study narrowed in on the context of receiving social support as a caregiver.

**Social support and caregivers.** Zarit and colleagues (1980) were some of the first researchers to begin to examine social support and caregiver burden. They found in a sample of caregivers for elderly individuals with dementia that caregiver burden was inversely related to the social support or the number of household visitors that the caregivers reported. Zarit and colleagues’ sample did not contain individuals with high perceived levels of caregiver burden, but the finding began to illustrate the importance of social support to family caregivers. As the
literature advanced, we began to learn more about the role of social support in caregivers and factors that influence social support. Thompson and colleagues (1993) helped to elucidate that certain types of social support may be more beneficial than others and specifically that fun and recreation social interaction reduced caregiver burden most effectively for familial caregivers of the elderly. Hayley and colleagues (1996) showed that caregiving stress was influenced by social support in a sample of familial caregivers for individuals with Alzheimer's disease. Their work also began to point to racial differences in how black and white caregivers responded differently to caregiving stress. Turner and colleagues (1998) helped to elucidate important gender differences in caregivers of individuals with AIDS, such that female friends of patients had the highest levels of emotional support, while male family members of patients had the lowest levels of support. Additional work in HIV/AIDS caregivers found that social support was inversely related to caregiver distress and poor adjustment (McCausland & Pakenham, 2003).

Improving receipt of social support has already been shown to be a possible intervention against caregiver burden. In a large longitudinal study, Roth and colleagues (2005) implemented interventions designed to enhance social support networks in a sample of spousal caregivers of Alzheimer's patients. They found that number of support persons, caregiving assistance from support persons, and satisfaction with support network all increased and these increases mediated the intervention's positive impact on caregiver depression.

While the literature on receiving social support in familial caregivers is informative, the present study specifically narrowed in on the receipt of social support in a population that has been relatively understudied to date, namely MS spousal/partner caregivers.

**Social support in MS spousal/partner caregivers.** Some research has been conducted on the receipt of social support in MS spousal/partner caregivers. Social support has been identified
as a predictor of perceived caregiver burden in MS spousal/partner caregivers, such that lack of social support is associated with increased burden (Knight et al., 1997). Additional research has shown that more perceived available social support is associated with reduced depression (88.1% of this sample was composed of MS spousal/partner caregivers; Bambara, Turner, Williams, & Haselkorn, 2014). Studies have shown that improved adjustment in informal MS caregivers (about 85% of whom were spouses) was predicted by less care recipient disability, less caregiving distress, and higher social support (in addition to a beneficial effect of certain coping strategies; Pakenham, 2001). These effects were found after controlling for gender. It has also been found that as caregiving stress increased, MS spousal/partner caregivers sought-out and used social support more (O'Brien, 1993b). A qualitative study found that MS caregivers went through various phases of rejecting, resisting, seeking, and accepting social support (though this research should be interpreted with some caution because it was conducted in only sixteen caregivers who were not all spouses/partners).

As alluded to above in regards to Pakenham's research, gender has been shown to impact the relationship between social support and perceived burden (e.g., Knight et al., 1997; Pakenham, 2001). Good and colleagues (1995) specifically investigated gender differences in social support for MS spousal caregivers. They found that female caregivers perceived more available social support, and in particular, informational or instrumental social support, compared to male caregivers. They also found in both male and female caregivers that perceived social support was positively correlated with commitment to the spousal relationship. Therefore, the current literature shows that receiving social support can predict reduced caregiver burden and improved outcomes in MS spousal/partner caregivers, with important gender differences and influence from the patient's disability level. Additional research, though largely preliminary, has
also explored the idea that giving social support can be beneficial, similar to how receiving social support is beneficial.

**Giving Social Support**

The concept of giving social support has been broadly examined in the general population. Findings have been somewhat mixed, suggesting that both giving and receiving social support can have positive and negative consequences on well-being (Liang, Krause, & Bennett, 2001). Some research has shown that giving and receiving social support are inherently linked in general adult samples such that giving social support is positively associated with receiving social support (e.g., Bowling, Beehr, & Swader, 2005). That particular study also showed that the nature of the social support might matter (i.e., job-related versus non-job related social support) and that personality factors may influence whether people engage in giving and receiving social support. Some additional earlier, general work showed reciprocity of social support was an important factor in couples. Research found that perceived reciprocity of social support (equal giving and receiving) in couples was related to wives' well-being more so than husbands' well-being (Acitelli & Antonucci, 1994). Research such as this began to suggest that giving and receiving social support may both be important, and that the concepts may also interact in dyads. Additional work has shown that perceptions of reciprocity of giving and receiving social support within familial dyads may change with age, such that older adults may experience and expect more unreciprocal social support (Ingersoll-Dayton & Antonucci, 1988).

While research has shown that giving social support is an important factor to examine, especially in couple dyads, very little research has examined giving social support in caregivers. This seems especially important to examine because caregivers, by definition, give social support. This begs the question as to whether they may benefit (or be harmed) by giving social
support in a manner similar to non-caregivers. Furthermore, spousal/partner caregivers seem to be an even more important population to study because research shows that giving and receiving social support interact within couple dyads. For example, Corry and While (2009) summarized that end of the day mood improved in spousal caregivers of individuals with MS when the caregiver was able to give instrumental social support and/or receive emotional support from the care receiver. This provides preliminary support for the notion that examining both giving and receiving social support in MS spousal/partner caregivers may be important.

Because spousal/partner caregivers are constantly giving and receiving social support and because some research already examined giving social support within relationship dyads, we decided to investigate whether giving social support outside of the dyadic relationship might be beneficial (or harmful) for spousal/partner caregivers. Specifically, we identified that engagement in volunteer work is a unique and largely non-researched way that individuals give social support.

**Volunteer work.** Volunteer work is considered a form of giving social support and is a core aspect of American society (e.g., Thoits & Hewitt, 2001). Many different people engage in volunteer work through charitable, religious, and community organizations. Research has been conducted on who engages in volunteer work, such as work by Wilson and Musick (1997). They conceptualized that volunteer work requires human, social, and cultural capital. Regarding human capital, they found that people of higher socioeconomic status were more likely to volunteer because these individuals had stronger skills that could provide the confidence needed to seek out volunteer opportunities. Regarding social capital, they found that African Americans volunteered less than Caucasians and that women perceived that they helped others more than
men did. Additional research by Wilson demonstrated that people who belonged to religious organizations were more likely to engage in volunteer work (Wilson & Janoski, 1995).

Research fairly consistently suggests that there are many positive benefits of volunteer work not just for institutions and society in general, but also for the volunteers. Individuals who volunteered reported higher levels of well-being and life satisfaction (e.g., Morrow-Howell, Hinterlong, Rozario, & Tang, 2003; Thoits & Hewitt, 2001). Also of note, Wilson and Musick (1999) reviewed that volunteer work built civic skills and was correlated with being involved in local politics and other clubs and social activities, suggesting that volunteer work may help individuals gain more social networks and therefore enhance receipt of social support. In fact, volunteers may expect some rewards from their work, including the opportunity to build social relationships (Gidron, 1978). Research has also demonstrated that the personality characteristic of altruism may be a leading factor to why individuals engage in volunteer work (e.g., Thoits & Hewitt, 2001; Unger, 1991).

Volunteer work and caregivers. While there is research available on volunteer work in general, very little published research examines volunteer work in caregivers. It is quite common for organizations aimed at raising money for research for chronic illnesses to offer many different volunteer opportunities. For example, the National MS Society organizes Bike MS and Walk MS and often recruit caregivers to volunteer and/or participate in these events. However, due to the lack of research, it is not clear whether engagement in these types of activities is beneficial to caregivers, or whether they may represent additional burden. Therefore, research regarding caregivers' engagement in volunteer work is needed.

One available study examined whether being a spousal caregiver (for older-age related functionality impairments) was related to involvement in formal or informal volunteer work.
The study showed that female spousal caregivers were less likely than non-caregivers to engage in volunteer work, which supported the idea that caregiving and volunteer work can be a "role overload" (Choi, Burr, Mutchler, & Caro, 2007). An additional study also found that women who spent time providing unpaid care for aging family members were less likely to volunteer (Taniguchi, 2006). A third study by Burr and colleagues (2005) found the opposite. They found that older adult caregivers were more likely to be volunteers than non-caregivers (Burr, Choi, Mutchler, & Caro, 2005). In that study, the authors hypothesized that caregivers were more likely to be asked to volunteer because they were involved in the networks that provided volunteer opportunities. Other available research seems to focus on individuals who perform caregiving on a volunteer basis (e.g., Hank & Stuck, 2008). Overall, the limited available research on volunteer work in caregivers shows inconsistent results. Furthermore, there is no known research on the impact of volunteer work specifically in MS spousal/partner caregivers.

**Synthesis and Hypotheses**

Taken together, the current literature suggests that more research is needed to clarify the impact of the receipt of social support on mental and physical health specifically in MS spousal/partner caregivers, and to begin to address the idea that giving social support may be beneficial in some of the same ways as receipt of support. The perceived receipt of social support has been studied in this population previously and the research has shown that higher social support predicts improved adjustment with important gender differences (Pakenham, 2001). The effects of giving social support, on the other hand, have been largely unstudied in caregivers. The specific form of giving social support by engaging in volunteer work has not been studied at all in MS spousal/partner caregivers. The available research on other caregiver populations
engaging in volunteer work suggests that age and gender are important factors to consider (Burr et al., 2005; Choi et al., 2007; Taniguchi, 2006).

We hypothesized that receipt of social support would be inversely correlated with caregiver burden such that higher social support would be associated with lower caregiver burden. We sought to expand the currently available research by hypothesizing that social support would moderate the relationship between caregiver burden and caregiver health outcomes in MS spousal/partner caregivers (see Figure 1 for hypothesized moderation model). We specifically sought to replicate findings from prior research in a sample that is composed entirely of MS spousal/partner caregivers, whereas prior research, specifically by Pakenham in 2001, was composed of about 85% MS spousal caregivers (with the remaining 15% other MS caregivers).

We also aimed to explore the impact of engagement in volunteer work in MS spousal/partner caregivers. We aimed to help define effects associated with engagement in MS-specific versus non-MS specific volunteer work. We sought to differentiate these types of volunteer work because previous research differentiated job-related versus non-job related social support (Bowling et al., 2005). We also hypothesized that significant differences between engagement in MS-related versus non-MS related volunteer work would emerge because these types of volunteer work seem to be inherently different. MS-related volunteer work may help caregivers to feel effective and feel as if they are fighting MS or may negatively remind them of the burden of MS. Non-MS related volunteer work may help distract caregivers from the burden of MS or may create too much role overload.

We hypothesized that engagement in volunteer work would be related to the personality characteristic of altruism. We additionally hypothesized that altruism, as a proxy for
engagement in volunteer work, would act as a buffer against adverse outcomes by moderating the relationship between caregiver burden and caregiver health outcomes in our sample of MS spousal/partner caregivers (see Figure 1 for hypothesized moderation model).

Methods

All methods were reviewed and approved by the local Institutional Review Board. All participants were informed of the nature and purpose of the research and consented prior to participation.

Participants

For information on recruitment, the sample size, and comparisons between completers and non-completers please see Chapter One.

Measures

Participants completed the following widely used and well-validated self-report measures (also, see Appendix B):

**Multidimensional Scale of Perceived Social Support.** The Multidimensional Scale of Perceived Social Support is a 12 item self-report measure that assesses social support (Zimet, Dahlem, Zimet, & Farley, 1988). The scale yields a total score of perceived social support (Cronbach’s $\alpha=.93$ in the present sample), which is summed from three subscale scores of sources of social support, namely “family” (Cronbach’s $\alpha=.91$), “friends” (Cronbach’s $\alpha=.92$) and “significant other” (Cronbach’s $\alpha=.90$). Participants answer questions such as "There is a special person who is around when I am in need," "I can talk about my problems with my family," and "I have friends with whom I can share my joys and sorrows" using a seven-point Likert scale ranging from “very strongly disagree” (one) to “very strongly agree” (seven). The
scale demonstrated good internal reliability and adequate test-retest reliability in general validation samples. The scale has been validated for use in numerous populations (Canty-Mitchell & Zimet, 2000; Kazarian & McCabe, 1991; Zimet, Powell, Farley, Werkman, & Berkoff, 1990).

**Engagement in volunteer work.** Given a lack of empirically validated measures of giving social support we developed a set of questions designed to quantify participants’ engagement in volunteer work, differentiating between general engagement in volunteer work and engagement in MS-specific volunteer activities (see Appendix B).

**Altruism.** Considering the possibility that the personality trait of altruism may drive participants' willingness to engage in volunteer work (as well as to care for a chronically ill spouse/partner) we included select items from the International Personality Item Pool, which provides personality trait assessment questions for use in the public domain (Goldberg, 1999; Goldberg et al., 2006; International Personality Item Pool). For the purposes of our study, participants were asked to rate how accurate ten different statements are about them were on a Likert-type scale of one ("very inaccurate") to five ("very accurate"). Statements included items such as "Anticipate the needs of others" and "Look down on others." The International Personality Item Pool is widely used. The International Personality Item Pool creators support creating "local norms" by finding the mean and standard deviation of scores from the researcher's own sample and then comparing sampled individual scores against those local norms. Cronbach's alpha in the present sample was 0.87, suggesting good internal consistency of the selected items.

**Caregiver Burden Inventory.** For information on the Caregiver Burden Inventory, please see Chapter One.
**Patient Health Questionnaire.** For information on the Patient Health Questionnaire, please see Chapter One.

**Short Form Health Survey.** Please see Chapter One.

**Satisfaction with Life Scale.** Please see Chapter One.

**Barthel Index of Activities of Daily Living.** Please see Chapter One.

**Statistical Analyses**

Prior to analysis, the data were examined for any outliers. No extraneous data points were identified. Only cases with complete responses on key variables of interest (defined as Caregiver Burden Inventory, Multidimensional Scale of Perceived Social Support, and Altruism) were included in the analysis. Violations of assumptions were examined prior to analysis to ensure that the statistical analyses could be appropriately completed. Violations of assumptions were evaluated by examining skewness and kurtosis, visual inspection of plots of the variables (quantile-quantile plots, histograms, and boxplots), and tests of normality. We expected that some of our variables would be skewed given that literature shows that our population experiences distress and mental and physical health impairments. Assessment of skewness and kurtosis indicated that none of the variables were severely skewed (e.g., all variables were within skew and kurtosis values of about negative 1.5 to 1.5). We did not apply any transformations in order to ease interpretation and to preserve the naturally expected distribution of the data.² Other

² The following variables violated the Kolmogorov-Smirnov and Shapiro-Wilk tests of normality: Altruism scale, Barthel Index, Patient Health Questionnaire, Satisfaction with Life Scale, and Short Form Health Survey Physical Component. The following variables violated only one of the tests of normality: Caregiver Burden Inventory (violated Shapiro-Wilk) and Short Form Health Survey Mental Health Component (violated Shapiro-Wilk). The Multidimensional Scale of Perceived Social Support did not violate either test of normality. We created natural log, log base ten, and square root transformations for all variables that violated at least one test of normality (after appropriately adding constants as needed). None of the transformations improved results on tests of normality and most transformations made skew and
similar studies in the same population also did not appear to transform variables and continued with similar statistical analyses (e.g., Pakenham, 2001). All data preparations and statistical analyses were completed using Statistical Package for the Social Sciences (SPSS) Version 21.0.

Associations between study variables and patient disability level (as measured by the Barthel Index of Activities of Daily Living) and caregiver age were examined using Pearson's correlation coefficients and linear regression (for measures with multiple subscales). Differences in study variables by gender were examined using independent samples t-tests and multivariate analysis of variance (for measures with multiple subscales). Partial correlations controlling for gender were used to examine relationships among all variables. Descriptive statistics, bivariate correlations, Chi-square tests, independent sample t-tests, and multivariate analyses of variance were used to examine engagement in volunteer work and altruism. Hierarchical multiple regression models and the SPSS macro PROCESS (“Model 1”) were used to test the hypothesis that perceived social support (as measured by the Multidimensional Scale of Perceived Social Support) and altruism (as measured by International Personality Item Pool items) moderate the relationship between caregiver burden (Caregiver Burden Inventory) and caregiver outcomes including depression (Patient Health Questionnaire), general mental health (Short Form Health Survey Mental Health Component), general physical health (Short Form Health Survey Physical Health Component), and satisfaction with life (Satisfaction with Life Scale).

Given that literature shows that patient disability level, age, and gender can impact our variables and the significant effects that we found these factors to have on our variables in kurtosis worse. The only transformation that made both tests of normality non-significant was the square root transformation of the Caregiver Burden Inventory. This transformation only slightly improved skewness and kurtosis and the original Caregiver Burden Inventory only violated one test of normality. Additionally, the transformed Caregiver Burden Inventory behaved similarly to the non-transformed version in our linear regression analyses.
preliminary analyses, we initially included patient disability level, age, and gender as covariates in all analyses, but subsequently removed them if found to be non-significant. All variables were standardized prior to regression analysis in order to reduce potentially problematic multicollinearity (Rosenthal & Rosnow, 2008).

**Results**

Please see Chapter One and Table 1 for information on caregivers' education and employment. Please also see Chapter One for information regarding participant's relationships with their spouses/partners and their children. Chapter One and Table 2 contain information regarding income and medical expenses. Chapter One also contains information regarding participants' spouses'/partners' course of MS (also see Table 3), caregiving duties performed, patient disability level, and care received from other people.

Table 4 contains the means and standard deviations for all study variables. Of note, on average, our sample was mildly depressed ($M=6.45$, $SD=6.26$; Kroenke et al., 2001). Our sample rated slightly less satisfaction with life than normative samples ($M=20.90$, $SD=8.53$, compared to $M$ of 23.5 and $SD$ of 6.43; Diener et al., 1985).

The relationships between all study variables and patient disability level are summarized in Table 5. Patient disability was significantly negatively correlated with total caregiver burden ($r=-0.55$, $p<0.001$) and depression ($r=-0.27$, $p<0.05$). Patient disability was significantly positively correlated with satisfaction with life ($r=0.23$, $p<0.05$) and general physical health ($r=0.32$, $p<0.01$). Patient disability accounted for 67% of the variance in caregiver burden subscales ($F(5, 70)=28.49$, $R^2=0.67$, $p<0.001$) with time-dependence caregiver burden ($\beta=-0.83$, $t(76)=-9.14$, $p<0.001$) and social caregiver burden ($\beta=0.44$, $t=3.43$, $p<0.01$) emerging as
significant predictors. Patient disability level did not have a significant multivariate main effect on combined subscale scores of perceived social support \(F(3, 83)=1.67, R^2=0.06, p=0.18\).

Table 6 contains all study variables as predictors of caregiver age. Age was significantly positively correlated with total caregiver burden \(r=0.25, p<0.05\). Age was significantly negatively correlated with satisfaction with life \(r=-0.29, p<0.05\) and total perceived social support \(r=-0.31, p<0.01\). Age accounted for 16% of the variance in caregiver burden subscale scores \(F(5, 73)=2.69, R^2=0.16, p<0.05\), with time-dependence caregiver burden subscale emerging as the single significant predictor in the model \(\beta=0.32, t(79)=2.23, p<0.05\). Age also accounted for 11% of the variance in perceived social support subscales \(F(3, 86)=3.42, R^2=0.11, p<0.05\), but did not have a significant effect on any of the perceived social support subscales.

The effect of gender on the study variables is summarized in Table 7. Results indicate that total caregiver burden \(t=-2.24(77), p=0.03, \text{Cohen's } d=0.51\) and depression \(t=-2.49(87), p=0.02, \text{Cohen's } d=0.52\) were significantly higher in females than males. There was no significant multivariate main effect of gender on combined Caregiver Burden Inventory subscale scores \(F(5, 73)=1.49, \text{Wilks' } \lambda=0.91, p=0.20, \eta_p^2=0.09\). The multivariate main effect of gender on combined social support subscale scores was not significant \(F(3, 87)=0.85, \text{Wilks' } \lambda=0.97, p=0.47, \eta_p^2=0.03\).

Partial correlations among all variables controlling for gender are included in Table 8. The strength of all significant correlations ranged between weak and strong. Of particular note, we observed that perceived social support was significantly negatively correlated with caregiver burden \(r=-0.29, p<0.05\) such that as perceived social support increased, caregiver burden decreased. We observed that the relationship between perceived social support and altruism was
not significant \((r=0.28, p=0.05)\). Because of our particular interest in these relationships, and the significant effect of gender on total perceived social support score and total caregiver burden score (see Table 7), we also assessed this relationship separately in each gender. The inverse correlation between perceived social support and caregiver burden was significant in males \((r=-0.68, p<0.001)\), but not in females \((r=-0.17, p=0.38)\). We also observed that the correlation between perceived social support and altruism was significant in males \((r=0.43, p<0.01)\), but not significant in females \((r=0.22, p=0.17)\).

**Caregiver Burden and Perceived Received Social Support Regression Analyses**

First, we examined the impact of caregiver burden and perceived receipt of social support on depression (Table 10). In the first step of hierarchical multiple regression, patient disability level accounted for a significant amount of the variance in depression \((R^2=0.09, p<0.05; F(1, 65)=6.34, p<0.05)\), and was retained as a covariate in subsequent steps. In the second step, the addition of caregiver burden and perceived social support accounted for 35% more of the variance in depression, compared to step one containing patient disability level \((R^2 \text{ Change}=0.35, p<0.001; F(3, 63)=16.48, p<0.001)\). Caregiver burden \((\beta=0.53, t=4.10, p<0.001)\) and perceived social support \((\beta=-0.24, t=-2.18, p<0.05)\) were each significant predictors of depression. The third step, which included the interaction term of caregiver burden and perceived social support, did not account for a significantly greater proportion of the variance in depression than the step that included caregiver burden and perceived social support as independent predictors \((R^2 \text{ Change}=0.03, p=0.88; F(4, 62)=12.18, p<0.001)\). Therefore, moderation was not observed.

Next, we examined the impact of caregiver burden and perceived social support on general mental health, as measured by the SF-12 (Table 10). None of the hypothesized covariates emerged as significant and were therefore removed. The first step, which contained caregiver
burden and perceived social support as independent predictor variables, accounted for 39% of the variance in general mental health ($R^2=0.39, p<0.001; F(2, 67)=21.44, p<0.001$). Caregiver burden ($\beta=-0.34, t=-3.32, p=0.00$) and perceived social support ($\beta=0.41, t=3.93, p=0.00$) were each significant predictors of general mental health. The second step, which included the interaction term of caregiver burden and perceived social support, did not account for a significantly greater proportion of the variance in general mental health than the step that contained caregiver burden and perceived social support as independent predictors ($R^2_{\text{Change}}=0.00, p=0.74; F(3, 66)=14.14, p<0.001$). Therefore, moderation was not observed.

Then, we examined the impact of caregiver burden and perceived social support on general physical health, as quantified by the SF-12 (Table 10). None of the hypothesized covariates emerged as significant and were therefore removed. In the first step, caregiver burden and perceived social support did not account for a significant amount of the variance in general physical health ($R^2=0.02, p=0.56; F(2, 67)=0.58, p=0.56$). Neither caregiver burden ($\beta=-0.14, t=-1.05, p=0.30$) nor perceived social support ($\beta=-0.02, t=-0.16, p=0.88$) were significant predictors of general physical health. In the second step, the addition of the interaction term of caregiver burden and perceived social support also did not account for a significant amount of the variance in general physical health ($R^2_{\text{Change}}=0.00, p=0.70; F(3, 66)=0.43, p=0.73$). Moderation was not observed.

Next, we examined the impact of caregiver burden and perceived social support on satisfaction with life (Table 10). In the first step, caregiver age accounted for a significant amount of the variance in satisfaction with life ($R^2=0.08, p<0.05; F(1, 68)=5.96, p<0.05$) and was retained as a covariate in subsequent steps. In the second step, the addition of caregiver burden and perceived social support as independent predictors accounted for 51% more of the
variance in satisfaction with life, compared to step one containing caregiver age ($R^2$ Change=0.51, $p<0.001$; $F(3, 66)=31.69, p<0.001$). Caregiver burden ($\beta=-0.30, t=-3.49, p<0.01$) and perceived social support ($\beta=0.58, t=6.56, p<0.001$) were each significant predictors of satisfaction with life. The third step, which included the interaction term of caregiver burden and perceived social support, did not account for a significantly greater proportion of the variance in satisfaction with life than the step that included caregiver burden and perceived social support on their own ($R^2$ Change=0.02, $p=0.10$; $F(4, 65)=25.16, p<0.001$). Therefore, moderation was not observed.

Preliminary analyses indicated that the social caregiver burden subscale of the Caregiver Burden Inventory was significantly associated with perceived social support. Preliminary analyses also indicated that the significant other social support subscale of the Multidimensional Scale of Perceived Social Support was significantly associated with general caregiver burden (total score on the Caregiver Burden Inventory). The indicated caregiver burden and perceived social support subscales were not significantly associated with one another. Therefore, we repeated our analyses examining the role of perceived social support on the relationship between social caregiver burden and all outcomes and the role of significant other social support on the relationship between caregiver burden and all outcomes using hierarchical multiple regression models. We did not observe any moderation.

**Exploratory Investigation of Giving Social Support**

In our sample, 25.0% of participants ($n=25$) reported that they volunteered for MS-related activities and 40.6% of participants ($n=39$) reported that they volunteered for non-MS related activities. Of these, eight participants endorsed that they volunteered with both MS-related and non-MS related activities. Of those who volunteered for MS-related activities, 80.0% reported
that they participated in walks \((n=20;\text{ see Table 11})\). Of those who volunteered for non-MS related activities, 51.3\% \((n=20)\) reported that they volunteered for religious organizations (Table 11). Participants reported that they spent an average of 3.33 hours per month volunteering for MS-related activities \((SD=3.17, \text{ range}=0-10 \text{ hours})\). Participants reported that they spent an average of 12.97 hours per month volunteering for non-MS related activities \((SD=25.96, \text{ range}=0-150 \text{ hours})\). It is of note that one participant reported that he/she spent about 150 hours per month volunteering for a non-profit, as this drove the mean up. When we removed that participant, we observed that participants spent an average of 8.94 hours per month volunteering for non-MS related activities \((SD=10.43, \text{ range}=0-40 \text{ hours})\).

There were no significant differences between those who reported that they volunteered for MS-related activities versus who reported that they did not volunteer for MS-related activities based on gender \((X^2(1, 100)=1.95, p=0.16, \Phi=-0.14)\) or age \((t(97)=-1.38, p=0.17, \text{ Cohen's } d=0.34; \text{ Table 12})\). There were also no significant differences between those who reported that they volunteered for non-MS related activities versus those who reported that they did not volunteer for non-MS related activities based on gender \((X^2(1,96)=0.00, p=0.98, \Phi=0.00)\) or age \((t(93)=-0.08, p=0.94, \text{ Cohen's } d=0.02; \text{ Table 13})\).

Whether or not participants volunteered for MS-related activities was significantly associated with altruism \((t(91)=2.48, p<0.05, \text{ Cohen's } d=0.65)\) and satisfaction with life \((t(90)=2.41, p<0.05, \text{ Cohen's } d=0.59)\), with participants who volunteered for MS-related activities scoring significantly higher on altruism and satisfaction with life (Table 12). There was a significant omnibus multivariate main effect of volunteer work for MS-related activities on combined caregiver burden subscales \((F(5, 71)=2.45, \text{ Wilks' } \lambda=0.85, p<0.05, \eta^2_p=0.15)\). However, none of the univariate \(F\) tests were significant, and therefore the omnibus effect could
not be further interpreted. The multivariate main effect of engagement in MS-related volunteer work on combined perceived social support subscales was not significant ($F(3, 85)=1.23$, Wilks' $\lambda=0.96$, $p=0.30$, $\eta^2_p=0.04$). There were no significant differences between participants who volunteered for non-MS related activities and those who did not in regards to altruism, satisfaction with life, caregiver burden, or perceived social support (see Table 13).

**Caregiver Burden and Altruism Regression Analyses**

In the following analyses, we used altruism as a proxy for giving social support due to the finding that individuals who volunteered for MS-related events scored significantly higher on altruism than those who did not ($t(91)=2.48, p<0.05$, Cohen's $d=0.65$). First, we examined the hypothesized role of altruism as a moderator of the relationship between caregiver burden and depression (Table 14). In the first step of hierarchical multiple regression, patient disability level accounted for a significant amount of the variance in depression ($R^2=0.10, p<0.05; F(1, 67)=7.43, p<0.05$) and was retained as a covariate in subsequent steps. In the second step, the addition of caregiver burden and altruism accounted for 34% more of the variance in depression, compared to step one containing patient disability level ($R^2$ Change$=0.34, p<0.001; F(3, 65)=17.13, p<0.001$). Caregiver burden ($\beta=0.55, t=4.28, p<0.001$) was a significant predictor of depression, while altruism was not ($\beta=-0.20, t=-1.86, p=0.07$). The third step, which included the interaction term of caregiver burden and altruism, did not account for a significantly greater proportion of the variance in depression than the step that contained caregiver burden and altruism as independent predictors ($R^2$ Change$=0.01, p=0.31; F(4, 64)=13.12, p<0.001$). Therefore, moderation was not observed.

Next, we examined the impact of caregiver burden and altruism on general mental health, as quantified by the SF-12 (Table 14). In the first step, caregiver gender accounted for a
significant amount of the variance in general mental health ($R^2=0.07, p<0.05$; $F(1, 70)=5.59, p<0.05$), and was retained as a covariate in subsequent steps. In the second step, caregiver burden and altruism accounted for 29% more of the variance in general mental health, compared to step one containing caregiver gender ($R^2\text{ Change}=0.29, p<0.001$; $F(3, 68)=12.78, p<0.001$). Caregiver burden ($\beta=-0.34, t=-2.93, p<0.05$) and altruism ($\beta=0.30, t=2.66, p<0.05$) were each significant predictors of general mental health. The third step, which included the addition of the interaction term of caregiver burden and altruism, did not account for a significantly greater proportion of the variance in general mental health than caregiver burden and altruism on their own ($R^2\text{ Change}=0.03, p=0.06$; $F(4, 67)=10.86, p<0.001$). Therefore, moderation was not observed.

Then, we examined the impact of caregiver burden and altruism on general physical health, as measured by the SF-12 (Table 14). None of the hypothesized covariates emerged as significant and were therefore removed. In the first step, caregiver burden and altruism did not account for a significant amount of the variance in general physical health ($R^2=0.01, p=0.64$; $F(2, 69)=0.45, p=0.64$). Neither caregiver burden ($\beta=-0.13, t=-0.95, p=0.35$) nor altruism ($\beta=-0.06, t=-0.44, p=0.66$) were significant predictors of general physical health. The second step, which included the addition of the interaction term of caregiver burden and altruism, accounted for a significantly greater proportion of the variance in general physical health than caregiver burden and altruism as independent predictors ($R^2\text{ Change}=0.09, p<0.05$; $F(3, 68)=2.52, p=0.07$). The two-way interaction of altruism on caregiver burden had a significant main effect on general physical health ($\beta=0.33, t=2.57, p<0.05$). Because the overall model was not significant, the interaction was not probed.
We also examined the impact of caregiver burden and altruism on satisfaction with life (Table 14). None of the hypothesized covariates emerged as significant and were therefore removed. The first step, which included caregiver burden and altruism as predictor variables, accounted for 30% of the variance in satisfaction with life ($R^2=0.30$, $p<0.001$; $F(2, 69)=14.49$, $p<0.001$). Caregiver burden ($\beta=-0.50$, $t=-4.51$, $p<0.001$) was a significant predictor of satisfaction with life while altruism was not ($\beta=0.10$, $t=0.88$, $p=0.38$). The second step, which included the interaction term of caregiver burden and altruism, accounted for a significantly greater proportion of the variance in satisfaction with life than step one ($R^2$ Change=$0.12$, $p<0.001$; $F(3, 68)=16.17$, $p<0.001$). The interaction term emerged as a significant predictor of satisfaction with life ($\beta=-0.38$, $t=-3.75$, $p<0.001$). Examination of the interaction plot showed an enhancing effect in which increasing altruism seemed to increase the negative impact of caregiver burden on satisfaction with life (Figure 2). At low (-1 SD) and moderate/average (0) levels of caregiver burden, satisfaction with life was highest for those with high altruism. At high levels (+1 SD) of caregiver burden, those with the highest altruism had the lowest satisfaction with life; however, at high levels of caregiver burden, satisfaction with life was similar for caregivers with low, average, or high altruism.

**Time-Dependence Caregiver Burden and Altruism Regression Analyses**

Preliminary analyses indicated that time-dependence caregiver burden subscale of the Caregiver Burden Inventory was significantly associated with altruism so hierarchical multiple regression models were also built to examine time-dependence caregiver burden and altruism with all outcomes (Table 15). First, we examined the impact of the specific subscale of time-dependence caregiver burden and altruism on depression (Table 15). In the first step of hierarchical multiple regression, patient disability level and caregiver gender accounted for a
significant amount of the variance in depression ($R^2=0.13$, $p<0.05$; $F(2, 79)=5.68$, $p<0.05$) and were retained as covariates in subsequent steps. The second step, which included the addition of time-dependence caregiver burden and altruism, accounted for 17% more of the variance in depression, than the first step containing patient disability level and caregiver gender ($R^2$ Change=0.17, $p<0.001$; $F(4, 77)=8.18$, $p<0.001$). Altruism ($\beta=-0.36$, $t=-3.64$, $p<0.001$) was a significant predictor of depression, while time-dependence caregiver burden was not ($\beta=0.28$, $t=1.80$, $p=0.08$). The third step, which included the interaction term of time-dependence caregiver burden and altruism, did not account for a significantly greater proportion of the variance in depression than time-dependence caregiver burden and altruism as independent predictors ($R^2$ Change=0.00, $p=0.82$; $F(5, 76)=6.47$, $p<0.001$). Therefore, moderation was not observed.

Next, we examined the impact of time-dependence caregiver burden and altruism on general mental health, as measured by the SF-12 (Table 15). None of the hypothesized covariates emerged as significant and were therefore removed. In the first step, time-dependence caregiver burden and altruism accounted for 25% of the variance in general mental health ($R^2=0.25$, $p<0.001$; $F(2, 87)=14.79$, $p<0.001$). Altruism ($\beta=0.41$, $t=4.30$, $p<0.001$) and time-dependence caregiver burden ($\beta=-0.21$, $t=-2.23$, $p<0.05$) were each significant predictors of general mental health. The second step, which included the interaction term of time-dependence caregiver burden and altruism, accounted for a significantly greater proportion of the variance in general mental health than time-dependence caregiver burden and altruism as independent predictors ($R^2$ Change=0.05, $p<0.05$; $F(3, 86)=12.24$, $p<0.001$). The two-way interaction of altruism on time-dependence caregiver burden and general mental health was also significant ($\beta=-0.23$, $t=-2.36$, $p<0.05$). Examination of the interaction plot showed a buffering effect such
that increases in altruism helped to protect against the effects of high time dependence burden on general mental health (Figure 3). At low, average, and high levels of time-dependence burden, those with the best general mental health had the highest altruism.

Next, we examined the impact of time-dependence caregiver burden and altruism on general physical health, measured by the SF-12 (Table 15). In the first step, patient disability level accounted for a significant amount of the variance in general physical health ($R^2=0.10$, $p<0.01$; $F(1, 84)=9.46, p<0.01$) and was retained as a covariate in subsequent steps. In the second step, time-dependence caregiver burden and altruism did not account for significantly more variance than the first step containing patient disability level ($R^2$ Change=0.00, $p=0.94$; $F(3, 82)=3.13, p<0.05$). Neither altruism ($\beta=-0.01, t=-0.12, p=0.90$) nor time-dependence caregiver burden ($\beta=0.06, t=0.33, p=0.74$) were significant predictors of general physical health. The third step, which contained the addition of the interaction term of time-dependence caregiver burden and altruism, accounted for a significantly greater proportion of the variance in general physical health than time-dependence caregiver burden and altruism as independent predictors ($R^2$ Change=0.12, $p<0.01$; $F(4, 81)=5.74, p<0.001$). The two-way interaction of altruism on time-dependence caregiver burden and general physical health was also significant ($\beta=0.39, t=3.50, p<0.01$). Examination of the interaction plot (Figure 4) showed a buffering effect such that increasing altruism buffered against the negative effects of increasing time-dependence burden on general physical health. At low time-dependence burden, those with high altruism had low general physical health. However, at high time-dependence burden, those with high altruism had high general physical health.

Finally, we examined the impact of time-dependence caregiver burden and altruism on satisfaction with life (Table 15). In the first step, caregiver age accounted for a significant
amount of the variance in satisfaction with life ($R^2=0.07, p<0.05; F(1, 87)=6.68, p<0.05$) and was retained in subsequent steps. In the second step, the addition of time-dependence caregiver burden and altruism accounted 17% more of the variance in satisfaction with life, compared to step one containing caregiver age ($R^2 \text{ Change}=0.17, p<0.001; F(3, 85)=9.10, p<0.001$). Time-dependence caregiver burden ($\beta=-0.23, t=-2.20, p<0.05$) and altruism ($\beta=0.32, t=3.29, p<0.01$) were each significant predictors of satisfaction with life. The third step, which included the interaction of time-dependence caregiver burden and altruism, did not account for a significantly greater proportion of the variance in satisfaction with life than time-dependence caregiver burden and altruism as independent predictors ($R^2 \text{ Change}=0.03, p=0.05; F(4, 84)=8.03, p<0.001$). Therefore, moderation was not observed.

**Discussion**

In the present study, we sought to investigate the impact of receiving and giving social support on psychosocial outcomes in MS spousal/partner caregivers. We hypothesized that social support would be inversely correlated with caregiver burden such that higher social support would be associated with lower caregiver burden. Interestingly, we only found a significant negative correlation between perceived social support and caregiver burden in males, suggesting that receiving social support may have benefits that are more positive for male caregivers than for female caregivers. This gender-specific finding expands upon previously available research (Knight et al., 1997; Pakenham, 2001).

We also hypothesized that receiving social support would moderate the relationship between caregiver burden and caregiver health outcomes in MS spousal/partner caregivers. Perceived received social support did not interact significantly with caregiver burden to predict outcomes in any of our models as we initially hypothesized. Results indicated that lower
caregiver burden and higher perceived social support were independently associated with improved outcomes for MS spousal/partner caregivers even after accounting for the effects of patient disability level, caregiver age, and caregiver gender. This finding generally supports previously available research (Pakenham, 2001); however, ours is the first known sample composed of only MS spousal/partner caregivers. Lower caregiver burden and higher perceived social support were associated with reduced depression, improved general mental health, and improved satisfaction with life. Neither lower caregiver burden nor higher perceived social support had a significant impact on caregivers' physical health.

We additionally aimed to investigate the effects of giving social support, in the form of engaging in volunteer work, and altruism in our sample. Ours is the first known study to investigate these concepts in MS spousal/partner caregivers. We hypothesized that significant differences between engagement in MS-related versus non-MS related volunteer work would emerge. We also hypothesized that engagement in volunteer work would be related to the personality characteristic of altruism. We found that engagement in MS-related volunteer work was significantly associated with altruism and satisfaction with life, but we did not find this relationship in those who volunteered for non-MS related activities. We also found that altruism was significantly positively associated with perceived social support in males, but not in females, suggesting additional interesting gender differences. Engagement in neither type of volunteer work was significantly associated with caregiver burden. We did not find that gender or age affected engagement in either type of volunteer work.

Our results indicate that the type of volunteer work influenced outcomes. It is possible that engagement in MS-related volunteer work has a more positive impact than engagement in non-MS related volunteer work because it may help caregivers to feel like they are doing
something to recognize themselves, to recognize their spouses/partners, and/or that they are doing something to fight MS. It is also possible that giving social support at MS-related volunteer events is a way of gaining social support by connecting individuals with their broader communities. However, we did not find a significant association between volunteering for MS-related activities (or non-MS related activities) and perceived social support. This suggests that giving social support in the form of engaging in volunteer work may be different from receiving social support and is not just a way of eliciting social support, as others have hypothesized.

Results also help to refine our definition of giving social support by demonstrating that engaging in a cause-specific type of volunteer work is related to the personality trait of altruism while engaging in more general community-based volunteer work is not related to altruism.

Furthermore, we hypothesized that altruism, as a proxy for engagement in volunteer work, would act as a buffer by moderating the relationship between caregiver burden and caregiver health outcomes in our sample of MS spousal/partner caregivers. We found that altruism significantly interacted with general caregiver burden to predict satisfaction with life. However, we did not observe the buffering effect that we would have expected. Instead, we observed that having high altruism was protective and associated with the highest levels of satisfaction with life at low and average levels of caregiver burden. At the highest levels of caregiver burden, high altruism was associated with the worst satisfaction with life; however, it should be noted that there was little difference in satisfaction with life scores based on levels of altruism at the highest levels of caregiver burden. Therefore, high altruism did not have a detrimental effect at the highest levels of caregiver burden. It is possible that at the highest levels of caregiver burden, caregivers are the most vulnerable and the addition of altruism created a role overload (e.g., Choi et al., 2007) that led to increased distress and reduced
satisfaction with life. In the addition to this moderation effect, we also found that lower caregiver burden was associated with reduced depression, improved general mental health, and improved satisfaction with life. Increased altruism was associated with improved general mental health.

We also narrowed in on the possible moderating role of altruism in the relationship between one specific type of caregiver burden, time-dependence caregiver burden, and outcomes. We found that altruism significantly interacted with time-dependence caregiver burden to predict general mental health and general physical health. We observed buffering effects such that increasing altruism buffered against the negative effects of increasing time-dependence burden on general mental health and general physical health. We also found that lower time-dependence burden and higher altruism were associated with improved general mental health and improved satisfaction with life. Higher altruism was also associated with reduced depression.

Taken all together, these results indicate that while decreasing caregiver burden and increasing altruism are generally associated with improved caregiver mental health outcomes, altruism can interact in a variety of different ways with caregiver burden to either protect against deleterious outcomes or to place caregivers at greater risk for deleterious outcomes. This expands on the idea that giving and receiving social support can have positive and negative consequences (Liang et al., 2001). We demonstrated that giving social support can be protective when caregivers are only moderately burdened by their caregiving duties. However, when caregivers are highly burdened, they should probably be discouraged from taking on additional responsibilities, such as in the form of volunteer work.
Limitations

The present study was not without limitations. First, this study relied on self-report measures, which may be subject to recall bias, and was cross-sectional. Second, the sample was potentially biased because it was composed of self-selecting caregivers who were willing and able to complete a relatively long survey, and who therefore may have been higher functioning than MS spousal/partner caregivers who did not participate. Enough data were not available to assess whether completers had lower overall caregiver burden than non-completers, as one may hypothesize. Furthermore, while multiple survey completion methods were available, the vast majority of participants completed surveys online, and therefore these individuals had access to the internet and may have had a higher socioeconomic status than non-completers. This assumption was supported by the relatively high levels of income reported by the majority of respondents in the present study. The sample was also potentially biased in terms of other participant demographics. Of those participants who answered what state they were from, all were from the Northeast (35 participants were from New York, one from New Jersey, and 12 from Connecticut). Additionally, 98.63% of our sample was Caucasian and 97.14% was non-Hispanic; however, given that some research indicates that rates of MS may be higher in Caucasian individuals (e.g., National Multiple Sclerosis Society, 2015) findings may nevertheless generalize to the vast majority of MS spousal/partner caregivers. Finally, our use of altruism as a proxy for giving social support may not be the most accurate way to measure giving social support and it is recommended that future studies create and use validated measures of giving social support.
Clinical Implications

Taken together, our results suggest that prevention work and interventions aimed at helping MS spousal/partner caregivers might include reducing caregiver burden, increasing perceived social support, MS-specific volunteer opportunities, and increasing altruism.

It might be possible to reduce caregiver burden from a prevention standpoint by teaching caregivers positive self-care at National MS Society events and giving informational tips out to caregivers at neurology offices, as they are expected to frequently attend visits with their spouses/partners. Sullivan and Miller (2015) made recent recommendations on integrating caregivers into MS neurology visits as part of a patient and caregiver multidisciplinary care model. They recommend teaching caregivers self-care, including healthy diet and exercise, socializing, connecting with local organizations, taking time away from caregiving, and accepting help, amongst other tips. This model should be empirically studied to assess effectiveness and should be implemented to try to prevent caregiver burnout.

The suggestion that MS spousal/partner caregivers should be encouraged to be altruistic and to participate in MS-related volunteer work is an especially important and exciting finding because organizations such as the National MS Society frequently host fundraising events and caregivers are often asked to participate. To date, it was not known whether such volunteer opportunities were helpful, or hurtful, to caregivers. Our research supports that these opportunities are helpful. However, caregivers should be encouraged to monitor their commitments to try to ensure that they do not experience role overload.
Chapter Three

Posttraumatic Stress Disorder in Multiple Sclerosis Spousal/Partner Caregivers

Abstract

The present study sought to examine the prevalence and correlates of posttraumatic stress disorder (PTSD) in MS spousal or partner caregivers. Participants (n=62, 58.9% male, mean age=53.25 years old, SD=12.27) completed self-report measures online assessing potentially traumatic events, PTSD, anticipatory grief, and a range of health outcomes. We found that 17.3% of our sample met criteria for probable diagnosis of PTSD, with comparison by gender showing that 22.7% of females and 13.3% of males in our sample met criteria. An additional 25.6% of our sample met criteria for subclinical PTSD symptoms. Prevalence rates by gender indicated that 35.3% of females and 19.2% of males in our sample met criteria for subclinical posttraumatic stress symptoms. These observed rates demonstrate that MS spousal/partner caregivers are at higher risk for PTSD and subclinical posttraumatic stress symptoms, compared to other caregiver populations and the general population. Our results also indicate that whether participants perceived that PTSD symptoms were directly related to their spouse or partner's MS had no impact on risk for PTSD or subclinical posttraumatic stress symptoms. Results also indicate that presence of probable PTSD was associated with higher anticipatory grief and worse general mental health while endorsement of subclinical posttraumatic stress symptoms was associated with worse physical health. Results demonstrate that MS spousal/partner caregivers should be screened for PTSD and that treating PTSD may be associated with additional gains in caregiver mental health and functioning.

Keywords: Multiple sclerosis, spousal caregivers, partner caregivers, posttraumatic stress disorder, posttraumatic stress symptoms, anticipatory grief
Introduction

Literature has paid much attention to the concept that chronic illness is associated with various adverse mental health outcomes, including depression and anxiety (e.g., Alonzo, 2000). However, it is only more recently that researchers have begun to examine the possible connections between the direct (i.e., as patient) and indirect (i.e., as family member or caregiver) experience of chronic illness and mental health outcomes, including posttraumatic stress disorder. In the following study, we tested the hypotheses that the experience of chronic illness is traumatic and is associated with an elevated risk for posttraumatic stress disorder and subclinical posttraumatic stress symptoms in a sample of individuals uniquely impacted by chronic illness, namely the spousal or partner caregivers of individuals diagnosed with MS.

Posttraumatic Stress Disorder

According to current diagnostic standards, in the *Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5)*, Posttraumatic stress disorder (PTSD) develops as a result of exposure to a Criterion A traumatic event and the presence of symptoms in four different clusters: intrusion (Cluster B), avoidance (Cluster C), negative alterations in cognitions and mood (Cluster D), and alterations in arousal and reactivity (Cluster E; American Psychiatric Association, 2013). Posttraumatic stress disorder has been associated with reduced functionality, an elevated risk for a host of other co-morbid psychiatric diagnoses, and has been linked to an increased likelihood of suicide attempts (e.g., Davidson, Hughes, Blazer, & George, 1991). Comorbidity rates of PTSD and substance are staggering, with estimates generally ranging between 21.6 to 43.0% in civilian populations (Jacobsen, Southwick, & Kosten, 2001). While several theories on this association exist, the most commonly accepted theory is that PTSD precedes substance use. Individuals may engage in substance use as an attempt to cope with
PTSD symptoms (Jacobsen et al., 2001). Then, if individuals try to withdraw from substances, PTSD symptoms may be exacerbated, thereby supporting continued use. While PTSD may confer risk for substance use disorders and other psychiatric problems, even individuals who do not meet criteria for PTSD but who demonstrate subclinical symptoms can be at heightened risk for additional mental health difficulties.

Posttraumatic stress disorder and subclinical posttraumatic stress symptoms have historically been studied as responses to a major, singular traumatic event. Posttraumatic stress disorder was originally conceptualized as a mental illness that occurred only in military personnel or in Veterans in response to combat. By the 1990s, large seminal studies began to prove that PTSD is quite common in civilian populations (e.g., Breslau, Davis, Andreski, & Peterson, 1991). Additional studies also started to mount evidence that women can be especially susceptible to experiencing potentially traumatic events, with staggering rates of sexual assault (e.g., Resnick, Kilpatrick, Dansky, Saunders, & Best, 1993).

In accordance with the way that PTSD was conceptualized as a response to the direct experience of a traumatic event, past editions of the DSM included the direct experience of a traumatic event as a diagnostic criterion (American Psychiatric Association, 2000). The most recent edition, the DSM-5, has expanded the definition of criterion A to include directly experiencing traumatic event(s), witnessing traumatic event(s), learning that traumatic event(s) occurred to a close family member or friend, or “experiencing repeated or extreme exposure to aversive details of the traumatic event(s)” (American Psychiatric Association, 2013, p. 271). The definition of “criterion A” was expanded in this manner due to mounting evidence that a person does not need to experience one traumatic event (defined as traumatic by most people) in order to experience a heightened risk of developing PTSD (e.g., Scott & Stradling, 1994; review
by Friedman, Resick, Bryant, & Brewin, 2011). Rather, PTSD and posttraumatic stress symptoms can occur in response to an accumulation of stressful and traumatic experiences, in response to chronic stressors, or in response to a significant other experiencing a trauma (also known as secondary or vicarious traumatization). For example, PTSD and posttraumatic stress symptoms may occur in reaction to chronic illness, either for the patient directly experiencing the illness, for close family members or friends who witness the effects of the illness, or even for medical professionals who are exposed to the trauma of chronic illness through their jobs. The potentially traumatic aspects of chronic illness might be the accumulation of chronic stress, the time of diagnosis, or a particularly salient experience with a symptom.

**Prevalence of Posttraumatic stress disorder.** Posttraumatic stress disorder has been studied in nationally representative samples. The 2005 National Comorbidity Survey Replication found that about 6.8% of Americans aged 18 and over met *DSM-IV* criteria for PTSD across their lifetimes (Kessler, Berglund, et al., 2005). Prevalence of PTSD in the past 12 months was about 3.5% (Kessler, Chiu, Demler, & Walters, 2005). Furthermore, the same study examined gender differences in base rates of PTSD and found that 12-month prevalence was 1.8% among men and 5.2% among women (National Center for PTSD, 2016; National Comorbidity Survey, 2005). Additional research has further highlighted important gender differences in PTSD that suggest that women are less likely to experience potentially traumatic events, but more likely than men to meet criteria for PTSD (Tolin & Foa, 2006).

A more recent study examining PTSD prevalence in a large, nationally representative adult sample found that Criterion A rates using *DSM-5* standards was high, with 89.7% of participants endorsing exposure to at least one traumatic event (Kilpatrick et al., 2013). Lifetime, past 12-months, and past 6-months rates of PTSD were 8.3%, 4.7%, and 3.8%
respectively. Past 12-month rate of PTSD was 3.0% in men and 6.2% in women. Rates of PTSD were slightly lower using DSM-5 standards than DSM-IV standards. Kilpatrick and colleagues (2013) postulated that part of the decrease might have been associated with the new inclusion of at least one active avoidance symptom. This research not only provides updated prevalence rates of PTSD, but it demonstrates that the expanded Criterion A captures more individuals who have experienced potentially traumatic events.

**Chronic Illness and Trauma**

The increasing recognition that PTSD is not confined to those who experience a singular traumatic event led researchers to begin to investigate posttraumatic stress in individuals diagnosed with chronic illnesses. In one of the earliest investigations of its kind, Shalev and colleagues (1993) documented symptoms of PTSD, depression, anxiety, panic attacks, and avoidance of follow-up medical care in four chronically ill patients who had undergone heart catheterization, craniotomy, coronary heart surgery, and tonsillectomy. Findings from more recent work supports the hypothesis that posttraumatic stress symptoms can develop as possible effects from acute medical events such as abortion or acute myocardial infarction (e.g., review by Alonzo, 2000).

One of the most studied areas of the connection between PTSD and chronic illness is in reaction to breast cancer. Some researchers argue that PTSD is not a good indicator of responses to breast cancer, but rather that the common outcome is general psychological distress. For example, Palmer and colleagues (2004) found that intense negative emotional reactions to breast cancer were common in the patients they surveyed, but few of the patients responded with intense fear, helplessness, or horror. Alternatively, other researchers describe that PTSD and subclinical posttraumatic symptoms are common amongst women with breast cancer because the
diagnostic criteria capture aspects of psychological distress that other mental health diagnoses such as depression and anxiety do not capture. A 1998 study of women with breast cancer found that while only 3% of the sample met full diagnostic criteria for PTSD, subclinical PTSD symptoms were common (Green et al., 1998). Butler and colleagues (1999) found significant levels of intrusion and avoidance symptoms in women with metastatic breast cancer. Another study found that the rate of cancer-related PTSD in a sample of women with breast cancer was 2.4% (Mehnert & Koch, 2007). The sample reported that the cancer diagnosis and subsequent feelings of uncertainty were traumatic. Taken together, this research in breast cancer patients demonstrates the potentially traumatic nature of chronic illnesses on patients and lends support for our proposed research to investigate the potentially traumatic effects of chronic illness on patients' caregivers.

Several seminal studies have established a connection between the experience of trauma and the risk of developing various medical problems and chronic illnesses. For example, data from the National Comorbidity Survey Replication showed that individuals with PTSD had the highest likelihood of 15 different chronic medical conditions (Sledjeski, Speisman, & Dierker, 2008). The Adverse Childhood Experiences study demonstrated that individuals who experienced four or more adverse childhood experiences, compared to those who had experienced none, were much more likely to endorse multiple health risk factors (Felitti et al., 1998). Davidson and colleagues (1991) found that PTSD was correlated with a heightened risk of asthma, bronchitis, and peptic ulcers in adulthood. Similarly, Goldberg and colleagues (1999) found that childhood trauma, including verbal, physical, and sexual abuse, was significantly associated with chronic pain in adulthood including fibromyalgia, myofascial, facial, and other pain. These observed links between traumatic experiences, PTSD, and chronic illness have been
attributed by some to neuroendocrine system dysfunction (e.g., Heim et al., 2009). Others have highlighted the importance of psychosocial factors, such as low socioeconomic status and poor mental health in accounting for the correlation between childhood trauma and adulthood chronic illness (Mock & Arai, 2011). Other research has documented a different link between lifetime trauma and chronic illness such that women were more likely to meet criteria for cancer-related PTSD if they had lifetime PTSD (Mehnert & Koch, 2007).

This research suggests that lifetime history of trauma may make caregivers more vulnerable to the adverse impact of caregiving, including the potential adverse impacts on physical health. The research further suggests that caregivers may be more likely to experience PTSD in reaction to chronic illness if they had lifetime PTSD. While the above research lends suggestions for hypotheses regarding the prevalence, risk factors, and correlates of PTSD in caregivers, there are few studies examining posttraumatic stress symptoms specifically in caregivers.

**Chronic Illness and Trauma in Caregivers**

Very little research examines the possibility that the experience of chronic illness may be traumatic to people other than those diagnosed with the illnesses. While we would expect to see the highest rates of PTSD and posttraumatic stress symptoms in patients due to the direct threat of death, personal experience with invasive medical procedures, etc..., it is also reasonable to expect to see elevated rates of PTSD in caregivers due to their indirect exposure to traumatic threats (Stukas et al., 1999), especially given the newly expanded *DSM-5* PTSD Criterion A.

Some research examines the possibility that health care workers may be impacted by the "trauma" of caring for critically ill patients through vicarious traumatization. One study identified compassion fatigue and burnout in a sample of health care workers from medicine,
nursing, social work, occupational therapy, physical therapy, audiology, child life, and psychology at a children's hospital (Robins, Meltzer, & Zelikovsky, 2009).

Other research has started to examine impacts of health-related events in caregivers. Arzi and colleagues (2000) found that wives taking care of their Veteran husbands with PTSD or "post-concussion syndrome" experienced high caregiver burden and general emotional distress. The study shows that the nature of caring for someone who is "impaired" can cause emotional distress and burnout in spousal caregivers; however, the study did not examine PTSD or posttraumatic stress symptoms. Stukas and colleagues (1999) directly examined PTSD in the familial caregivers of heart transplant recipients. They found transplant-related PTSD in 7.7% of caregivers with another 11% of caregivers showing PTSD-symptoms within one year post transplant. Wight and colleagues (2007) studied HIV caregiver dyads of mothers with adult sons infected with HIV and wives with husbands infected with HIV. They found that caregivers reported significant avoidance and intrusive thoughts related to the HIV status of their care receiver, the position of needing to be a caregiver, and resulting stress of what caregiving entailed.

The established literature demonstrates that caregivers may experience symptoms of PTSD; however, there is a paucity of available research. Furthermore, to our knowledge, spousal/partner caregivers have only been included in samples composed of family caregivers in general, and PTSD in MS spousal/partner caregivers has not been studied at all. The investigation of PTSD in caregivers is a relatively new concept and one that necessitates further exploration.
**Anticipatory Grief**

Similar to the recent ways that the conceptualization and study of PTSD have expanded, the concept of grief has also been expanded to include anticipatory grief. Anticipatory grief is the process of experiencing the phases of post-death grief in the face of a potential loss (Theut, Jordan, Ross, & Deutsch, 1991). Anticipatory grief is an important phenomenon to consider because it is associated with chronic stress in individuals caring for a loved one with a chronic and/or terminal illness. Thus far, anticipatory grief has only been studied in populations of dementia, Alzheimer's disease, and AIDS caregivers (e.g., Theut et al., 1991; Walker, Pomeroy, McNeil, & Franklin, 1996). We hypothesized that anticipatory grief is associated with PTSD in MS spousal/partner caregivers such that caregivers who have experienced trauma suffer greater anticipatory grief.

**Multiple Sclerosis Spousal/Partner Caregivers**

The spousal/partner caregivers of individuals with MS are uniquely vulnerable to mental and physical health impairments as a result of their caregiving duties. Multiple sclerosis symptoms are often unpredictable and debilitating and diagnosed individuals can experience such symptoms for decades. Therefore, individuals with MS often need a caregiver who is flexibly available to help manage their symptoms and to provide assistance with activities of daily living (e.g., McKeown et al., 2003). Individuals with MS are most often cared for by family members (O’Hara et al., 2004) and specifically, by spouses. It was estimated in one sample of individuals diagnosed with MS that 65% of caregivers were spouses and 75% of those spousal caregivers lived with the person for whom they cared (Aronson et al., 1996; Aronson, 1997). Due to the unpredictable nature of symptoms and the early onset of the disease (e.g., National Multiple Sclerosis Society, 2015), MS spousal/partner caregivers may face caregiving
challenges for years and often need to balance working full time, raising children, and being a caregiver. These caregiving challenges are unique in comparison to other caregiver populations such as dementia and Alzheimer's disease caregivers. Therefore, MS spousal/partner caregivers have been shown to be especially susceptible to the deleterious impacts of caregiver burden (e.g., Buhse, 2008; Corry & While, 2009).

Synthesis and Hypotheses

Extant literature establishes that PTSD and subclinical symptoms may exist in family caregivers for individuals with chronic illnesses (e.g., Stukas et al., 1999; Wight, Beals, Miller-Martinez, Murphy, & Aneshensel, 2007). Literature also documents that PTSD is a debilitating illness that can have profound effects on overall mental health and functionality (e.g., Davidson et al., 1991). The presence of PTSD or subclinical symptoms may significantly impact caregiver well-being and ability to provide good care. To our knowledge, there is no research examining prevalence and correlates of PTSD or posttraumatic stress symptoms specifically in MS patients or their caregivers. Therefore, we aimed to expand the literature by examining the presence of PTSD and subclinical posttraumatic stress symptoms in a sample of MS spousal/partner caregivers.

We hypothesized that MS spousal/partner caregivers would demonstrate higher rates of PTSD than the general population. The 12-month prevalence base rate of PTSD in the general population is estimated to be 4.7% (Kilpatrick et al., 2013) with 12-month PTSD rates of 3.0% in men and 6.2% in women. Estimates of past 12-month prevalence of PTSD in caregivers typically fall around 7.7% (Stukas et al., 1999). Therefore, we expected the rate of PTSD in our sample of caregivers to be about twice that observed in the general population. We also hypothesized that an even greater portion of our caregiver sample would endorse subclinical
posttraumatic symptoms. Previous studies found 12-month prevalence estimates of subclinical posttraumatic symptoms in caregivers to be around 11% (Stukas et al., 1999). Therefore, we expected to find that about 11% of our sample would endorse subclinical posttraumatic symptoms. Furthermore, given the documented adverse effects of PTSD on broader psychological and physical functioning, we hypothesized that PTSD and subclinical posttraumatic symptoms would be positively associated with anticipatory grief, caregiver burden, and drug and alcohol use, and inversely correlated with dyadic adjustment.

Methods

All methods were reviewed and approved by the local Institutional Review Board. All participants were informed of the nature and purpose of the research and consented prior to participation.

Participants

Participants (n=62) were recruited using a variety of means including through collaborators at the National Multiple Sclerosis Society Upstate New York Chapter, by posting flyers at local neurologist offices, posting advertisements on MS and caregiver related websites and social media pages, and through word of mouth. All participants responded that they provide care for their spouse/partner diagnosed with MS. Participants completed self-report surveys online. Participants were offered the opportunity to enter a raffle for one of five different seventy-five dollar gift cards in exchange for time spent completing the survey.

One-hundred and three participants accessed the survey online and 62 completed the survey (60.19% completion rate). A priori power analyses (using G*Power 3.1.9.2) indicated a required sample size of at least 98 participants for adequate power (1-β ≥ .80) to detect a large
effect in multivariate analysis of variance analyses. Our achieved sample size is therefore underpowered. Even though findings should be interpreted cautiously given concerns about power, this is the first known study to examine PTSD specifically in MS spousal/partner caregivers. Therefore, findings should still add significantly to the literature and lay the foundation for future studies in this area.

Participants qualified to take the survey based on their answers to inclusion criteria questions which were: participants were 18 years old or older, could read, write, and understand English, were currently caring for their significant other who was diagnosed with MS, the individual they cared for was their spouse or partner, the individual they cared for was diagnosed with MS by a health care professional, and they did not receive any financial payment for the care they provided. Seven individuals accessed the survey online but did not meet inclusion criteria. Another 11 individuals qualified to complete the survey based on the online inclusion questions, but did not provide consent and were therefore not offered the opportunity to complete the survey. Another eight individuals provided consent to take the online survey, but did not answer any survey questions. All surveys were completed between January 6, 2015 and February 2, 2016.

Participants were an average of 53.25 years old (SD=12.27), 58.9% male (n=43), and 97.1% non-Hispanic (n=68). In regards to race, 69.9% of participants reported that they were Caucasian/White (n=72), 1.9% were African-American/Black (n=2), 0% were Asian (n=0), 1.9% were Native American (n=2), and 2% reported that they were mixed race (n=2). There were no significant differences between completers and non-completers in regards to age (t(71)=0.85, p=0.40, Cohen's d=0.25), gender ($\chi^2(1, 73)=2.81, p=0.09, \Phi=0.20$), or ethnicity ($\chi^2(1, 70)=1.57$, 

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Of those 12 non-completers who provided demographic information, all 12 self-identified as Caucasian/White.

**Measures**

Participants completed the following widely used and well-validated self-report measures (also, see Appendix B):

**Life Events Checklist.** The Life Events Checklist (LEC) is a self-report measure designed to evaluate the presence of potentially traumatic events. The current LEC-5 contains 17 questions that assess possible difficult or stressful events respondents may have experienced (Weathers, Blake, et al., 2013). The measure was included here to assess for lifetime trauma. Respondents answer each question with “Happened to me,” “Witnessed it,” “Learned about it,” “Part of my job,” “Not sure,” or “Doesn’t apply.” The LEC-5 also contains an additional eight questions that probe for supplemental information about any difficult or stressful events that respondents endorsed on the standard measure. In psychometric studies, the LEC yielded stable responses across one-week periods and it converged as expected with measures of psychopathology that is associated with traumatic events exposure (Gray, Litz, Hsu, & Lombardo, 2004).

**PTSD Checklist.** The PTSD Checklist Civilian Version (PCL-C) is a brief self-report measure that assesses current PTSD symptoms in general populations. It was originally developed in 1993 by Weathers and colleagues (Weathers, Litz, Herman, Huska, & Keane, 1993) and it is currently in its fifth edition (PCL-5). The PCL-C has previously been found to be valid, sensitive, specific, and reliable (Cronbach’s alpha=0.94; Blanchard, Jones-Alexander, Buckley, & Forneris, 1996; reviewed by Norris & Hamblen, 2003). The current PCL-5 version consists of 20 questions that map onto *DSM-5* diagnostic criteria for PTSD (American Psychiatric
Association, 2013; Weathers, Litz et al., 2013). Respondents answer each question on a Likert-type scale of zero to four where zero equals “not at all,” one equals “a little bit,” two equals “moderately,” three equals “quite a bit,” and four equals “extremely.” The PCL-5 yields a total symptom severity score of zero to 80, as well as symptom cluster severity scores, and allows clinicians to make provisional PTSD diagnoses according to current DSM-5 criteria. Cronbach's alpha for our sample was 0.95, demonstrating excellent internal consistency.

**Additional questions to support the life events checklist.** In an effort to determine whether participants perceive any aspect directly related to their partner’s MS as traumatic, we developed several questions to provide collateral information to the LEC-5 and PCL-5. We independently generated these questions given the lack of research base to guide the development. See Appendix B for added questions.

**Anticipatory Grief Scale.** The Anticipatory Grief Scale (AGS) is a 27-item self-report measure that assesses a special type of grief, known as anticipatory grief (Theut et al., 1991). The construct of anticipatory grief was developed after interviewing wives of partners with dementia and includes anger, anxiety, guilt, sadness, feelings of loss, and impaired functionality. Respondents answer each question on a Likert scale of one to five, where one equals “strongly disagree,” two equals “disagree,” three equals “somewhat agree,” four equals “agree,” and five equals “strongly agree.” The AGS is valid and reliable (Cronbach’s alpha of 0.84 in prior studies). Cronbach's alpha for our sample was 0.80, suggesting good internal consistency.

**Alcohol Use Disorders Identification Test.** The Alcohol Use Disorders Identification Test (AUDIT) is a 10 item widely used self-report measure that assesses alcohol use, drinking behavior, adverse psychological reactions, and alcohol use related problems (Saunders, Aasland, Babor, de la Fuente, & Grant, 1993; Reinert & Allen, 2007). The AUDIT was included in the
present study to assess for alcohol use as a possible correlate of PTSD, showing maladaptive coping. Each item on the AUDIT is scored zero to four for a maximum score of 40 (each response rated a four represents the most frequent experience of the problem). A score of eight indicates a strong likelihood of hazardous or harmful alcohol consumption. Validation studies show that the scale is sensitive (93% to 100% for different cut-off points) and valid (98% to 99% for different cut-off points) in detecting the likely presence of problem drinking. Cronbach's alpha in our sample was 0.61, demonstrating questionable internal consistency.

**Drug Abuse Screening Test.** To further assess potentially maladaptive coping strategies that are correlates of PTSD, we also included the 10-item version of the Drug Abuse Screening Test (DAST-10), which is a brief self-report measure that assesses problematic drug use (Bohn, Babor, & Kranzler, 1991). Respondents answer each question with “yes” or “no.” Responses are scored by assigning one point for every “yes” response, except for item number three (“Are you unable to stop abusing drugs when you want to?”) for which “no” response receives one point. A total score of zero indicates no problems, score of one-two indicates low-level of problems, three-five demonstrates a moderate level of problems, six-eight substantial level, and nine-10 indicates severe level of drug use problems. The DAST has been found to be reliable, valid, sensitive, and specific (Yudko, Lozhkina, & Fouts, 2007). In validation studies, the DAST-10 correctly classified drug use problems in over 93% of patients (Bohn et al., 1991). It has been used in the general population, inpatients on substance abuse units, and in adults with severe mental illness (Bohn et al., 1991; Maisto, Carey, M., Carey, K., Gordon, & Gleason, 2000). Cronbach's alpha in our sample was 0.12, indicating unacceptable internal consistency. We observed a very low endorsement of problematic drug use in our sample ($M=1.1$, $SD=0.66$),
which may have contributed to the poor internal consistency of the measure in the present sample of respondents.

**Caregiver Burden Inventory.** The Caregiver Burden Inventory (CBI) is a 24 item self-report measure that assesses caregivers' needs or caregiving strain (Novak & Guest, 1989). It loads onto five different factors, labeled “time-dependence burden” (burden due to restrictions on caregivers' time), “developmental burden” (feeling 'off-time' in their development from peers), “physical burden” (chronic fatigue and damage to physical health), “social burden” (feeling role conflict), and “emotional burden” (negative feelings towards care receivers). Later critiques of the CBI cautioned that factors such as depression may impact scores (Caserta et al., 1996). Cronbach's alphas for our sample suggested good to excellent internal consistency (total score 0.94, time-dependence burden 0.93, developmental burden 0.92, physical burden 0.87, social burden 0.80, and emotional burden 0.86), consistent with prior findings from validation samples.

**Dyadic Adjustment Scale.** The Dyadic Adjustment Scale (DAS) is a 32 item self-report measure designed to assess the quality of marriage and other non-married cohabitating dyads (Spanier, 1976). The concept of quality of marriage or marital adjustment has been researched since at least the 1920s and the DAS is one of the most popular and widely used measures to date. The scale yields a total score and four different subscale scores: "dyadic satisfaction" (satisfaction in the relationship), "dyadic consensus"(agreement on family and household related decisions and behavioral conventions, "dyadic cohesion" (shared interests and activities), and "affectional expression" (demonstrations of affections, often physical). Responses to questions vary from yes/no answers to Likert-type ratings. According to validation samples, it is valid and reliable. Cronbach's alphas in our sample suggest excellent internal consistency for total scores
(α=0.91) and dyadic consensus subscale scores (α=0.92), good internal consistency for dyadic cohesion subscale scores (α=0.84), acceptable internal consistency for affectional expression subscale scores (α=0.67), and unacceptable internal consistency for dyadic satisfaction subscale scores (α=0.19). The use of the four subscales has been criticized based on results of confirmatory factor analyses which support using the total, and not subscale scores (Kazak et al., 1988; Sharpley & Cross, 1982; Spanier & Thompson, 1982). Given this criticism in the existing literature and evidence for generally poor internal consistency of subscales in our sample, we only used the total dyadic adjustment score in the analyses presented here. The DAS has been used in the similar population of cancer caregivers (Toseland et al., 1995).

**Patient Health Questionnaire.** The Patient Health Questionnaire (PHQ-9) is a brief self-report measure of depression severity (Kroenke et al., 2001). We included the PHQ-9 in the present study as a possible correlate of PTSD. The PHQ-9 assesses all nine criteria for major depressive disorder from the *Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV-TR)*; American Psychiatric Association, 2000) on a scale of zero ("not at all") to three ("nearly every day"). It is designed for use in the general population and was normed based on a large sample from primary care and obstetrics-gynecology clinics. It was found to be a valid and reliable measure of depression severity (Cronbach's alpha = 0.89). PHQ-9 scores of five, 10, 15, and 20 represent thresholds of mild, moderate, moderately severe, and severe depression, respectively. Cronbach's alpha for our sample was 0.87, demonstrating good internal consistency.

**Short Form Health Survey.** The 12-item Short Form Health Survey (SF-12) is a measure of general physical and mental health. This short self-report measure was developed as an alternative to the longer 36-item version because the two subscales of physical health and
mental health were found to account for 80% to 85% of the variance on the 36-item version (Ware Jr et al., 1996). SF-12 scoring is proprietary. We only have access to subscale and total scores and we are unable to compute reliability estimates within our sample. However, prior research suggests that the SF-12 is valid and reliable (test-retest reliability of physical health component=0.89; mental health component=0.76).

**Barthel Index of Activities of Daily Living.** The Barthel Index of Activities of Daily Living is an assessment designed for caregivers to complete regarding a patient’s level of physical disability or functionality (Mahoney & Barthel, 1965). Participants responded to 10 questions covering feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers, mobility, and stairs. Higher scores indicate more independent functioning. The measure is widely used, valid, reliable, and sensitive to change (Collin et al., 1988). Cronbach's alpha for our sample was 0.88, indicating good internal consistency.

**Statistical Analyses**

Prior to analysis, the data were examined for any outliers. No extraneous data points were identified. Only cases with complete responses on key variables of interest (defined as Life Events Checklist and PTSD Checklist) were included in the analysis. Violations of assumptions were examined prior to analysis to ensure that the statistical analyses could be appropriately completed. Violations of assumptions were evaluated by examining skewness and kurtosis, visual inspection of plots of the variables (quantile-quantile plots, histograms, and boxplots), and tests of normality. We expected that some of our variables would be skewed given that literature shows that our population experiences distress and mental and physical health impairments. Assessment of skewness and kurtosis indicated that none of the variables were severely skewed (e.g., all variables were within skew and kurtosis values of about negative 1.5 to 1.5) with the
exception of the Alcohol Use Disorders Identification Test, which demonstrated skew of 1.92 and kurtosis of 4.91. The following variables violated the Kolmogorov-Smirnov and Shapiro-Wilk tests of normality: PTSD Checklist, Barthel Index, Patient Health Questionnaire, Alcohol Use Disorders Identification Test, and Drug Abuse Screening Test. The Caregiver Burden Inventory, Dyadic Adjustment Scale, Short Form Health Survey Physical Health Component and Mental Health Component, and Anticipatory Grief Scale did not violate either test of normality. We created natural log, log base ten, and square root transformations for all variables that violated the tests of normality (after appropriately adding constants as needed). Almost none of the transformations improved results on tests of normality and most transformations made skewness and kurtosis worse. The only transformations that made both tests of normality non-significant were the natural log and log base ten transformations of the Alcohol Use Disorders Identification Test. (Note: The square root transformation of the PTSD Checklist made the Kolmogorov-Smirnov test of normality nonsignificant and the Shapiro-Wilk test remained significant). The Alcohol Use Disorders Identification Test transformations each required that a constant was added to the variable to raise minimum values above one (constant of 1 was added), which changed the ability to interpret results.
a total PTSD Checklist cut-score of 33 as a probable PTSD diagnosis, as suggested for this current version of the PCL (Weathers, Litz et al., 2013). Finally, participants who endorsed at least four symptoms on the PTSD Checklist (items rated as a two or higher) and who did not meet criteria for full probable diagnosis of PTSD were considered as meeting criteria for the presence of subclinical posttraumatic stress symptoms.

To examine our main hypotheses, we utilized descriptive statistics, partial correlations, Chi-square tests of independence, independent samples t-tests, one-way analysis of variance tests, and univariate and multivariate analyses of variance models. Gender was initially included as a covariate in all analyses but subsequently removed if found to be non-significant.

**Results**

Participants provided information on demographics, their relationships, their partners who they care for, and their caregiving duties. Regarding their relationships, 100% of our sample's participants reported that they lived with their partner for whom they provide care (n=71), 88.7% (n=63) reported that they were married to their partner. Participants had been in their relationships for an average of 25.00 years (SD=14.67, range=1-56 years), were married for an average of 23.63 years (SD=15.11, range=0-55 years), and 88.9% (n=64) of participants reported that they were in heterosexual relationships. Participants also reported that they had an average of 2.61 children (SD=1.42, range=1-7) and 20 participants reported that they had at least one child currently living with them. Their partners/spouses were on average 53.34 years old (SD=11.11, range=25-78 years old).

Table 16 provides information on caregivers' education and employment. Most commonly, participants reported that they completed some college and were working full time. Table 17 provides information on income and medical expenses. The majority of our sample
reported that they shared finances with their partner/spouse (94.4%, n=68). Most commonly, our sample reported annual estimated household incomes before taxes of $50,000-74,999 (22.2%, n=16). When asked to estimate what they spent per year on out-of-pocket medical costs, most commonly participants reported that they spent $501-1000 (23.2%, n=16). Participants reported that they spent a range of between $1 to $6001 and more per year on out-of-pocket medical expenses. This study did not assess medical insurance coverage.

The majority of participants reported that their partners/spouses were diagnosed with Relapsing-Remitting MS (57.7%, n=41; Table 18). There was a significant effect of the partner's/spouse's gender on course of MS such that females were significantly more likely to be diagnosed with Relapsing-Remitting MS than males ($\chi^2$(4, 71)=13.98, $p<0.05$, $\Phi=0.44$). Participants reported that their partners/spouses were diagnosed on average 12.96 years ago ($SD=10.74$, range=0-48 years). The patient's level of disability, as rated by their caregiver, was significantly and inversely associated with years since diagnosis ($r=-0.50$, $p<0.001$) such that disability level decreased (indicating less independent functioning) as the numbers of years since diagnosis increased. The average patient disability level was 77.46 ($SD=23.11$, range=5-100). There was a significant effect of type or course of MS on total patient disability level ($F$(4, 51)=4.95, $p<0.01$). Post-hoc Tukey analysis indicated that those diagnosed with Relapsing-Remitting MS ($M=86.83$, $SD=16.79$) were on average significantly higher functioning than those diagnosed with Secondary-Progressive MS ($M=62.92$, $SD=23.78$; post-hoc $p<0.05$).

Participants reported that they had spent an average of 8.41 years caring for their significant other ($SD=8.06$, range=0-36 years). About one third of participants (35.2%, n=25) estimated that they provided 25% of their partner's/spouse's total care, 25.4% (n=18) estimated that they provided 50% of care, 16.9% (n=12) estimated that they provided 75% of care, and
22.5% \((n=16)\) estimated that they provided 100% of care. There was no significant effect of
caregiver gender on estimated percentage of care provided \(\chi^2(3, 70)=5.33, p=0.15, \Phi=0.28\).
Participants reported (in overlapping percentages) that they provided a wide range of caregiving
duties including toileting (10.7%, \(n=11\)), transportation (35.0%, \(n=36\)), bathing (10.7%, \(n=11\)),
feeding (10.7%, \(n=11\)), help with medications (31.1%, \(n=32\)), personal care (20.4%, \(n=21\)),
transferring or transitioning (25.2%, \(n=26\)), chores (64.1%, \(n=66\)), emotional support (63.1%,
\(n=65\)), and help with making family or household decisions (54.4%, \(n=56\)).

A total of 22.9% endorsed that their partner/spouse received care from someone else
\((n=16)\), whereas the remaining 77.1% \((n=54)\) of our sample indicated being the sole caregiver for
their partner/spouse outside of routine care provided by primary care and specialist doctors or
mental health professionals. Of those who endorsed that their partner/spouse received additional
care, they reported that they received care for an average of 18.04 hours per week \(SD=37.52,
range=0-168\) hours. About 6.8% \((n=7)\) of participants reported that other care was provided by a
family member, friend (2.9%, \(n=3\)), home health care aide or home health care professional
(6.8%, \(n=7\)), or home respite care worker (1%, \(n=1\)). Furthermore, 24.2% \((n=16)\) of our sample
endorsed that they wanted additional health care for their spouse/partner but could not afford to
pay for additional care.

Table 19 contains the means and standard deviations of all study variables and subscales.
Of note, on average, our sample was mildly depressed \(M=4.63, SD=5.04;\) Kroenke et al., 2001).
The effect of gender on each study variable is included in Table 20. Results indicated that male
caregivers endorsed significantly higher level of independent functioning or a lower level of
disability in their spouse/partner, compared to female caregivers \(t(55)=2.34, p<0.05,\) Cohen's
\(d=0.62\). Results indicated that females had significantly higher total caregiver burden \(t(49)=-
2.96, \( p<0.05 \), Cohen's \( d=0.82 \)), significantly higher depression \((t(55)=-3.21, p<0.01, \text{Cohen's} \ d=0.83)\), and significantly worse general mental health \((t(57)=3.99, p<0.001, \text{Cohen's} \ d=1.04)\). Gender did not have a multivariate main effect on combined caregiver burden subscales \((F(5, 45)=2.24, \text{Wilks' } \lambda=0.80, p=0.07, \eta^2_p=0.20)\) or PTSD clusters \((F(4, 55)=1.89, \text{Wilks' } \lambda=0.88, p=0.13, \eta^2_p=0.12; \text{Table 20})\).

Partial correlations among all variables controlling for gender are included in Table 21. Of particular interest, we observed that the total number of stressful life events was significantly correlated with PTSD total score such that as stressful life events increased, PTSD severity increased \((r=0.72, p<0.001)\). Total number of stressful life events was also significantly correlated with depression such that as the number of stressful events increased, depression increased \((r=0.71, p<0.001)\).

**Stressful Life Events in MS Spousal or Partner Caregivers**

Participants endorsed that they experienced an average of 7.28 stressful life events \((SD=4.58, \text{range}=0-17)\) as assessed by the Life Events Checklist. Consistent with DSM-5 Criterion A, events were those that happened directly to them, that they witnessed, that they heard about, or that they experienced as part of their job. About 93% \( (n=53) \) of our sample met criterion A for the DSM-5 diagnosis of PTSD by endorsing at least one stressful life event on the Life Events Checklist. There was no significant difference between number of potentially traumatic events between men \((M=6.67, SD=4.59)\) and women \((M=8.13, SD=4.52; t(55)=-1.19, p=0.24, \text{Cohen's} \ d=0.32)\). Participants scored an average of 14.85 \((SD=16.01, \text{range}=0-66)\) on the PTSD Checklist. There was also no significant difference in PTSD total score between men \((M=11.45, SD=14.17)\) and women \((M=19.00, SD=17.39; t(58)=-1.85, p=0.07, \text{Cohen's} \ d=0.48)\). Information on endorsement of potentially traumatic events is included in Table 22. Most
commonly, 52.3% (n=34) of participants reported that a transportation accident happened to
them, 39.1% (n=25) witnessed a life-threatening illness or injury, 28.1% (n=18) learned about a
sudden accidental death, and 7.8% (n=5) were exposed to a toxic substance as part of their job.

In responses to open-ended questions, three participants reported that the worst traumatic
events they experienced were related to their partner's MS. One participant stated that the worst
event was when his/her husband was diagnosed, another participant stated, "My wife's MS," and
the third participant stated that the worst event was when his/her husband was hospitalized for
two weeks due to his MS and almost died. When we directly asked participants if they thought
about when their spouse/partner first started showing MS symptoms when they answered the
PTSD Checklist, 30.6% (n=19) of participants responded yes. There was no significant
difference between those who thought about when their spouse/partner first started showing
symptoms (M=14.39, SD=15.71) and those who did not (M=15.41, SD=16.35) in regards to total
PTSD score (t(57)=-0.22, p=0.82, Cohen's d=0.06). When we asked if they thought about when
their spouse/partner was diagnosed with MS, 36.7% (n=22) responded yes. There was also no
significant difference between those who thought about when their spouse/partner was diagnosed
(M=14.38, SD=16.31) and those who did not (M=15.78, SD=15.29) on total PTSD score (t(55)=-
0.31, p=0.76, Cohen's d=0.09). Finally, when we asked participants if they thought about when
their spouse/partner's MS symptoms were especially difficult to handle, 50% (n=31) responded
yes. Again, there was no significant difference between those who thought about when their
spouse/partner's MS symptoms were especially difficult to handle (M=14.10, SD=13.46) and
those who did not (M=16.07, SD=18.36) in regards to total PTSD score (t(57)=-0.47, p=0.64,
Cohen's d=0.12). There were also no significant gender differences between those who thought
about when their spouse/partner first started showing symptoms (χ²(1, 62)=0.05, p=0.82, Φ=-
was diagnosed ($\chi^2(1, 60)=0.35, p=0.55, \Phi=-0.08$), or when their spouse/partner's MS symptoms were especially difficult to handle ($\chi^2(1, 62)=1.04, p=0.31, \Phi=-0.13$).

**PTSD in MS Spousal or Partner Caregivers**

We found that 17.3% ($n=9$) of our sample met full criteria for the probable presence of PTSD (Criterion A and B). Regarding gender differences, 22.7% ($n=5$) of females in our sample and 13.3% ($n=4$) of males in our sample met full probable criteria for PTSD. The gender difference was not significant ($\chi^2(1, 52)=0.78, p=0.38, \Phi=0.12$). Considering total scores on the PTSD Checklist, 11.7% ($n=7$) of respondents scored at least 33 points. Regarding gender differences, 14.8% ($n=4$) of females and 9.1% ($n=3$) of males scored at least 33 points on the PCL, with no significant gender difference ($\chi^2(1, 60)=0.47, p=0.49, \Phi=0.09$). When we narrowed our sample down to only those participants who met criterion A for PTSD, we found that 14.6% (same $n=7$) of participants met the cut-score criteria for PTSD of at least 33 points.

We examined the effects of meeting full probable diagnosis of PTSD (Criterion A and B) on several hypothesized factors (Table 23). After controlling for gender as a significant covariate, there was no significant multivariate main effect of probable diagnosis of PTSD on combined subscales scores of caregiver burden ($F(5, 36)=1.90$, Wilks' $\lambda=0.79, p=0.12, \eta^2_p=0.21$). Anticipatory grief was significantly higher in those with PTSD ($t(39)=-2.77, p<0.05$, Cohen's $d=1.37$). After controlling for gender, general mental health was significantly worse in those with PTSD ($F(1, 45)=6.64, p<0.05, \eta^2_p=0.13$). Probable PTSD diagnosis did not have a significant effect on dyadic adjustment ($t(40)=0.17, p=0.87$, Cohen's $d=0.07$), drug use ($t(41)=-0.27, p=0.79$, Cohen's $d=0.12$), general physical health ($t(46)=-0.04, p=0.97$, Cohen's $d=0.02$), or alcohol use (after controlling for gender; $F(1, 39)=0.19, p=0.67, \eta^2_p=0.01$).
Regarding subclinical symptoms, 25.6% (n=11) of participants met criteria for subclinical posttraumatic stress symptoms (did not meet full probable criteria for PTSD and endorsed at least 4 PTSD symptoms). 35.3% (n=6) of females and 19.2% (n=5) of males in our sample met criteria for subclinical posttraumatic stress symptoms. The gender difference was not significant ($\chi^2(1, 43)=1.39, p=0.24, \Phi=0.18$). When we broadened to examine the sample as a whole regardless of whether participants met criteria for PTSD, 38.3% of participants endorsed at least four symptoms of PTSD (n=23).

We also examined the effects of the presence of subclinical posttraumatic stress symptoms (no PTSD and at least 4 PTSD symptoms) on several measures of psychosocial adjustment (Table 24). Presence of subclinical posttraumatic stress symptoms had a significant effect on general physical health such that participants who endorsed subclinical symptoms had significantly worse general physical health than participants who did not endorse subclinical symptoms ($t(38)=2.54, p<0.05$, Cohen's $d=0.94$). There was no significant multivariate main effect of subclinical posttraumatic stress symptoms on combined subscale scores of caregiver burden ($F(5, 29)=1.78$, Wilks' $\lambda=0.77, p=0.15, \eta_p^2=0.24$). Presence of subclinical posttraumatic stress symptoms also did not have a significant effect on anticipatory grief ($t(33)=-1.77, p=0.10$, Cohen's $d=0.65$), dyadic adjustment ($t(34)=0.54, p=0.59$, Cohen's $d=0.20$), drug use ($t(35)=0.38$, p=0.70, Cohen's $d=0.14$), alcohol use ($t(32)=0.79, p=0.44$, Cohen's $d=0.34$), or general mental health ($t(38)=1.70, p=0.10$, Cohen's $d=0.64$).

**Discussion**

The present paper sought to add novel research to the literature by examining the presence of PTSD and subclinical posttraumatic stress symptoms in the spousal/partner
caregivers of individuals with MS, which to our knowledge, was not previously studied. We hypothesized that prevalence of PTSD and subclinical symptoms in our sample would be markedly higher than what is observed in the general population. We found that 93.0% of our sample met Criterion A by endorsing at least one potentially traumatic event. This is similar to nationally representative comparison rate of 89.7% (Kilpatrick et al., 2013). Our examination of correlations revealed that the more stressful life events participants experienced, the worse PTSD symptoms and depression they experienced.

We found that 17.3% of our sample met full probable criteria for PTSD. Regarding gender differences, 22.7% of females and 13.3% of males in our sample met full probable criteria for PTSD. When we scored PTSD differently by examining participants who endorsed at least one Criterion A event and at least 33 points on the PTSD Checklist, we found that 14.6% of our sample met criteria for PTSD. These PTSD rates are higher than we expected in comparison to a documented PTSD rate of 7.7% in general caregiver populations (Stukas et al., 1999). Therefore, our sample endorsed a much higher rate of PTSD than other types of caregivers.

Additionally, 25.6% of our sample met criteria for subclinical PTSD symptoms (did not meet full probable criteria for PTSD and endorsed at least 4 PTSD symptoms). 35.3% of females and 19.2% of males in our sample met criteria for subclinical posttraumatic stress symptoms. This rate of subclinical posttraumatic stress symptoms was over double what was expected based on our only comparison rate of 11% of heart transplant caregivers who endorsed subclinical PTSD symptoms (Stukas et al., 1999).

Interestingly, we observed that presence of PTSD or subclinical posttraumatic stress symptoms did not differ according to whether participants endorsed that the trauma they thought of when answering questions was related to their spouse/partner's MS. Therefore, we observed
that MS spousal/partner caregivers have extremely high rates of PTSD and subclinical symptoms, irrespective of whether they perceive MS to be traumatic.

We hypothesized that probable PTSD diagnosis and subclinical posttraumatic stress symptoms would be associated with higher anticipatory grief, higher caregiver burden, lower dyadic adjustment, and higher drug and alcohol use. We found that probable PTSD diagnosis was significantly correlated with anticipatory grief and general mental health such that participants with probable PTSD had higher anticipatory grief and worse general mental health. Of note, we observed low endorsement of alcohol and/or drug use in our sample. It is possible that our sample did not engage much in substance use due to the demands on their time and physical capabilities as caregivers. We also found that subclinical posttraumatic stress symptoms were significantly correlated with general physical health such that participants who endorsed subclinical symptoms had significantly worse general physical health. This supports literature that documents associations between PTSD and physical health problems (e.g., Sledjeski et al., 2008) and expands upon it by showing a link between subclinical posttraumatic stress symptoms and physical health impairment in a novel population.

Limitations

The present study had a number of limitations. First, this study relied on self-report measures, which may be subject to recall bias. It is also not possible to make confirmed diagnoses of PTSD using self-report measures alone, and thus our data should be considered to reflect “probable” diagnoses of PTSD. We sought to address the limits of self-report by developing probable diagnostic criteria that closely mirrored current diagnostic standards. Second, the sample was potentially biased because it was composed of self-selecting caregivers who were willing and able to complete a relatively long survey, and who therefore may have
been higher functioning than MS spousal/partner caregivers who did not participate. Enough data were not available to assess whether completers had lower overall caregiver burden than non-completers, as one may hypothesize. Furthermore, while a paper-and-pencil option was also available to complete the survey, the vast majority of participants completed surveys online, and therefore these individuals had access to the internet and may have had a high socioeconomic status than non-completers. The sample was also potentially biased because 69.9% of our sample was Caucasian and 97.1% was non-Hispanic; however, some research does indicate that rates of MS may be higher in Caucasian individuals. The present paper did use an exploratory approach to expand the current research knowledge on an especially unique and vulnerable population of familial caregivers.

**Clinical Implications**

Results demonstrate that MS spousal/partner caregivers are especially vulnerable to experiencing trauma and associated adverse mental health outcomes in comparison to other caregivers of chronically ill patients and to the general population. Our results have important implications for treatment and prevention interventions targeting this population. These unique familial caregivers should be screened for PTSD and subclinical PTSD symptoms, both related to their partner's MS and unrelated to MS. The National MS Society and other MS-related organizations frequently host various events. One possible way to help screen spousal/partner caregivers might be to hand out self-report measures at events and encourage caregivers to talk to their health care providers if their PTSD score is elevated. Screenings should also help caregivers to identify elevated anticipatory grief.

It is also recommended that future research examine PTSD and subclinical PTSD symptoms in longitudinal designs in order to create a gold-standard baseline of the experience of
PTSD in spousal/partner caregivers. The present study offered an exploratory first step to elucidate the presence of PTSD and subclinical posttraumatic stress symptoms in MS spousal/partner caregivers and began to uncover important associations with other aspects of mental health and functioning.
General Discussion

In conclusion, the present studies examined protective psychosocial factors and trauma in the uniquely vulnerable and largely understudied population of MS spousal/partner caregivers. The results of two separate cross-sectional research investigations replicated and expanded upon the currently available knowledge about these caregivers.

We learned in Chapter One (Study One) that lower caregiver burden was associated with reduced depression and mental health problems, while higher dyadic adjustment was inversely associated with mental health problems and positively correlated with satisfaction with life. Caregiver burden and dyadic adjustment were unrelated to physical health problems. Results from Chapter One also replicated similar previous research (Perrone et al., 2006) that dyadic adjustment was negatively correlated with caregiver burden, and improved upon that research by demonstrating gender differences such that the association was only significant in males. This suggests that males may particularly benefit from increasing dyadic adjustment.

In Chapter Two (Study One), we learned that higher receipt of social support and lower caregiver burden were associated with reduced depression, improved general mental health, and improved satisfaction with life. Giving social support by engaging in MS-related volunteer work was significantly and positively associated with altruism and satisfaction with life, but engagement in non-MS related volunteer work was not, suggesting that only specific types of volunteer work may benefit caregivers. Chapter Two also demonstrated that increasing altruism buffered against the negative effects of increased caregiver burden on general mental health and general physical health. Increasing altruism only protected against negative effects of caregiver burden on satisfaction with life at low and average levels of caregiver burden. These results
expand upon the current literature by identifying multiple possible pathways to help protect MS spousal/partner caregivers against the potentially deleterious outcomes of caregiver burden.

Chapter Three (Study Two) provided novel data on the presence of trauma, PTSD, and subclinical posttraumatic stress symptoms in MS spousal/partner caregivers. Results show that our sample of MS spousal/partner caregivers endorsed higher rates of probable PTSD and higher rates of subclinical PTSD than not only the general population, but of other caregiver samples. Results also show that presence of PTSD or subclinical posttraumatic stress symptoms did not differ based on whether the trauma(s) caregivers identified were related to their partner’s MS or their caregiving duties or not. Furthermore, Chapter Three conceptualized PTSD as representing current effects of trauma and anticipatory grief as expecting future trauma. We found that probable PTSD diagnosis was significantly indicative of higher anticipatory grief, showing that experiencing the current effects of trauma placed caregivers at higher risk for expecting future effects of trauma. We also found that probable PTSD diagnosis was associated with significantly worse general mental health. Finally, our results show that endorsement of subclinical PTSD symptoms was associated with significantly worse general physical health, which supports and expands upon literature that links PTSD with physical health problems, but in a novel population (e.g., Sledjeski et al., 2008).

Taken all together, our results indicate that MS spousal/partner caregivers experience significant caregiver burden, a host of negative mental and physical health impairments including PTSD and subclinical posttraumatic stress disorder symptoms, and that they also find benefit and protection through several psychosocial factors. The present studies replicate and expand upon current literature and add completely novel research to our knowledge of MS spousal/partner caregivers. The present studies demonstrate that MS spousal/partner caregivers
Future Directions

As discussed in each chapter, the present studies are not without limitations. Additional research is needed to better understand MS spousal/partner caregivers. It is recommended that longitudinal research be conducted in order to establish causation of factors that confer risk and resilience. Longitudinal research should also ideally identify the presence of trauma and any mental health impairments prior to becoming a MS spousal/partner caregiver. It is also recommended that future research directly compare MS spousal/partner caregivers with other familial MS caregivers and compare MS spousal/partner caregivers with spousal/partner caregivers of other diseases to best understand how and why MS spousal/partner caregivers are unique.

Clinical Implications

The results of the present studies suggest prevention and intervention efforts aimed at improving the well-being and functioning of MS spousal/partner caregivers. At present, there are some trials underway to investigate possible interventions that may benefit MS spousal/partner caregivers. For example, one trial is examining a mindfulness based intervention for MS patients that includes group sessions with MS patients and their family members and/or caregivers (Carletto et al., 2016). Another trial is examining a telemedicine meditation intervention for MS patients and their primary caregiver who they live with (who should largely be expected to be spouses/partners; Cavalera et al., 2016). While these trials are exciting, we recommend additional prevention and intervention efforts that specifically target MS spousal/partner caregivers.
Our results suggest that caregivers should be screened for PTSD and subclinical posttraumatic stress symptoms. Our results also suggest that MS spousal/partner caregivers should be encouraged to participate in MS-related volunteer work, which lends support for the many volunteer opportunities that organizations such as the National MS Society offer. However, as our results also suggest, caregivers should be encouraged to monitor their commitments to try to ensure that they do not experience role overload. Furthermore, our research also shows that reducing caregiver burden and increasing perceived social support may be beneficial to caregivers. Therefore, we suggested teaching caregivers positive self-care at National MS Society events and at neurology office visits. Finally, our results also inform that couple therapy interventions should be adapted for delivery to MS spousal/partner caregivers, and especially male caregivers, in order to increase dyadic adjustment.

All of these proposed prevention and intervention efforts should dually help to provide additional research on MS spousal/partner caregivers and should aim to improve these caregivers' wellbeing and functioning. Taken all together, the present studies replicated and expanded upon current literature and presented novel evidence that all inform clinical implications aimed at supporting and improving MS spousal/partner caregivers' mental and physical health.
References


Anonymous (Personal Interview, March 14, 2011).

Aronson, K. J., Cleghorn, G., & Goldenberg, E. (1996). Assistance arrangements and use of


Goldberg, L. R. (1999). A broad-bandwidth, public domain, personality inventory measuring the
lower-level facets of several five-factor models. In I. Mervielde, I. Deary, F. De Fruyt, & F. Ostendorf (Eds.), *Personality Psychology in Europe, Volume 7* (7-28). The Netherlands: Tilburg University Press.


Appendix A: Tables and Figures

Study One Tables and Figures

Figure 1

Hypothesized Moderator:
Dyadic Adjustment (DAS)

Hypothesized Moderator:
Perceived Social Support
(MSPSS)

Hypothesized Moderator:
Altruism

Caregiver Burden (CBI)

Outcomes:
Depression (PHQ)
General Mental Health (SF-12)
General Physical Health (SF-12)
Satisfaction with Life (SWLS)
Table 1

*Caregiver Education and Employment Demographic Information*

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<thead>
<tr>
<th>Highest level of education</th>
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<td>Some high school</td>
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<tr>
<td>High school diploma or GED</td>
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<tr>
<td>Some college</td>
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<td>23</td>
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<tr>
<td>Associate's degree</td>
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<td>11</td>
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<tr>
<td>Bachelor's degree</td>
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<td>23</td>
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<tr>
<td>Some graduate school</td>
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<td>Master's degree</td>
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<td>Doctorate, medical, or law degree</td>
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<td>Part time</td>
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<td>15</td>
</tr>
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<td>Unemployed and seeking work</td>
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<td>3</td>
</tr>
<tr>
<td>Unemployed and not seeking work</td>
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<td>Retired</td>
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### Table 2

**Financial Demographic Information**

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<th>Estimated household income before taxes</th>
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<td>$10,000-19,999</td>
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<td>$20,000-29,999</td>
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<td>9</td>
</tr>
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<td>$30,000-39,999</td>
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<td>18</td>
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<td>$40,000-49,999</td>
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<td>8</td>
</tr>
<tr>
<td>$50,000-74,999</td>
<td>18.5</td>
<td>17</td>
</tr>
<tr>
<td>$75,000-99,999</td>
<td>12.0</td>
<td>11</td>
</tr>
<tr>
<td>$100,000 and higher</td>
<td>21.7</td>
<td>20</td>
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<th>Out-of-pocket medical expenses per year</th>
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<td>$1-500</td>
<td>12.6</td>
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<td>$1001-2000</td>
<td>20.0</td>
<td>19</td>
</tr>
<tr>
<td>$2001-3000</td>
<td>13.7</td>
<td>13</td>
</tr>
<tr>
<td>$3001-4000</td>
<td>3.2</td>
<td>3</td>
</tr>
<tr>
<td>$4001-5000</td>
<td>6.3</td>
<td>6</td>
</tr>
<tr>
<td>$5001 and more</td>
<td>31.6</td>
<td>30</td>
</tr>
<tr>
<td>Multiple sclerosis course</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>------------------------------</td>
<td>-------</td>
<td>----</td>
</tr>
<tr>
<td>Relapsing-Remitting</td>
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<td>55</td>
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<td>Secondary-Progressive</td>
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<td>19</td>
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<tr>
<td>Primary-Progressive</td>
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</tr>
<tr>
<td>Progressive-Relapsing</td>
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Table 4

*Means and Standard Deviations for All Study Variables*

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<th>Standard deviation (SD)</th>
<th>n</th>
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<tr>
<td>Patient disability level</td>
<td>76.34</td>
<td>29.17</td>
<td>97</td>
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<td>Caregiver burden</td>
<td>30.30</td>
<td>21.40</td>
<td>79</td>
</tr>
<tr>
<td>Time-dependence burden</td>
<td>8.73</td>
<td>5.07</td>
<td>100</td>
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<tr>
<td>Developmental burden</td>
<td>8.78</td>
<td>6.16</td>
<td>96</td>
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<tr>
<td>Physical burden</td>
<td>5.59</td>
<td>4.26</td>
<td>98</td>
</tr>
<tr>
<td>Social burden</td>
<td>5.46</td>
<td>5.04</td>
<td>83</td>
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<td>Emotional burden</td>
<td>3.75</td>
<td>4.60</td>
<td>96</td>
</tr>
<tr>
<td>Dyadic adjustment</td>
<td>105.11</td>
<td>18.60</td>
<td>70</td>
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<tr>
<td>Depression</td>
<td>6.45</td>
<td>6.26</td>
<td>89</td>
</tr>
<tr>
<td>Satisfaction with life</td>
<td>20.90</td>
<td>8.53</td>
<td>93</td>
</tr>
<tr>
<td>General mental health</td>
<td>43.50</td>
<td>10.79</td>
<td>93</td>
</tr>
<tr>
<td>General physical health</td>
<td>52.13</td>
<td>8.74</td>
<td>93</td>
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<tr>
<td>Perceived social support</td>
<td>52.77</td>
<td>16.38</td>
<td>91</td>
</tr>
<tr>
<td>Significant other</td>
<td>19.38</td>
<td>6.79</td>
<td>96</td>
</tr>
<tr>
<td>Family</td>
<td>16.58</td>
<td>6.26</td>
<td>93</td>
</tr>
<tr>
<td>Friends</td>
<td>17.22</td>
<td>6.16</td>
<td>94</td>
</tr>
<tr>
<td>Altruism</td>
<td>40.96</td>
<td>6.65</td>
<td>95</td>
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Table 5

**Study Variables as Predictors of Patient Disability Level: Pearson's Correlation Coefficient and Linear Regression**

<table>
<thead>
<tr>
<th>Variable</th>
<th>$r$</th>
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<tbody>
<tr>
<td>Caregiver burden total score</td>
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</tr>
<tr>
<td>Dyadic adjustment</td>
<td>0.14</td>
</tr>
<tr>
<td>Depression</td>
<td>-0.27*</td>
</tr>
<tr>
<td>Satisfaction with life</td>
<td>0.23*</td>
</tr>
<tr>
<td>General mental health</td>
<td>0.11</td>
</tr>
<tr>
<td>General physical health</td>
<td>0.32**</td>
</tr>
<tr>
<td>Perceived social support total score</td>
<td>0.10</td>
</tr>
<tr>
<td>Altruism</td>
<td>0.16</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable</th>
<th>$\beta$</th>
<th>$t(df)$</th>
<th>$F(df)$</th>
<th>$R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver burden</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time-dependence burden</td>
<td>-0.83</td>
<td>-9.14(76)***</td>
<td></td>
<td>0.67</td>
</tr>
<tr>
<td>Developmental burden</td>
<td>0.11</td>
<td>0.90(76)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical burden</td>
<td>-0.24</td>
<td>-1.85(76)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social burden</td>
<td>0.44</td>
<td>3.43(76)**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional burden</td>
<td>-0.21</td>
<td>-1.72(76)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived social support</td>
<td></td>
<td></td>
<td></td>
<td>0.06</td>
</tr>
<tr>
<td>Significant other</td>
<td>0.26</td>
<td>1.92(87)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td>-0.19</td>
<td>-1.33(87)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td>0.05</td>
<td>0.32(87)</td>
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</table>

*Notes.* $\beta$=Standardized beta coefficient. $df$ = degrees of freedom. *p<0.05. **p<0.01. ***p<0.001.
Table 6

*Study Variables as Predictors of Age: Pearson’s Correlation Coefficient and Linear Regression*

<table>
<thead>
<tr>
<th>Variable</th>
<th>r</th>
<th>β</th>
<th>t(df)</th>
<th>F(df)</th>
<th>R²</th>
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<tbody>
<tr>
<td>Caregiver burden total score</td>
<td>0.25*</td>
<td>0.32</td>
<td>2.23(79)*</td>
<td>2.69(5, 73)*</td>
<td>0.16</td>
</tr>
<tr>
<td>Dyadic adjustment</td>
<td>-0.30*</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>0.07</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfaction with life</td>
<td>-0.29*</td>
<td>-0.31**</td>
<td>-1.53(79)</td>
<td>3.42(3, 86)*</td>
<td>0.11</td>
</tr>
<tr>
<td>General mental health</td>
<td>-0.07</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General physical health</td>
<td>-0.08</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived social support total score</td>
<td>-0.31**</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Altruism</td>
<td>0.02</td>
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<td></td>
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<td></td>
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</table>

Notes. β=Standardized beta coefficient. df=degrees of freedom.
*p<0.05. **p<0.01. ***p<0.001.
Table 7

Effect of Gender on All Study Variables: Independent Samples T-Tests and Multivariate Analysis of Variance

<table>
<thead>
<tr>
<th>Variable</th>
<th>Males</th>
<th>Females</th>
<th>t (df)</th>
<th>Cohen's d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient disability</td>
<td>77.79(28.24)</td>
<td>74.67(30.44)</td>
<td>0.52(95)</td>
<td>0.11</td>
</tr>
<tr>
<td>Caregiver burden total score</td>
<td>25.73(20.43)</td>
<td>36.35(21.46)</td>
<td>-2.24(77)*</td>
<td>0.51</td>
</tr>
<tr>
<td>Dyadic adjustment</td>
<td>104.90(19.30)</td>
<td>105.40(17.94)</td>
<td>-0.11(68)</td>
<td>0.03</td>
</tr>
<tr>
<td>Depression</td>
<td>5.10(5.38)</td>
<td>8.35(6.95)</td>
<td>-2.49(87)*</td>
<td>0.52</td>
</tr>
<tr>
<td>Satisfaction with life</td>
<td>21.36(8.20)</td>
<td>20.30(9.02)</td>
<td>0.59(91)</td>
<td>0.12</td>
</tr>
<tr>
<td>General mental health</td>
<td>45.32(10.57)</td>
<td>41.19(10.74)</td>
<td>1.86(91)</td>
<td>0.39</td>
</tr>
<tr>
<td>General physical health</td>
<td>52.50(8.04)</td>
<td>51.67(9.65)</td>
<td>0.45(91)</td>
<td>0.09</td>
</tr>
<tr>
<td>Perceived social support total score</td>
<td>52.86(16.31)</td>
<td>52.65(16.67)</td>
<td>0.06(89)</td>
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<tr>
<td>Altruism</td>
<td>40.59(6.93)</td>
<td>41.38(6.35)</td>
<td>-0.58(93)</td>
<td>0.12</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable</th>
<th>Males</th>
<th>Females</th>
<th>F(df)</th>
<th>η²</th>
<th>Wilks’ λ</th>
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<td>1.49(5, 73)</td>
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<td>Time-dependence burden</td>
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<td>9.26(4.90)</td>
<td>2.56(1, 77)</td>
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<td></td>
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<td>Developmental burden</td>
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<td>9.68(6.33)</td>
<td>4.52(1, 77)*</td>
<td>0.06</td>
<td></td>
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<tr>
<td>Physical burden</td>
<td>4.31(4.07)</td>
<td>6.50(4.00)</td>
<td>5.68(1, 77)*</td>
<td>0.07</td>
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</tr>
<tr>
<td>Social burden</td>
<td>4.22(4.86)</td>
<td>6.71(4.94)</td>
<td>4.99(1, 77)*</td>
<td>0.06</td>
<td></td>
</tr>
<tr>
<td>Emotional burden</td>
<td>2.91(4.26)</td>
<td>4.21(5.01)</td>
<td>1.53(1, 77)</td>
<td>0.02</td>
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<tr>
<td>Perceived social support</td>
<td></td>
<td></td>
<td>0.85(3, 87)</td>
<td>0.03</td>
<td>0.97</td>
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<tr>
<td>Significant other</td>
<td>19.61(6.54)</td>
<td>18.60(7.28)</td>
<td>0.48(1, 89)</td>
<td>0.01</td>
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<tr>
<td>Family</td>
<td>16.61(6.24)</td>
<td>16.53(6.31)</td>
<td>0.00(1, 89)</td>
<td>0.00</td>
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<td>Friends</td>
<td>16.65(6.37)</td>
<td>17.53(5.81)</td>
<td>0.46(1, 89)</td>
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Notes. df=degrees of freedom. *p<0.05. **p<0.01. ***p<0.001.
### Table 8

**Partial Correlations among All Study Variables Controlling for Gender**

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<th></th>
</tr>
</thead>
<tbody>
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<td>1. Patient disability</td>
<td>-0.51***</td>
<td>-0.00</td>
<td>-0.25</td>
<td>0.12</td>
<td>0.14</td>
<td>0.28</td>
<td>-0.02</td>
<td>0.11</td>
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</tr>
<tr>
<td>2. Caregiver burden</td>
<td>-0.49***</td>
<td>0.55***</td>
<td>-0.55***</td>
<td>-0.54***</td>
<td>-0.08</td>
<td>-0.29*</td>
<td>-0.50***</td>
<td>-0.33*</td>
<td></td>
</tr>
<tr>
<td>3. Dyadic adjustment</td>
<td>-0.11</td>
<td>0.71***</td>
<td>0.58***</td>
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<td>9. Altruism</td>
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*Notes.*  *p<0.05.  **p<0.01.  ***p<0.001.*
Table 9

*Regression Equations for Caregiver Outcomes from Caregiver Burden, Dyadic Adjustment, and Their Interactions*

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*Notes.* $\beta=$Standardized regression coefficient. $df=$degrees of freedom. *$p<0.05$. **$p<0.01$, ***$p<0.001$. Only significant covariates, which were retained, are shown in step one. All variables from each step are carried into the next step.
Table 10

Regression Equations for Caregiver Outcomes from Caregiver Burden, Perceived Social Support, and Their Interaction

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<th>$R^2$ Change</th>
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<td>31.69(3, 66)***</td>
<td>0.51***</td>
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Notes. β=Standardized regression coefficient. df=degrees of freedom. *p<0.05. **p<0.01, ***p<0.001. Only significant covariates, which were retained, are shown in step one. All variables from each step are carried into the next step.
Table 11

*Participation in Volunteer Related Activities*

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<td>Bicycle rides</td>
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<td>Other fundraising events</td>
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<tr>
<td>Events to raise awareness</td>
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<tr>
<td>Help to lead support groups</td>
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<td>Help administratively</td>
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<td>Educational related group</td>
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Table 12

**Effect of MS-Related Volunteer Status on Study Variables: Independent Samples T-Tests and Multivariate Analysis of Variance**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Volunteer</th>
<th>Do not volunteer</th>
<th>( t (df) )</th>
<th>Cohen's ( d )</th>
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<tbody>
<tr>
<td>Caregiver age</td>
<td>46.04 (11.12)</td>
<td>50.26 (13.83)</td>
<td>-1.38 (97)</td>
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<tr>
<td>Altruism</td>
<td>43.74 (4.82)</td>
<td>39.87 (6.93)</td>
<td>2.48 (91)*</td>
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<td>Satisfaction with life</td>
<td>57.45 (14.50)</td>
<td>51.42 (16.95)</td>
<td>2.41 (90)*</td>
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<td>Caregiver burden total score</td>
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<td>-1.01 (75)</td>
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<td>Perceived social support total score</td>
<td>57.45 (14.50)</td>
<td>51.42 (16.95)</td>
<td>1.50 (87)</td>
<td>0.38</td>
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</table>

<table>
<thead>
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<th>Variable</th>
<th>Volunteer</th>
<th>Do not volunteer</th>
<th>( F(df) )</th>
<th>( \eta^2 )</th>
<th>Wilks' ( \lambda )</th>
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<td>7.29 (4.61)</td>
<td>8.64 (5.23)</td>
<td>1.18 (1, 75)</td>
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<td>Developmental burden</td>
<td>6.38 (6.25)</td>
<td>8.64 (5.91)</td>
<td>2.35 (1, 75)</td>
<td>0.03</td>
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<td>Physical burden</td>
<td>5.63 (4.19)</td>
<td>5.13 (4.25)</td>
<td>0.22 (1, 75)</td>
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<td>5.00 (4.53)</td>
<td>5.45 (5.32)</td>
<td>0.13 (1, 75)</td>
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<tr>
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<td>2.17 (3.13)</td>
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<td>2.50 (1, 75)</td>
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<td>18.63 (6.96)</td>
<td>3.22 (1, 87)</td>
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<td>18.59 (5.92)</td>
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<td>1.91 (1, 87)</td>
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*Notes. df=degrees of freedom. *p<0.05. **p<0.01. ***p<0.001.*
Table 13

Effect of Non-MS Related Volunteer Status on Study Variables: Independent Samples T-Tests and Multivariate Analysis of Variance

<table>
<thead>
<tr>
<th>Variable</th>
<th>Volunteer</th>
<th>Do not volunteer</th>
<th>t (df)</th>
<th>Cohen's d</th>
<th>Variable</th>
<th>Volunteer</th>
<th>Do not volunteer</th>
<th>F(df)</th>
<th>η²</th>
<th>Wilks' λ</th>
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</thead>
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<td>Caregiver age</td>
<td>48.59(11.92)</td>
<td>48.80(14.21)</td>
<td>-0.08(93)</td>
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<td>Caregiver burden</td>
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<td>0.04</td>
<td>0.96</td>
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<tr>
<td>Altruism</td>
<td>40.76(6.61)</td>
<td>40.94(6.69)</td>
<td>-0.13(88)</td>
<td>0.03</td>
<td>Time-dependence burden</td>
<td>0.00(1, 74)</td>
<td>0.00</td>
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<tr>
<td>Satisfaction with life</td>
<td>21.70(8.06)</td>
<td>20.65(8.86)</td>
<td>-0.57(86)</td>
<td>0.12</td>
<td>Developmental burden</td>
<td>0.01(1, 74)</td>
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<td>Caregiver burden total score</td>
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<td>30.42(22.46)</td>
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</tbody>
</table>

Notes. df=degrees of freedom. *p<0.05. **p<0.01. ***p<0.001.
Table 14

*Regression Equations for Caregiver Outcomes from Caregiver Burden, Altruism, and Their Interaction*

<table>
<thead>
<tr>
<th></th>
<th>β</th>
<th>t</th>
<th>F (df)</th>
<th>R²</th>
<th>R² Change</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Depression</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step one</td>
<td></td>
<td></td>
<td>7.43(1, 67)*</td>
<td>0.10*</td>
<td></td>
</tr>
<tr>
<td>Patient disability</td>
<td>-0.32</td>
<td>-2.73*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(covariate)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step two</td>
<td></td>
<td></td>
<td>17.13(3, 65)***</td>
<td>0.34***</td>
<td></td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>0.55</td>
<td>4.28***</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Altruism</td>
<td>-0.20</td>
<td>-1.86</td>
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</tr>
<tr>
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<td></td>
<td></td>
<td>13.12(4, 64)***</td>
<td>0.01</td>
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<tr>
<td>Caregiver burden x</td>
<td>-0.11</td>
<td>-1.02</td>
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<tr>
<td>Altruism</td>
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<td></td>
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<tr>
<td><strong>General mental health</strong></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step one</td>
<td></td>
<td></td>
<td>5.59(1, 70)*</td>
<td>0.07*</td>
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</tr>
<tr>
<td>Caregiver gender</td>
<td>-0.27</td>
<td>-2.36*</td>
<td></td>
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<tr>
<td>(covariate)</td>
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</tr>
<tr>
<td>Step two</td>
<td></td>
<td></td>
<td>12.78(3, 68)***</td>
<td>0.29***</td>
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<td>Caregiver burden</td>
<td>-0.34</td>
<td>-2.93*</td>
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</tr>
<tr>
<td>Altruism</td>
<td>0.30</td>
<td>2.66*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step three</td>
<td></td>
<td></td>
<td>10.86(4, 67)***</td>
<td>0.03</td>
<td></td>
</tr>
<tr>
<td>Caregiver burden x</td>
<td>-0.20</td>
<td>-1.90</td>
<td></td>
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<tr>
<td>Altruism</td>
<td></td>
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<tr>
<td><strong>General physical health</strong></td>
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<td></td>
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<tr>
<td>Step one</td>
<td></td>
<td></td>
<td>0.45(2, 69)</td>
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<td>Caregiver burden</td>
<td>-0.13</td>
<td>-0.95</td>
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<td>Altruism</td>
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<td>-0.44</td>
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<tr>
<td>Step two</td>
<td></td>
<td></td>
<td>2.52(3, 68)</td>
<td>0.09*</td>
<td></td>
</tr>
<tr>
<td>Caregiver burden x</td>
<td>0.33</td>
<td>2.57*</td>
<td></td>
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</tr>
<tr>
<td>Altruism</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Satisfaction with Life</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step one</td>
<td></td>
<td></td>
<td>14.49(2, 69)***</td>
<td>0.30***</td>
<td></td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>-0.50</td>
<td>-4.51***</td>
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<tr>
<td>Altruism</td>
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<td>0.88</td>
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<td></td>
</tr>
<tr>
<td>Step two</td>
<td></td>
<td></td>
<td>16.17(3, 68)***</td>
<td>0.12***</td>
<td></td>
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<tr>
<td>Caregiver burden x</td>
<td>-0.38</td>
<td>-3.75***</td>
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<tr>
<td>Altruism</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
Notes. $\beta=$Standardized regression coefficient. $df=$degrees of freedom. *p<0.05. **p<0.01, ***p<0.001. Only significant covariates, which were retained, are shown in step one. All variables from each step are carried into the next step.
Table 15

*Regression Equations for Caregiver Outcomes from Time-Dependence Caregiver Burden, Altruism, and Their Interaction*

<table>
<thead>
<tr>
<th></th>
<th>β</th>
<th>t</th>
<th>F (df)</th>
<th>R²</th>
<th>R² Change</th>
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<td><strong>Depression</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step one</td>
<td></td>
<td></td>
<td>5.68(2, 79)*</td>
<td>0.13*</td>
<td></td>
</tr>
<tr>
<td>Patient disability level (covariate)</td>
<td>-0.27</td>
<td>-2.56*</td>
<td></td>
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</tr>
<tr>
<td>Caregiver gender (covariate)</td>
<td>0.24</td>
<td>2.24*</td>
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</tr>
<tr>
<td>Step two</td>
<td></td>
<td></td>
<td>8.18(4, 77)***</td>
<td>0.17***</td>
<td></td>
</tr>
<tr>
<td>Time-dependence burden</td>
<td>0.28</td>
<td>1.80</td>
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<td>Altruism</td>
<td>-0.36</td>
<td>-3.64***</td>
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<td>Step three</td>
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<td></td>
<td>6.47(5, 76)***</td>
<td>0.00</td>
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</tr>
<tr>
<td>Time-dependence burden x Altruism</td>
<td>-0.02</td>
<td>-0.23</td>
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<td><strong>General mental health</strong></td>
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<tr>
<td>Step one</td>
<td></td>
<td></td>
<td>14.79(2, 87)***</td>
<td>0.25***</td>
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<td>-2.23*</td>
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<td>Altruism</td>
<td>0.41</td>
<td>4.30***</td>
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</tr>
<tr>
<td>Step two</td>
<td></td>
<td></td>
<td>12.24(3, 86)***</td>
<td>0.05*</td>
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</tr>
<tr>
<td>Time-dependence burden x Altruism</td>
<td>-0.23</td>
<td>-2.36*</td>
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</tr>
<tr>
<td><strong>General physical health</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step one</td>
<td></td>
<td></td>
<td>9.46(1, 84)**</td>
<td>0.10**</td>
<td></td>
</tr>
<tr>
<td>Patient disability level (covariate)</td>
<td>0.32</td>
<td>3.08**</td>
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<tr>
<td>Step two</td>
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<td></td>
<td>3.13(3, 82)*</td>
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</tr>
<tr>
<td>Time-dependence burden</td>
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<td>0.33</td>
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</tr>
<tr>
<td>Altruism</td>
<td>-0.01</td>
<td>-0.12</td>
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<td></td>
</tr>
<tr>
<td>Step three</td>
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<td>5.74(4, 81)***</td>
<td>0.12**</td>
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<tr>
<td>Time-dependence burden x Altruism</td>
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<td>3.50**</td>
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</tr>
<tr>
<td><strong>Satisfaction with Life</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step one</td>
<td></td>
<td></td>
<td>6.68(1, 87)*</td>
<td>0.07*</td>
<td></td>
</tr>
<tr>
<td>Caregiver age (covariate)</td>
<td>-0.27</td>
<td>-2.59*</td>
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</tr>
<tr>
<td>Step two</td>
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<td></td>
<td>9.10(3, 85)***</td>
<td>0.17***</td>
<td></td>
</tr>
<tr>
<td>Time-dependence burden</td>
<td>-0.23</td>
<td>-2.20*</td>
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<tr>
<td></td>
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<td>-----</td>
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<td></td>
</tr>
<tr>
<td>Altruism</td>
<td>0.32</td>
<td>3.29**</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Step three</td>
<td></td>
<td>8.03(4, 84)***</td>
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</tr>
<tr>
<td>Time-dependence burden x Altruism</td>
<td>-0.19</td>
<td>-1.98</td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes. $\beta$=Standardized regression coefficient. $df$=degrees of freedom. *p<0.05, **p<0.01, ***p<0.001. Only significant covariates, which were retained, are shown in step one. All variables from each step are carried into the next step.
Figure 2

*Satisfaction with Life from the Interaction of Caregiver Burden and Altruism*
Figure 3

*General Mental Health from the Interaction of Time-Dependence Caregiver Burden and Altruism*
Figure 4

*General Physical Health from the Interaction of Time-Dependence Caregiver Burden and Altruism*
Study Two Tables

Table 16

*Caregiver Education and Employment Demographic Information*

<table>
<thead>
<tr>
<th>Highest level of education</th>
<th>%</th>
<th>n</th>
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</thead>
<tbody>
<tr>
<td>Some high school</td>
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<td>0</td>
</tr>
<tr>
<td>High school diploma or GED</td>
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<td>12</td>
</tr>
<tr>
<td>Some college</td>
<td>27.0</td>
<td>20</td>
</tr>
<tr>
<td>Associate's degree</td>
<td>14.9</td>
<td>11</td>
</tr>
<tr>
<td>Bachelor's degree</td>
<td>17.6</td>
<td>13</td>
</tr>
<tr>
<td>Some graduate school</td>
<td>4.1</td>
<td>3</td>
</tr>
<tr>
<td>Master's degree</td>
<td>16.2</td>
<td>12</td>
</tr>
<tr>
<td>Doctorate, medical, or law degree</td>
<td>4.1</td>
<td>3</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment status</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full time</td>
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</tr>
<tr>
<td>Part time</td>
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<td>5</td>
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<td>Unemployed and seeking work</td>
<td>1.4</td>
<td>1</td>
</tr>
<tr>
<td>Unemployed and not seeking work</td>
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<td>4</td>
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<tr>
<td>Retired</td>
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</table>
Table 17

**Financial Demographic Information**

<table>
<thead>
<tr>
<th>Estimated household income before taxes</th>
<th>%</th>
<th>n</th>
</tr>
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<tbody>
<tr>
<td>$10,000-19,999</td>
<td>9.7</td>
<td>7</td>
</tr>
<tr>
<td>$20,000-29,999</td>
<td>6.9</td>
<td>5</td>
</tr>
<tr>
<td>$30,000-39,999</td>
<td>8.3</td>
<td>6</td>
</tr>
<tr>
<td>$40,000-49,999</td>
<td>13.9</td>
<td>10</td>
</tr>
<tr>
<td>$50,000-74,999</td>
<td>22.2</td>
<td>16</td>
</tr>
<tr>
<td>$75,000-99,999</td>
<td>20.8</td>
<td>15</td>
</tr>
<tr>
<td>$100,000 and higher</td>
<td>18.1</td>
<td>13</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Out-of-pocket medical expenses per year</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>$1-500</td>
<td>15.9</td>
<td>11</td>
</tr>
<tr>
<td>$501-1000</td>
<td>23.2</td>
<td>16</td>
</tr>
<tr>
<td>$1001-2000</td>
<td>15.9</td>
<td>11</td>
</tr>
<tr>
<td>$2001-3000</td>
<td>10.1</td>
<td>7</td>
</tr>
<tr>
<td>$3001-4000</td>
<td>10.1</td>
<td>7</td>
</tr>
<tr>
<td>$4001-5000</td>
<td>4.3</td>
<td>3</td>
</tr>
<tr>
<td>$5001-6000</td>
<td>4.3</td>
<td>3</td>
</tr>
<tr>
<td>$6001 and more</td>
<td>15.9</td>
<td>11</td>
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</tbody>
</table>
Table 18

*Multiple Sclerosis Course of Caregivers' Spouses/Partners*

<table>
<thead>
<tr>
<th>Multiple sclerosis course</th>
<th>%</th>
<th>n</th>
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<tr>
<td>Relapsing-Remitting</td>
<td>57.7</td>
<td>41</td>
</tr>
<tr>
<td>Secondary-Progressive</td>
<td>16.9</td>
<td>12</td>
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<tr>
<td>Primary-Progressive</td>
<td>12.7</td>
<td>9</td>
</tr>
<tr>
<td>Progressive-Relapsing</td>
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<td>4</td>
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<tr>
<td>No course specified</td>
<td>7.0</td>
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</table>
Table 19

*Means and Standard Deviations for All Study Variables*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean (M)</th>
<th>Standard deviation (SD)</th>
<th>n</th>
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<tbody>
<tr>
<td>Patient disability level</td>
<td>77.46</td>
<td>23.11</td>
<td>57</td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>29.88</td>
<td>16.92</td>
<td>51</td>
</tr>
<tr>
<td>Time-dependence burden</td>
<td>8.84</td>
<td>4.62</td>
<td>57</td>
</tr>
<tr>
<td>Developmental burden</td>
<td>7.73</td>
<td>5.30</td>
<td>59</td>
</tr>
<tr>
<td>Physical burden</td>
<td>5.30</td>
<td>3.89</td>
<td>61</td>
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<tr>
<td>Social burden</td>
<td>5.07</td>
<td>4.33</td>
<td>58</td>
</tr>
<tr>
<td>Emotional burden</td>
<td>3.10</td>
<td>3.57</td>
<td>59</td>
</tr>
<tr>
<td>Dyadic adjustment</td>
<td>106.59</td>
<td>15.90</td>
<td>51</td>
</tr>
<tr>
<td>Depression</td>
<td>4.63</td>
<td>5.04</td>
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<tr>
<td>General mental health</td>
<td>46.52</td>
<td>10.41</td>
<td>59</td>
</tr>
<tr>
<td>General physical health</td>
<td>49.75</td>
<td>7.95</td>
<td>59</td>
</tr>
<tr>
<td>Drug use</td>
<td>1.10</td>
<td>0.66</td>
<td>52</td>
</tr>
<tr>
<td>Alcohol use</td>
<td>3.35</td>
<td>2.47</td>
<td>51</td>
</tr>
<tr>
<td>PTSD total score</td>
<td>14.85</td>
<td>16.01</td>
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<tr>
<td>Cluster B (Intrusion)</td>
<td>0.92</td>
<td>1.53</td>
<td>62</td>
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<tr>
<td>Cluster C (Avoidance)</td>
<td>0.45</td>
<td>0.76</td>
<td>62</td>
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<tr>
<td>Cluster D (Alterations)</td>
<td>1.23</td>
<td>1.92</td>
<td>61</td>
</tr>
<tr>
<td>Cluster E (Reactivity)</td>
<td>1.26</td>
<td>1.68</td>
<td>61</td>
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<tr>
<td>Anticipatory grief</td>
<td>75.37</td>
<td>13.70</td>
<td>51</td>
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<tr>
<td>Stressful life events</td>
<td>7.28</td>
<td>4.58</td>
<td>57</td>
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</tbody>
</table>
Table 20

**Effect of Gender on All Study Variables: Independent Samples T-Tests and Multivariate Analysis of Variance**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Males</th>
<th>Females</th>
<th>t (df)</th>
<th>Cohen's d</th>
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</thead>
<tbody>
<tr>
<td>Patient disability</td>
<td>84.00(21.15)</td>
<td>70.19(23.39)</td>
<td>2.34(55)*</td>
<td>0.62</td>
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<tr>
<td>Caregiver burden total score</td>
<td>23.96(14.11)</td>
<td>37.09(17.52)</td>
<td>-2.96(49)*</td>
<td>0.82</td>
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<tr>
<td>Dyadic adjustment</td>
<td>110.46(14.71)</td>
<td>102.56(16.38)</td>
<td>1.81(49)</td>
<td>0.51</td>
</tr>
<tr>
<td>Depression</td>
<td>2.88(3.23)</td>
<td>6.88(6.04)</td>
<td>-3.21(55)**</td>
<td>0.83</td>
</tr>
<tr>
<td>General mental health</td>
<td>51.11(8.48)</td>
<td>41.44(10.11)</td>
<td>3.99(57)**</td>
<td>1.04</td>
</tr>
<tr>
<td>General physical health</td>
<td>49.94(8.75)</td>
<td>49.54(7.11)</td>
<td>0.19(57)</td>
<td>0.05</td>
</tr>
<tr>
<td>Drug use</td>
<td>1.11(0.69)</td>
<td>1.08(0.65)</td>
<td>0.13(50)</td>
<td>0.04</td>
</tr>
<tr>
<td>Alcohol use</td>
<td>3.93(2.98)</td>
<td>2.65(1.43)</td>
<td>1.88(49)</td>
<td>0.55</td>
</tr>
<tr>
<td>PTSD total score</td>
<td>11.45(14.17)</td>
<td>19.00(17.39)</td>
<td>-1.85(58)</td>
<td>0.48</td>
</tr>
<tr>
<td>Anticipatory grief</td>
<td>72.27(15.22)</td>
<td>78.60(11.33)</td>
<td>-1.68(49)</td>
<td>0.47</td>
</tr>
<tr>
<td>Stressful life events</td>
<td>6.67(4.59)</td>
<td>8.13(4.52)</td>
<td>-1.19(55)</td>
<td>0.32</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable</th>
<th>M (SD)</th>
<th>M (SD)</th>
<th>F(df)</th>
<th>ηp²</th>
<th>Wilks’ λ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver burden</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time-dependence burden</td>
<td>7.25(4.72)</td>
<td>10.17(3.86)</td>
<td>5.70(1, 49)*</td>
<td>0.10</td>
<td></td>
</tr>
<tr>
<td>Developmental burden</td>
<td>6.11(4.30)</td>
<td>9.78(5.29)</td>
<td>7.50(1, 49)*</td>
<td>0.13</td>
<td></td>
</tr>
<tr>
<td>Physical burden</td>
<td>4.18(2.80)</td>
<td>6.61(4.28)</td>
<td>5.94(1, 49)*</td>
<td>0.11</td>
<td></td>
</tr>
<tr>
<td>Social burden</td>
<td>3.86(3.54)</td>
<td>6.52(4.39)</td>
<td>5.77(1, 49)*</td>
<td>0.11</td>
<td></td>
</tr>
<tr>
<td>Emotional burden</td>
<td>2.57(3.38)</td>
<td>4.00(3.75)</td>
<td>2.04(1, 49)</td>
<td>0.04</td>
<td></td>
</tr>
<tr>
<td>PTSD</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cluster B (Intrusion)</td>
<td>0.58(1.28)</td>
<td>1.41(1.74)</td>
<td>4.56(1, 58)*</td>
<td>0.07</td>
<td></td>
</tr>
<tr>
<td>Cluster C (Avoidance)</td>
<td>0.40(0.70)</td>
<td>0.56(0.85)</td>
<td>0.65(1, 58)</td>
<td>0.01</td>
<td></td>
</tr>
<tr>
<td>Cluster D (Alterations)</td>
<td>1.03(1.78)</td>
<td>1.52(2.10)</td>
<td>0.95(1, 58)</td>
<td>0.02</td>
<td></td>
</tr>
<tr>
<td>Cluster E (Reactivity)</td>
<td>0.88(1.36)</td>
<td>1.74(1.95)</td>
<td>4.03(1, 58)</td>
<td>0.07</td>
<td></td>
</tr>
</tbody>
</table>

*Notes. df=degrees of freedom. *p<0.05. **p<0.01. ***p<0.001.*
### Table 21

**Partial Correlations among All Study Variables Controlling for Gender**

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Patient disability</td>
<td>-0.41</td>
<td>-0.10</td>
<td>-0.02</td>
<td>-0.10</td>
<td>-0.15</td>
<td>0.15</td>
<td>-0.23</td>
<td>-0.20</td>
<td>-0.14</td>
<td>-0.09</td>
<td></td>
</tr>
<tr>
<td>2. Caregiver burden</td>
<td>-0.44</td>
<td>0.58*</td>
<td>-0.53*</td>
<td>0.06</td>
<td>-0.00</td>
<td>0.38</td>
<td>0.01</td>
<td>0.42</td>
<td>0.19</td>
<td>0.32</td>
<td></td>
</tr>
<tr>
<td>3. Dyadic adjustment</td>
<td>-0.05</td>
<td>0.50*</td>
<td>-0.13</td>
<td>-0.04</td>
<td>-0.11</td>
<td>0.42</td>
<td>0.19</td>
<td>0.32</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Depression</td>
<td>-0.60**</td>
<td>-0.15</td>
<td>0.38</td>
<td>0.41</td>
<td>0.41</td>
<td>0.39</td>
<td>0.71***</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. General mental health</td>
<td>-0.19</td>
<td>-0.40</td>
<td>-0.41</td>
<td>-0.08</td>
<td>-0.24</td>
<td>-0.27</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. General physical health</td>
<td>0.10</td>
<td>0.25</td>
<td>-0.29</td>
<td>0.22</td>
<td>0.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Drug use</td>
<td>0.31</td>
<td>0.12</td>
<td>-0.07</td>
<td>0.27</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Alcohol use</td>
<td>-0.03</td>
<td>0.15</td>
<td>0.37</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. PTSD total score</td>
<td>0.46</td>
<td>0.72***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>10. Anticipatory grief</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.37</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Stressful life events</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Notes.*  
* p<0.05. ** p<0.01. *** p<0.001.
Table 22

Potentially Traumatic Events as Endorsed on the Life Events Checklist

<table>
<thead>
<tr>
<th>Event</th>
<th>Happened to me % (n)</th>
<th>Witnessed it % (n)</th>
<th>Learned about it % (n)</th>
<th>Part of my job % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natural disaster</td>
<td>41.5% (27)</td>
<td>6.2% (4)</td>
<td>15.4% (10)</td>
<td>4.6% (3)</td>
</tr>
<tr>
<td>Fire or explosion</td>
<td>16.1% (10)</td>
<td>21.0% (13)</td>
<td>12.9% (8)</td>
<td>4.8% (3)</td>
</tr>
<tr>
<td>Transportation accident</td>
<td>52.3% (34)</td>
<td>16.9% (11)</td>
<td>13.8% (9)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Serious accident at work, home, or during recreational activity</td>
<td>20.0% (13)</td>
<td>21.5% (14)</td>
<td>9.2% (6)</td>
<td>6.2% (4)</td>
</tr>
<tr>
<td>Exposure to toxic substance</td>
<td>9.4% (6)</td>
<td>3.1% (2)</td>
<td>12.5% (8)</td>
<td>7.8% (5)</td>
</tr>
<tr>
<td>Physical assault</td>
<td>24.6% (16)</td>
<td>4.6% (3)</td>
<td>12.3% (8)</td>
<td>6.2% (4)</td>
</tr>
<tr>
<td>Assault with a weapon</td>
<td>15.4% (10)</td>
<td>4.6% (3)</td>
<td>9.2% (6)</td>
<td>4.6% (3)</td>
</tr>
<tr>
<td>Sexual assault</td>
<td>15.4% (10)</td>
<td>1.5% (1)</td>
<td>12.3% (8)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Other unwanted or uncomfortable sexual experience</td>
<td>27.7% (18)</td>
<td>3.1% (2)</td>
<td>12.3% (8)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Combat or exposure to a war-zone</td>
<td>3.2% (2)</td>
<td>0% (0)</td>
<td>19.0% (12)</td>
<td>1.6% (1)</td>
</tr>
<tr>
<td>Captivity</td>
<td>4.6% (3)</td>
<td>1.5% (1)</td>
<td>7.7% (5)</td>
<td>1.5% (1)</td>
</tr>
<tr>
<td>Life-threatening illness or injury</td>
<td>18.8% (12)</td>
<td>39.1% (25)</td>
<td>4.7% (3)</td>
<td>3.1% (2)</td>
</tr>
<tr>
<td>Severe human suffering</td>
<td>4.6% (3)</td>
<td>20.0% (13)</td>
<td>12.3% (8)</td>
<td>7.7% (5)</td>
</tr>
<tr>
<td>Sudden violent death</td>
<td>1.6% (1)</td>
<td>9.4% (6)</td>
<td>26.6% (17)</td>
<td>6.3% (4)</td>
</tr>
<tr>
<td>Sudden accidental death</td>
<td>12.5% (8)</td>
<td>15.6% (10)</td>
<td>28.1% (18)</td>
<td>1.6% (1)</td>
</tr>
<tr>
<td>Serious injury, harm, or death you caused to someone else</td>
<td>3.1% (2)</td>
<td>6.3% (4)</td>
<td>0% (0)</td>
<td>1.6% (1)</td>
</tr>
</tbody>
</table>
Table 23

**Effect of Probable PTSD Diagnosis on Study Variables Controlling for Gender: Independent Samples T-Tests and Univariate and Multivariate Analyses of Variance**

<table>
<thead>
<tr>
<th>Variable</th>
<th>PTSD</th>
<th>No PTSD</th>
<th><strong>t (df)</strong></th>
<th>Cohen's <strong>d</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipatory grief</td>
<td>89.17(9.30)</td>
<td>73.51(13.20)</td>
<td>-2.77(39)*</td>
<td>1.37</td>
</tr>
<tr>
<td>Dyadic adjustment</td>
<td>106.00(20.51)</td>
<td>107.22(15.77)</td>
<td>0.17(40)</td>
<td>0.07</td>
</tr>
<tr>
<td>Drug use</td>
<td>1.17(0.75)</td>
<td>1.08(0.72)</td>
<td>-0.27(41)</td>
<td>0.12</td>
</tr>
<tr>
<td>General physical health</td>
<td>50.62(7.18)</td>
<td>50.48(7.97)</td>
<td>-0.04(46)</td>
<td>0.02</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable</th>
<th>PTSD</th>
<th>No PTSD</th>
<th><strong>F(df)</strong></th>
<th><strong>η[^2]</strong></th>
<th>Wilks' λ</th>
</tr>
</thead>
<tbody>
<tr>
<td>General mental health (covariate of gender)</td>
<td>37.71(13.15)</td>
<td>48.56(9.23)</td>
<td>6.64(1, 45)*</td>
<td>0.13</td>
<td></td>
</tr>
<tr>
<td>Alcohol use (covariate of gender)</td>
<td>3.50(3.70)</td>
<td>3.50(2.40)</td>
<td>0.19(1, 39)</td>
<td>0.01</td>
<td></td>
</tr>
<tr>
<td>Caregiver burden</td>
<td></td>
<td></td>
<td>1.90(5, 36)</td>
<td>0.21</td>
<td>0.79</td>
</tr>
<tr>
<td>Time-dependence burden</td>
<td>11.00(5.60)</td>
<td>8.03(4.27)</td>
<td>2.55(1, 40)</td>
<td>0.06</td>
<td></td>
</tr>
<tr>
<td>Developmental burden</td>
<td>10.71(5.28)</td>
<td>7.06(4.84)</td>
<td>3.23(1, 40)</td>
<td>0.08</td>
<td></td>
</tr>
<tr>
<td>Physical burden</td>
<td>6.71(4.03)</td>
<td>4.71(3.62)</td>
<td>1.72(1, 40)</td>
<td>0.04</td>
<td></td>
</tr>
<tr>
<td>Social burden</td>
<td>8.71(5.02)</td>
<td>4.26(3.59)</td>
<td>7.86(1, 40)*</td>
<td>0.16</td>
<td></td>
</tr>
<tr>
<td>Emotional burden</td>
<td>4.57(4.39)</td>
<td>2.91(3.47)</td>
<td>1.22(1, 40)</td>
<td>0.03</td>
<td></td>
</tr>
</tbody>
</table>

*Notes.* df=degrees of freedom. *p<0.05. **p<0.01. ***p<0.001. Covariate of gender was only retained in analyses in which it was significant.
Table 24

Effect of Subclinical Posttraumatic Stress Symptoms on Study Variables Controlling for Gender: Independent Samples T-Tests and Multivariate Analysis of Variance

<table>
<thead>
<tr>
<th>Variable</th>
<th>Subclinical PTSD M (SD)</th>
<th>No Subclinical PTSD M (SD)</th>
<th>t (df)</th>
<th>Cohen's d</th>
<th>F(df)</th>
<th>η²</th>
<th>Wilks' λ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipatory grief</td>
<td>79.18(12.65)</td>
<td>70.92(12.87)</td>
<td>-1.77(33)</td>
<td>0.65</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dyadic adjustment</td>
<td>104.29(21.15)</td>
<td>107.93(14.57)</td>
<td>0.54(34)</td>
<td>0.20</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drug use</td>
<td>1.00(0.87)</td>
<td>1.11(0.69)</td>
<td>0.38(35)</td>
<td>0.14</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol use</td>
<td>2.86(2.27)</td>
<td>3.67(2.45)</td>
<td>0.79(32)</td>
<td>0.34</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General mental health</td>
<td>44.07(9.04)</td>
<td>49.86(9.01)</td>
<td>1.70(38)</td>
<td>0.64</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General physical health</td>
<td>44.93(7.77)</td>
<td>52.09(7.38)</td>
<td>2.54(38)*</td>
<td>0.94</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable</th>
<th>Subclinical PTSD M (SD)</th>
<th>No Subclinical PTSD M (SD)</th>
<th>F(df)</th>
<th>η²</th>
<th>Wilks' λ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver burden</td>
<td></td>
<td></td>
<td>1.78(5, 29)</td>
<td>0.24</td>
<td>0.77</td>
</tr>
<tr>
<td>Time-dependence burden</td>
<td>8.00(4.43)</td>
<td>8.04(4.32)</td>
<td>0.00(1, 33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developmental burden</td>
<td>8.86(6.67)</td>
<td>6.61(4.31)</td>
<td>1.22(1, 33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical burden</td>
<td>7.71(4.53)</td>
<td>3.96(3.00)</td>
<td>7.09(1, 33)*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social burden</td>
<td>6.14(4.60)</td>
<td>3.79(3.22)</td>
<td>2.52(1, 33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional burden</td>
<td>4.43(4.31)</td>
<td>2.54(3.20)</td>
<td>1.70(1, 33)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes. df=degrees of freedom. *p<0.05. **p<0.01. ***p<0.001. Gender was not a significant covariate in any of the analyses and was therefore not retained.
Appendix B: Measures Utilized

Copyright Permissions

All of the below measures were utilized in the present studies and are available for use in the public domain. We also utilized the Short Form Health Survey, which is copyright protected by QualityMetric and cannot be replicated in this dissertation; however, we obtained full permission to use the measure for the purposes of this dissertation research.
Study One Measures

Altruism and volunteer work.

Altruism items from International Personality Item Pool.

The following items are phrases that describe people’s behavior. Please use the rating scale below to describe how accurately each statement describes you. Describe yourself as you generally are now, not as you wish to be in the future. Describe yourself as you honestly see yourself, in relation to other people you know of the same sex as you are, and roughly your same age. Please read each statement carefully.

Make people feel welcome.

1= Very Inaccurate  
2= Moderately Inaccurate  
3= Neither Inaccurate nor Accurate  
4= Moderately Accurate  
5= Very Accurate

Anticipate the needs of others.

1= Very Inaccurate  
2= Moderately Inaccurate  
3= Neither Inaccurate nor Accurate  
4= Moderately Accurate  
5= Very Accurate

Love to help others.

1= Very Inaccurate  
2= Moderately Inaccurate
Am concerned about others.

1= Very Inaccurate
2= Moderately Inaccurate
3= Neither Inaccurate nor Accurate
4= Moderately Accurate
5= Very Accurate

Have a good word for everyone.

1= Very Inaccurate
2= Moderately Inaccurate
3= Neither Inaccurate nor Accurate
4= Moderately Accurate
5= Very Accurate

Look down on others.

1= Very Inaccurate
2= Moderately Inaccurate
3= Neither Inaccurate nor Accurate
4= Moderately Accurate
5= Very Accurate

Am indifferent to the feelings about others.
1= Very Inaccurate
2= Moderately Inaccurate
3= Neither Inaccurate nor Accurate
4= Moderately Accurate
5= Very Accurate

Make people feel uncomfortable.
1= Very Inaccurate
2= Moderately Inaccurate
3= Neither Inaccurate nor Accurate
4= Moderately Accurate
5= Very Accurate

Turn my back on others.
1= Very Inaccurate
2= Moderately Inaccurate
3= Neither Inaccurate nor Accurate
4= Moderately Accurate
5= Very Accurate

Take no time for others.
1= Very Inaccurate
2= Moderately Inaccurate
3= Neither Inaccurate nor Accurate
4= Moderately Accurate
5= Very Accurate
Altruism and volunteer work items written by the author of the present paper.

• Are you a volunteer for any MS related organizations?
  □ Yes
  □ No

• If yes, please check all that apply:
  □ I volunteer with MS related organizations with:
    □ Walks
    □ Bike rides
    □ Other fundraising events
    □ Events to raise awareness
    □ Help to lead support group meetings
    □ Help administratively
    □ Other: __________________________________

• How many hours per month, on average, do you spend volunteering with MS related organizations?
  ___________ Hours per month

• Do you volunteer with any other organizations that are not related to MS?
  □ Yes
  □ No

• If yes, please check all that apply:
  □ Religious group
  □ Rotary Club
• Community volunteer group

• Job related group

• Educational related group

• Other: Enter here: ___________________________________

• How many hours per month, on average, do you spend volunteering with non-MS related organizations?
  __________ Hours per month

• Around what year did you first start volunteering with any MS-related or non-MS related organizations (please estimate year if you do not remember)?
  Enter year here: __________

• Please rate below how your involvement with MS related or non-MS related organizations makes you feel:

  Volunteering makes me feel:

  • Alienated
    1 = Never
    2 = Sometimes
    3 = A lot of the time
    4 = Always

  • Sad
    1 = Never
    2 = Sometimes
    3 = A lot of the time
    4 = Always
• At ease
  1 = Never
  2 = Sometimes
  3 = A lot of the time
  4 = Always

• Determined
  1 = Never
  2 = Sometimes
  3 = A lot of the time
  4 = Always

• Happy
  1 = Never
  2 = Sometimes
  3 = A lot of the time
  4 = Always

• Inspired
  1 = Never
  2 = Sometimes
  3 = A lot of the time
  4 = Always

• Optimistic
  1 = Never
  2 = Sometimes
3 = A lot of the time
4 = Always

• Proud
  1 = Never
  2 = Sometimes
  3 = A lot of the time
  4 = Always

• Why did you decide to volunteer or why have you decided not to volunteer?

Barthel Index.

Please answer the following questions about your spouse/partner. Think about what your spouse/partner has done over the past 1 to 2 days, NOT what they could do.

Feeding
  0 = Unable
  5 = Needs help cutting, spreading butter, etc., or requires modified diet
  10 = Independent

Bathing
  0 = Dependent
  5 = Independent (or in shower)

Grooming
  0 = Needs help with personal care
  5 = Independent face/hair/teeth/shaving (implements provided)

Dressing
0= Dependent
5= Needs help but can do about half unaided
10= independent (including buttons, zips, laces, etc.)

Bowels
0= Incontinent (or needs to be given enemas)
5= Occasional accident
10= Continent

Bladder
0= Incontinent, or catheterized and unable to manage alone
5= Occasional accident
10= Continent

Toilet Use
0= Dependent
5= Needs some help, but can do something alone
10= Independent (on and off, dressing, wiping)

Transfers (Bed to chair and back)
0= Unable, no sitting balance
5= Major help (one or two people, physical), can sit
10= Minor help (verbal or physical)
15= Independent

Mobility (on level surfaces)
0= Immobile or less than 50 yards
5= Wheelchair independent, including corners, greater than 50 yards
10= Walks with help of one person (verbal or physical) greater than 50 yards
15= Independent (but may use any aid; for example, stick) greater than 50 yards

Stairs
0= Unable
5= Needs help (verbal, physical, carrying aid)
10= Independent

**Caregiver Burden Inventory.**
The following questions ask about **you as a caregiver**. Please think about each question carefully. Use the scale below each item to answer the question.

My care receiver needs my help to perform many daily tasks.

0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

My care receiver is dependent on me.

0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

I have to watch my care receiver constantly.
0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

I have to help my care receiver with many basic functions.

0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

I don’t have a minute’s break from my caregiving chores

0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

I feel that I am missing out on life.

0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always
I wish I could escape from this situation.

0 = Never
1 = Rarely
2 = Sometimes
3 = Quite frequently
4 = Nearly always

My social life has suffered.

0 = Never
1 = Rarely
2 = Sometimes
3 = Quite frequently
4 = Nearly always

I feel emotionally drained due to caring for my care receiver.

0 = Never
1 = Rarely
2 = Sometimes
3 = Quite frequently
4 = Nearly always

I expected that things would be different at this point in my life.

0 = Never
1 = Rarely
2 = Sometimes
3 = Quite frequently
4= Nearly always

I’m not getting enough sleep.

0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

My health has suffered.

0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

Caregiving has made me physically sick.

0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

I’m physically tired.

0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

I don’t get along with other family members as well as I used to.

0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

My caregiving efforts aren’t appreciated by others in my family.

0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

I’ve had problems with my marriage.

0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

I don’t do as good a job at work as I used to.

0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

I feel resentful of other relatives who could but do not help.
0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

I feel embarrassed over my care receiver’s behavior.
0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

I feel ashamed of my care receiver.
0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

I resent my care receiver.
0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

I feel uncomfortable when I have friends over.

0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

I feel angry about my interactions with my care receiver.

0= Never
1= Rarely
2= Sometimes
3= Quite frequently
4= Nearly always

**Dyadic Adjustment Scale.**

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following lists.

Handling family finances

5= Always Agree
Almost Always Agree
Occasionally Disagree
Frequently Disagree
Almost Always Disagree
Always Disagree

Matters of recreation

Always Agree
Almost Always Agree
Occasionally Disagree
Frequently Disagree
Almost Always Disagree
Always Disagree

Religious matters

Always Agree
Almost Always Agree
Occasionally Disagree
Frequently Disagree
Almost Always Disagree
Always Disagree

Demonstrations of affection

Always Agree
4= Almost Always Agree
3= Occasionally Disagree
2= Frequently Disagree
1= Almost Always Disagree
0= Always Disagree

Friends

5= Always Agree
4= Almost Always Agree
3= Occasionally Disagree
2= Frequently Disagree
1= Almost Always Disagree
0= Always Disagree

Sex relations

5= Always Agree
4= Almost Always Agree
3= Occasionally Disagree
2= Frequently Disagree
1= Almost Always Disagree
0= Always Disagree

Convetionality (correct or proper behavior)

5= Always Agree
4= Almost Always Agree
3= Occasionally Disagree
2= Frequently Disagree
1= Almost Always Disagree
0= Always Disagree

Philosophy of life

5= Always Agree
4= Almost Always Agree
3= Occasionally Disagree
2= Frequently Disagree
1= Almost Always Disagree
0= Always Disagree

Ways of dealing with parents or in-laws

5= Always Agree
4= Almost Always Agree
3= Occasionally Disagree
2= Frequently Disagree
1= Almost Always Disagree
0= Always Disagree

Aims, goals, and things believed important

5= Always Agree
4= Almost Always Agree
3= Occasionally Disagree
2= Frequently Disagree
1= Almost Always Disagree
0= Always Disagree

Amount of time spent together

5= Always Agree
4= Almost Always Agree
3= Occasionally Disagree
2= Frequently Disagree
1= Almost Always Disagree
0= Always Disagree

Making major decisions

5= Always Agree
4= Almost Always Agree
3= Occasionally Disagree
2= Frequently Disagree
1= Almost Always Disagree
0= Always Disagree

Household tasks

5= Always Agree
4= Almost Always Agree
3= Occasionally Disagree
2= Frequently Disagree
1= Almost Always Disagree
0= Always Disagree

Leisure time interests and activities

5= Always Agree
4= Almost Always Agree
3= Occasionally Disagree
2= Frequently Disagree
1= Almost Always Disagree
0= Always Disagree

Career decisions

5= Always Agree
4= Almost Always Agree
3= Occasionally Disagree
2= Frequently Disagree
1= Almost Always Disagree
0= Always Disagree

Read the following questions carefully and notice that your options for answers have changed.
How often do you discuss or have considered divorce, separation, or terminating your relationship?

0= All the time
1= Most of the time
2= More often than not
3= Occasionally
4= Rarely
5= Never

How often do you or your mate leave the house after a fight?

0= All the time
1= Most of the time
2= More often than not
3= Occasionally
4= Rarely
5= Never

In general, how often do you think that things between you and your partner are going well?

0= All the time
1= Most of the time
2= More often than not
3= Occasionally
4= Rarely
5= Never
Do you confide in your mate?

0 = All the time
1 = Most of the time
2 = More often than not
3 = Occasionally
4 = Rarely
5 = Never

Do you ever regret that you married? (or lived together)

0 = All the time
1 = Most of the time
2 = More often than not
3 = Occasionally
4 = Rarely
5 = Never

How often do you and your partner quarrel?

0 = All the time
1 = Most of the time
2 = More often than not
3 = Occasionally
4 = Rarely
5 = Never
How often do you and your mate “get on each other’s nerves?”

0= All the time
1= Most of the time
2= More often than not
3= Occasionally
4= Rarely
5= Never

Please remember to keep looking at your options carefully.

Do you kiss your mate?

4= Every Day
3= Almost Every Day
2= Occasionally
1= Rarely
0= Never

Do you and your mate engage in outside interests together?

4= All of them
3= Most of them
2= Some of them
1= Very few of them
0= None of them

How often would you say the following events occur between you and your mate?
Have a stimulating exchange of ideas

0= Never
1= Less than once a month
2= Once or twice a month
3= Once or twice a week
4= Once a day
5= More often

Laugh together

0= Never
1= Less than once a month
2= Once or twice a month
3= Once or twice a week
4= Once a day
5= More often

Calmly discuss something

0= Never
1= Less than once a month
2= Once or twice a month
3= Once or twice a week
4= Once a day
5= More often
Work together on a project

0= Never
1= Less than once a month
2= Once or twice a month
3= Once or twice a week
4= Once a day
5= More often

These are some things about which couples sometimes agree and sometimes disagree. Indicate if either item below caused differences of opinions or were problems in your relationship during the past few weeks. (Select yes or no.)

Being too tired for sex

0= Yes
1= No

Not showing love

0= Yes
1= No

The following scale represents different degrees of happiness in your relationship. The middle point, “happy,” represents the degree of happiness of most relationships. Please choose the number which best describes the degree of happiness, all things considered, of your relationship.

0= Extremely Unhappy
1= Fairly Unhappy
2= A Little **Un**happy
3= Happy
4= Very Happy
5= Extremely Happy
6= Perfect

Which of the following statements best describes how you feel about the future of your relationship?

5= I want desperately for my relationship to succeed, and *would go to almost any length* to see that it does
4= I want very much for my relationship to succeed, and *will do all I can to see* that it does.
3= I want very much for my relationship to succeed, and *will do my fair share* to see that it does.
2= It would be nice if my relationship succeeded, but I *can’t do much more than I am doing* now to help it succeed.
1= It would be nice if it succeeded, but I refuse *to do any more than I am doing* now to keep the relationship going.
0= My relationship can never succeed, and *there is no more that I can do* to keep the relationship going.

**Multidimensional Scale of Perceived Social Support.**
We are interested in **how you feel about the following statements**. Read each statement carefully. Indicate how you feel about each statement.

There is a special person who is around when I am in need.

1=Very Strongly Disagree  
2=Strongly Disagree  
3=Mildly Disagree  
4=Neutral  
5=Mildly Agree  
6=Strongly Agree  
7=Very Strongly Agree

There is a special person with whom I can share my joys and sorrows.

1=Very Strongly Disagree  
2=Strongly Disagree  
3=Mildly Disagree  
4=Neutral  
5=Mildly Agree  
6=Strongly Agree  
7=Very Strongly Agree

My family really tries to help me.

1=Very Strongly Disagree  
2=Strongly Disagree  
3=Mildly Disagree  
4=Neutral
5=Mildly Agree
6=Strongly Agree
7=Very Strongly Agree

I get the emotional help and support I need from my family.

1=Very Strongly Disagree
2=Strongly Disagree
3=Mildly Disagree
4=Neutral
5=Mildly Agree
6=Strongly Agree
7=Very Strongly Agree

I have a special person who is a real source of comfort to me.

1=Very Strongly Disagree
2=Strongly Disagree
3=Mildly Disagree
4=Neutral
5=Mildly Agree
6=Strongly Agree
7=Very Strongly Agree

My friends really try to help me.

1=Very Strongly Disagree
2=Strongly Disagree
3=Mildly Disagree
4=Neutral
5=Mildly Agree
6=Strongly Agree
7=Very Strongly Agree

I can count on my friends when things go wrong.

1- Very Strongly Disagree
2- Strongly Disagree
3- Mildly Disagree
4- Neutral
5- Mildly Agree
6- Strongly Agree
7- Very Strongly Agree

I can talk about my problems with my family.

1=Very Strongly Disagree
2=Strongly Disagree
3=Mildly Disagree
4=Neutral
5=Mildly Agree
6=Strongly Agree
7=Very Strongly Agree
I have friends with whom I can share my joys and sorrows.

1=Very Strongly Disagree
2=Strongly Disagree
3=Mildly Disagree
4=Neutral
5=Mildly Agree
6=Strongly Agree
7=Very Strongly Agree

There is a special person in my life who cares about my feelings.

1=Very Strongly Disagree
2=Strongly Disagree
3=Mildly Disagree
4=Neutral
5=Mildly Agree
6=Strongly Agree
7=Very Strongly Agree

My family is willing to help me make decisions.

1=Very Strongly Disagree
2=Strongly Disagree
3=Mildly Disagree
4=Neutral
5=Mildly Agree
6=Strongly Agree
7=Very Strongly Agree

I can talk about my problems with my friends.

1=Very Strongly Disagree
2=Strongly Disagree
3=Mildly Disagree
4=Neutral
5=Mildly Agree
6=Strongly Agree
7=Very Strongly Agree

**Patient Health Questionnaire.**

Over the *last two weeks*, how often have you been bothered by any of the following problems?

**Little interest or pleasure in doing things**

0= Not at all
1= Several Days
2= More than half the days
3= Nearly every day

**Feeling down, depressed, or hopeless**

0= Not at all
1= Several Days
2= More than half the days
3= Nearly every day

Trouble falling or staying asleep, or sleeping too much

0= Not at all
1= Several Days
2= More than half the days
3= Nearly every day

Feeling tired or having little energy

0= Not at all
1= Several Days
2= More than half the days
3= Nearly every day

Poor appetite or overeating

0= Not at all
1= Several Days
2= More than half the days
3= Nearly every day

Feeling bad about yourself- or that you are a failure or have let yourself or your family down

0= Not at all
1= Several Days
2= More than half the days
3= Nearly every day
Trouble concentrating on things, such as reading the newspaper or watching television

0= Not at all
1= Several Days
2= More than half the days
3= Nearly every day

Moving or speaking so slowly that other people could have noticed? Or the opposite- being so fidgety or restless that you have been moving around a lot more than usual

0= Not at all
1= Several Days
2= More than half the days
3= Nearly every day

Thoughts that you would be better off dead or of hurting yourself in some way

0= Not at all
1= Several Days
2= More than half the days
3= Nearly every day

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

- Not difficult at all
- Somewhat difficult
- Very difficult
Satisfaction with Life Scale.

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

In most ways my life is close to my ideal.

1= strongly disagree
2= disagree
3= slightly disagree
4= neither agree nor disagree
5= slightly agree
6= agree
7= strongly agree

The conditions of my life are excellent.

1= strongly disagree
2= disagree
3= slightly disagree
4= neither agree nor disagree
5= slightly agree
6= agree
7= strongly agree
I am satisfied with my life.

1= strongly disagree
2= disagree
3= slightly disagree
4= neither agree nor disagree
5= slightly agree
6= agree
7= strongly agree

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

1= strongly disagree
2= disagree
3= slightly disagree
4= neither agree nor disagree
5= slightly agree
6= agree
7= strongly agree

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

1= strongly disagree
2= disagree
3= slightly disagree
4= neither agree nor disagree
5= slightly agree
6= agree
7= strongly agree

Selection of caregiver questions written by the author of the present paper.

• Please respond to each item below by checking the number on the scale that best describes to what degree you are considering the following items:

  • I am thinking about putting my spouse/partner into a nursing home:
    1=Not considering at all
    2=Considering a little
    3=Considering a lot
    4=Have decided to do so

  • I am thinking about hiring respite care:
    1=Not considering at all
    2=Considering a little
    3=Considering a lot
    4=Have decided to do so

  • I am thinking about hiring home health care aides:
    1=Not considering at all
    2=Considering a little
    3=Considering a lot
    4=Have decided to do so

  • To what extent do you feel like a caregiver?
    1=I rarely feel like a caregiver
2=I sometimes feel like a caregiver
3=I feel like a caregiver a lot of the time
4=I always feel like a caregiver

• To what extent do you feel like a spouse/partner and NOT a caregiver?

1=I rarely feel like a spouse/partner
2=I sometimes feel like a spouse/partner
3=I feel like a spouse/partner a lot of the time
4=I always feel like a spouse/partner

• In your own words, how do you feel about being a caregiver?

• What is the biggest challenge you have had to overcome in order to care for your spouse/partner?
Study Two Measures

Alcohol Use Disorders Identification Test.

The following questions ask about your use of alcohol. Please circle your answers.

<table>
<thead>
<tr>
<th>Question</th>
<th>Circle</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Have you ever felt you should cut down on your drinking?</td>
<td>Yes</td>
</tr>
<tr>
<td>2. Have people annoyed you by criticizing your drinking?</td>
<td>Yes</td>
</tr>
<tr>
<td>3. Have you ever felt bad or guilty about your drinking?</td>
<td>Yes</td>
</tr>
<tr>
<td>4. Have you ever had a drink first thing in the morning to steady your nerves or to get rid of a hangover (eye-opener)?</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Anticipatory Grief Scale.

The following statements represent feelings and attitudes of some relatives of patients with MS. Answer the statements as you are feeling now. Read each statement carefully and circle the number at the right which most closely reflects your degree of agreement or disagreement.

1=Strongly disagree
2=Disagree
3=Somewhat agree
4=Agree
5=Strongly agree

1. I daydream about how life with my relative was before the diagnosis of MS was made. 1 2 3 4 5
2. I feel close to my relative who has MS. 1 2 3 4 5
<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>3</td>
<td>I seem to be more irritable since the diagnosis of MS was made for my relative.</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>I am preoccupied with thoughts about my relative and his/her illness.</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>I have discovered new personal resources since my relative's illness was diagnosed.</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>I very much miss my relative the way he/she used to be.</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>I have felt very much alone since the diagnosis of MS was made for my relative.</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>I am able to move ahead with my life.</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>I blame myself for my relative's illness.</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>I find it hard to concentrate on my work since the diagnosis of MS was made for my relative.</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>I have the personal resources to help me cope with my relative and his/her illness.</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>I have periods of tearfulness as I think about the course of my relative's illness.</td>
<td></td>
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<tr>
<td>13</td>
<td>I feel detached from my relative.</td>
<td></td>
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<tr>
<td>14</td>
<td>I feel a need to talk to others regarding my relative's illness.</td>
<td></td>
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<tr>
<td>15</td>
<td>I feel it is unfair that my relative has MS.</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>I find it hard to sleep since the diagnosis of MS was made for my relative.</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>No one will ever take the place of my relative in my life.</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>I avoid some people since my relative was diagnosed with MS.</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>I feel I have adjusted to my relative's illness.</td>
<td></td>
</tr>
</tbody>
</table>
20. Since my relative was diagnosed with MS I find it more difficult to get along with certain people.  

21. I wonder what life would be like if my relative had not been diagnosed with MS.  

22. I feel more competent since my relative was diagnosed with MS.  

23. I get angry when I think about my relative having MS.  

24. Since the diagnosis of MS was made for my relative, I don't feel interested in keeping up with the day to day activities (T.V., newspapers, friends).  

25. I am unable to accept the fact that my relative has a diagnosis of MS.  

26. I am now functioning about as well as before my relative was diagnosed with MS.  

27. I am planning for the future.  

<table>
<thead>
<tr>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>20. Since my relative was diagnosed with MS I find it more difficult to get along with certain people.</td>
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<tr>
<td>21. I wonder what life would be like if my relative had not been diagnosed with MS.</td>
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<tr>
<td>22. I feel more competent since my relative was diagnosed with MS.</td>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>23. I get angry when I think about my relative having MS.</td>
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<td></td>
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</tr>
<tr>
<td>24. Since the diagnosis of MS was made for my relative, I don't feel interested in keeping up with the day to day activities (T.V., newspapers, friends).</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. I am unable to accept the fact that my relative has a diagnosis of MS.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. I am now functioning about as well as before my relative was diagnosed with MS.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. I am planning for the future.</td>
<td></td>
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</tbody>
</table>

**Barthel Index.**

See Study One Measures.

**Caregiver Burden Inventory.**

See Study One Measures.

**Drug Abuse Screening Test.**

The following questions concern information about your possible involvement with drugs *not including alcoholic beverages* during the past 12 months.
"Drug abuse" refers to (1) the use of prescribed or over-the-counter drugs in excess of the directions, and (2) any nonmedical use of drugs.

The various classes of drugs may include cannabis (marijuana, hashish), solvents (e.g., paint thinner), tranquilizers (e.g., Valium), barbiturates, cocaine, stimulants (e.g., speed), hallucinogens (e.g., LSD) or narcotics (e.g., heroin). Remember that the questions do not include alcoholic beverages.

Please answer every question. If you have difficulty with a statement, then choose the response that is mostly right.

<table>
<thead>
<tr>
<th>In the past 12 months…</th>
<th>Circle</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Have you used drugs other than those required for medical reasons?</td>
<td>Yes No</td>
</tr>
<tr>
<td>2. Do you abuse more than one drug at a time?</td>
<td>Yes No</td>
</tr>
<tr>
<td>3. Are you unable to stop abusing drugs when you want to?</td>
<td>Yes No</td>
</tr>
<tr>
<td>4. Have you ever had blackouts or flashbacks as a result of drug use?</td>
<td>Yes No</td>
</tr>
<tr>
<td>5. Do you ever feel bad or guilty about your drug use?</td>
<td>Yes No</td>
</tr>
<tr>
<td>6. Does your spouse (or parents) ever complain about your involvement with drugs?</td>
<td>Yes No</td>
</tr>
<tr>
<td>7. Have you neglected your family because of your use of drugs?</td>
<td>Yes No</td>
</tr>
<tr>
<td>8. Have you engaged in illegal activities in order to obtain drugs?</td>
<td>Yes No</td>
</tr>
<tr>
<td>9. Have you ever experienced withdrawal symptoms (felt sick) when you stopped taking drugs?</td>
<td>Yes No</td>
</tr>
<tr>
<td>10. Have you had medical problems as a result of your drug use (e.g. memory loss, hepatitis, convulsions, bleeding)?</td>
<td>Yes No</td>
</tr>
</tbody>
</table>
**Dyadic Adjustment Scale.**

See Study One Measures.

**Life Events Checklist.**

Listed below are a number of difficult or stressful things that sometimes happen to people. For each event check one or more of the boxes to the right to indicate that: (a) it *happened to you* personally; (b) you *witnessed it* happen to someone else; (c) you *learned about it* happening to a close family member or close friend; (d) you were exposed to it as *part of your job* (for example, paramedic, police, military, or other first responder); (e) you’re *not sure* if it fits; or (f) it *doesn’t apply* to you.

Be sure to consider your *entire life* (growing up as well as adulthood) as you go through the list of events.

<table>
<thead>
<tr>
<th>Event</th>
<th>Happened to me</th>
<th>Witnessed it</th>
<th>Learned about it</th>
<th>Part of my job</th>
<th>Not Sure</th>
<th>Doesn’t Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Natural disaster (for example, flood, hurricane, tornado, earthquake)</td>
<td></td>
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<td>2. Fire or explosion</td>
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<td>3. Transportation accident (for example, car accident, boat accident, train wreck, plane crash)</td>
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<td>4. Serious accident at work, home,</td>
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<td>or during recreational activity</td>
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<tr>
<td>5. Exposure to toxic substance</td>
<td></td>
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<tr>
<td>(for example, dangerous chemicals, radiation)</td>
<td></td>
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<tr>
<td>6. Physical assault (for example, being attacked, hit, slapped, kicked, beaten up)</td>
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<tr>
<td>7. Assault with a weapon (for example, being shot, stabbed, threatened with a knife, gun, bomb)</td>
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<tr>
<td>8. Sexual assault (rape, attempted rape, made to perform any type of sexual act through force or threat of harm)</td>
<td></td>
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<tr>
<td>9. Other unwanted or uncomfortable sexual experience</td>
<td></td>
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<tr>
<td>10. Combat or exposure to a war-zone (in the military or as a civilian)</td>
<td></td>
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<tr>
<td>11. Captivity (for example, being kidnapped, abducted)</td>
<td></td>
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</tr>
</tbody>
</table>
PART 1:

1. Being held hostage, prisoner of war

2. Life-threatening illness or injury

3. Severe human suffering

4. Sudden violent death (for example, homicide, suicide)

5. Sudden accidental death

6. Serious injury, harm, or death you caused to someone else

7. Any other very stressful event or experience

PART 2:

A. If you checked anything for #17 in PART 1, briefly identify the event you were thinking of:

__________________________________________________________________________

B. If you have experienced more than one of the events in PART 1, think about the event you consider the worst event, which for this questionnaire means the event that currently bothers you the most. If you have experienced only one of the events in PART 1, use that one as the worst event. Please answer the following questions about the worst event (check all options that apply):

1. Briefly describe the worst event (for example, what happened, who was involved, etc.).

__________________________________________________________________________
2. How long ago did it happen? ________________ (please estimate if you are not sure)

3. How did you experience it?
   ___ It happened to me directly
   ___ I witnessed it
   ___ I learned about it happening to a close family member or close friend
   ___ I was repeatedly exposed to details about it as part of my job (for example, paramedic, police, military, or other first responder)
   ___ Other, please describe:

4. Was someone’s life in danger?
   ___ Yes, my life
   ___ Yes, someone else’s life
   ___ No

5. Was someone seriously injured or killed?
   ___ Yes, I was seriously injured
   ___ Yes, someone else was seriously injured or killed
   ___ No

6. Did it involve sexual violence? ___ Yes ___ No

7. If the event involved the death of a close family member or close friend, was it due to some kind of accident or violence, or was it due to natural causes?
   ___ Accident or violence
   ___ Natural causes
   ___ Not applicable (The event did not involve the death of a close family member or
8. How many times altogether have you experienced a similar event as stressful or nearly as stressful as the worst event?

___ Just once

___ More than once (please specify or estimate the total # of times you have had this experience _____)

**Patient Health Questionnaire.**

See Study One Measures.

**PTSD Checklist.**

Part 3: Below is a list of problems that people sometimes have in response to a very stressful experience. Keeping your worst event in mind, please read each problem carefully and then circle one of the numbers to the right to indicate how much you have been bothered by that problem in the past month.

<table>
<thead>
<tr>
<th>In the past month, how much were you bothered by:</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Repeated, disturbing, and unwanted memories of the stressful experience?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Repeated, disturbing dreams of the stressful experience?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Suddenly feeling or acting as if the stressful experience were actually happening again <em>(as if you</em></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>
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<tr>
<td>were actually back there reliving it)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Feeling very upset when something reminded you of the stressful</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>experience?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Having strong physical reactions when something reminded you of the</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>stressful experience (for example, heart pounding, trouble breathing,</td>
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<tr>
<td>sweating)?</td>
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</tr>
<tr>
<td>Avoiding memories, thoughts, or feelings related to the stressful</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>experience?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoiding external reminders of the stressful experience (for example,</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>people, places, conversations, activities, objects, or situations)?</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Trouble remembering important parts of the stressful experience?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Having strong negative beliefs about yourself, other people, or the</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>world (for example, having thoughts such as: I am bad, there is</td>
<td></td>
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<tr>
<td>something seriously wrong with me, no one can be trusted, the world is</td>
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<tr>
<td>completely dangerous)?</td>
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</tr>
<tr>
<td>Blaming yourself or someone else for the stressful experience or what</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>happened after it?</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Having strong negative feelings such as fear, horror, anger, guilt, or</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>shame?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of interest in activities that you used to enjoy?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Feeling distant or cut off from other people?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

190
<table>
<thead>
<tr>
<th>Question</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trouble experiencing positive feelings <em>(for example, being unable to feel happiness or have loving feelings for people close to you)</em></td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>Irritable behavior, angry outbursts, or acting aggressively?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>Taking too many risks or doing things that could cause you harm?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>Being “superalert” or watchful or on guard?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>Feeling jumpy or easily startled?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>Having difficulty concentrating?</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>Trouble falling or staying asleep?</td>
<td>0 1 2 3 4</td>
</tr>
</tbody>
</table>

*Additional questions to support the Life Events Checklist and PTSD Checklist.*

The following questions were written by the author of the present paper and were posed before administration of the LEC-5:

- How long did your spouse/partner experience symptoms before a diagnosis was given?
- In your own words, please describe when it hit you the most that your spouse/partner is ill. For example, was it when he/she started showing symptoms before a diagnosis? Was it when he/she was diagnosed? Was it when a symptom was particularly difficult, etc...?
- In your own words, how did you feel when your spouse/partner was first diagnosed with MS?

The following questions were written by the author of the present paper and were posed after administration of the LEC-5 and PCL-C:
• When you answered the previous questions about hard experiences you may have had in your life…

  a. Did you think about when your spouse/partner first started showing MS symptoms?

     Please circle: Yes No

  b. Did you think about when your spouse/partner was diagnosed?

     Please circle: Yes No

  c. Did you think about a time when your spouse/partner’s symptoms were especially difficult to handle?

     Please circle: Yes No

Selection of caregiver questions written by the author of the present paper.

• Please respond to each item below by checking the number on the scale that best describes to what degree you are considering the following items:

  • I am thinking about putting my spouse/partner into a nursing home:

     1 = Not considering at all
     2 = Considering a little
     3 = Considering a lot
     4 = Have decided to do so

  • I am thinking about hiring respite care:

     1 = Not considering at all
     2 = Considering a little
     3 = Considering a lot
4=Have decided to do so

• I am thinking about hiring home health care aides:
  1=Not considering at all
  2=Considering a little
  3=Considering a lot
  4=Have decided to do so

• To what extent do you feel like a caregiver?
  1=I rarely feel like a caregiver
  2=I sometimes feel like a caregiver
  3=I feel like a caregiver a lot of the time
  4=I always feel like a caregiver

• To what extent do you feel like a spouse/partner and NOT a caregiver?
  1=I rarely feel like a spouse/partner
  2=I sometimes feel like a spouse/partner
  3=I feel like a spouse/partner a lot of the time
  4=I always feel like a spouse/partner
Acknowledgements

First and foremost, I thank my committee chair and advisor, Dr. Julia Hormes. Dr. Hormes was a constant source of support and guidance throughout the process of my dissertation. Her suggestions and edits were insightful and intelligent. Her flexibility and expertise were vital to my ability to complete my dissertation. She has truly taught me to be a better researcher and writer.

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