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Predictors of Stress in Caregivers of Family Members with Multiple Sclerosis

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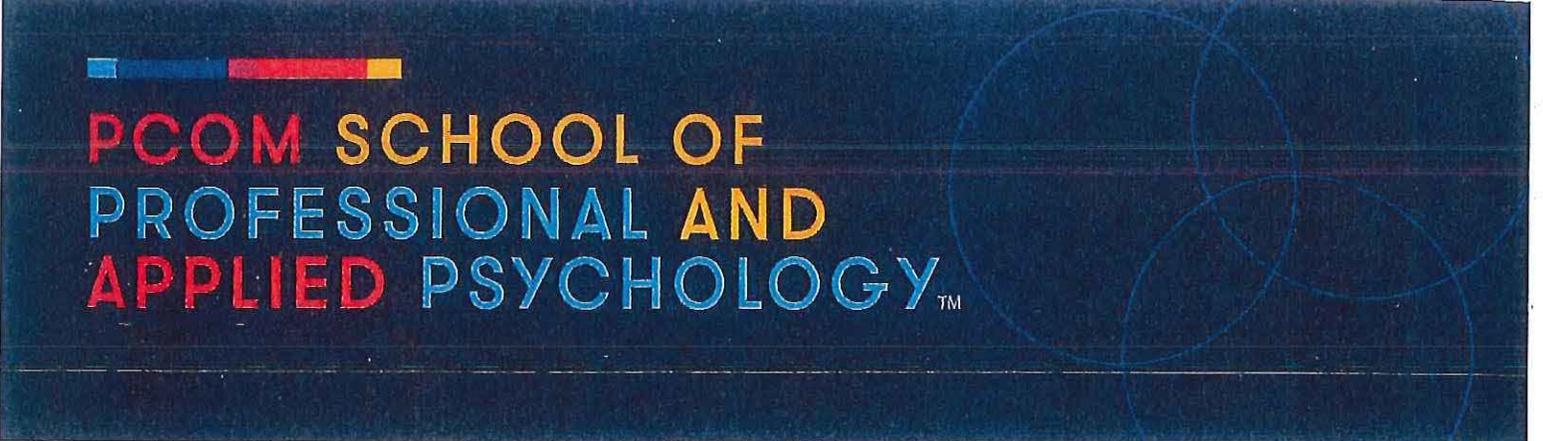
PREDICTORS OF STRESS IN CAREGIVERS OF FAMILY MEMBERS
WITH MULTIPLE SCLEROSIS

By Lucy Lubinski

Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Psychology

June 2019



**PCOM SCHOOL OF
PROFESSIONAL AND
APPLIED PSYCHOLOGY™**

DISSERTATION APPROVAL

This is to certify that the thesis presented to us by Lucy Lubowski
on the 23rd day of May, 2019, in partial fulfillment of the
requirements for the degree of Doctor of Psychology, has been examined and is
acceptable in both scholarship and literary quality.

COMMITTEE MEMBERS' SIGNATURES

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Abstract

Multiple sclerosis (MS) is a disease of the central nervous system that typically results in cognitive and physical impairment. Depending upon the severity of symptoms, persons with MS often need assistance from caregivers in their daily lives. Research has shown that when a family member is diagnosed with the disease, household members become a source of caregiver support. The relationships between caregiver burden and chronic illness and between stress and health are well-documented. The impact of caregiving on individuals with MS remains a continued clinical concern, particularly because depression is highly co-occurring in those with the disease. Understanding the predictors of stress will hopefully provide more knowledge on how to best support caregivers and family members living with MS. This study sought to determine which factors increase or mitigate stress in caregivers of family members with MS. These factors were the level of depressive symptoms, perceived social support, level of coping processes, and patient care satisfaction from the caregiver's perspective. A total of 40 caregiver participants completed an online survey targeting these factors. The results showed that the level of depressive symptoms was the only variable that predicted the level of perceived stress among caregivers. Thus, depression remains an important clinical consideration in the MS population and their caregivers. Future research should specifically explore the types of coping methods and other factors that predict stress in family caregivers in order to support this population.

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Chapter 1: Introduction

Statement of the Problem

Multiple sclerosis (MS) is a disease of the central nervous system that often results in cognitive and physical impairment. A person with the disease may experience vision loss, problems with gait and motor coordination, fatigue, pain, muscle spasticity and weakness, slurred speech, memory, difficulty, processing and other executive function changes, and mood changes (National Multiple Sclerosis Society, 2016).

Depending upon the severity of symptoms, patients with MS often need assistance from caregivers in their daily lives. When a family member is diagnosed with the disease, the family household must become a significant source of support and consideration for coping and care (National Multiple Sclerosis Society, 2016). Boström & Nilsagård (2016) have shown that when a parent is diagnosed with MS, the entire family is affected. At the time of diagnosis, parents reported wanting more support from health care professionals, specifically in relation to addressing their children's needs (Boström & Nilsagård, 2016). In studies of adolescents living with a parent with a chronic medical condition, approximately 10% were at increased risk for persistent stress and adjustment difficulties, internalization of problems, and somatic difficulties (Sieh, Visser-Meily, & Meijer, 2013). Therefore, education about disease management and resources for supportive services may reduce the risk of socioemotional concerns that may emerge in households adjusting to a chronic illness such as MS.

MS is a disease that is managed at many levels, usually by both a neurologist and primary care physician. At the primary care level, health care professionals address the

overall health of patients, including both physical and psychological symptoms, such as problems with gait and depressive symptoms. Primary care health professionals may be better positioned to assess stressors and offer support services to patients and families who have a chronic illness. Primary care offers a wide range of health care services that can be offered to families, such as prevention screenings. Primary care providers this level may have a comprehensive record of the patient's medical history, and recommendations may be tailored according to the patient's unique needs. Qualitative research on the health care management experiences of patients with a neurological condition and their caregivers has shown that general practitioners are valued for their communication skills and ability to advocate for their patients (Smithson & Hukins, 2006). Thus, primary care professionals may be better able to recognize and address the additional needs of patients and communicate these issues with other specialists.

Education and information on symptom management and treatment options can provide a sense of empowerment over the disease and provide people with the tools that allow them to make informed decisions regarding their well-being (McCabe, Ebacioni, Simmons, McDonald, & Melton, 2015). This sense of patient empowerment is thought to play an important role in the successful management of MS and highlights the need for access to education about MS (McCabe et al., 2015). Many factors may play a role in the patient's management of the disease, including medication, nutrition, psychosocial and coping skills, caregiver and social support, and exercise. The emerging data on lifestyle and psychosocial factors in individuals with MS has been shown to improve quality of life and slow the progression of the disease (Jelinek & Hassed, 2009). Based on time available and training, it has been suggested that primary care professionals may be better

suited to offer disease management strategies (Jelinek & Hased, 2009). Such strategies have the capacity to reduce the symptomatic burden of MS and thereby improve adjustment and acceptance of the disease.

Major depression has been shown to be a significant clinical issue in individuals with MS (Patten, Berzins, & Metz, 2010). Epidemiologic studies indicate that the annual prevalence of depression is 16%, and the lifetime prevalence may be as high as 50% in those with MS (Patten et al., 2010). Given the high co-occurrence of major depression and MS, it is important for health care professionals to screen for and recognize this health determinant in patients. Depression may also be a health factor to consider in patients' family members. In one study that examined the emotional health of caregivers of persons with MS, emotional symptoms were ascertained using the Beck Anxiety Inventory and Beck Depression Inventory. The results showed that severe depressive symptoms in MS caregivers were independently associated with information processing speed impairment in individuals with the disease (Labiano-Fontcuberta, Mitchell, Moreno-García, & Benito-León, 2015). This study highlights the positive relationship between symptom severity in individuals with MS and their caregivers. The emotional stress of a caregiver may be negatively associated with the mental health of the care receiver. Recent evidence has shown that the emotional stress level of caregivers has a direct and positive association with the level of depression on the care recipient (Ejem, Drentea, & Clay, 2015).

Those who provide care to persons with MS may manage and address the physical, emotional, and other needs of the person with the disease. These may include financial strains, such as loss of wages or costs of health care, and changes in family roles

(Bambara, Turner, Williams, & Haselkorn, 2014). Level of social support has been shown to have an impact on the individual's response to caregiving. Research has revealed a modest relationship between the level of social supports and stresses and caregiver depressive symptoms (Bambara et al., 2014). In addition, low caregiver perceived support has been associated with caregiver depressive symptoms. The growing evidence of caregiver emotional distress and its impact on care receivers demonstrates a need for assessment and education of the caregiver by health care professionals who may offer a range of services and primary care.

In summary, MS is a disease of the central nervous system that has an impact on an individual's physical and mental health. It is a disease that may also affect the mental health of caregivers, which may, in turn, also influence the individual with the disease. The primary care physician can assess for and identify stressors and offer intervention for caregivers. Understanding the predictors of stress may elucidate areas that are critical for caregivers to facilitate family adjustment (Lorefice et al., 2013).

Purpose of the Study

The chronic illness of one family member has an impact on all family members. This, in turn, may also affect the physical and psychosocial functioning of the individual with the disease. Health care professionals in primary care often encounter caregivers experiencing challenges and stressors that are an extension of the patient's disease. Physicians in primary care have the opportunity to integrate caregivers into patient care and promote the well-being of the patient and the family. The present study sought to understand which factors increase and/or mitigate stress in caregivers. It also sought to understand whether other factors, such as level of perceived social support, level of

coping, level of depressive symptoms, and satisfaction with medical care, may be associated with level of stress in caregivers. How these factors relate to stress levels in caregivers is important for fostering appropriate adjustment.

Chapter 2: Literature Review

What Is Multiple Sclerosis?

Multiple sclerosis (MS) is a disease involving an immune-mediated process in which an abnormal response of the body's immune system is directed against the central nervous system, which consists of the brain, spinal cord, and optic nerves (National Multiple Sclerosis Society, 2016). Within the central nervous system, the immune system attacks myelin, the fatty substance that insulates nerve fibers. Axons, the extension of a neuron's cell body, are wrapped in myelin and proteins. Myelin insulates and protects the axon and helps speed nerve transmission. The damaged myelin forms scar tissue, called sclerosis, which gives the disease its name. When myelin or the nerve fiber is damaged, nerve impulses that travel to and from the brain and spinal cord are interrupted and produce a range of physical, cognitive, and even psychological symptoms (National Multiple Sclerosis Society, 2016).

The immune system consists of two types of white blood cells. The first type is called B cells because they develop from bone marrow and produce antibodies, which identify and neutralize pathogens in the body. The second type of white blood cell is called T cells because they develop in the thymus gland and are responsible for a variety of immune responses. These involve direct attacks on pathogens, such as bacteria, viruses, or foreign tissues. T cells also augment B cells and produce substances called cytokines that direct responses and activities in other immune cells (National Multiple Sclerosis Society, 2016). The three main types of T cells are helper T cells, regulatory T cells, and cytotoxic or killer T cells. Helper T cells enhance the immune response by recognizing the presence of a foreign antigen, stimulating antibody production, and

producing cytokines that activate other T cells. Regulatory T cells function by inhibiting the immune response, whereas cytotoxic or killer T cells directly attack and destroy antigens (National Multiple Sclerosis Society, 2016). In MS, the breakdown of myelin, or demyelination, is caused by an abnormal immune process. This involves the activation of T cells against some component of the myelin in the central nervous system.

Etiology.

One hypothesis suggests that MS has a multifactorial etiology that consists of both genetic and nongenetic, or environmental, factors. Although MS is not considered hereditary, epidemiological studies have shown that having a first-degree relative, such as a parent or sibling with MS, significantly increases an individual's risk for developing the disease. Studies have also shown that there is a higher prevalence of certain genes in populations with higher rates of MS (National Multiple Sclerosis Society, 2016). The nongenetic factors may involve exposure to infections or chemical and physical agents, vaccinations, hormonal factors, nutritional habits, and psychological stress (Zorzon et al., 2003). MS tends to occur more frequently in areas that are farther from the equator. Studies suggest that vitamin D plays an important role in the disease because people who live closer to the equator are exposed to higher amounts of sunlight during the entire year. They tend therefore to have greater levels of naturally produced vitamin D, which helps support immune function (National Multiple Sclerosis Society, 2016). Research has shown that low levels of vitamin D are strongly associated with more aggressive types of MS, as well as more brain lesions found on magnetic resonance imaging (Jelinek & Hassed, 2009). Research has further shown a genetic and environmental relationship between human leukocyte antigen (HLA) alleles and ultraviolet (UV) exposure and

smoking activity as risk factors. HLA alleles are considered the major genetic component of MS susceptibility and interact in a complex manner with UV and smoking behavior, which has been shown to determine a large proportion of MS susceptibility (Handel, Handunnetthi, Giovannoni, Ebers, & Ramagopalan, 2010). Smoking behavior is associated with more severe disease and more rapid disease progression; however, stopping smoking either before or after the onset of MS has been shown to slow progression of disability (National Multiple Sclerosis Society, 2016).

Another potential risk factor for MS involves infectious diseases, such as viruses, that have been recognized as causes of demyelination and inflammation. Researchers believe that it is possible that a virus or other infectious agent is a triggering factor in MS. Several viruses and bacteria are being investigated to determine if they are involved in the development of the disease (National Multiple Sclerosis Society, 2016). Although none of the infectious diseases have been definitively proven to trigger MS, studies examining Epstein Barr virus (EBV) have shown that it is significantly involved in the etiology of the disease when combined with smoking and tobacco consumption (Nielsen, Pedersen, Rostgaard, Frisch, & Hjalgrim, 2007). EBV-specific immune responses, smoking behavior, and tobacco consumption have been shown to be positively correlated, particularly in women.

Prevalence.

According to the National Multiple Sclerosis Society (2016), MS is thought to affect more than 2.3 million people worldwide. Because MS is not considered a reportable disease, the exact incidence is currently unknown. However, prevalence studies are ongoing and conducted worldwide with data from the northern hemisphere

(National Multiple Sclerosis Society, 2016). One study (Dilokthornsakul et al., 2016) estimated the annual prevalence of commercially insured individuals with MS from in 2012 in the United States to be 149.2 per 100,000 individuals. The prevalence was consistent from 2008 to 2012. Women were 3.13 times more likely to have MS, and the highest prevalence was in participants who were 45 to 49 years of age. Other notable findings were that the East Census region recorded the highest prevalence and the West Census region had the lowest prevalence (Dilokthornsakul et al., 2016).

Symptoms.

MS symptoms range from common to less common and secondary to tertiary types. The symptoms are variable and unpredictable because they may change or fluctuate over time (National Multiple Sclerosis Society, 2017). The common and less common MS symptoms are considered the primary symptoms because they are the direct result of damage to the myelin and nerve fibers in the central nervous system. The more common symptoms include fatigue, walking or gait difficulties, numbness or tingling, muscle spasticity and weakness, vision problems, dizziness and vertigo, bowel problems, pain, cognitive and emotional changes, and depression. The less common symptoms include speech problems, swallowing problems, tremors, seizures, breathing problems, pruritus, headache, and hearing loss (National Multiple Sclerosis Society, 2017).

Secondary symptoms are the complications that may emerge as a result of the primary symptoms. Secondary symptoms may include repeated urinary tract infections, muscle tone loss and weakness as result of inactivity, decreased bone density, inefficient breathing, and pressure sores from immobility. Tertiary symptoms, a consequence of the impact of the disease on the patient's life, include social, vocational, and psychological

complications. The stress of coping with MS may alter employment or social networks, which may lead to withdrawal or isolation from social interactions. Depression is a very common mental health disorder in people with MS. It may be both a primary or tertiary symptom, based on whether it is triggered by the disease process itself or by complications of the disease (National Multiple Sclerosis Society, 2017).

Types of MS.

The National MS Society reports four disease courses: clinically isolated syndrome (CIS), relapsing-remitting MS (RRMS), primary progressive MS (PPMS), and secondary progressive MS (SPMS). CIS is a first episode of neurological symptoms that is caused by inflammation and demyelination in the central nervous system. The episode must last for 24 hours and is characteristic of MS, but does not meet the criteria for a diagnosis. Those who experience a CIS may or may not develop MS. When a CIS is typically accompanied by an MRI that has brain lesions consistent with those observed in MS, then there is an increased likelihood of a second episode of neurological symptoms and a diagnosis of relapsing-remitting MS (RRMS) (National Multiple Sclerosis Society, 2017). RRMS is the most common disease course, characterized by clearly defined attacks of new or increasing neurological symptoms. The attacks are referred to as relapses or exacerbations of symptoms and are followed by periods of partial or complete recovery or remissions. During remissions, some or all of the symptoms may disappear. Some of the symptoms may also become permanent features, but there is no apparent progression of the disease during remission (National Multiple Sclerosis Society, 2017). Primary progressive MS (PPMS) is generally characterized by a worsening of neurological function from the onset of symptoms, without early relapses or remissions.

In both RRMS and PPMS, symptoms may be active or not active, with relapses and/or evidence of new MRI activity. Secondary progressive MS (SPMS) follows an initial relapsing-remitting course. Most people who are diagnosed with RRMS will eventually transition to a secondary progressive disease course in which there is a progressive worsening of neurological function over time (National Multiple Sclerosis Society, 2017).

Neurological and Psychological Perspectives

The neurological and psychological symptoms of MS may include cognitive impairment, fatigue, and depression. Individuals with MS may experience cognitive impairment with a range in symptomatology. The most common cognitive deficits are related to memory, verbal fluency, speed of information processing, and visuospatial and executive functions (López-Góngora et al., 2015). Nearly two thirds of people with MS experience cognitive impairment, particularly cognitive inefficiency and memory decline (Sumowski & Leavitt, 2013). Patients with cognitive inefficiency require more time to perform mental tasks, and memory problems often lead to disorganization and forgetfulness.

Not all individuals with MS will experience considerable disease burden, based on certain protective factors. These include heritable larger maximal brain growth and environmental, intellectual enrichment (Sumowski & Leavitt, 2013). This type of enrichment may include reading, hobbies, and education. Research suggests that individuals with MS may be able to preserve or maintain their existing brain reserve by living a healthy lifestyle, which includes physical activity, healthy food choices, adequate sleep, and adherence to prescribed disease-modifying therapies (Sumowski & Leavitt,

2013). Although cognitive impairment is a common manifestation of MS, it may go unnoticed in recently diagnosed patients. Studies have found that 27% of patients with a clinically isolated syndrome and 40% of patients with relapsing-remitting multiple sclerosis had some degree of cognitive impairment, primarily in complex attention and processing speed (López-Góngora et al., 2015). Early cognitive impairment has been found as soon as 1 month after the first neurological symptom; however, this seems to have no effect on daily life activities. Thus, the development of compensatory strategies in the early stages of MS may improve cognitive deficits (López-Góngora et al., 2015).

Fatigue is considered a frequent disabling symptom of MS, yet the pathogenesis is still poorly understood (Wijenberg, Stapert, Köhler, & Bol, 2016). It is one of the major reasons for disability and decreased societal participation and quality of life. Fatigue has been studied from a biopsychosocial perspective that integrates factors of disease severity, depression, catastrophizing, and the fear-avoidance cycle (Wijenberg et al., 2016). The model suggests that catastrophizing about fatigue has a central role fueled by depression. Catastrophizing about fatigue is defined as a fearful interpretation of the meaning of fatigue by exaggerated negative thinking, magnification of symptoms, and helplessness. Cross-validation studies have found that catastrophizing about fatigue mediates the relationship between fatigue and fatigue-related fear and avoidance behavior (Wijenberg et al., 2016).

Fatigue, depression, and sleep disorders have been associated with reduced health-related quality of life in patients with MS in both cross-sectional and longitudinal studies. This relationship has been found in patients with early MS, as well as more advanced forms of MS (Nourbakhsh, Julian, & Waubant, 2016). Sleep quality is an

important health consideration in multiple sclerosis. Lack of sleep is associated with greater disease severity, pain, and poor mental and physical quality of life. Insomnia is reported as one of the most prevalent sleep complaints in those with MS (Baron, Corden, Jin, & Mohr, 2011). Studies have found that over half of patients with MS have more difficulty initiating and maintaining sleep with or early morning awakenings than the general population. One study showed that rates of insomnia in patients with comorbid MS and depression are higher than those reported in the general MS population (Baron et al., 2011).

Management of MS

The management of MS is comprehensive and individualized, based on the patient's level of disability. MS is not a curable disease; however, effective strategies can help modify or slow its progression. Disease management includes any or all of the following: disease-modifying therapies, specific medications for symptom management, lifestyle modification, rehabilitation, and psychological care. There are currently 14 disease-modifying medications approved by the Food and Drug Administration for use in relapsing forms of MS; however, there is no disease-modifying medication currently approved to treat primary progressive MS (National Multiple Sclerosis Society, 2017). The types of treatment include injectable, oral, and intravenous routes of administration. Each medication has specific side effects, and not everyone will experience side effects. Depending on the medication, side effects also need to be strictly monitored for patient safety reasons (Sedal, Wilson, & McDonald, 2014). The treatment of choice is based upon several factors and will be influenced by lifestyle issues and adherence to and responsiveness to therapy. In general, the range of disease-modifying agents has been

shown to reduce relapse rate and brain lesions. However, they are only partially effective and do not prevent axonal injury, which produces the symptomatic burden of MS (Samkoff & Goodman, 2011). Treatment of MS-related symptoms is multifactorial and dependent on the patient's presentation.

Neurology.

Although MS frequently requires comprehensive disease management by a range of professional disciplines, it is primarily managed by the practice specialty of neurology (Buchanan, Kaufman, Zhu, & James, 2008). People with MS whose chief physician is a neurologist often receive diagnostic and treatment-related tests and disease-modifying treatments under this specialty provider's care. In contrast, primary care physicians provide patient care coordination, gatekeeping services, and preventative care and treat a range of conditions (Buchanan et al., 2008). One study that examined patient perceptions of MS-related care compared patient-identified differences in care received from various specialties, such as neurology, family or general practitioners, and medical internists. The study also examined patient-identified differences by practice specialty in understanding the medical aspects of MS and quality of care (Buchanan et al., 2008). Mean differences showed that patients considered MS-related care to be satisfactorily better in several areas when delivered by neurologists than by other specialties. These areas include physician understanding of the disease and satisfaction with access to and quality of care (Buchanan et al., 2008).

Primary Care.

The role of primary care providers in MS is serving as a source of lifestyle and psychosocial support. Lifestyle modification in individuals with MS may not only

improve overall quality of life, but slow the progression of the disease. The research suggests that lifestyle therapies that are employed in the primary care management of MS optimize overall care, particularly when coordinated with specialist care. Specific nondrug therapies include management of nutrition, sunlight and vitamin D exposure, consideration of psychosocial factors, and incorporation of exercise (Jelinek & Hassed, 2009). Additionally, the education about symptom management is a significant component of health care of persons living with MS. Research suggests that education on symptom management and treatment options provides a sense of empowerment over the disease and resources for informed decision-making (McCabe et al., 2015). The sense of patient empowerment has been shown to be associated with successful management of MS, leading to a satisfied quality of life. In turn, family members and significant others who are well supported and informed tend to also experience better well-being (McCabe et al., 2015). In a needs assessment study, gender, age, and symptom severity were factors associated with level of satisfaction with educational, psychological, and peer support services of people with MS. It was noted that females were less satisfied with access to relationship and family counseling. Additionally, there was a need for more varieties of peer support groups, times, and communication modes, such as e-mail or Skype, among young people and mildly affected groups. The level of symptom severity was also associated with a greater need for educational and psychological support services. Psychological support and continuity and coordination of care have been demonstrated to be to be major unmet needs in patients with severe MS symptoms (McCabe et al., 2015).

Daily Management of MS.

Fatigue, one of the common symptoms of MS, is considered one of the leading causes of neurological disability, affecting the majority of people with the disease. One study explored the use of health services in people with MS with and without fatigue over a period of 30 months (Johansson, Ytterberg, Gottberg, Widén Holmqvist, & von Koch, 2009). Data were collected from a computerized registry and by interviews and analyzed according to disease severity, which was categorized as mild, moderate, or severe. The analyses revealed that fatigued patients with mild MS used more hospital outpatient care and primary care including rehabilitation. A higher proportion of this group had transportation service in comparison to nonfatigued patients with mild MS. In patients with moderate and severe MS, the results showed that nonfatigued people accessed more occupational therapy in primary care. Many more of these patients also had paid care services; however, informal care from spouses or partners was more common among fatigued patients, regardless of disease severity (Johansson et al., 2009). This study demonstrates that support for informal caregivers is of importance when patients experience symptoms that require more health services. About 30% of people with MS need some form of home care assistance, and 80% of that assistance is provided by informal or unpaid caregivers, usually family members (Buchanan, Radin, Chakravorty & Tyry, 2010). A national survey study that explored informal caregiving of people with MS and greater dependency showed that assistance with daily activities or personal care consumed the largest amount of caregiving time. Caregivers reported that a range of home and community-based services would make caregiving easier or improve the care provided. Caregivers had low levels of satisfaction with access the MS patients had to

home health or rehabilitation services and with the quality of mental health care received (Buchanan et al., 2010).

Education and medical care satisfaction.

The barriers to health or rehabilitation services among patients with MS have been shown to be related to cost, coverage, and availability of medical services. Informal caregivers have generally reported low satisfaction with health insurance coverage for various support services, particularly by health maintenance organizations (HMOs) and other managed care plans (Buchanan et al., 2010; Putnam & Tang, 2007). The types of support services include home health aides, housekeeping services, adult day care, and respite care for those who experience physical impairment (Buchanan et al., 2010).

Caregivers have also reported dissatisfaction with access to quality mental health care services in comparison to MS-focused medical care. Previous studies have found that psychiatric symptoms, such as depression, in people with MS can increase distress in their caregivers. Treatment of depression in people with MS has been shown to improve the quality of life for their caregivers (Buchanan et al., 2010). Thus, it is important for people with MS, caregivers, and family members to receive the necessary education about the disease, health insurance coverage, and policies that influence symptom and lifestyle management.

The complexity of MS and the varied course it may take make it a challenging disease for the person with MS as well as for those who provide care. People with MS often place a high level of importance on support from caregivers, often a partner or spouse, and family members (McCabe et al., 2015). MS may cause impairment in various areas of life, influencing family roles, employment, quality of life, and daily

functioning. Educational, psychological, and peer support needs have been shown to be important factors in fostering adjustment to the disease (McCabe et al., 2015). In a study that explored the level of satisfaction with access to education services, access to psychological services, and current peer support services, symptom severity was associated with greater need for almost all education and psychological support services. Gender was as an important predictor of satisfaction with support services, as women were less satisfied with access to relationship and family counseling than men. Peer support was found to be an overall unmet need; largest group differences were observed when participants were grouped by symptom severity. Individuals with moderate to severe MS symptoms had a greater perceived need for almost all levels of services. Interestingly, age was an important predictor of satisfaction with services. Older individuals with MS are managing the aging process coupled with disability and disease progression (McCabe et al., 2015).

Another study evaluated what MS patients and caregivers perceived as unmet needs by comparing responses on the domains of global care, information about the disease, medical treatment and rehabilitation, patients' relationships with medical staff, and psychosocial life (Lorefice et al., 2013). The results showed that the majority of participants, both patients and caregivers, were satisfied with medical staff, but expressed a desire for them to be more forthcoming with information about MS. Patients more than caregivers perceived medical treatment to be implemented from a multidisciplinary approach. Patients and caregivers agreed upon the need for psychological support; however, patients felt a greater need for it at the time of diagnosis. Caregivers, on the other hand, felt that more psychological support was required after diagnosis (Lorefice et

al., 2013). Both patients and caregivers perceived the care from medical staff, such as neurologists, to be thorough, attentive, and kind. It is suggested that the psychological needs of caregivers and patients evolve over the course of the disease, resulting in changes in patients' relationships and having an impact on clinical outcome. This study did not explore the need for psychological support for caregivers, but indicated that caregivers should be involved in more aspects of patient care (Lorefice et al., 2013). Thus, the management of chronic illness is a major influence of the patient's and family's response to adjustment and quality of life.

Chronic Illness

Impact on the patient and family.

Several studies have examined the effect of chronic illness on patients and their families. In one review, 73 articles reported what is known about families in which a member has a chronic illness (Knafl & Gilliss, 2002). The literature shows that families, in the context of illness, typically rise to meet the challenges presented by the illness. Over time, most families tend to find positive meaning in the illness experience and incorporate illness management into their everyday routine. Studies also identified family adjustment to chronic illness in stages with a theme of a process that leads to eventual acceptance and normalization (Knafl & Gilliss, 2002). This review demonstrates, however, that not all families normalize or positively adapt to chronic illness. Some families experience great burden incorporating illness management into a family routine. Some evidence suggests that uncertainty surrounding the course of a potentially fatal illness may pose a serious threat to families' efforts to lead a normal family life. For example, the effects of parental chronic illness have been examined in

because approximately 10% of children grow up in households in which a parent has a medical chronic illness (Chen, 2017; Sieh, Visser-Meily, & Meijer, 2013). Emerging evidence suggests that children of chronically ill parents are at risk for adjustment difficulties and the development of emotional, behavioral, and learning problems. Children are likely to feel overwhelmed with the threat of a loss of a parent, decreased parental availability, increased household responsibilities, changing schedules and routines, and risk for reduced social and financial resources. Children and adolescents may assume a parental role before they are developmentally or emotionally ready (Chen, 2017). It has been suggested that adolescents whose parents have a chronic illness may be at elevated risk for internalizing problems, more caregiving responsibilities, daily hassles, stress, and worsening grade point average (Sieh et al., 2013). Studies involving the impact of chronic illness on the family system suggest that both disease type and cultural context influence the degree of impact. A family's adaptive response to illness has been consistently associated in the literature with fewer stressors and better functioning (Knafl & Gilliss, 2002).

In the context of multiple sclerosis, families face challenges in many areas, beginning at the time of diagnosis. The effect of MS on individuals and family members is related to loss and change. Because MS often takes a degenerative course, loss and change of functionality, physically or cognitively, impact both the individual and family (Bowen, MacLehose, & Beaumont, 2011). For the individual and family members, the early stages of MS can be a time of uncertainty about the future, helplessness, loss of control, and social isolation. As the disease progresses or worsens, family members are thought to be at risk of strain as roles change, especially for spouses who become

caregivers (Bowen et al., 2011). The impact of MS, and more generally chronic illness, on the family has been conceptualized in the literature using a family systems model. It is argued that the way chronic illness affects the family depends on a number of factors. These include psychosocial dimensions, time-related stages, family or life cycle issues, and other areas, such as financial, social, and quality of life issues (Bowen et al., 2011). Some additional factors of MS reported in the literature that affect the family include age at onset of MS, chronic course of the disease, unpredictability of MS, progressive course of MS, and neuropsychiatric symptoms of MS (Kouzoupis, Paparrigopoulos, Soldatos, & Papadimitriou, 2010).

Child and adolescent perspectives.

The growing research on the impact of parental MS on children and adolescents suggests that children feel more responsible, have more fear and anxiety during states of illness, have an increased sense of burden, and feel more anger. Social and educational plans may also be curtailed due to practical and financial reasons. Problems for children are also magnified in single-parent households, as fewer adults are available to assist with caregiving (Kouzoupis et al., 2010). Research suggests that MS exacerbations are associated with a decrease in maternal affection. Paternal functional impairment is also associated with children's lower life satisfaction. Cross-sectional studies in parental MS show that family dysfunction, parental depressive symptoms, and lack of social support are associated with externalizing symptoms in children, such as aggression (Bogosian, Hadwin, Hankins, & Moss-Morris, 2016). One way to explore the emotional relationship between children and their parents is the measurement of expressed emotion. Research has shown that high parental expressed emotion is associated with greater internalizing

and externalizing symptoms in children. One study investigated the impact of the severity of parental MS, parent's expressed emotion, and psychological well-being on children's psychological difficulties (Bogosian, Hadwin, Hankins, & Moss-Morris, 2016). It was hypothesized that greater illness severity, progressive types of MS, longer duration of illness, and increased anxiety and depression in parents at baseline would be positively associated with higher reports of internalizing and externalizing symptoms in adolescents both cross-sectionally and longitudinally (Bogosian et al., 2016). The results show that higher depression scores of parents with MS at baseline correlated with increased adolescents' internalizing symptoms at a 6-month follow-up. Scores indicating higher expressed emotion of parents with MS at baseline were also associated with increased adolescent externalizing symptoms at a 6-month follow-up. Additionally, severity or type of MS was not found to have an impact on adolescents' psychological difficulties (Bogosian et al., 2016). This study highlights the importance of the influence and risk of potentially deleterious emotional effects on children and adolescents of parents who have MS and who also experience emotional difficulties.

Because emotional distress and expressed emotion in parents with MS can have an impact on the well-being of children in the household, some general guidelines for parents are recommended. These include the explanation of MS in age-appropriate or developmentally appropriate terms, sensitivity to children's emotional needs, and scheduling activities and discussions that do not pertain to MS in order to communicate that a disease does not dictate the family's life (Kouzoupis et al., 2010). The researchers also recommended that a parent with MS remain a parent to his or her children, even if

caring becomes limited, in order to provide a stable and nurturing environment (Kouzoupis et al., 2010).

Spouse and partner perspectives.

Partners of people with MS are also at increased risk of challenges, such as relationship and marital discord. Research has shown that partners of people with MS have a higher risk of depression, higher levels of distress and anxiety, and lower quality of life compared to other categories of caregivers. A sixfold increase in risk of divorce has been reported in the literature after a woman is diagnosed with MS, likely related to the disruption in the balance of the relationship (Kouzoupis et al., 2010). Qualitative research has explored the experience of couples in the first years after diagnosis, a particularly difficult adjustment period. Couples experience shock from the diagnosis, with feelings of loss of control and social isolation. Partners may often feel that others do not understand or support their experience (Bogosian, Moss-Morris, & Dennison, 2009). Additional adjustment difficulties include lifestyle changes, such as reduced employment or constant planning based on disease symptoms. The nature of the relationship in the early years of diagnosis may also change, based on the partner or spouse's preoccupation in the caregiving role. Couples may subsequently experience loneliness as certain needs are put aside in the interest of caregiving and accommodation of the illness (Bogosian et al., 2009). In longitudinal studies, significant differences were noted between patient and spouse adjustment. Patients reported poorer adjustment than spouses, and positive affect and relationship satisfaction declined over time for both patients and spouses, suggesting implications for intervention and coping resources (Samios, Pakenham, & O'Brien, 2015).

Caregivers

Caregivers and chronic illness.

The body of literature on informal caregivers substantiates both the mental and physical health impacts. Caregiving has been related to significant mental health problems, physical illness, and even mortality (Cassidy, 2013). For example, becoming a family caregiver for patients with a brain tumor has been associated with psychological distress (Cassidy, 2013). Associations between high psychological distress and poor physical health in family caregivers may reduce caregivers' ability to provide quality care, which warrants early intervention (Choi et al., 2012). The trajectory of chronic illness presents new challenges over time, calling for an adjustment or new coping resources. Research suggests that the manner in which caregivers respond to the news of an illness diagnosis may depend on both the caregiver's personal and social characteristics and their care recipient's disease characteristics (Choi et al., 2012). Predictors of psychological distress patterns that have been studied among family caregivers of patients with primary malignant brain tumors include depressive symptoms, anxiety, and schedule burden (Cassidy, 2013). Moderators that may ameliorate depressive symptoms higher income and social support for caregivers. Younger caregivers have also been shown to report high levels of anxiety over time, regardless of the care recipient's health (Choi et al., 2012).

The effects of caregiver emotional distress have been shown in the aging population to have a deleterious effect on the mental health of the care recipient. Elderly depression is considered a leading mental health issue worldwide and is associated with impaired social functioning and health-related quality of life (Ejem et al., 2015).

Caregiver emotional distress as a chronic life stressor is associated with a higher likelihood of depressive symptoms in the care recipient (Ejem et al., 2015). The well-being of the caregiver has important implications for the health of the recipient. Family caregivers of patients with cancer often report deficits in education and skills related to their patients' care, lack of assistance from healthcare professionals, an absence of social support, increased stress, and complex care demands (Tamayo, Broxson, Munsell, & Cohen, 2010). Many factors have been noted in the literature as contributing to caregivers' well-being, including expression of feelings and household maintenance. Caregivers also identified giving medications and management of side effects as important to learning needs. Additionally, communication, positive attitudes, support, and education were also vital considerations in promoting the quality of life in caregivers (Tamayo et al., 2010).

Caregivers and MS.

Informal caregivers make a considerable contribution to the care and well-being of people with MS. Caregiver burden in MS encompasses what the individual does in addition to his or her feelings about the caring role (Forbes, While, & Mathes, 2007). Caregiver health-related problems have been found to be associated with greater disease impact, high caregiving activity levels, and burden. Specific caregiver health problems that emerged included tiredness, back pain, anxiety, insomnia, depression, shortness of breath, and sexual and relationship problems. These problems also tend to increase with disease progression (Forbes et al., 2007). As depression has been noted to be elevated in caregivers who care for family members with chronic illness, supportive interventions have been shown to ameliorate symptoms in the context of MS. In contrast to the

documented negative impact that MS may have on both the patient and caregiver, research has found that MS patients reported benefit-finding or positive changes as a result of the diagnosis. These changes include feeling closer to their families and gaining an enhanced appreciation of life (Hart, Vella, & Mohr, 2008). It is suggested that benefit-finding may lead to positive health outcomes in MS patients, such as improved immune functioning, reduced medical visits, and better physical functioning, thereby reducing caregiver burden (Hart, Vella, & Mohr, 2008).

Stress.

The effects of stress on psychological and physical health are well documented in the literature. Beginning in late 1970s, Richard Lazarus and Susan Folkman led studies on stress and coping in adults of varying ages (Lazarus & Folkman, 1987). Stress may be conceptualized as person-environment relationships, cognitive appraisals, and emotional response states. These emotional states may be positive, characterized by joy, happiness, love, and relief. These states may also be negative, characterized by fear, anger, guilt, and shame. Research has also captured how coping processes affect the emotional response. Within animal models, coping is defined as learned behaviors that contribute to survival when faced with immediate dangers. Such behaviors are initiated by fear, which initiates avoidance and escape behaviors, whereas anger motivates confrontation or attack (Folkman & Lazarus, 1988). Earlier studies on the relationship between emotion and coping in humans described two mechanisms, which are motivational and cognitive in nature (Folkman & Lazarus, 1988). Stress may motivate an individual to focus on an emergent task, but may also induce anxiety-related thoughts, thereby impeding performance and functioning.

Transactional model of stress and coping.

The transactional model of stress and coping is grounded in a metatheoretical approach to emotion, involving three themes: relationship or transaction, process, and a view of emotion as an interdependent system of variables (Lazarus & Folkman, 1987). According to this metatheory, transaction is an understanding of the relationship and dynamic interplay between the person and the environment. Process involves change over time or across situations. Stress or negative emotions imply process as humans strive to change what is undesirable or distressing, and coping may be considered a process when it is measured over time. Emotion as a system depends on a variety of mediating variables and processes (Lazarus & Folkman, 1987). Taken together, the transactional model of stress and coping is based on the basic constructs of cognitive appraisal and coping. Cognitive appraisal involves the evaluation of a stressor or threat. Two forms of appraisal exist in the model: primary appraisal and secondary appraisal. Primary appraisal involves an individual's evaluation of an event as potentially relevant and whether it is has negative or positive value. Secondary appraisals entail what an individual can do to exert control over a stressful situation by assessing coping resources (Lazarus & Folkman, 1987). According to Lazarus and Folkman, coping serves two main functions: to change the actual terms of the troubled person-environment, referred to as problem-focused coping, and to regulate emotional distress, referred to as emotion-focused or cognitive coping (Lazarus & Folkman, 1987).

Stress and health.

Stress has been demonstrated to detrimentally influence health status and interfere with the performance of health practices. Based on the model by Lazarus and Folkman,

stressful events are assumed to increase risk of disease when they are appraised as threatening or demanding and when coping resources are judged to be insufficient to address the threat or demand (Cohen & Williamson, 1988). Perceived stress is assumed to be an important mediator of the pathway linking stressful events to poorer health and health practices. Research has established associations between perceived stress and illness, illness symptoms, and a wide range of health behaviors. In addition, individuals with less power and wealth are more likely to generalize perceptions of stress (Cohen & Williamson, 1988). In the context of caregivers, perceived stress and burden have been described in the aging population. Caregiving consumes considerable energy among informal caregivers who have reduced feelings of control over the care situation (Gräbel & Adabbo, 2011). Factors that have been associated with perceived stress in elderly caregivers include pain, sleep difficulties, and impaired cognitive status. Poorer cognitive status and higher levels of burden related to care have been found in caregivers who are more stressed (Luchesi et al., 2016). The health and well-being of caregivers is of significance as the population ages.

Coping with chronic illness.

Coping refers to cognitive and behavioral efforts to manage demands of a stressful situation. Better caregiver adjustment has been found to be related to greater reliance on problem-focused coping and less reliance on emotion-focused coping (Pakenham, 2001). In the context of MS caregiving, higher levels of couple problem-focused coping and lower couple emotion-focused coping have been associated with lower levels of couple distress (Pakenham, 2001). As a coping resource, social support has been linked to MS caregivers' general health, mood, and family satisfaction. Certain

groups, including males and spouses who have experienced a longer duration of caregiving, may be more vulnerable to less social support (Pakenham, 2001). Thus, problem-focused coping may yield a higher level of social support in MS caregivers.

Social support.

The relationship between social support and caregiver burden suggests that a caregiver's perception of available practical, instrumental support (e.g., transportation or house sitting) and emotional support may reduce burden and promote better quality of life (Chronister & Chan, 2006). The research on social support has been conducted in many populations. In young caregivers between the ages of 10 and 25 years, better adjustment has been associated with social support. Additional predictors of caregiving adjustment that have been studied in this group include choice in caregiving, stress appraisal, and coping; however, social support has been shown as the strongest predictor (Pakenham, Chiu, Bursnall, & Cannon, 2007). Perceived social support has also been shown to predict burden and quality of life in caregiving. General social support research suggests that social support acts as a buffer against stress and moderates family functioning, distress, and well-being. Caregivers with more social support have reported lower perceived stress and better physical and mental health (Chronister & Chan, 2006). In the MS population, social support and depressive symptoms have been studied among caregivers of veterans with the disease. As part of a larger study, 42 family caregivers of veterans with MS completed questionnaires by telephone. A hierarchical regression was used to examine the relationship between caregiver depressive symptoms and perceived social support (Bambara et al., 2014). Results showed that greater MS disease severity and poorer overall veteran health were associated with higher levels of depressive

symptoms among caregivers. Perceived social support among caregivers was associated with fewer depressive symptoms, suggesting that interventions aimed at enhancing social support may be important for mood management because MS disease severity increases over time (Bambara et al., 2014).

Coping strategies.

Because fatigue is a common symptom among those with chronic illnesses, the role of perceived stress has been examined as it relates to hope. Both state and trait hope have been associated with less pain, perceived stress, and fatigue (Hirsch & Sirois, 2016). In terms of coping strategies, the ability to identify a personally meaningful goal and work toward it may be related to less perception of stress and fatigue. The promotion of hope through goal-oriented thoughts and behaviors may allow individuals with chronic illness and their caregivers to perceive experiences and situations as more manageable. It is suggested that brief interventions that include strategies from motivational interviewing and problem-solving therapy and goal identification and attainment exercises be implemented in medical settings for patients or caregivers who lack such skills (Hirsch & Sirois, 2016). Moreover, the impact of chronic illness has been demonstrated to adversely affect the physical and socioemotional health of individuals with the disease, their caregivers, and other family members in the household. Factors such as social support and coping strategies may lessen stressful experiences and improve adjustment to chronic illness. Several factors may influence perceptions of stress in caregivers of family members with MS, and the present study sought to ascertain the predictors of stress in this population so that health care professionals may address those needs.

Chapter 3: Research Questions and Hypotheses

Research Questions

What factors increase or mitigate stress in caregivers of family with multiple sclerosis?

Are factors, such as depressive symptoms, perceived social support, coping processes, and patient care satisfaction, are associated with the level of perceived stress in family caregivers of people with multiple sclerosis?

What factors predict the level of perceived stress in family caregivers of people with multiple sclerosis?

Hypotheses

H₁: The level of depressive symptoms in caregivers, as measured by the Caregiver Self-Assessment Questionnaire, will be positively and significantly correlated with the level of perceived stress among caregivers of patients with MS, as measured by the Perceived Stress Scale.

H₂: The level of perceived social support among caregivers, as measured by the Multidimensional Scale of Perceived Social Support, will be negatively and significantly correlated with the level of perceived stress among caregivers of patients with MS, as measured by the Perceived Stress Scale.

H₃: Coping processes among caregivers, as measured by the Ways of Coping Questionnaire, will be negatively and significantly correlated with the level of perceived stress among caregivers of patients with MS, as measured by the Perceived Stress Scale.

H₄: The level of patient care satisfaction among caregivers, as measured by a subscale of the DiTomasso Willard Patient Satisfaction Questionnaire, Satisfaction with Physician, will be negatively and significantly correlated with the level of perceived stress among caregivers of patients with MS, as measured by the Perceived Stress Scale.

H₅: The level of perceived stress among caregivers of patients with MS, as measured by the Perceived Stress Scale, will be predicted by the linear combination of depressive symptoms, as measured by the Caregiver Self-Assessment Questionnaire, the level of perceived social support, as measured by the Multidimensional Scale of Perceived Social Support, coping processes, as measured by Ways of Coping Questionnaire, and the level of patient care satisfaction among caregivers, as measured by the DiTomasso Willard Patient Satisfaction Questionnaire.

Chapter 4: Methods

Study Design

A cross-sectional correlational design was employed to determine which factors predicted stress in caregivers of people with MS.

Participants

The participants in this study were family members who provided physical, emotional, or cognitive care to patients with multiple sclerosis. Participants were referred to as caregivers in this study and recruited from the National Multiple Sclerosis Society, a national caregiver organization website, and Facebook. The role of social media, particularly in MS research, has been considered a feasible choice in recruitment and tracking of participants (Simpson, Taylor, & van der Mei, 2015). The national caregiver website utilized in this study was the Family Caregiver Alliance (FCA), a nonprofit organization headquartered in San Francisco, CA. Their mission is to improve the quality of life for family caregivers and the people who receive their care (Family Caregiver Alliance, 2019). The FCA provides a number of services for caregivers, such as assessment, care planning, direct care skills, wellness program, respite services, and legal/financial consultation (Family Caregiver Alliance, 2019). Additionally, the FCA offers support in areas of policy, health and social system development, research, and public awareness on the state, national, and international levels (Family Caregiver Alliance, 2019). In this study, permission was obtained from the FCA to post the study recruitment message, containing the survey link, on the Research Registry page for 3 months at no charge. The FCA also posted the message in three successive issues of each of their two nationally distributed monthly e-newsletters. The audience for these

newsletters was caregiving families and health and service providers, policy makers, and others interested in long-term care issues.

The recruitment message (see Appendix) was distributed to support groups associated with the National Multiple Sclerosis Society through the following chapters: Greater Delaware Valley, Pennsylvania Keystone, New York City–Southern New York, Upstate New York, New Jersey Metro, Greater DC–Maryland, Connecticut, and Virginia–West Virginia. Permission was obtained by each of the chapters to distribute the recruitment message to support groups. Recruitment was also expanded to advertise and distribute the survey link at an annual event hosted by the National Multiple Sclerosis Society called MS Breakthroughs, held on December 12, 2018, in Berlin, NJ. The event provided an opportunity for people living with MS, donors, friends, family members, and caregivers to learn more about MS, ask questions, make connections with others, and recognize the achievements by the Society in the past year. A brief overview of the dissertation study was presented, and cards containing the survey link were available for distribution at the vendor exposition.

Inclusion criteria.

Individuals were required to be a family member of an individual with multiple sclerosis and provide some level of caregiver support. Participants were also required to have provided caregiving for a minimum of 1 month prior to participation in this study and to know the patient's primary care provider, having at least one interaction. Participants had to be 18 years of age or older and have at least an eighth grade education. They had to speak English fluently and reside in the United States. Access to the Internet was required. Participants completed an eligibility questionnaire with

information on caregiving. If they answered no to any of the questions, their participation was immediately discontinued.

Measures

Perceived Stress Scale (PSS). The PSS, the most widely used psychological instrument for measuring the perception of stress, was used to assess the predicted level of stress in caregivers. The PSS is a 10-item measure that ascertains how unpredictable, uncontrollable, and overloaded respondents believe their lives are in the context of feelings and thoughts during the past month (Cohen, Kamarck & Mermelstein, 1983). It was originally designed for use with community samples with at least a junior high school education. The evidence for the reliability and validity of the PSS originates from three samples: two college student populations and a community smoking cessation program (Cohen et al., 1983). The coefficient alpha reliability for the PSS was .84, .85, and .86 in the three samples, respectively (Cohen et al., 1983). The PSS has adequate internal and test-retest reliability and is correlated with a range of self-report and behavioral criteria. It has been correlated with life-event scores, depressive and physical symptomatology, utilization of health services, social anxiety, and smoking reduction maintenance (Cohen et al., 1983).

Caregiver Self-Assessment Questionnaire (CSAQ). The CSAQ is an 18-item self-report screening measure for the detection of depressive symptoms in caregivers. Respondents are asked to consider the past week and check yes or no for each item (Epstein-Lubow, Gaudiano, Salloway, Miller & Hinckley, 2010). The CSAQ has been reported to have a reliability coefficient of 0.78. In a sample of 106 family caregivers from an inpatient geriatric psychiatry unit, the CSAQ was compared with validated

measures for depression, burden, stress, and grief. It was hypothesized that the CSAQ would demonstrate acceptable sensitivity and specificity as a screen for depression (Epstein-Lubow et al., 2010). The short form of the Center for Epidemiological Studies Depression Scale (CES-D) is a reliable and valid 10-item screening tool that is widely used to assess depression severity. The CES-D and CSAQ were co-administered along with three other measures to assess psychological syndrome aside from depression: the Perceived Stress, 4-item version, the Rapid Screen for Caregiver, and the Inventory of Traumatic Grief, pre-loss version (Epstein-Lubow et al., 2010). The results indicated that the CES-D and CSAQ were highly correlated (Pearson $r = .807$, $p < .001$) and had similar patterns of correlation with other measures. The CSAQ also demonstrated high internal consistency (Cronbach's alpha = 0.82). Thus, the results supported the CSAQ as a screening measure for depressive symptoms (Epstein-Lubow et al., 2010).

Ways of Coping Questionnaire (WCQ). The WCQ was used to assess ways and processes of coping in caregivers. This 66-item measure assesses coping processes that are used in a particular stressful encounter, not coping style or traits. Respondents are asked to identify a stressful encounter that occurred recently, where it took place, and what happened. The extent to which coping processes were used in the situation is rated using a 4-point Likert scale of 0 (*Not Used*), 1 (*Used Somewhat*), 2 (*Used Quite A Bit*), or 3 (*Used a Great Deal*); Folkman & Lazarus, 1988). The WCQ is one of the most widely used instruments to assess coping and is used in clinical settings involving cancer, multiple sclerosis, Parkinson's disease, fibromyalgia, stroke, chronic fatigue syndrome, and spinal cord injury (Lundqvist & Ahlström, 2006). An early study using the WCQ evaluated the extent to which coping mediated emotions during stressful encounters.

Participants were evaluated on their emotions and the ways in which they coped with the demands of the encounters (Folkman & Lazarus, 1988). Regression analyses identified four types of coping that were strongly associated with changes in emotion: planful problem-solving, positive reappraisal, confrontive coping, and distancing (Folkman & Lazarus, 1988). Results also indicated that both problem- and emotion-focused forms of coping were associated with more positive changes in emotions; whereas confrontive coping and distancing may yield more negative changes in emotions (Folkman & Lazarus, 1988).

A more recent study of the WCQ involved 510 participants who were students, chronically disabled patients, and their next of kin. The aim of this study was to describe coping and evaluate the psychometric properties of the WCQ and its generalizability across the three different groups (Lundqvist & Ahlström, 2006). The results indicated medium to high Cronbach's alpha for the WCQ total score from the total sample and subsamples (Lundqvist & Ahlström, 2006). Additionally, the coping patterns that emerged for the patients were very similar to those of the next of kin. The results also demonstrated support for the eight factors in within-sample analyses: confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem solving, and positive reappraisal (Lundqvist & Ahlström, 2006).

Usually, subscales scores are used for this scale. However, in the present study, relevant negatively worded items (negative coping items) on this scale were reversed scored according to the manual and a total score of positive coping was calculated. The use of a total score was supported by a coefficient alpha of .89 for the entire scale.

Multidimensional Scale of Perceived Social Support (MSPSS). The MSPSS was used to assess the level of perceived social support in caregivers. The MSPSS is 12-item self-report measure that assesses the perceptions of social support adequacy (Canty-Mitchell & Zimet, 2000). The MSPSS has been found to have good internal and test-retest reliability. One early study found that high levels of perceived social support were associated with low levels of depression and anxiety symptomatology, as measured by the Hopkins Symptom Checklist (Zimet, Dahlem, Zimet, & Farley, 1988). Further evidence for use of the MSPSS was obtained from study in a sample of 222 urban, largely African American adolescents; however, the reliability and validity of the measure has been demonstrated in several populations (Canty-Mitchell & Zimet, 2000). The MSPSS has three subscales for family, friends, and significant other. To assess internal reliability, Cronbach's coefficient alpha was calculated for the total MSPSS and for each subscale (Canty-Mitchell & Zimet, 2000). The 12-item MSPSS has been shown to have internal reliability with a coefficient alpha of .93. The family, friends, and significant other subscales had internal reliability, with a coefficient alpha of .91, .89, and .91, respectively (Canty-Mitchell & Zimet, 2000). The Adolescent Family Caring Scale (AFCS; Canty-Mitchell, 2000) was used to evaluate the discriminant validity of the family subscale of the MSPSS. The AFCS is a 44-item scale that measures adolescents' perception of caring by family members and has been found to have high internal consistency, with a Cronbach's alpha of .97 (Canty-Mitchell & Zimet, 2000). The AFCS correlated significantly with the MSPSS family subscale ($r = .76, p < .001$), friends subscale ($r = .33, p < .001$), and significant other subscale ($r = .48, p < .001$). The correlation of the AFCS with the friends subscale was significantly stronger than the

correlations with the friends ($t = 10.44, p < .001$) and significant other ($t = 7.74, p < .001$) subscales, which demonstrated discriminant validity for the family subscale of the MSPSS (Canty-Mitchell & Zimet, 2000).

DiTomasso-Willard Patient Satisfaction Questionnaire (DWPSQ). The DWPSQ was used to assess patient care satisfaction experienced by the caregiver, specifically the satisfaction with physician subscale. This 60-item questionnaire assesses the extent of patient satisfaction using a 4-point Likert scale from *Strongly Disagree* to *Strongly Agree* (DiTomasso & Willard, 1991). In a study that examined the psychometric properties of a patient satisfaction questionnaire, a preliminary 80-item questionnaire was created with a sample of 268 family practice patients (DiTomasso & Willard, 1991). Following a factor analysis, five factors emerged: satisfaction with physician, dissatisfaction with practice management, physician availability, receptionist behavior, and wait time. The alpha reliability coefficients for the five factors were .96, .93, .89, .84, and .78, respectively (DiTomasso & Willard, 1991). The findings indicated that patients who were more satisfied with their physicians were more satisfied with the manner in which the practice is managed, perceived their physician as being more available, and were more satisfied with the behavior of the receptionists and with the waiting time in the office. Conversely, patients who were more dissatisfied with the practice management perceived their physicians as less available and were more dissatisfied with the receptionists' behavior and waiting time (DiTomasso & Willard, 1991). The DWPSQ was modified to reflect the perspective of the caregiver.

Procedure

Potential participants were contacted through support groups and were asked to consider participating in a study on caregivers of family members with multiple sclerosis. They were provided with a Survey Monkey link to an extensive explanation of the study, including that participation would be anonymous and voluntary, and they could withdraw from the study at any time without consequence. Prospective participants were informed that the known risks were minimal, that there were potential benefits to others, and that completing the questionnaires would make them eligible for a raffle to win one of two \$50 Amazon gift cards. Information was provided on how to contact the investigators if they had questions. After completed all of the questionnaires were completed, participants were given the principal investigator's e-mail address to enter the raffle. Participants were informed e-mails would not be linked to their responses in any way.

Following data collection, measures were scored according to each measure's manual and analyzed using a regression model. The total score was used for each measure, and reverse scores were used in the analysis, where indicated.

Chapter 5: Results

Statistical Analyses

The goal of the current study was to determine whether four independent variables, level of depressive symptoms, level of perceived social support, level of coping processes, and level of patient care satisfaction, were predictive of one outcome variable, level of perceived stress in caregivers of patients with MS. A power analysis was conducted to determine the number of participants needed for the study. At the .05 level of significance for a medium effect size for a correlational analysis at 80% power, 111 participants were needed. At the .05 level of significance with a medium effect size at 80% power for a multiple regression analysis, a total of $104 + m$ where m = the number of predictors, 108 participants would be needed. In order to allow for all analyses to be conducted with sufficient power, 370 participants were requested to obtain 111. The statistical analyses were performed using SPSS Version 24.0 statistical software for Windows (IBM Corp., 2016). Separate descriptive analyses were conducted on MS diagnosis type in the family member, other medical diagnoses in the family member, as well as the caregiver's own medical or psychological diagnoses that could make caregiving difficult. Pearson correlation coefficients were used to identify the relationships between the hypothesized variables and perceived stress. All assumptions were met.

For the planned multiple regression analysis, the investigator originally planned to test all assumptions. However, only one predictor correlated with the criterion and, therefore, only a simple regression was conducted.

Pearson's correlation coefficient was used to examine the relationship between the independent variable, level of depressive symptoms, and the dependent variable, level of perceived stress among caregivers for H₁.

Pearson's correlation coefficient was used to examine the relationship between the independent variable, level of perceived social support, and the dependent variable, level of perceived stress among caregivers for H₂.

Pearson's correlation coefficient was used to examine the relationship between the independent variable, level of coping processes, and the dependent variable, level of perceived stress among caregivers for H₃.

Pearson's correlation coefficient was used to examine the relationship between the independent variable, level of patient care satisfaction, and the dependent variable, level of perceived stress among caregivers for H₄.

In order to test whether the linear combination of level of perceived social support, level of coping processes, level of depressive symptoms, and level of patient care satisfaction predicted level of perceived stress for H₅, a multiple regression with a test of assumptions was planned but not conducted as noted above since only one predictor correlated significantly with the criterion.

Demographics

A total of 40 individuals participated and completed this research study. In terms of the family member's MS diagnosis, 62.5% had relapsing-remitting MS, 12.5% had primary progressive MS, 22.5% had secondary progressive MS, and 2.5% were unsure or of the type, or it was unknown. Additionally, 52.5% of caregiver participants reported that their family member had other medical diagnoses in addition to MS. In terms of the

caregiver participants, 42.5% reported that they had their own medical or psychological diagnosis that may make caregiving for their family member difficult. Table 1 lists the family member's other medical diagnoses reported by caregiver participants. Table 2 displays the caregiver's own medical and/or psychological diagnoses.

Depression Symptoms and Perceived Stress

The first hypothesis was that the level of depressive symptoms in caregivers of family members with MS would be positively and significantly correlated with the level of perceived stress among caregivers. The results, as shown in Table 3, indicated that the level of depressive symptoms was significantly and positively correlated with the level of perceived stress among caregivers $r(40) = .43, p < .05$. Therefore, this hypothesis was supported.

Table 1

Family Members' Other Medical Diagnoses

Atrial fibrillation, neuropathy
Adult onset of Type 1 Diabetes, Celiac disease, Graves' disease
Asthma, osteoarthritis
Degenerative disc disease, endometriosis
Depression
Depression, anxiety
Depression, stomach surgery, head injury due to fall
Diabetes
Diabetes, hypertension
Failed back surgeries and bulging discs
Glaucoma, colon cancer in remission, atrial fibrillation, suprapubic catheter
Hypertension
Hypertension, chronic kidney disease stage 3 (moderate)
Hypothyroidism, psoriasis, eczema, high cholesterol
Legally blind, kidney stones, osteoporosis, depression
Non-relapsing (MS?)
Pancreatitis, diabetes
Sleep apnea
Triple vessel syndrome, obstructive sleep apnea, thyroid issues, familial hypercholesterolemia, sarcoidosis

Table 2

Caregivers' Other Medical or Psychological Diagnoses

Anxiety
Anxiety, depression
Arthritis
Chronic pain
Depression, anxiety
Diabetes
Fibromyalgia, degenerative joint arthritis, tendonitis, torn right rotator cuff, degenerative disc disease
Heart attack two years ago, anxiety
Multiple sclerosis and bone disease
Multiple sclerosis
Osteoarthritis of the knees
Primary Immune Deficiency Disease
Thyroid issues, ADHD, sleep apnea, wet macular degeneration, cardiac valve problem
Traumatic brain injury, anxiety

Table 3

Intercorrelations for Perceived Stress Scale and Other Study Measures

Measure	1	2	3	4	5
1. Perceived Stress Scale	--	.22	-.01	-.13	.43
2. Ways of Coping Questionnaire	.22	--	.12	.07	.04
3. Patient Care Satisfaction	-.01	-.08	--	.22	-.34*
4. Perceived Social Support	-.13	.02	.22	--	-.16
5. Caregiver Depression	.43**	.17	-.34	-.16	--

* $p < .05$ ** $p < .01$ **Perceived Social Support and Perceived Stress**

The second hypothesis was that the level of perceived social support in caregivers of family members with MS would be negatively and significantly correlated with the level of perceived stress among caregivers. The results, as shown in Table 3, did not

achieve significance $r(40) = -.13, p = .21$. Therefore, this hypothesis was not supported.

Coping Processes and Perceived Stress

The third hypothesis was that the level of coping processes would be negatively and significantly correlated with the level of perceived stress. Usually, subscales scores are used in the application of this scale. However, in the present study, relevant negatively worded items (negative coping items) on this scale were reversed scored according to the manual and a total score of positive coping was calculated. The use of a total score was supported by a coefficient alpha of .89. The results, as shown in Table 3, indicated that the result did not meet significance $r(40) = .22, p = .08$. Therefore, this hypothesis was not supported.

Patient Care Satisfaction and Perceived Stress

The fourth hypothesis was that the level of patient care satisfaction would be negatively and significantly correlated with the level of perceived stress. The results indicated that the relationship did not meet significance $r(40) = -.01, p = .47$. Therefore, this hypothesis was not supported.

Regression Analysis

Given that only the level of depressive symptoms in the first hypothesis reached statistical significance, a simple regression was used to investigate whether the level of depressive symptoms could significantly predict the level of perceived stress among caregivers. The other predictor variables did not correlate with the criterion, and a multiple regression was therefore not conducted. The results of the regression analysis indicated that the model explained 18.5% of the variance and that depressive symptoms, as a variable, were a significant predictor of perceived stress among caregivers, $F(1,38) =$

8.60, $p = .006$. The level of depressive symptoms contributed significantly to the model ($B = .646, t = 2.93 p < .01$).

Chapter 6: Discussion

This study sought to understand which factors, such as depressive symptoms, social support, ways of coping, and patient care satisfaction, affect stress in caregivers of family members with multiple sclerosis (MS). The effects of chronic illness on the individual and families are well documented. Prior studies have demonstrated that individuals with multiple sclerosis and their families face challenges on various levels after the disease is diagnosed. These challenges can change over time and may include loss of control, social isolation, role changes, and financial issues. MS is an unpredictable disease and often takes a physically and cognitively degenerative course (Bowen et al., 2011). Not surprisingly, caregiver health-related problems have been found to be associated with greater disease impact, high caregiving activity, and burden (Forbes et al., 2007). The variables selected to be examined in this study were based on research on chronic illness, caregivers, and multiple sclerosis. For instance, major depression has been shown to be a highly co-occurring clinical issue in individuals with MS (Labiano-Fontcuberta et al., 2015; Patten et al., 2010). Studies have also shown that emotional stress in caregivers has been positively correlated with depression in the care recipient (Ejem et al., 2015). Social support, coping to reduce the demands of stressful situations, and patient care satisfaction have all been shown to reduce stress and the burden of chronic illness management.

Significance of the Findings

Among the participants in this study, 62.5% of family members had relapsing-remitting MS, the most common disease type. This type is characterized by a relapse or exacerbation of symptoms, followed by periods of partial or complete recovery or

remission. Secondary progressive MS, which typically follows an initial relapsing-remitting course of the disease, was reported for 22.5% of family members. Most people with relapsing-remitting MS transition to secondary progressive MS, in which there is a progressive worsening of neurological function over time (National Multiple Sclerosis Society, 2017). It can be inferred that the family members who are receiving caregiving support from study participants had been living with MS for several years, experiencing cognitive and/or physical deterioration. Additionally, 12.5% of participants reported that family members had progressive MS, which is characterized by a worsening of neurological function from the onset of symptoms without early relapses or remission. Only 2.5% of participants reported that they were unsure of the MS type in their family member. Participants reported that they and their family member with MS also had other medical and/or psychological diagnoses that may make caregiving difficult. A range of conditions from hypertension to primary immune deficiency disease were reported for family members and caregivers. A number of participants listed depression or anxiety in the family member as well as in the caregiver.

The results of this study supported the hypothesis that depression is associated with perceived stress. It was predicted that the level of depressive symptoms would be positively and significantly correlated with the level of perceived stress in MS family caregivers. This hypothesis was supported, and the regression analysis explained 18.5% of the variance, indicating it is a significant predictor of perceived stress in caregivers. The level of coping processes and perceived stress only approached significance in the positive direction. It is possible that with more participants, this relationship may have become significant in the negative direction, as well. Had it been significant, this would

have been an unexpected finding and would have indicated that caregivers utilize more coping methods when they perceive themselves to be stressed.

Although not a part of the original hypotheses, additional findings included negative correlational relationships between patient care satisfaction and depression and between perceived social support and depression. These results suggest that caregivers have lower levels of depressive symptoms when they perceive themselves to have social support and when they are satisfied with their family member's patient care.

Implications

The results of this study have several implications. First, a large proportion of participants' family members had the most common disease type, relapsing-remitting MS. Whereas the current study did not stratify the MS diagnosis type and hypothesized variables, a recent study examined factors associated with caregiver strain in life partners of persons with mild disability, specifically cognitive and neuropsychiatric problems, due to relapsing-remitting MS (Van der Hiele et al., 2019). The results indicated that 24% of life partners experienced above average levels of caregiver strain. Specific factors, such as higher age of the person with MS, more physical disability, more neuropsychiatric problems of the person with MS, and higher severity of the neuropsychiatric symptoms, were associated with high caregiver strain (Van der Hiele et al., 2019). Second, the level of depressive symptoms predicted the level of perceived stress in caregivers. This finding is consistent with the current research regarding depression among caregivers of family members with MS. Third, the original hypothesis involving coping predicted an inverse relationship between coping and perceived stress. However, the results only approached significance in the positive direction. A possible explanation for this is that

participants were largely recruited from support groups associated with the National Multiple Sclerosis Society. These participants may have been told the importance of increasing coping responses when experiencing increased stress.

The National MS Society has support groups for those who have the disease and for caregivers or other family members. Research on participation in support groups has shown an overall positive effect. In the dementia population, for example, support groups have been shown to be effective in reducing caregiver burden, particularly socially and emotionally, by helping caregivers obtain knowledge, reduce stress, and find acceptance (Kucukguclu, Soylemez, Yener & Isik, 2018). In the MS population, support groups have been found to have a positive effect on the mental health of individuals with the disease when they identify with and are engaged with the groups, rather than merely attend them (Wakefield, Bickley, & Sani, 2013). Research has observed these positive effects specifically in relapsing-remitting and primary progressive MS. In addition, a recent study of a program developed by the National MS Society, called Everyday Matters, evaluated whether it had a positive effect on resilience and other related outcomes in adults with MS (Alschuler, Arewasikporn, Nelson, Molton & Ehde, 2018). The program was developed because individuals with MS are confronted with simultaneous challenges of coping with advancing MS and age-related changes (Alschuler et al., 2018). Everyday Matters was a 6-week program teaching positive psychology principles and was delivered through group teleconference supplemented with readings, videos, and online participation. Participants who completed the program revealed improved satisfaction with social roles, affect, and mood, specifically depression (Alschuler et al., 2018). This study illustrates that adaptive forms of coping and

education have a positive effect on individuals with MS. Individuals with MS, their caregivers, and other family members in the household may therefore benefit from education about disease management, stress management, and self-care to reduce the burden of symptoms and stress associated with caregiving. Factors such as regular exercise, nutrition, sleep, and social support have all been associated with reducing symptom intensity and improving quality of life. Primary care physicians may represent the first point of contact in providing access or referral to these services.

Limitations

The first major limitation involves the number of participants who completed the survey and the effect size. The study is underpowered, which could account for the lack of significant findings. Only 40 caregivers began and completed the survey in this study. It was not feasible to achieve a larger sample size within the timeframe established for this study. Self-selection may have resulted in characteristics unique to those who participated, which may have implications for generalization of the findings. There may have been differences in support group involvement among caregivers and family members with MS and in stress levels among those who chose to participate in and complete the study. The requirement for Internet access may have also limited generalizability.

A second major limitation is the failure to obtain demographic information. Although inclusion and exclusion criteria provide some information, the absence of other demographic information precluded additional analysis and a more exact description of the sample. More specifically, it would have been useful to know specific and exact amount of time the participant had been providing care; the type and level of care being

provided; age, race, ethnicity, marital status, socioeconomic status; current involvement in and history of psychotherapy, psychotropic and other medications being taken; availability of support; family characteristics; and responsibilities.

A third limitation was the presentation of survey questions. It may have been useful to randomize the order in which the questionnaires were presented to the participants. There may have been effects related to the presentation of the questionnaires in the standard order that was used in the study. The potential impact of completing the questionnaires in a standard order was therefore not distributed equally across the participants. A related issue is that participants may have been fatigued by the end of the entire survey, which may have impacted the completion of the last questionnaire.

A fourth limitation is that data were collected only from the caregivers' perspective. Future researchers conducting cross-sectional studies may wish to collect data from caregivers and family members with MS, comparing differences in perceived stress. Finally, a fifth limitation was the coping variable. The hypotheses examined only the total scores of this measure. Although not done in the present study, the Ways of Coping measure is usually scored according to the eight coping styles: confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem-solving, and positive appraisal.

Future Directions

This study could be replicated to collect additional data and recruit a larger sample. Inviting participants to use the Survey Monkey phone application may increase study access. Although age was an inclusion criterion, the specific ages of the caregiver

and family member were not requested. Given the previous research on age of the individual with MS and caregiver, it would be helpful to ascertain whether age had an effect on the level of perceived stress. This study did not ask participants how long they had been providing caregiving support to their family member.

Future researchers may wish to conduct a stratified analysis of whether MS type influences the level of perceived stress. The eight coping scales may also be examined separately in a regression analysis to determine if certain coping styles predict the level of perceived stress in caregivers. Additionally, research questions about perceived stress in children of people with MS is could be added to examine adjustment and support in people living with chronic illness.

Although MS commonly occurs in adults, it is also diagnosed in children and adolescents. It would therefore be interesting to examine the level of depressive symptoms, perceived social support, level of coping processes, and patient care satisfaction from the caregiver's perspective and perceived stress among parents of children and adolescents with MS. This study could also be repeated with MS patients and family caregivers who do not participated in support. Finally, other factors contributing to perceived stress among caregivers of family members with MS may also be examined in future studies.

Conclusions

In conclusion, the level of depressive symptoms was shown to be predictive only of the level of perceived stress in caregivers of family members with multiple sclerosis (MS). The other variables examined in this study, level of coping process, perceived social support, and patient care satisfaction, were not significantly associated with the

level of perceived stress. A substantial proportion of both caregivers and family members had medical and/or psychological diagnoses that may make caregiving difficult. The main MS diagnosis type reported by caregiver participants in this study was relapsing-remitting MS, which suggests that the unpredictability and exacerbation of symptoms may increase the level of depressive symptoms and subsequently the level of perceived stress in caregivers. The information obtained from this study demonstrates the importance of considering the needs of caregivers, particularly those who support a family member with MS. Given the high prevalence of depression in the MS population, which also predicted caregiver stress in this study, it remains an important clinical consideration.

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Appendix

My name is Lucy Lubinski, and I am a doctoral student in the Clinical Psychology program at Philadelphia College of Osteopathic Medicine. You are invited to participate in a study about those who care for a family member with multiple sclerosis (MS). The study's purpose is to understand what may add to stress in people who care for a family member who has MS. You must meet some conditions to enter the study. All of your answers will be kept confidential. Your answers will not be connected to any of your personal information. You can also end your participation from the study at any time. You may find out some things about yourself that you did not know before by answering the questions. It is possible that this may cause some emotional discomfort. The survey will take about 25 to 35 minutes to complete. You will have the chance to send an email to a separate e-mail address to enter in a drawing to win a \$50 Amazon gift card after you finish the survey. Your e-mail address will not be connected to information that you give in the survey. If you are interested in participating, please click on the link: **<https://www.surveymonkey.com/r/WQZLXPD>**.

If you have any questions about this study, you may contact Robert A. DiTomasso, PhD, ABPP, at robertd@pcom.edu, or me at lucylu@pcom.edu. This study has been approved by the Philadelphia College of Osteopathic Medicine Institutional Review Board (protocol approval #H18-047X). Thank you for your time and assistance.

Sincerely,

Lucy Lubinski, M.S., M.S.

Philadelphia College of Osteopathic Medicine