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The Impacts of Caregiving and Social Support on Stress for Multiple Sclerosis: A Study on Informal Caregivers

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THE IMPACTS OF CAREGIVING AND SOCIAL SUPPORT ON STRESS FOR MULTIPLE SCLEROSIS: A STUDY ON INFORMAL CAREGIVERS

A Dissertation

by

JACQUELINE MERCADO

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December 2023

ABSTRACT

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The purpose of the present quantitative study was to gain an increased understanding of the impacts of caregiving and social support on stress for unpaid informal caregivers of persons with Multiple Sclerosis. Caregiving for MS can be rewarding yet stressful. Informal caregivers are the primary source of ongoing home care for family members or friends with MS. Due to the complexity of care, caregivers are especially vulnerable to higher strain as they often feel unprepared for this role. This study examined perceived social support and demographic variables on caregivers' stress to gain insight into mediating caregiver psychosocial challenges. This study comprised individuals (N=122) who provide unpaid informal care to a loved one with MS. Overall, results from statistical analysis revealed that participants experienced moderate levels of perceived social support and perceived stress. However, analysis of frequency levels indicated that MS spousal caregivers experienced higher stress than mothers/fathers and daughters/sons under certain circumstances. A moderate relationship was found between perceived social support and perceived stress. However, analysis of the frequencies of disagreement on perceived social support items found a lack of support from family and friends. Furthermore, there were no differences between gender and ethnicity regarding perceived stress.

DEDICATION

This study is dedicated to all informal caregivers. Thank you for your altruism, commitment, and many hours of hard work dedicated to your loved ones.

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This dissertation would not have been possible without my dissertation committee. To my dissertation chair, Dr. Barbara Schoen, I cannot express my gratitude enough for your commitment and endless support. I want to thank my committee members, Dr. Noreen Graf, and Dr. Roy Chen, for all their advice and guidance. Their commitment, contributions, and feedback were very valuable to the completion of this study.

To my family and friends who supported me throughout this journey. For my grandfather in heaven, Juan Lopez, who pushed me every day to be better and reminded me of the importance of education. Thank you for believing in me.

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CHAPTER I

INTRODUCTION

Informal caregiving for persons with multiple sclerosis (MS) can be a rewarding but stressful role (Maguire & Maguire, 2020; National Multiple Sclerosis Society, 2019; Pristavec, 2019). While millions of Americans provide unpaid care to a person with a chronic illness or disability such as MS, caregivers are especially vulnerable to higher levels of strain as they endure complex care situations (American Association of Retired Persons, 2020; National Alliance for Caregiving, 2021; Schulz & Sherwood, 2008). Recent studies have reported an increase in adverse impacts among caregivers in comparison to non-caregiving individuals, mainly due to the sudden change of learning to balance outside employment, household duties, and personal needs (Gupta et al., 2022; Lohne et al., 2012; Moghaddam et al., 2023; Petrikis et al., 2019). For this reason, informal caregivers are at higher risk of experiencing unmanaged stress, leading to severe physical and emotional afflictions (Kim, 2017; Petrikis et al., 2019; Maguire & Maguire, 2020; Schulz & Sherwood, 2008).

Background

MS is a chronic progressive neurological disorder affecting more than one million adults in the United States (National Multiple Sclerosis Society, 2019; Wallin et al., 2019). It is characterized by impairment of the Central Nervous System (CNS), resulting in limitations to an individual’s ability to engage in daily activities, employment, childcare, and self-care (Cameron et al., 2013; National Multiple Sclerosis Society, 2019; Rajachandrakumar & Finlayson, 2022). People with MS may experience diverse symptoms ranging from physical deterioration (e.g., fatigue, loss of balance, mobility, spasticity, bowel dysfunction) (Petrikis et al., 2019) to cognitive and emotional impairments (Cameron et al., 2013; Rajachandrakumar & Finlayson, 2022). Although MS limitations may be addressed through personal support such as long-term care, insurance, or private pay home-care services, most caregiving activities are performed by family members or friends (Petrikis et al., 2018; Perrin et al., 2015; Rajachandrakumar & Finlayson, 2022; Zhang et al., 2023). Thus, the majority of home care support for individuals with MS is provided by informal caregiving, namely, a spouse, sibling, parent, or other relative/friend (Bayen et al., 2015; Maguire & Maguire, 2020; Rajachandrakumar & Finlayson, 2022).

Formal and informal caregiving involves a broad scope of activities requiring preparedness, specialized knowledge, and skills (Committee on Family Caregiving, 2016; Wolff & Gitlin, 2011). By definition, informal caregivers are individuals who assist with unpaid activities of daily living (e.g., toileting, feeding, bathing, walking, clothing) or instrumental activities of daily living (e.g., shopping, meal preparation, housecleaning, and managing finances) (Edemekong et al., 2023; Roth et al., 2015). Informal caregivers facilitate continuity of care as a means to help their loved ones remain at home with their families, friends, and communities (Martin et al., 2016; Rajachandrakumar & Finlayson, 2022; Slatyer et al., 2019).

The caregiving trajectory has brought positive societal changes, increasing public policy and advocacy. Not long ago, caregivers were not recognized as a pivotal part of the medical team despite their essential contributions to continuity of care (Friedman & Tong, 2020; Saltz &

Schaefer, 1996; Sherman, 2019). Although caregivers are now more commonly recognized for their vital role in providing quality care at home (Friedman & Tong, 2020; Raj et al., 2023), caregivers experience higher financial stress, physical deterioration, and an overall decline in well-being compared to non-caregivers (Liu et al., 2020; Schulz & Eden, 2016). In addition, while caregiving can be fulfilling, caregivers have been reported to face challenges managing the many integrated and overlapping care components involving role ambiguity, surrogacy, parenting, respite, and self-care (National Academies of Sciences, 2016; Schulz & Eden, 2016).

U.S. Caregiver Demographics

The United States is in the initial stages of an unprecedented rise in the number of older adults living at home with physical or cognitive disabilities (American Association of Retired Persons, 2020; Committee on Family Caregiving, 2016; Roth et al., 2015). With the rise of an aging population and advances in modern medicine, individuals living at home and needing assistance will continue to grow (Edwards et al., 2020; Rowe et al., 2016). A 2020 study by the American Association of Retired Persons (AARP) and the National Alliance for Caregiving (NAC) revealed an increase in the number of family caregivers in the United States by 9.5 million from 2015 (43.5 million) to 2020 (53 million). According to their study, the average span of the caregiving role is four years, with 24% of individuals providing care for more than five years. Most caregivers (82%) surveyed by AARP & NAC (2020) cared for one other adult with a disability or illness, 15% cared for two adults, and 3% cared for two or more adults. Most caregivers (89%) reported providing unpaid care to a relative, while (10%) reported unpaid caregiving for a friend, neighbor, or other non-relative. The National Alliance for Caregiving (2020) also reported that three in five caregivers were female (61%), while two in five were male (39%).

Family caregivers may reside in the same household as the care recipient; others may live nearby or farther away. The geographical distance between caregivers and the care recipient was noted to have impacted the number of hours caregivers provided. The AARP & NAC survey (2020) found that informal family caregivers provide an average of 24.4 hours per week caring for their loved ones. Those who resided with the care recipient reportedly spent about 40.5 hours per week providing care. Most caregivers (75%) lived within 20 minutes of the care recipient, while 13% resided 20 minutes to an hour away. Individuals providing long-distance care reported the highest annual caregiving expenses ($8,728) compared to co-residents ($5,885). This may be due to taking additional time off work, travel expenses, and out-of-pocket medical costs (Schulz et al., 2016). The economic value of unpaid caregiving in 2013 was estimated at $470 billion (about $1,400 per person in the U.S.), exceeding the value of paid caregiving and Medicaid. Unpaid caregiving is part of family life in the United States as they remain essential collaborators in the planning and continuity of care for others (Edwards et al., 2020; Law et al., 2021; Raj et al., 2023).

MS Caregiving

A progressive neurological disorder, such as multiple sclerosis, is a condition that gradually worsens over time, resulting in a decline in overall health or function (Aarsland et al., 1999). In progressive disabilities, the development is not always linear, creating uncertainty about the future for both the caregiver and care recipient (Gibbons et al., 2014; Schultz et al., 2016). MS has distinct stages; depending on the type, the disease may progress quickly or slowly (Baloyannis, 2020; Jacques, 2020). Subsequently, the extent of caregiving responsibilities also depends on the type, severity, and progression of MS. In primary progressive MS, individuals may require a complex scheme of personal assistance services to continue living at home (Ong, 2018). In a systemic scoping review on multiple sclerosis caregiving, Rajachandrakumar and Finlayson (2022) noted that informal caregivers were responsible for delaying or avoiding crises in patients with MS, which may otherwise result in hospitalization or long-term care centers.

Advances in diagnostic tools have made diagnosing patients at earlier stages easier, increasing the cases among children and adolescents (Banwell et al., 2016; Duignan et al., 2019; Maguire & Maguire, 2020). Following early diagnosis or the onset of MS symptomology, some individuals may require 40 years or more of caretaking (Finlayson & Cho, 2008; Rajachandrakumar & Finlayson, 2022). On the other side, for the caregiver, the long duration of this disease can result in more significant strain and burden. Fortunately, studies have indicated that psychosocial coping resources may reduce these effects (Akbar & Aisyawati, 2021).

Social Support

Close and caring relationships are shown to protect and promote better health and well-being for individuals (Feeney & Collins, 2015; Pietromonaco & Collins, 2017). Social support can be received from a variety of people and is described as “providing assistance or comfort to others, typically to help them cope with biological, psychological, and social stressors” (American Psychological Association, 2018, para. 1). Being part of a support system allows individuals going through similar circumstances feel comfort knowing they are not alone. Supportive relationships may also help cope successfully during adversities and enable personal growth and development (Feeney & Collins, 2015).

Specific to MS caregiving, there is a lack of research on the role social support has on individuals caring for a loved one with a progressive neurological disorder. However, Maguire & Maguire (2020) found that MS caregivers in their study expressed needing regular social support (Grimby et al., 2015). Subsequently, greater social support was associated with decreased caregiver burnout (Dayapoğlu & Tan, 2017; Maguire & Maguire, 2020). Receiving emotional support, whether it comes from family members, social media support groups, neighbors, or friends, can help protect against mental health disorders and life's hardships (American Psychological Association, 2022; da Silva et al., 2022; Sillence et al., 2016; Zhang et al., 2023). To further support this concept, Leung and colleagues (2020) added that carers who perceived having a higher level of family support tended to have a higher self-efficacy, lower burden, and better quality of life.

Caregiver Stress

The term *stress* was first introduced into the medical lexicon by Hans Selye, who described it as a non-specific bodily response to any demand for change (Tan & Yip, 2018). Stress is also described as a physical, mental, or emotional strain or tension experienced in the body (The American Institute of Stress, 2022). Regarding caregiver stress, studies conclude that stress levels may rise when coupled with familial tensions, pressure, and imbalances between caregiving responsibilities and the capacity to care for another individual (Cejalvo et al., 2021; Raj et al., 2023).

Due to the litany of challenges associated with caring for a family member or friend, self-care may be neglected, affecting caregiver strain (Committee on Family Caregiving, 2016; Petrikis et al., 2019; Schulz et al., 2016). Caregivers may endure diverse levels of stress based on their individual experiences, including hours caring for a loved one, perceived social support, and time of entry into the role. In a mixed-methods study on caregiver strain, researchers found negative associations between caregiver strain and QoL (Di Lorito et al., 2021). According to their 2021 study, caregivers reported a lack of support, reinforced by a reluctance to seek help.

Dooley et al. (2022) state that caregivers may prioritize their loved ones over their needs and inadvertently neglect their own daily activities and routines, consistent with self-care, social participation, and physical activity. Bužgová et al. (2019) also found that a lack of familial cohesiveness, medical information, insufficient support, and high caregiving demands were contributors to negative aspects of a caregiver well-being. These differences can have a significant influence on individual stress levels. For example, Kim (2017) found differences among caregiver stress on demographic factors such as gender, age, kinship to the care recipient, marital status, occupation, expenses, caregiving hours, and monthly income. Stressors can significantly influence an individual’s health and well-being. Nevertheless, psychosocial interventions have proven helpful in reducing stress-related disorders impacting long-term chronic health (Schneiderman et al., 2005). Stress levels may fluctuate, and caregivers are advised to seek help to handle or reduce stressors (Kim, 2017).

Statement of the Problem

Throughout the progression of the disease, people with MS may endure multiple unmet physical, cognitive, psychosocial, and spiritual needs, including the continuity of home care (Boersma et al., 2014; Oliver et al., 2017), significantly interfering with patients’ social and emotional lives and those of their families (Aarsland et al., 1999; Schulz, 2016). As reported, parents, siblings, spouses, or acquaintances frequently provide primary care to a person with MS, increasing their risk of experiencing worsening health effects as they often neglect to address their own needs (National Alliance for Caregiving, 2020). Informal caregivers are also at risk of experiencing higher stress (Petrikis et al., 2019). Despite the critical support they provide to individuals needing at-home care, there is a surprising lack of research studies reporting the impacts of caregiving and social support on stress (Bassi et al., 2020). Further exploration is necessary to examine the impacts of caregiving among informal caregivers of persons with MS, specifically, the effects of caregiving and social support on stress.

Purpose of the Study

To better assist individuals impacted by the nuances of informal caregiving for a loved one with MS, a greater understanding of their unique experiences is warranted. The purpose of this study was to examine MS caregiver demographic variables and perceived social support on perceived stress.

Research Questions

The following research questions were used to guide this quantitative empirical study:

1. What are the frequency levels of perceived stress among informal caregivers?
2. What are the frequency levels of perceived social support among informal caregivers?
3. Is there a relationship between caregiver perceived stress and perceived level of social support?
4. Are there differences in caregiver perceived stress based on demographic variables (gender, ethnicity, and kinship to the person cared for)?

Definition of Terms

Caregiver stress is defined as stress that manifests in the form of familial tensions and pressure, which is experienced due to the imbalances between caregiving responsibilities and the capability to provide care (Cejalvo et al., 2021).

Informal caregivers (IC) are defined as family members or other people who provide daily care or supervision of a frail, elderly, incapacitated, or someone in need (Kasle, 1995). In this study, informal caregivers provide unpaid care to a loved one with multiple sclerosis.

Multiple Sclerosis (MS) is defined as a disease that impacts the brain, spinal cord, and optic nerves, which comprise the central nervous system, controlling everything an individual does (Ford, 2020).

Psychological stress is defined as the "relationship between the person and the environment that is appraised by the person as taxing or exceeding their resources and endangering their well-being" (Lazarus & Folkman, 1984, p. 19).

Social Support is defined as the "provision of assistance or comfort to others, typically to help them cope with biological, psychological, and social stressors. Support may come from different individuals and may take the form of practical, tangible support or other direct material assistance and emotional support" (American Psychological Association, 2018, para. 1).

Summary

Caregiving studies have brought significant insight to help individuals cope, find the support they need, and improve overall emotional and physical health. However, every population is unique and may face distinct challenges. Caring for a loved one with a progressive neurological disorder such as MS can be rewarding yet stressful, especially for family members and friends who feel unprepared for the changes they may endure (Maguire & Maguire, 2020; National Multiple Sclerosis Society, 2018; Pristavec, 2019). Therefore, studies must provide detailed findings to address the gap in the literature on informal caregiving for individuals with MS and their families. Understanding MS caregiver experiences is necessary to promote and ensure caregivers receive the tailored psychosocial support they need (Kalb, 2019; Maguire & Maguire, 2020; Rajachandrakumar & Finlayson, 2022).

The following chapters describe the direction of the study. The second chapter details the literature review and theoretical framework. The third chapter presents the methodology used to address the research questions. The fourth chapter provides the results and data analysis. Finally, the fifth chapter describes the discussion of the results.

CHAPTER II

REVIEW OF LITERATURE

The purpose of this study was to examine variables that impact unpaid informal caregivers of persons with MS, including perceived social support and perceived stress. This chapter presents a review of 1) the manifestation and symptomology of multiple sclerosis— a progressive neurological disorder, 2) the roles and responsibilities of unpaid caregivers, 3) significant issues related to the impact of family caregiving, and 4) the theoretical framework to examine the associated impact including demographic factors, perceived social support, and stress-related issues.

Multiple Sclerosis: A Progressive Neurological Disorder

A progressive neurological disorder (PND) is characterized by a condition in which there is an advancing deterioration in function due to damage to the central or peripheral nervous system (Bužgová & Kozáková, 2019; Lamptey et al., 2022; Seeber et al., 2019). PND is also referred to as neurodegenerative or degenerative disorders, which affect people's movement, balance, and communication abilities, likely affecting the individual for the rest of their life (Lamptey et al., 2022; McIsaac et al., 2018). PNDs are diagnosed mid- to late-life, and prevalence is expected to increase with the aging population (McIsaac et al., 2018; Reeve et al., 2014; Reitz et al., 2011).

According to a study by the National Multiple Sclerosis Society, about 1 million people in the U.S. live with MS (2019). Their study revealed that these numbers had increased more than twice compared to a similar study they conducted in 1975. Nevertheless, receiving an MS diagnosis can be a slow and complicated process (Topcu et al., 2020). While some people learn of their disease immediately, others undergo multiple and repetitive health examinations before receiving an accurate diagnosis from their physician (Bužgová & Kozáková, 2019; Rolak, 2003). Due to the complexity of MS symptomology and diagnosis, people may experience further confusion. For instance, Bužgová and Kozáková (2019) reported that some patients had been misdiagnosed by their doctors. Additionally, insufficient knowledge from medical staff from non-specialized hospitals regarding MS prognoses was reported among patient family members (Bužgová & Kozáková, 2019). In addition to the stress of receiving a diagnosis, individuals may find it challenging to come to terms with the disease (Topcu et al., 2020). Individuals have expressed that in spite of the timing between suspecting and receiving the diagnosis, they will experience denial. Hosseini and colleagues (2022) found that despite the years after onset, some patients were still unable to accept and come to terms with MS.

The exact cause of MS, to this day, is unknown. Scientists believe it is derived from genetic susceptibility or infectious diseases (Multiple Sclerosis Association of America, 2023). Experts also believe environmental factors may trigger or exacerbate MS symptomology (Ransohoff et al., 2015). Studies have found that something triggers the immune system to attack the central nervous system (CNS), comprised of the brain, spinal cord, and optic nerves (Ransohoff et al., 2015; Topcu et al., 2020). The interruption of communication signals in the CNS may cause unpredictable symptoms such as numbness, tingling, memory problems, pain, fatigue, blindness, and paralysis (Topcu et al., 2020). Disease symptomology may be temporary or long-lasting (Lamptey et al., 2022; Topcu et al., 2020).

There are four known types of MS: clinically isolated syndrome (CIS), relapsing-remitting MS (RRMS), secondary progressive MS (SPMS), and primary progressive MS (PPMS) (Multiple Sclerosis Association of America, 2023). They also reported CIS is the first episode of neurological symptoms caused by inflammation and demyelination in the CNS; but for some this episode may not result in further complications and MS progression. They also stated RRMS is the most common disease course; characterized by new or increasing neurologic symptoms followed by partial or complete recovery (remissions) with an estimated 85% of people with MS are initially diagnosed with RRMS. The next type reported, SPMS, follows the initial relapsing-remitting course and will eventually transition into a secondary progressive form. Finally, the study concluded, PPMS is characterized by worsening neurologic function (accumulation of disability) from the onset of symptoms without early relapse and remissions with approximately 15% of people with MS are diagnosed with PPMS.

People between the ages of 20-50 are more commonly diagnosed with MS, which is reportedly three times more common among women than men (Maguire & Maguire, 2020; Multiple Sclerosis Association of America, 2023; Opara & Brola, 2018; Ransohoff et al., 2015). Experts hypothesize that hormones play a significant role in MS susceptibility (Ysrraelit & Correale, 2019). It is presumed that MS is not inherited, and the risk of developing the disease is about 1 in 750-1000 (Multiple Sclerosis Association of America, 2023).

An international collaborative of scientists worldwide are actively working to find effective treatments for progressive forms of MS and address the many challenges of the disease (Fox et al., 2012). The U.S. Food and Drug Administration (FDA) has approved various disease-modifying therapies to treat each type of MS diagnosis (Lamptey et al., 2022; National Multiple Sclerosis Society, 2023). There is currently more accessibility to relapsing forms of MS treatment than progressive forms (Fox et al., 2012).

Multiple Sclerosis and Caregiving

The course of MS is onerous and tedious (Ransohoff et al., 2015). It is a chronic disease that affects people's overall quality of life and requires long-term care (Hosseini et al., 2022; Santos et al., 2019). Generally, immediate family members or friends take on the role of caring for a loved one (Benini et al., 2023; Bulley et al., 2021; Forbes et al., 2007; Topcu et al., 2016). However, family members rarely receive adequate information on managing MS from diagnosis to later stages of the disease (Bužgová & Kozáková, 2019; Xia et al., 2017). This could result from poor communication between healthcare providers and patients, or the type of information received to support their loved ones (Alroughani, 2015; Golla et al., 2022). Likewise, some patients feel they cannot openly talk about their diagnosis with family because they do not feel as if they fully understand MS as a result of insufficient information and the complexity of the disease (Hosseini et al., 2022; Köpke et al., 2018).

The type of support in caring for a family member with MS may be in the form of emotional support, helping with injections of a disease-modifying medication, and offering support with medical decision-making (Benini et al., 2023; Kesselring et al., 2022; Radford, 2019). Individuals at different stages of MS will require individualized levels of care (Klineova & Lublin, 2018). For instance, people with primary progressive MS may manage a complex scheme of personal assistance services to continue living at home (Ogg, 2019). In the later stages of MS and during exacerbations, people with MS cannot manage daily living activities alone and can become functionally dependent on others (Dehghani et al., 2019).

Providing ongoing care to a loved one with MS is not an easy task (Golla et al., 2022; Radford, 2019). MS caregiving can be physically and emotionally exhausting for the primary caregiver (Radford, 2019). Financial impacts are also common among MS caregivers. Bulley et al. (2021) noted that families reported economic burden due to the high cost of special equipment and reduced personal income. At times, providing care can feel like an unpaid full-time job (Rollero, 2016).

To provide optimal care, the carer must maintain adequate health (Bužgová et al., 2020). In their study, Benini et al. (2023) revealed that MS caregivers coped with intrinsic motivation (i.e., love towards their family members, patience, and dedication) or extrinsic resources (i.e., hobbies, reading, sports) to subside the burden. Benini and colleagues also found that some relatives felt they had to manage care responsibilities in complete solitude and their study reported that while some caregivers received support from family and friends, as the disease progressed, support occurred less. This was most frequently reported among those caring for a loved one for a more extended period of time, feeling neglected by their friends and family.

There are many ways in which a caregiver can positively impact the management of the disease progression (Family Caregiver Alliance, 2022). The Family Caregiver Alliance recommends that caregivers join their loved ones in seeking mental health counseling, preparing healthy meals, walking outdoors together, and creating a comfortable living environment (Family Caregiver Alliance, 2022). Specifically for the caregiver, making time for themselves, having someone to share responsibilities, seeking MS caregiver self-help groups, and receiving economic aid are needed to help improve the caregiver's quality of life (Benini et al., 2023; Sillence et al., 2016; Zhang et al., 2023).

Family Caregiving

The impacts of informal caregiving have progressively made its way into academic research as studies have demonstrated that caregivers play a vital role in providing quality care, often called the second-order patient (Sherman, 2019). Prior to the establishment of the Family Caregiver Alliance (FCA) in 1977, family caregivers were largely unseen, unheard, and unrecognized as part of the healthcare team. In past times, family caregivers were not comfortable sharing their personal and private issues for fear of public scrutiny. Reasonably, there was a hesitation to express their emotional, financial, and physical challenges of caregiving— resulting in isolation and silent suffering (Benini et al., 2023; Family Caregiver Alliance, 2018). As awareness of caregiving issues was heightened, change began (Family Caregiver Alliance, 2018).

Kasle (1995) defines an informal caregiver (IC) as a family member or other person who provides daily care or supervision of a frail, elderly, or incapacitated person. As a society, families are expected to provide emotional support and assist family members when they can no longer function independently (National Academies of Sciences, 2016; Sherman, 2019). ICs may endure hardships as they typically provide care with minimal or no training and for nonpayment of services (Matthews, 2018). Caregivers come from different backgrounds and how they integrate into this role will vary from person to person (National Academies of Sciences, 2016).

Family Challenges

ICs face unique adversities when caring for a loved one (Matthews, 2018). For instance, coordinating the appropriate care for a loved one may be challenging, especially for individuals seeking the resources they need (i.e., specialized medical doctors and rehabilitation facilities) from afar. At times, caregivers and their loved ones must travel long distances to receive medical attention for the care recipient (Cagle & Munn, 2012; Zucchetto et al., 2022). Individuals have also reported difficulty scheduling appointments with specialized medical doctors and, at times, must wait months to be seen (McGinnis et al., 2015; Koopman & Schweitzer, 1999).

The many concerns involving continuity of care have raised concerns and drawn attention to family challenges. As reported by The American Association of Retired Persons (AARP) and the National Alliance for Caregiving (NAC) (2020), caregivers reported an increased difficulty in care coordination from (19%) in 2015 to (26%) in 2020. Financial implications may also arise. The AARP & NAC (2020) reported that about 45% of caregivers had experienced at least one economic impact. Concerning employment, 61% of caregivers were employed outside the home. Although most participants reported outside work, Petrikis (2019) found that income did not affect caregiver strain. However, it did impose restrictions on leisure activities. Additional factors associated with financial stress may include residing at a long distance from a loved one, limited availability from others to share caregiving tasks and costs, and those with outside employment having limited flexibility or personal time off (Benini et al., 2023; Lwi et al., 2017; Maguire & Maguire, 2020).

Role pressure can also contribute to familial challenges, thus creating social isolation (Benini et al., 2023; Matthews, 2018). Role strain causes imbalances in family dynamics by decreasing intimacy, generating tension, and decreasing support (Matthews, 2018; Polenick & Depasquale, 2019). Coupled with daily tasks and challenges, quality of life may negatively impact relationships (Lwi et al., 2017; Maguire & Maguire, 2020). A qualitative study examining the changes in family dynamics in family caregivers of people with dementia found that caregiving had substantially impacted the entire family unit (Oh et al., 2019). Therefore, considering the impact on family dynamics is integral to understanding the function of family caregiving. Tramonti and colleagues (2019) also conveyed the importance of examining caregiving roles and family cohesion within the context of the family unit. Wawrziczny et al. (2021) recommend rehabilitation and early intervention strategies between family caregivers and their loved ones with MS before the relationship becomes avoidant and entrenched.

Emotional and Mental Health Challenges

Caregiver commitments and social obligations can become secondary stressors to physical and emotional difficulties (Benini et al., 2023; Matthews, 2018). Family caregivers reporting poorer health has increased, with 23% reporting that caregiving had affected their health (American Association of Retired Persons, 2020). Supporting research demonstrates that the rigorous activities performed by ICs may cause a decline in overall health and well-being (Matthews, 2018). Moreover, ICs who fail to compartmentalize their emotions reportedly experience higher emotional loss, sadness, and helplessness (Benini et al., 2023; Matthews, 2018; Rodenbach et al., 2019). A study examining QoL and emotional strain in MS caregivers found that carers experienced higher levels of stress and rates of clinical depression than non-carers (Petrikis et al., 2019).

Moreover, the researchers found that higher depression and comorbidity were more prominent among female carers. Similarly, a study on gender differences between caregivers found that women reported lower mental health and social support than men (Perrin et al., 2015). Studies note that females experience more strain and psychological distress (Lee et al., 2015; Maguire & Maguire, 2020; McKenzie et al., 2015; Perrin et al., 2015), while males experience higher physical caregiving concerns (McKenzie et al., 2015).

Feelings of anger, irritation, and frustration may also emerge for caregivers. The situation can feel unfair for the patient and the carers coping with a progressive neurological disorder

(Kalb, 2019). Furthermore, anger and frustration can build when caregivers bottle up their feelings. Thus, abusive relationships can form when carers fail to address their feelings of anger and frustration. The dangers of physical abuse can begin in the context of giving or getting personal help. Although physical abuse can be blatant, emotional abuse can be less conspicuous, unhealthy, and damaging.

Caregiving Statistics

The American Association of Retired Persons (AARP) and The National Alliance for Caregiving (NAC) produce a research report on caregiving in the United States every five years. Their most recent update in 2020 revealed a significant increase in family caregivers in the U.S. of 9.5 million from 2015 to 2020. The survey data found that about one in five (19%) Americans provides unpaid care to an adult with a health or functional need. Americans caring for more than one person increased from (18%) in 2015 to (24%) in 2020.

Many studies demonstrate that the population of female caregivers surpasses that of men. NAC and AARP reported that 61% of caregivers identified as female compared to 39% of males. Several motives may rationalize the substantial imbalance of gender participation in this role (Sharma et al., 2016). Previous research indicates that culture may influence caregiving characteristics (Maguire & Maguire, 2020). Although most caregiving literature denotes that women typically fulfill this role, other studies have comprised male participants (Rajachandrakumar & Finlayson, 2021). In this regard, a study measuring QoL in caregivers of people with MS reported that 53.4% were male caregivers (Petrikis, 2019). According to the researchers, this may be partly because MS is more prevalent among women, and spouses are likely to be the primary caregiver (Petrikis, 2019; Rajachandrakumar & Finlayson, 2021).

Nevertheless, gender participation can vary by disability (del-Pino-Casado et al., 2012; Sharma et al., 2016).

Culture and Diversity in Caregiving

How caregivers manage their caregiving tasks can be determined by their values, preferences, knowledge, and skills. A study by Moon and colleagues reported that aspects of caregiving can vary by ethnicity (2020). This aligns with findings supported by Cohen and colleagues (2019), who studied gender differences in race and ethnicity among informal caregivers and noted substantial inequalities among gender and racial/ethnic groups, mainly economic impacts in minority caregiving groups. Familism may also be shaped by ethnicity. Campos et al. (2014) defined *familism* as a "cultural value that emphasizes warm, close, and supportive family relationships and that family is prioritized over self" (p. 191). Overall, familism demonstrates interconnectedness and prosperity.

Although differences may vary among groups, it is vital to bring attention onto other caregiving characteristics clinicians must consider when working with diverse individuals. Caregiving interventions suggested by Sander et al. (2019) propose considering sociocultural variables such as "appraisals, level of acculturation, neighborhood characteristics, financial resources, social support, and non-injury-related stressors" (p. 8). Additionally, the authors suggest that a comprehensive examination of sociocultural factors should be addressed when working with caregivers rather than focusing on one aspect.

Hispanic Families

According to AARP and NAC (2020), Hispanic caregivers are, on average, younger than other racial/ethnic groups. Hispanic caregivers are commonly married or live with a partner and typically have lower incomes and education than other ethnic groups. Hispanic caregivers work

36.7 hours a week while providing care and experience more financial impacts than non-Hispanic whites. About 43% of Hispanic caregivers care for a parent, while 14% care for a grandparent. Concerning living arrangements, nearly half (48%) of Hispanic caregivers live in the same home with their care recipient. Hispanic caregivers also provided more hours of care than Non-Hispanic White caregivers.

Aranda and Knight (1997) studied the influence of ethnicity and culture on caregiver stress in Latino caregivers. The researchers recognized that ethnic minority carers and culture played a role in Latinos stress and coping processes. Hispanic and Latino communities often take on the role of a family caregiver out of familial obligation (Llanque & Enriquez, 2012). On the other hand, others may not view this role as a cultural commitment and take pride and honor in caring for a loved one (Nava-Schellinger, 2021). Regarding gender differences, Hispanic/Latino women may feel a sense of duty or may be expected to fulfill the role of caring for a family member. Similarly, Virginia et al. (2019) found that the Hispanic population in their study held higher expectations of their daughters as primary caregivers.

African American Families

African American caregivers are more often unmarried than other racial/ethnic groups and report lower household incomes (National Association of Retired Persons, 2020). The average age of the typical caregiver is 47.7 years old. Additionally, they experience higher impact care situations than other racial/ethnic groups. On average, they work about 37.5 hours per week providing care. About 55% were reportedly the sole unpaid caregiver for a loved one compared to (44%) of Non-Hispanic White caregiver counterparts. The AARP and NAC (2020) found that while African American caregivers felt they had no choice in taking on the role, they reported a sense of purpose and meaning.

Patterns of familism and perceived social support have been reported. According to Falzarano and colleagues (2021), higher levels of social support were seen among the African American participants, who experienced lower burden and depression than White participants. Closeness and familism are also mediating components within this population. For example, a study on cross-cultural differences found that African American participants exhibited higher levels of familism than White participants (Falzarano et al., 2021). They also noted that compared to white participants, the African American participants' endorsement of familism predicted increased positive caregiving appraisals.

Asian Pacific Islander Families

As one of the fastest-growing ethnic groups in the U.S., Asian Americans and Pacific Islanders (AAPI) are generally reported to hold strong cultural norms and values. Similar to other ethnic groups, cultural norms and values strongly shape the role and experiences of AAPI caregivers. AAPIs are more likely than other groups to live in multigenerational homes (Montenegro, 2014), and caregivers typically care for a parent or parent-in-law with a long-term physical condition (National Alliance for Caregiving, 2020). Concerning living conditions, 51% of AAPI reported living in the same home as their care recipient, significantly more than Non-Hispanic White caregivers. In line with general statistics, AAPI informal caregivers are expected to increase with the rise of an aging population.

Psychological Stress and Caregiving

Caregiver stress is experienced when a person endures unmanageable stress and anxiety due to caregiving. Stress is a common reaction to everyday pressures, but too much stress can become unhealthy when it upsets day-to-day function (Fuller et al., 2003). In their theory of stress and coping, Lazarus and Folkman (1984) note how psychological stress affects individuals learning to cope with their new situation. Further, they illustrate psychological stress as the relationship between a person and their environment, which is appraised as taxing or exceeding their resources, thus affecting their welfare. Lazarus and Folkman (1984) also propose that aside from concrete costs, stress is subjective and can determine the impacts of stressors on caregiver well-being. Therefore, individual stress and coping styles affect carer adaptation (Lazarus & Folkman, 1984; Lee & Song, 2022).

Stress is known to cause changes in the body that can affect every bodily system, influencing how people feel and manage (Fuller et al., 2003). Excess stress can cause mind-body changes, directly contributing to psychological and physiological disorders and disease. Unmanaged stress can take hold of mental and physical health and ultimately reduce the quality of life. Kim (2017) studied the relationship between caregiver stress, depression, and self-esteem in family caregivers of adults with a disability and found that stress had a significant positive correlation with depression and psychological stress. Furthermore, the study found that female participants who were unemployed with higher caregiving costs and longer time spent providing care reported higher stress. Regarding employment and stress, Longacre et al. (2017) revealed that participants who experienced work interferences or changes in work status were more likely to report higher levels of emotional stress due to caregiving demands among informal caregivers for older adults. Moreover, McKenzie and colleagues (2015) found moderate stress levels reported among MS caregivers in their study.

Other negative determinants among stressed caregivers are that they may interact negatively with the care recipient, voice criticism, express discouragement, or provide poor emotional support to their loved one (Pristavec, 2019). Although a plethora of factors may contribute to caregiver strain, Sullivan and Miller (2015) note that sharing emotions with others helps relieve stress and may offer a different perspective on life. Mitigating stress is vital to cope with the future demands of informal caregiving (Lindt et al., 2020).

The Transactional Theory of Stress and Coping

The Transactional Theory of Stress and Coping (TSC), developed by Lazarus and Folkman (1984), has been instrumental in the development of stress and coping research over the past decades (Biggs et al., 2017). Presently, it remains one of the most widely accepted and influential theoretical models (Losada-Baltar, 2017) to conceptualize the impacts of caregiving research and presents a visionary approach to stress with a focus on cognitive appraisal (Lazarus & Folkman, 1984). Lazarus conceptualized stress as an organizational model for understanding phenomena critical to human adaptation, which can manifest as a response, stimulus, and transaction (Lazarus, 1966).

Further, Lazarus and Folkman (1984) state that stress is part of a sphere of a meaning which is as follows: Psychological stress, the "relationship between the person and the environment that the person appraises as taxing or exceeding their resources and endangering his or her well-being" (p. 19). Stressors involving significant change affect people in distinct ways. Stressors may range from daily hassles (i.e., having too many responsibilities), excess workload (Janah & Hargiana, 2021), and loneliness (Lazarus & Cohen, 1977).

People and groups respond differently based on their sensitivity and vulnerability to specific events. To expand on this framework, Lazarus and Folkman (1984) introduced the concept of cognitive appraisal. Cognitive appraisal is the "process of categorizing an encounter, and its various facets, concerning its significance for well-being" (p. 31). This process reflects on the unique and challenging characteristics (values, commitments, styles of perceiving and thinking) and the environment in which these aspects must be predicted and interpreted. Haley et al. (1996) support the concept of cognitive appraisal, as noted in their study, to mediate the adverse effects of stressors among caregivers.

The appraisal process is needed to recognize that to survive and flourish, people must distinguish between benign (e.g., not harmful) and dangerous situations. Lazarus and Folkman (1984) explained that there are two main concepts within appraisal: primary appraisal and secondary appraisal and they differ by “Am I in trouble or being benefited, now or in the future, and in what way?” and “What if anything can be done about it?” (p. 31). Lazarus and Folkman (1984) further clarified that primary appraisals are the judgment that an encounter is irrelevant, benign-positive (positive encounters), or stressful (harm/loss, threat, and challenge). While the secondary appraisal is what might and can be done when in jeopardy or facing a threat or challenge. They concluded that it is a complex evaluative process to consider which coping options are available to the person and secondary appraisals assess what is at stake in shaping the emotional reaction's degree of stress, strength, and quality.

The transactional stress and coping theory also emphasize assessing the individual and their society and that this is vital since society is often viewed as shaping people's basic survival-related adaptational needs (Lazarus & Folkman, 1984). Moreover, culture can play a critical role as it helps define what is essential, desirable, damaging, or ignorable to a person. Following significant stressors, Saban et al. (2010) suggest that race and culture may mediate the relationship between social support and psychological stress in family caregivers and cultural influences may define how emotions are expressed and managed. They further assert that despite the unifying effects of social context, it is essential to mention that there are individual differences in thoughts, feelings, and behaviors and therefore, stress and adaptational outcomes must be viewed in the context of people's relationships with the society in which they live.

As Lazarus and Folkman (1984) conceptualized, the transactional theory proposes that people's capacity to overcome and adjust to challenges and problems is due to the consequences of transactions (interactions) between the individual and their environment and stress is experienced distinctly through emotions and behaviors. As earlier explained their theory differentiated primary appraisal which identifies perceived stress and the symptoms associated with it and the secondary appraisal which assesses coping efficacy, such as social support resources and resilience. Therefore, this framework can evaluate the damages, threats, and challenges experienced by informal caregivers.

Perceived Social Support and Challenges

Social support remains integral to human nature regardless of demographics. A solid emotional support system has many advantages. Support can also protect against life's hardships (American Psychological Association, 2018). The American Psychological Association (2018) defines social support as providing help or comfort and helping others cope with biological, psychological, and social stressors. They further assert that the type of support may develop through interpersonal relationships and networks such as family members, friends, neighbors, religious institutions, colleagues, or support groups and that it may take the form of practical help (e.g., doing chores, offering advice), "tangible support that involves giving money or other direct material assistance, and emotional support that allows the individual to feel valued, accepted, and understood" (para. 1).

According to Hailey (2023), there is a distinction between support received and the perceived availability of support during a time of need. Perceived social support is the extent to which an individual perceives friends' and family members' availability for them and the degree of attentiveness to their needs (Ioannou et al., 2019; Scarapicchia, 2017). Receiving support lends to a sense of being part of a community that loves, supports, cares for, and values each other. Perceived social support has also been associated with health aspects such as improved psychological well-being (Wilson et al., 2020). Studies support that socially integrated individuals who form social ties live happier and longer lives (Inagaki & Orehek, 2017).

Caregiving literature has demonstrated the needs and benefits of being part of a social support system. Different levels of stress require different types of support. The quality and quantity of one's social relationships are even more significant for stressed and busy family caregivers (Morris, 2020). Leung and colleagues (2020) found that carers who perceived having a higher level of family support tended to have a higher self-efficacy and lower burden. In comparing informal and formal social support, Shiba et al. (2016) also found that informal social support was significantly associated with lower strain. Furthermore, Leung and colleagues (2020) found that caregivers with higher perceived familial support had higher self-efficacy. Ultimately, social support is strongly associated with psychological resilience; although it may not be universally helpful, its effectiveness will vary to match individual needs, which may change over time (Southwick et al., 2017).

Theoretical Framework

Providing care to a loved one can be long-lasting and is associated with many demands and responsibilities that impact the caregiver's life (Losada-Baltar, 2017). Although society has relied on informal family caregiving as the primary source of care, we still need an accurate understanding of which individual components affect caregiver well-being. According to previous studies on family caregiving, conditions such as gender, ethnicity, age, marital status, kinship to the person being cared for, and perceived social support may impact additional daily stressors for the caregiver and, therefore, should be further investigated. This study investigated the impacts of caregiving and social support on stress for unpaid informal caregivers of people with multiple sclerosis. Due to the lack of literature specifically reporting on the interaction between MS caregiving, demographic variables, and social support, there is a need for additional research on how these factors may aggregate or mitigate the effects of stress. Therefore, this study explores variables such as gender, ethnicity, kinship, and social support on perceived stress to determine the areas of greater need. Findings can assist clinicians, health professionals, and others to work with this population more effectively. This study comprises four research questions to explore the impacts of caregiving by assessing caregiver demographic characteristics, perceived social support, and perceived stress.

Summary

Ongoing home care for persons with MS relies largely on informal caregivers; spouses' other family members and friends. Informal caregiver's ability to work, engage in social relationships, and maintain adequate physical and mental health may become challenging (Talley & Crews, 2007). Caregivers usually do not provide care in isolation from other responsibilities. Thus, these roles may overlap with other aspects of their lives as spouses, partners, parents, employees, and community members (Committee on Family Caregiving, 2016). In their study, Madan and Pakenham (2015) found that stress was a focal predictor of adjustment to caregiving. Accordingly, mitigating the effects of stress is necessary to coping with the future demands of informal caregiving (Lindt et al., 2020). Identifying MS informal caregiver needs and understanding how caregiver demographic factors may contribute to physical and emotional strain are critical to developing the appropriate interventions for this population.

CHAPTER III

RESEARCH METHODOLOGY

Few studies have addressed the impacts of stress on unpaid informal caregiving for people with multiple sclerosis. The overall purpose of this study was to examine the implications of caregiving and perceived social support on perceived stress for unpaid informal caregivers of persons with MS. This chapter discusses the study design used to address the research questions. Participants, recruitment, procedures, data collection, instrumentation, protection of human subjects, and data analysis are presented. The instruments that were utilized were Cohen et al. (1983) Perceived Stress Scale (Appendix A), Zimet et al. (1988) Multidimensional Scale of Perceived Social Support (Appendix B), and a caregiver demographic questionnaire (Appendix C).

Participants

The sample for this study consisted of adult caregivers in the United States who provide care to a loved one with MS. The study consisted of 122 informal, unpaid caregivers. The sample size for this study was calculated using G*Power, Version 3.1 software. An a priori calculation yielded a sample size of 111 participants with three comparison groups at a medium effect size (F = .30) and a power of .80.

The inclusion criteria for participation were: (a) individuals 18 years or older who identified as a caregiver for a person with MS, (b) have a minimum of six months unpaid caregiving experience, and (c) the ability to read and understand the English language (see Appendix D).

Recruitment, Procedures, Data Collection

Recruitment

Invitations for participation were distributed using an informational flyer sent to emails, online social media platforms, blogs, and websites supporting MS carers and relative populations. The informational flyer was also published online by organizations like The National MS Society and the Family Caregiving Alliance. The study flyer provided information on the purpose of the study, benefits of participation, inclusion criteria, the researcher's contact information, information on an incentive opportunity, the online Qualtrics survey link, and a QR code. Participants were offered the option to enter an anonymous, randomized drawing of ten $25.00 Amazon eGift cards as an incentive for completing the online survey instrument (see Appendix D).

Procedures

Permission to use the Perceived Stress Scale (PSS-10) was waived as it is not required for research purposes. The items of the PSS-10 are available in the article's appendix by Cohen et al. (1983). Permission to use the Multidimensional Scale of Perceived Social Support (MSPSS) is also waived as it is free of use and does not require a license. The demographic questionnaire was created for this study by the researcher.

Data Collection

Approval from the University of Texas Rio Grande Valley's Institutional Review Board was granted prior to data collection (see Appendix E). Informal caregivers were recruited from July 2023 to October 2023. Recruitment occurred on an ongoing basis until the desired sample size was met. Data was managed by Qualtrics software and downloaded as an Excel sheet. The file contained participant responses recorded anonymously. The researcher collected the study data, oversaw logistics, and kept all electronic files in password-protected software. The data collection's date, time, and location were established at the convenience of the caregiver. The actual setting for the data collection is unknown as the method used to collect data consisted of an anonymous online Qualtrics survey.

Instrumentation

This study consolidated three instruments (demographic questionnaire, Perceived Stress Scale, and Multidimensional Scale of Perceived Social Support) to assess caregiver demographic characteristics, perceived social support, and perceived stress. The online Qualtrics survey included a total of 33 items and had a completion time of about 10 minutes.

The first item presented the informed consent form, eliciting an “I consent” or “I do not consent” response (see Appendix F). Participants who granted consent were prompted to the survey questions. An “I do not consent” response would disqualify people from completing the survey and be redirected to a “Thank you” page to end the survey.

The following questions prompted participants with demographic questions and summaries of the instructions for each section of the above-stated instruments. The first nine items included caregiver demographic questions (2-10). The two additional psychometric instruments included the *Perceived Stress Scale* (items 11-21) and the *Multidimensional Scale of Perceived Social Support* (items 22-32). Both instruments are comprised of Likert scale questions. A final item (item 33) asked participants if they would like to voluntarily enter the randomized drawing for a chance to receive one out of 10 $25 Amazon eGift cards. Participants who agreed “Yes” were prompted into a separate Qualtrics survey to enter a preferred email.

This method was used to ensure participant responses remained anonymous from their survey responses.

Descriptive data were obtained through demographic questions developed for this study (see Appendix C**)**. The researcher created the demographic questionnaire and refined it based on expert advice from three professionals from the South-Central region of the United States with extensive experience in rehabilitation counseling. The demographic portion of the survey included gender, ethnicity, marital status, educational level, household income, employment status, hours per week of caregiving, and kinship to the person being cared for.

Perceived Stress Scale is a stress assessment scale developed by Cohen et al. (1983). The PSS-10 is a 10-item scale measured on a five-point Likert scale (0= Never, 1= Almost never, 2= Sometimes, 3= Fairly often, 4= Very often), assessing individual stress levels (see Appendix A). The questions on this scale elicit participants' feelings and thoughts during the last month. Participants are advised to answer questions quickly for accuracy. Higher scores indicate higher levels of perceived stress. This tool is widely used to help people understand how different situations affect feelings and perceived stress (She et al., 2021). Specifically, it intends to evaluate how individuals perceived life as unpredictable, uncontrollable, and overloading within the previous month (Cohen et al.,1983). Perceived Stress Scale items are stress-based, for example, "*In the last month, how often have you been upset because of something that happened unexpectedly*?"

To calculate the total PSS score, items (4, 5, 7, 8) must be reversed. The total PSS score is then calculated by summing across all items. Individual scores on the PSS can range from 0 to 40 (Cohen et al., 1983).

- Scores ranging from 0-13 are considered low stress.

- Scores ranging from 14-26 are considered moderate stress.
- Scores ranging from 27-40 are considered high perceived stress.

The PSS-10 can be used with adolescent and adult populations. Research suggests that the instrument demonstrates meaningful comparisons among racial, ethnic, and linguistic groups (Kechter, 2019) and has been translated into 25 languages other than English (Lee, 2012). A study on the evaluation of the measurement properties of the Perceived Stress Scale in Hispanic caregivers found that the instrument's reliability estimates were high, with a coefficient alpha of 0.88 for the total sample (Teresi et al., 2020). Another study on perceived stress levels and sleep quality among caregivers found the PSS-10 reliable, with a score of 0.82 and an internal validity of 0.78 (Yildirim & Karakurt, 2022). The PSS-10 is a recognized and acceptable instrument for caregiving research studies.

The Multidimensional Scale of Perceived Social Support (see Appendix B) is a long-established self-report assessment developed by Zimet et al. (1988). The MSPSS is a 12-item instrument measured on a seven-point Likert scale (1 = Very strongly disagree, 2 = Strongly disagree, 3 = Mildly disagree, 4 = Neutral, 5 = Mildly agree, 6 = Strongly agree, 7 = Very strongly agree). The instrument contains three informal sources relating to the source of social support, namely, family, friends, or significant others. The total scores range from a minimum of 12 to 84 between all three sources. Higher scores indicate higher total perceived social support. Items included are related to social support, for example, "*I can talk about my problems with my friends*" and "*I get the emotional help and support I need from my family*."

Scoring for the MSPSS is obtained by calculating the value for each participant (Zimet et al., 1988). All 12 items must be summed and then calculated by the mean score to calculate the total score.

- Scores ranging from 1 to 2.9 indicate low support.
- Scores ranging from 3 to 5 indicate moderate support.
- Scores ranging from 5.1 to 7 indicate high support.

Zimet et al. (1988) reported a high internal consistency of 0.88 and a test-retest reliability of 0.85 over 2 to 3 months after completing the MSPSS questionnaire. The results of their study indicated that the MSPSS is a psychometrically sound instrument. The instrument's authors hypothesize that higher levels of perceived social support are associated with lower levels of depression and anxiety symptomology. In a study on older adult caregivers by Ong et al. (2018), the MSPSS had a Cronbach's alpha of 0.92. A study on family caregivers reported that the MSPSS demonstrated a Cronbach's alpha between 0.70 and 0.92 (Menekli & Şentürk, 2022). Cartwright and colleagues (2022) reported a good internal consistency of 0.92 for the MSPSS in their study on perceived social support for family caregivers. Therefore, the MSPSS shows good internal reliability among caregiving populations.

Human Subjects

Participants in this study were protected at all times under the guidelines of the Investigational Review Board (IRB) set forth by The University of Texas Rio Grande Valley (Appendix E). Potential risks and benefits of the study were stated on the informed consent and the recruitment email obtained by each participant (see Appendix F and G). The risks to each participant were minimal. The informed consent contained social support references for individuals who needed emotional support assistance. Participant information remained anonymous throughout the study, and all data was kept private and confidential. Participation was entirely voluntary, and participants were informed that they may withdraw at any time without penalty. The benefits of participation allowed individuals to share their perceptions and help formulate an understanding of the impacts of informal caregiving. Furthermore, participation granted firsthand perceptions to assess what is needed to mediate caregiver psychosocial challenges. Participation in this study was an essential contribution to the body of knowledge on the impacts of informal caregiving for persons with MS.

Data Analysis

Data analysis was imported and analyzed using IBM Statistical Package for Social Sciences (SPSS) version 28 software. Statistical analyses, such as descriptive and inferential statistics, frequencies, independent sample t-test, and analysis of variance (ANOVA), were employed to evaluate the study's research questions. Statistical mean differences between independent and dependent variables were examined. Descriptive statistics and frequencies were used to assess central tendency and variability, specifically the mean and standard deviation. Frequencies were used to analyze participant demographic characteristics, perceived social support, and stress. Descriptive statistics and frequencies were employed to address research questions one and two, assessing perceived social support and stress among informal caregivers.

To examine the relationship between caregiver stress and social support, a bivariate correlation analysis was applied to address research question three, which examined the relationship between caregiver perceived stress and perceived level of social support. Correlational research is a statistical analysis used to assess the tendency or pattern for two or more variables that may vary consistently (Creswell, 2008). Pearson's correlation was assessed for linearity by visual inspection of a scatterplot. No significant outliers were detected.

Frequencies, independent sample t-tests, and one-way ANOVAs were applied to address research question four. Independent sample t-tests quantify and determine significant differences between the mean scores of two groups while considering the variance or distribution (Wadhwa

& Marappa-Ganeshan, 2023). The independent sample t-test examined mean differences between male and female informal caregivers and perceived stress. ANOVAs are statistical tests that assess for statistical differences between the means of three or more independent groups (Kim, 2017). A one-way ANOVA examined mean differences between ethnicity and perceived stress. A second one-way ANOVA was employed to analyze mean differences between kinship and perceived stress. Quantitative results were reported regarding strength, direction, and statistical significance. The research questions selected for this study are consistent with the study design. The significant level for the above-mentioned analyses was set at p <. 05.

CHAPTER IV

RESULTS

The purpose of this study was to examine caregiving impacts and social support on stress for unpaid informal caregivers of persons with MS. Through quantitative data analysis using descriptive, inferential, frequencies, and correlation methods, the current study aimed to a) assess correlations of perceived stress and perceived social support, b) examine if there is a relationship between perceived social support and perceived stress, and c) examine whether participant demographic characteristics (i.e., gender, ethnicity, kinship to the person cared for) are associated with perceived stress. This chapter presents the survey data results.

Demographics

The sample data was collected from 330 participants nationwide from July 2023 to October 2023. Of the 330 responses, only 122 surveys met the criteria. Data discarded from the analysis were excluded if less than 80% were completed or due to fraudulent and suspicious behavior. False data suspected to be fraudulent may be submitted by individuals who employ bots to complete surveys (Lawrence et al., 2023). Bots are automated computer program fillers that complete online forms (Rauchfleisch & Kaiser, 2020). The researcher detected bots after receiving a large number of submissions in a small window of time (e.g., 80 surveys completed in rapid succession), which typically takes 10 to 15 minutes to complete. Qualtrics was notified and took measures to prevent multiple submissions by the same individual. The researcher reviewed all 330 survey responses to identify fraudulent versus authentic survey submissions. To ensure the validity of participant responses, the researcher completed a multi-stage check review by assessing the timeline and submission of surveys. Submissions that occurred within a short time (less than 5 minutes) were considered suspicious and removed (Lawrence et al., 2023). Final completed surveys were assessed for quality and authenticity by the researcher by assessing 1) the timestamp of the survey, and 2) reviewing the beginning and end of the survey (Pozzar et al., 2020).

The mean age of participants was 45.1 (range 20-84). The sample was predominately comprised of females 81 (*n* = 66.4) and males 41 (*n* = 33.6). Ethnicity (*N* = 122) was identified as a majority Caucasian 67.2% (*n*= 82), Latino/Hispanic 28% (*n* = 23), multiracial 5.7% (*n* = 7), and African American 4.1% (*n* = 5). Regarding marital status, the majority of participants reported married 73.8% (*n* = 90), single 11.5% (*n* = 14), divorced 9.8% (*n* = 12), and widowed 3.3% (*n* = 4). Participants reported the highest educational level they achieved (N = 122) as: bachelor's degree 37.7% (*n* = 46), high school 27% (*n* = 33), trade/vocational school 13.9% (*n* = 17), graduate degree 13.1% (*n* = 16), and some high school 8.2% (*n* = 10). Participants reported a majority of household income of $50,000 - $99,999, 54% (*n* = 66), followed by $25,000 - $49,999, 19.7% (*n* = 24), less than $24,999, 13.1% (*n* = 16), $100,000 - $199,000, 11.5% (*n* = 14), and $200,000 or more, 0.8% (*n*= 1). In terms of employment status, the majority of participants reported full-time employment 54.1% (*n* = 66), retired 23% (*n* = 28), unemployed 12.3% (*n* = 15), and employed part-time 10.7% (*n* = 13). Participants reported hours of unpaid care: 6 to 20 hours per week 45.9% (*n* = 56), 21 to 40 hours per week 19.7% (*n* = 24), 40 hours or more per week 27% (*n* = 56), and 5 hours per week or less 7.4% (*n* = 9). In terms of kinship to the person cared for, the majority of participants reported they were a spouse or partner, 42.6%

(*n* = 52), followed by daughter/son, 22.1% (*n* = 27), mother/father 14.8% (*n* = 18), sister/brother 10.7% (*n* = 13), aunt/uncle 2.5% (*n* = 3), or friend 5.7% (*n* = 3).

Table 1 contains participant demographic characteristics, which include gender, ethnicity, marital status, educational level, household income, employment status, hours per week caring for the care recipient, and kinship to the person cared for.

Table 1

Frequency of Demographic Variables

Characteristic	*n*	%
Gender		
Female	81	66.4
Male	41	33.6
Other		
Ethnicity		
African American	5	4.1
Caucasian	82	67.2
Latino/Hispanic	28	23.0
Multiracial	7	5.7
Marital Status		
Single	14	11.5
Married	90	73.8
Divorced	12	9.8
Widowed	4	3.3
Educational Level		
Some high school	10	8.2
High school	33	27.0
Bachelor's degree	46	37.7
Graduate degree	16	13.1
Trade/Vocational	17	13.9
Household Income		
Less than \$24,999	16	13.1
\$25,000 - \$49,999	24	19.7
\$50,000 - \$99,999	66	54.1
\$100k - \$199k	14	11.5
\$200k +	1	.8
Employment Status		
Employed full-time	66	54.1
Employed part-time	13	10.7
Unemployed	15	12.3
Retired	28	23.0

Table 1 (continued)

Characteristic	*n*	%
Hrs. per week Caring		
5hrs. per wk. or less	9	7.4
6 – 20hrs.	56	45.9
21 – 40hrs	24	19.7
40+ hrs. per week	33	27.0
Kinship		
Aunt/Uncle	3	2.5
Daughter/Son	27	22.1
Friend	7	5.7
Spouse/Partner	52	42.6
Mother/Father	18	14.8
Sister/Brother	13	10.7

Note. *N* = 122

Descriptive Statistics

To address research question one, "What are the frequency levels of stress among informal caregivers?" Descriptive statistics were employed to examine the oftenness of perceived stress for the population sample. Participants were asked to complete the Perceived Stress Scale (PSS) by Cohen and colleagues (1983). The PSS survey consists of 10 items on a 5-point Likert scale ranging from (0 = Never, 1 = Almost never, 2 = Sometimes, 3 = Often, and 4 = Very often) with higher scores indicating higher perceived stress. The theme of the PSS questions is stress-based, denoting stress experiences within the past month.

Participants reported, "Sometimes" to the statements, "*In the last month, how often have you been upset because of something that happened unexpectedly*?" (*M* = 2.28, *SD* = .85), "*In the last month, how often have you felt that you were unable to control the important things in your life*?" (*M* = 2.36, *SD* = .98), "*In the last month, how often have you found that you could not cope with all the things that you had to do*?" (*M* = 2.27, *SD* = 1.01), "*In the last month, how often have you been able to control irritations in your life*?" (*M* = 2.29, *SD* = .82), "*In the last month, how often have you felt that you were on top of things*?" (*M* = 2.21, *SD* = .99), "*In the last month, how* *often have you been angered because of things that happened that were outside of your control*?" (*M* = 2.27, *SD* = .85), and "*In the last month, how often have you felt difficulties were piling up so high that you could not overcome them*?" (*M* = 2.27, *SD* = 1.01).

Participants reported "Fairly often" to the statement, "*In the last month, how often have you felt nervous and stressed*?" (*M* = 2.54, *SD* = .98)

Analysis of frequencies on the oftenness of PSS items for participants reporting "Fairly often" and "Very often" warranted further inspection. Second, the (*n*) and percentages for "Fairly often" and "Very often" were consolidated for review, and the results are as follows. On item one, "*In the last month, how often have you been upset because of something that happened unexpectedly*?" 36.9% (*n* = 45) of participants reported feeling upset about unexpected events fairly often and very often. On the item "*In the last month, how often have you felt that you were unable to control the important things in your life*?" 43.4% (*n* = 53) of participants reported an inability to control the important things in life fairly often and very often. On the third item, "*In the last month, how often have you felt nervous and stressed*?" 51.6% (*n* = 63) of participants reported feeling stressed and nervous fairly often and very often. On item four, "*In the last month, how often have you found that you could not cope with all the things that you had to do*?" 39.3% (*n* = 48) of participants reported an inability to cope with all the things they had to do fairly often and very often. On item five, "*In the last month, how often have you been able to control irritations in your life*?" 36.9% (*n* = 45) of participants reported being able to control irritations fairly often and very often. On item six, "*In the last month, how often have you felt that you were on top of things*?" 36.1% (*n* = 44) of participants reported they were able to stay on top of things fairly often and very often. On the two final items, "*In the last month, how often have you been angered because of things that happened that were outside of your control*?"

40.2% (*n* = 49), and "*In the last month, how often have you felt difficulties were piling up so high that you could not overcome them*?" 40.2% (*n* = 49) of participants reported experiencing anger and difficulties fairly often and very often.

After computing a reliability analysis on the original PSS-10 items, removal of questions four, "*In the last month, how often have you felt confident about your ability to handle your personal problems*?" and five, "*In the last month, how often have you felt that things were going your way*?" increased the Cronbach's Alpha to .78. Therefore, eight of the ten items were used to compute the statistical analysis. Overall, the total score of the PSS with the removal of the items mentioned above indicated that unpaid informal caregivers experienced moderate perceived stress (*M* = 17.5, *SD* = 4.72) as indicated by Cohen et al. (1983) scale measurement (scores ranging from 14-26 are considered moderate stress). However, after a review of the frequency and percentage on the oftenness of participants reporting "Fairly often" and "Very often," it is evident that informal MS caregivers experience high perceived stress under certain circumstances, such as being unable to control the important things in life and feeling nervous and stressed in the last month.

Table 2 identifies mean scores, standard deviations, and frequencies for all eight Likert questions on participant perceived stress.

Table 2

Frequency of Cohen et al. (1983) Perceived Stress Scale (n= 122)

Items	*n*	*M (SD)*	Never *n (%)*	Almost Never *n (%)*	Sometimes *n (%)*	Fairly Often *n (%)*	Very Often *n (%)*	Skewness	Kurtosis
1. In the last month, how often have you been upset because of something that happened unexpectedly?	122	2.28 (.85)	2 (1.6)	16 (13.1)	59 (48.4)	35 (28.7)	10 (8.2)	.04	.04
2. In the last month, how often have you felt that you were unable to control the important things in your life?	122	2.36 (.98)	2 (1.6)	21 (17.2)	46 (37.7)	36 (29.5)	17 (13.9)	.00	-.60
3. In the last month, how often have you felt nervous and stressed?	122	2.54 (.98)	2 (1.6)	15 (12.3)	42 (34.4)	41 (33.6)	22 (18.0)	-.19	-.50
4. In the last month, how often have you found that you could not cope with all the things that you had to do?	122	2.27 (1.01)	5 (4.1)	20 (16.4)	49 (40.2)	33 (27.0)	15 (12.3)	-.08	-.36
5. In the last month, how often have you been able to control irritations in your life?	122	2.29 (.82)	1 (0.8)	16 (13.1)	60 (49.2)	36 (29.5)	9 (7.4)	.13	-.03
6. In the last month, how often have you felt that you were on top of things?	122	2.21 (.99)	2 (1.6)	29 (23.8)	47 (38.5)	29 (23.8)	15 (12.3)	.21	-.66
7. In the last month, how often have you felt angered because of things that happened that were outside of your control?	122	2.27 (.85)	1(0.8)	21(17.2)	51 (41.8)	41(33.6)	8(6.6)	-.00	-.40
8. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	122	2.27 (1.01)	6 (4.9)	18 (14.8)	49 (40.2)	35 (28.7)	14 (11.5)	-.17	-.25
9. Total	122	17.0(4.72)						-.53	59

To address research question two, “What are the frequency levels of perceived social support among informal caregivers?” descriptive statistics and frequencies were employed to examine the degree of agreement on perceived social support among informal caregivers of persons with MS. Participants were prompted to complete Zimet et al. (1988) Multidimensional Scale of Perceived Social Support (MSPSS). The survey consists of 12 items on a 7-point Likert scale ranging from (1 = Very strongly disagree, 2 = Strongly disagree, 3 = Mildly disagree, 4 = Neutral, 5 = Mildly agree, 6 = Strongly agree, 7 = Very strongly agree). Higher scores indicate higher perceived social support. The theme of the MSPSS items is based on individual perceptions of social support.

Participants reported “Neutral” to the statements, “*My family really tries to help me*” (*M* = 4.45, *SD* = 1.65), “*I get the emotional help and support I need from my family*” (*M* = 4.39, *SD* = 1.61), “*My friends really try to help me*” (*M* = 4.42, *SD* = 1.51), “*I can count on my friends when things go wrong*” (*M* = 4.43, *SD* = 1.63), “*I can talk about my problems with my family*” (*M* = 4.45, *SD* = 1.54), and “*My family is willing to help me make decisions*” (*M* = 4.45, *SD* = 1.71).

Participants reported “Mildly agree” to the statements, “*There is a special person who is around when I am in need*” (*M* = 4.53, *SD* = 1.59), “*There is a special person with whom I can share joys and sorrows*” (*M* = 4.73, *SD* = 1.52), “*I have a special person who is a real source of comfort to me*” (*M* = 4.68, *SD* = 1.61), “*I have friends with whom I can share my joys and sorrows*” (*M* = 4.55, *SD* = 1.54), “*There is a special person in my life who cares about my feelings*” (*M* = 5.03, *SD* = 1.46), and “*I can talk about my problems with my friends*” (*M* = 4.54, *SD* = 1.54).

Analysis of frequencies on the level of agreement on MSPSS items for participants reporting "Very strongly disagree, Strongly disagree, and Mildly disagree" warranted further inspection. Second, the (*n*) and percentages for the statements mentioned above were consolidated for review, and the results are as follows. For items one and three, "*There is a special person who is around when I am in need*," 24.6% (*n* = 30) and "*My family really tries to help me*," 24.6% (*n* = 30) of participants reported disagreement on having a special person when in need and feeling that family tries to help them. For items two, five, and twelve, "*There is a special person with whom I can share joys and sorrows*" 23.8% (*n* = 29), "*I have a special person who is a real source of comfort to me*" 23.8% (*n* = 29), and "*I can talk about my problems with my friends*" 23.8% (*n* = 29) of participants reported disagreement on not having a special person as a source of support or friends to talk about problems.

For items seven and eight, "*I can count on my friends when things go wrong*," 27.8% (*n* = 34) and, "*I can talk about my problems with my family*," 27.8% (*n* = 34) of participants reported disagreement in terms of counting on family when things go wrong or being able to talk about problems with them. For item four, "*I get the emotional help and support I need from my family*," 28.6% (*n* = 35) of participants reported disagreement with getting emotional help and support from family. For item six, "*My friends really try to help me*," 22.9% (*n* = 28) of participants reported disagreement with receiving help from friends. For item nine, "*I have friends with whom I can share my joys and sorrows*," 25.4% (*n* = 31) of participants reported disagreement in sharing joys and sorrows with friends. For item 10, "*There is a special person in my life who cares about my feelings*," 14.8% (*n* = 18) of participants reported disagreement with having a special person who cares about their feelings. For item 11, "*My family is willing to help* *me make decisions*." 32.8% (*n* = 40) of participants reported disagreement in having a family who helps them make decisions.

Overall, the total score for the MSPSS indicated that participants in this sample experienced moderate perceived social support (*M* = 4.56, *SD* = 1.52) as indicated by the Zimet et al. (1983) scale measurement (scores between 3 and 5 are considered moderate support). However, the frequencies in disagreement with statements on perceived social support indicate that participants also feel a lack of perceived support from some external sources such as family and friends.

Table 3 identifies mean scores, standard deviations, and frequencies for all 12 Likert questions about participant's perceived social support.

Table 3

Frequency of Zimet et al. (1983) Multidimensional Scale of Perceived Social Support (n= 122)

Items	n	M (SD)	Very Strongly Disagree n (%)	Strongly Disagree n (%)	Mildly Disagree n (%)	Neutral n (%)	Mildly Agree n (%)	Strongly Agree n (%)	Very Strongly Agree n (%)	Skewness	Kurtosis
1. There is a special person who is around when I am in need.	122	4.53 (1.59)	7 (5.7)	10 (8.2)	13 (10.7)	18 (14.8)	37 (30.3)	29 (23.8)	8 (6.6)	-.63	-.35
2. There is a special person with whom I can share joys and sorrows.	122	4.73 (1.52)	2 (1.6)	14 (11.5)	13 (10.7)	10 (8.2)	37 (30.3)	38 (31.1)	8 (6.6)	-.69	-.50
3. My family really tries to help me.	122	4.45 (1.66)	9 (7.4)	10 (8.2)	11 (9.0)	23 (18.9)	36 (29.5)	21 (17.2)	12 (9.8)	-.50	-.42
4. I get the emotional help & support I need from my family	122	4.39 (1.61)	7 (5.7)	11 (9.0)	17 (13.9)	22 (18.0)	30 (24.6)	27 (22.1)	8 (6.6)	-.42	-.63
5. I have a special person who is a real source of comfort to me,	122	4.68 (1.61)	5 (4.1)	11 (9.0)	13 (10.7)	16 (13.1)	33 (27.0)	32 (26.2)	12 (9.8)	-.60	-.45
6. My friends really try to help me.	122	4.42 (1.51)	6 (4.9)	10 (8.2)	12 (9.8)	29 (23.8)	37 (30.3)	19 (15.6)	9 (7.4)	-.45	-.21
7. I can count on my friends when things go wrong.	122	4.43 (1.63)	6 (4.9)	12 (9.8)	16 (13.1)	23 (18.9)	31 (25.4)	22 (18.0)	12 (9.8)	-.33	-.64

Table 3 (continued)

			Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree	Skewness	Kurtosis
Items	n	M (SD)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)		
8. I can talk about my problems with my family.	122	4.45 (1.57)	6 (4.9)	9 (7.4)	19 (15.6)	19 (15.6)	37 (30.3)	22 (18.0)	10 (8.2)	-.41	-.47
9. I have friends with whom I can share my joys and sorrows.	122	4.55 (1.54)	5 (4.1)	7 (5.7)	19 (15.6)	22 (18.0)	35 (28.7)	21 (17.2)	13 (10.7)	-.36	-.40
10. There is a special person in my life who cares about my feelings.	122	5.03 (1.46)	3 (2.5)	6 (4.9)	9 (7.4)	18 (14.8)	33 (27.0)	36 (29.5)	17 (13.9)	-.79	.24
11. My family is willing to help me make decisions.	122	4.45 (1.71)	7 (5.7)	13 (10.7)	20 (16.4)	10 (8.2)	31 (25.4)	31 (25.4)	10 (8.2)	-.44	-.88
12. I can talk about my problems with my friends.	122	4.54 (1.54)	5 (4.1)	9 (7.4)	15 (12.3)	24 (19.7)	36 (29.5)	21 (17.2)	12 (9.8)	-.41	-.34
13. Total	122	4.55(1.15)								-.42	.217

Correlation Analysis

To address research question three, “Is there a relationship between caregiver perceived stress and perceived level of social support?” a bivariate correlation was applied to evaluate the relationship between the dependent and independent variables. The analysis included the total score for the eight items on the Perceived Stress Scale and the total score for the 12 items on the Multidimensional Scale of Perceived Social Support. The results of Pearson’s correlation coefficient between the total PSS score and the total MSPSS score resulted in a moderate negative correlation $r = -.312$, $N = 122$, with a significance of ($p = .001$), indicating that higher perceived social support is correlated with lower perceived stress. Figure 1 depicts the strength and direction between the PSS and MSPSS total scores.

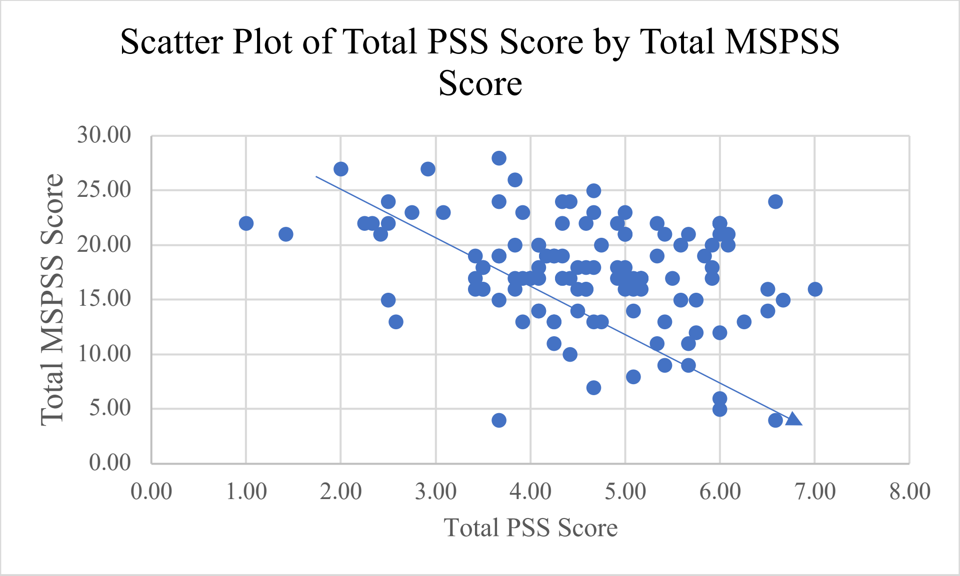

Figure 1. *Total PSS and MSPSS Scatter Plot*

Inferential Statistics

To address research question four, "Are there differences in caregiver stress based on demographic variables (i.e., gender, ethnicity, and kinship to the person being cared for)?" An independent sample t-test and one-way analysis of variance (ANOVA) were employed to examine the differences between perceived stress and demographic variables.

Gender

The demographic gender variable was collected as female or male and manually coded as (1, 2) on SPSS. An independent sample t-test was employed to compare the means between gender and the eight individual items on the Perceived Stress Scale. However, no significant mean differences were found. The variable of gender was then analyzed with the total PSS score. The results indicated there were no significant mean differences for gender $t(72.9) = 1.13$, $p = .26$. Therefore, the independent sample t-test demonstrated that there are no differences in perceived stress among females and male informal caregivers of persons with MS. Table 4 presents the results for gender and total Perceived Stress Scale score.

Table 4

T-Test Table Results on Gender and Total Perceived Stress Scale Score

Variable	*N*	*M*	*SD*	*t*	*df*	*p*	*d*
Gender							
Female	81	17.8	4.52	1.13	72.9	.262	.22
Male	41	16.8	5.06				

Ethnicity

A one-way ANOVA was conducted to test the mean differences between kinship to the person cared for and the total Perceived Stress Scale score. Participants were classified into three groups: Caucasian ($n = 82$), Latino/Hispanic ($n = 28$), and Other ($n = 12$). There was homogeneity of variance, as assessed by Levene's test for equality of variances ($p = .69$), indicating that the assumption of variances was not violated. PSS score increased from Latino/Hispanic (*M* = 16.1, *SD* = 5.41) to Caucasian (*M* = 17.9, *SD* = 4.49) and Other (*M* = 18.0, *SD* = 4.32), in that order. However, the differences between these groups were not statistically significant, *F*(2,119) = 1.53, *p* = .22. Table 5 presents results for ethnicity and total Perceived Stress Scale score.

Table 5

ANOVA Table- Ethnicity and Total Perceived Stress Scale Score (n= 122)

Measure	Perceived Stress Scale		*F*(2,119)	*p*
	M	*(SD)*		
Caucasian	17.9	4.49	1.53	.22
Latino/Hispanic	16.1	5.41		
Other	18.0	4.32		

Kinship

A final one-way ANOVA was conducted to test the mean differences between kinship to the person cared for and eight PSS items. Participants were classified into five groups: Spouse/Partner (*n* = 52), Daughter/Son (*n* = 27), Mother/Father (*n* = 18), Sister/Brother (*n* = 13), and Other (*n* = 12). Homogeneity of variance was not violated, as assessed by Levene's Test of Homogeneity of Variance. However, significant differences within groups were found.

On the item, "*In the last month, how often have you felt that you were unable to control the important things in your life?*" there was a significant difference (*p* = .00) between Other (*M* = 2.91, *SD* = .90) and Mother/Father (*M* = 1.72, *SD* = .89), indicating that participants who identified as another relative reported higher stress in being able to control the important things in their life than mothers and fathers. A second significant difference on the above-stated item (*p* = .02) was found between Spouse/Partner (*M* = 2.51, *SD* = .99) and Mother/Father (*M* = 1.72, *SD* = .89), indicating that spouses and partners experienced higher stress in being able to control of the important things in life than mothers and fathers. On the item, "*In the last month, how often have you felt nervous and stressed*?" there was a significant difference (*p* = .01) between Spouse/Partner (*M* = 2.77, *SD* = 1.01) and Mother/Father (*M* = 1.94, *SD* = .80), indicating that spouses and partners reported feeling more nervous and stressed than mothers and fathers. To the item, "*In the last month, how often have you been able to control irritations in your life?*" a significant difference (*p* = .00) was found between Spouse/Partner (*M* = 2.55, *SD* = .86) and Daughter/Son (*M* = 1.85, *SD* = .71), indicating that spouses and partners felt higher stress in controlling irritations in their life compared to daughters and sons. Table 6 presents the results for kinship and PSS items.

Table 6

ANOVA Table – Kinship and Cohen et al. (1983) Perceived Stress Scale (n= 122)

	(1) Spouse/Partner		(2) Daughter/Son		(3) Mother/Father		(4) Sister/Brother		(5) Other			
Items	*M*	*(SD)*	*M*	*(SD)*	*M*	*(SD)*	*M*	*(SD)*	*M*	*(SD)*	*F*(4,117)	*p*
1. In the last month, how often have you been upset because of something the happened unexpectedly?	2.46	.85	2.26	.71	1.88	.90	2.23	1.01	2.25	.87	1.56	
2. In the last month, how often have you felt that you were unable to control the important things in your life?	2.51	.99	2.37	.79	1.72	.89	2.15	1.06	2.91	.90	3.64	.00(5&3) .02(3&1)
3. In the last month, how often have you felt nervous and stressed?	2.77	1.01	2.62	.88	1.94	.80	2.61	.87	2.16	1.02	3.08	.01(1&3)
4. In the last month, how often have you found that you could not cope with all the things that you had to do?	2.36	1.07	2.29	.99	2.00	.97	2.38	.87	2.08	1.08	.575	
5. In the last month, how often have you been able to control irritations in your life?	2.55	.80	1.85	.71	2.11	.90	2.30	.63	2.41	.79	3.95	.00(2&1)
6. In the last month, how often have you felt that you were on top of things?	2.21	1.03	2.22	.97	2.16	1.09	2.07	.86	2.41	.99	.191	
7. In the last month, how often have you felt angered because of things that happened that were outside of your control?	2.25	.86	2.48	.80	1.88	1.02	2.38	.50	2.41	.90	1.48	
8. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	2.21	1.11	2.48	.75	1.83	.78	2.38	1.04	2.58	1.24	1.53	

CHAPTER V

DISCUSSION

According to the National MS Society, about one million people in the U.S. live with MS (2019). Progressive neurological disorders (PND), such as MS, are characterized by a condition in which there is an advancing deterioration in function due to damage to the central or peripheral nervous system, leading to limitations in the ability to engage in activities (Bužgová & Kozáková, 2019; Lamptey et al., 2022; Seeber et al., 2019). PNDs are diagnosed mid- to late-life, and prevalence is expected to rise (McIsaac, 2018; Reeve et al., 2014; Reitz et al., 2011). People between the ages of 20-50 are more commonly diagnosed with MS, and it is three times more common among women than men (National Multiple Sclerosis Society, 2023; Ransohoff et al., 2015).

To better understand MS caregiving, it is vital to understand their unique experiences and the challenges they cope with (Rajachandrakumar & Finlayson, 2021). The progression of MS is onerous and tedious (Ransohoff et al., 2015). It is a chronic disease that affects people's overall quality of life and requires long-term care (Hosseini et al., 2022; Santos et al., 2019), provided mainly by an informal caregiver, such as a spouse, sibling, parent, or other relative/friend (Bayen et al., 2015; Maguire & Maguire, 2020; Rajachandrakumar & Finlayson, 2022). Informal caregiving is multidimensional, and individual experiences are not linear (Bayen et al., 2017). Caregivers may prioritize their loved ones over their needs and inadvertently neglect their own daily activities and routines, consistent with self-care, social participation, and physical activity (Dooley et al., 2022). Informal caregivers are also at risk of experiencing higher stress (Petrikis et al., 2019). Carers may encounter a lack of familial support, a lack of assistance from medical professionals, and high caregiving demands, which create negative experiences leading to a decline in well-being (Bužgová et al., 2019).

The purpose of this study was to examine the multidimensional impacts of caregiving and social support on stress for informal, unpaid caregivers of persons with MS. Four research questions were selected for this study. This chapter will discuss the data analysis findings, limitations, future directions, and conclusions from the study results.

Research Questions

The following research questions were used to guide this quantitative study:

1. What are the frequency levels of perceived stress among informal caregivers?
2. What are the frequency levels of perceived social support among informal caregivers?
3. Is there a relationship between caregiver perceived stress and perceived level of social support?
4. Are there differences in caregiver perceived stress based on demographic variables (gender, ethnicity, and kinship to the person cared for)?

The study's research questions focused on the following aims: (a) to determine the frequency levels of stress among informal caregivers, (b) to determine the frequency levels of social support among informal caregivers, (c) to explore the relationship between caregiver stress and perceived social support, and (d) investigate whether demographic variables impact stress.

Summary of Findings

Society has depended on unpaid informal caregiving as the primary source of ongoing home care (Schulz & Tompkins, 2010). Informal caregiving is a role typically filled by family members or friends who provide unpaid care to someone with whom they have a close or personal relationship (Kasle, 1995; Rajachandrakumar & Finlayson, 2021). Caregiving studies report that informal carers are the primary source of care for people with a progressive neurological disorder such as MS, and the trajectory for both the care recipient and the caregiver can be taxing (Rajachandrakumar & Finlayson, 2021). While the findings of this study align with the current literature, they also illuminated several important caregiving insights. As reported by Pooyania and colleagues (2016), MS caregivers are at higher risk for experiencing psychological distress as they face unprecedented challenges associated with suboptimal care. Generally, caregivers must learn to manage work-life integration while providing unpaid care to a loved one, and the heterogeneity of individual caregiver characteristics may contribute to perceived stress, thus uniquely impacting the caregiver psychosocially.

Stress and Caregiving

It has been well established that stress may arise in caregivers learning to cope with life's circumstances (Lazarus & Folkman, 1984; Pinquart, 2003). For this study, it was imperative to examine the extent of perceived stress experienced by MS caregivers. Therefore, the first research question explored the frequency of stress levels among the sample population. Participants were prompted to report their experiences from data collection within the month as instructed by the Perceived Stress Scale (PSS). Descriptive statistics and frequencies on the PSS items revealed that MS caregivers overall experienced moderate perceived stress. However, further analysis of the frequency of the Likert scale questions revealed that participants also experienced higher stress under certain circumstances, such as emotional and stress regulation.

Comparably, McKenzie and colleagues (2015) reported moderate levels of stress in MS caregiver participants in their study. So, while this study also resulted in overall average moderate level of perceived stress, on review, a substantial number of participants also reported high perceived stress. This study’s findings align with Pakenham’s (2001), who found that one-third of the caregivers reported significant levels of psychological distress. This study also found that although caregivers may experience stress, their levels will vary. For instance, the majority of participants in this study reported feeling nervous and stressed often in the last month. A higher percentage of participants also reported an inability to control the important things in life often in the last month. While about half of the participants felt that they sometimes could not cope with all the things they had to do, the other half reported that they sometimes felt unable to cope.

Additionally, about half of the sample population felt angered because of things outside their control, and the other half felt they often could not cope. Some individuals reported they sometimes felt difficulties were piling up high and could not overcome them; the other half reported they often could not. MS is highly variable; likewise, caregiver variability in experiences is also evident (Maguire & Maguire, 2020). Studies note that higher caregiver stress is associated with adverse health outcomes (Figved et al., 2007; MacKenzie et al., 2020; Maguire & Maguire, 2020), thus highlighting the importance of investigating factors unique to many subpopulations (e.g., spouses, parents).

Perceived Social Support Outcomes

Social support can serve as a buffering effect for caregivers grappling with an MS journey (Rommer et al., 2017). Perceived social support is the availability and degree of attentiveness from family and friends to someone's needs (Ioannou et al., 2019; Scarapicchia, 2017). A social support system, whether it comes from family, neighbors, friends, support groups, or online social media platforms, can help protect against adversities (American Psychological Association, 2019; da Silva et al., 2022; Sillence et al., 2016; Zhang et al., 2023).

The second research question examined the frequency levels of perceived social support among MS caregivers. The Multidimensional Scale of Perceived Stress (MSPSS) was used to survey participants on their perceived social support. Descriptive statistics and frequencies were employed on the total MSPSS score to assess several variables associated with perceived social support. Results revealed that participants, on average, experienced a moderate level of perceived social support. However, analysis of the frequency level of agreement for participants who disagreed with individual MSPSS items warranted further inspection to address the greater areas of need.

A substantial number of participants reported disagreement regarding counting with a family willing to help them make decisions. There was a substantial difference in participants who reported disagreement in feeling their family tries to help them and getting the emotional help needed. Participants also reported disagreement with feeling like they can discuss problems with family. Concerning informal caregivers and friends, participants reported disagreement with having friends who try to help them. Likewise, participants reported disagreement in having friends they can talk about problems, share joys and sorrows, or count on when things go wrong. So, while there was some consensus among informal caregivers and their agreement on external sources for support, others reported a lack of support and help from family and friends. Another important finding was that there was a higher level of agreement with participants who perceived having someone special as a source of support. The totality of these factors identified that there was variability between types of perceived support between participant subgroups.

Caregiver Perceived Social Support on Perceived Stress

As previously discussed, having a social support system to turn to has been demonstrated to help maintain positive health outcomes in caregivers (Feeney & Collins, 2015). The third research question examined whether perceived social support impacted perceived stress. Results from a Pearson's correlation indicated that higher perceived social support moderately lowered the levels of perceived stress in the sample population. These results align with the existing literature, demonstrating that social support lowers the negative impacts of caregiving (Wilson, 2020).

Maguire and Maguire (2020) found that using personal and family resources had a positive adjustment among MS carers. As Benini and colleagues (2023) reported, friends and family members are esteemed as essential presences in the life of the MS carer. They also serve as a point of reference in times of need, to extend reassurance, and to find comfort in moments of discouragement. Although social support moderately lowered perceived stress, it is essential to note that to survive and flourish, determining what is helpful and damaging to the caregiver is crucial (Lazarus & Folkman, 1984). Carers were unseen and unheard not long ago, creating hesitancy to seek help and share experiences. Therefore, continuing to raise awareness and setting forth these issues is progress for the future. Implementing tailored psychosocial interventions is also a crucial initiative recommended by this study. Moreover, there should be a focus on strengthening social support interventions, such as providing individuals with information on local social support services, perhaps local MS support groups.

MS Caregiver Stress Characteristics

The fourth research question examined differences in caregiver stress based on demographic variables: gender, ethnicity, and kinship to the person cared for. An independent sample t-test was employed to assess whether there were differences in stress between female and male MS caregivers. Results from the analysis revealed there were no significant differences in stress between male and female carers. This sample consisted of 66.4% females and 33.6% males, yet the levels of perceived stress were alike. Caregiver stress regarding gender may pose diverse views. Firstly, while some studies mainly comprise women, with women experiencing higher psychological distress (Lee et al., 2015; Maguire & Maguire, 2020; McKenzie et al., 2015; Perrin et al., 2015), others comprise male caregivers experiencing higher physical caregiving concerns (McKenzie et al., 2015).

However, studies also show that differences in gender carer characteristics can be dependent on the type of disability. For example, with progressive neurological disorders, women are more likely to receive an MS diagnosis, making male counterparts the primary caregivers (Buhse et al., 2015; Madan & Pakenham, 2013; Maguire & Maguire, 2020; Opara & Brola, 2018; Wallin et al., 2019). The findings of this study found that overall stress-related perceptions were similar in both male and female MS carers. Once again, this study adds to the existing research, which shows that gender differences do not contribute to caregiver strain (Sharma et al. 2016).

Regarding caregiver ethnicity, The American Psychological Association (2019) reports that race and culture can impact caregiving. Maguire and Maguire (2020) note that the population of MS caregivers is expected to increase; thus, ethnic considerations must be observed. A scoping review by Rajachandrakumar and Finlayson (2021) examined 108 peer-reviewed articles on informal MS caregiving and found that very few studies reported on the ethnic backgrounds of caregivers. Therefore, there is an evident gap in the literature determining the impacts of perceived MS caregiver stress and ethnic groups.

A one-way ANOVA was conducted to determine if there were differences in caregiver-perceived stress and ethnic groups. The results found no differences based on ethnicity (i.e., Caucasian, Latino/Hispanic, or other) and the total Perceived Stress Scale score. The absence of differences in stress among ethnic groups could be argued that in some cultures, people are likely to provide care in a collectivist versus an individualistic approach and have a more robust cultural purpose for providing care to a loved one (Amankwaa, 2017).

A second one-way ANOVA was employed to determine if there were differences in caregiver-perceived stress and kinship to the person cared for. Analysis of the eight items on the Perceived Stress Scale found significant differences between groups on three items. A significant difference between other relatives and mothers/fathers was found on the item inquiring about the frequency with which they felt unable to control the important things in their lives. The responses indicated that other relatives (i.e., cousins, grandparents, aunts, and uncles) reported higher stress in being able to control the important things in their lives as opposed to mothers and fathers.

A second significant difference was found on the same item between spouses/partners and mothers/fathers, indicating that spouses and partners experienced higher stress in controlling the important things in their lives than mothers and fathers. Most of the existing literature has focused on spousal MS caregivers (Maguire & Maguire, 2020; McKenzie et al., 2015), with limited information on the nature of parental caregivers. While future research on the impacts of caregiving among spousal partners is essential since spousal carers are a primary source of care, this study's findings suggest that an investigation of parental caregiver support may benefit other groups of caregivers.

A significant difference was found between spouses/partners and mothers/fathers concerning how often they felt nervous and stressed. Responses indicated that spouses and partners experienced higher stress and nervousness than mothers and fathers. Moreover, there was a significant difference between spouses/partners and daughters/sons on an item inquiring how often they could not control the irritations in their lives. Responses indicated that spouses and partners experienced higher stress in controlling irritations. According to Maguire and Maguire (2020), unpaid informal MS care is more commonly provided by spousal (53-70%) caregivers (Bayen et al., 2015; Giordano et al., 2016). Perhaps the disproportionate differences in experiences are due to the nature of the relationship between spousal carers and their loved ones. While mothers and fathers may be a reference point in care, spouses residing with their loved ones fulfill the larger part of caregiving responsibilities. As the disease progresses, quality care may become more physically and emotionally demanding (Buchanan & Huang, 2011; Petrikis et al., 2019; Penwell-Waines et al., 2016). A lack of support from friends and family may be attributed to the length of MS progression. Benini et al. (2023) reported that carers who had been providing care for longer felt that support from friends and family occurred less. Therefore, taking the variation of care components into perspective is essential.

Limitations and Future Directions

There are several limitations to the present study. The first limitation is the lack of generalizability of the results. The interpretation of the survey data is based solely on individuals providing care to people with MS residing in the U.S. Therefore, the responses received from participants may not reflect the responses of other caregiver populations or MS caregivers outside the United States.

Sampling errors may arise as part of data collection, limiting the generalizability of the results. Although self-report online surveys are a convenient and speedy method for data collection, they risk attracting fraudulent responses and Internet bots, which may threaten the validity and integrity of the data (Lawrence et al., 2023). Although the initial data set detected fraudulent and suspicious activity, the researcher completed a multistage process to discard corrupt entries by assessing 1) the timestamp of the survey and 2) the beginning and end of the survey (Pozzar et al., 2020).

Finally, the results of this study are limited to caregiver characteristics used for analysis (social support, gender, ethnicity, kinship, and stress). Moreover, the majority of participants identified as (67.2%) Caucasian, (23.0%) Latino/Hispanic, multiracial (5.7%), and African American (4.1), yet MS is prevalent among other racial groups, thus limiting the sample to the populations mentioned above. There is an evident lack of studies reporting on MS caregiving impacts and ethnicity.

Future research should further examine ethnic groups and other variables that may impact the carer. Caregiving is highly variable, and studies should further assess other demographic characteristics and expand on current findings. Future research should also expound on understanding MS caregiver characteristics to develop tailored psychosocial support. Additionally, to examine the effects of stress and better determine effective interventions to mitigate caregiver-related stress. Caregivers can be considered second-order patients in extension to their loved ones. Therefore, healthcare services specializing in MS should focus on these factors to respond to the future needs of this population.

Conclusion of the Study

In conclusion, this study provided an overview of the implications of informal caregiving for multiple sclerosis. The purpose of this study was to examine the impacts of caregiving and social support on stress for unpaid informal caregivers of persons with MS. While results revealed that, on average, MS caregivers experience moderate levels of perceived social support and stress, there was variability in responses between participants who reported moderate and higher stress concerning emotional and stress regulation indicating that participants feel a lack of perceived support from external sources such as family and friends. Likewise, while some participants reported moderate perceived social support, others reported lacking support from external sources such as family and friends. The analysis also found that informal MS caregivers experience high perceived stress under certain circumstances, such as being unable to control the important things in life and feeling nervous and stressed in the last month.

Additionally, a moderate negative correlation was found between caregiver-perceived social support and stress, demonstrating that higher support lowered stress. This finding supports the concept that social support can be a buffering effect for caregivers navigating. Findings also revealed homogeneity in gender and stress, with results demonstrating that females and males experienced similar levels of perceived stress. Likewise, ethnic groups were homogenous, reporting similar levels of perceived stress within groups.

However, heterogeneity was found among kinship and stress. Results indicated that spouses and partners experienced higher stress than parents, daughters, and sons. These findings highlight the importance of assessing individual variables among caregiving populations, specifically the nature of the relationship between family members and friends providing care.

In summation, this study provided insight into participant’s perceptions and firsthand experiences to help better understand caregiver characteristics and demographic variables that may impact their overall stress levels. Most notably, findings identify that caregivers are heterogeneous, and researchers, interventionists, and allies need to take these identified differences into account. This study’s findings add to the growing body of literature and further validate the need to raise awareness of the need for and expand opportunities for increased caregiver social support.

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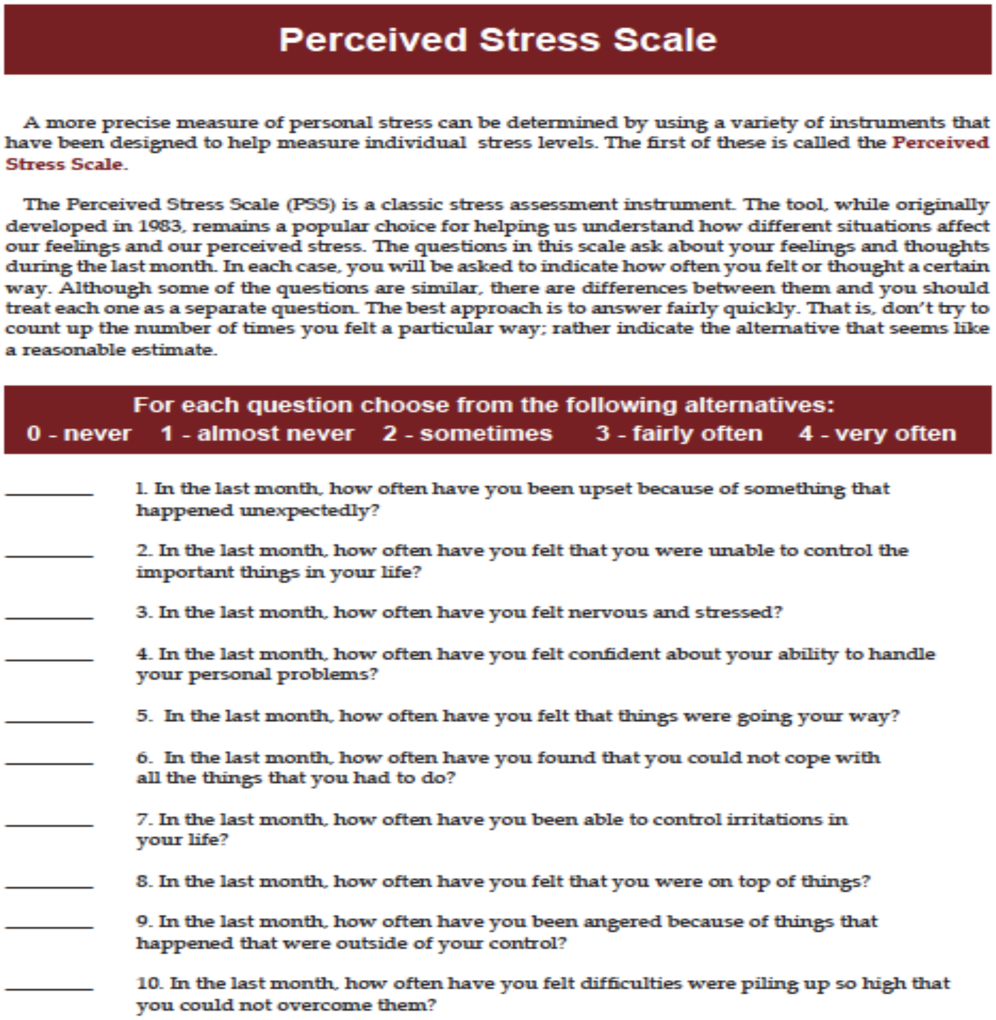
APPENDIX A

APPENDIX A

PERCIEVED STRESS SCALE



Perceived Stress Scale

A more precise measure of personal stress can be determined by using a variety of instruments that have been designed to help measure individual stress levels. The first of these is called the **Perceived Stress Scale**.

The Perceived Stress Scale (PSS) is a classic stress assessment instrument. The tool, while originally developed in 1983, remains a popular choice for helping us understand how different situations affect our feelings and our perceived stress. The questions in this scale ask about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer fairly quickly. That is, don't try to count up the number of times you felt a particular way; rather indicate the alternative that seems like a reasonable estimate.

For each question choose from the following alternatives:
0 - never 1 - almost never 2 - sometimes 3 - fairly often 4 - very often

________ 1. In the last month, how often have you been upset because of something that happened unexpectedly?

________ 2. In the last month, how often have you felt that you were unable to control the important things in your life?

________ 3. In the last month, how often have you felt nervous and stressed?

________ 4. In the last month, how often have you felt confident about your ability to handle your personal problems?

________ 5. In the last month, how often have you felt that things were going your way?

________ 6. In the last month, how often have you found that you could not cope with all the things that you had to do?

________ 7. In the last month, how often have you been able to control irritations in your life?

________ 8. In the last month, how often have you felt that you were on top of things?

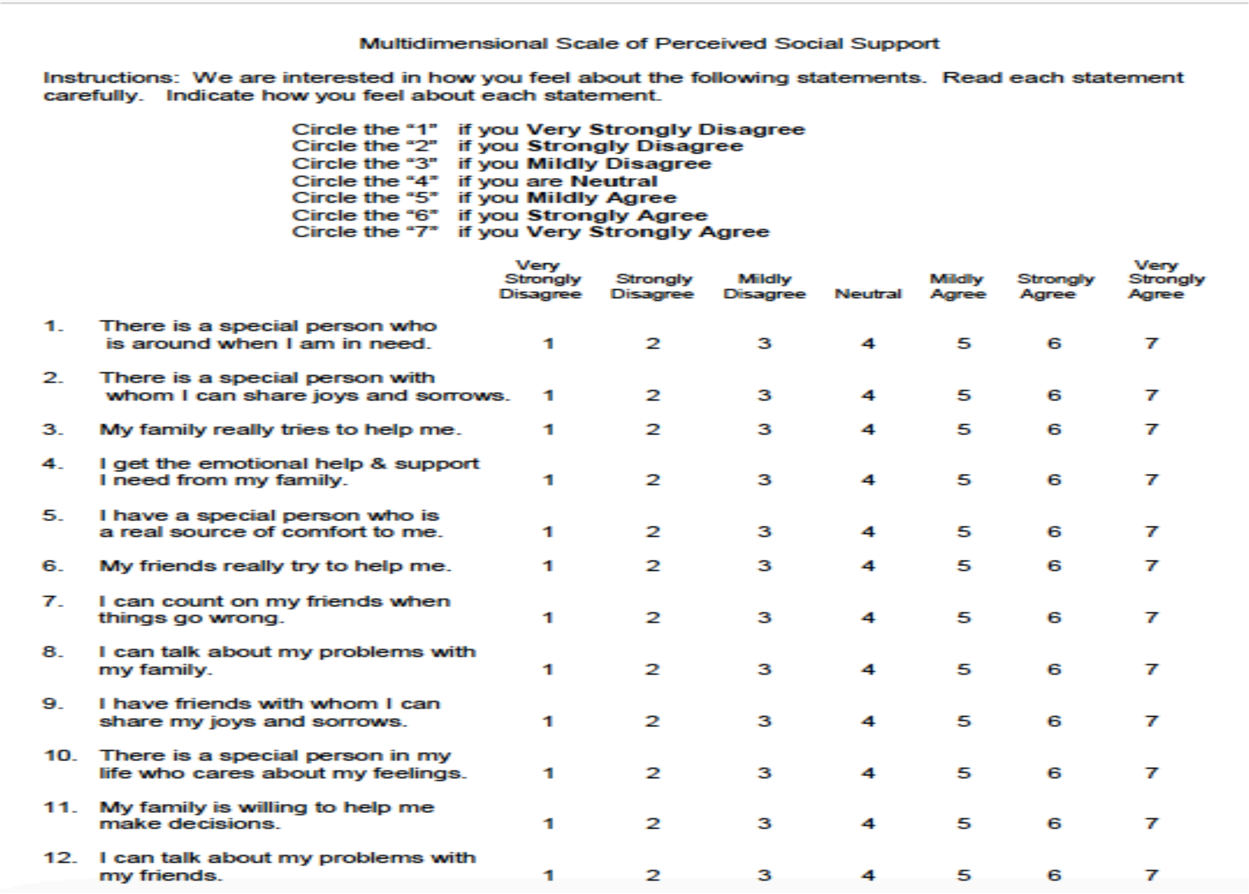
________ 9. In the last month, how often have you been angered because of things that happened that were outside of your control?

________ 10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

APPENDIX B

APPENDIX B

MULTIDIMENSIONAL SCALE OF PERCIEVED SOCIAL SUPPORT



Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
Circle the "2" if you **Strongly Disagree**
Circle the "3" if you **Mildly Disagree**
Circle the "4" if you are **Neutral**
Circle the "5" if you **Mildly Agree**
Circle the "6" if you **Strongly Agree**
Circle the "7" if you **Very Strongly Agree**

		Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2.	There is a special person with whom I can share joys and sorrows.	1	2	3	4	5	6	7
3.	My family really tries to help me.	1	2	3	4	5	6	7
4.	I get the emotional help & support I need from my family.	1	2	3	4	5	6	7
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6.	My friends really try to help me.	1	2	3	4	5	6	7
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7

APPENDIX C

APPENDIX C

CAREGIVER DEMOGRAPHIC QUESTIONAIRE

Gender

A. Male
B. Female
C. Others ___________

Age of caregiver

Fill in: ___________

Ethnicity

A. Caucasian
B. African American
C. Latino or Hispanic
D. Asian
E. Native American
F. Native Hawaiian or Pacific Islander
G. Multiracial
H. Other/Unknown

Marital status

A. Single
B. Married
C. Divorced
D. Widowed

Highest educational level

A. Some High School
B. High School
C. Bachelor's Degree
D. Graduate Degree (e.g., master's & PhD)
E. Trade School

Household Income

A. Less than $24,999
B. $25,000 - $49,999
C. $50,000 - $99,999
D. $100,000 - $199,999
E. $200,000 and higher

Employment status

A. Employed Full-Time
B. Employed Part-Time
C. Unemployed
D. Retired

Hours per week caring for the care recipient

A. 5 hours per week or less
B. 6 to 20 hours per week
C. 21 to 40 hours per week
D. More than 40 hours per week

Kinship to the person being cared for

A. Parent
B. Sister/Brother
C. Son/Daughter
D. Uncle/Aunt
E. Partner/Spouse
F. Grandmother/Grandfather
G. Other relative _____________

APPENDIX D

APPENDIX D

RECRUITMENT FLYER

UTRGV | UTHealth RioGrandeValley

Rehabilitation Services
& Counseling

WANT TO HELP FELLOW MS CAREGIVERS?

Seeking MS caregivers to take part in an important online survey.

What is this study about?

This study aims to examine the impacts of caregiving and social support on stress among unpaid informal caregivers of persons with multiple sclerosis.

Why participate?

- Sharing your experience will help us understand the impact of caregiving and what is needed to mediate both the physical and emotional challenges caregivers encounter.
- To compensate for your contribution, after completing your survey, you will be provided an anonymous link to a separate survey where you can voluntarily enter into a drawing to win one of ten **$25 Amazon eGift cards**.

Who can participate?

- Adults 18 years or older.
- Individuals providing unpaid caregiving to a family member or friend with MS & must have at least six months of experience.

If you're interested in participating, please click on the online survey link or scan the QR code

https://utrgv.co1.qualtrics.com/jfe/form/SV_02gU1onP4dqtKsK

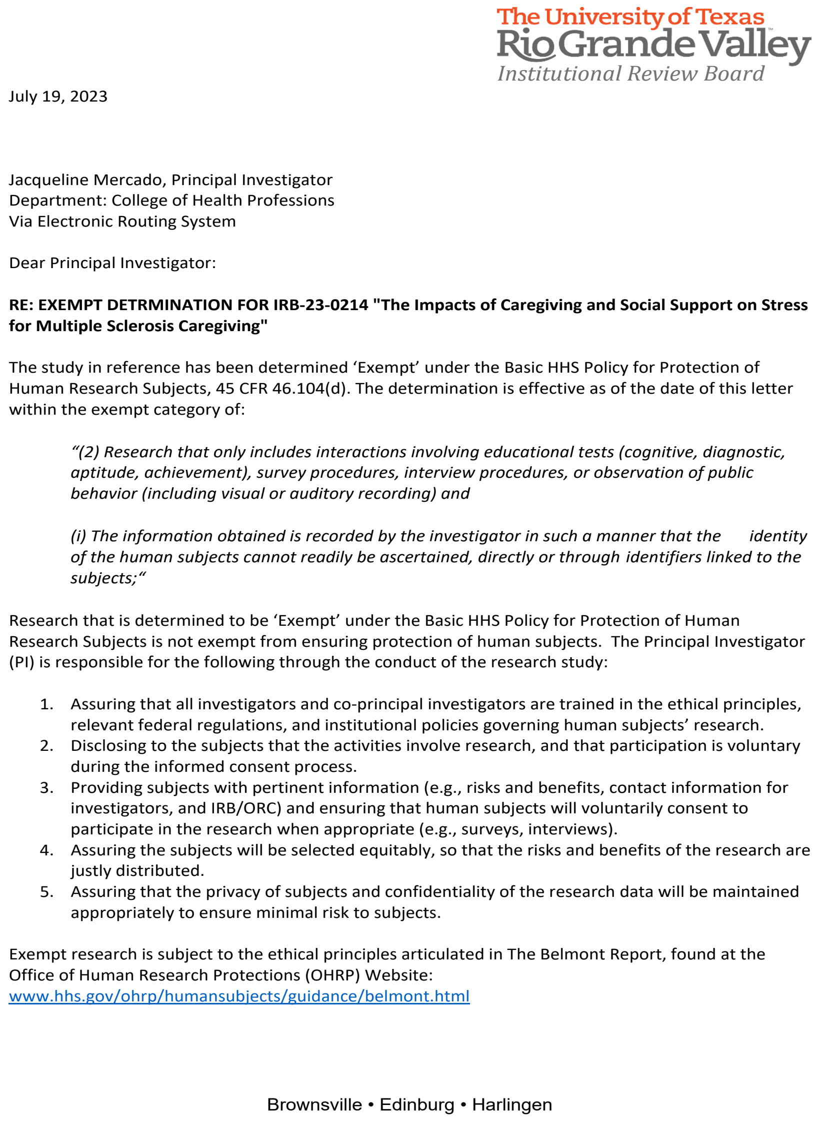
CONTACT FOR MORE INFORMATION:
Jacqueline Mercado, PhD candidate, LCDC-I
jacqueline.mercado01@utrgv.edu or
(956)353-0091

UTRGV IRB-23-0214

APPENDIX E

APPENDIX E

INTERNAL REVIEW BOARD APPROVAL



The University of Texas
Rio Grande Valley
Institutional Review Board

July 19, 2023

Jacqueline Mercado, Principal Investigator
Department: College of Health Professions
Via Electronic Routing System

Dear Principal Investigator:

RE: EXEMPT DETRMINATION FOR IRB-23-0214 "The Impacts of Caregiving and Social Support on Stress for Multiple Sclerosis Caregiving"

The study in reference has been determined ‘Exempt’ under the Basic HHS Policy for Protection of Human Research Subjects, 45 CFR 46.104(d). The determination is effective as of the date of this letter within the exempt category of:

> *“(2) Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) and*
>
> *(i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects;“*

Research that is determined to be ‘Exempt’ under the Basic HHS Policy for Protection of Human Research Subjects is not exempt from ensuring protection of human subjects. The Principal Investigator (PI) is responsible for the following through the conduct of the research study:

1. Assuring that all investigators and co-principal investigators are trained in the ethical principles, relevant federal regulations, and institutional policies governing human subjects’ research.
2. Disclosing to the subjects that the activities involve research, and that participation is voluntary during the informed consent process.
3. Providing subjects with pertinent information (e.g., risks and benefits, contact information for investigators, and IRB/ORC) and ensuring that human subjects will voluntarily consent to participate in the research when appropriate (e.g., surveys, interviews).
4. Assuring the subjects will be selected equitably, so that the risks and benefits of the research are justly distributed.
5. Assuring that the privacy of subjects and confidentiality of the research data will be maintained appropriately to ensure minimal risk to subjects.

Exempt research is subject to the ethical principles articulated in The Belmont Report, found at the Office of Human Research Protections (OHRP) Website:
www.hhs.gov/ohrp/humansubjects/guidance/belmont.html

Brownsville • Edinburg • Harlingen

APPENDIX F

APPENDIX F

INFORMED CONSENT

A STUDY ON THE IMPACTS OF CAREGIVING AND SOCIAL SUPPORT ON STRESS FOR MULTIPLE SCLEROSIS

Investigator: Jacqueline Mercado, M.S.

DESCRIPTION OF THE RESEARCH

This research study is being conducted by Jacqueline Mercado, PhD Candidate, in the School of Rehabilitation Services and Counseling at the University of Texas Rio Grande Valley. This research has been reviewed and approved by the University of Texas Rio Grande Valley Institutional Review Board for Human Subjects Protection (IRB).

The purpose of this study is to examine the impacts of caregiving and social support on stress among unpaid informal caregivers of persons with MS.

Qualifications to this research include:

- You must be at least 18 years old.
- You must have provided unpaid caregiving assistance for a loved one (e.g., family member or friend) for at least 6 months.
- The recipient in your care must be diagnosed with multiple sclerosis.

WHAT WILL MY PARTICIPATION INVOLVE?

- You will be asked to provide information about you and your experience. The time completion of this survey takes about 10 minutes and must be completed at one time.
- Participation in this research is entirely anonymous and voluntary.
- If there are any questions or parts of this study you are uncomfortable completing, feel free to skip that question or terminate your participation at any time without question or comment.

ARE THERE ANY RIKS TO ME?

All survey responses will be treated confidentially and stored on a secure server. However, because you will be completing this information using a computer of your choice (e.g., personal, work, school), there is no guarantee of the security of the computer on which you choose to enter

your responses. As a participant in this study, please be aware that certain technologies exist that can be used to monitor or record data and/or visited website. Because this survey asks for your personal caregiving experience, emotions or feelings of stress may surface.
Please visit the following resource for support:
https://www.nationalmssociety.org/Living-Well-With-MS/Relationships/Family-Matters/Carepartners

ARE THERE BENEFITS TO TAKING PART IN THIS STUDY?

This research may help us to understand the impacts of caregiving among MS caregivers, specifically to improve our understanding of the influence of perceived social support and stress on the caregiving role or how we can mediate and improve specific mental health interventions for caregivers.

INCENTIVE OPPORTUNITY

After completing your survey, you will be provided a link redirecting you to a separate survey link where you can enter a **drawing to win one of ten $25 Amazon gift cards**. You will be instructed to provide a preferred email. Winners will be emailed the electronic gift card after data collection.
Personal identifiable information, such as your preferred email, will be used to provide the compensation. However, this information is anonymous (not linked to your survey response). Personal information will be stored and secured with data encryption software managed by the principal investigator.
All data, including personal identifiers, will be destroyed three months after the conclusion of data collection.

WHOM SHOULD I CONTACT IF I HAVE QUESTIONS?

If you have questions, you should email the principal investigator Jacqueline Mercado at jacqueline.mercado01@utrgv.edu or by phone at (956) 353-0091.

WHOM TO CONTACT REGARDING YOUR RIGHTS AS A PARTICIPANT

This research has been reviewed and approved by the University of Texas Rio Grande Valley Institutional Review Board for Human Subjects Protections (IRB). If you have any questions about your rights as a participant or if you feel that your rights as a participant were not adequately met by the researcher, please contact the IRB at (956) 665-3598 or irb@utrgv.edu.
IRB-23-02

APPENDIX G

APPENDIX G

RECRUITMENT EMAIL

Hello,
My name is Jacqueline Mercado, and I am a PhD candidate in the Doctor of Philosophy in Rehabilitation Counseling program at the University of Texas Rio Grande Valley (UTRGV). I would like to invite you to participate in my research study to examine the impacts of informal caregiving and social support on stress among caregivers of persons with multiple sclerosis.

This research study has been reviewed and approved by the Institutional Review Board for the Protection of Human Subjects (IRB) at the University of Texas Rio Grande Valley. IRB-23-0214

In order to participate, you must:

- Be at least 18 years old.
- Provided unpaid caregiving assistance for a loved one with MS (e.g., family member or friend) for at least 6 months.
- The recipient in your care must be diagnosed with multiple sclerosis.

Participation in this research is entirely voluntary, and you may choose not to participate without penalty.

As a participant, you will be asked to complete an online survey which should take about 10 minutes to complete. All data will be treated as confidential. Your participation is completely anonymous, and no information regarding your identity will be collected for research purposes.

If you would like to participate in this research study, please click on the survey link below and read the consent page carefully. If you would like to complete the survey, click on “I consent”. If not, simply exit the web browser or click on “I do not consent”.

Survey Link: **https://utrgv.co1.qualtrics.com/jfe/form/SV_02gU1onP4dqtKsK**

If you have questions related to the research, please contact me by telephone at (956) 353-0091 or by email at Jacqueline.mercado01@utrgv.edu.
If you have any questions regarding your rights as a participant, please contact the Institutional Review Board (IRB) by telephone at (956) 665-2889 or by email at irb@utrgv.edu.

Thank you for your cooperation!
Jacqueline Mercado
PhD Candidate, UTRGV - Department of Rehabilitation Services & Counseling

BIOGRAPHICAL SKETCH

Jacqueline Mercado earned her Doctor of Philosophy in Rehabilitation Counseling from The University of Texas Rio Grande Valley in 2023. Her career in rehabilitation began after earning a bachelor's in Rehabilitation Services in 2018. She then pursued a graduate degree in Clinical Rehabilitation Counseling in May 2020. Jacqueline Mercado can be reached at Jacquelinemercado1839@gmail.com