

A Dyadic Approach to Adjustment to Disability: An Exploratory Study of the Relationship Between  
Caregiver Burden and Love Styles for Individuals with Multiple Sclerosis and Parkinson's Disease and  
Spousal Caregivers

By

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## **DEDICATION**

I dedicate this dissertation to my family, friends, professors, and colleagues who have provided support and encouragement throughout my academic career. You all believed in me more than I ever could, and I am eternally grateful.

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## ABSTRACT

The progression of chronic illness and disability, like multiple sclerosis (MS) and Parkinson's disease (PD), can lead to the need for a caregiver. A spouse often fills the role, and the caregiving stressors can lead to caregiver burden. There is a cyclical nature to burden and adjustment to disability and the shared experiences inevitably alters the nature of the spousal relationship. In practice and research, the spouses have been viewed and explored independently, with each individual being seen as having separate concerns and experiences, rather than the cyclical and interdependent experience. The present study examined the relationship between caregiver burden and love styles in an attempt to better understand meaning in the caregiving role, changes in love styles, and the lived experiences shared between spouses.

Participants included 89 individuals with MS or PD and spousal caregivers. Online surveys consisting of several self-reported measurements were used collect data from eligible participants through the National Multiple Sclerosis Society and several Parkinson's disease associations. The results suggest a relationship between caregiver burden and love styles. There were significant perceived changes in love styles from the first year of marriage to the first year of symptom onset, the first year of caregiving, and current love styles. There were also significant perceived changes between the first year of symptom onset and the first year of caregiving.

The findings provide insight into understanding the role of love styles and caregiver burden in the complex changes couples experience during adjustment to disability. Caregiver depression and anxiety has a significant relationship with caregiver burden and should be considered by Rehabilitation Counselors working with spouses. Additional research and longitudinal studies are required to better understand the relationships and changes in love styles; however, Rehabilitation Counselors can utilize the value-based trends to work with couples in a more holistic way.

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## CHAPTER ONE: INTRODUCTION

### The Need for Caregivers

Living with a chronic illness or disability (CID) can result in the need for a caregiver, often leading spouses to take on the role of informal caregiver (Myhre et al., 2017). After the acquisition or progression of CID, the spouse with disability and the spousal caregiver begin the journey of adjusting to disability and caregiving together (Baumunk, 2023). As the spouse adjusts to their disability, the caregiver is typically managing changes, challenges, and stressors as they arise (Myhre et al., 2017). Caregivers commonly report stressors, including increased isolation and parental responsibilities and reduced income and intimacy (Arun et al., 2018; Häusler et al., 2016; Llanque et al., 2016). Caregivers report increased feelings of frustration, anger, resentment, and worry for the future (Vatter et al., 2018). Research has shown caregivers can experience ambiguous loss and grief, feel as if there is a lack of meaning in life (Myhre et al., 2017), and an increased risk of caregiver burden (Penning & Wu, 2016). Importantly, research shows that hours spent caregiving has little impact on levels of burden (Hagell et al., 2017; Mosley et al., 2017), meaning that spouses do not have to be a full-time caregiver to experience caregiver burden. Even in cases where caregiving is also provided by external supports, spousal caregiving becomes an integral part of the spousal relationship (Monin et al., 2019).

The transition into the role of caregiver emerges from the existing relationship when caregiver behaviors and role identity in relation to the care recipient change (Montgomery & Kosloski, 2013). This change in identity occurs because the tasks required to maintain the health and well-being of the recipient are often inconsistent with the initial and later established expectations in the relationship. For caregivers of a spouse with a CID, the change in role identity can be a slow and “insidious” process that results in a significant shift from the initial role relationship (Montgomery & Kosloski, 1994; 2013; Seltzer & Li, 1996). “Incongruence between caregiving tasks and the meaning attached to these tasks [...] causes caregivers distress, and prompts actions to restore congruence, in whatever way possible, to relieve this distress [...] such relief may ultimately require an identity change” (Montgomery & Kosloski, 2013, p. 137).

For most spouses, the caregiving role is unexpected, unplanned, and not entered by choice (Pearlin & Aneshensel, 1994; Seltzer & Li, 2000). Development into the role of caregiver is a process. For a number of reasons, there is ambiguity in defining the onset of the role, particularly for spousal caregivers when compared to other family caregivers (e.g., adult children, siblings; Montgomery & Kosloski, 1994; Seltzer & Li, 2000). First, caregivers are often functioning as a caregiver before they identify as a caregiver (Seltzer & Li, 2000). Second, the type of exchange that occurs between caregiver and recipient is a natural extension of prior patterns of support and assistance shared between spouses (Montgomery & Kosloski, 1994; Seltzer & Li, 1996; 2000). Finally, the tasks, responsibilities, and types of support differ greatly for caregivers, not only from day-to-day, but between caregivers, causing further difficulty clearly defining the role and identifying the time of onset (Chou, 2000; Edwards & Ruettiger, 2002; Montgomery & Kosloski, 1994; Seltzer & Li, 1996; 2000; Shin & Habermann, 2020).

### **Caregiver Burden**

Caregiver burden (CGB) is generally conceptualized as the physical, psychological, emotional, social, and financial stressors that are experienced due to caregiving and the caregiver role (George & Gwyther, 1986). CGB is the most commonly investigated caregiving outcome. This research is mostly quantitative, potentially failing to fully capture the complex subjective experience of caregiving (Bastawrous, 2013). Further, many studies have not adequately conceptualized or defined CGB, resulting in vague findings that are challenging to summarize or effectively apply in clinical settings (Bastawrous, 2013; Wang et al., 2020). Despite these limitations, research has shown that CGB is associated with increased risk of mental and physical health issues (e.g., anxiety, depression, fatigue, cardiovascular disease, and hypertension), mortality, and reduced quality of life (Gaynor, 1990; Rodriguez-Gonzalez & Rodriguez-Miguez, 2020; Schulz et al., 1997; Schulz & Beach, 1999). Based on these factors and experiences, it is common for caregivers to report having trouble coping, and research has shown that CGB is likely intensified by poor or ineffective coping skills (Myhre et al., 2017).

CGB has significant consequences for both spouses (Lyons et al., 2002; Wang et al., 2020). Historically, research specific to CGB has treated the spouses as separate units, despite the impact of

CGB on both spouses and the dynamic, inherently shared nature of this experience (Lyons et al., 2002; Monin et al., 2019; Myhre et al., 2017; Vedes et al., 2016; Wang et al., 2020).

Many spouses may view the acquisition of CID and/or need for caregiving to be part of their vow to stay together through *sickness and in health* (Singleton, 2009; Wang et al., 2020). Some relationships may still end in rupture, although it is unclear how many divorces and separations are caused by the acquisition of CID. Some of the most cited reasons for divorce include lack of commitment (75%), infidelity (60%), too much conflict/arguing (58%), financial problems (37%), lack of support from family (18%), and health problems (17%; Scott et al., 2013). Research has shown the prevalence of divorce for women with chronic illness and acquired disabilities (CIAD) is significantly higher than for men (Karraker & Latham, 2015). Men with multiple sclerosis (MS) have a 21% higher risk of divorce than non-disabled men (Landfeldt et al., 2018). Five years after onset of MS, the probability of staying in the same relationship was 86% for people with MS versus 89% for non-disabled individuals, and after 24 years, decreases to 33% and 53% respectively (Pfleger, et al., 2010). Rod and colleagues (2010) found that individuals with Parkinson's disease (PD; typical onset only) did not have an increased risk of divorce when compared to non-disabled individuals. However, this may be due to the typical onset of PD occurring in older populations and may not hold true for individuals with young onset PD. The interaction between the "incidence of disability onset" and "negative impacts on the value of marriage" (measured by marital values pre- and post-disability) can help explain the effect of disability on divorce (Singleton, 2009, p. 986). This effect is greatest when disability is largely unanticipated, highly uncertain (e.g., unknown progression), and has substantial effects on the value of marriage (e.g., relationship, career, and/or lifestyle goals; Singleton, 2009). According to Singleton (2009), the association between divorce and disability decreases with age and increases with severity of disability.

When spouses stay in the relationship as the caregiver role emerges, it may be helpful for practitioners working with couples to understand the meaning and purpose in their staying. Frankl (1959; 2014) believed that when people have meaning and purpose, suffering is reduced, and that in any situation, love may provide the meaning to reduce suffering. Research suggests that levels and risk of

burden are reduced when caregivers find meaning in the stressors that come along with the caregiving role (Hosseinigolafshani et al., 2020; Montgomery & Kosloski, 2013; Myhre et al., 2017). In addition to finding meaning in stressors, meaning in the relationship has likely been altered for both spouses. What the spouses value in each other and in the relationship can provide further meaning and purpose.

### **Love Styles**

Love styles are the attitudes that explain how individuals define love within the context of their romantic relationships (Vedes et al., 2016). The attitudes impact how an individual feels about and behaves in their relationship (Lee, 1977; Vedes et al., 2016). Love is displayed, received, and experienced in many forms and in various relationship types (e.g., parental, friendly, romantic, etc.), and different expressions of love can be seen within the same relationship (Raffagnino & Puddu, 2018). There has been an array of classifications of love, including Sternberg's (1986) Triangular Theory of Love (i.e., intimacy, passion, and commitment), and Hatfield and Rapson's (1987) two general types of love: passionate love (desire to bond) and compassionate love (affection). Lee's (1977) conceptualization of love styles is the most utilized categorization of love, and is viewed as the most complete, structured, and focused explanation of spousal and romantic relationships (Hendrick & Hendrick, 1989; Raffagnino & Puddu, 2018).

Lee (1977) defined six love styles: three primary and three secondary styles. The primary styles include Eros (romantic, passionate love), Ludus (game-playing love), and Storge (friendship love). The secondary styles are a combination of two primary styles and include Mania (dependent, possessive love; combination of Eros and Ludus), Pragma (practical love; combination of Storge and Ludus), and Agape (unselfish, altruistic love; combination of Eros and Storge; Hendrick & Hendrick, 1986; Lee, 1977; Lin & Huddleston-Casas, 2005; Raffagnino & Puddu, 2018; Vedes et al., 2016). While secondary styles are combinations of the primary styles, there are six distinct love profiles (Smith & Klases, 2016). The Love Attitudes Scale (LAS; Hendrick & Hendrick, 1986) measures love styles based on Lee's (1977) definitions and is the most commonly used tool in love style research (Raffagnino & Puddu, 2018; Vedes et al., 2016).

Lee originally developed love styles as the Colors of Love (Lee, 1973), with six distinct styles made up of three primary and three secondary colors. With the development of the LAS, Hendrick and Hendrick's essentially eliminated the primary and secondary distinction and with factor analyses of the responses, the styles turned into a six-factor solution with one factor for each style (Butler et al., 1995). The styles should be viewed as orthogonal and can be compared to chemical compounds (Hendrick & Hendrick, 1986). Although the styles are interrelated, each style contains qualitative properties that are independent of all other styles (Hendrick & Hendrick, 1986). An analog for this would be the chemical elements carbon (C), oxygen (O), and the compound of carbon dioxide (CO<sub>2</sub>). While carbon dioxide is made of the elements of carbon and oxygen, it is considered a distinct chemical compound. Thus, even though agape is a compound of eros and storge, it is a distinct style.

### ***Eros***

Eros includes passionate and romantic attitudes toward love and based on feelings of physical and emotional attraction, and passion (Hendrick & Hendrick, 1989; Lee, 1977; Raffagnino & Puddu, 2018). There have been direct connections between Eros and intimate closeness, positive conflict resolution strategies (e.g., compromise), and dyadic coping (Raffagnino & Puddu, 2018; Vedes et al., 2016). Eros has also been associated with higher commitment in relationships and decreased avoidance coping and anxiety. Relationship length may be a negative predictor, meaning that the longer the relationship lasts, the less likely the partner is to endorse Eros (Raffagnino & Puddu, 2018; Smith & Klases, 2016).

### ***Ludus***

Ludus is typical for individuals who see love as a game, are uncommitted, and focus on having fun in the moment (Hendrick & Hendrick, 1989; Lee, 1977; Raffagnino & Puddu, 2018). Ludus is related to weak effort in relationships, lack of commitment and care for the partner, and positive feelings at termination of the relationship. Ludus has been considered a risk factor to quality and stability in romantic relationships and is less likely to occur in longer relationships (Raffagnino & Puddu, 2018; Smith & Klases, 2016).



### ***Agape***

Agape is common with individuals who have unconditional and unselfish love, and they are willing to sacrifice anything for someone they care for or support (Hendrick & Hendrick, 1989; Lee, 1977; Raffagnino & Puddu, 2018). Agape has been positively correlated with duration and quality of relationship, and relational satisfaction (Raffagnino & Puddu, 2018). High levels of Agape often result in an increase of support given to stressed partners, and stressors are approached in jointly avoiding the stressors (Vedes et al., 2016). However, the likelihood of joint efforts in avoiding stressors seems to decrease with the length of the relationship (Vedes et al., 2016). Agape is more likely to be endorsed in longer relationships (Smith & Klases, 2016).

### ***Storge***

Storge relationships are based on friendship, commitment, and similar interests, rather than passion (Hendrick & Hendrick, 1989; Lee, 1977; Raffagnino & Puddu, 2018). Storge has been shown to be positively correlated with dyadic coping, secure attachment, satisfaction in love life, and the use of functional strategies (e.g., compromise) in marital conflict (Raffagnino & Puddu, 2018). Storge becomes less likely to occur as the length of the relationship increases (Raffagnino & Puddu, 2018).

### ***Pragma***

Pragma incorporates pragmatic and rational attitudes toward love. Individuals choose partners based on important characteristics and typically share similar goals (e.g., professional goals; Hendrick & Hendrick, 1989; Lee, 1977; Raffagnino & Puddu, 2018). Pragma is related to stable relationships, relationship satisfaction, and subjective well-being (Raffagnino & Puddu, 2018). Individuals are more likely to use strategies like avoidance and compromising and show fluctuations and uncertainty with emotional attachment. Pragma is more common in longer relationships (Smith & Klases, 2016).

### ***Mania***

Mania is expressed with obsessive and possessive behaviors; individuals are often jealous and need to be loved by their partner (Hendrick & Hendrick, 1989; Lee, 1977; Raffagnino & Puddu, 2018). This love style has limited research in comparison to the other styles. Mania is a strong predictor of

negative relational behaviors, jealousy, pathological love, destructive communication behavior, and negative reactions to conflict (Raffagnino & Puddu, 2018). Mania is less likely to be endorsed in longer relationships (Smith & Klases, 2016).

Evidence of love styles changing over time is limited and most researchers describe the prevalence of the different love styles in older versus younger participants, rather than changes over time (Smith & Klases, 2016). Despite this, Lee (1977) and Hendrick and Hendrick (1986) claim love styles change between and within relationships. Smith and Klases (2016) found a significant relationship between age and some love styles, and that love styles appear to remain relatively constant into middle-age.

### **Multiple Sclerosis**

Multiple sclerosis (MS) is a chronic, unpredictable, and occasionally progressive disease that impacts the central nervous system (CNS; Bishop & Rumrill, 2015). While the etiology of MS is not yet fully understood, it is characterized by lesions on the brain caused by degraded myelin (also known as white matter), leading to impairment of transmissions from the CNS (Santos et al., 2019). The neurological changes can lead to a wide range of symptoms and concerns, including problems with cognition, vision, balance, and mobility (Maguire & Maguire, 2020). Common reported symptoms are primarily sensory- and motor-related, including fatigue, tremors, speech disorders, pain disorders, intestinal issues, and double-vision (Santos et al., 2019).

MS impacts more than 2.3 million people globally, is more frequent in women, and typically presents in young to middle adulthood, or 20 – 40 years old (Bishop & Rumrill, 2015; Maguire & Maguire, 2020; Santos et al., 2019; Tzitzika et al., 2020). There are four forms of MS that manifest with varying progressions and symptomology which include (1) clinically isolated syndrome (CIS), (2) relapsing-remitting (RRMS), (3) primary progressive (PPMS), and (4) secondary progressive (SPMS; Bishop & Rumrill, 2015; Santos et al., 2019). Roughly 85% of individuals with MS have an initial diagnosis of RRMS, characterized by flares (or relapses) lasting days or weeks that are followed by remissions (or recovery periods; Bishop & Rumrill, 2015). PPMS accounts for 10% – 15% of MS

diagnoses, and SPMS is developed by at least 50% of those originally diagnosed with RRMS (Bishop & Rumrill, 2015; National Multiple Sclerosis Society [NMSS], 2024).

### ***Multiple Sclerosis and Caregivers***

Individuals with MS frequently require assistance with daily activities and tasks (Rajachandrakumar & Finlayson, 2022). Caregiving tasks can range greatly and include instrumental tasks (e.g., transportation, house chores), personal assistance (e.g., bathing, toileting), and general emotional and social support. Like the symptoms and progression of MS, caregiving for individuals with MS is unpredictable. Some tasks may come with a pattern or routine, others do not, and with this uncertainty can cause additional stress, leading to an increased risk of burden.

MS CGB has not been shown to directly relate to disease duration (Maguire & Maguire, 2020) and time spent on care tasks does not necessarily lead to higher levels of burden (Mosley et al., 2017). However, diagnosis typically occurs in early adulthood, meaning the duration of caregiving can be three decades or more (Rajachandrakumar & Finlayson, 2022) and MS caregivers spend, on average, 6.5 hours per day on care tasks (Maguire & Maguire, 2020). Nearly 40% of MS caregivers report missing work in the past year and 24% report reducing or leaving employment completely due to caregiving tasks, demonstrating the “considerable economic burdens” caregiving can place on this population (Maguire & Maguire, 2020).

### **Parkinson’s Disease**

Parkinson’s disease (PD) is a chronic, progressive neurodegenerative disease that results in motor and non-motor symptoms that impact several life domains (McDaniels et al., 2021). Common motor symptoms include tremors, muscle rigidity or stiffness, bradykinesia (i.e., slowness of movement), and difficulties with balance, speech, and coordination (American Parkinson Disease Association [APDA], 2023; National Institute of Environmental Health Sciences [NIEHS], 2023). Non-motor symptoms can include sleep problems (e.g., REM sleep behavior disorder [dream-enacting behavior]), anxiety, fatigue, and poor sense of smell, among others (APDA, 2023; NIEHS, 2023). Individuals with PD also frequently experience depression, cognitive impairment, and psychosis; these symptoms (also referred to as mental

or neuropsychiatric disturbances) are predictors of quality of life (QOL) in patients, and are often treatable (Aarsland et al., 1999).

There are more than 10 million people worldwide living with PD and an estimated 1 million people in the United States (APDA, 2023). The average age of onset is 60 years old. People with PD commonly experience co-occurring diagnoses associated with aging (e.g., kidney disease and diabetes; McDaniels et al., 2021). Most individuals develop symptoms after the age of 50, however, between 2% and 10% of PD diagnoses are Early Onset PD, which occurs before the age of 50 (APDA, 2023; NIEHS, 2023).

### ***Parkinson's Disease and Caregivers***

Informal caregivers are an integral component of care and support for people living with PD (Macchi et al., 2020). Yet, as is the case with caregivers of people with other chronic illnesses, caregivers for spouses or partners of individuals living with PD can experience significant stress and CGB. Indeed, Aarsland and colleagues (1999) found that caregivers of spouses with PD reported higher levels of caregiver stress and emotional distress compared with other caregivers (e.g., daughter, daughter-in-law, and son), and higher rates of tiredness, sadness, depression, and less satisfaction with life compared with older adults without PD or other chronic illnesses or disabilities.

Several characteristics have been found to contribute to these higher levels of burden (Aarsland et al., 1999; Macchi et al., 2020), including, primarily, the severity of the PD, and the presence of non-motor symptoms, particularly with neuropsychiatric disturbances (Macchi et al., 2020). Caregiver grief, anxiety, depression, perception of spouse's QOL, spouse and caregiver psychological states, and the spiritual and health-related well-being and QOL of the spouse with PD have all been found to influence CGB in PD caregivers (Macchi et al., 2020). Duration of disease is also associated with increased levels of CGB (Macchi et al., 2020). PD duration can influence whether the spouse with PD stays home for care or moves into a care facility; and spouse's living situation can also impact CGB (Torny et al., 2018). Higher levels of caregiver stress are observed in cases with public home care (Aarsland et al., 1999). This association is likely due to higher severity of symptoms and limitations for patients receiving home care

(Aarsland et al., 1999). PD caregivers who report having a disability or illness experience significantly higher burden than those who report not having a disability (Hagell et al., 2017).

People with MS or PD and their spousal caregivers are the focus of this study. MS and PD are both progressive neurological conditions that are typically diagnosed in middle-adulthood. Both conditions are also associated with typical lifespan expectancies, suggesting long-term caregiving needs. While there is sufficient evidence of CGB in MS and PD caregivers, this study brings a needed new approach to supporting both spouses. To date, no research has examined the role of meaning in this relationship through love styles. This may prove not only to be a significant predictor of CGB, but also a focus amenable to intervention.

### **Statement of the Problem**

As the progression of MS or PD leads to the need for caregiving and the stress of that role leads to CGB, there is a shared experience between the spouse adjusting to their disability and the spouse managing the stressors that accompany the role of caregiver. There is a cyclical nature to burden and adjustment to disability. While the spouse is adjusting to CID, their needs and roles likely change. This dynamic interaction impacts the spousal caregiver by changing and often increasing responsibilities within the relationship (e.g., housekeeping, childcare, financial, etc.), possibly exacerbating CGB. This burden not only increases the risk of biopsychosocial impacts for the caregiver, but also increases risk for the spouse with CID and interferes with their adjustment process. These shared experiences inevitably alter the nature of the spousal relationship.

In practice and research to-date, the spouses have typically been viewed and explored independently, with each individual being seen as having separate concerns and experiences, rather than recognizing and appreciating the couple's interdependence, and the cyclical and interdependent experience the dyad is facing. To best support the spouse adjusting to their disability, focus must also be given to the spouse providing support, and the concerns of both spouses should be processed in the context of an interacting dyad. Understanding how the dyad works together and changes in this process requires a deeper understanding of their relationship and what they need and want in the relationship and

from their spouse. The research on how the couples in spousal relationships manage disability-related stressors together is extremely limited. Analysis of love styles in this context may provide important perspectives and information on CGB and suggest meaningful therapeutic understanding, responses, and interventions. No other study has evaluated the relationship between love styles and CGB for spouses with CID. The purpose of this study is to investigate the potential relationship between love styles and CGB. Specifically, the following research questions are addressed.

### ***Research Questions***

**Research question 1.** What is the relationship between love styles and caregiver burden among couples in which one partner is living with Parkinson's disease or multiple sclerosis?

**Research question 2.** Do certain love styles serve as protective factors against caregiver burden?

**Research question 3.** How do love styles change after caregiving begins among couples in which one partner is living with Parkinson's disease or multiple sclerosis?

## CHAPTER TWO: LITERATURE REVIEW

### Multiple Sclerosis

Multiple sclerosis (MS) is a chronic, unpredictable, and occasionally progressive disease that impacts the central nervous system (CNS; Bishop & Rumrill, 2015). While the etiology of MS is not yet fully understood, it is characterized by lesions on the brain caused by degraded myelin (also known as white matter), leading to impairment of transmissions from the CNS (Santos et al., 2019). The neurological changes can lead to a wide range of symptoms and concerns, including problems with cognition, vision, balance, and mobility (Maguire & Maguire, 2020). Common reported symptoms are primarily sensory- and motor-related, including fatigue, tremors, speech disorders, pain disorders, intestinal issues, and double-vision (Santos et al., 2019). The most common mental health concerns for adults with MS are depression and anxiety (Bishop & Rumrill, 2015).

MS impacts more than 2.3 million people globally, including over 900,000 in the U.S., is more frequent in women, and typically presents in young to middle adulthood, or 20 – 40 years old (Bishop & Rumrill, 2015; Maguire & Maguire, 2020; Santos et al., 2019; Tzitzika et al., 2020). There are four forms of MS that manifest with varying progressions and symptomology. These include (1) clinically isolated syndrome (CIS), (2) relapsing-remitting (RRMS), (3) primary progressive (PPMS), and (4) secondary progressive (SPMS; Bishop & Rumrill, 2015; Santos et al., 2019).

CIS refers to the first episode of neurologic symptoms, which may or may not result in other forms of MS (NMSS, 2024a). Symptoms can include vision problems (e.g., blurred vision, optic neuritis, painful eye movements), numbness or tingling of face, body, arms, or legs, spasticity, fatigue, walking difficulties, and weakness. A CIS diagnosis requires the episode to last at least 24 hours and the neurological symptoms must be caused by inflammation and demyelination. The diagnosis would change from CIS to other forms of MS when an individual experiences more than one episode and more than one area of the brain and spinal cord are impacted by lesions. Individuals with CIS with similar brain lesions to those with MS are predicted to have a 60% - 80% chance of a second episode and an MS diagnosis within several years.

Roughly 85% of individuals with MS have an initial diagnosis of RRMS, characterized by flares (or relapses) lasting days or weeks that are followed by remissions (or recovery periods; Bishop & Rumrill, 2015). During remissions, individuals may experience a *complete recovery* (all symptoms disappear) or a *partial recovery* (some symptoms become permanent), and disease progression during remissions is unpredictable (NMSS, 2024b). Symptoms are episodic and commonly include fatigue, numbness, cognition problems (e.g., learning, memory, information processing), vision problems, stiffness, and spasticity. Individuals with RRMS are likely to be diagnosed in their 20s and 30s, more likely to be women, and experience the development of more new brain lesions (NMSS, 2024b).

SPMS is developed by at least 50% of those originally diagnosed with RRMS, and generally occurs for individuals living with RRMS for at least 10 years (Bishop & Rumrill, 2015; NMSS, 2024b). This form can be characterized as active (relapses and/or new MRI activity) or not active, and with progression (more severe disability over time) or without progression (NMSS, 2024c). Symptoms are similar to those of RRMS.

PPMS accounts for 10% – 15% of MS diagnoses (NMSS, 2024d). This form can also be described as active, not active, and with progression, or without progression. However, PPMS does not include relapses or remissions. In addition to previously described symptoms, PPMS can also include symptoms like electric-shock sensations, mood changes, paralysis, and tremors.

### **Parkinson's Disease**

Parkinson's disease (PD) is a chronic, progressive neurodegenerative disease and is the second most common neurodegenerative disorder after Alzheimer's Disease (NIESH, 2023). PD results in motor and non-motor symptoms that impact several life domains (McDaniels et al., 2021). Common motor symptoms include tremors (i.e., form of rhythmic shaking), muscle rigidity or stiffness, bradykinesia (i.e., slowness of movement), and difficulties with balance, speech, and coordination (APDA, 2023; NIESH, 2023). Non-motor symptoms can include sleep problems (e.g., REM sleep behavior disorder [dream-enacting behavior]), anxiety, fatigue, and poor sense of smell, among others (APDA, 2023; NIEHS, 2023). PD patients also frequently experience depression, cognitive impairment, and psychosis; these



cognitive and emotional symptoms (also referred to as mental disturbances) are predictors of quality of life (QOL) in people with PD, and are often treatable (Aarsland et al., 1999).

There are more than 10 million people worldwide living with PD and an estimated 1 million people in the United States (APDA, 2023). The average age of onset is 60 years old and people commonly experience co-occurring diagnoses that are associated with aging (e.g., kidney disease and diabetes; McDaniels et al., 2021). Most individuals develop symptoms after the age of 50, however, between 2% and 10% of PD diagnoses are Early Onset PD, defined as diagnosis before the age of 50 (APDA, 2023; NIEHS, 2023).

### **Caregiver Role**

Chronic conditions and disabilities often result in the need for a caregiver; frequently, an individual's spouse will become an informal caregiver (Myhre et al., 2017). Katz and colleagues (2000) evaluated gender disparities in older adults with disabilities receiving care. The study required participants to be 70 years of age or older, live in the community, and disabled (i.e., difficulty with activities of daily living [ADLs] and instrumental activities of daily living [IADLs] in the previous month; Katz et al., 2000). The sample ( $n = 3,109$ ) consisted of 2,006 women (mean age = 80.0) and 1,103 men (mean age = 78.0), and diagnoses including dementia (22%), stroke (18.4%), diabetes (18.3%), and heart disease (41.5%). Katz et al. (2000) found that only 10% received formal care (e.g., paid services), and being married was associated with a higher number of hours of informal care received. Married men with disabilities were found to receive over 26 hours of informal care per week, while married women received less than 15 hours, on average (Katz et al., 2000). Having supportive and caring relationships is a core component of older adults' QOL, regardless of whether the caregiver and care recipient fit in traditional caregiver or receiver roles (Hoppmann et al., 2016; Monin et al., 2019). Therefore, for this study, the distinction between formal and informal caregivers, specification of hours and/or tasks, or living situation (in-home care, nursing home, care facility, etc.) will be used only when necessary and to build a clearer picture of the couples' experience.

Spousal caregivers typically experience difficulties coping with the stress from the changes that come with the acquisition of a disability or progression of a chronic condition and may feel they are unable to support their spouse (Myhre et al., 2017). Commonly reported sources of stress include reduced income, isolation, increases in parental responsibilities, and a lack of intimacy (Arun et al., 2018; Häusler et al., 2016; Llanque et al., 2016). CGB and a lack of meaning are also commonly reported by spousal caregivers (Myhre et al., 2017; Penning & Wu, 2016), as are feelings including frustration, anger, sadness, resentment, and worry for the future (Vatter et al., 2018). Spousal caregivers can experience ambiguous loss and grief which creates additional difficulty coping with change and can result in the caregiver questioning the meaning in life (Myhre et al., 2017). Caregivers must identify new meaning in life while managing new changes, stresses, and challenges to lower the risk of CGB (Myhre et al., 2017).

For most individuals, the caregiving role is unexpected, unplanned, and not entered by choice (Hiseman & Fackrell, 2017; Pearlin & Aneshensel, 1994; Seltzer & Li, 2000). Caregivers are often functioning as a caregiver before they identify as a caregiver (Seltzer & Li, 2000). This is a common ambiguity of the onset of the role, particularly for spousal caregivers when compared to other family caregivers (e.g., adult children, siblings; Montgomery & Kosloski, 1994; Seltzer & Li, 2000). The type of exchange that occurs between caregiver and recipient is a natural extension of prior patterns of support and assistance shared between spouses, continuing to blur the point in time when the caregiver role is acquired (Montgomery & Kosloski, 1994; Seltzer & Li, 1996; 2000). Tasks, responsibilities, and types of support differ greatly for caregivers, not only from day-to-day, but between caregivers, causing further difficulty clearly defining the role and the onset (Chou, 2000; Edwards & Ruettiger, 2002; Montgomery & Kosloski, 1994; Seltzer & Li, 1996; 2000; Shin & Habermann, 2020). The transition into the role emerges out of the existing relationship; the caregiver's behaviors and role identity in relation to the care recipient change (Montgomery & Kosloski, 2013). This change in identity occurs because the tasks required to maintain health and well-being of the recipient are often inconsistent with the initial expectations in the relationship. For caregivers of persons with CID, the change in role identity can be a slow and "insidious" process that results in a significant shift from their initial role in the relationship

(Montgomery & Kosloski, 1994; 2013; Seltzer & Li, 1996). “Incongruence between caregiving tasks and the meaning attached to these tasks that causes caregivers distress, and prompts actions to restore congruence, in whatever way possible, to relieve this distress...such relief may ultimately require an identity change.” (Montgomery & Kosloski, 2013, p. 137).

### **Caregiver Burden**

Caregiver burden (CGB) is generally conceptualized to include the physical, psychological, emotional, social, and financial stressors that are experienced due to the caregiving role (George & Gwyther, 1986) and is the most common caregiving outcome to be investigated (Bastawrous, 2013). The majority of CGB research has failed to conceptualize or define CGB adequately and is quantitative, which risks not fully capturing the complex and subjective experience of caregiving (Bastawrous, 2013). These limitations can result in vague findings that are difficult to summarize or apply in clinical settings (Bastawrous, 2013) and demonstrate the need for measures and researchers to capture both objective (e.g., financial strain) and subjective (e.g., emotional well-being) aspects of burden (Zarit, 2018). Despite the limitations, research has shown that CGB is associated with increased risk of mental and physical health issues (e.g., depression, anxiety, fatigue, cardiovascular disease, and hypertension), mortality, and reduced QOL (Gaynor, 1990; Rodriguez-Gonzalez & Rodriguez-Miguez, 2020; Schulz et al., 1997; Schulz & Beach, 1999). It is common for caregivers to report having trouble coping, and research has shown that CGB is the result of caregivers lacking effective coping skills (Myhre et al., 2017). In a meta-analysis, Rodriguez-Gonzalez & Rodriguez-Miguez (2020) found that the highest levels of burden were in caregivers of individuals with mental illnesses, and the burden increased with the severity of the illness.

Of family caregivers, 47 – 80% are women, and women report nearly twice as much burden when compared to men (Chou, 2000; Edwards & Scheetz, 2002). Researchers believe women experience higher stress due to balancing many roles (e.g., spouse, mother, household manager, primary emotional support), while men are more focused on task accomplishment and tend to report less stress (Chou, 2000). However, male caregivers often report feeling less certain about how to provide care and experience more frustration with lifestyle restrictions compared to women (Mui, 1995; Unson et al., 2015). The financial

expense of caregiving is believed to be the best predictor of CGB (Fink, 1995), as access to resources and support depend greatly on socioeconomic status, income, and employment (Chou, 2000).

Researchers have embraced several theories explaining relationships between caregivers and recipients (e.g., social exchange theory, equity theory, communal relationship theory; Lyons et al., 2002). Relationship quality has also been linked to burden, anxiety, frustration, time costs, depression, health, and tension, and the care recipient's well-being (Lyons et al., 2002). It appears that CGB and relationship satisfaction are cyclical, and causation, correlation, and directionality are unclear. Lyons and colleagues (2002) found caregiver relationship strain to be positively associated with caregiver negative health, caregiver depression, and care recipient's appraisal of the caregiving situation. Further, relationship strain of the caregiver (and not the care recipient) was a predictor of discrepancy in dyadic appraisal of caregiving difficulties, meaning greater relationship strain predicted greater discrepancy. Lyons et al. (2002) suggested interventions that target the caregiving relationship could offset discrepancies in the caregiving situation and caregiver strain, reducing levels of burden.

Although both spouses are affected by CGB, CGB research typically treats spouses as separate units with separate issues (e.g., spouse with diagnosis receives treatment; caregivers learn coping skills) instead of a dyadic approach in which the shared experiences of the spouses are recognized (Lyons et al., 2002). Evidence also shows that spousal caregiving places significant strain on the quality of marital relationships, however, it is often assumed that the care-receiving spouse's health status is the source of stress impacting the caregiver's psychological well-being (Monin et al., 2019). When marital satisfaction is included in research, it is typically only reported by caregivers (Monin et al., 2019). Monin and colleagues (2019) reported that no research had considered "associations of both caregivers' and care recipients' health conditions and disability with both partners' relationship satisfaction" (p. 1744). The full story of spouses with CID and caregivers is missing from the research.

### ***Multiple Sclerosis Caregivers***

Individuals with MS frequently require assistance with daily activities and tasks (Rajachandrakumar & Finlayson, 2022). Caregiving tasks can range greatly and include instrumental tasks (e.g., transportation, house chores), personal assistance (e.g., bathing, toileting), and general emotional and social support. Like the symptoms and progression of MS, caregiving for individuals with MS is unpredictable. Some tasks may come with a pattern or routine, others do not, and this uncertainty can cause additional stress, leading to an increased risk of burden. MS caregivers tend to report a moderate level of burden, with frequently reported concerns relating to fear for their relative's future, care-related stress while balancing other personal and professional responsibilities, feelings of embarrassment about their care-receiver, not having enough time for themselves, and feeling they should be doing more for the care-receiver (Bayen et al., 2015).

MS CGB has not been shown to directly relate to disease duration (Maguire & Maguire, 2020) and time spent on care tasks does not necessarily lead to higher levels of burden (Mosley et al., 2017). However, diagnosis typically occurs in early to mid-adulthood, meaning the duration of caregiving can be three decades or more (Rajachandrakumar & Finlayson, 2022) and MS caregivers spend, on average, 6.5 hours per day on care tasks (Maguire & Maguire, 2020). Nearly 40% of MS caregivers report missing work in the past year and 24% report reducing or leaving employment completely due to caregiving tasks, demonstrating the "considerable economic burdens" caregiving can place on this population (Maguire & Maguire, 2020).

Bayen et al. (2015) examined patterns of objective and subjective burden in MS caregiving in a sample of people with MS ( $n = 96$ ) and their informal caregivers ( $n = 99$ ). The people with MS were mostly women ( $n = 59$ ) and averaged 46.4 years of age ( $SD = 13.9$ ). The average MS duration was 14.8 years ( $SD = 10.2$ ). Two MS subtypes, RRMS ( $n = 41$ ) and PPMS/SPMS ( $n = 58$ ) were represented. Of the caregiver sample, nearly all were family members ( $n = 98$ ), 83% were living with the person with MS, and 70% ( $n = 69$ ) were spouses. Bayen et al. (2015) assessed objective burden by examining the informal care time and tasks. 19 patient-caregiver pairs reported 0 hours of informal care time per day, while 77

pairs reported a range of .07 – 24 hours per day ( $M = 6.5$ ;  $SD = 8.2$ ). Tasks included ADLs, IADLs, and supervision time (ST). 44 pairs reported ADL task assistance ( $M = 2.1$  hours per day;  $SD = 1.7$ ), 76 reported IADL assistance ( $M = 1.79$  hours per day;  $SD = 1.6$ ), and 34 reported needing a range of 15 minutes to 24 hours per day of supervision time ( $M = 9.6$  hours per day;  $SD = 9.6$ ). The researchers assessed CGB with the Zarit Burden Inventory and divided the scores into four subgroups according to severity of burden: mild (0 – 20), mild to moderate (21 – 40), moderate to severe (41 – 60), and severe (61 – 88). Bayen et al. found that 44 caregivers reported mild burden ( $M = 9.6$ ;  $SD = 5.7$ ), 25 reported mild to moderate ( $M = 30$ ;  $SD = 4.7$ ); 21 reported moderate to severe ( $M = 48.9$ ;  $SD = 6.1$ ), and 6 reported severe burden ( $M = 69.7$ ;  $SD = 7.3$ ). The researchers also found that both objective and subjective burden are higher at onset of symptoms when early and severe cognitive limitations were present and were predicted by patient clinical outcomes (e.g., cognitive-behavioral impairment). Bayen et al. suggested that a major finding in the study is the high levels of both objective and subjective burden starting at the onset of MS, and the absence of clear patterns of gradual increases for either objective or subjective burden over time. They concluded that the high level of burden at onset and throughout the early stages of MS might be explained by the frequency and severity of relapses and rapid progression patterns. This suggests that, when evaluating and monitoring burden, simply evaluating duration of disease is not sufficient. Both burdens were also decreased by additional care-support (e.g., home health care organizations, formal care), and Bayen and colleagues suggested that “positive caregiving experiences and a sensation of fulfilment may also result in alleviating [informal caregiving] subjective burden over time” (Bayen et al., 2015, p. 8).

Tzitzika et al. (2020) evaluated the relationships between relational commitment, caregiving burden, and pro-relational behavioral tendencies for spousal/partner informal caregivers of people with MS. The sample consisted of 909 participants (62.5% men) ranging from 25 – 80 years of age ( $M = 48.9$ ;  $SD = 27.13$ ). 85% of the sample were married, with marriage/relationship duration ranging from 1 – 60 years ( $M = 13.39$ ;  $SD = 9.34$ ). The researchers found CGB was moderate (Zarit Burden Inventory [ZBI];  $M = 49.61$ ;  $SD = 16.07$ ) and relationship satisfaction and commitment to relationship to be high. Pro-

relational behavioral tendencies were mainly characterized by public (e.g., tendency to help only while around others) and altruistic (e.g., selfless helping behavior) tendencies, and less by emotional (e.g., helping during emotional situations) and compliant (e.g., helping when asked, not spontaneously). Intent to persist seemed to define the commitment to relationship more than long-term orientation and psychological attachment. When higher levels of CGB were reported, lower relationship satisfaction was also reported. However, although CGB was moderate, commitment to relationship was high, and commitment to relationship had the highest positive effect on relationship satisfaction. The researchers believe that this suggests commitment to relationship, specifically the intent to persist, could be the motivation for spousal caregivers to continue striving for satisfaction from a relationship that has been negatively impacted by the other spouse's health condition.

### ***Parkinson's Caregivers***

Individuals with PD commonly require assistance with instrumental activities of daily living (IADLs; e.g., household chores, shopping, finances), activities of daily living (ADLs; e.g., personal care), and daily disease management (e.g., medication and therapy schedules; Shin & Habermann, 2020). Despite the importance and commonality of caregiving for individuals with PD, there is limited research on PD caregiver activities and detailed U.S. statistics are unavailable (Shin & Habermann, 2020). Shin and Habermann (2020) examined the caregiving experience of individuals with PD ( $n = 54$ ). Common supports with ADLs reported by caregivers included getting in and out of beds and chairs (70.4%); getting dressed (57.4%); getting to and from toilet (48.1%); bathing or showering (46.3%), feeding spouse (37.0%), and dealing with incontinence or diapers (25.9%). Common IADLs included transportation (87.0%); grocery or other shopping (79.6%); managing finances (68.5%); giving medicines (64.8%); preparing meals (63.0%); housework (61.1%); and arranging outside services (48.1%). Nearly 52% of the sample reported never being asked by medical professionals about what is necessary to care for the individual with PD and more than 70% reported never being asked about self-care (Shin & Habermann, 2020).

Aarsland et al. (1999) found that PD spousal caregivers reported higher levels of caregiver stress and emotional distress compared with other caregivers (e.g., daughter, daughter-in-law, and son). Spousal caregivers also reported higher rates of tiredness, sadness, depression, and less satisfaction with life compared with healthy older adult subjects (Aarsland et al., 1999). Higher rates of patient-reported depression and lower patient-reported QOL lead to higher levels of CGB (Macchi et al., 2020). Aarsland et al. (1999) and Macchi et al. (2020) also found that higher levels of education correlated with lower levels of depression, and higher levels of caregiver stress were observed in cases with public home care. Aarsland et al. (1999) suggested the association between stress and public home care is due to more severe limitations in patients receiving home care. Both emotional distress and caregiver stress were impacted by mental disturbances, while functional impairment predicted caregiver stress only. These researchers concluded that, while caregiver stress is associated with the severity of motor, functional, and mental disturbances, mental-related symptoms had the most significant relationship with caregiver stress (Aarsland et al., 1999). Further, because cognitive and emotional symptoms are the most impactful symptoms on caregiver stress, and many of the symptoms are treatable, clinicians were encouraged to prioritize the identification and treatment of these symptoms to enable spousal caregivers to maintain care in home for a longer duration (Aarsland et al., 1999).

Hagell et al. (2017) found that PD caregivers who report having a disability or disease of their own experience significantly higher burden than those who did not. Those who reported having a disease of their own had a median score of 30 on the Zarit Burden Inventory – 22 (ZBI-22), compared to the median score of 16.5 for those who did not report having a disease ( $p = 0.011$ ). Burden scores are typically higher for people with very low income (Mosley et al., 2017), and income was found to be a predictor of burden in a longitudinal study (O'Connor & McCabe, 2011). In a number of studies, the number of hours spent caregiving has been found to correlate, to varying degrees, with burden. Specifically, researchers have found (a) no correlation (Martinez-Martin et al., 2012; Martinez-Martin et al., 2008; Shin et al., 2012), (b) weak correlation (Kim et al., 2007; Razali et al., 2011; Tew et al., 2013), or (c) moderate correlation (Sanyal et al., 2015; Zhong et al., 2016). These varying findings may be due to



the fact that caregivers who feel burdened may overestimate the time they perceive as caregiving (Mosley et al., 2017).

### **Logotherapy**

Viktor Frankl's logotherapy is an empowering, meaning-focused, and value-based approach with three main tenets: meaning to life, will to meaning, and freedom of will (Schulenberg et al., 2010). Frankl (1959; 2014) believed that life was not made to be unbearable by circumstances, rather, it was made unbearable by the lack of meaning and purpose; the only thing humans are truly in control of is their attitude. He suggested that when the search for meaning is successful, happiness and the ability to cope with suffering will both increase.

Frankl (1959; 2014) believed that love could be a nearly universal meaning in life. When people have meaning and purpose, suffering is reduced and, in any situation, love could be the meaning to reduce any type of suffering. In evaluating someone with whom one has a loving relationship, one can see the loved one's essential traits and features, and their potential that has yet to be actualized (Frankl, 1959; 2014). Logotherapy has been shown to improve resilience and adjustment, and reduce CGB (Ghazali et al., 2018; Hosseinigolafshani et al., 2020; Moein & Houshyar, 2015).

### **Love Styles**

Love styles are the attitudes that explain how individuals define love within the context of their romantic relationships (Vedes et al., 2016). The attitudes impact how an individual feels about and behaves in their relationship (Lee, 1977; Vedes et al., 2016). Love is displayed, received, and experienced in many forms and in various relationship types (e.g., parental, friendly, romantic, etc.), and different expressions of love can be seen within the same relationship (Raffagnino & Puddu, 2018). The many variations make clear classification difficult and there has been an array of classifications of love, including Sternberg's (1986) Triangular Theory of Love (e.g., intimacy, passion, and commitment), and Hatfield and Rapson's (1987) two general types of love: passionate love (e.g., desire to bond) and compassionate love (e.g., affection). Lee's (1977) conceptualization of love styles is the most utilized

categorization of love, and is viewed as the most complete, structured, and focused explanation of spousal and romantic relationships (Hendrick & Hendrick, 1989; Raffagnino & Puddu, 2018).

Lee (1977) defined six love styles: three primary and three secondary styles. The primary styles include Eros (romantic, passionate love), Ludus (game-playing love), and Storge (friendship love). The secondary styles are a combination of two primary styles and include Mania (dependent, possessive love; combination of Eros and Ludus), Pragma (practical love; combination of Storge and Ludus), and Agape (unselfish, altruistic love; combination of Eros and Storge; Hendrick & Hendrick, 1986; Lee, 1977; Lin & Huddleston-Casas, 2005; Raffagnino & Puddu, 2018; Vedes et al., 2016). While secondary styles are combinations of the primary styles, there are six distinct love profiles (Smith & Klases, 2016). Although there appears to be overlap between styles, each love style is qualitatively different and has a different profile (Smith & Klases, 2016). The Love Attitudes Scale (LAS; Hendrick & Hendrick, 1986) measures the love styles based on Lee's (1977) definitions and is the most commonly used tool in love style research (Raffagnino & Puddu, 2018; Vedes et al., 2016).

Smith and Klases (2016) explored the potential combination of cultural orientation, gender, attachment style, and relationship in order to predict different love styles with samples from Britain ( $n = 56$ ) and Hong Kong ( $n = 52$ ;  $N = 108$ ). The two locations allowed for the comparison of collectivist and individualist cultures. Multiple regression analyses were utilized to evaluate the relationship between the six predictor variables (gender, relationship length, avoidant attachment, anxious attachment, individualism, and collectivism) and the six love styles. Smith and Klases found all love styles accounted for significant levels of variance in the regression models. The model for Eros explained 22% of the variance, however, the only significant individual predictor of Eros was relationship length (e.g., the longer the relationship, the weaker endorsement of Eros). The model accounted for 33% of the variance in Ludus, with individualism and insecure avoidance being the strongest predictor variables. The model explained 23% of the variance in Storge scores, with gender (males higher than females) and relationship length (longer relationships express less Storge) as key predictors. The model accounted for 22% of variance in Pragma scores; gender positively predicted (i.e., females scored higher than males), and

individualism negatively predicted (i.e., the more individualistic, the less likely to endorse pragma) Pragma scores. The model explained 52% of the variance in Mania scores. The most significant predictors were relationship length and collectivism, which positively predicted Mania scores, and anxious insecurity, that negatively predicted scores, suggesting longer relationships have fewer expressions of Mania. Finally, the model accounted for 25% of the variance in Agape scores, with significant predictors including relationship length (i.e., longer relationships had more expressions of Agape), insecure anxiety positively predicting Agape scores, and gender (males endorsed more than females). The model was significant for each style with varying levels of contribution, supporting the concept that the six love styles are distinct profiles (Smith & Klases, 2016). Smith and Klases (2016) concluded that significant amount of love styles can be explained by social factors (e.g., cultural background, relationship length), rather than personality factors (e.g., anxious or avoidant attachment, self-esteem; Smith & Klases, 2016). Relationship length was the most significant predictor in four of the six love styles. Agape was the only love style for which this relationship was a positive, rather than negative, relationship. This can be interpreted either as meaning that longer relationships become more ideal, or that self-sacrificing behaviors (e.g., Agape) become required to make a relationship last (Smith & Klases, 2016).

### ***Eros***

Eros includes passionate and romantic attitudes toward love and based on physical and emotional attraction and feelings of passion (Hendrick & Hendrick, 1989; Lee, 1977; Raffagnino & Puddu, 2018). Eros has stable positive correlations with quality of life, subjective well-being, and dyadic satisfaction that do not change over time, exist in all age groups, short-term and long-term relationships, and stay consistent throughout many cultures (Raffagnino & Puddu, 2018). There have been direct connections from Eros to intimate closeness, positive conflict resolution strategies (e.g., compromise), and dyadic coping (Raffagnino & Puddu, 2018; Vedes et al., 2016). Eros has also been associated with higher commitment in relationships and decreases in avoidance and anxiety. Eros also has inverse relationships with relational behavior (e.g., avoidance), destructive communication behaviors (e.g., contempt, defense,

criticism), and dysfunctional coping strategies (e.g., dominance and interactional impulsiveness), and no correlation with dysfunctional emotional reactions. Conversely, Eros has also been correlated with negative relational behaviors (e.g., spying on partner and feelings of jealousy; Raffagnino & Puddu, 2018). Additionally, relationship length may be a negative predictor; the longer the relationship lasts, the less the partner may show Eros (Raffagnino & Puddu, 2018; Smith & Klases, 2016).

### ***Ludus***

Ludus is typical of individuals who see love as a game; they are often uncommitted and focus on having fun in the moment (Hendrick & Hendrick, 1989; Lee, 1977; Raffagnino & Puddu, 2018). Ludus is related to weak effort in relationships, lack of care for commitment and of the partner, and positive feelings at relationship termination, and has been considered a risk factor to quality and stability in romantic relationships (Raffagnino & Puddu, 2018). Ludus has been shown to be a good predictor of destructive communicative behavior and is correlated with avoidant forms of attachment.

### ***Agape***

Agape is common with individuals who have unconditional and unselfish love, and are willing to sacrifice anything for someone they care for or support (Hendrick & Hendrick, 1989; Lee, 1977; Raffagnino & Puddu, 2018). This love style has been described as the idealized love style, which many seek to achieve, yet is often elusive (Lee, 1973; Smith & Klases, 2016). Agape has been positively correlated with length of relationship, relational satisfaction, and relationship quality (Raffagnino & Puddu, 2018). Agape has been related to the avoidance of destructive communication behaviors, negative conflict resolution, and negative relational behavior (Raffagnino & Puddu, 2018; Vedes et al., 2016). High levels of Agape often increase support given to a stressed partner and jointly avoiding stressors (Vedes et al., 2016). However, the likelihood of joint efforts in avoiding stressors seems to decrease with the length of the relationship (Vedes et al., 2016). Researchers tend to agree that there is a connection between agape and relationship satisfaction and relationship strength, however, the existence of gender differences is unclear. Vedes et al. (2016) concluded spouses can be satisfied and cope with stress within their relationship more effectively by endorsing agape or eros love attitudes, and individuals with higher

scores in eros and agape love styles are more satisfied with their relationship. In their sample of 92 heterosexual couples, these characteristics held true for men and women, however most strongly and consistently for women (Vedes et al., 2016). Kimberly and Werner-Wilson (2013) evaluated relationships between Lee's six love styles, John Gottman's *Four Horsemen* (i.e., criticism, contempt, defensiveness, and stonewalling; 1994), and relationship satisfaction with 644 individuals (177 males). They found that agape resulted in a stronger relationship in males than in females. Fehr et al., (2013) examined the relationship between agape, passionate love, relational satisfaction, and commitment with 119 individuals (60 males). The researchers concluded that there were no gender differences in relationship satisfaction. Males have been found to report higher levels of Agape than females (Lin & Huddleston-Casas, 2005), however Davies (2001) found that Agape is a more socially desirable style for females, and is undesirable for males.

### ***Storge***

Storge relationships are based on friendship, commitment, and similar interests, rather than passion (Hendrick & Hendrick, 1989; Lee, 1977; Raffagnino & Puddu, 2018). Storge has been shown to be positively correlated with dyadic coping, secure attachment, satisfaction in love life, and the use of functional strategies (e.g., compromise) in marital conflict, while negatively correlated with dysfunctional strategies (e.g., interaction impulsiveness; Raffagnino & Puddu, 2018). Storge becomes less likely to occur as the length of the relationship increases (Raffagnino & Puddu, 2018).

### ***Pragma***

Pragmatic and rational attitudes toward love characterize the Pragma love style. Individuals endorsing Pragma choose partners based on important characteristics and typically share similar goals (e.g., professional goals; Hendrick & Hendrick, 1989; Lee, 1977; Raffagnino & Puddu, 2018). Pragma is related to stable relationships, relationship satisfaction, and subjective well-being (Raffagnino & Puddu, 2018). Individuals are more likely to use strategies like avoidance and compromising and show fluctuations and uncertainty with emotional attachment.

### ***Mania***

Mania is expressed with obsessive and possessive behaviors; individuals are often jealous and need to be loved by their partner (Hendrick & Hendrick, 1989; Lee, 1977; Raffagnino & Puddu, 2018). Mania is a strong predictor of negative relational behaviors, jealousy, pathological love, destructive communication behavior, and negative reactions (Raffagnino & Puddu, 2018).

### ***Love Styles and Marital Satisfaction***

Love in romantic relationships can be viewed as the combination of the measurable constructs of passionate love, companionate love, and commitment (Graham, 2011). Using this definition of love, Graham (2011) conducted a meta-analysis ( $n = 19,387$  individuals in 81 studies) and found a strong relationship between love and relationship satisfaction with a correlation of .793, and love predicted 79.5% of the variance in relationship satisfaction ( $p < .001$ ). Graham (2011) suggested that the strong relationship between love and relationship satisfaction stems from the centrality of love to romantic relationships, especially in Western cultures that believe love is the most important factor for entering marriage. Feelings of love in a romantic relationship are one of the most significant components in relationship quality and maintaining a satisfying relationship (Raffagnino & Puddu, 2018). This is not to say that all spousal relationships exhibit the same type of romance, but to distinguish the feelings of love in spousal (romantic) relationships from feelings of love in other relationships (e.g., child/parent or sibling relationships). Relationship quality has been connected to aspects of subjective well-being (SWB) including life satisfaction, happiness, and having more positive experiences (Dush & Amato, 2005; Kansky, 2018; Raffagnino & Puddu, 2018). Other forms of love can have a negative effect on the duration and quality of the relationship, and be a source of discomfort, struggle, and stress (Acevedo & Aron, 2009; Doron et al., 2012; Graham, 2011; Raffagnino & Puddu, 2018). For example, dependent or obsessive behaviors (exhibited by the love style Mania and sometimes referred to as pathological love) can negatively impact the relationship's quality and duration (Raffagnino & Puddu, 2018).

**Love Styles, Dyadic Coping, and Marital Satisfaction.** Vedes and colleagues (2016) evaluated how Eros, Agape, and Ludus love styles are associated with dyadic coping and relationship satisfaction,

and why couples engage in dyadic coping. The study focused on supportive and common dyadic coping types. The researchers found that an individual's attitude toward love, in terms of specific love styles, is associated with the way they support their partner and cope together with coping behaviors. Dyadic coping mediates the association between love styles and relationship satisfaction (Vedes et al., 2016). Vedes et al. reported that individuals with higher scores in eros and agape love styles are more satisfied with their relationship, meaning spouses can be satisfied and cope with stress within their relationship more effectively by endorsing agape or eros love attitudes.

Gana and colleagues (2013) found that only Eros contributed to marital satisfaction for both women and men; wives' Eros had a positive impact on husbands' marital satisfaction, while husbands' Eros had no influence on wives' marital satisfaction. Lin and Huddleston-Casas (2005) tested the correlation between age, gender, religiosity, education, and relationship satisfaction with an individual's aptitude for agape. They found that age and religion were not significantly associated with agape, while religiosity was significantly related. When controlling for the other variables, the researchers found that men scored higher on agape when compared to women. Individuals that reported higher levels of education scored lower in agape than individuals that reported lower levels of education. Relationship satisfaction was strongly associated with agape, however, regardless of gender, age, or levels of education and religiosity. Individuals who reported feeling more satisfied in their relationships also had higher agape scores (Lin & Huddleston-Casas, 2005). To date, most researchers have examined love styles based on individual responses, rather than comparing dyads (Gana et al., 2013), limiting the understanding of how love styles interact between spouses.

### ***Changes in Love Styles Over Time***

Most conceptualizations of love provide evidence for how different elements of love differ over time (Graham, 2011). Hatfield and Walster (1978) suggested that early relationships have more passion, and it fades over time, and successful relationships have a stronger companionship that replaces the fading passion. Sternberg (1986) agreed that passion peaks in the beginning of the relationship, and intimacy and commitment increase over time. While Hatfield et al. (2008) found companionship and

passion decline over time, Acevedo and Aron (2009) presented evidence that the *romantic obsession* component of passion decreases, and *romantic* components can be long lasting. Graham (2011) concluded that relationships with high levels of romantic obsession (e.g., Mania) result in shorter relationships, and practical friendship components (e.g., Pragma and Storge), while statistically significant, had small effect sizes on relationship length and relationship satisfaction.

Individuals can have one relationship that is more characteristic of one love style and the next relationship that is more characteristic of an entirely different style, and styles change within the same relationship (Lee, 1977; Smith & Klases, 2016). Baumunk (2023) posited that love styles not only influence the decision to stay in a relationship and engage in dyadic coping, but also change and adapt to the changed circumstances in the relationship. As marital circumstances change, love styles can shift in order for the relationship to remain fulfilling and satisfactory. Baumunk (2023) theorized that some type of value-change may occur within spouses that impacts their love style, thus altering the meaning in the relationship. There are three proposed changes that occur: (a) what is valued in a spouse changes (for example, physical attraction may become less important and increased value placed on spouse's characteristics/goals; i.e., eros decreases, pragma increases); (b) what is valued in the relationship changes (e.g., societal position and career aspirations become less important and greater value is placed on sharing hobbies; i.e., pragma decreases, storge increases); or (c) neither change occurs and the relationship suffers negative consequences (e.g., a partner has an affair in an attempt to fulfill needs, or the relationship ends).

### ***Love Styles and Caregiver Burden***

**Love Styles & Perceived Caregiver Burden.** Diaz and colleagues (2019) evaluated love styles, perceived CGB, and received and perpetrated violence to understand predictive roles of violence and burden, and to determine if love styles mediate the relationship between violence and burden. With a sample of 250 women (mean age = 58.66; *SD* = 10.46), Diaz et al. (2019) used the Zarit Burden Inventory, Revised Conflicts Tactics Scale-2 (CTS2), and the Love Attitudes Scale. To date, this is the only study evaluating love styles, CGB, and violence and the only study discussing potential connections between love styles and CGB (Diaz et al., 2019). Differences in violence and love styles as a function of



CGB were analyzed. Diaz et al. (2019) found severe psychological aggression (received and perceived) was highest for the group with mild burden levels. Differences in love styles were not significant, yet Pragma scores were highest across the three burden levels (mild, moderate, high). Perpetrated psychological aggression (severe and minor) predicted CGB in Agape styles, as well as the impact of caregiving on interpersonal relationships in Storge styles.

**Love Styles, Dyadic Coping, and Caregiver Burden.** As one spouse goes through changes in various domains, like physical health or employment status, the other spouse must shift in their own role regardless of the cause for change. Not only could these changes lead to additional responsibilities (e.g., childcare, financial, transportation, or household duties), but they could also impact aspects that are attractive in partners or important in relationships. Couples enter relationships and marriage with varying levels of expectations and certainties (Singleton, 2009). When unanticipated changes occur and uncertainty increases, there is a higher risk for separation or divorce (Singleton, 2009). However, most couples will go through many uncertainties throughout their relationship, including but not limited to CID; the question therefore arises, how are couples adjusting to these changes? Research focuses on dyadic coping as an effective process (e.g., Lee & Roberts, 2018; Meier et al., 2019), yet there is limited information provided on why couples choose to engage in dyadic coping (Vedes et al., 2016). Love styles are associated with various coping styles (e.g., Eros and dyadic coping, Storge and functional coping, Pragma and avoidant coping; Vedes et al., 2016). Based on these findings, Baumunk (2023) hypothesized that love style analysis could help clarify why couples engage in dyadic coping, rather than avoiding or exiting stressful situations. The love style of the caregiver may influence how the caregiver behaves in the dyadic coping process (Baumunk, 2023), and dyadic coping has been found to mediate CGB (Vedes et al., 2016). Likewise, the love style of the spouse with the disability influences their behavior in the dyadic coping process, and dyadic coping mediates adjustment to disability. Evaluating this relationship must include both spouses, as the caregiver's love style interacts with the disabled spouse's dyadic coping behaviors and adjustment to disability (and vice versa), both spouse's dyadic coping behaviors interact, and CGB and adjustment to disability may also influence each other.

## CHAPTER THREE: METHODOLOGY

### Research Design

The study incorporated quantitative, descriptive, and correlational, cross-sectional survey research design. A quantitative descriptive design (Heppner et al., 2015) was used to investigate the relationship between love styles and caregiver burden in spousal dyads, and changes in love styles overtime. The study was exploratory and descriptive in nature because it aimed to examine relationships between love styles, caregiver burden, and MS and PD severity. A correlational research design was appropriate since the study examined the relationships between variables of interest, and no treatments or interventions were included. A cross-sectional survey research design was used to capture individual perspectives on the variables of interest at a specific point in time.

### Sampling Plan

A non-random convenience sample was used. Eligible participants were recruited through multiple Parkinson's disease associations and the National Multiple Sclerosis Society (NMSS). In the summer of 2023, the researcher contacted multiple regional and national PD associations and three regional organizations agreed to distribute the survey (Parkinson's Association of Pennsylvania; Parkinson's Wellness Recovery; and Young Onset Parkinson's Network).

After approval for the study from the UW-Madison Institutional Review Board (IRB) was obtained the researcher provided the PD organizations with recruitment flyers, which included a description of the study, a link and QR code to the survey, and contact information (see Appendix A). The PD survey was opened January 3, 2024. The researcher contacted the NMSS in late February 2024 and the organization agreed to publish the survey on their webpage for individuals with MS to find and participate in research. On March 11, 2024, the NMSS published a brief description of the study and a link to the survey (see Appendix B).

The following criteria was used to determine the inclusion of participants: (a) a resident of the United States, (b) 18 years of age and older, (c) comprehends written English at a 6<sup>th</sup>-grade reading level, (d) either have MS or be the spousal caregiver of an individual with MS, or have PD diagnosed by a

movement specialist or be the spousal caregiver of an individual with PD, and (e) both spouses agree to participate in the study.

The researcher offered an incentive of a \$50 electronic gift card to the first 40 couples completing the surveys. At the end of both surveys, participants were presented a link to an optional survey to provide an email address if they wanted to receive a virtual gift card. The first 40 couples to complete either the MS or PD survey and submit matching email addresses on the gift card survey were eligible to receive one \$50 gift card.

## **Research Questions and Analyses Procedures**

### **Data Summarization and Analysis**

The Statistical Package for Social Sciences (SPSS; version 28.0.1.0) Mac was used to screen and manage data and perform the analyses. Data was analyzed using descriptive statistics, hierarchical regression, ANOVA, and repeated measures ANOVA analyses to test the hypothesized relationships among the variables of interest, as well as the hypothesized changes in love styles.

### **Research Questions and Analyses**

- Research question 1: What is the relationship between love styles and caregiver burden among couples in which one partner is living with Parkinson's disease or multiple sclerosis?
- Research question 2: Do certain love styles serve as protective factors against caregiver burden?
- Research question 3: How do love styles change after caregiving begins among couples in which one partner is living with Parkinson's disease or multiple sclerosis?

### ***Descriptive Statistics***

Descriptive statistics were calculated for socio-demographic information (e.g., age, gender, employment status), multiple sclerosis and Parkinson's disease-specific information (e.g., age of onset), and marriage-specific information (e.g., length of relationship). The statistical analyses used to address the research questions are described below.

### ***Research Question 1***

A backward hierarchical regression analysis was used to address Research Question 1. Specifically, a two-step hierarchical regression analysis was used to investigate the relationship between love styles and caregiver burden, while controlling for variables that have been found to be predictors of caregiver burden, including demographic (gender, age, race/ethnicity, income, and employment status), and caregiver disability status (Ampalam et al., 2012; Chou, 2000; Edwards & Scheetz, 2002; Hagell et al., 2017; Torny et al., 2018; Unson et al., 2015). Hierarchical regression was appropriate because it analyzes the unique effects of sets of predictors (Cohen et al., 2013), with variables analyzed simultaneously within sets with equal priority (e.g., demographics) and hierarchically between sets with different causal and logical status.

The first step of the analysis (Model 1) included the demographic variables (gender, age, race/ethnicity, income, employment status, caregiver disability status, caregiver anxiety and depression) as predictors, with CGB as the dependent variable (DV). The second step (Model 2) included the six love styles (Eros, Agape, Storge, Pragma, Ludus, Mania). Both models provided  $R^2$ , or the proportion of DV variance explained by the model. The change in  $R^2$  ( $\Delta R^2$ ) between Models 1 and 2 was evaluated to assess whether Model 2 explained significantly more variance in CGB than Model 1.

- Model 1:  $CGB = \text{Intercept} + \text{gender} + \text{age} + \text{race/ethnicity} + \text{income} + \text{employment status} + \text{caregiver disability status} + \text{caregiver anxiety and depression} (R^2)$
- Model 2:  $CGB = \text{Intercept} + \text{gender} + \text{age} + \text{race/ethnicity} + \text{income} + \text{employment status} + \text{caregiver disability status} + \text{caregiver anxiety and depression} + \text{love styles} (R^2, \Delta R^2)$

**Assumptions.** The assumptions for regression analyses are (a) linearity, (b) correct specification of the independent variables (IVs), (c) no measurement error in the IVs, (d) homoscedasticity, (e) independence of residuals, (f) normality, and (g) multicollinearity (Cohen et al., 2013). First, the relationship between IV and the DV should be linear. This assumption can be tested through scatterplots to verify the presence of a linear relationship. If violated, an inaccurate representation of population estimates can occur. Second, correct specification of the IVs focuses on IVs in the regression model,

assuming all relevant variables from the theory are included, are measured properly, and the form of the relationship between IV and DV is specified. This assumption ensures unbiased estimates of regression coefficients and population estimates and can be evaluated with visual inspection of scatterplots. Linear trends in the scatterplots suggest correct specification, whereas outliers or no clear pattern may suggest incorrect specification. Third, no measurement error in the IVs is the assumption that each IV in the regression model is measured without error. If violated, the estimate of correlations will be biased and is impossible to fully eliminate. This assumption can be evaluated by examining the validity and reliability of the measures used to collect data to reduce measurement error and evaluating the quality of the data to reduce noise error. Fourth, homoscedasticity, or constant variance of residuals, assumes the variance of the DV is the same across all data. A variety of tests can determine if this assumption was met or not (e.g., Goldfeld-Quandt test, Park test). Fifth, independence of residuals assumes there is no relationship among the residuals and can be met with any random sample from a population. If violated, there may be biased estimates of regression coefficients, standard errors, significance tests, and confidence intervals. Sixth, normality assumes normal distribution of observed and predicted values and can be tested through reviewing scatterplots, tests of kurtosis and skewness, a histogram of standardized residuals, and other normality tests. Finally, multicollinearity is a high correlation between IVs and should not be present. If multicollinearity exists, the individual effects of each IV on the DV will be difficult to distinguish. This assumption can be evaluated with many methods, including correlation matrixes, Variance Inflation Factor (VIF), and examining scatterplots or partial regression plots.

### ***Research Question 2***

ANOVA analyses were used to determine if the relationships between the different love styles and CGB were significant. The DV was CGB and the IV was love styles, with the six distinct styles representing six groups within the IV. The null hypothesis for a one-way ANOVA is that the means are equal. The data for CGB is continuous and love styles were entered as categorical variables. Categorical data entry was appropriate because love styles are inherently categorical and non-ordinal. Trends in CGB scores within the love style categories were examined to understand if particular love styles are more

protective against CGB when compared to other styles. Post-hoc tests were performed on analyses that showed significant differences between groups, to identify specific group differences. Bonferroni corrections were performed in SPSS, which uses *t*-tests to perform pairwise comparisons between group means and controls for overall error rate, and the significance level is adjusted for multiple comparisons (Field, 2018).

**Assumptions.** The assumptions for ANOVA are the same as regression, except that there is no assumption of linearity. Three of the assumptions are essential: (a) homogeneity of variances, (b) independence of observations, and (c) normality. First, homogeneity is the assumption that the variances within each love style group are roughly equal. This can be checked by using Levene's test. Second, independence is the assumption that observations within each group are independent of each other. Finally, normality is the assumption that the DV (CGB) follows normal distribution within each love style group. This can be checked with histograms, normal probability plots, or a formal test like Shapiro-Wilk test for each love style group.

### ***Research Question 3***

Repeated measures ANOVA were used to address research questions 3. The analysis was used to determine if there was a statistically significant difference between love styles at four points in time (T1 = today/current, T2 = caregiving, T3 = symptom onset, T4 = marriage). The DVs were love styles and the IVs were time points (referred to as the within-subjects factor). The same participants were measured over four time points, reducing individual differences. Scatterplots from the repeated measures ANOVA analyses were examined to evaluate whether the caregiving role facilitates change in different love styles.

Time-specific love style questions (see *Love Styles Over Time* section below) were entered with two within-subject factors, (1) time and (2) love styles. The time factor was entered with four levels (T1 – T4), and love styles was entered with six levels. The 24 values from the love styles over time questionnaire were entered in order of time and love styles (e.g., T1-Eros, T1-Ludus, T1-Storage [...], T2-Eros, T2-Ludus, [...], T4-Mania, T4-Agape]. Between-subject factors (e.g., groups) were not utilized for every analysis and are discussed further in the results sections. The use of repeated measures ANOVA

allowed for the examinations of changes in love styles within the same group of participants over time. This accounted for the correlation between repeated measures on the same subjects, making it ideal for studying the evolution of love styles across multiple time points within individuals.

**Assumptions.** There are five assumptions for repeated measures ANOVA. First, the DV must be continuous. Second, the IV must consist of at least two categorical related groups. Third, there are no significant outliers in the related groups. Fourth, the DV in the related groups should have approximately normal distribution. Finally, sphericity, or the variances of the differences between all combinations of related groups must be equal. The violation of the sphericity assumption is common and increases Type I error. Sphericity can be identified using Mauchly's test.

### ***Estimating Sample Size***

To determine the sample size for this study, an a priori power analysis was conducted using G\*Power (software tool for generating power analysis; Faul et al., 2007; Faul et al., 2009) based on the proposed statistical analysis requiring the largest sample (hierarchical regression). Alpha level ( $\alpha$ ) was set at 0.05, desired power ( $1-\beta$ ) is set at the typical level of 0.80, and a small effect size was set at 0.2. The number of predictors ( $k$ ) increased for each model. Model 1 included the intercept, gender, age, race/ethnicity, income, employment status, caregiver disability status, caregiver anxiety and depression as the eight predictors ( $k_1$ ). Model 2 added six predictors (Eros, Agape, Storge, Ludus, Mania, Pragma) for a total of fourteen predictors ( $k_2$ ). Total  $k$  ( $k_1 + k_2$ ) was 22. The total sample size required was 127 caregivers, meaning 127 couples (or a total of 254 individuals).

## **Instrumentation**

### ***Demographic Variables***

A demographic questionnaire was developed for the purpose of this study. Participants self-reported demographic data. The demographic information collected included: gender (0 = female, 1 = male, 2 = non-binary; 3 = prefer not to say; 4 = not listed/specify); age (continuous); race/ethnicity (0 = African American/Black, 1 = Asian/Pacific Islander, 2 = Hispanic or Latinx, 3 = Native American/American Indian, 4 = White, 5 = Multiracial; 6 = prefer not to say; 7 = not listed/specify);

household income (0 = 0 – 24,999, 1 = 25,000 – 44,999, 2 = 45,000 – 59,999, 3 = 60,000 – 84,999, 4 = 85,000 – 99,999, 5 = 100,000 – 114,999, 6 = 115,000 – 129,999, 7 = 130,000 – 149,999, 8 = 150,000+); changes to income (0 = no change to income due to MS/PD or Caregiving (CG), 1 = reduced income due to MS/PD or CG, 2 = increased income due to MS/PD or CG); percentage of change in income (0 = 0 – 9%, 1 = 10% – 19%, 2 = 20% – 29%, 3 = 30% – 39, 4 = 40%+); education attainment (0 = less than high school, 1 = high school diploma or equivalent, 2 = some college, 3 = Associate’s degree, 4 = Bachelor’s degree, 5 = Master’s degree or higher); employment status (0 = retired, 1 = employed part-time, 2 = employed full-time, 3 = unemployed and looking, 4 = unemployed and not looking, 5 = stopped due to caregiving, 6 = stopped due to MS/PD; 7 = other/specify); changes to employment (0 = no change to employment due to MS/PD or CG, 1 = reduced employment due to MS/PD or CG, 2 = increased employment due to MS/PD or CG); governmental benefits status (0 = no, 1 = yes); government benefits received (0 = TANF, 1 = SNAP, 2 = WIC, 3 = SSI, 4 = SSDI, 5 = Unemployment, 6 = other/specify); marital status (0 = married, 1 = not legally married, 2 = domestic partnership, 3 = divorce/separated, 4 = other/specify); type of insurance (0 = employer/private, 1 = public/marketplace, 2 = Medicare, 3 = Medicaid, 4 = no insurance; 5 = other/specify); living situation (0 = living together in personal residence, 1 = living together in assisted living situations, 2 = living together in nursing home, 3 = living apart in separate personal residence, 4 = living apart in assisted living situations, 5 = living apart in nursing home); assistance type (0 = no assistance, 1 = family/friends, 2 = agency without cost, 3 = agency with out of pocket costs, 4 = other/specify); and caregiver disability status (0 = reported having CID, 1 = reported not having CID).

### ***Relationship-Specific Instruments***

**Relationship Timeline Questionnaire.** A relationship timeline questionnaire was developed for the purpose of this study. Participants self-reported relationship data. The relationship information collected included total years of being together with current spouse (including dating), years of marriage to current spouse, number of marriages total, and number of unique spouses. These data points were continuous.



### ***Diagnosis-Specific Information***

A diagnosis-specific questionnaire was developed for the purpose of this study. This was a self-report style questionnaire. Data collected included the age of the participant at the time of diagnosis, at symptom onset, and at start of MS or PD-related caregiving.

### ***Multiple Sclerosis-Specific Information***

The Multiple Sclerosis Impact Scale (MSIS-29; Hobart et al., 2001) is a 29-item self-report questionnaire that assesses the impact MS has on functioning using two subscales: physical functioning (20 items) and psychological functioning (9 items; Hoogervorst et al., 2004; Phillips et al., 2014). The MSIS-29 takes 5 – 10 minutes to complete and utilizes a 5-point ordinal scoring system that includes a range of 1 = *not at all*, 2 = *a little*, 3 = *moderately*, 4 = *quite a bit*, 5 = *extremely* (Hobart et al., 2001; McGuigan & Hutchinson, 2004). A total score is calculated by summing the item scores and converting them into a score out of 100, with higher scores indicating greater degrees of disability (Phillips et al., 2014). Both subscales have been found to have good to excellent internal consistency across multiple studies (Hobart et al., 2001; McGuigan & Hutchinson, 2004; Riazi et al., 2002). Specifically, the internal consistency was reported within the following ranges for the scales have been reported for the physical scale (Cronbach's  $\alpha = 0.88 - 0.96$ ) and the psychological scale (Cronbach's  $\alpha = 0.87 - 0.92$ ), and test-retest reliabilities for both scales range from 0.87 – 0.94 (Hobart et al., 2001; McGuigan & Hutchinson, 2004; Riazi et al., 2002). In the present study, the internal consistency was high (Cronbach's  $\alpha = .916$  and  $.872$ , respectively).

### ***Parkinson's Disease-Specific Information***

The Parkinson's Disease Questionnaire – 39 (PDQ-39; Peto et al., 1995) is a 39-item self-report questionnaire that assesses PD-specific health-related quality over the last month, how often individuals experience difficulties across QOL dimensions, and the impact of PD on functioning and well-being (Hagell & Nygren, 2007; Shirley Ryan Ability Lab, 2014). The PDQ-39 utilizes a 5-point ordinal scoring system that includes a range of 0 = *never*, 1 = *occasionally*, 2 = *sometimes*, 3 = *often*, and 4 = *always (or cannot do at all)*; Shirley Ryan Ability Lab, 2014). The assessment provides scores for each of eight QOL

subscales (described below) and the sum of scores is used as the overall health-related QOL. The PDQ-39 required licensing and cost roughly \$315.00 USD (£250) for the assessment tool, and approximately \$189.00 (£150) for the user manual, which included the scoring system.

The QOL dimensions include: (1) mobility (questions 1 – 10), (2) activities of daily living (ADLs; 11 – 16), (3) emotional well-being (17 – 22), (4) stigma (23 – 26), (5) social support (27 – 29), (6) cognition (30 – 33), (7) communication (34 – 36), and (8) bodily discomfort (37 – 39; Shirley Ryan Ability Lab, 2014). The dimension score range for each dimension is 0 – 100, with lower scores reflecting better QOL. The dimension score is the sum of scores of each item divided by the possible score of all dimension items and multiplied by 100. The assessment takes 10-20 minutes to administer and is appropriate for adults ranging from 18-64 years old and 65 years or older. Internal consistency for the eight subscales ranges from 0.73 – 0.96 (Hagell et al., 2003), and test-retest reliabilities range from 0.76 – 0.93 (Hagell et al., 2007). The summary index score has good to excellent internal consistency (Cronbach's  $\alpha = 0.84 - 0.94$ ; Damiano et al., 2000; Jenkinson et al., 1995; Jenkinson et al., 1997). In the present study, the internal consistency was excellent (Cronbach's  $\alpha = .934$ ).

### ***Caregiver Burden***

The Zarit Caregiver Burden Inventory (ZBI; Zarit, 2018) is a 22-item self-report inventory assessing subjective burden, with a 2-factor structure containing personal strain and role strain (Mosley et al., 2017). Scores range from 0 – 88, with higher scores demonstrating higher levels of burden. Items are scored on a 5-point Likert scale with response sets ranging from 0 – 4 (items 1-21: 0 = *never* to 4 = *nearly always*; item 22: 0 = *not at all* to 4 = *extremely*; Zarit, 2018). The ZBI uses the term “relative” in reference to the person the receiving care and is a placeholder that can be substituted with the most appropriate term (Zarit, 2018). For this study, the term “spouse” will be the substituted phrase.

Internal consistency has been found to be good, with Cronbach's alphas ranging from 0.83 – 0.93 (Bedard et al., 2001; Hébert et al., 2000; Majerovitz, 1995; Zarit et al., 1987). The ZBI-22 has been validated in a sample of people with PD and their caregivers ( $n = 80$  people with PD;  $n = 79$  caregivers;  $N$

= 159) and maintained high internal consistency (Cronbach's  $\alpha = 0.93$ ; Martinez-Martin et al., 2007). In the present study, the internal consistency was excellent (Cronbach's  $\alpha = .930$ ).

### ***Caregiver Anxiety and Depression***

The Patient Health Questionnaire – 4 (PHQ-4; Kroenke et al., 2009) is a 4-item self-report questionnaire screening for depression and anxiety and does not require permission to use (Lowe et al., 2010). The measure was developed by combining items from the PHQ-2 (depression screener modified from the PHQ-9) and the GAD-2 (anxiety screener modified from the GAD-7; Caro-Fuentes et al., 2023; Kroenke et al., 2009; Lowe et al., 2010). The subscales can be scored separately, or a total score can be used for a distress screener (Caro-Fuentes et al., 2023). Items are scored on a 4-point Likert scale with response sets ranging from 0 – 3 (0 = *not at all*, 1 = *several days*, 2 = *more than half the days*, and 3 = *nearly every day*), with total scores ranging from 0 – 12 (Lowe et al., 2010). Internal consistency ranges across studies from moderate to high (Cronbach's  $\alpha = 0.71–0.88$ ) and test-retest reliability ranges from 0.89 – 0.98 (Caro-Fuentes et al., 2023; Christodoulaki et al., 2022; Khubchandani et al., 2016; Lowe et al., 2010). In the present study, the internal consistency was good (Cronbach's  $\alpha = .848$ ).

### ***Love Styles***

The Love Attitudes Scale – Short form (LAS; Hendrick et al., 1998) is a 24-item self-report inventory with six subscales (4-items per subscale) representing the six distinct love styles (Eros, Ludus, Agape, Mania, Storge, and Pragma). The original LAS (Hendrick & Hendrick, 1986) also has six subscales with 7 items each subscale for a 42-item scale. Items are scored with a Likert scale (1 = *strongly agree*, 2 = *moderately agree*, 3 = *neutral*, 4 = *moderately disagree*, and 5 = *strongly disagree*), with higher scores indicating lower endorsement of the love style, and lower scores indicating higher endorsement of the love style. The 42-item LAS contained items referring to a specific relationship and loving relationships in general (Hendrick et al., 1998). The internal consistency for the subscales was reported to be acceptable to good, with all subscales Cronbach's alpha coefficients above .70, except for Storge ( $\alpha = .62$ ). The authors revalidated the measure (Hendrick & Hendrick, 1990) to be relationship-specific and in this version the Cronbach's alpha coefficients improved to range between .74 – .84, with a

test-retest reliability of .60 – .78 ( $n = 112$ ). There have been several attempts at creating a valid short form (e.g., Grote & Frieze, 1994; Sprecher et al., 1994; Thompson & Borrello, 1987). Hendrick and Hendrick developed 3- and 4-item short forms and they believed that the 4-item subscale would “optimize alpha coefficients, factor structures, test-retest reliability” (Hendrick et al., 1998, p. 149). The validation of the 4-item subscales consisted of three studies with Cronbach’s alpha coefficients ranging between .68 – .88 (study 1:  $n = 1090$ ,  $\alpha = .72 - .86$ ; study 2:  $n = 834$ ,  $\alpha = .75 - .88$ ; study 3:  $n = 847$ ,  $\alpha = .68 - .85$ ; Hendrick et al., 1998). Hendrick et al. (1998) concluded that the 4-item subscales are psychometrically equal, and possibly superior, to the 42-item scale. In the present study, the internal consistency ranged from acceptable to good (Cronbach’s  $\alpha = .69 - .93$ ).

### ***Love Styles Over Time Questionnaire***

A four-item questionnaire was developed for this study to evaluate love styles at different time points. Each question asked participants how strongly they agreed with six statements based on their current relationship during a specific point in time. The statements were written to encompass the six distinct love styles and were the same for each question. Participants rated items based on a Likert scale (1 = *strongly agree*, 2 = *moderately agree*, 3 = *neutral*, 4 = *moderately disagree*, and 5 = *strongly disagree*), with higher scores indicating lower endorsement of the love style. Items were scored as separate data points (as opposed to a composite or subscale score), resulting in 24 data points for each participant. To attempt to limit order-effect bias, the questions were ordered by (1) today; (2) during the first year of marriage/cohabitation, (3) during the first year of symptom onset; and (4) during the first year of MS-/PD-related caregiving.

In order to evaluate the amount of time it would take participants to complete this section of the survey, and get feedback on the readability and clarity of the statements, a pilot test was conducted with a small sample of graduate-level students, who were asked to complete this scale along with the LAS – Short form. Four graduate students completed the pilot questionnaire and completion times ranged between 5 – 7 minutes. All participants reported to be in committed relationships (e.g., long-term, married). One participant recommended the statements for question 1 (today) be written in present-tense,

rather than past-tense, to help with clarity. The researcher modified the statements in question 1 to present tense for the final survey.

Only responses from the first question (today) were examined, due to the participants not matching the target populations (e.g., people with MS/PD and spousal caregivers). This question had a Cronbach's  $\alpha$  of 0.86, suggesting strong internal reliability. Validity was examined using Pearson's correlation and ranged from weak to strong (Eros:  $r = .91$ ; Storge and Pragma:  $r = .25$ ; agape:  $r = .82$ ). Only Ludus and Mania (both  $r = .99$ ;  $p = 0.05$ ) had significant correlations. Bivariate correlations were also conducted on each statement with the correlating subscale of the LAS. Validity increased for all love styles (Eros:  $r = .58$ ; Storge:  $r = .94$ ; Mania:  $r = .85$ ; Pragma  $r = .57$ ; Agape:  $r = .92$ ), yet only Ludus ( $r = .98$ ;  $p = 0.05$ ) was statistically significant. The preliminary findings are interpreted with caution due to the low response rate and participants were instructed to focus on time and clarity, which could have decreased the accuracy of responses.

- 1) Passion and romance are/were the most important feelings in our relationship, and physical and emotional attraction are/were the driving forces that keep/kept us together. (Eros)
- 2) We live(d) in the moment and are/were just having fun; we sort of play(ed) a game with love, and rarely take/took the relationship too seriously. (Ludus)
- 3) Our friendship is what brought us together and keeps/kept us close; we like(d) the same things, have/had the same hobbies, and our deep friendship is the most important aspect of the relationship. (Storge)
- 4) Feelings of infatuation and jealousy are/were the most common in our relationship, battling for attention and affection keeps/kept our relationship alive. (Mania)
- 5) Shared goals (such as career and/or parenting aspirations) brought us together and knowing our common goals would positively serve and reflect on us keeps/kept us together. (Pragma)
- 6) Unconditional love and sacrifice brings/brought happiness and fulfillment to our relationship; sometimes suffering is necessary to support others. (Agape)

***Qualitative Prompt***

Open-ended prompts were used to gather qualitative information to help support the reflective perspectives and provide participants an opportunity to share information they believed was not captured in the survey. Prompts included: (1) Is there any information that you believe is important for the researchers to know that was not fully captured regarding: (a) love styles, (b) adjustment to caregiving role, (c) adjustment to Parkinson's disease, and (d) changes in your relationship/marriage. The qualitative data was reviewed but not scored or interpreted for the purposes of this study.

## CHAPTER FOUR: RESULTS

In this chapter I present the results of the analyses described in Chapter 3. I first address the preliminary data screening, procedures to address missing data, and the analysis of the statistical assumptions for hierarchical linear regression and repeated-measures ANOVA.

### Preliminary Screening

A preliminary screening was conducted by the researcher using SPSS to ensure accuracy of data, address missing data, and test statistical assumptions. A total of 210 responses were collected, with 121 respondents agreeing to the informed consent. 19 respondents did not complete the question that identified the role of the participant (e.g., person with MS, PD, or caregiver), which determined the remaining questions presented to participants (e.g., ZBI, PDQ-39, or MSIS). When respondents did not answer the question about their role, the remaining survey questions that were tailored specifically to roles would not have been presented. As a result, the survey ended prematurely, and their incomplete responses could not be used in the analyses. The researcher reviewed answers to security questions (e.g., select “cabbage”) and questions with connected answers (e.g., current age, age at time of marriage, total years married), and removed responses (13) with clear errors or repeated answers (e.g., selected answers other than “cabbage”, provided the same number in all fields, selected all “*neutral*” answers in questionnaires). Thus, the data of 89 participants were used for the screening process and statistical analyses. The screening process addressed missing data and checked assumptions including (a) linearity, (b) correct specification of the independent variables (IVs), (c) no measurement error in the IVs, (d) homoscedasticity, (e) independence of residuals, (f) normality, and (g) multicollinearity (Cohen et al., 2013).

### Missing Data

Missing data is one of the most common problems in data analysis and may lead to invalid results (Cohen et al., 2013). In the 89 responses, there were 57 missing data points. Cohen et al. (2013) stated that, for any variable, less than 10% of missing values is not extensive and therefore the variables can be retained. 52 of the data points were missing from age when married (12 values, 13.5%), age at time of

diagnosis and at symptom onset (13 values each, 14.6% each), and age at caregiving onset (14 values, 15.7%). Although missing data for these variables did exceed the recommendations from Cohen et al., the responses and items were retained. Analysis of the patterns of the missing values suggested that 11 participants did not answer the questions inquiring about age for specific events (e.g., at the time of marriage, diagnosis, symptom onset, and caregiving role), 6 participants did not answer one of the questions, and 1 did not answer two of the questions. There are numerous reasons that participants might not answer these questions. For example, some participants noted that they met their spouse after they received their diagnosis, and some noted large age gaps between spouses in addition to meeting after diagnosis and symptom onset. For example, one respondent indicated they were a child at the age of their spouse's symptom onset, even though they met two decades later. This illuminated the reality that not all couples experience the same progression of events (e.g., [1] marriage, [2] diagnosis, and [3] caregiving), and assuming a pattern of onset could risk misinterpreting results. Further, at the risk of losing meaningful antecedents, the intent of the data points was to capture time and experiences during the relationship, not necessarily prior to the relationship. Since these data points were not used in the main analyses but only for attempting to understand the couples' situation, the researcher retained the variables and noted the sample size changes when appropriate.

According to Fox-Wasylyshyn and El-Masri (2005), simple imputation and multiple imputation methods yield similar results when missing data are less than 5%. The remaining 5 missing values were in the MSIS and ZBI scales (less than 2% per scale) and these were addressed using the procedures recommended by the scale developers. The MSIS subscales must be at least 50% complete to retain the response. Then, the completed items are summed and divided by the number of completed items to provide a value for the missing data point (Hobart et al., 2001). Similarly, the ZBI must be 75% complete to retain the response, the completed items are summed and divided by the number of items answered, then multiplied by total items in the scale (22 items; Zarit, 2018). Both scales assume that the participant would have answered the missing items with similar intensity as the other items (Hobart et al., 2001; Zarit, 2018).



## Statistical Assumptions

The assumptions for hierarchical regression are discussed here, and those for the repeated-measures ANOVA are discussed in the following section. The first assumption, linearity, is that the IV and DV have a linear relationship (Cohen et al., 2013). Linearity was tested through examining scatterplots and comparing means of the ZBI and love styles through SPSS. It was found that only Eros ( $F = 17.89, p < .001$ ), Ludus ( $F = 13.23, p = .001$ ), and Pragma ( $F = 5.37, p = .028$ ) had significant linearity, and Storge, Mania, and Agape did not. Further, the only predictor variables that had a linear relationship with burden were caregiver depression and anxiety (PHQ-4) and an employment status of retired. This could lead to inaccurate representation of population estimates and caution must be taken when interpreting results. Therefore, two regression analyses were conducted. The first was completed as planned. The second only included the variables with significant linear relationships.

Correct specification of the IVs was tested by examining scatterplots for patterns and outliers. Patterns were more consistent for the love styles with linearity and less evident for the love styles without linearity. Outliers were also present; however, the outliers were consistent with assumptions and expected patterns (e.g., no endorsement of Eros and high caregiver burden) and therefore were not removed. The third assumption, no measurement error in the IVs, was tested by examining the reliability and validity of the measures in SPSS, including the Zarit Burden Inventory (ZBI; caregiver burden), Parkinson's Disease Questionnaire – 39 (PDQ-39; PD impact), Multiple Sclerosis Impact Scale (MSIS; MS impact), the Love Attitudes Scale – short form (LAS; love styles), Love Styles Over Time, and the Patient Health Questionnaire – 4 (PHQ-4; caregiver depression and anxiety). All measures were valid and reliable, which further justified not removing the outlier cases in the previous assumption. Reliability of each measure is presented in Table 1.

Homoscedasticity was tested by visually examining a scatter plot of the DV (CGB) and the standardized residual. The assumption is that the variance between observed and predicted values is constant across the range of predicted values. This assumption is important for valid statistical inferences (Cohen et al., 2013). Normal distribution was tested by examining a probability-probability (P-P) plot of

the expected cumulative probability and the observed cumulative probability. Normality assumes the residuals follow normal distribution and is required for validity of inferences and for constructing reliable confidence intervals and hypothesis testing. Both suggest acceptable homoscedasticity and normality. While the plots display a lack of heteroscedasticity, some of the study variables had high skewness (e.g., Eros, Ludus, Agape, MSIS-Physical). Independence of residuals was tested by examining the scatterplot of the standardized residual and standardized predicted value. The scatterplot displayed residuals that were random and without patterns or trends, and spread (homoscedasticity) around the zero lines, suggesting this assumption was met. The final assumption for the hierarchical regression was the lack of multicollinearity, which was tested by examining a correlation matrix and the variance inflation factor (VIF) in SPSS. Multicollinearity is a high correlation between the IVs and should not be present. It is typically suggested that VIFs below 10 are acceptable with tolerances above .1, however this may be too high for the behavioral sciences (Cohen et al., 2013; O'Brien, 2007). VIFs above 4 with a tolerance below .25 indicate that multicollinearity could exist and require further investigation (O'Brien, 2007). All VIFs were below 10, but ranged between 1 – 9.2, with tolerances ranging .108 - .572; thus, multicollinearity likely existed. The additional assumption from the repeated-measures ANOVA was sphericity. This can be identified using Mauchly's test and will be addressed in the repeated-measures ANOVA section.

**Table 1***Reliability Coefficients for Study Measures*

Variable	Measure	Number of items	Rating Scale	Cronbach's Alpha
Caregiver Burden	ZBI	22	0 - 88	.930
Disability Impact	MSIS			
	Physical	20	0-100	.916
	Psychological	9		.872
	PDQ-39	39	0-100	.934
Love Styles				
	LAS		1 - 5	.856
	Eros	4		.835
	Ludus	4		.833
	Storge	4		.889
	Pragma	4		.752
	Mania	4		.694
	Agape	4		.888
	LAS Over time	24		.925
Caregiver Depression and Anxiety	PHQ-4	4	0-3	.848

**Results**

The main goals of this study were to examine the relationships between caregiver burden and love styles and explore how spouses'/partners' experiences with disability adjustment interact. Specifically, the purpose was to examine (a) the relationship between caregiver burden and love styles, (b) love styles as protective factors against burden, (c) how love styles change over time, and (d) how the impact of disability changes the relationship between burden and love styles. This section presents participant characteristics, including sociodemographic, relationship-, MS-, PD-, and caregiver-specific; descriptive statistics of study variables; results of the hierarchical regression; ANOVA; and the repeated-measures ANOVA analyses.

## Participant Characteristics

### *Sociodemographic Characteristics*

A total of 89 participants were included in the final sample, of which 42 (47.2%) were individuals with MS, 26 (29.2%) MS caregivers, 7 (7.9%) people with PD, and 14 (15.7%) PD caregivers. Participant sociodemographic characteristics for the total sample and the subgroups are presented in Table 2. 46 (51.7%) participants identified as female, 41 (46.1%) identified as male, and 2 (2.2%) identified as non-binary. 45 (50.6%) participants identified as white, 27 (30.3%) as African American/Black, 6 (6.7%) as Multiracial, 5 (5.6%) as Hispanic/Latinx, 3 (3.4%) as Asian/Pacific Islander, 2 (2.2%) as Native American/American Indian, and 1 (1.1%) preferred to not disclose. The mean age of the total sample was 45.21 ( $SD = 12.63$ ) years, ranging from 26 to 83 years old. The mean age for people with MS was 40.55 ( $SD = 8.6$ ), for people with PD was 63.86 ( $SD = 13.08$ ), for MS caregivers was 41.85 ( $SD = 6.9$ ), and for PD caregivers was 56.14 ( $SD = 16.33$ ).

A total of 41 (46.1%) reported their highest level of education as a bachelor's degree, 16 (18%) reported a master's degree or higher, 16 (18%) reported some college, 10 (11.2%) reported high school diploma or equivalent, and 6 (6.7%) reported an associate's degree. 28 (31.5%) of participants were employed full-time, 23 (25.8%) were employed part-time, 18 (20.2%) were retired, 12 (13.5%) reported they stopped working due to MS or PD, 5 (5.6%) stopped working due to caregiving, 2 (2.2%) were unemployed and looking for work, and 1 (1.1%) was unemployed and not looking for work. In terms of household income ( $n = 88$ ), 2 (2.2%) reported income less than \$24,999, 8 (9%) reported \$25,000 – \$44,999, 14 (15.7%) reported \$45,000 – \$59,999, 19 (21.3%) reported \$60,000 – \$84,999, 10 (11.2%) reported \$85,000 - \$99,999, 5 (5.6%) reported \$100,000 – \$114,999, 7 (7.9%) reported \$115,000 – \$129,999, 9 (10.1%) reported \$130,000 – \$149,999, 14 (15.7%) reported over \$150,000. In terms of insurance status, 37 (41.6%) of participants reported having private insurance, 20 (22.5%) reported had Medicaid, 14 (15.7%) had Medicare, 11 (12.4%) had no insurance, 4 (4.5%) had public insurance through marketplace, and 3 (3.4%) reported other and specified “VA disability benefits ( $n = 2$ ), or “State of Alaska and retirement provider” ( $n = 1$ ). Regarding disability benefits, 24 (27%) participants reported

receiving government benefits, and of those 5 (20.8%) were receiving SSI, 4 (16.7%) were receiving SSDI, 3 (12.5%) were receiving SNAP, 3 (12.5%) were receiving unemployment, 2 (8.3%) reported SNAP and SSDI, 1 (4.2%) reported TANF, 1 (4.2%) reported TANF and SNAP, 1 (4.2%) reported TANF, SNAP, and SSDI, 1 (4.2%) reported WIC, and 3 (12.5%) did not specify benefit type.

In terms of living situation, 84 (94.4%) lived together with their spouse in a personal residence, 2 (2.2%) lived apart from their spouse in personal residences, 1 (1.1%) lived together with their spouse in an assisted living situation, 1 (1.1%) lived together with their spouse in a nursing home, and 1 (1.1%) self-reported as living alone since their spouse's death. With respect to marital status, 83 (93%) of the participants were married, 3 (3.4%) were not legally married, 2 (2.2%) had domestic partnerships, and 1 (1.1%) self-reported as widowed. In terms of support for care, 66 (74.2%) participants reported that they do not receive support with care (i.e., "no, only my spouse and I take care of our needs"), 20 (22.5%) stated their family members or friends help with tasks, 1 (1.1%) reported paying out of pocket for an agency or service to help with tasks, 1 (1.1%) self-reported having for a cleaner twice monthly, and 1 (1.1%) did not respond. Of the caregivers ( $n = 40$ ), 8 (20%) reported having a disability, 5 self-reported specific conditions, including "COPD/Asthma", "Diabetes", "Epilepsy", "Osteoarthritis", and "Spinal Stenosis", and 3 did not specify disability type. For the questions concerning survey completion assistance, 23 (25.8%) were assisted in completing the survey by their spouse/partner, 4 (4.5%) received assistance from someone other than their spouse/partner, and 62 (69.7%) did not receive assistance.

**Table 2***Descriptive Statistics of Sociodemographic Information of the Participants*

Demographic Variables	<i>n</i> (%)		<i>M</i> ( <i>SD</i> )		
Age (years)			45.21 (12.63)		
People with MS	42 (47.2)		40.55 (8.6)		
People with PD	7 (7.9)		63.86 (13.08)		
Caregivers	40 (44.9)		46.85 (12.93)		
MS Caregivers	26 (29.2)		41.85 (6.9)		
PD Caregivers	14 (15.7)		56.14 (16.33)		
Role					
Person with MS	42 (47.2)				
MS Caregiver	26 (29.2)				
PD Caregiver	14 (15.7)				
Person with PD	7 (7.9)				
	Total Sample	Person with MS	Person with PD	MS Caregiver	PD Caregiver
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Gender					
Female	46 (51.7)	14 (33.3)	3 (42.9)	17 (65.4)	12 (85.7)
Male	41 (46.1)	26 (61.9)	4 (57.1)	9 (34.6)	2 (14.3)
Non-binary	2 (2.2)	2 (4.8)			
Race/Ethnicity					
White	45 (50.6)	17 (40.5)	5 (71.4)	12 (46.2)	11 (78.6)
African American/Black	27 (30.3)	15 (35.7)	1 (14.3)	8 (30.8)	3 (21.4)
Asian/Pacific Islander	3 (3.4)	3 (7.1)			
Hispanic/Latinx	5 (5.6)	3 (7.1)		2 (7.7)	
Native American/ American Indian	2 (2.2)	2 (4.8)			
Multiracial	6 (6.7)	2 (4.8)		4 (15.4)	
Prefer not to say	1 (1.1)		1 (14.3)		
Education Level					
Bachelor's degree	41 (46.1)	21 (50)	4 (57.1)	12 (46.2)	4 (28.6)
Master's degree, or higher	16 (18)	9 (21.4)		2 (7.7)	5 (35.7)
Some college	16 (18)	4 (9.5)	1 (14.3)	10 (38.5)	1 (7.1)
High school diploma or equivalent	10 (11.2)	4 (9.5)	1 (14.3)	2 (7.7)	3 (21.4)
Associate's degree	6 (6.7)	4 (9.5)	1 (14.3)		1 (7.1)
Employment Status					
Employed full-time	28 (31.5)	14 (33.3)		11 (42.3)	3 (21.4)
Employed part-time	23 (25.8)	11 (26.2)	1 (14.2)	8 (30.8)	3 (21.4)
Retired	18 (20.2)	5 (11.9)	4 (57.1)	2 (7.7)	7 (50)

**Table 2** (continued)

	Total Sample	Person with MS	Person with PD	MS Caregiver	PD Caregiver
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Stopped due to MS/PD	12 (13.5)	10 (23.8)	2 (28.6)		
Stopped due to caregiving	5 (5.6)			4 (15.4)	1 (7.1)
Unemployed and looking	2 (2.2)	2 (4.8)			
Unemployed and not looking	1 (1.1)			1 (3.8)	
Income*					
0 – 24,999	2 (2.2)	1 (2.4)		1 (3.8)	
25,000 – 44,999	8 (9)	4 (9.5)		3 (11.5)	1 (7.1)
45,000 – 59,999	14 (15.7)	6 (14.3)	3 (42.9)	3 (11.5)	2 (14.3)
60,000 – 84,999	19 (21.3)	9 (21.4)	1 (14.3)	6 (23.1)	3 (21.4)
85,000 – 99,999	10 (11.2)	4 (9.5)	1 (14.3)	5 (19.2)	
100,000 – 114,999	5 (5.6)	2 (4.8)		3 (11.5)	
115,000 – 129,999	7 (7.9)	2 (4.8)	1 (14.3)	1 (3.8)	3 (21.4)
130,000 – 149,999	9 (10.1)	8 (19.0)	1 (14.3)		
150,000+	14 (15.7)	6 (14.3)		4 (15.4)	4 (28.6)
Did not answer					1 (7.1)
Insurance					
Private/Employer	37 (41.6)	18 (42.9)	3 (42.9)	8 (30.8)	8 (57.1)
Medicaid	20 (22.5)	12 (28.6)		7 (26.9)	1 (7.1)
Medicare	14 (15.7)	5 (11.9)	3 (42.9)	3 (11.5)	3 (21.4)
No insurance	11 (12.4)	5 (11.9)		6 (23.1)	
Public/Marketplace	4 (4.5)	2 (4.8)		2 (7.7)	
Other	3 (3.4)		1 (14.3)		2 (14.3)
Government Financial Support					
Yes	24 (27)	11 (26.2)	1 (14.3)	9 (34.6)	3 (21.4)
TANF	1 (4.2)			1 (3.8)	
SNAP	3 (12.5)	1 (2.4)		2 (7.7)	
WIC	1 (4.2)			1 (3.8)	
SSI	5 (20.8)	2 (4.8)		2 (7.7)	1 (7.1)
SSDI	4 (16.7)	2 (4.8)	1 (14.3)		1 (7.1)
Unemployment	3 (12.5)	3 (7.1)			
TANF and SNAP	1 (4.2)			1 (3.8)	
TANF, SNAP, and SSDI	1 (4.2)			1 (3.8)	
SNAP and SSDI	2 (8.3)	2 (4.8)			
Other/did not specify	3 (12.5)			1 (3.8)	1 (7.1)

**Table 2** (continued)

	Total Sample <i>n</i> (%)	Person with MS <i>n</i> (%)	Person with PD <i>n</i> (%)	MS Caregiver <i>n</i> (%)	PD Caregiver <i>n</i> (%)
<b>Relationship</b>					
Married	83 (93.3)	39 (92.9)	7 (100)	24 (92.3)	13 (92.9)
Not legally married	3 (3.4)	2 (4.8)		1 (3.8)	
Domestic Partnership	2 (2.2)	1 (2.4)		1 (3.8)	
Other	1 (1.1)				1 (7.1)
<b>Living situation</b>					
Together (personal residence)	84 (94.4)	40 (95.2)	7 (100)	24 (92.3)	13 (92.9)
Apart (personal residence)	2 (2.2)	1 (2.4)		1 (3.8)	
Together (assisted living)	1 (1.1)			1 (3.8)	
Together (nursing home)	1 (1.1)	1 (2.4)			
Other	1 (1.1)				1 (7.1)
<b>Care Support*</b>					
Only spouses	66 (74.2)	31 (73.8)	4 (57.1)	20 (76.9)	11 (78.6)
Family & Friends	20 (22.5)	10 (23.8)	3 (42.9)	6 (23.1)	1 (7.1)
Service (out-of-pocket cost)	1 (1.1)	1 (2.4)			
Other	1 (1.1)				1 (7.1)
Did not answer					1 (7.1)
<b>Assistance on Survey</b>					
No	62 (69.7)	22 (52.4)	6 (85.7)	21 (80.8)	13 (92.9)
Yes, spouse/partner	23 (25.8)	16 (38.1)	1 (14.3)	5 (19.2)	1 (7.1)
Yes, someone else	4 (4.5)	4 (9.5)			
<b>Caregiver Disability (<i>n</i> = 40)</b>					
No	32 (80)			23 (88.5)	9 (64.3)
Yes	8 (20)			3 (11.5)	5 (35.7)
<b>Income Reduced</b>					
0 - 9%**	2 (3)	1 (2.4)		1 (3.8)	
10 - 19%**	6 (8.9)	3 (7.1)	1 (14.3)	1 (3.8)	1 (14.3)
20 - 29%**	36 (53.7)	21 (43.5)	2 (28.6)	10 (38.5)	3 (21.4)
30 - 39%**	11 (16.4)	5 (11.9)		5 (19.2)	1 (7.1)
40%+**	10 (14.9)	5 (11.9)		3 (11.5)	2 (14.3)
<b>Income Increased</b>					
Income Increased	3 (3.4)	1 (2.4)	1 (14.3)		1 (7.1)
<b>Income No Change</b>					
Income No Change	19 (21.3)	6 (14.3)	3 (42.9)	5 (19.2)	5 (35.7)
<b>Employment Reduced</b>					
Employment Reduced	50 (56.2)	31 (73.8)	1 (14.3)	14 (53.8)	4 (28.6)
<b>Employment Increased</b>					
Employment Increased	1 (1.1)	1 (2.4)			
<b>Employment No Change</b>					
Employment No Change	38 (42.7)	10 (23.8)	6 (85.7)	12 (53.8)	10 (71.4)

*Note.* \**n* = 88 for total sample, \*\**n* = 66 for total sample with reduced income



### ***Relationship-Related Characteristics***

Relationship-related characteristics of the participants are presented in Table 3. For the total sample ( $N = 89$ ), the total years the couple knew each other was  $M = 18.75$  ( $SD = 14.07$ ; range = 3 – 59). The mean number of years the participants knew their partner prior to marriage (referred to as cohabitation for non-married participants) was  $M = 2.75$  ( $SD = 1.61$ ; range = .16 – 10). The mean number of years married (cohabitating) was  $M = 15.2$  ( $SD = 13.97$ ; range = 1 – 58), and age at the time of marriage (cohabitation) was  $M = 29.94$  ( $SD = 8.27$ ; range = 17 – 67;  $n = 77$ ). For people with MS ( $n = 42$ ), the total number of years the participants knew their spouse/partner was  $M = 13.19$  ( $SD = 8.34$ ), years prior to marriage was  $M = 2.58$  ( $SD = 1.58$ ), years married was  $M = 9.67$  ( $SD = 7.64$ ), and age at the time of marriage was  $M = 31.94$  ( $SD = 7.32$ ;  $n = 31$ ). For people with PD ( $n = 7$ ), the total number of years the participants knew their spouse/partner was  $M = 40.0$  ( $SD = 10.94$ ), years prior to marriage was  $M = 2.57$  ( $SD = 1.39$ ), years married was  $M = 37.43$  ( $SD = 11.93$ ), and age at the time of marriage was  $M = 26.0$  ( $SD = 5.07$ ). For MS Caregivers ( $n = 26$ ), the total number of years the participants knew their spouse/partner was  $M = 14.46$  ( $SD = 7.83$ ), years prior to marriage was  $M = 2.78$  ( $SD = 1.41$ ), years married was  $M = 10.5$  ( $SD = 6.80$ ), and age at the time of marriage was  $M = 30.12$  ( $SD = 6.48$ ;  $n = 25$ ). For PD Caregivers ( $n = 14$ ), the total number of years the participants knew their spouse/partner was  $M = 32.79$  ( $SD = 15.37$ ), years prior to marriage was  $M = 3.29$  ( $SD = 2.09$ ), years married was  $M = 29.43$  ( $SD = 18.82$ ), and age at the time of marriage was  $M = 27.14$  ( $SD = 12.67$ ).

**Table 3**

*Descriptive Statistics of Relationship-Related Characteristics of the Participants*

	<i>n</i>	Total Years Known		Years Prior to Marriage		Years Married		<i>n</i>	Age at Marriage	
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		<i>M</i>	<i>SD</i>
People with MS	42	13.19	8.34	2.58	1.58	9.67	7.64	31	31.94	7.32
People with PD	7	40.00	10.94	2.57	1.39	37.43	11.93	7	26.00	5.07
MS Caregivers	26	14.46	7.83	2.78	1.41	10.50	6.80	25	30.12	6.48
PD Caregiver	14	32.79	15.37	3.29	2.09	29.43	18.82	14	27.14	12.67
Total Sample	89	18.75	14.07	2.75	1.61	15.20	13.97	77	29.94	8.27

### **Diagnosis-Related Characteristics**

Diagnosis-related characteristics are presented in Table 4. The average age of participants ( $n = 76$ ) at the age of diagnosis was  $M = 39.76$  ( $SD = 11.75$ ; range = 21 – 72). Age at symptom onset was  $M = 40.05$  ( $SD = 12.18$ ; range = 19 – 74), and age at the onset of caregiving specific to MS or PD was  $M = 42.07$  ( $SD = 12.52$ ; range = 23 – 78). For participants with MS ( $n = 32$ ), the age at diagnosis was  $M = 36.03$  ( $SD = 7.89$ ), at symptom onset was  $M = 36.28$  ( $SD = 8.75$ ), and at caregiving onset was  $M = 37.87$  ( $SD = 7.86$ ;  $n = 31$ ). For participants with PD ( $n = 7$ ), the age at diagnosis was  $M = 59.0$  ( $SD = 11.69$ ), at symptom onset was  $M = 55.29$  ( $SD = 14.99$ ), and at caregiving onset was  $M = 62.83$  ( $SD = 12.58$ ;  $n = 6$ ). For MS Caregivers ( $n = 25$ ), the age at diagnosis was  $M = 36.08$  ( $SD = 7.66$ ), at symptom onset was  $M = 37.29$  ( $SD = 7.89$ ;  $N = 24$ ), and at caregiving onset was  $M = 38.36$  ( $SD = 7.35$ ;  $n = 25$ ). For PD Caregivers, the age at diagnosis was  $M = 46.17$  ( $SD = 14.52$ ;  $n = 12$ ), at symptom onset was  $M = 46.23$  ( $SD = 16.36$ ;  $n = 13$ ), and at caregiving onset was  $M = 49.62$  ( $SD = 16.93$ ;  $n = 13$ ).

**Table 4**

*Descriptive Statistics for Diagnosis-Related Characteristics of the Participants*

	Age at Diagnosis			Age at Symptom Onset			Age at Caregiving Onset		
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>
People with MS	32	36.03	7.89	32	36.28	8.75	31	37.87	7.86
People with PD	7	59.0	11.69	7	55.29	14.99	6	62.83	12.58
MS Caregivers	25	36.08	7.66	24	37.29	7.89	25	38.36	7.35
PD Caregiver	12	46.17	14.52	13	46.23	16.36	13	49.62	16.93
Total Sample	76	39.76	11.75	76	40.05	12.18	75	42.07	12.52

### **Descriptive Statistics for Study Variables**

The descriptive statistics for the variables of interest, including caregiver burden, disability severity (e.g., MS impact and PD-HRQOL), and love styles are presented in Table 5. For the caregiver burden measure (ZBI), the total average score was 42.13 ( $SD = 17.33$ ). The average scores assessing disability severity were 51.85 ( $SD = 17.11$ ) for the MSIS Physical subscale, 63.09 ( $SD = 19.28$ ) for the MSIS Psychological subscale, and 30.89 ( $SD = 14.59$ ) for PDQ-39. The average scores for the LAS were

7.31 ( $SD = 3.56$ ) for Eros, 13.39 ( $SD = 5.05$ ) for Ludus, 8.48 ( $SD = 4.23$ ) for Storge, 9.67 ( $SD = 4.11$ ) for Pragma, 11.68 ( $SD = 3.85$ ) for Mania, and 9.13 ( $SD = 4.16$ ) for Agape.

**Table 5**

*Descriptive Statistics for the Study Variables*

Variables	<i>n</i> (%)	Range	<i>M</i> ( <i>SD</i> )	Skewness	Kurtosis
Caregiver Burden	40 (44.9)	5 – 79	42.13 (17.33)	-.120	-.349
Disability Severity					
MSIS Phys	42 (47.2)	5 – 76.25	51.87 (17.03)	-.958	.552
MSIS Psych		16.67 – 100	63.09 (19.28)	-.364	-2.64
PDQ-39	7 (7.9)	12.14 – 49.48	30.89 (14.59)	-.111	-2.04
Love Styles	89 (100)				
Eros		4 – 20	7.31 (3.56)	1.498	2.02
Ludus		4 – 20	13.39 (5.05)	-.047	-1.31
Storge		4 – 20	8.48 (4.23)	.965	.058
Pragma		4 – 20	9.67 (4.11)	.383	-.738
Mania		5 – 20	11.68 (3.85)	.524	-.631
Agape		4 – 20	9.13 (4.16)	.937	.376

**Hierarchical Regression**

Two hierarchical regression analyses were conducted. The first included all predictor variables as originally proposed and supported by the relevant literature. The second included only predictor variables with significant linear relationships with CGB for this sample, including Eros, Ludus, Pragma, caregiver depression and anxiety, and the employment status of retired.

Backward Hierarchical Regression was conducted with CGB as the criterion variable, initially including gender, age, race/ethnicity, income, employment status, caregiver disability status, caregiver anxiety and depression, and the six love styles as predictor variables. The analysis utilized a backward elimination method, with a criterion set at a probability of *F*-to-remove greater than or equal to .100. The initial model containing all variables had an  $R^2 = .817$ ,  $F(24, 14) = 2.611$ ,  $p = .033$  ( $n = 39$ ).

The final model, entered with Agape love style, caregiver depression and anxiety, and the employment status of unemployed and not looking, exhibited a strong degree of predictability for caregiver burden. The final model was statistically significant in predicting caregiver burden ( $R^2 = .657$ ,  $F(1, 34) = 22.39$ ,  $p < .001$ ), suggesting the combination of agape love style, depression and anxiety, and

unemployed and not looking predicted differences in caregiver burden among participants. However, the change in  $F$  ( $= 1.69$ ) was not significant ( $p = .202$ ). The standardized coefficients indicated significant contributions from caregiver depression and anxiety ( $\beta = .782, t(35) = 7.84, p < .001$ ) and Agape love style ( $\beta = .372, t(35) = 3.35, p = .002$ ). Unemployed and not looking was not significant ( $\beta = -.221, t(35) = -1.99, p = .054$ ). Specifically, higher levels of caregiver depression and anxiety were strongly associated with higher levels of caregiver burden. Higher Agape scores (meaning less/weak endorsement of the love style) were also associated with higher levels of caregiver burden. The adjusted  $R^2$  of .657 suggested that approximately 65.7% of the variance in caregiver burden was explained by depression and anxiety, Agape love style, and unemployed and not looking. While compelling, the model was not significant, and the assumptions of linearity was not met; findings cannot be generalized, and null hypotheses cannot be rejected.

The second regression included caregiver depression and anxiety and the employment status of retired in the first model, and Eros, Ludus, Pragma in the second model. The initial model containing all variables had an  $R^2 = .652, F(5, 34) = 12.76, p < .001$ . The final model was entered with Eros love style and caregiver depression and anxiety. The model was statistically significant in predicting caregiver burden ( $R^2 = .622, F(1, 36) = 30.38, p < .001$ ), suggesting the combination of eros love style and depression and anxiety, predicted differences in caregiver burden among participants. However, the change in  $F$  ( $= 1.60$ ) was again not significant ( $p = .214$ ). The standardized coefficients indicated significant contributions from caregiver depression and anxiety ( $\beta = .640, t(37) = 5.79, p < .001$ ) and Eros love style ( $\beta = .269, t(37) = 2.44, p = .020$ ). The adjusted  $R^2$  of .622 suggested that approximately 62.2% of the variance in caregiver burden was explained by depression and anxiety and Eros love style. This regression model is also lacking significance and should be interpreted with caution.

## ANOVA

An ANOVA was conducted to assess the differences in caregiver burden across love styles. Normality was assessed by examining skewness and kurtosis of the variables, as presented in Table 6. Skewness less than -1 or greater than 1 indicates the distribution is highly skewed (Eros = 1.53; Field, 2018). Skewness between -1 and -.5 or .5 and 1 indicates moderate skewness (Storge = .917; Mania = .696; Agape = .838). Finally, approximately symmetric distribution is indicated by values between -.5 and .5 (CGB = -.120; Ludus = -.266; Pragma = .223). Kurtosis describes the degree to which data clusters in either the peak or the tails of frequency distribution. Mesokurtic, kurtosis values equal to 3, indicates a medium peak, or normal distribution. Values near 3 can be considered near mesokurtic (e.g., Eros) Leptokurtic, kurtosis values greater than 3, indicates high peaks and thick tails, demonstrating more values are close to the mean. Platykurtic, kurtosis values less than 3, is less peaked than normal distribution, with fewer values in shorter (or thinner) tails (e.g., CGB, Ludus, Storge, Pragma, Mania, Agape).

**Table 6**

*Descriptive Statistics of Caregiver Specific Variables*

Variables	<i>n</i> (%)	Range	<i>M</i> ( <i>SD</i> )	Skewness	Kurtosis
Caregiver Burden	40 (100)	5 – 79	42.13 (17.33)	-.120	-.349
Love Styles	40 (100)				
Eros		4 – 20	7.20 (3.52)	1.534	3.10
Ludus		4 – 20	13.95 (5.14)	-.266	-1.26
Storge		4 – 20	8.85 (4.48)	.917	.067
Pragma		4 – 20	10.73 (4.29)	.223	-.660
Mania		5 – 20	12.18 (3.75)	.696	-.631
Agape		4 – 20	9.00 (4.10)	.838	.364
<b>High Endorsement</b>					
Eros	28 (70)			-.907	-1.24
Ludus	6 (15)			2.04	2.26
Storge	23 (57.5)			-.315	-2.00
Pragma	15 (37.5)			.537	-1.81
Mania	5 (12.5)			2.36	3.74
Agape	23 (57.5)			-.315	-2.00

Although assumptions of homogeneity and normal distribution were not met, the ANOVA was conducted and can be interpreted with caution. Due to the nonlinear relationship between CGB and Storge, Mania, and Agape, Spearman's correlation values are presented in Table 7. The overall model was significant ( $R^2 = .450$ ;  $F(6, 33) = 4.498$ ,  $p = .002$ ). However, the only group difference that was statistically significant was Eros ( $\beta = .567$ ,  $t = 3.032$ ,  $p = .005$ ).

**Table 7**

*Nonparametric Correlations for Caregiver Variables*

Variable	1	2	3	4	5	6	7	8
1. Caregiver Burden	1							
2. CG Depression and Anxiety	.709**	1						
3. Eros	.542**	.544**	1					
4. Ludus	-.486**	-.419**	-.537**	1				
5. Storge	.181	.065	.421**	-.299	1			
6. Pragma	-.360*	-.343*	-.040	.382*	.655	1		
7. Mania	-.163	-.180	.226	.173	.261	.304	1	
8. Agape	.238	-.014	.463**	-.339*	.485**	-.027	.350*	1

*Note.* \* $p < .05$ , \*\* $p < .01$ ,  $n = 40$

Love style scores were then converted to dichotomous groups of “high endorsement” (subscale scores less than 8, indicating most answers were “Strongly agree” or “Moderately agree”) and “low endorsement” (subscale scores above 9 points, indicating most answers were “Neutral”, “Moderately disagree”, and “Strongly disagree”) for a Univariate ANOVA. The assumption of homogeneity was tested with Levene's test in SPSS. Levene's test was significant ( $p = .025$ ), meaning the assumption was not met. Skewness and Kurtosis for high-endorsed groups were also evaluated to assess distribution. Ludus and Mania were highly skewed, Eros and Pragma were moderately skewed, and Storge and Agape were approximately symmetric. Most groups were Platykurtic (Eros, Ludus, Storge, Pragma, and Agape), and Mania was Leptokurtic. It is important to note that participants may belong to multiple high-endorsed groups, which may act as a confounding variable; thus, interpretations of cause and effect are limited. The

between-subject effects were not significant (Eros:  $F(1, 21) = 2.65, p = .12$ ; Ludus:  $F(1, 21) = 2.07, p = .165$ ; Storge  $F(1, 21) = .001, p = .97$ ; Pragma:  $F(1, 21) = 2.57, p = .124$ ; Mania:  $F(1, 21) = .215, p = .648$ ; Agape:  $F(1, 21) = .467, p = .502$ ).

The mean comparisons and pairwise comparisons (adjusted for multiple comparisons using the Bonferroni correction) are presented in Table 8. Line plots are presented in Appendix C. High Eros had a mean burden score of 43.66 ( $SD = 3.69, 95\% CI [35.97, 51.35]$ ), compared to low Eros with a mean score of 51.65 ( $SD = 4.74, 95\% CI [41.79, 61.49]$ ). The mean difference ( $-7.98, SE = 6.01, 95\% CI [-20.48 - 4.52]$ ,  $p = .198$ ) was not significant. The effect of high Eros on CGB was not significant ( $F(1, 21) = 1.76, p = .198$ ). While not significant, these findings suggest those who highly endorse Eros experience less burden than those who do not.

High Ludus had a mean CGB score of 59.30 ( $SD = 6.39, 95\% CI [46.01, 72.59]$ ), compared to low Ludus with a mean score of 42.60 ( $SD = 3.25, 95\% CI [35.88, 49.39]$ ). The mean difference ( $16.66, SE = 7.17, 95\% CI [1.72 - 31.57]$ ,  $p = .030$ ) was significant. The effect of high Ludus on CGB was significant ( $F(1, 21) = 5.40, p = .030$ ). This indicates that as Ludus is more highly endorsed, burden increases.

High Storge had a mean CGB score of 48.83 ( $SD = 4.044, 95\% CI [40.42, 57.24]$ ), compared to low Storge with a mean score of 45.02 ( $SD = 4.24, 95\% CI [36.20, 53.83]$ ). The mean difference ( $3.81, SE = 5.86, 95\% CI [-8.37, 15.99]$ ,  $p = .522$ ) was not significant. The effect of high Storge on CGB was not significant ( $F(1, 21) = .423, p = .522$ ). While not significant, these findings suggest those who highly endorse Storge experience more burden than those who do not.

High Pragma had a mean CGB score of 50.02 ( $SD = 4.45, 95\% CI [40.76, 59.28]$ ), compared to low Pragma with a mean score of 44.33 ( $SD = 3.85, 95\% CI [36.32, 52.34]$ ). The mean difference ( $5.69, SE = 5.89, 95\% CI [-6.56, 17.94]$ ,  $p = .345$ ) was not significant. The effect of high Pragma on CGB was not significant ( $F(1, 21) = .933, p = .345$ ). While not significant, these findings suggest those who highly endorse Pragma experience more burden than those who do not.

High Mania had a mean CGB score of 53.56 ( $SD = 7.67$ , 95% CI [37.61, 69.50]), compared to low Mania with a mean score of 45.79 ( $SD = 4.24$ , 95% CI [39.22, 52.38]). The mean difference (7.76,  $SE = 8.29$ , 95% CI [-9.49, 25.01],  $p = .360$ ) was not significant. The effect of high Mania on CGB was not significant ( $F(1, 21) = .874$ ,  $p = .360$ ). While not significant, these findings suggest those who highly endorse Mania experience more burden than those who do not.

High Agape had a mean CGB score of 44.37 ( $SD = 4.11$ , 95% CI [35.81, 52.92]), compared to low Agape with a mean score of 49.42 ( $SD = 4.15$ , 95% CI [40.79, 58.04]). The mean difference (-5.05,  $SE = 5.84$ , 95% CI [-17.19, 7.09],  $p = .397$ ) was not significant. The effect of high Agape on CGB was not significant ( $F(1, 21) = .748$ ,  $p = .397$ ). While not significant, these findings suggest those who highly endorse Agape experience less burden than those who do not.

**Table 8**

*Mean Comparisons and Pairwise Comparisons of High Endorsed Groups and ZBI Scores*

	ZBI $M(SD)$	CI at 95%	$MD(SE)$	CI at 95%	$F$	$p$
High Eros	43.66 (3.69)	35.97, 51.35				
Low Eros	51.65 (4.74)	41.79, 61.49	-7.98 (6.01)	-20.48, 4.52		.198
High Eros Effect					1.76	.198
High Ludus	59.30 (6.39)	46.01, 72.59				
Low Ludus	42.60 (3.25)	35.88, 49.39	16.66 (7.17)	1.72, 31.57		.030*
High Ludus Effect					5.40	.030
High Storge	48.83 (4.044)	40.42, 57.24				
Low Storge	45.02 (4.24)	36.20, 53.83	3.81 (5.86)	-8.37, 15.99		.522
High Storge Effect					.423	.522
High Pragma	50.02 (4.45)	40.76, 59.28				
Low Pragma	44.33 (3.85)	36.32, 52.34	5.69 (5.89)	-6.56, 17.94		.345
High Pragma Effect					0.933	.345
High Mania	53.56 (7.67)	37.61, 69.50				
Low Mania	45.79 (4.24)	39.22, 52.38	7.76 (8.29)	-9.49, 25.01		0.36
High Mania Effect					.874	0.36
High Agape	44.37 (4.11)	35.81, 52.92				
Low Agape	49.42 (4.15)	40.79, 58.04	7.76 (8.29)	-9.49, 25.01		0.36
High Agape Effect					0.874	0.36

*Note.* \* $p < .05$



## Repeated-Measures ANOVA

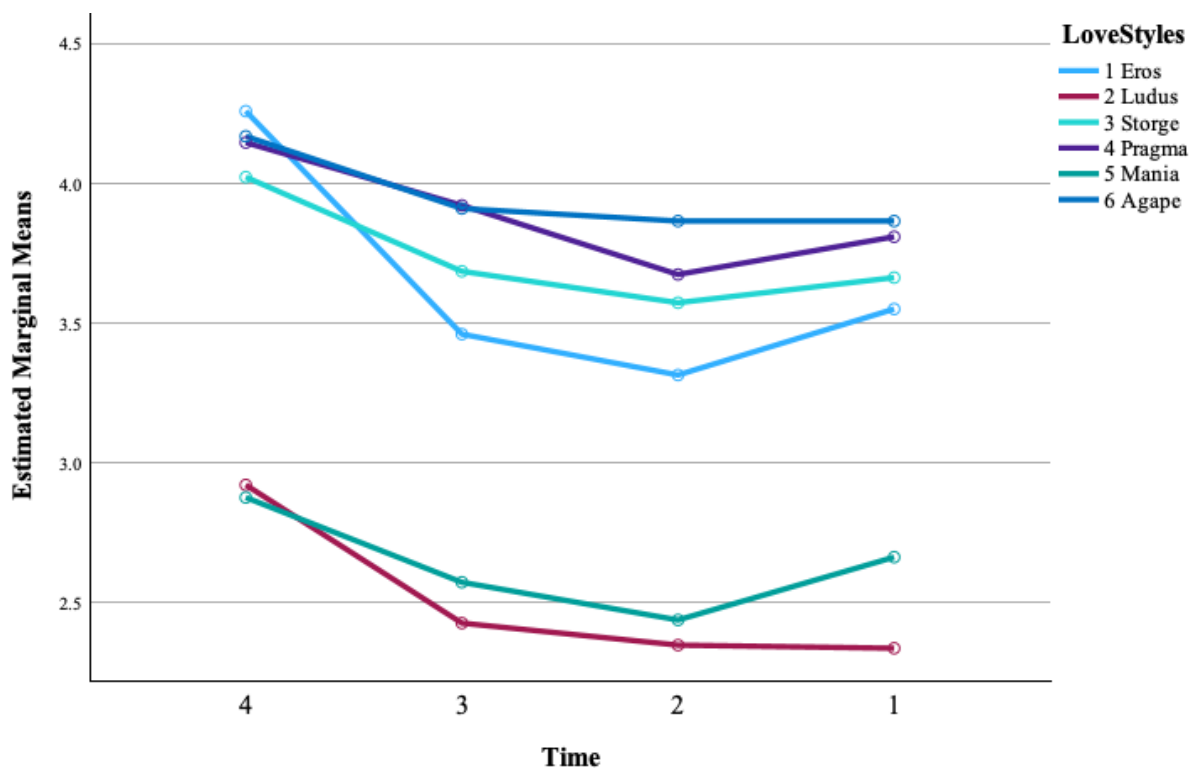
**Assumptions.** The assumptions of continuous DVs and the IVs consisting of at least two categorical related groups have been met. Another assumption is that data is normally distributed (Cohen et al., 2013). Using the Shapiro-Wilk test of normality in SPSS, the love styles over time data points were evaluated for normality. In order for the data to suggest normality, the  $p$  value should not be significant. This assumption was not met, as all data points were significant ( $p < .001$ ) and are not normally distributed. Sphericity is the final assumption of repeated-measure ANOVA and demonstrates the homogeneity of variance of differences, which must be met to trust significance levels. This assumption was tested by using Mauchly's test but is frequently violated, which increases Type I error. The significance of the test should be greater than .05 and would indicate sphericity. To calculate reliable  $p$  values, the degrees of freedom of  $F$  can be adjusted by using either the Greenhouse-Geisser (when the Greenhouse-Geisser  $\epsilon < .75$ ) or Huynh-Feldt (when the Greenhouse-Geisser  $\epsilon > .75$ ) estimates.

**Results.** A repeated-measures ANOVA was performed to evaluate the effect of time on love styles. The means and standard deviations for love styles over time are presented in Table 9. Mauchly's test indicated that the assumption of sphericity had been violated ( $\chi^2(119) = 246.41, p < .001$ ), and therefore degrees of freedom were corrected using Greenhouse-Geisser estimates of sphericity ( $\epsilon = .72$ ). The effect of time on love styles was significant ( $F(10.77, 947.49) = 2.29, p = .01$ , partial  $\eta^2 = .025$ ), suggesting the differences in love styles over time are statistically significant.

Post-hoc pairwise comparisons with a Bonferroni adjustment indicated that there were significant differences between T4 with T1 ( $MD = -.418, p < .001$ ), T4 and T2 ( $MD = -.530, p < .001$ ), T4 and T3 ( $MD = -.403, p < .001$ ), and T2 and T3 ( $MD = .127, p = .021$ ). There was no significant difference between the love styles at T1 and T2 ( $MD = -.112, p = .375$ ), or T1 and T3 ( $MD = .015, p = 1$ ). Line plots of the findings are presented in Figure 1. Love style scores are reverse scored in the figure for readability. These findings suggest there are significant changes in love styles between the first year of marriage (T4) with all other time points (T1 = current, T2 = first year of caregiving, T3 = first year of symptom onset), and between the first year of caregiving (T2) and the first year of symptom onset (T3).

**Table 9***Descriptive Statistics for Love Styles Over Time Scores*

	Today		Caregiving		Symptom Onset		Year of Marriage	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Eros	2.45	1.37	2.69	1.51	2.54	1.44	1.74	.911
Ludus	3.66	1.44	3.65	1.54	3.57	1.47	3.08	1.63
Storge	2.34	1.34	2.43	1.36	2.31	1.39	1.98	1.16
Pragma	2.19	1.29	2.33	1.41	2.08	1.19	1.85	1.124
Mania	3.34	1.43	3.56	1.45	3.43	1.43	3.12	1.56
Agape	2.13	1.18	2.13	1.25	2.09	1.26	1.83	1.09

**Figure 1***Repeated-Measures ANOVA: Time and Love Styles Over Time*

*Note.* T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored in the figure for readability.

A second repeated measures ANOVA was conducted to further investigate changes in love styles over time. Specifically, this analysis compared differences between groups of participants (e.g., person with MS, person with PD, MS caregiver, PD caregiver). Means and standard deviations for love styles

over time by group are presented in Table 10. Mauchly's test indicated that the assumption of sphericity had been violated ( $\chi^2(119) = 236.21, p < .001$ ), and therefore degrees of freedom were corrected using Greenhouse-Geisser estimates of sphericity ( $\epsilon = .72$ ). The interaction of time, love styles, and groups was significant ( $F(32.20, 912.41) = 1.92, p = .002$ , partial  $\eta^2 = .064$ ).

Post-hoc pairwise comparisons with a Bonferroni adjustment indicated that there were significant differences between T4 with T1 ( $MD = -.427, p < .001$ ), T4 and T2 ( $MD = -.577, p < .001$ ), T4 and T3 ( $MD = -.403, p < .001$ ), and T3 and T2 ( $MD = -.024, p = .021$ ). There was no significant difference between the love styles at T1 and T2 ( $MD = -.150, p = .214$ ), or T1 and T3 ( $MD = .024, p = 1$ ). Line plots of the findings are presented in Appendix D.

**Table 10***Descriptive Statistics for Love Styles Over Time Scores by Group*

Persons with MS								
	Today		Caregiving		Disability Onset		Year of Marriage	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Eros	3.86	1.46	4.29	2.24	3.71	1.38	1.86	.690
Ludus	4.00	1.53	4.29	1.496	3.71	1.60	3.71	1.38
Storge	2.00	1.16	2.57	.787	2.43	1.13	2.29	.488
Pragma	3.14	1.22	2.86	1.46	2.14	1.35	2.14	.900
Mania	3.71	1.60	4.43	1.51	4.29	1.49	4.14	1.07
Agape	2.29	1.25	1.71	.488	1.71	.488	2.00	.577
Persons with PD								
	Today		Caregiving		Disability Onset		Year of Marriage	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Eros	3.86	1.46	4.29	1.49	3.71	1.38	1.86	.690
Ludus	4.00	1.53	4.29	1.49	3.71	1.60	3.71	1.38
Storge	2.00	1.16	2.57	.787	2.43	1.13	2.29	.488
Pragma	3.14	1.22	2.86	1.46	2.14	1.34	2.14	.900
Mania	3.71	1.60	4.43	1.51	4.29	1.49	4.14	1.07
Agape	2.29	1.25	1.71	.488	1.71	.488	2.00	.577
MS Caregivers								
	Today		Caregiving		Disability Onset		Year of Marriage	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Eros	2.27	1.15	2.65	1.55	2.35	1.55	1.42	.758
Ludus	3.54	1.48	4.08	1.19	3.69	1.41	2.65	1.77
Storge	2.31	1.12	2.65	1.29	2.62	1.39	1.81	1.09
Pragma	2.27	1.31	2.54	1.39	2.27	1.25	1.69	1.09
Mania	2.85	1.16	3.62	1.29	3.27	1.25	2.88	1.48
Agape	2.27	1.22	2.38	1.36	2.35	1.38	1.81	1.06
PD Caregivers								
	Today		Caregiving		Disability Onset		Year of Marriage	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Eros	2.93	1.49	3.43	1.56	3.07	1.439	2.00	1.04
Ludus	4.21	1.19	4.36	1.15	4.29	1.20	4.00	1.52
Storge	2.50	1.40	2.50	1.74	2.43	1.51	2.14	1.35
Pragma	2.29	1.33	2.43	1.74	2.07	1.44	2.14	1.35
Mania	4.21	1.37	4.21	1.42	4.21	1.31	4.00	1.57
Agape	1.93	1.07	1.57	1.09	2.07	1.54	1.79	1.25

A third repeated-measures ANOVA was performed to evaluate the effect of time on love styles with group differences between caregivers and spouses with MS/PD. The means and standard deviations for love styles over time are presented in Table 11. Mauchly's test indicated that the assumption of sphericity had been violated ( $\chi^2(119) = 241.61, p < .001$ ), and therefore degrees of freedom were corrected using Greenhouse-Geisser estimates of sphericity ( $\epsilon = .72$ ). The interaction of time, love styles, and caregiving role was not significant ( $F(10.82, 941.46) = 1.31, p = .22, \text{partial } \eta^2 = .015$ ). Post hoc tests were not completed, as the model was not significant. However, interesting trends did emerge and are presented in Appendix E.

**Table 11**

*Descriptive Statistics for Love Styles Over Time Scores by Spouse Group*

	Current		Caregiving		Symptom Onset		Marriage	
	M	SD	M	SD	M	SD	M	SD
<i>Spouses with Disability*</i>								
Eros	2.41	1.30	2.49	1.43	2.49	1.37	1.84	.920
Ludus	3.57	1.41	3.22	1.67	3.31	1.52	3.04	1.51
Storge	2.31	1.21	2.29	1.28	2.12	1.39	2.02	1.18
Pragma	2.12	1.30	2.18	1.33	1.98	1.11	1.86	1.08
Mania	3.35	1.39	3.35	1.49	3.29	1.50	3.00	1.54
Agape	2.12	1.17	2.16	1.19	1.96	1.15	1.86	1.08
<i>Caregiver Spouses**</i>								
Eros	2.50	1.30	2.93	1.58	2.60	1.53	1.63	0.89
Ludus	3.78	1.41	4.18	1.17	3.90	1.36	3.13	1.79
Storge	2.38	1.21	2.60	1.45	2.55	1.41	1.93	1.14
Pragma	2.28	1.30	2.50	1.50	2.20	1.31	1.85	1.19
Mania	3.33	1.39	3.83	1.36	3.6	1.34	3.28	1.59
Agape	2.15	1.17	2.10	1.32	2.25	1.43	1.80	1.11

*Note.* \* $n = 49$ , \*\* $n = 40$

A final repeated measures ANOVA was conducted to further explore changes in love styles over time for caregivers. Specifically, this analysis compared differences between groups defined by three CGB levels (low, moderate, high). The *Low* group included CGB scores of 30 and below, the *moderate* group included scores ranging from 31 – 50, and the *high* group included scores of 51 and above. The means and standard deviations for love styles over time are presented in Table 12. Mauchly's test

indicated that the assumption of sphericity had been violated ( $\chi^2(119) = 204.37, p < .001$ ), and therefore degrees of freedom were corrected using Greenhouse-Geisser estimates of sphericity ( $\epsilon = .55$ ). The interaction of time, love styles, and burden was not significant,  $F(16.61, 307.25) = .783, p = .71$ , partial  $\eta^2 = .041$ . Post hoc tests were not completed, as the model was not significant. However, interesting trends did emerge and are presented in Appendix F.

**Table 12***Descriptive Statistics for Love Styles Over Time Scores by Burden Levels*

Today	Low ( <i>n</i> = 9)		Moderate ( <i>n</i> = 18)		High ( <i>n</i> = 13)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Eros	2.56	1.51	1.89	1.18	3.31	.855
Ludus	4.56	1.01	3.67	1.45	3.38	1.45
Storge	2.22	1.30	2.22	1.16	2.69	1.25
Pragma	2.33	1.41	2.06	1.21	2.54	1.39
Mania	4.33	1.41	3.39	1.24	2.54	1.13
Agape	1.67	1.00	2.00	1.14	2.69	1.18

Caregiving	Low		Moderate		High	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Eros	2.89	1.83	2.39	1.29	3.69	1.55
Ludus	4.33	1.32	4.06	1.26	4.23	1.01
Storge	2.00	1.32	2.28	1.41	3.46	1.26
Pragma	2.44	1.81	2.11	1.28	3.08	1.49
Mania	4.44	1.33	3.61	1.34	3.69	1.38
Agape	1.33	1.00	1.78	1.17	3.08	1.18

Symptom onset	Low		Moderate		High	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Eros	2.67	1.50	1.78	1.17	3.69	1.37
Ludus	4.22	1.39	3.72	1.52	3.92	1.16
Storge	2.11	1.16	2.22	1.26	3.31	1.55
Pragma	2.00	1.41	1.78	.943	2.92	1.44
Mania	4.11	1.36	3.72	1.32	3.08	1.26
Agape	1.67	1.41	1.89	1.28	3.15	1.28

Marriage	Low		Moderate		High	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Eros	1.89	1.26	1.61	.778	1.46	.776
Ludus	4.11	1.53	3.72	1.67	1.62	1.04
Storge	1.89	1.05	2.06	1.34	1.77	.927
Pragma	2.56	1.51	1.89	1.08	1.31	.855
Mania	4.22	1.56	3.56	1.25	2.23	1.54
Agape	1.56	1.01	1.94	1.26	1.77	1.01

## CHAPTER FIVE: DISCUSSION

In this chapter, I discuss the findings of the results described in chapter 4, including the relationships between caregiver burden and love styles and the changes in love styles over time. Due to the small sample size and the violation of many assumptions of the planned statistical analyses, as discussed in chapter 4, the results of the study must be interpreted with caution, and generalizability is limited as noted. However, the results did present intriguing trends that warrant further investigation in future research.

### Caregiver Burden and Love Styles

One of the main purposes of this study was to examine the potential relationship between caregiver burden (CGB) and love styles. First, correlations between CGB, the six love styles (Eros, Ludus, Storge, Pragma, Mania, Agape), and caregiver (CG) depression and anxiety were evaluated. Eros had a significant positive correlation with CGB, while Ludus and Pragma had significant negative correlations with CGB. Higher scores for love styles indicate lower endorsement of the style, and lower scores indicate higher endorsement. Meaning, the correlation between higher Eros scores and higher burden level suggest that the less Eros is endorsed, the higher the burden level. Similarly, lower Eros scores and lower burden would suggest that the more Eros is endorsed, the lower the burden level. For Ludus and Pragma, with negative correlations with CGB, as the love style is more endorsed (indicated by lower scores), burden levels increase. While not significant, Mania also had a negative correlation, and Storge and Agape had positive correlations.

It was expected that Eros, Agape, and Storge would have positive correlations with burden. According to Vedes et al. (2016), individuals who endorse Eros or Agape love styles are able to cope more effectively with stress in the relationship and be more satisfied in relationships. Eros has been associated with higher quality of life, subjective well-being, and dyadic satisfaction, and individuals that endorse Eros typically use more effective dyadic coping tendencies, fewer avoidant coping strategies, and positive conflict resolution (e.g., compromising; Raffagnino & Puddu, 2018; Vedes et al., 2016). These individuals also tend to have higher commitment in relationships, and less anxiety about their relationship



(Raffagnino & Puddu, 2018). This would suggest that individuals whose relationship is primarily categorized as Eros would be at less risk for burden, due to more effective coping and emphasis on working through conflict as a dyad. Agape has been shown to be correlated with relationship satisfaction and quality (Raffagnino & Puddu, 2018), as well as avoiding destructive communication and negative conflict resolution, and increased support given to a stressed partner (Vedes et al., 2016). While Vedes et al. did not find a significant correlation for Storge either, the love style maintains a profile that prioritizes commitment, friendship, and similar interests, and may still provide some benefit in lowering burden levels. It has been shown to correlate with dyadic coping, secure attachment, higher satisfaction in their relationships, and the use of functional resolution in marital conflicts (Raffagnino & Puddu, 2018).

It was expected that Ludus, Pragma, and Mania would have negative correlations with burden. Ludus has been related to weak effort in relationships, low quality and stability in relationships, and is a predictor of destructive communication and avoidant forms of attachment (Raffagnino & Puddu, 2018). According to Vedes et al. (2016), Ludus endorsement is “detrimental” for dyadic coping and relationship satisfaction for women, but not men (p. 93). Women endorsing Ludus may therefore be at significantly higher risk of burden than not only women endorsing other love styles, but men endorsing Ludus. This may be explained, at least in part, by societal norms expecting and accepting Ludus behaviors from men more so than women (Vedes et al., 2016). For example, the divorce rates for women with chronic illness and acquired disabilities are significantly more prevalent than for men, and women more likely to take on a caregiving role in a marital relationship (Karraker & Latham, 2015; Katz et al., 2000). It may be more socially acceptable for men to leave the relationship, which follows the Ludus profile of lacking commitment and feelings of relief or joy when a relationship ends. Similarly, it may be more socially expected that women are the caregivers and less accepted when women leave the relationship. As Ludus women stay in stressful relationships to avoid social repercussions, their dyadic coping behaviors and relationship satisfaction are sacrificed, which could ultimately lead to higher burden.

Pragma is related to stable relationships, relationship satisfaction, and subjective well-being (Raffagnino & Puddu, 2018), however, Pragma individuals choose partners based on important

characteristics and similar goals (Hendrick & Hendrick, 1989; Lee, 1977). It can be assumed that stability and satisfaction for Pragma individuals are highly dependent on the maintenance of the characteristics and shared goals. As onset of disability and the caregiver role change are unpredictable and unexpected, there can be a significant change from the original expectations in the relationship (Montgomery & Kosloski, 2013; Pearlin & Aneshensel, 1994; Seltzer & Li, 1996). The capacity of the partner to maintain previous roles and goals may be affected by the onset and experience of chronic illness and disability. As the relationship and the roles within the relationship that Pragma individuals expected change, the relationship is no longer stable, the couple may no longer share similar goals, and satisfaction is threatened, leading to a higher risk of burden.

Mania has been shown to be a strong predictor of destructive communication behaviors and negative relationship behaviors (Raffagnino & Puddu, 2018). There also tends to be feelings of jealousy and a deep need to be loved by their partner. As stressors come between two spouses, it may bring dyads together (e.g., Eros), but it may also pull spouses apart. If a spouse feels as if their spouse is drifting apart or is less emotionally available, they may experience a deep desire or need for love from their spouse. If the need goes unfulfilled, they may be more susceptible to feelings of depression, anxiety, and, ultimately, burden.

Hierarchical regressions were used to further examine the relationships between burden and love styles, along with predictor variables supported by the literature. The results of the first regression showed that 65.7% ( $R^2 = .657$ ,  $F(1, 34) = 22.39$ ,  $p < .001$ ) of the variance in caregiver burden could be explained by (a) caregiver depression and anxiety ( $\beta = .782$ ,  $t(35) = 7.84$ ,  $p < .001$ ), (b) Agape love style ( $\beta = .372$ ,  $t(35) = 3.35$ ,  $p = .002$ ), and (c) the employment status unemployed and not looking ( $\beta = -.221$ ,  $t(35) = -1.99$ ,  $p = .054$ ). The standardized beta for employment status of unemployed and not looking was not significant, but for caregiver depression and anxiety, and Agape love style were significant. The results from the second regression analysis (including only caregiver depression and anxiety, the employment status of retired, and Eros, Ludus, and Pragma) showed that 62.2% of the variance in caregiver burden

could be explained by caregiver depression and anxiety ( $\beta = .640, t(37) = 5.79, p < .001$ ) and the Eros love style ( $\beta = .269, t(37) = 2.44, p = .020$ ).

### ***Depression and Anxiety and Caregiver Burden***

Caregiving literature recognizes caregiver depression and anxiety as having strong correlations with burden and as a strong predictor of burden (Bastawrous, 2013; Gaynor, 1990; Rodriguez-Gonzalez & Rodriguez-Miguez, 2020; Schultz et al., 1997; Schulz & Beach, 1999; Wang et al., 2020) and these variables were highly correlated in the present study ( $r = .71, p < .01$ ). In this cross-sectional study, it is impossible to parse out whether depression and anxiety are predicting burden, are a result of burden, or are simply cooccurring experiences. However, it is clear that higher depression and anxiety levels are related to higher levels of burden.

Eros ( $r = .54, p < .01$ ) had a significant positive correlation, and Ludus ( $r = -.42, p < .01$ ) and Pragma ( $r = -.34, p < .05$ ) had significant negative correlations with depression and anxiety. These relationships were an unexpected finding that suggests that love styles may potentially serve risk or protective roles in the caregiver relationship. Specifically, although it is not possible to evaluate a causal relationship in the present study, individuals endorsing Ludus and Pragma may be associated with higher risk of experiencing depression and anxiety, whereas individuals endorsing Eros may be at lower risk.

As discussed above, Eros and Agape individuals have been shown to cope with relationship stressors more effectively and remain more satisfied when facing stressors than other love styles (Vedes et al., 2016). Since Agape individuals tend to be more supportive and giving, the caregiving tasks may not be as unexpected or out of character, potentially resulting in a lower risk for caregiver burden. The relationship between Eros and CGB was further supported with the results from the ANOVA, which examined group differences based on love styles and CGB levels, as it was the only love style with a significant difference from the others.

Since individuals can endorse multiple love styles, love styles were converted to groups of high-endorsement and low-endorsement to attempt to capture clearer trends in love styles and potentially

reduce the impact of neutral endorsements. High endorsement of Eros tended to have lower CGB scores than those with low endorsement, deepening the evidence of potential relationships. High endorsement of Ludus did show a significant difference ( $MD = 16.66, p = .030$ ), demonstrating high endorsement of Ludus is related to higher CGB. Higher endorsements of Pragma, Agape, and Mania suggested trends of differences, but are inconclusive. Storge had little difference between low and high endorsement, and the literature provides limited significant correlations other than relationship length (Vedes et al., 2016). This may indicate that Storge does not have an impactful relationship with CGB, for better or worse.

### **Love Styles Over Time**

The second main purpose of this study was to examine how love styles change over time, specifically during major life events. The life events were defined by the first year of marriage (T4), the first year of symptom onset (T3), the first year of PD or MS specific caregiving (T2), and the present day (T1). While analyzing the results required a specific order for comparison, it is reasonable to assume that these events can occur in different orders. Therefore, interpreting the results should focus more on the event as a facilitator of change, rather than a timeline of changes, meaning comparisons can be drawn between the events in any order.

Most of the love style literature examines changes in love styles over time by comparing age and length of relationship differences. While asking individuals to recollect feelings of the past does expose findings to bias (e.g., recollection bias, social desirability bias), it was assumed that the life events were impactful enough for salient memories, and that perceived feelings are as important in telling the story of changing love styles as comparing factors like age and relationship length. For example, an individual recalling how they felt toward their spouse in their first year of marriage and then again today, may heighten the scrutiny of the ‘slow and insidious’ changes, illuminating distinct perceived changes, positive and negative, in the relationship for the individual. Thus, perceived changes are not generalizable, but are valid for the individual experience and can provide meaningful considerations.

### ***First Year of Marriage***

In this present study, the first year of marriage was significantly different from the other time events. In the first year of marriage, Eros ( $M = 1.74$ ) was more highly endorsed than other love styles and was endorsed more in the first year of marriage than at the other time points. Eros has been shown to be negatively correlated with length of relationship, meaning the style is typically less endorsed as relationship duration increases (Raffagnino & Puddu, 2018; Smith & Klases, 2016; Vedes et al., 2016).

Overall, all love styles were more highly endorsed in the first year of marriage. This may be reflecting the many conceptualizations of relationships over time that assume new relationships are more passionate and fervent, and as the relationship continues, passion fades (Graham, 2011; Hatfield et al., 2008; Hatfield & Walster, 1978; Sternberg, 1986). Some researchers believe companionship (e.g., Storge) also fades with time (Hatfield et al., 2008), however literature also shows companionship may replace passion as relationships develop (Acevedo & Aron, 2009; Hatfield & Walster, 1978). Another distinction that has been described as a component of passion is romantic obsession, which decreases over time, while the romantic components are long lasting (Acevedo & Aron, 2009; Graham, 2011). For the entire sample in this study, love styles were not necessarily replaced with another style, but the level of overall endorsement changed, with less endorsement from marriage to symptom onset, and from symptom onset to caregiving, and then more endorsement from caregiving to current.

### ***Symptoms and Caregiving Onset***

The other significant change was observed between the first year of symptom onset and the first year of caregiving ( $MD = .127, p = .02$ ), in which love styles were less endorsed overall from symptom onset to the year of caregiving. The events of symptom and caregiving onset suggest impactful changes in how an individual exists in and engages with their environment (e.g., function, roles, responsibilities), regardless of how major, or minute, the change may have been. While the beginning of a caregiving role can be ambiguous (Montgomery & Kosloski, 1994; Seltzer & Li, 2000), and the progression of MS and PD symptoms can take time to fully present or result in limitations, reflecting on larger timeframes (one year) likely captures when the incongruence between pre-disability expectations and post-disability

realities were at one of the highest peaks. This provided a salient memory to reflect on. Meaning, it was less important for individuals to choose the “correct” timeline of symptom onset, or the exact date caregiving began, and more important to reflect on their feelings toward their spouse and relationship during potentially distressing and difficult experiences of adjustment. Without providing participants with definitions or guidelines about when symptom onset occurs or when caregiving begins, individuals were able to respond with their fully subjective experience, resulting in the most salient and impactful points in time being captured.

Love styles are expected to change yet clear patterns of change seem to remain unclear. However, love styles do indeed change throughout the duration of the relationship. It may not be possible or helpful to predict which love styles are more or less likely throughout the relationship. It may be more important to explore what is causing the change and the resulting impacts of the changes.

### ***Love Style Changes for People with Disabilities and Caregiving Spouses***

In order to explore potential causes in changes, love styles over time were reexamined and separated by groups. First by role and diagnosis (e.g., MS caregiver, person with MS), and then again by only role (e.g., caregivers and spouses with disability). Since this was not supported with prior research, there were few assumptions made about what would transpire. However, with the noted significant differences between symptom onset and caregiving role onset, there was reason to believe there may have been further explanation by separating caregivers from the spouses with disabilities.

For caregivers, there tended to be weaker overall endorsement of love styles during the first year of symptom onset and first year of caregiving, except for Agape during the first year of caregiving. Agape was the only love style for caregivers that was endorsed more during the first year of caregiving, all others were less endorsed. Agape has been shown to be positively correlated with relationship length (Raffagnino & Puddu, 2018; Vedes et al., 2016), meaning it is more likely to be endorsed in longer relationships. Agape has also been described as an idealized love style that is often sought after but is elusive (Lee, 1977; Smith & Klases, 2016), making it difficult to determine if Agape inherently develops

in longer, satisfying relationships, or if long, satisfying relationships require at least some endorsement of Agape.

While it is still impossible to confirm these relationships one way or the other, the trends in this study warrant further research. Agape having less endorsement at symptom onset indicates that the individual may have to make some sacrifices (e.g., changes in roles, responsibilities, social life) and the sacrifices may lack value or meaning (e.g., the purpose of the sacrifice is less important than what is being sacrificed). Agape trending back to being more endorsed in the year of caregiving onset, may demonstrate an aspect of caregivers adjusting to the new role and expectations, suggesting a value change may have occurred, as proposed by Baumunk (2023). The sacrifices may have more meaning and purpose, meaning they may simply be less negatively impactful and no longer viewed as “sacrifices”, indicating higher Agape endorsement.

### ***Love Style Changes and Caregiver Burden***

Love style changes were also evaluated by CGB levels (e.g., low burden, moderate burden, and high burden), and intriguing and impactful trends were revealed. Low and moderate burden level groups seemed to remain generally consistent across time periods, with small but noticeable changes in endorsement at symptom onset and caregiving, as discussed. The high burden group, in contrast, reported higher endorsement of love styles overall at the time of marriage, resulting in a cluster of data points. This cluster of endorsements is intriguing, as research has shown that the six love styles are six distinct profiles (Smith & Klases, 2016), meaning farther distribution between points would be expected, for example, between the low and moderate burden groups. The clusters indicate more neutral endorsements of the love styles, and potentially indicate neutral or impartial feelings toward the spouse or the relationship. The cluster of high endorsement may be reflecting the previously discussed dynamic that higher overall endorsement at the time of marriage may indicate the more intense feelings in the first year of marriage. It may also suggest that, in reflecting upon the first year of marriage, a feeling of “the good old days” has inflated the perceived feelings of the past. The comparison of an intense love that was shared in the first

year of marriage, relative to salient and distressing more recent experiences, may be contributing to both responses to love styles and burden.

The love styles between symptom onset and caregiving remain quite similar for the high burden group, and only slight increases in endorsements from caregiving to current. This suggests that the potential value change that may have occurred overall for caregivers discussed above, likely did not occur for those experiencing high burden. It is impossible to conclude if the lack of clear love style endorsement (e.g., the clusters of data) is causing higher burden, or if burden is causing a lack of strong endorsement (e.g., neutrality toward relationship/spouse). However, the findings do show trends that could be important to consider when working with spouses after disability acquisition.

### **Methodological Limitations**

The methodology related to data collection was associated with several potential limitations. First, the sample size was small and severely impacted the normality and power for each analysis. Meaning, the risk of Type I error was high, and the generalizability of the findings was impossible.

Second, because participants completed the survey on an online platform, this may have excluded couples without internet access or with limited technological skillsets. Older adults with CID may have been less likely to complete the survey if they had more severe functional and/or cognitive impairments that may inhibit navigating online surveys. Additionally, individuals that are involved with associations may have more available resources (e.g., internet access, healthcare) and are likely active in disability or treatment-related activities (e.g., support groups, research, therapy, etc.). Therefore, disadvantaged or underserved individuals were more likely to be omitted from the study.

Third, self-report surveys can lead to social desirability response bias. Respondents may have provided answers that they perceived as more socially desirable, rather than their honest response. When asking sensitive or vulnerable questions (e.g., caregiving behaviors, perceptions of relationships), respondents may overreport “good” and underreport “bad” behaviors/attitudes.

Fourth, the order of questions must be carefully considered to reduce the impact of order effects bias. For example, first answering questions on CGB could lead the respondents to dwell on their



perceived burden in the relationship. If the next set of questions are on the relationship, the respondent may be overly focused on the negative aspects, rather than the overarching and general satisfaction.

Fifth, the onset of MS and PD typically occurs at different points in life, suggesting the impact on various life domains (e.g., employment, income, social life) varies between the populations, making generalizing impacts and experiences of the two populations impossible. In the present study, individuals with MS reported mean ages ranging from 36 years old to nearly 38 years old for diagnosis, symptom onset, and the need for caregiving (reported in Table 4). Whereas the ages reported by individuals with PD ranged from 55 years old to nearly 63 years old. While there may be similarities, it can be assumed that the impact of symptomology and an individual's experience would vary greatly for someone in mid-career versus nearing retirement. This study focused more on CGB and love styles, rather than examining disability experiences. However, it is difficult to explore CGB and love styles without making some assumptions about the disability experiences, yet doing so should be done with caution and respect to differences in life stages.

Finally, the methodology for addressing research question 3 created the risk for recall bias. Recall bias occurs when respondents misremember or misinterpret the events of interest (Khare & Vedel, 2019). Misremembering can appear as events that occurred before the time period of interest may be remembered as occurring within the time period (forward telescoping) or events occurred after the time period of interest (reverse telescoping). Misinterpretation and confusion can happen when poor-quality or ambiguous questions are presented. Recall bias cannot be completely eliminated. Backwards recall, forward recall, causal sequencing, and memory aids (e.g., landmark events) can help facilitate memory recall. The researcher utilized two approaches to reduce recall bias. First, time points were focused on specific landmark events (marriage, disability onset) to provide salient points of time. Second, the sequence of the time periods was T1 (current), T4 (marriage), T3 (onset), and T2 (CG duties). T1 was first to reduce order effects bias, then going back to a salient landmark and utilizing forward recall for the remaining time points.

## Implications and Conclusions

Despite the lack of generalizability and statistical significance, this study did reveal fascinating trends and important considerations for rehabilitation counselors working with spouses/partners. The findings also contribute to a large gap in research and literature and further exploration of (1) the relationships between caregiver burden and love styles, (2) how love styles change over time, and (3) a potential dyadic approach to disability adjustment is warranted.

Love style literature has historically focused on Eros, Ludus, and Agape, because of the consistent significant correlations and relationships, and Storge, Pragma, and Mania seem less significant and under researched (Raffagnino & Puddu, 2018; Vedes et al., 2016). This study echoed the literature in this way. It may be more important to focus on the values of the love styles, rather than the love styles themselves. Eros values romance and passion, Agape values unconditional love and putting others first, and Ludus values fun and low commitment. These values could be largely impacted when a major life event, like disability, occurs. Storge values friendship, Mania values being intensely loved, and Pragma values goals and interests. These values may be impacted less or have less of an impact on mediating negative impacts from major life events. Rehabilitation counselors may begin with assessing love styles with the Love Attitudes Scale to begin identifying values, especially if describing what an individual deems important or valued in their relationship seems challenging. It may not be necessary to assess love styles specifically, and “diagnosing” love styles could be unnecessary and potentially harmful. However, understanding what a person values in the relationship and in their spouse, and how that has changed could provide rehabilitation counselors with useful information and a solid foundation to build on in counseling.

While the goal would be to work with both spouses in couple’s counseling, rehabilitation counselors can still work with clients in an individual setting. As proposed by Baumunk (2023), counselors can guide conversations on both the individual level and the couple level for specific love styles. This approach could help counselors explore how clients can more effectively cope with their adjustment journeys. It could also help facilitate change in values, and ultimately change which love

styles are endorsed. Working with love style related values on the individual level and the couple level will likely include three similar approaches, (1) psychoeducation regarding the values and areas of importance, (2) explore changes in values and satisfaction in related areas (e.g., values pre- and post-disability and/or caregiving), and (3) emphasizing the benefits of redirecting or reframing values and importance. Counselors would modify the approach for the individual level to shift focus to the individual client's experience while avoiding speaking for or making assumptions about the spouse's experience. The counselor can assist the client with communication approaches to have similar conversations to the couple level approaches with their spouse outside of the counseling setting.

For example, counselors working with clients with Eros-related values (e.g., emotional and physical attraction, passion, intimate closeness) can begin by understanding elements of intimacy and how intimacy strengthens the relationship, and this will likely include some psychoeducation. There could then be an exploration of value changes and satisfaction in the areas of importance. This may include topics like how intimacy has changed for the couple pre- and post- disability and/or the need for caregiving, and how satisfied the couple is with the intimate aspects of their relationship. When working with only the individual, the counselor and client focus more closely on the client's perspective and the impact of changed or lacking intimacy on the client and working on communication techniques for the client to discuss areas of need with the spouse (e.g., "I feel like our intimacy has changed and I'm curious to know how you feel about it"). By utilizing psychoeducation, exploration of value changes, and strengthening coping skills, clients may shift values (e.g., Coping versus Succumbing) and importance in life domains (e.g., Disability Centrality model) which would ultimately shift love style endorsement.

The distinct changes that individuals perceive may provide meaningful insights to sources of dissatisfaction by reflecting on the comparisons of what their history held. The comparison is likely not stemming from negative intent, but rather from a feeling of loss: loss of the known and comfortable, loss of expectations, and fear of the unknown. These feelings reflecting ambiguous loss and grief, are experienced by many caregivers (Myhre et al., 2017), which often increases risk of CGB (Penning & Wu, 2016). In other words, the spouse is grieving the loss of what they may now perceive as the best or

happiest part of the relationship, relative to a relationship filled with the unknown, new, and potentially significant stressors.

The weakening of endorsement in overall love styles may provide meaningful insights to relationship satisfaction and quality, commitment within the relationship, or signs of emotional withdrawal. The withdrawal may not be intentional, and may be occurring slowly and subconsciously, as stressors in the relationship build barriers to connection. The spouse may still desire connection, but the distress is overshadowing the ability to remain connected.

As relationships change, it may be more difficult to find the connections that were once readily available. Instead of prioritizing finding new connections, navigating the present stressors is inherently prioritized, or there is a desire to hold on to the old connections, rather than prioritizing and discovering the new. Rehabilitation counselors can assist spouses, on an individual or dyadic level, to navigate the changes in roles, identities, responsibilities, and connections.

These processes would likely mirror the services many rehabilitation counselors are already providing with disability adjustment, as suggested in Dembo, Leviton, and Wright's (1956) Coping versus Succumbing approach and value-change model, or Bishop's (2005) Disability Centrality Model, but would also include the caregiving spouse. The spouses would work through similar and intertwined, yet unique, changes in values and importance in life domains. Rehabilitation counselors would include relationship factors, consider both spouses' perspectives, and be mindful of how these two adjustment processes interlace and interact. With this dyadic approach, the adjustment counseling could be more holistic, and may reduce burden and enhance adjustment, and ultimately improve health and quality of life for both spouses.

Future research is necessary to understand the dynamic and complex relationship between love styles and caregiver burden, because there does appear to be a relationship. The extent of that relationship remains unclear, but there are important trends that deserve further exploration.

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## APPENDIX A

### Parkinson's Disease Associations' Distribution Letter

#### Seeking Participants with Parkinson's Disease and their Spousal/Partner Caregivers for Research Study on Relationship between Caregiver Burden and Relationship Styles

Researchers at the University of Wisconsin – Madison are seeking participants for a research study exploring relationships between caregiver burden and relationship styles.

Spouses/Partners go through many changes together. How each responds to changes can impact not only the other spouse/partner, but the nature of the relationship and their roles within the relationship. The development of chronic conditions and disability can greatly impact how people function, behave, and exist in their relationships. For a diagnosis as complex and dynamic as Parkinson's disease, this impact can affect the person with Parkinson's disease and the person that takes on a caregiving role. Historically, research has viewed individuals with disabilities and chronic conditions and their caregivers as experiencing two separate journeys. This study is intended to explore the joint experience of adjustment to disability and the caregiving role for spouses/partners by considering the relationship style.

By participating in this research, you can help tell the story of how couples experience these changes together, and ultimately influence a new approach to education and counseling about adjustment to disability. Couples will be invited to individually complete an on-line survey. After completing the survey, participants will receive a virtual packet of caregiving resources and have the option to provide an email address for one of forty \$50 gift cards. The first 40 couples to complete both the (a) study survey and the (b) gift card survey, will receive one \$50 gift card per couple.

To help ensure the researchers can best understand the joint experience, both spouses/partners must agree to participate in the study. Other eligibility requirements include: (a) must be 18 years or older, (b) comprehend written English at a 6<sup>th</sup> grade reading level, and (c) either have a Parkinson's disease diagnosis from a movement specialist or be the spousal/partner caregiver of an individual with Parkinson's. Couples do not have to be legally married to participate.

If you are interested in participating, you can access the survey by using the following link [https://uwmadison.co1.qualtrics.com/jfe/form/SV\\_0GO69xw7D5X3UKq](https://uwmadison.co1.qualtrics.com/jfe/form/SV_0GO69xw7D5X3UKq) or scan the QR code below:



If you have any questions about the study, please contact researcher Megan Baumunk at [baumunk@wisc.edu](mailto:baumunk@wisc.edu) or the project PI Dr. Malachy Bishop at [mlbishop4@wisc.edu](mailto:mlbishop4@wisc.edu)

## APPENDIX B

### NMMS Recruitment Post

Researchers at the University of Wisconsin – Madison are seeking 150 – 200 participants for a research study exploring the relationships between caregiver burden and relationship styles. Spouses/Partners go through many changes together. For a diagnosis as complex and dynamic as multiple sclerosis, this impact can affect the person with multiple sclerosis and the person that takes on a caregiving role. This study is intended to explore the joint experience of adjustment to disability and the caregiving role for spouses/partners by considering the relationship style. Participants will respond to questions regarding their experiences with multiple sclerosis or as a caregiving spouse/partner and questions about their relationship styles at different points in their relationship. The survey takes roughly 35 – 45 minutes and first 40 couples who complete the survey will receive one \$50 gift card per couple. To help ensure the researchers can best understand the joint experience, both spouses/partners must agree to participate in the study. Other eligibility requirements include: (a) must be 18 years or older, (b) comprehend written English at a 6th grade reading level, and (c) either have a multiple sclerosis diagnosis or be the spousal/partner caregiver of an individual with multiple sclerosis. Couples do not have to be legally married to participate.

APPENDIX C

Mean Differences in CGB for Low and High Endorsement by Love Style

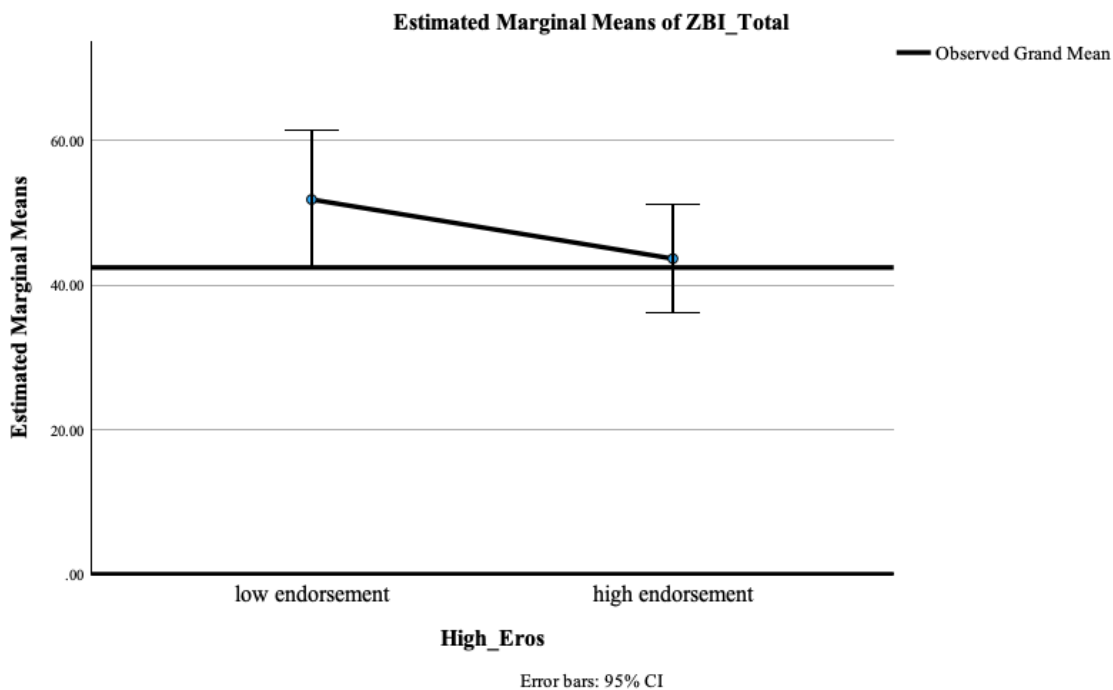


Figure C1. Mean Differences in CGB for Low and High Endorsement of Eros

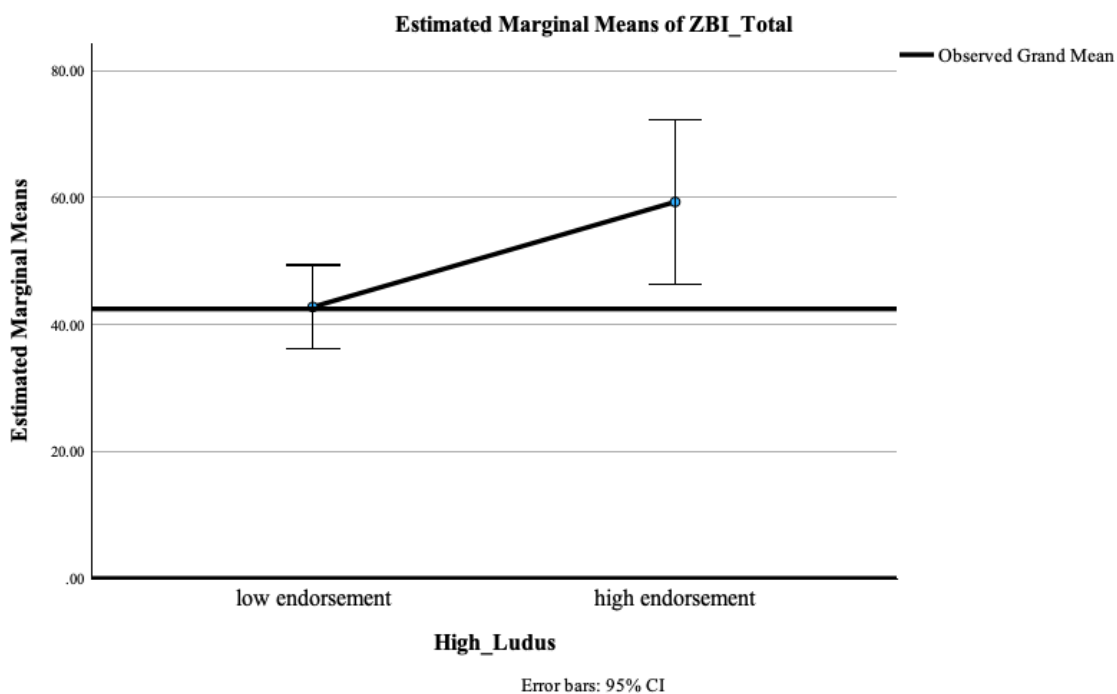


Figure C2. Mean Differences in CGB for Low and High Endorsement of Ludus

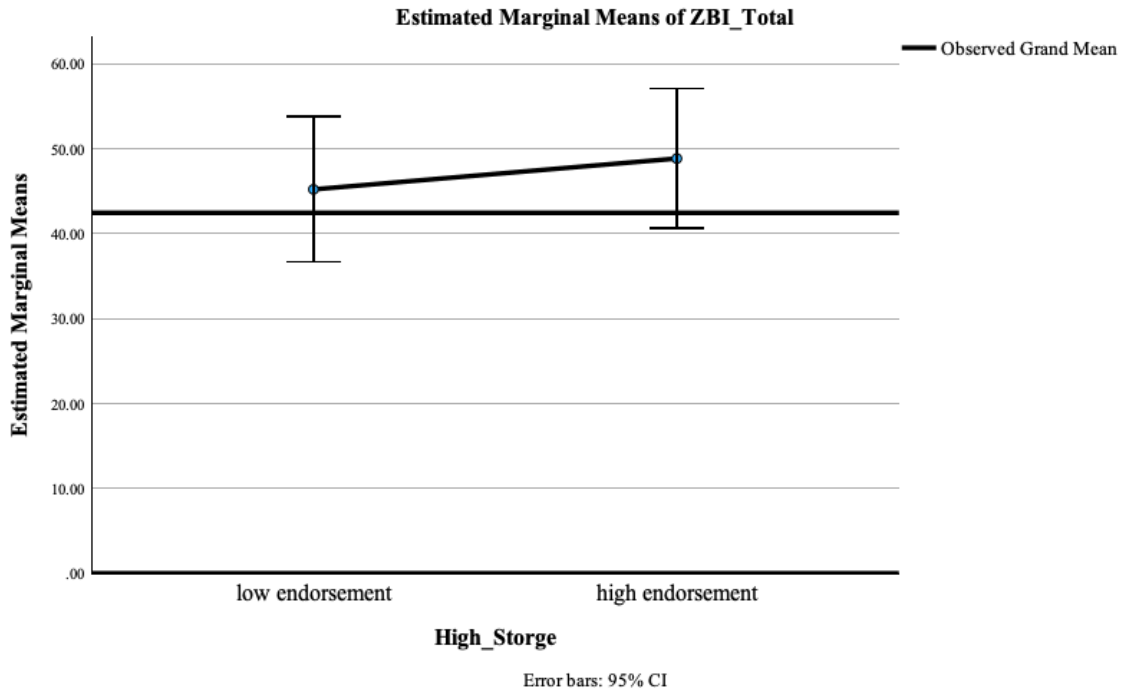


Figure C3. Mean Differences in CGB for Low and High Endorsement of Storge

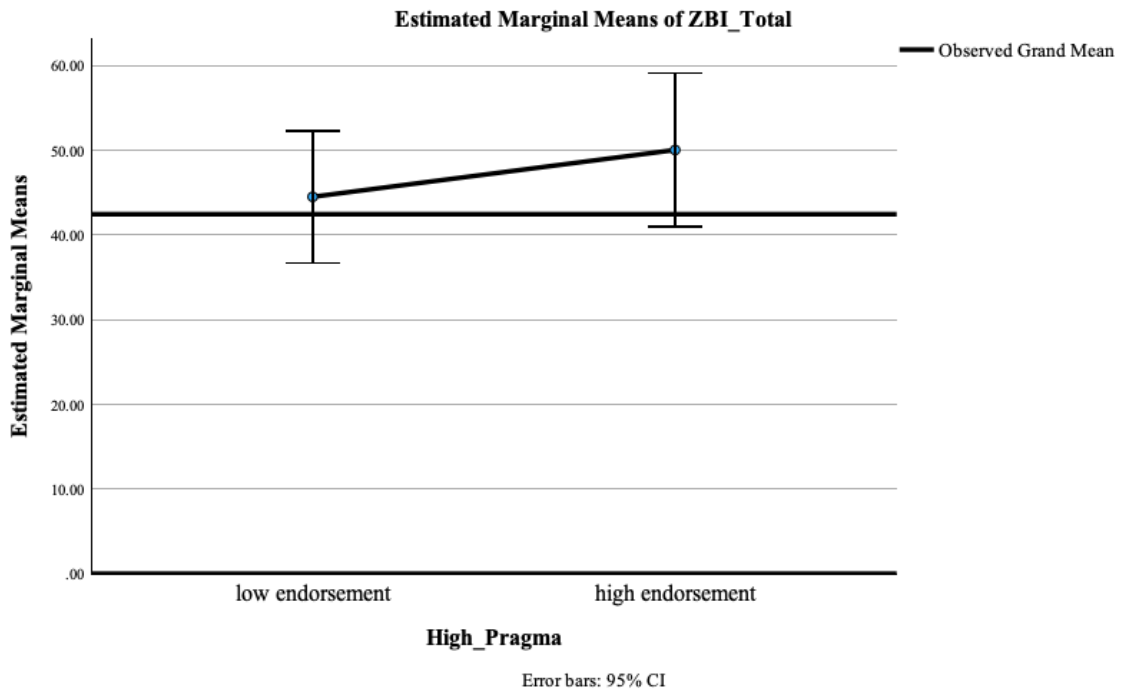


Figure C4. Mean Differences in CGB for Low and High Endorsement of Pragma

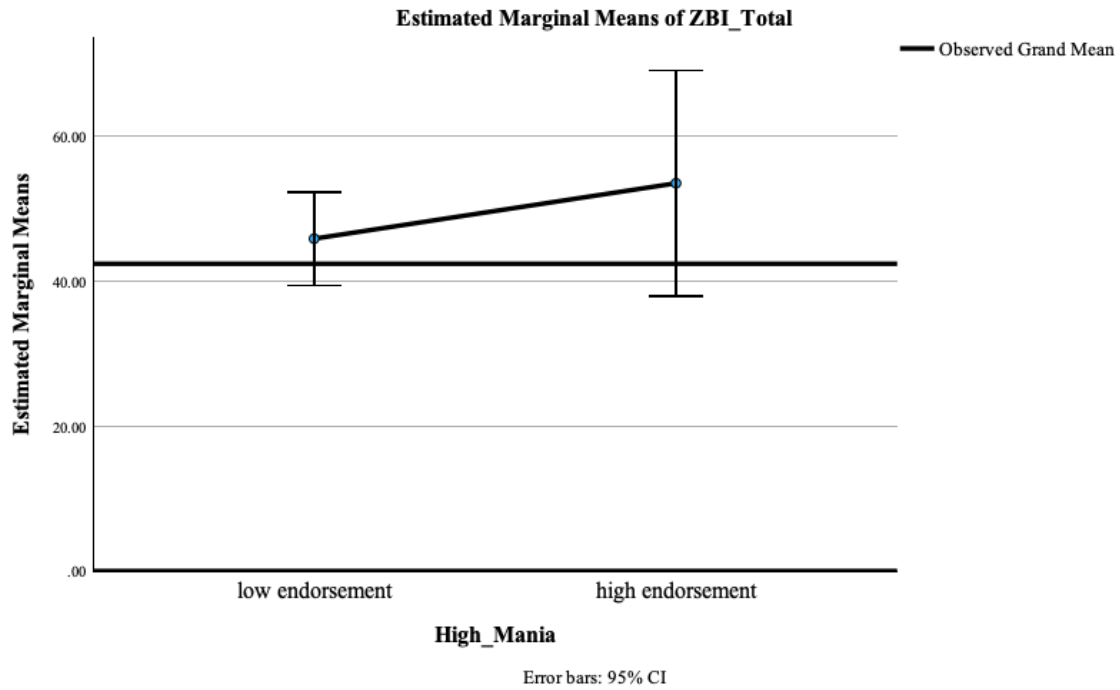


Figure C5. Mean Differences in CGB for Low and High Endorsement of Mania

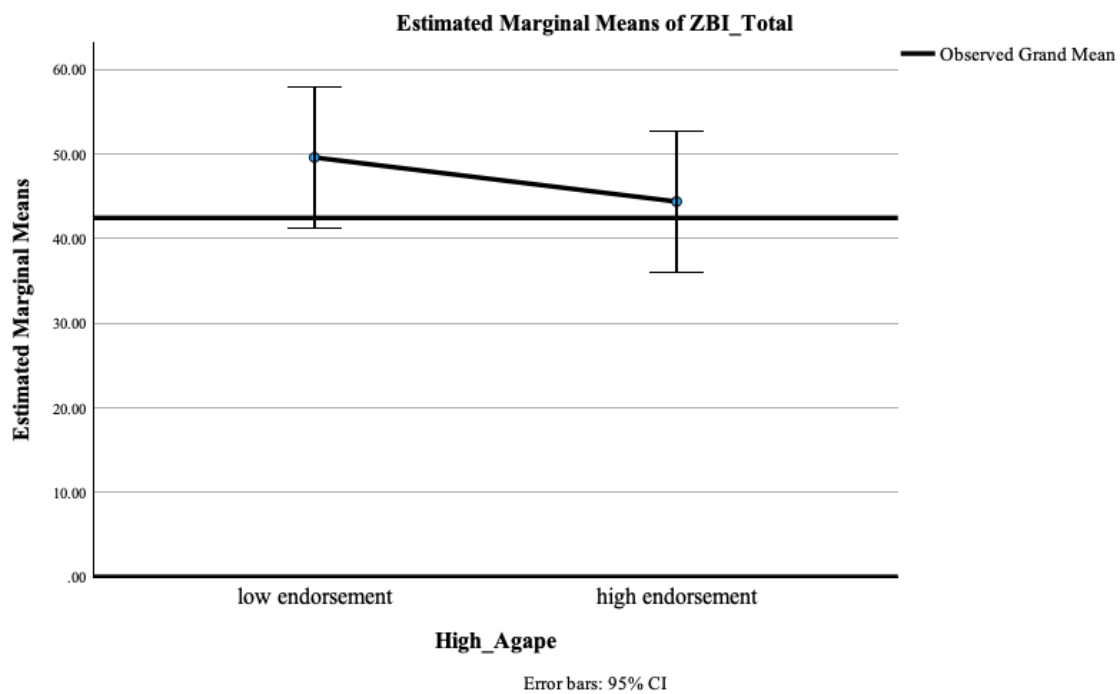


Figure C6. Mean Differences in CGB for Low and High Endorsement of Agape



APPENDIX D

Repeated-Measures ANOVA: Time and Love Styles Over Time by Group

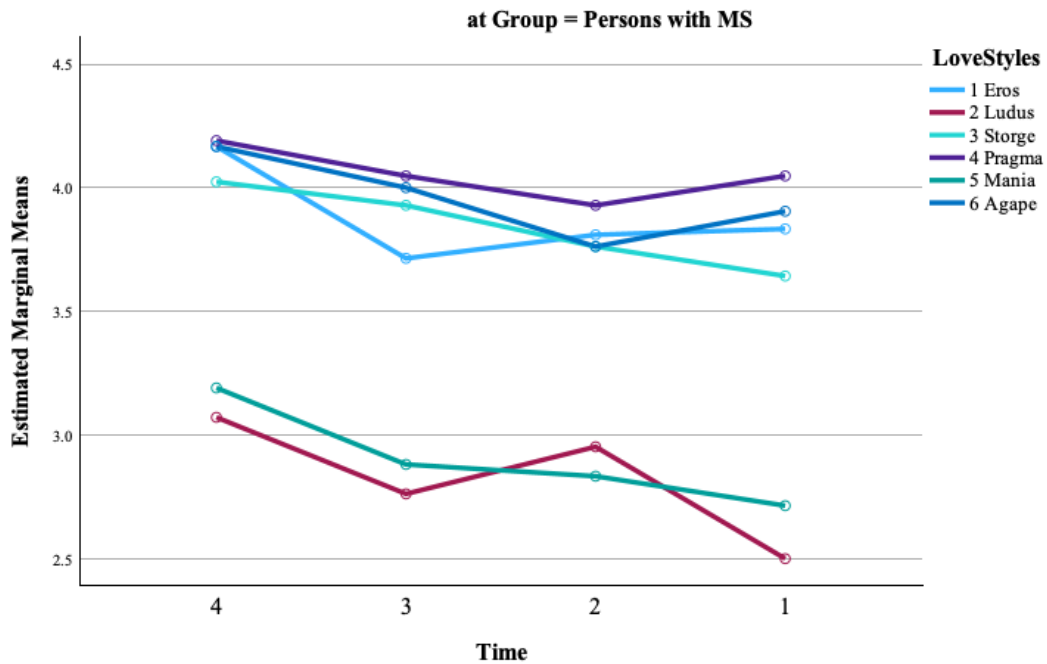


Figure D1. Repeated-Measures ANOVA: Time and Love Styles Over Time Persons with MS. Note. T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored for readability.

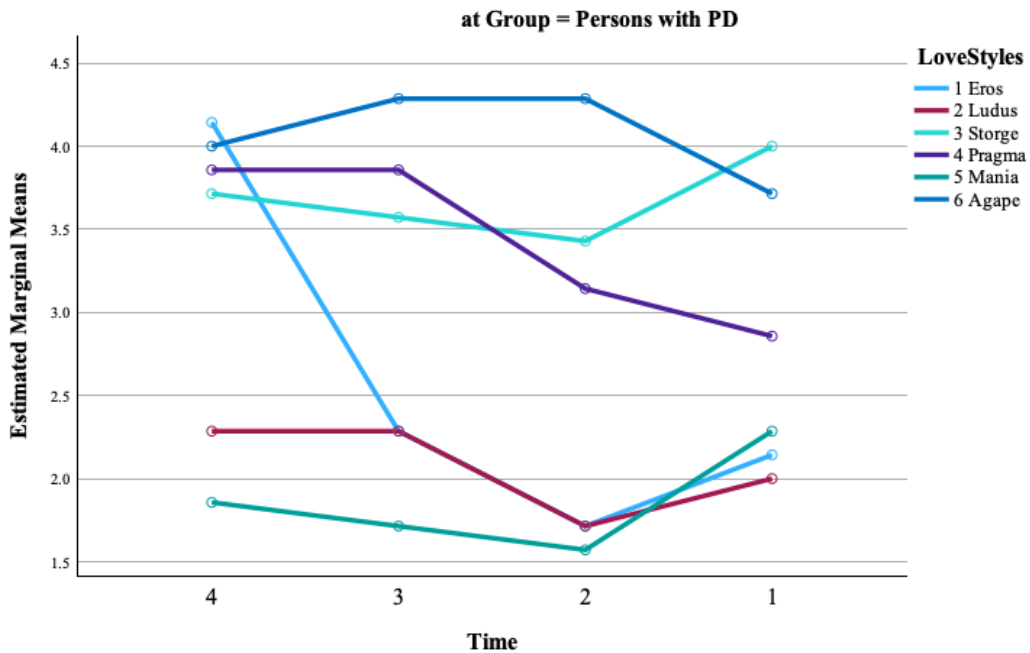


Figure D2. Repeated-Measures ANOVA: Time and Love Styles Over Time Persons with PD. Note. T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored for readability.

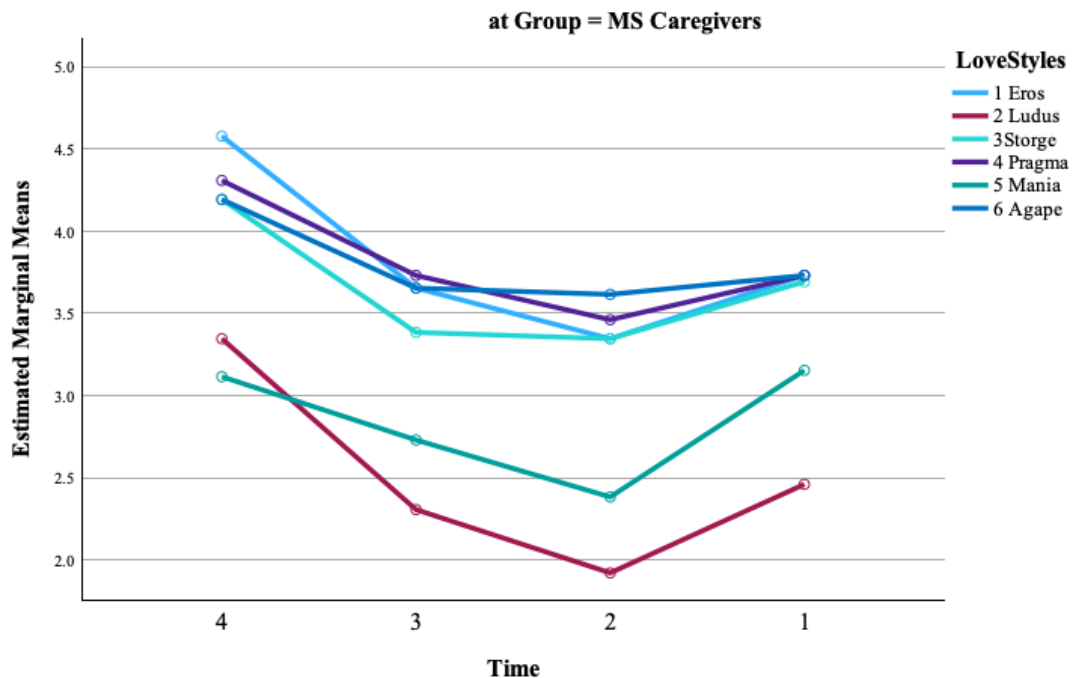


Figure D3. Repeated-Measures ANOVA: Time and Love Styles Over Time MS Caregivers. Note. T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored for readability.

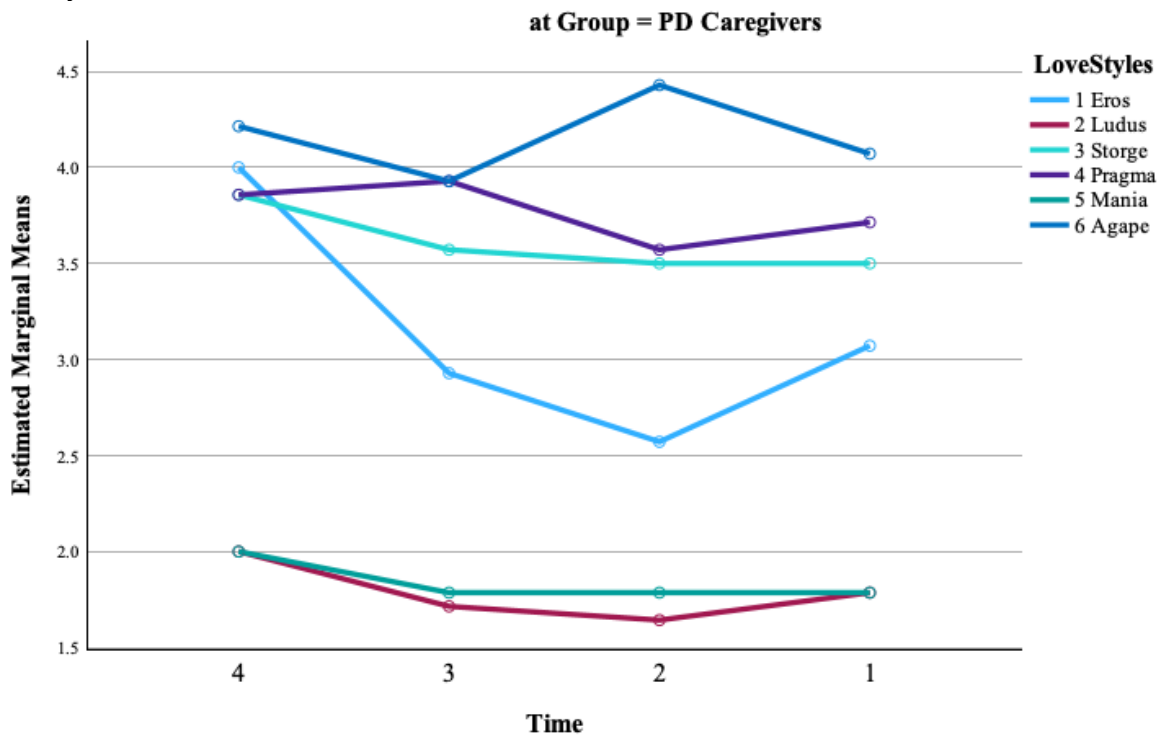


Figure D4. Repeated-Measures ANOVA: Time and Love Styles Over Time PD Caregivers. Note. T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored for readability.

## APPENDIX E

Repeated-Measures ANOVA: Time and Love Styles Over Time by Role

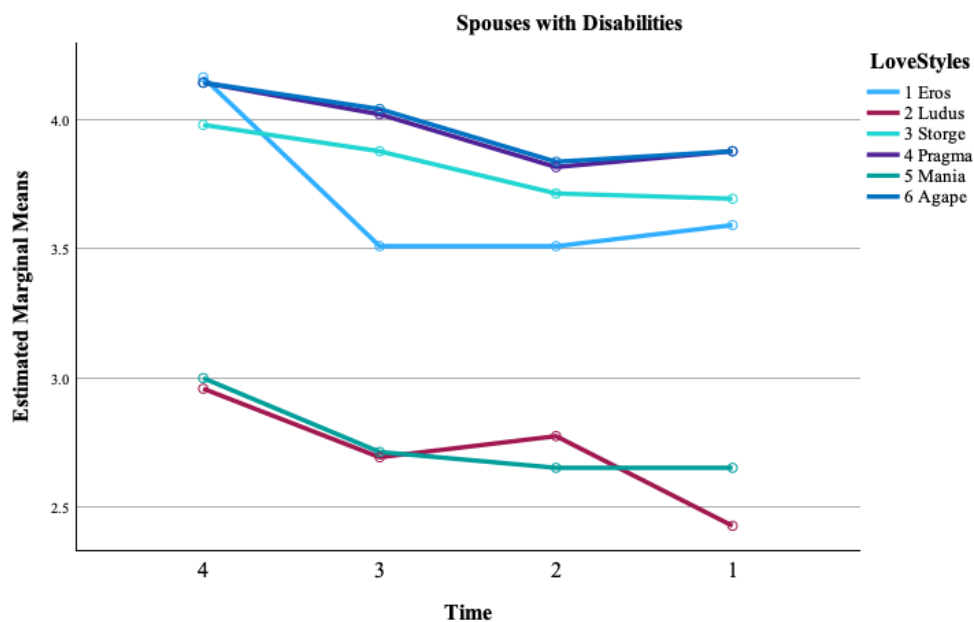


Figure E1. Repeated-Measures ANOVA: Time and Love Styles Over Time Spouses with Disabilities. Note. T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored for readability.

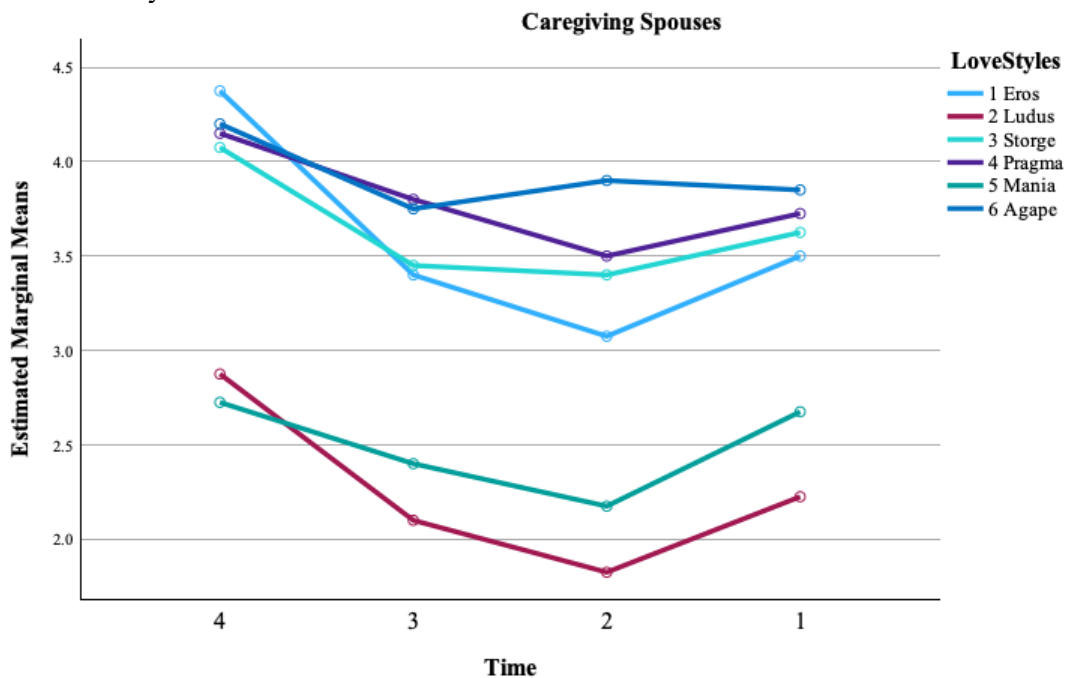


Figure E2. Repeated-Measures ANOVA: Time and Love Styles Over Time Caregiving Spouses. Note. T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored for readability.

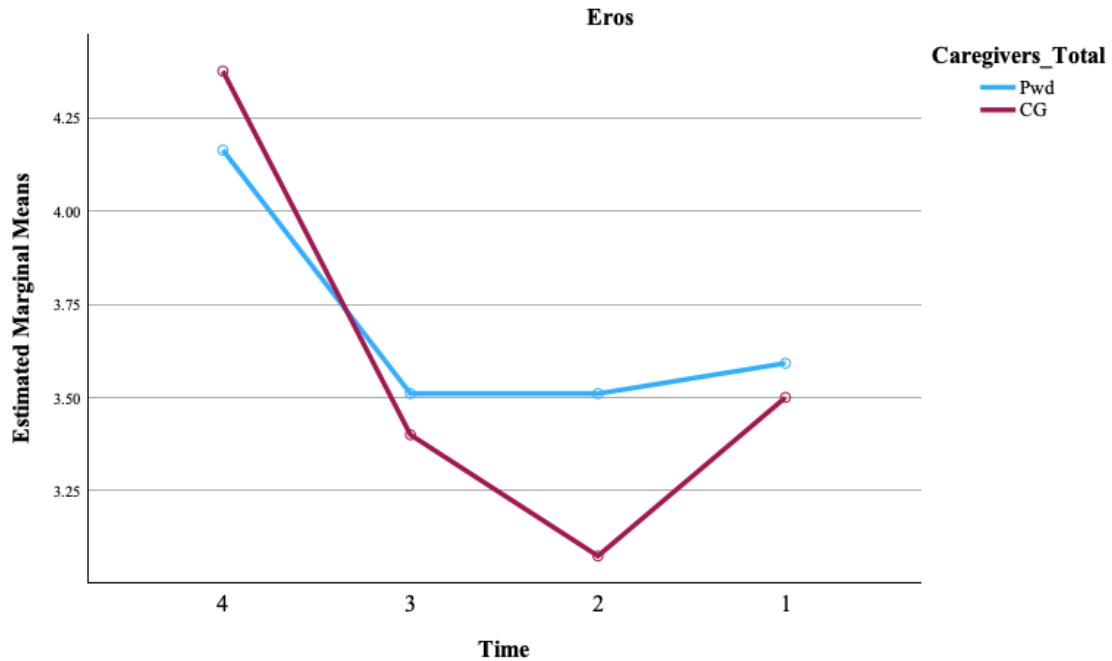


Figure E3. Repeated-Measures ANOVA: Time and Love Styles Over Time by Role, Eros.  
 Note. T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored for readability.

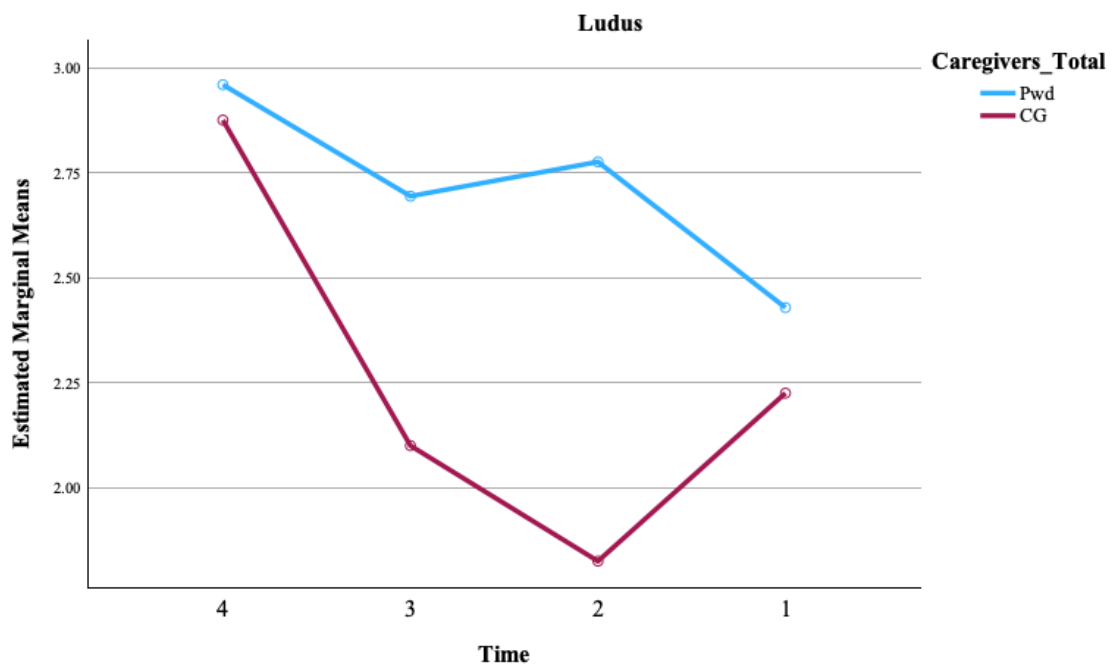


Figure E4. Repeated-Measures ANOVA: Time and Love Styles Over Time by Role, Ludus  
 Note. T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored for readability.

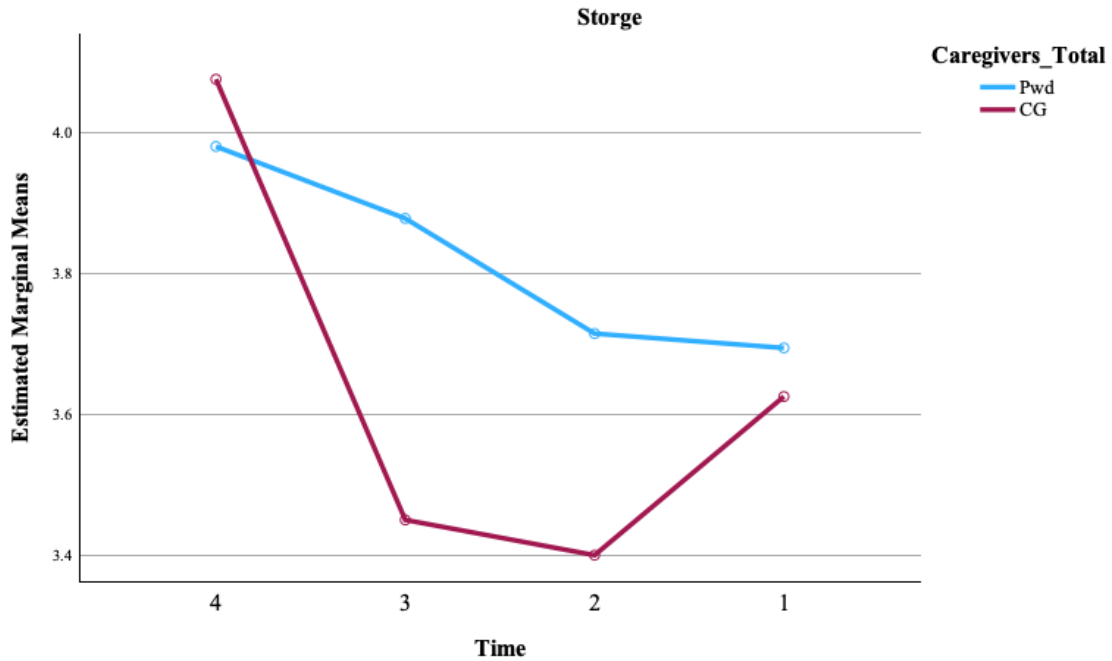


Figure E5. Repeated-Measures ANOVA: Time and Love Styles Over Time by Role, Storge. Note. T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored for readability.

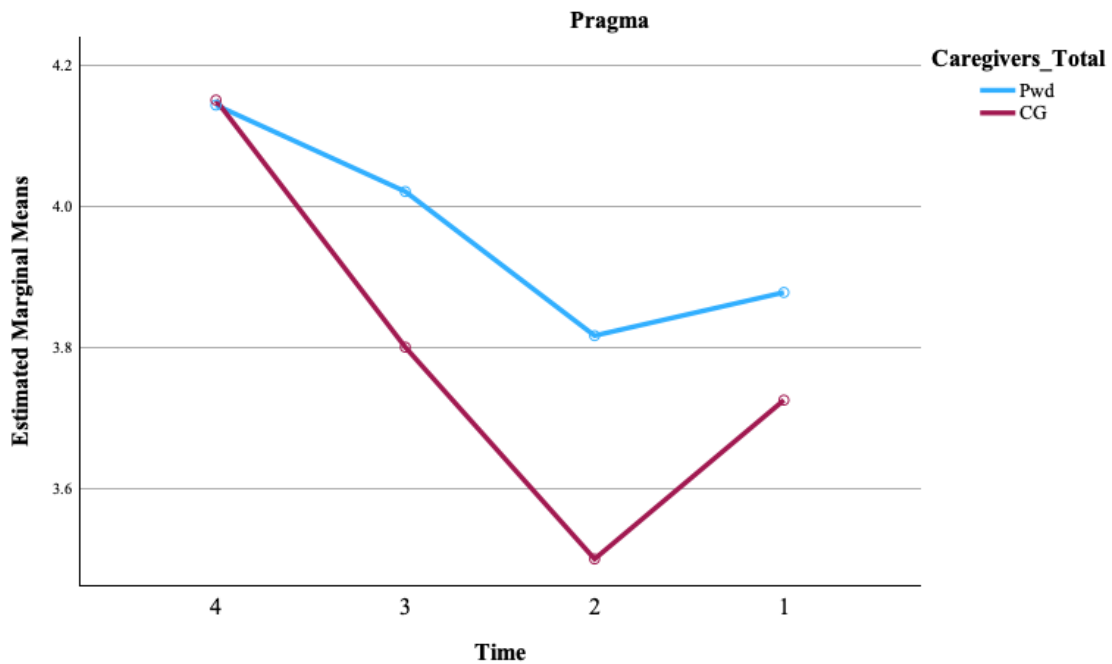


Figure E6. Repeated-Measures ANOVA: Time and Love Styles Over Time by Role, Pragma. Note. T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored for readability.

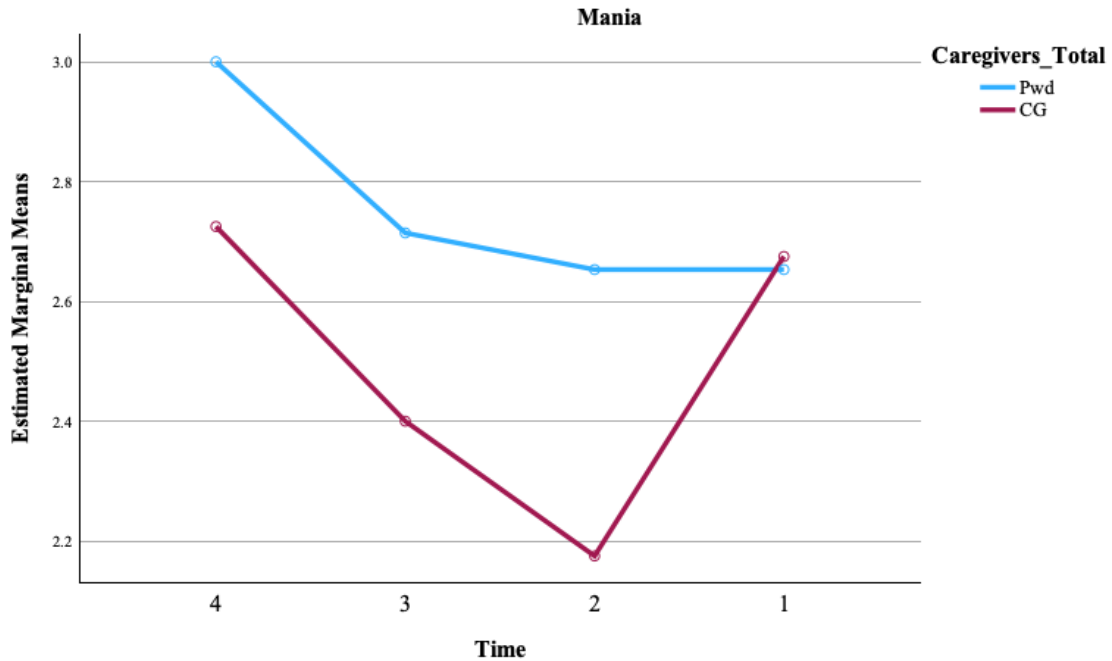


Figure E7. Repeated-Measures ANOVA: Time and Love Styles Over Time by Role, Mania  
 Note. T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored for readability.

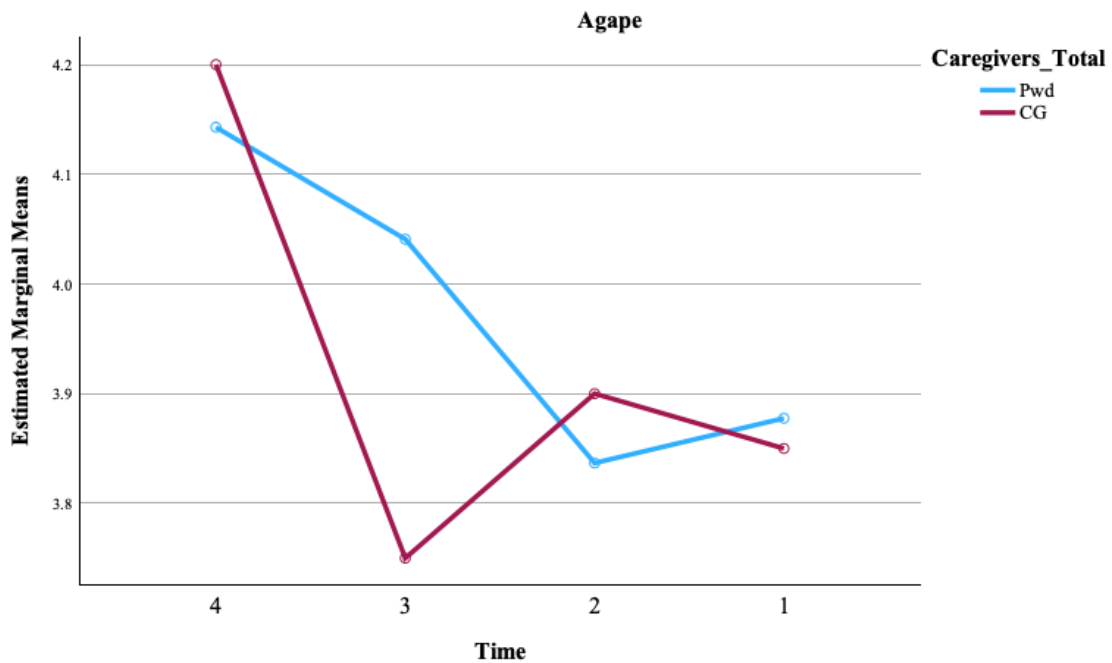


Figure E8. Repeated-Measures ANOVA: Time and Love Styles Over Time by Role, Agape  
 Note. T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored for readability.

APPENDIX F

Repeated-Measures ANOVA: Time and Love Styles Over Time by CGB Level

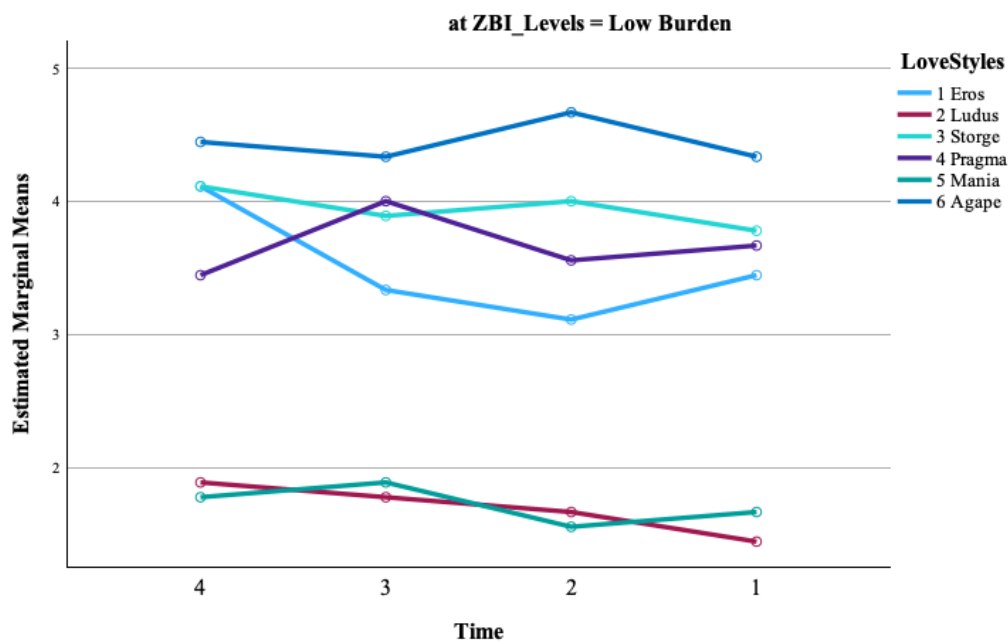


Figure F1. Repeated-Measures ANOVA: Time and Love Styles Over Time by CGB Level, Low. Note. T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored for readability.

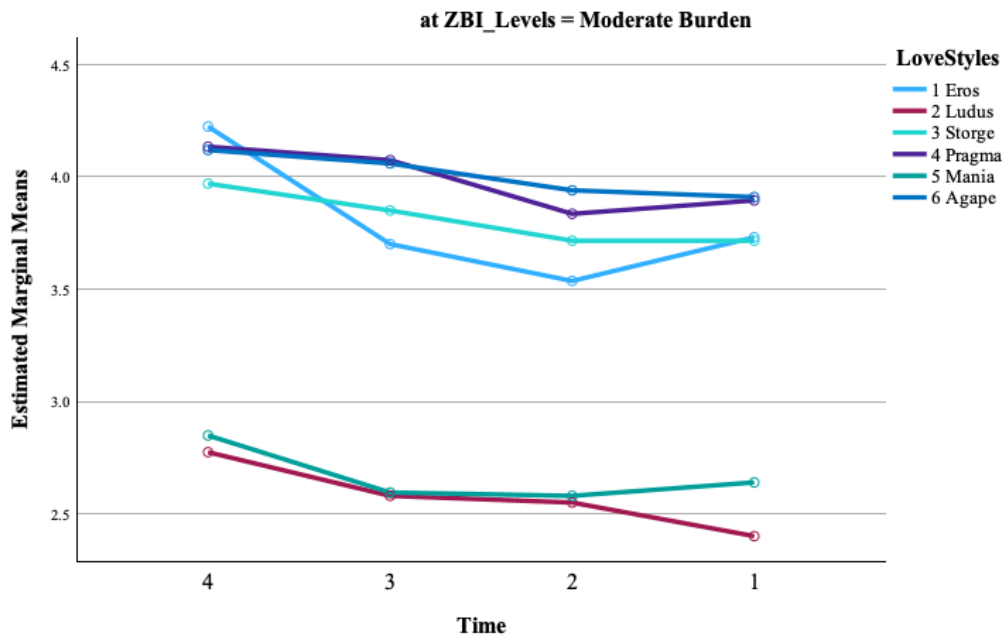


Figure F2. Repeated-Measures ANOVA: Time and Love Styles Over Time by CGB Level, Moderate. Note. T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored for readability.

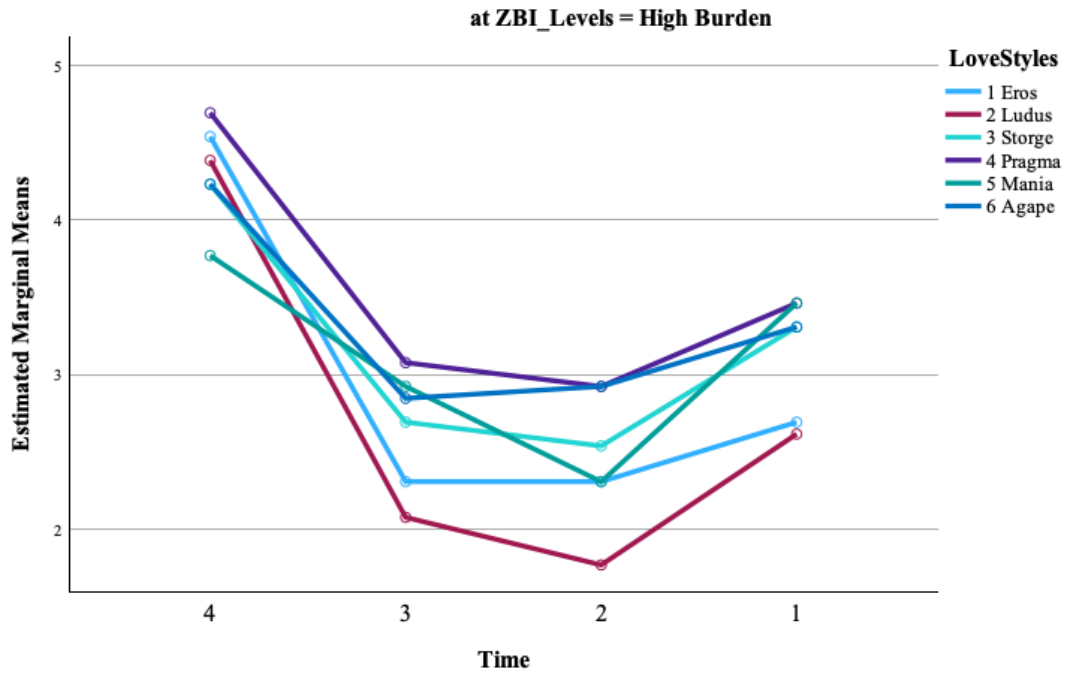


Figure F3. Repeated-Measures ANOVA: Time and Love Styles Over Time by CGB Level, High Note. T4 = marriage, T3 = symptom onset, T2 = caregiving, T1 = current. Love style scores are reverse scored for readability.



**APPENDIX G**

## Survey Questions

1. What is your gender?
  - Male
  - Female
  - Non-binary
  - Not listed (please specify)
  - Prefer not to say
2. What is your current age?
  - Text entry
3. Select your Race/Ethnicity (Check all that apply)
  - African American/Black
  - Asian/Pacific Islander
  - Hispanic or Latinx
  - Native American/Native Indian
  - White
  - Multiracial
  - Not listed (please specify)
  - Prefer not to answer
4. What is your current relationship status with the person you are completing this survey with (i.e., caregiver or person with multiple sclerosis/Parkinson's disease)?
  - Married
  - Not legally married
  - Domestic partnership
  - Divorced/Separated and still together
  - Other (please specify)
5. What is your current living situation?
  - I live with my spouse/partner in a personal residence (e.g., home, apartment, etc.)
  - I live with my spouse/partner in an assisted living community
  - I live with my spouse/partner in a nursing home
  - I live apart from my spouse/partner in a personal residence (e.g., home, apartment, etc.)
  - I live apart from spouse/partner in an assisted living community
  - I live apart from spouse/partner in a nursing home
  - Other (please specify)
6. Other than you and your spouse/partner, does anyone assist with care (health, home, or otherwise)? Select all that apply
  - No, only my spouse/partner and I take care of our needs
  - Yes, family members or friends help with tasks
  - Yes, people from an agency or service help with tasks (you do not pay out of pocket)
  - Yes, we pay an agency or service to help with tasks
  - Other (please specify)
7. Do you currently receive any government assistance (e.g., TANF, WIC, SSI, SSDI)?
  - No
  - Yes
8. Select all services you are currently receiving
  - Temporary Assistance for Needy Families (TANF)
  - Supplemental Nutrition Assistance Program (SNAP)
  - Special Supplemental Nutrition Assistance for Women, Infants, and Children (WIC)
  - Supplemental Security Income (SSI)

- Social Security Disability Insurance (SSDI)
  - Unemployment Insurance
  - Other (please specify)
9. What is your highest level of education?
- Less than high school
  - High school graduate
  - Some college, no degree
  - Associate's, 2 year degree
  - Bachelor's, 4 year degree
  - Master's degree, or higher
10. What is your current annual household income?
- \$0 - \$24,999
  - \$25,000 - \$44,999
  - \$45,000 - \$59,999
  - \$60,000 - \$84,999
  - \$85,000 - \$99,999
  - \$100,000 - \$114,999
  - \$115,000 - \$129,999
  - \$130,000 - \$149,000
  - \$150,000+
11. Has your income changed due to caregiving responsibilities or multiple sclerosis-/Parkinson's disease related changes?
- Yes, the household income has decreased for these reasons
  - No, the household income has not changed for these reasons
  - Yes, the household income has increased for these reasons
12. By about what percentage has your household income changed?
- 0% - 9%
  - 10% - 19%
  - 20% - 29%
  - 30% - 39%
  - 40% or more
13. What is your current employment status?
- Retired
  - Employed part-time
  - Employed full-time
  - Unemployed and looking for work
  - Unemployed and not looking for work
  - Stopped working due to caregiving responsibilities
  - Stopped working due to multiple sclerosis/Parkinson's disease
  - Other (please specify)
14. Has your employment changed due to caregiving responsibilities or multiple sclerosis-/Parkinson's disease related changes?
- Yes, my employment has decreased for these reasons
  - No, my employment has not changed for these reasons
  - Yes, my employment has increased for these reasons
15. How has your employment changed?
- Text entry
16. What type of health insurance do you currently have?
- Private insurance (e.g., through your employer)
  - Public insurance (e.g., purchased through marketplace)
  - Medicare

- Medicaid
  - No health insurance
  - Other (please specify)
17. When asked for your favorite snack, you must select cabbage. What is your favorite snack? (MS survey only)
- Chocolate
  - Chips
  - Fruit salad
  - Cabbage
18. How many years have you and your spouse/partner known each other?
- Text entry
19. For how many years did you and your spouse/partner date prior to marriage/cohabitating?
- Text entry
20. For how many years have you been married/cohabitating?
- Text entry
21. Including your current relationship, how many times have you been legally married?
- Text entry
22. If you have been legally married more than once, how many times have you been married to your current spouse/partner?
- Text entry
23. How old were you when:
- You married/cohabitated with your spouse/partner? (Text entry)
  - You were (or your spouse/partner was) diagnosed with multiple sclerosis/Parkinson's disease? (Text entry)
  - Your (or your spouse's/partner's) multiple sclerosis/Parkinson's disease symptoms started? (Text entry)
  - You (or your spouse/partner) started caregiving for multiple sclerosis/Parkinson's disease related tasks/needs? (Text entry)
24. Love Attitudes Scale
25. Love Styles Over Time
26. Are you taking this survey as the individual with multiple sclerosis/Parkinson's disease or the caregiver?
- Individual with multiple sclerosis/Parkinson's disease
  - Caregiver
27. Is someone assisting you in completing this survey?
- No
  - Yes, my spouse/partner
  - Yes, someone other than my spouse/partner
28. In order to for the researchers to connect responses from spouses/partners while maintaining confidentiality, please provide the year and location (city and state) in which you MET your spouse/partner. (Please discuss and confirm with spouse/partner to help ensure consistency - thank you!)
- Year: (text entry)
  - City: (text entry)
  - State: (text entry)
29. Do you have a disability or chronic condition/illness? (Caregiver only)
- Yes
  - No
30. Please list your disability or chronic condition(s) here. If you prefer not to answer, please enter "N/A". (Caregiver only)
- Text entry

31. Zarit Burden Inventory (ZBI; Caregivers only)
32. Patient Health Questionnaire – 4 (PHQ-4; Caregivers only)
33. Parkinson’s Disease Questionnaire – 39 (PDQ-39; Spouses with PD only)
34. Multiple Sclerosis Impact Scale (MSIS; Spouses with MS only)
35. Is there **any** information that you believe is important for the researchers to know that was not fully captured? Perhaps regarding: (a) your relationship or beliefs about love, (b) adjustment to caregiving role, (c) adjustment to multiple sclerosis, (d) changes in your relationship/marriage, and/or any other important factors you believe should be considered.
  - Text entry
36. Thank you for completing the survey! We greatly appreciate your time and energy. You will find a digital packet of Caregiving Resources at the bottom of this page. On the following page, you will find a list of additional national resources. Finally, you will be presented with an optional separate survey for the opportunity to be selected for a gift card. The gift card survey must be completed by both spouses and contain matching contact information. The first 40 couples to complete the study survey and the gift card survey with matching contact information will receive one \$50 gift card per couple. Thank you again for your time!
37. National resources that may also be helpful:
  - [American Association for Marriage and Family Therapy \(AAMFT\)](https://www.aamft.org/) is the professional association for the field of marriage and family therapy. Their website offers online education and training, webinars and publications related to marriage and family therapy, and a “Find a Therapist” directory that is searchable by zip code. <https://www.aamft.org/>
  - [988 Suicide & Crisis Lifeline](http://www.988lifeline.org) is available 24 hours a day, 7 days a week for free, confidential help if you or somebody you know is experiencing a mental health, substance use, or suicide crisis. Call or text 988, or chat at [www.988lifeline.org](http://www.988lifeline.org) in English or Spanish to be connected to a trained crisis counselor. Deaf and Hard of Hearing call 711, then 988. Veterans call 988, then press 1 or text any word to 838255. For other language support, you must call 988 and ask for help in the language you speak. They will get you a Tele-Interpreter.
  - [NAMI National Warmline Directory](https://www.nami.org/NAMI/media/NAMI-Media/Hotline/NAMI-National-HelpLine-WarmLine-Directory.pdf). Warmlines are free, confidential emotional support hotlines staffed by peer-specialists with lived experience with mental health conditions. NAMI's Warmline Directory can be found here: <https://www.nami.org/NAMI/media/NAMI-Media/Hotline/NAMI-National-HelpLine-WarmLine-Directory.pdf>
38. Would you like to provide contact information for a \$50 gift card? Only the first 40 couples to complete the survey and provide an email address will be eligible for a gift card. By clicking the link below, you will be taken to a separate survey that will ask for an email address. Please discuss with your spouse/partner and provide the same email address. Click the link and then submit the survey. If you do not wish to be entered for the gift card, simply click the submit button and the survey will end.