Physical Therapy and Caregiver Burden: A Mixed Methods Design

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ABSTRACT

PHYSICAL THERAPY AND CAREGIVER BURDEN: A MIXED METHODS DESIGN

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Northern Illinois University, 2023
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This dissertation explores the value and impact of physical therapists working with caregiver-care recipient dyads. A convergent mixed methods design was used to assess the impact physical therapy can have on burden experienced by the primary caregiver, caring for a loved one with a chronic neurological condition. The purpose of this study was to examine the role of physical therapy on caregiver burden by answering the following research questions: 1) Does caregiver burden as measured by the Zarit Burden Interview change over time when the care recipient receives physical therapy services? 2) Does patient function improve over time in individuals receiving physical therapy services? 3) Is there a relationship between caregiver burden and care recipient function at baseline and discharge from physical therapy services?

The research design employed for this study was a convergent mixed methods design exploring perceived burden experienced by the caregiver and the role of physical therapy. Through the method of data analysis using NVivo software, interviews with caregivers generated four main themes: caregivers not feeling prepared to take on their role as caregiver, available assistance needed to reduce burden, aspects of physical therapy caregivers found burdensome, benefits of physical therapy. The significance of this study shows how physical therapists may
impact and mediate the stress perceived by caregivers by improving care recipient functional outcomes. It is important to understand both the facilitating factors and barriers faced by caregivers to improve physical therapy practices to assist caregivers. The findings of this study can be used to help evaluate and improve physical therapy practices with monitoring individuals for perceived burden.
ACKNOWLEDGMENTS

I would like to thank several people for helping me achieve such a great accomplishment. I would like to thank Dr. MJ Blaschak my committee chair and Dr. Beverly Henry my co-chair for your support and guidance during my educational journey. I would also like to thank Dr. Janet Olson, committee member, for your guidance during the dissertation process.

I would like to thank my family and friends for your unwavering support while I finished my Ph.D. Thank you to my husband Chad for supporting me in all my educational endeavors especially over the past five years. To my children Colton, Emma, and Gabe thank you for being supportive and your words of encouragement. Thank you to my mother who has always believed in me and continues to offer encouragement in everything I do.
DEDICATION

I would like to dedicate this dissertation to a co-worker, Brenda Pratt, who has been a caregiver for many years while working full time, and while being active in her community. Brenda has shared her wisdom and gave me support through my doctoral journey and I will be forever grateful for her support.
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CHAPTER 1: INTRODUCTION

Providing long-term care for individuals with disabilities for an extended period of time can negatively affect the caregiver. In 2019, approximately one in five adults in the United States, roughly 53.0 million people, provided some form of caregiving to an individual with disabilities (American Association of Retired Persons & The National Alliance for Caregiving, 2020). An informal, or unpaid, caregiver is an individual who provides care to a friend or family member who requires assistance with activities of daily living (ADLs) on a regular basis (Centers for Disease Control and Prevention, 2021). In a 2020 report by the American Association of Retired Persons, 1,392 caregivers were surveyed to determine characteristics and prevalence of caregivers in the United States. Researchers found individuals being cared for was driven by age; older caregivers (50-74 years old) were more likely to be caring for a spouse or sibling; and younger caregivers (18-49 years old) were more likely caring for a parent or grandparent. Caregiver gender was predominantly female (61%). Average duration of care was four and a half years, and the average number of hours spent providing care was 23 hours per week. Another significant finding of this report was 53% of the caregivers did not feel they had a choice when taking on the caregiving role and 63% reported caring for an individual with a long-term physical condition (American Association of Retired Persons & The National Alliance for Caregiving, 2020). This suggests the caregiving role is not only affecting older individuals, but that the length of time in the caregiving role can be consequential. According to a report by the U.S. Department of Commerce Economics and Statistics Administration, by 2050, the projected
population of citizens over the age of 65 years will be 83.7 million people (Ortman et al., 2014). With these projections, and the current state of healthcare pushing for home-based care, this could result in increasing demands placed on family caregivers (American Association of Retired Persons & The National Alliance for Caregiving, 2020).

Buhse (2008) defines caregiver burden as a “multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience” (p. 27). Kasuya and colleagues (2000) described caregiver burden as the stress placed on an individual who cares for a disabled, chronically ill or elderly family member or individual. Caregiver burnout was described as the progression of caregiver burden when the experience is no longer healthy for the person giving care or for the person receiving care (Kasuya et al, 2000). Caregiver burden has become more prevalent over the last two decades due to changes in healthcare with people spending less time in the hospital resulting in family members caring for individuals with more extensive disabilities in their home. (Cochrane et al., 2002; Pinquart & Sörensen, 2011). Caregivers are at risk of long-term effects of physical strain, emotional stress, social isolation, and financial strain, and frequently they take on the caregiving role out of obligation.

A prime example of conditions that necessitate extensive support are neurological in origin. Neurological conditions are disorders in which patients may experience impairments in physical, psychosocial, and cognitive function that require support from a caregiver. Parkinson’s disease (PD), cerebrovascular accident (CVA), spinal cord injury (SCI), traumatic brain injury (TBI), and dementia are common neurological disorders that result in long-term disability. Some
conditions are progressive in nature with varying symptoms and longer durations of care needs, which puts greater burden on family members as they coordinate care while maintaining other life roles (Sullivan & Miller, 2015). Disabilities from a neurological condition may last for years or the patient may never recover from the disabilities, which leads to a caregiver experiencing burden for a longer, unpredictable period of time. Although caregiver burden has been vastly studied and well documented (Adelman et al., 2014; Akila & Monica, 2016; Cochrane et al., 2002; Gordon et al., 2012), there is no clear consensus regarding when and who should be assessing the caregiver for signs of distress and burden. Equally as important, no treatment or intervention has been found to be beneficial in managing the long-term consequences of being a caregiver.

**Significance of the Problem**

As the number of older adults over 65 years of age continues to rise, the resultant increased demands on healthcare systems, caregivers, and families must be addressed. A major area of concern and an area requiring significant attention is the assessment of caregiver burden. The literature is rich in information on the impact of being a caregiver, including information regarding characteristics of caregivers and care recipients, impact of caregiving, and the recognition for effective treatment strategies (American Association of Retired Persons & The National Alliance for Caregiving, 2020). Caregivers often take on their role out of obligation, and are unprepared for all the tasks associated with caring for an individual with disabilities (Adelman et al., 2014). Caregivers often neglect their own needs by not attending regular
wellness visits, putting them at greater risk of developing an illness themselves (American Association of Retired Persons & The National Alliance for Caregiving, 2020).

Caregiver perceptions of burden must be understood within the context of their physical health, psychological health, financial resources, and social support in order to design interventions unique to their needs. Unfortunately, the demands of contemporary healthcare systems hamper the ability of healthcare providers to understand these complex needs as the number of tasks to be accomplished in each physician-patient visit remain high while time to complete those tasks continues to shrink. Tai-Seale and colleagues (2007) conducted a study examining how time was spent during visits with primary care physicians and their elderly patients. Results indicated the average length of time for primary care visits was 15.7 minutes with only five minutes being spent on the patient’s most demanding problem for which they were seeking care.

As physician demands increase while time dwindles, it is important to have an interdisciplinary team working together for best patient outcomes including those related to caregiver needs. Physical therapists spend a significant amount of time with patients and their caregivers, which puts them in a position to assess for burden. In a 2013 report by Centers for Medicare and Medicaid Services, physical therapists in one year treated 275,532 patients with neurological conditions. Physical therapists work with patients and their families to tailor interventions that are specific to the patient and caregivers’ needs. They are in a valuable position to assess the caregiver for burden and provide intervention.
While much is known of the problem of caregiver burden, studies focusing on resources to reduce caregiver perception of burden are limited. Furthermore, information gained from research has not necessarily translated to routine assessment of burden and effective strategies or treatments for the caregiver. The purpose of the current study was to examine the role of physical therapy as a potential mediator to help reduce burden experienced by the caregiver, specifically whether physical therapy assessment and interventions can reduce this burden. It is important for physical therapists working with clients with disabilities to take time to assess the caregiver for burden, plan interventions to ease strain on the caregiver, and refer to community resources. Additional research is needed to understand what medical providers caregivers feel should be assessing for burden and resources needed to improve quality of life for the caregiver.

The current study was a convergent mixed methods design and was proposed to assess the relation between physical therapy and burden experienced by the caregiver, caring for a loved one with a chronic neurological condition. This design was selected to support collection of quantitative data through a self-report survey entitled The Zarit Burden Interview and expand on the quantitative results with in-depth qualitative data collected through face-to-face interviews with caregivers. In this study, quantitative data was collected to determine care recipient functional status using a survey entitled the Barthel Index. Quantitative and qualitative data were collected concurrently while merging the data for interpretation of the overall results. Contrasting findings were further evaluated with follow up interviews with the caregivers. The specific aims of this study and research questions were as follows:

- To examine caregivers’ perceptions regarding who should be assessing for burden.
To examine caregivers’ perceptions of burden and utilization of physical therapy services to reduce burden.

To examine care recipient function and determine what activities lead to greater burden for the caregiver.

**Research Questions**

Research Question 1 (RQ1): Does caregiver burden as measured by the Zarit Burden Interview change over time when the care recipient receives physical therapy services?

Research Question 2 (RQ2): Does patient function improve over time in individuals receiving physical therapy services?

Sub questions:

- Does performance in activities of daily living (ADLs) as measured by the Barthel Index change over time in individuals receiving physical therapy services?
- Does balance as measured by the Berg Balance scale improve over time in individuals receiving physical therapy services?
- Does walking distance as measured by the 6 Minute Walk Test improve over time in individuals receiving physical therapy services?

Research Question 3 (RQ3): Is there a relationship between caregiver burden and care recipient function at baseline and discharge from physical therapy services?

**Theoretical Framework**

Theories have provided the foundation in which researchers try to understand the multidimensional aspects of caregiver burden. This research was guided by The Stress Process...
Model shown in Figure 1.1 (Pearlin et al., 1990). Pearlin and colleagues explored the relations between conditions related to personal stress, how those associations change over time, and if certain relations led to increased levels of stress. The Stress Process Model has four domains including background and context of stress, the stressors, the mediators of stress, and the outcomes or manifestations of stress. The background and context of stress domain addresses the characteristics of the caregiver, the history of the caregiving relationship, network of the caregiver, and program availability. Stressors are divided into primary and secondary stressors that rarely occur in isolation since caregivers typically take on multiple roles. Mediators are considered to combat the negative effects of stress and may include coping strategies and social support. Outcomes or manifestations of stress are related to the physical, psychological, and emotional conditions that result from prolonged exposure to stressors. In summary, The Stress Process Model is the theoretical framework that will guide this study to examine whether physical therapy is a potential mediator to combat the negative effects of stress. In Chapter Two, an in-depth review of literature for The Stress Process Model is provided.
Figure 1.1: The Stress Process Model

CHAPTER 2: REVIEW OF LITERATURE

This literature review will utilize Pearlin and colleagues’ (1990) Stress Process Model (refer to Figure 1.1) as a method of organization of literature related to the domains of caregiver burden. Pearlin and colleagues viewed caregiver burden or stress as a process in which multiple factors contribute to the shift in care from a positive experience to an unequal distribution of burden resulting in potential negative consequences. This literature review will use the four domains of The Stress Process Model to describe factors that contribute to overall burden: Background and Context, Stressors, Mediators of Stress, and Outcomes or Manifestations for Stress (Pearlin et al., 1990).

Background and Context

The background and context of stress domain addresses the characteristics of the caregiver, the history of the caregiving relationship, network of the caregiver, and program availability. Pearlin and colleagues (1990) found certain characteristics they thought played a role in caregivers’ level of stress. Those characteristics included age, gender, ethnicity, education level, occupation, and economic attainment. The latter three characteristics reflect socioeconomic status and the inequalities in regard to opportunities and responsibilities within certain statuses, which puts individuals at greater risk for burden. Pearlin and colleagues (1990) performed a multistep study of 555 primary caregivers of individuals with Alzheimer’s disease. Out of the 326 spousal caregivers, 58% were female, 87% were white, 29% had a high school education with 14% having a college education, 83% were not employed, 37% had been giving care for one to two years, and 30% for three to five years. Spousal and care recipient mean age
was 70 and 72 years old, respectively. Out of 229 children caregivers, 76% were daughters, 80% were white, 32% had some college education with 18% being college graduates, 57% were employed, 36% had been giving care for one to two years, and 33% for three to five years. The mean age of children caregivers was 51-years-old, and care recipient mean age was 80-years-old (Pearlin et al., 1990). These characteristics are similar to what other researchers found.

Adelman and colleagues (2014) conducted a review of a meta-analysis to delineate the epidemiology of caregiver burden and found similar caregiver characteristics to Pearlin and colleagues. The characteristics of caregivers that put them at risk for higher levels of burden included female gender, a low educational level, living with the care recipient, financial stress, and high number of hours giving care (Adelman et al., 2014). The Caregiving in the U.S. study (2020), reported similar characteristics with respect to gender, ethnicity, education level, and employment, and the mean age of the caregiver in this study was 49-years-old. There are differing opinions regarding the characteristics that may lead to increased caregiver burden. Mosley and colleagues (2017) performed a critical review of literature specifically for caregivers and individuals with Parkinson’s disease. They found age, gender, education level, and social class were not related to increased levels of burden. Characteristics of the caregiver and care recipient are important when studying the impact of burden, but there are other factors to consider.

Pearlin and colleagues (1990) mentioned the network of the caregiver as an important factor when trying to understand the stress process. They differentiated between the network of the caregiver and social support. The caregiver’s network included individuals with whom the
caregiver had a relationship and included the frequency and quality of the contacts with those individuals. Social support was seen as a mediator, because it is the support received from the network that may potentially reduce burden (Pearlin et al., 1990). Rodakowski and colleagues (2012) examined the role of social network among 173 caregivers who were the primary caregivers to individuals with spinal cord injuries. The researchers discovered not all social support was considered beneficial, especially when caregivers experienced criticism from individuals in their social network (Rodakowski et al., 2012). This could be an issue if a family member does not agree with how the care recipient is being cared for, which could lead to disputes with the caregiver. Program availability is another type of resource Pearlin and colleagues (1990) discussed. Community programs are beneficial for the patient and caregiver, but the availability of such programs can be an issue in terms of costs of the programs, transportation to the program, and availability of hours of operation. Community based programs could be considered a benefit to help reduce social isolation for the caregiver, but could end up being a bigger burden with the energy it might take to get the patient to the program. It is important for physical therapists working with patient-caregiver dyads to understand contextual characteristics and how they can be a source of stress or mediate the stress process.

**Stressors**

Stressors are at the center of The Stress Process Model and can be described as the conditions, experiences, and activities that are difficult for the caregiver to manage. Pearlin and colleagues (1990) described stressors by breaking them down into primary and secondary stressors. Primary stressors relate directly to the needs of the patient and the assistance required
by the caregiver. The greater the assistance required from the caregiver, the greater the perceived burden. Kim and colleagues (2011) performed a secondary data analysis from a nationwide telephone survey administered by the National Alliance for Caregiving using data from 307 caregivers across seven states. They wanted to gain a better understanding of what caregiving factors were related to caregiver burden. Participants were asked to complete a caregiver burden self-report questionnaire about physical strain, emotional stress, and financial hardship; this gave the researchers a composite score on the level of burden the caregivers perceived. Care-recipient functional status was measured using the Katz Index of Independence in Activities of Daily Living (Katz) to assess transferring, dressing, toileting, bathing, feeding, managing medications, shopping, and finances. Higher scores on this tool indicated greater dependence of the care-recipient for daily activities. Caregivers experienced higher levels of burden when the care recipient required assistance with both activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (Kim et al., 2012), which was also a common finding in other research studies (Park et al., 2015; Rigby et al., 2009; Sit et al., 2004). Rodakowski and colleagues (2012) found ADL status predicted higher levels of caregiver burden, but IADL status did not. Kim and colleagues (2012) also reported a linkage between the number of hours providing care and burden such that as hours giving care increased, burden also increased, which was similar to findings in other studies (Adelman et al., 2014; Akila & Monica, 2016; Zhong et al., 2016). Other primary stressors identified in The Stress Process model included cognitive status of the care recipient, the ability of the caregiver to manage the relationship with their loved one, and the ability to manage behavior of the care recipient.
Caregivers of individuals with Parkinson’s disease (PD) with mild cognitive impairment (PD-MCI) experience high levels of burden (Jones et al., 2017). Researchers assessed 96 patients with PD and classified them into one of the following categories: Parkinson’s disease with dementia (PDD), Parkinson’s disease with mild cognitive impairment (PD-MCI), or Parkinson’s disease with normal cognition (PD-N). Individuals with PD were assessed for behavioral disturbances such as delusions, hallucinations, irritability, dysphoria, anxiety, and disinhibition using the Neuropsychiatric Inventory (NPI). ADLs were assessed using the Activities of Daily Living-International Scale (ADL-IS) with higher scores indicating the individual required more assistance for activities. Both the caregiver and patient were given screening scales for depression and anxiety. Caregivers were evaluated for burden using the Zarit Burden Inventory (ZBI), which was a 22-item scale with scores ranging from 0 to 88 (0-indicated no burden to 88-indicated high levels of burden). Caregiver coping strategies were quantified using the Coping Orientations for Problems Experienced (COPE). Burden was significantly higher in carers of PD-MCI and PDD compared to carers of PD-N with the highest level of burden in carers of PDD. The effect of patient cognitive status on ZBI scores persisted even after controlling for assistance with ADLs, duration of the disease, patient neuropsychiatric symptoms, and motor difficulties (Jones et al., 2017). Thommessen and colleagues (2002) reported similar findings as Jones and colleagues with higher levels burden in carers when individuals with PD and stroke were found to have cognitive impairments. The authors differed in their findings with reporting a weak association between burden scores of caregivers of patients with dementia (Thommessen et al., 2002). Primary stressors are related to the care recipient’s symptoms and disease progression.
whereas, secondary stressors focus on role strains and intrapsychic strains, which involves dimensions of self-concept, that are the result of providing care (Pearlin et al., 1990).

Secondary stressors can be just as powerful in producing poor outcomes for the caregiver. Role strain can occur when caregivers have multiple overlapping roles and cannot meet the demands of each role. An area where conflict can arise is when caregivers are working and trying to care for a family member. According to the National Caregiving report, 61% of caregivers were employed in 2020, and of those employed 60% worked full time 40 hours or more a week, 15% worked between 30-39 hours, and 25% worked less than 30 hours while maintaining caregiver duties. It was also reported 58% of employers offered paid sick days, 56% of caregivers reported having flexible work hours, and 53% reported having unpaid family leave. The authors reported an association between caregivers reducing the number of hours they worked or stopping work and the care-recipient’s need for more care. Role conflict between employee and caregiver often results in reductions or changes to the employee role. About 53% of the respondents reported work was impacted by going in late, leaving early, or taking time off to provide care, and 15% of caregivers went from working full time to part time (American Association of Retired Persons & The National Alliance for Caregiving, 2020). Gordon and colleagues (2012) wanted to better understand the relationship between caregiving and work in regards to role conflict. They identified a national sample of 583 women between the ages of 50 and 64 years who agreed to participate in phone interviews that lasted about one hour. Instruments were used to assess caregiving demands, support, work demands, work support, role conflict and role strain. The authors reported work-related demands and caregiving-related
demands had more of an effect on older working caregivers and the demands created greater work-caregiving conflict. With increased conflict, caregivers showed higher levels of stress and the authors reported the need for social support. The authors reported that a reduction in overall stress inside and outside of the workplace could help improve overall quality of caregiving and work and reducing negative outcomes (Gordon et al., 2012). Kayaalp and colleagues (2020) looked at caregiver burden affecting mental health through work-family conflict. They surveyed 1,007 individuals in a three-wave process over two years assessing for burden, work-family conflict (WFC), depression, and anxiety. They also compared data of caregivers and noncaregivers. Work-family conflict was described as the work role interfering with the family role or vice versa. The conflict between the two roles was broken down into strain-based and time-based conflict. Strain-based conflict referred to the decreased energy and physical capacity from one role that lead to difficulty maintaining other roles. Time-based conflict referred to spending so much time in one role and not having enough time for other roles. The authors found mental health problems in caregivers was a consequence of strain-based conflict (Kayaalp et al., 2021).

Role strain can also occur between family members of the care recipient and caregiver. Conflicting ideas between family members regarding the nature, severity, and how to appropriately deal with the care recipient’s disabilities can lead to strain on family relationships (Pearlin et al., 1990). A caregiver that is still working may find it difficult to continue their duties at work as well as take care of their loved one. This can lead to financial strain on several levels; a loss of income if they are not able to continue with full time employment and increased
expenditures related to treatment for the care of the patient. Intrapsychic strains are also considered secondary stressors and they relate to the caregiver’s self-concept. Caregivers spend a significant amount of time managing the care recipient, and can lose their sense of identity, which may be exacerbated when they are unable to engage in activities they find enjoyable (Pearlin et al., 1990). Healthcare providers should be cognizant of the multiple roles that caregivers take on, the caregivers’ self-concept, and what ways they can intervene to reduce stress on the caregivers.

**Mediators of Stress**

Pearlin and colleagues (1990) looked at coping and social support as two principle mediators to determine if they could have an impact on the negative outcomes associated with long-term caregiving. Outcomes are variable, specific to individual caregivers, and are related to the caregiver’s physical health, mental health, and ability to maintain their current roles. Coping refers to behaviors and practices the caregiver uses to manage stressful situations. Caregivers with good coping skills may be positioned better to ward off the negative effects of caregiving. Mosley and colleagues (2017) discussed coping and adaptation for caregivers working with individuals with Parkinson’s disease. They proposed challenges experienced by caregivers could be influenced by the caregiver’s personality style. Personality is a set of traits which cause individuals to respond to situations or stressors in a certain way. Caregivers who were optimistic would have a more effective coping strategy to handle stressful situations and would report less burden (Mosley et al., 2017). Social support has been recognized as a potential mediator for burden in caregivers. Rodakowski and colleagues (2012) examined the role of social support in
173 caregivers who were the primary caregivers to individuals with spinal cord injuries. They used the Lubben Social Network Index and a modified version of the Social Support Scale to assess social support. When caregivers received social support in the form of physical assistance and emotional and informational support, caregivers experienced lower levels of burden.

McCabe and colleagues (2016) performed a systematic review of 12 qualitative studies and their aim was to determine perceived needs of the primary caregivers to combat the negative consequences of burden. They found themes and subthemes that were common throughout their review. The two major themes were “(a) caregiver needs related to the management of care recipients and (b) caregivers’ personal needs” (McCabe et al., 2016). Subthemes related to the major theme (a) related to the caregiver’s knowledge of the care recipient’s diagnosis, prognosis, progression of the disease, behavioral problems. Out of 12 studies, caregivers in nine of the studies wanted more education regarding strategies to manage the care recipients’ ADLs, IADLs, cognitive functioning, medications, and how to access care services. Subthemes related major theme (b) related to the caregivers’ physical and psychological health. In eight of the studies, caregivers reported a need to address their own physical health to prevent worsening of chronic conditions. They also reported the need to address psychological health by reporting emotional burden.

Rehabilitation programs designed specifically for the care recipient and caregiver can be a potential mediator for burden. Merali and colleagues (2020) performed a descriptive qualitative study to determine perceptions of individuals with neurological conditions and their caregivers who participated in a community exercise program. The participants were nine individuals post-
stroke, four individuals with multiple sclerosis, and their caregivers. The care recipients participated in a community-based group exercise program one to two times a week for 60 minutes. The exercise program was provided by licensed instructors that addressed strength deficits, balance deficits, and mobility issues. The caregivers had the choice to participate in the exercise routine or help the care recipient during exercise sessions. The authors reported care recipients and their caregivers perceived a benefit in strength, balance, and improved everyday functioning. As the care recipient’s function improved, less assistance was required by the caregiver (Merali et al., 2020), which, in theory, would help reduce overall perceived burden experienced by the caregiver.

**Outcomes or Manifestations of Stress**

Pearlin and colleagues (1990) describe the effects or outcomes of stress related to the well-being of caregivers, their physical and mental health, and their ability to maintain social roles. Cochrane and colleagues (2002) performed an epidemiological study to describe the physical and mental health of informal caregivers. Although this study is more than 20 years old, the results are valuable due to the comprehensive nature of the methodology. Approximately 32,000 people were interviewed in their own home by trained statistics Canada interviewers. The interviewers obtained information regarding physical health, health risk data, prevalence of psychiatric disorders and disability, and service utilization among residents of Ontario. A strength of the study was the comparison of caregivers and non-caregivers on occurrence of physical illness, utilization of mental health services and disability. The authors found informal caregivers had higher rates of psychiatric disorders, disability, physical illness, and it was
uncommon for caregivers to seek out assistance for these problems. Caregivers reported rates of anxiety and depression that led to greater utilization of mental health services. Caregivers had a greater occurrence of physical illness and disability. The authors conclude by discussing the importance of community-based service systems recognizing the burden on caregivers and being attentive to their physical and mental needs. If caregivers are healthy, patients may live longer in their own homes, which leads to lower healthcare costs.
CHAPTER 3: METHODOLOGY

Chapters one and two established that caregivers who provide prolonged care are at risk for a multitude of physical, emotional, financial and social difficulties. This study examined burden experienced by the primary caregiver along with assessing the needs of the care recipient through physical therapy.

Research Methodology

This study utilized a mixed methods design. Creswell and Creswell (2018) described quantitative research as using objective instruments with numbered data. The numerical data are analyzed through statistical procedures to determine relationships between variables. Qualitative includes exploring and understanding concepts or issues through the perspectives of individuals or groups. In this type of research, data are gathered through questions and interviews while interpreting data and synthesizing into themes to create meaning. Mixed-methods research includes collecting both quantitative and qualitative data, combining the data, and drawing interpretations based on the strengths of both sets of data to understand the research problem (Merriam & Tisdell, 2016). The mixed-methods study design was deemed appropriate for understanding the impact of physical therapy on the perceived burden experienced by the caregiver because it allowed for in-depth interviews with the caregiver to understand their lived experiences and perceptions while collecting numeric data through surveys.

A convergent mixed-methods design was used to assess the role of physical therapy on caregiver burden among people caring for a loved-one with a chronic neurological condition. This design involved collecting quantitative and qualitative data concurrently while merging the
data for interpretation of the overall results. Contrasting findings were evaluated in this design in follow up interviews with the caregivers.

**Sampling Population and Sample Selection**

Participants were recruited for the study from a *pro bono* clinic on the campus of a Midwestern university. Physicians and physical therapists refer individuals with chronic neurological conditions to the pro bono clinic through outside referrals after the patient has exhausted services through their insurance coverage. After recruitment to the clinic, an initial phone call by the primary investigator was placed to ask for participation in the study. The sample consisted of 11 care recipients and 12 caregivers, one caregiver-care-recipient dyad opted not to participate in the study due to personal reasons. Merriam and Tisdell (2016) proposed sample size was dependent on “informational considerations.” Researchers should continue to sample until no new information is gathered which is considered the point of saturation or redundancy. Merriam and Tisdell (2016) recommended giving an approximate number for the sample with the understanding it could change throughout the research process.

Merriam and Tisdell (2016) describe purposeful sampling as the investigator trying to “discover, understand, and gain insight” and should pick a sample where the most can be learned. This was a sample of convenience, a dyad was included in the study if their relationship had persisted for at least three months, the caregiver provided some form of support to the care recipient, and both individuals spoke fluent English. Dyads were excluded if the caregiver worked for an agency receiving payment for caregiving services, if they were not able to attend
the pro bono clinic for at least seven weeks, or if either the caregiver or the care recipient had a terminal illness.

Phenomenology is the study of lived experiences, everyday life, and interaction. A phenomenological approach is appropriate when studying feelings, emotions and strong human experiences. This approach allowed for the study of caregivers’ lived experiences, and emotions associated with the caregiving role. This approach revealed activities that were difficult for the caregiver, and what services caregivers perceived to be important for maintaining their caregiving role. Qualitative data were collected using a phenomenological study approach. An application was submitted to the IRB at Northern Illinois University prior to initiating the study. Approval from the IRB was attained prior to any type of consent process or data collection.

**Instrumentation and Data Collection**

This study addressed the perceived burden experienced by the primary caregiver while providing care for a family member with a chronic neurological condition alongside the delivery of physical therapy services.

The primary researcher gave a presentation to physical therapy students along with their faculty mentors to describe the process that should be followed and tests that should be performed on the care-recipient in the Clinic for Fitness and Function during physical therapy sessions. All physical therapy students had a module to complete prior to the start of the Clinic for Fitness and Function that included specific directions for the 6-Minute Walk Test, Berg Balance Scale, Barthel Index and the Function In Sitting Test and links to videos for each of the tests to review. Students filled out a Google document after watching the videos confirming this
process was followed. The primary investigator confirmed through the Google document all students had completed the training prior to the first day of the *pro bono* clinic.

Caregivers completed a demographic survey and the Zarit Burden Interview either on campus in a private room without the researchers being present or at home and brought back to the researcher (see Appendices A & B, respectively). Demographic information was important to consider because certain characteristics have been found to play a role in caregiver level of stress or burden (Adelman et al., 2014; Mosley et al., 2017). Caregivers were asked to fill out the Zarit Burden Interview (ZBI) at four time points, first day of the clinic (initial evaluation), mid-way which was five weeks after initial evaluation, at discharge ten weeks following initial evaluation, and one month following discharge. Originally, caregivers were also going to fill out the Zarit Burden Interview one month prior to starting the *pro bono* clinic, but due to COVID-19 the schedulers were unable to fill the clinic spots until one week prior to the start of the *pro bono clinic*. Figure 3.1 shows the timeline for caregiver data collection points.
The ZBI measured perceived burden of the caregiver and assessed different constructs of burden including physical, emotional, social and financial burden (Van Durme et al., 2012). The ZBI has been widely validated in multiple patient populations, is easy to administer, assesses different constructs of burden, and has been well-studied. The ZBI can be completed as a self-report questionnaire or can be administered in an interview with the caregiver. In the current study, caregivers completed the questionnaire as a self-report. Approximate time to complete the demographic survey and ZBI was 20 minutes. The ZBI consisted of 22 questions, in which the caregiver rated their perception of burden on a 5-point Likert scale of 0 (never) to 4 (nearly always) with higher scores indicating more perceived burden. An individual that scored in the range of 0-20 indicated very little or no burden, scores 21-40 mild to moderate burden, scores 41-60 moderate to severe burden, and scores 61-88 indicated severe burden. Having caregivers complete the Zarit Burden Interview on a regular basis at appointments with physical therapists
gave the provider a sense of how the caregiver was feeling and functioning in their daily activities. Physical therapists can look at the different constructs of the ZBI and direct care according to what domain the caregiver is feeling the most burden or make recommendations for appropriate care. Caregivers underwent an audio-recorded baseline interview in a private area that was completed by the primary investigator, which lasted on average 45-60 minutes. The interviews were semi-structured with questions being open-ended related to the caregiving experience, assessment of caregiver burden, and the interactions with physical therapists. Interview guides were completed with a list of questions that each participant was asked (Appendix C). Interviews were flexible in nature if a concept kept reemerging or was confusing the researcher asked follow up questions. The six types of interview questions included experience and behavior questions, opinion and values questions, feeling questions, knowledge questions, sensory questions, background and demographic questions (Merriam & Tisdell, 2016). Experience and behavior questions assessed responsibilities of the caregiver, their behaviors, and actions. Opinion and value questions allowed the researcher to learn about the caregiver’s beliefs and opinions about perceived burden. Feelings questions tapped into how the caregiver was experiencing perceived burden. Knowledge questions assessed caregiver understanding about the care recipient’s diagnosis, needs for the future and potential available resources. Sensory questions asked about more specific data of what the caregiver had seen, heard or touched. Background questions asked about demographic information. Each interview was transcribed verbatim within 48 hours and was reviewed by the primary investigator for potential follow up questions. Initial interview transcriptions were reviewed by the caregiver as member-checking; a
technique to determine accuracy and trustworthiness of the information. Follow up interviews were completed to ask questions to clarify any confusing statements, or until there was saturation of information. Participants were made aware of the time commitment with a baseline interview of 45-60 minutes and a follow up interview.

Care-recipient function was assessed using the Barthel Index (BI), Berg Balance Scale (BBS), and the six-minute walk test (6MWT). The BBS and 6MWT are common tests administered by physical therapists to gain a sense of walking and balance abilities. The Barthel Index (provided in Appendix D) is a measure used with individuals who have a neuromuscular or musculoskeletal disorder to assess their independence with activities of daily living. This was administered as a self-report by the patient and family. The BI assesses ten ADL and mobility activities with scores ranging from 0 (unable to do), 5 (requires some assistance), to 10 (independent). Individuals that score between 80-100 are considered independent, 60-79 minimally dependent, 40-59 partially dependent, 20-39 very dependent, and < 20 completely dependent. Lower scores represented the more likely the individual required assistance from their caregiver for activities of daily living. This gave an indication of how much assistance the caregiver was providing. Kim and colleagues (2012) found caregivers experienced higher levels of burden when they had to provide assistance with ADLs.

The BBS (provided in Appendix E) is an objective measure used to assess sitting and standing static and dynamic balance and fall risk in adults. This is a 14-item scale with varying difficulty, item-level scores range from 0-4 (0= indicates lowest level of function, 4= highest level of function). Scores were added up and ranged from 0-56, with lower scores representing
higher risk for falls. Shumway-Cook and colleagues (1997) developed a model for predicting falls in community dwelling adults and reported a score of 56 indicates functional balance, a history of falls and BBS score less than 51 or no history of falls and BBS score less than 42 was predictive of falls. A score of less than 40 on the BBS is associated with 100% fall risk. This test provided a comprehensive picture of the care recipient’s balance and mobility. The 6MWT (provided in Appendix F) assessed distance the care recipient was able to walk in six minutes as a sub-maximal test for walking endurance and aerobic capacity. The purpose of this test was to gage the care recipient’s functional ability, fitness level, and overall exercise tolerance. The BBS and 6MWT were administered by the primary physical therapist and physical therapy students, at the physical therapy initial evaluation, midpoint of treatment, and at discharge from physical therapy services. Figure 3.2 shows the care recipient data collection points.

![Figure 3.2: Care Recipient Data Collection Points](image)
Physical therapy intervention consisted of caregiver education regarding the care recipient’s neurological diagnosis, care recipient’s potential needs now and in the future. The caregiver was educated on how to manage their care recipient’s physical disabilities (transfers, ambulation, dressing, etc.) to reduce physical demands of the caregiver. The physical therapy plan of care was set by the primary physical therapist at the initial evaluation with a focus on the care recipient’s functional deficits. The primary physical therapist and physical therapy students carried out interventions with the care recipients. Figure 3.3 shows physical therapy interventions that care recipients received.

Figure 3.3: Physical Therapy Interventions

The pro-bono clinic was scheduled for two times a week for ten weeks for a total of 20 physical therapy sessions. Figure 3.4 shows the number of physical therapy visits the care
recipients attended. None of the care recipients attended all 20 of the physical therapy sessions, though the fewest sessions attended was 15. Three of the care recipients attended 19 physical therapy sessions.

Figure 3.4: Physical Therapy Visits

Data Analysis

Data were analyzed from 12 primary caregivers and 11 care recipients. Quantitative and qualitative data were analyzed separately. Quantitative survey data collected were separated in a Microsoft Excel file, coded, and evaluated. IBM SPSS Statistics, 25.0 was used to provide descriptive statistics including frequencies, one-way repeated measures ANOVA, and correlation analysis to determine the impact that providing care for an individual with a neurological condition has on the primary caregiver.
Prior to data analysis, the primary researcher went through an NVivo online certified course followed by a one-hour webinar with a certified NVivo trainer through QRS International to gain better insight on how to use the software. Qualitative data analysis began with listening to the audio recordings from the caregiver interviews during transcription. Interview transcripts were read multiple times to gain familiarization with the data. Notes were taken on the hard copy of the interviews to highlight aspects the primary researcher felt were significant. A reflective diary was used to monitor thoughts and feelings of the primary researcher during the interview process. The primary researcher imported the transcripts into the NVivo software to assist with organizing and analysis of the data. Gale and colleagues (2013) reported using a Framework Method to assist with the management and analysis of qualitative data was becoming more popular among health researchers. The Framework Method allowed the researcher to organize an extensive amount of qualitative data in a systematic and hierarchical fashion. Ritchie and Spencer’s framework was used as a systematic approach to analyzing the data (Ritchie & Spencer, 1994). Ritchie and Spencer’s framework has five stages of analysis which include 1) familiarization, 2) identifying a thematic framework, 3) indexing, 4) charting, and 5) mapping and interpretation (Bryman & Burgess, 1994).

During the familiarization stage, the primary researcher listened to the interview recordings, transcribed the recordings, read the interview transcripts and field notes multiple times to gain a better understanding of the data and contemplated possible themes of the data. The second stage, identifying a thematic framework, was achieved by performing open coding of the transcripts using NVivo to reduce the data into broad themes. A code is a unit of analysis that
represents themes in the data. In this stage, there were 62 parent codes with 446 references to the parent codes. The third stage, indexing, involved studying the parent codes from the previous stage and organizing them in a hierarchical fashion with parent codes at the top and child codes or sub codes underneath in a way that made sense of the data. This stage included reducing the 62 parent codes of data from the second stage of data analysis into 28 parent codes with 48 child codes or sub codes. The fourth stage, charting, involved going back through the transcripts and field notes and rearranging the codes into the main themes that made sense of the data. This stage included reducing the 28 parent codes and 45 sub codes to 19 parent codes and 53 sub child codes. The fifth, and last, stage mapping and interpretation was achieved by studying all of the codes and sub codes, revisiting the research questions, and identifying the final themes based on the data.

**Role of the Researcher**

A primary investigator and two graduate students worked on the research project. The primary investigator is a clinician with 20 years of experience in the field of physical therapy and a doctoral candidate who was responsible for ensuring all ethical requirements were met to conduct research. The researcher determined initial questions with follow up probing questions to ensure the questions were related directly to the research study. The researcher developed open-ended questions that allowed the participants to speak candidly yet on target for the purpose of the study. The researcher used a taped recording and computer audio recording of the interviews with participant authorization via consent form. The researcher took notes during the interview sessions; interviews were transcribed by the researcher and one graduate assistant
within 24-48 hours after the interview. Interview transcripts were uploaded to a Non-Numerical Unstructured Data Indexing Searching and Theorizing (NVivo) program to assist with organizing and analyzing qualitative data. Anonymity of each participant was preserved by assigning a pseudonym name to correspond with each participant.

**Validity, Reliability, and Ethics**

Merriam and Tisdell (2016) recommend using triangulation of the data sources (interviews, observations, documents) to address validity. Triangulation compares and cross-checks the data sources to help counter the assumption that a study’s findings is related to the biases of the researcher. Another way to address validity is by investigator triangulation, investigators reviewing the same data independently and comparing the results (Merriam & Tisdell, 2016). Member checks were performed to check the accuracy of the researcher’s notes by having the participant check the notes for accuracy and clear up any misconceptions. Merriam and Tisdell (2016) recommend interviewing participants until the information gained was saturated, which helps the researcher understand the phenomenon. This gives credibility to the researcher since this takes time requiring multiple interviews. Triangulation of data also ensures reliability of the data because the use of multiple data sources helps obtain dependable and consistent data (Merriam & Tisdell, 2016). Reliability was ensured by having an audit trail. This allows anyone assessing the study to see how data was collected, how codes/themes were derived and how decisions were made throughout the study (Merriam & Tisdell, 2016).

**Biases and Assumptions**
The researcher admitted potential personal biases or beliefs could sway how questions are asked or may influence the results of the interviews. The researcher kept a journal to evaluate feelings and details of how the researcher may have influenced the outcomes of the interviews. The researcher acknowledged a certain level of subjectivity remained and focused on the experiences of the caregiver. The researcher has been in the caregiving role for a loved one for a short period, but did not live with the care recipient. Family members took turns staying with their loved one in the care recipient’s house. There was no financial responsibility because the loved one had good financial stability to fully pay for her care (supplies, food, household bills). There are different aspects to caregiver burden including, physical, emotional, and financial burden. In the end, the care recipient did require assistance for transfers, which put strain on the family members’ bodies, and there was a lot of emotional grief. The researcher also acknowledged potential biases since she is a physical therapist and feels physical therapy can be beneficial to this population of individuals in many ways. Physical therapy could have benefited the patient to keep her body strong as long as possible and education to family members to understand the importance of transferring the patient correctly to reduce the physical strain on their bodies.
CHAPTER 4: RESEARCH FINDINGS

The purpose of the current study was to examine the role of physical therapy as a potential mediator to help reduce burden experienced by the caregiver. The following research questions guided the study: 1) Does caregiver burden as measured by the Zarit Burden Interview change over time when the care recipient receives physical therapy services? 2) Does patient function improve over time in individuals receiving PT services? and 3) Is there a relationship between caregiver burden and care recipient function at baseline and discharge from physical therapy services?

This convergent mixed-methods study recruited a sample of 11 care recipients and 12 caregivers. This research focused on the primary caregiver caring for an individual with a chronic neurologic condition. The site chosen was on the campus of Midwestern University where individuals that had a chronic neurologic condition were receiving physical therapy services and had a caregiver. It involved collecting quantitative data using the Zarit Burden Interview (ZBI) to understand areas of caregiver distress and expanding on that data during semi-structured face to face and virtual interviews. During the quantitative data collection, care recipient function was assessed using the Barthel Index (BI), 6 Minute Walk Test (6MWT), Berg Balance Scale (BBS), and Function In Sitting Test (FIST) to understand areas that would result in assistance from the caregiver and that was expanded on in caregiver semi-structured interviews. Information gained from both quantitative and qualitative data collection were used to test The Stress Process Theory to determine potential stressors and mediators and their relation to the caregiver’s perception of burden.
Demographics of Participants

Nine caregivers were female (75%) and three were male (25%). Ten of 12 caregivers reported being White (83%) and two reported being Asian (17%). Age of the caregiver ranged from 40 to 80 years old, with five caregivers falling in the age range of 61-70 years (42%), three caregivers in 40-50 years (25%), two caregivers in 51-60 years (17%), one caregiver in 71-75 range (8%), and one caregiver in 76-80 age range (8%). Forty-two percent of the caregivers were still working, and of those still working 25% worked greater than 40 hours per week. Income of the participants ranged from $20,000 to greater than $60,000, with three participants falling within $20,000 to $39,000 range (25%), and nine participants falling in range >$60,000 (75%; see Table 4.1).

Three care recipients were female (27%), and eight were male (73%). Eight of the care recipients reported being white (72%), two reported being Asian (18%), and one reported being African American (10%). Age of the care recipients ranged from 30-80 years old, with three falling in the range of 51-60 years (27%), two in range of 40-50 years (18%), two in range 61-70 years (18%), two in range 76-80 years (18%), one in range 30-39 years (10%), and one in range of 71-75 years (10%). Of the care recipients, five had a diagnosis of CVA (45%), two care recipients had MS (18%), two had TBI (18%), one had PD (10%), and one had CNS disorder (10%; see Table 4.2).
Table 4.1

**Demographics**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Caregivers</th>
<th>Care-Recipients</th>
</tr>
</thead>
<tbody>
<tr>
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<td></td>
</tr>
<tr>
<td>Female</td>
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<td>3</td>
</tr>
<tr>
<td>Male</td>
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<td>8</td>
</tr>
<tr>
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<td>11</td>
</tr>
<tr>
<td><strong>Age in years</strong></td>
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</tr>
<tr>
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</tr>
<tr>
<td>40-50</td>
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<tr>
<td>76-80</td>
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<td>11</td>
</tr>
<tr>
<td><strong>Race</strong></td>
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</tr>
<tr>
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<tr>
<td>Asian</td>
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<tr>
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</tr>
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<tr>
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</tr>
<tr>
<td><strong>Hours Worked/Week</strong></td>
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</tr>
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</tr>
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<tr>
<td><strong>Total</strong></td>
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<td></td>
</tr>
<tr>
<td><strong>Yearly Income</strong></td>
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</tr>
<tr>
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<td></td>
</tr>
<tr>
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<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>12</td>
<td></td>
</tr>
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*Note: Numbers are raw data*
Table 4. 2

*Diagnosis of Care Recipient*

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>CVA</td>
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</tr>
<tr>
<td>PD</td>
<td>1</td>
</tr>
<tr>
<td>MS</td>
<td>2</td>
</tr>
<tr>
<td>TBI</td>
<td>2</td>
</tr>
<tr>
<td>CNS disorder</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>11</strong></td>
</tr>
</tbody>
</table>

Note: CVA = Cerebrovascular Accident, PD = Parkinson’s Disease, MS = Multiple Sclerosis, CNS Disorder = Central Nervous System Disorder

Most caregivers were related to care recipients (Table 4.3). Seven caregivers were spouses to the care recipient (58%), three were parents (25%), one was an adult child (8%), and one was a significant other (8%). Caregivers had been providing care for their loved one anywhere from one to greater than 10 years. Six caregivers had been giving care for greater than 10 years (50%), three had been giving care 5-6 years (25%), two had been giving care 1-2 years (17%), and one had given care 3-4 years (8%). Caregiving hours ranged from 1-40+ hours per week. Seven caregivers reported caring for their loved one greater than 40 hours per week (58%), three reported caring between 10-19 hours per week (25%), one provided care between 20-29 hours (8%), and one provided care between 1-9 hours (8%). Half of the caregivers were caring for other family members including children (50%), grandchildren (17%), and parents (33%).

**Quantitative Analysis**

*Findings Related to Research Question One: Does caregiver burden as measured by the Zarit Burden Interview change over time when the care recipient receives physical therapy services?*
Table 4.3

*Caregiver Characteristics*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationship to care recipient</strong></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
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</tr>
<tr>
<td>Parent</td>
<td>3</td>
</tr>
<tr>
<td>Adult child</td>
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<tr>
<td>Significant other</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>12</strong></td>
</tr>
<tr>
<td><strong>Length of time as caregivers</strong></td>
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</tr>
<tr>
<td>1-2 years</td>
<td>2</td>
</tr>
<tr>
<td>3-4 years</td>
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<td>5-6 years</td>
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<td>&gt;10 years</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>12</strong></td>
</tr>
<tr>
<td><strong>Hours provided care per week</strong></td>
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<tr>
<td>1-9</td>
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</tr>
<tr>
<td>10-19</td>
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<td>20-29</td>
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<td>40+</td>
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<tr>
<td><strong>Total</strong></td>
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</tr>
<tr>
<td><strong>Care for others</strong></td>
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</tr>
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<td>No</td>
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</tr>
<tr>
<td><strong>Total</strong></td>
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</tr>
<tr>
<td><strong>Other family caring for</strong></td>
<td></td>
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<tr>
<td>Children</td>
<td>3</td>
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<tr>
<td>Grandchildren</td>
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</tr>
<tr>
<td>Parent</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>6</strong></td>
</tr>
</tbody>
</table>

*Note: Numbers are raw data*

A one-way repeated measures ANOVA was conducted to determine whether there was a statistically significant difference in Zarit Burden Interview scores over the course of a 10-week physical therapy intervention with care recipients. There were no outliers and the data were
normally distributed at each time point, as assessed by boxplot and Shapiro-Wilk test ($p > .05$), respectively. The assumption of sphericity was met, as assessed by Mauchly’s test of sphericity, $\chi^2(5) = 2.20, p = .821$. Physical therapy intervention did not lead to any statistically significant changes in Zarit Burden Interview scores over time, $F(3,33) = 1.94, p = .143, \omega^2 = .06$. There were no changes in mean ZBI scores from the initial evaluation to midpoint $31.75 \pm 12.20$ then decreased at discharge $29.08 \pm 11.90$, but then mean burden scores increased again at one-month post discharge to $32 \pm 14.14$.

**Findings Related to Research Question Two: Does patient function improve over time in individuals receiving PT services?**

**Sub Questions to Research Question Two.**

*Does performance in activities of daily living (ADLs) as measured by the Barthel Index change over time in individuals receiving physical therapy services?*

A one-way repeated measures ANOVA was conducted to determine whether there were statistically significant differences in Barthel Index scores over the course of a 10-week physical therapy intervention program. A boxplot revealed two outliers at the midpoint in cases 3 and 10. Scores were inspected and there was no indication of measurement error nor were the values considered extreme. The scores were kept in the analysis. The Shapiro-Wilk test was used to assess normality in the Barthel Index outcome variable. Of the three groups, two groups violated the assumption of normality. The Barthel Index midpoint and discharge significance level was $p = .030$ and $p = .019$, respectively. Since the one-way repeated measures ANOVA is considered robust to deviations from normality the test was still run. The assumption of sphericity was not
violated, as assessed by Mauchly’s test of sphericity, $\chi^2(2) = 2.75, p = .253$. Physical therapy intervention led to statistically significant changes in BI scores over time, $F(2, 18) = 5.656, p < .05$, partial $\omega^2 = .19$, with BI scores increasing from $71.50 \pm 18.42$ at initial evaluation to $78.50 \pm 20.28$ at midpoint (5 weeks) and $80.00 \pm 19.72$ at discharge. The tests of within-subjects effects did demonstrate significance in at least one of the pairwise comparisons, but post hoc analysis with a Bonferroni adjustment did not reveal significance in any of the pairs therefore, an additional test was run. The Least Significant Difference test revealed BI scores were statistically significantly increased from initial evaluation to midpoint (7.0 (95% CI, 2.14 to 13.79, $p = .045$), and from initial evaluation to discharge (8.5 (95% CI, 1.54 to 15.46, $p = .022$), but not from midpoint to discharge (1.5 (95% CI, -2.65 to 5.65, $p = .434$).

Does balance as measured by the Berg Balance scale improve over time in individuals receiving physical therapy services?

A one-way repeated measures ANOVA was conducted to determine whether there were statistically significant differences in Berg Balance scores over the course of a 10-week physical therapy intervention program with care recipients. There were no outliers and the data were normally distributed, as assessed by boxplot and Shapiro-Wilk test ($p > .05$), respectively. The assumption of sphericity was violated, as assessed by Mauchly’s test of sphericity, $\chi^2(2) = 10.01, p = .007$. Therefore, a Greenhouse-Geisser correction was applied ($\varepsilon = 0.568$). Physical therapy intervention led to statistically significant changes in BBS scores over time, $F(1.136, 9.087) = 9.802, p < .05$, partial $\omega^2 = .39$, with BBS scores increasing from $38.22 \pm 10.59$ at initial evaluation to $44.22 \pm 7.01$ at the midpoint and increased to $47.00 \pm 4.24$ at
discharge. Post hoc analysis with a Bonferroni adjustment revealed that BBS scores were statistically significantly increased from initial evaluation to midpoint (6.0 (95% CI, 1.48-10.52, \( p < .05 \)), and from initial evaluation to discharge (8.79 (95% CI, .42-17.14), \( p = .040 \)), but not from midpoint to discharge (2.78 (95% CI, -1.88 to 7.43), \( p = .329 \)).

**Does walking distance as measured by the 6 Minute Walk Test improve over time in individuals receiving physical therapy services?**

A one-way repeated measures ANOVA was conducted to determine whether there were statistically significant differences in 6MWT scores over the course of a 10-week physical therapy intervention with care recipients. There were no outliers in the data, as assessed by inspection of a boxplot. Six MWT scores were normally distributed at each time point, as assessed by Shapiro-Wilk’s test (\( p > .05 \)). Mauchly’s test of sphericity indicated that the assumption of sphericity had not been violated, \( \chi^2(2) = 5.98, p = .050 \). Physical therapy intervention did not lead to any statistically significant changes in 6MWT scores over time, \( F(2,16) = 1.33, p = .292 \), partial \( \omega^2 = .02 \), with 6MWT mean scores decreasing from initial evaluation 557.11 ± 396.12 feet to 540.77 ± 374.08 feet at the midpoint and increasing to 598.37 ± 390.64 feet at discharge.

**Findings Related to Research Question 3:**

**Is there a relationship between caregiver burden and care recipient function at baseline and discharge from physical therapy services?**

A Spearman’s rank order correlation was performed to see if there was an association between patient function and caregiver perceived burden. Prior to the running the Spearman’s
rank order correlation a new variable was created for a change score from initial evaluation to discharge in patient function scores (Barthel Index) and burden scores (Zarit Burden Interview). The Spearman’s rank order correlation analysis showed the relationship to be monotonic, as assessed by visual inspection of a scatterplot. There was not a statistically significant correlation between burden experienced by caregivers and care recipient function \( r_s(11) = .206, p = .543 \).

Table 4.4 shows descriptive statistics for the outcome variables at each collection time point.

**Table 4.4**

*Descriptive Statistics for Outcome Variables*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Day 1</th>
<th>5 Weeks</th>
<th>10 Weeks</th>
<th>14 Weeks</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>ZBI</td>
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<td>12.20</td>
<td>31.75</td>
<td>12.20</td>
</tr>
<tr>
<td>BI</td>
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<td>18.42</td>
<td>78.50</td>
<td>20.28</td>
</tr>
<tr>
<td>BBS</td>
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<td>10.59</td>
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<tr>
<td>6MWT</td>
<td>557.11</td>
<td>396.12</td>
<td>540.77</td>
<td>374.08</td>
</tr>
</tbody>
</table>

Note: SD = Standard Deviation, ZBI = Zarit Burden Interview, BI = Barthel Index, BBS = Berg Balance Scale, 6MWT = Six Minute Walk Test

**Qualitative Analysis**

Through semi-structured face to face and virtual interviews, which included a 20-question baseline interview guide and one follow up interview with an 8-question interview guide the primary researcher was able to gain a better understanding of the caregivers’ experiences. Four main themes emerged through the qualitative data analysis. Theme 1: caregivers not feeling prepared to take on their role as caregiver; Theme 2: available assistance needed to reduce burden; Theme 3: aspects of physical therapy caregivers found burdensome; Theme 4: benefits of physical therapy. Each theme, subthemes, and examples of quotations were
reviewed to give recognition and a voice to the caregivers in this study. Table 4.5 shows caregiver profiles to highlight each individual caregiver.

**Table 4.5**

*Caregiver Profiles*

<table>
<thead>
<tr>
<th>Caregiver Alias</th>
<th>Years Providing Care</th>
<th>Hours Per Week Providing Care</th>
<th>Sex</th>
<th>Age in Years</th>
<th>Race</th>
<th>Education</th>
<th>Caring for Others</th>
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</thead>
<tbody>
<tr>
<td>Mary</td>
<td>1-2</td>
<td>40+</td>
<td>F</td>
<td>51-60</td>
<td>Asian</td>
<td>Master’s</td>
<td>Children</td>
</tr>
<tr>
<td>Tyler</td>
<td>&gt;10</td>
<td>40+</td>
<td>M</td>
<td>40-50</td>
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<td>Master’s</td>
<td>Mother</td>
</tr>
<tr>
<td>Karen</td>
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<td>20-29</td>
<td>F</td>
<td>61-70</td>
<td>Caucasian</td>
<td>Some College, No Degree</td>
<td>Mother</td>
</tr>
<tr>
<td>Sheila</td>
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<td>Caucasian</td>
<td>Master’s</td>
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<tr>
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<td>Associate’s</td>
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</table>

**Theme 1: Caregivers Not Feeling Prepared for Caregiving Role**

Caregivers shared their experiences as they took on their new role as caregiver and challenges they faced. The first subtheme included transition to caregiver, the second subtheme included physical assistance provided by caregiver, and the third subtheme included caregiver perception of barriers to good health.
Transition to Caregiver.

Many of the caregivers were not expecting to become a caregiver and felt they were thrown into the role due to the acute onset of the neurological incident. Other caregivers had a brief time to prepare themselves because their care recipient may not have had a sudden onset of debilitating symptoms, but a new neurological diagnosis. Regardless of the acuteness of symptoms, caregivers faced many challenges of their new roles as caregiver. Several caregivers highlighted the lack of preparation and the emotional challenges for both themselves and their loved ones.

People don’t prepare you for the fact that you grieve. I mean I didn’t even realize that is what I was going through was grieving. I mean I wasn’t grieving just for myself I was grieving for him. You know for the loss of his function and his abilities. I mean before his stroke, there was nothing that man couldn’t do or wouldn’t try to do. Going from that, being super active and always doing something or helping people, to almost needing 100% assistance. (Linda)

As far as I’m concerned, it’s just like being a new parent. You don’t know until you are thrown into it. Everything is a first on that personal emotional level. (Mindy)

I was not prepared for anything. I was not prepared to start doing all the things I had to do. Not only taking care of him, but also the things he did now I had to take over and do. Even from the littlest things of changing the furnace filters, changing a lightbulb, getting someone to mow the grass, changing batteries, and going to the store. He used to be the one to go to the store all the time. So, all the bills, everything was left up to me. (Neena)

Physical Assistance Provided by Caregiver.

Caregivers described aspects that were difficult because of the physical assistance they needed to provide. Physical assistance ranged from meal preparation, bathing, dressing, brace management, and balance assistance. Caregivers highlighted physical challenges they faced:

In the beginning it was difficult because all the physical aspects. I had to help him get up and down, get his shoes on and off. He required the most physical help showering and dressing. I help him with his shower, pretty much anything that needs to be washed that he can’t wash in the shower himself which would be his armpits, and his back. You know he cannot wash his left side because his right arm would need to do it. He needs help washing his right foot and then drying off, and setting up his toothbrush, and putting his deodorant on. (Mary)

You can see how big he is, physically it is not easy. We do use the stand assist to get him out of bed, and out of his wheelchair. Getting him out of the car is something we have figured out how to do. He stands up, I get my arm under his arm to pull him up, he stands up, steadies himself, tries to turn as best he can and I try to hold him as he goes down. When he goes down, he doesn’t have a way of holding as he goes down so it is a plop kind of thing. Anytime he needs to get up out of the chair he cannot do that by himself. (Sheila)

He needs help to get ready. He has a brace and only one hand works so it is a struggle to get his shoes on with the brace so usually when he is ready to get up I help with the brace. (Tina)

Any time she stands up, she has balance issues. In any situation where she is not sitting down, we have to be there for transferring. If she's going to get up and walk with her cane we have to walk with her. Transferring isn't a matter of lifting; she can do all that, it's just balance. We have to make sure she doesn’t lose her balance in the process of going from a chair, walking and sitting down or walking to get into bed. (Lora)

**Barriers to Caregiver Exercise.**

The majority of caregivers felt they were in good health and were able to attend regular doctor visits and perform regular health and wellness visits. Caregivers faced challenges to exercise which included lack of motivation and needing to schedule exercise time for assistance with care recipient.

If we signed up to go to a gym, one of us could go. Someone has to be there at all times. So probably the exercise portion is the hardest. It's okay to say I got an appointment. A regular exercise routine, we have a couple things in the basement. It's like as soon as you go down there she’s going to need to go to the bathroom. (Lora)
I mean I totally could do it (exercise), I have things at home and stuff like that. I think it’s just part of the depression. Part of it is Chuck will literally be irritated by it. He will not want me to exercise. He just wants to be by me all the time. (Linda)

I have to work hard to find time to exercise. Everything has to be planned so I can have someone come over why I do things. (Tyler)

I do when I am in the bathtub. I do leg lifts, lift my hips up off ground, do my shoulders back and forth and I also clean houses so to me I get enough exercise. I am not out of shape. I keep busy, I am very active. I never sit around even if this was not wrong with Ryan. I have never been one to sit in front of the television. (Neena)

I don’t have much motivation to exercise. (Jack)

**Theme 2: Available Assistance Needed to Reduce Burden**

Caregivers discussed aspects of care that were burdensome and assistance that would help reduce burden. The first subtheme that emerged was respite care. Many caregivers felt some form of respite care would be beneficial whether that was having someone come into the home for assistance or just having someone spend time with the care recipient. The second subtheme was continuation of exercise. Caregivers mentioned the importance of keeping the care recipient physically active and the benefits of having an individual to help assist the care recipient with exercises. The third subtheme was care recipient independence. Care recipient independence was another factor that was mentioned to reduce overall caregiver burden.

**Respite Care.**

Respite care is considered short-term relief that is provided to the caregiver. This looked a little different to each of the caregivers. Some of the caregivers described respite care as personal assistants coming into the home to relieve the caregiver. Others described respite care as personal assistants coming to assist the care recipient with home exercises or getting them out...
in the community. Many of the caregivers discussed the need for respite care, but the reality of not receiving respite care on a regular basis for many reasons.

Derek describes an instance when his daughter was able to give him and his wife some respite care:

We would love to be able to relax and not have to worry about her. Our youngest daughter did give us a couple of days last June. We got a little Airbnb up in Galena. We spent the night both Saturday and Sunday and came home on Monday. That was the first time we've been out alone overnight in four or five years. That just doesn't happen very often. (Derek)

Linda also talked about not having enough personal time:

I mean I would love to have personal time to myself. He very much wants me there. Before his stroke we both ran and fitness was very important to us. I don't see my friends anymore. I don't workout at all. If I would leave to go do something whoever is with him would pay for it. (Linda)

Many of the caregivers talked about having a personal assistant come in to help, but they either did not know where to find one or mentioned a previous bad experience. Barriers included fear of having someone in the house, taking the time to train someone then they leave, or not finding dependable personal assistants.

Lora describes her experience with having a personal assistance:

Having someone there with her just to be able to give us a break. We have some help through DORS. It's hard to find a personal assistant who wants to come to the house. Finding reliable ones (personal assistants) has really been hard over the years. We have had quite a few. They seemed really nice and they did well, but it's really for a short time. If you have three years with a personal assistant you're doing pretty good. Something comes up in their lives. It seems like we haven't got to the place where most of them have good transportation. We are second on the list of course, if anything goes wrong in their life we're going to get the call we're not going to be there. Instead of them having to find someone to cover so they can get to work. Being at work is number two in their priorities. (Lora)
Jane described a few encounters she had with personal assistants and why she is leery of having someone in her house:

I found a personal assistant so I had her came over to the house and there were certain things, I always felt that I should lock in my bedroom. I kept anything personal in my bedroom. I had a pair of Maui Jim sunglasses the kids bought me for my birthday a couple years ago, they were really a nice pair of glasses and those came up missing. There was another instance I had a bracelet my grandma had given me it was a gold bracelet and it had like seven blue stones in it. While I was at work the lady picked the stones out and left the gold bracelet there. If she would have taken the bracelet I would have never noticed. I found one of the stones on the dining room floor. So now I’m very leery about letting anybody in my house. These people were supposed to be reputable and they stole from me. (Jane)

Probably a personal assistant for someone to come in and relieve her mom and I. Most of the time Cora is no problem until you get relaxed in the middle of a t.v. show and then she needs something. (Derek)

A few caregivers mentioned having someone come take the care recipient out into the community or do activities that the care recipient wanted to do. Jack mentioned he worked long hours and his wife doesn’t get out and do many things while he is at work. Jack described having someone take Ali places would be beneficial:

You know somebody to take her out places because she is a little shut in especially since COVID has made it worse by far. Just somebody that would be able to take her out and run errands. Just get her out of the house. I would feel less guilty knowing someone was getting her out of the house regularly. (Jack)

Mindy reported she would like for Don to have someone that was more like a friend:

Having somebody come in to do things with him that he wants to do. More like a friendship. It would be nice for someone to take him someplace even to a car wash or you know a restaurant. Getting him out of the house even to go for a drive. (Mindy)
Continuation of Exercise.

Many caregivers had a good understanding of the importance of the care recipient continuing with exercises following physical therapy, but felt this was burdensome at times. Despite knowing the importance of continuing with regular exercise, caregivers reported the dyad was not always able to keep up with the exercises. Many stated it would be beneficial to have someone work with the care recipient other than the caregiver.

Lora mentioned it would be beneficial to have someone work with Cora during Lora’s work out session:

It would be nice if I could find where she can go to some kind of a gym to workout. It would be great to find a place where someone could work with Cora at the same time I had a workout. I would be more apt to exercise regularly if I could find a place like this. (Lora)

Tyler reported spending a lot of his day trying to get his dad to exercise which was frustrating at times and felt if they had someone else to help with the exercises that would free up a lot of his time. Tyler described what it was like to get his dad to exercise:

If he could take ownership of his exercise that would help me out. He just doesn’t have the ability to do his exercises on his own. He needs someone to remind him hey you gotta do this, you gotta do that. If he could take ownership of his health a little bit more. He won’t get on the bike unless you tell him to. We put out an exercise routine, he won’t follow it. He will wait until someone tells him to do it then we spend all day nagging at him to do the exercises. (Tyler)

Tina reports how it would be beneficial to have someone help Phil with his exercises:

I think it would be beneficial to have someone come to our home to do exercises with Phil. I still work full time and by the time I get home after work I have other chores to do and make supper. There just isn’t enough time to do everything at night. I thought about paying the physical therapy students to come help with his exercises. (Tina)
Independence.

Caregivers reported the significance of the care recipient being more independent with activities and how that would change the level of assistance needed by the caregiver. Derek described a time when Cora was more independent prior to a fall:

Back before she fell and had the subdural hematoma she would get up in the morning and put her brace on and walk out and start the coffee pot, and drink coffee and play on the computer until we got up. We didn’t have to worry about her. That changed after her fall and now we have to be with her anytime she is standing. If she could get back to where she was able to move around on her own or with a walker or a cane that would free up some of our time. (Derek)

You know, she’s just, there’s things she just can’t do. So I’ve been trying to find someone who can move in and basically live there for free but that would get along with her and help take care of her. Like maybe, not do everything for her but like take her to appointments. (Jane)

Sheila reported she has to help Luke anytime he needs to go to the bathroom and how that is a challenge:

He does not let anyone in the bathroom with him. H is able to pee by himself but when he has to go number two I will have to drop what I am doing and go home. There are lots of times like on Tuesdays and Thursdays when he's with Ashley (caregiver) and he’ll call me and say you need to come home I need to go to the bathroom. My sisters tell me they will come sit with Luke, but I know I can’t get too far from the house. That is the main thing if he could get to the bathroom by himself I would be a lot less tied down than I am. (Sheila)

Tina stated she would like Phil to be more independent with his daily activities and not have to remind him all the time to do things. She details the reminders she has to give him to do things:

I think if he could just be a little more motivated to do things on his own like walking around. He needs reminders to get up and move around or he will just stay down in the basement and lay down there the whole day. I think he's not motivated enough to do
things. On one hand it's good, you know he's like okay I'm relaxed I just do whatever I can. On the other hand, I think he could do better. Some of the exercises he can do by himself and he should do, but I have to remind him sometimes. After four to five years of being rushed and getting angry I think that’s probably just the way he is. Sometimes I understand I cannot push more than that. (Tina)

**Theme 3: Aspects of Physical Therapy Caregivers Found Burdensome**

Caregivers found aspects of physical therapy to be burdensome when they were faced with so many other challenges of being a caregiver. Often, caregivers did not communicate challenges with the physical therapist. The first subtheme included the caregiver role in helping their care recipient perform a home exercise program prescribed by the physical therapist. A second subtheme included attending physical therapy sessions. Finally, the third subtheme included inadequate physical therapy intervention.

**Caregiver Role Helping with Home Exercise Program.**

Caregivers identified gaps in their knowledge, care recipient refusal, physical requirements, and time commitment as barriers for completion of the home exercise program. Jane described her experience and the lack of knowledge with assisting Alice with her home exercises:

Getting her to do them (exercises), I am very scared because when she loses her balance, she just goes flying and I can’t stop her. So maybe it is my fault because I am not equipped to handle her. I do not have any formal training like a physical therapist. I tried to help her a couple days, she was doing a sit to stand exercise, and on the second or third time, she fell back and hit her head on the wall so we have not been doing the exercises (Jane).
Caregivers appeared frustrated by lack of experience of what to do when the exercises did not go as planned and not having the knowledge to improvise. Care recipients refusing to do the exercises when asked was a challenge for many of the caregivers. Several caregivers discussed the frustration of arguing with their loved one to do the exercises. Tyler described his experience trying to get his dad to do the home exercises:

He would resist wanting to do exercises. I had to spend a lot of my day pushing him to do the exercises every day. When he did the exercise, he’d get a little tired, he would stop and I’d have to encourage him to continue and actually had therapists telling him Listen, you can’t just do one little exercise and then take a 15-minute break. You’re going to be doing exercises all day long. We had to push him a lot to get him to a certain point where he’d do one of the exercises after the next after the next. For example, we used to do a walk forwards and backwards. He would walk forwards and backwards once he was supposed to do 10 of them. We had to reduce it down to four because he’d do one forward and backward and then take a 15-minute break and then one forward and backward and then a 15-minute break. So, we had a lot of exercises to do and just to do the walk forwards and backwards would take an hour. I’m sitting there waiting for him to be ready to do the next exercise and that’s where the burden came in is getting him to do the exercise. It took a lot of convincing for him to realize, hey you know you’re not getting yourself anywhere by doing a little bit and then stopping, doing a little bit and then stopping. (Tyler)

Linda also had issues with trying to get Chuck to do his exercises as she explained:

Sometimes I have to fight with him to get up and do the exercises. If he’s not going to do it we just don’t do them. He is stubborn and I can’t make him do them. His stubbornness has gotten him this far, but it still can be quite frustrating. (Linda)

Jane described her tactics of getting Alice to complete her home exercise program:

She refused to do the exercises that were giver to her and I would say, Alice you need to do these. She would just be like I don’t feel like doing them. I’m tired. She just would refuse to do them. I was talking to my friend telling her I needed to make her do the exercises. I told my friend I am supposed to have her phone when she goes to bed at night, I’m not going to give her phone back to her until she does the exercises. Yesterday I didn’t give her phone back to her until she got the exercises done and she still didn’t do
them until 1:30. She asked for her phone back multiple times so I still had to argue with her about the phone and the exercises. (Jane)

Physical requirements of completing the exercises was reported as challenge. Caregivers had concerns of being able to complete the exercises in a safe manner to reduce risk of injury to themselves and the care recipient. Two caregivers described how they felt trying to complete home exercises:

I was helping Alice with some standing exercises I was standing directly behind Alice and I didn’t expect her to plop into the chair. She fell backwards and hit her head and it freaked me out. I screamed her name because I was so afraid. She wasn’t hurt, but I was afraid she could have been hurt. (Jane)

Well it gets harder because I’m going to be eighty this year. You can see how big he is, physically it is not easy. My concern is always what if I pull a muscle, thankfully I haven’t ever pulled a muscle. (Sheila)

Time commitment of performing the home exercise program after many other challenges the caregivers faced was an area that was acknowledged by the caregiver. Time to complete the exercises often interfered with other activities that caregiver needed to complete. A few caregivers explained their challenges.

You’re going to end up doing exercises all day long and everyone that’s helping you do exercises; their day is done. They can’t do anything that day. It’s like my day is kidnapped by my father. (Tyler)

Making the time to do it when you have other things in your life and you're tired and getting older. (Lora)

It seems the most difficult part is finding the time to do them. Working exercises into our routine. She is always willing to do the exercises and we are willing to do them. Sometimes the day just gets away from us. (Derek)
In summary, caregivers described aspects they felt were problematic when completing the prescribed home exercise program. When the caregiver lacked knowledge how to alter home exercises it led to greater strain on the caregiver. The care recipient refusing to complete the home exercise program resulted in arguments between the caregiver and care recipient dyad leading to greater burden for the caregiver. The physical requirements and time commitment were also problematic for the caregivers.

**Attending Physical Therapy Sessions.**

Caregivers found it was difficult to get their loved one to physical therapy sessions having to assist the care recipient to get ready for the appointment, transport the care recipient, or spending time at the clinic during the session. Tina described her experiences with her husband following his stroke:

> I feel like after his stroke he is slower. Everything is slower. I rush and I’m worried because he has got to get ready. I remind and encourage him to get ready. Sometimes I get a little uncomfortable and get a little mad inside because the process is slower. You think we will be late for an appointment. The appointment part is no problem. Time management is a struggle. I have to make sure to set enough time to get ready and sometimes I struggle with the idea of being late. (Tina)

Linda acknowledged there were days when Chuck did not want to attend physical therapy sessions, and she would have to strongly encourage him to attend:

> It wasn’t a problem getting him to come to these physical therapy sessions, but when he went to another clinic he would groan, kick, and moan all the way out the door to the physical therapy clinic. (Linda)

Caregivers expressed their need for time to themselves, but felt guilty if they did not stay for the physical therapy session. One caregiver mentioned the hostility she felt from the physical
therapist when she did not stay for the session. Neena described her negative experience with a physical therapist:

When Ryan was attending an outpatient, physical therapy place they would get mad at me for not staying during the session. Some of them (physical therapists) were nice and some were not so nice. Some of them would want to yell at me for not staying. I looked at it this way, when I didn’t stay it gave me time to be by myself. There were so many things I needed to do when I got home it just gave me a break. Sometimes they would say, “you are not here to see what is going on and what you need to do for him.” Sometimes they would get on my nerves. (Neena)

Lora gave two examples why she felt compelled to stay during physical therapy sessions:

Cora has communication issues where she needs to be able to read lips to understand the therapists and with everyone wearing masks it makes it even more difficult for her to understand what she needs to do. I feel it is necessary for us to be there so she is understood and they understand her too. There are times it would be nice if she would have her own time without us present. (Lora)

The type of therapy session played a role in when we could escape for a few minutes to take a breather. We had an experience with having physical therapy over zoom last year. Not that we would not do it again, but it was more of an effort. It took two of us, one would be helping her and the other person would be holding the device for the physical therapist to be able to Cora on the screen. There was no way she could have completed the physical therapy session without us. (Lora)

Tyler communicated why he thought it was important to attend physical therapy sessions with his dad:

The physical therapists would give suggestions on things to try with my dad. I was getting information from them just by watching them interact with my dad and not necessarily teaching me personally something but watching their interaction and what they’re saying and I could repeat those same things at home. (Tyler)

**Inadequate Physical Therapy Intervention.**

As noted by several caregivers, there were instances when the physical therapy intervention did not meet their expectations. Some caregivers felt their loved one needed to be
challenged more during physical therapy sessions to gain maximal benefit from services. Helping the caregiver navigate where to find equipment in the community was mentioned as a means to reduce frustrations of the caregiver searching on their own. Caregivers recognized the chronic nature of their loved one’s condition, but sometimes perceived that the physical therapist had a preconceived idea about the care recipient not being able to make progress, which was frustrating. A few caregivers described instances when they felt their loved one did not receive adequate physical therapy services:

At one of the major outpatient physical therapy clinics in town, the services were not all that. Alice only got physical therapy, speech therapy, and occupational therapy one time of each one time a week, if that. So one time a week for an hour and it was very basic. (Jane)

I just do not feel he had enough physical therapy services when it (stroke) first happened. I am not even a therapist, but to me they did not spend enough time with him. I know there were other patients. I really believe if they would have worked more with him while he was in the hospital even before he came home from the hospital he would have improve at much faster rate and would have been better then what he is now. (Neena)

Ali and I concluded after a week of physical therapy at another clinic they weren’t really doing her a lot of good. They were so timid with her and they weren’t pushing her. She is very competitive and we felt she needed to be pushed more so she stopped going. (Jack)

Mary explained how she felt when an experienced physical therapist was working with her husband:

When the therapist has so much experience they think they already know the limitations of the patient. They might think a certain treatment might not be possible so they don’t even try it which could be detrimental to the patient. (Mary)

Finding equipment in the community was frustrating at times when the caregiver didn’t know where to look. Mary described her experience:
The therapist was using an electrical stimulator unit during physical therapy sessions. I wanted to use this at home. We always had to do the research and look it up no one ever gave us the information. We had to figure it out by ourselves. They would mention something and we would go home and google it. In the beginning, they were using a mirror to do therapy. I went and bought him a makeup mirror to do the same exercises at home. Things like that would have been beneficial to know to be able to supplement things in therapy at home. Those types of resources would have been beneficial. (Mary)

**Theme 4: Benefits of Physical Therapy**

Caregivers discussed the benefits they saw in their care recipient after receiving physical therapy with improvements in function, strength and balance. The first subtheme that emerged was care recipient function. The second subtheme was gait and balance. The third subtheme was strength.

**Care Recipient Function.**

Caregivers reported positive changes in their care recipient’s function. Caregivers reported seeing their loved ones become more confident, being able to perform more activities at home, and requiring less assistance. Mary describes how Marc has been performing more things independently:

He is doing more things at home independently. He is able to make his own coffee and has even been able to carry hot coffee into his office by himself. I was worried that he was going to spill it on himself and burn him, but that did not happen. he has been starting to do things by himself. He was before too, but now he is doing much more. He kind of takes more charge of things. He will wash his own dish sometimes and his coffee cup. He gets his own snacks, he doesn’t wait for me to get food or anything. (Mary)

Derek described an incident when Cora surprised him when getting ready to leave the house:
Just yesterday when we were getting ready to go somewhere, it was when she was getting her shoes and socks on, she usually hands this off to me, but when I was out of the room she was able to do it herself. I thought I don’t have to do that anymore. (Derek)

Jane describes Alice’s progress over the course of physical therapy:

Alice is more willing I guess you could say to get up and do things herself. Prior to PT she would just sit in her chair and watch t.v. or play on her phone. Well definitely since prior to coming the first time, she wasn’t able to do hardly anything for herself. When we go to Costco she doesn’t use a scooter anymore she is able to get around the store. (Jane)

Linda shows excitement when discussing Chuck’s recent activities when they were on vacation:

I mean did you see the videos of him pushing the cart? He pushed the cart in the grocery store and he carried the bag up the stairs at the beach house and obviously I wasn’t planning on it or I would have had the right bag but it was what we had and he was carrying it and that was shocking. (Linda)

Linda also described an incident at home when she was trying to cook dinner and how she had to chase Chuck down:

I’ve seen some more independence with him. He definitely has, like that day after therapy he snuck out and was trying to get down in the crick and you know things like that. He had a great day of walking around outside and I thought this is awesome, he’s gonna be worn out. So while I was making dinner he wanted to be outside so that was fine you know, I can watch him out the window while I’m making dinner. And he starts off towards the back crick and was getting down into the crick before I could get there. I mean he was so fast like a little kid. Yeah, he was like I did so great in therapy today I can down here and you know, play around in this crick. He was almost down in it by the time I got to him. We live on a huge lot it’s like three quarters of an acre and the house sits all the way on the front of the lot so he was all the way at the back, he even had to go through fences. He got through two fences. I mean, he was fast. (Linda)

Mindy explains a time when she felt comfortable enough to leave Don for the weekend so, she could go on a trip with friends.
I had a weekend plan to go to Florida and I was able to go, I left on a Friday morning and didn’t get home until Monday afternoon. He was by himself and he did great. That was a big difference him staying by himself while I went to Florida. He took his pills, and he only missed one night. He went out to dinner with some friends. The next day he and one of his friends went into Peoria shopping for the dog. He was bathing and fixing food. I came home and the laundry was done, the dishes were done, he had the house cleaned. He was so proud of himself. (Mindy)

Mindy also explains how helpful Don has been around the kitchen:

We will be getting ready for lunch, and I’ll ask what are we gonna have, we’re gonna have a sandwich, okay. I’ll ask him do you want me to fix yours. And he says no, I can do it. I can fix my own sandwich. He will also say what can I do to help you. I may say will you fix the bacon. He offers to clean up quite a bit which is nice. If I give him something to do and I am not in the kitchen he’s more apt to do it. He’s gotta have his own space. You know I can tell him to peel the potatoes or you know when I was gone he boiled eggs and ate them. (Mindy)

Neena talks about Ryan completing more tasks at home now:

Another good thing that he does that I told him and he has been doing it, he goes to the kitchen and I told him to close the blind. It is one of those bamboo blinds, I tell him to pull the string that comes down. He does that and he’ll turn the t.v. on because I never have the t.v. on in the living room when I’m not home. So, he does that. Now yesterday since they had him doing it up here, folding towels, I thought hey you know what, you can start folding these towels that go in your room and they’re only the small kitchen ones that you dry up dishes with. I think there were five of them. They weren’t perfect but they were good, that was good. I was proud of him because he done it. I even had him sweep his room. I got out the small vacuum because I got a smaller one and I said here I’m going to get this vacuum. See if you can vacuum your area right here. He did. Very good, that’s what I told him. (Neena)

**Gait and Balance.**

Caregivers described improvements in the care recipient’s gait and balance. Some of the caregivers discussed the improvement in confidence with walking while others reported improvement in gait pattern. Some of the caregivers mentioned their care recipient being able to
walk further when going to stores requiring less assistance using a scooter. Mary reports Marc has much more confidence when he is walking:

He is walking about the house without his cane. His confidence has gotten much better since starting physical therapy. As his confidence has gotten better he will try new things like walking without the cane. (Mary)

Jane talks about going to Costco and how Alice is able to make it around the store:

She can walk further distances. She probably doesn't get as tired or exhausted as she would have had she not been doing the therapy. The different activities that they do with her, making her do obstacle courses, and walking up and down the stairs. The other group made her walk stairs a couple times. She is proud of the fact that when we go to Costco she doesn't use a scooter. I told her she has to walk now. She will sit down a couple times while we're in the store so we usually park close to the door, walk in, and she will sit down at the either the outdoor furniture or a couch. She'll sit there for a little while then she'll get up and walk some more. She'll stop once more on the way out and have a seat and then make it out to the car. At least she’s not riding and driving one of those scooters. She did have someone with her last week and they walked about seven or eight houses down the road which is about how far she was able to go the first time she did that, which was last semester. (Jane)

Linda reports how she was able to get Chuck out and walk:

While we were on vacation he did go with me to take the dogs for walks and stuff because it's on like kind of little dead-end street. I would say it's probably about 600 ft to the stop sign and another 600 ft back and he did that most nights with me which was an improvement. (Linda)

Mary expresses how confident Marc has become with walking:

He is more confident walking outside on the sidewalk and getting from the house to the car. The first time I had to bring him inside to the PT clinic. He now has been walking in by himself from downstairs. He is doing the stairs better. Even the stairs going outside he is able to do by himself. I think one big difference is his overall confidence has increased a lot. That means he is comfortable climbing the stairs and getting down by himself. (Mary)

Mary described a test Marc did the first day of the physical therapy clinic and compared
it to the last day and talked about how much better Marc was walking:

They did the exercise of him walking on the plank or the little strip. They had a video of him doing it on the first day. Yesterday, it was so much better. He had better balance. He is walking without the brace much better. His foot touches the floor now. Overall, he is much stronger in everything. Especially walking, he is walking better. His gait pattern is better. Especially with the trolley thing at the store. There are a lot of ideas we got with walking with the trolley at the store. Since they were having him push things with the sit to stand. We thought he could push the trolley at the store so he has been doing it ever since he was pushing things during PT. That was a major improvement. That was something he has never done anywhere else was push the sit to stand and we immediately started doing that outside of the clinic. He used to sit in the cart and ride it around the store. Since they did the exercise here, I thought ok let’s try the grocery cart in the store because it is almost the same thing. The first time it was difficult, he was doing it very slowly. It was hard for him to coordinate the arms and legs in motion. By the 2nd or 3rd time he was more comfortable. He will stand, look around, go get something with the cart and come back. I will say that is a big plus with him pushing the grocery cart. We didn’t think he could do it. We tried it a long time ago and his hand was not that strong to hold the cart. His walking is much better with the grocery cart. (Mary)

Mindy describes a time when she would have to steady Don with walking and how much better he has gotten:

You know it’s kind of funny because a lot of times I’m in the habit now of kind of grabbing him or guiding him and he’ll say, “You can’t help me, I can do this.” You know, I can’t even think of when I’ve had to help him physically. I think he is more confident and I think that’s why he’s like “Don’t help me. Don’t touch me.” I’m hoping we don’t have a setback. He’s doing really good. It’s been very good for helping him to swing his arms. And when he swings his arms, then his legs are coordinated and he seems to be taking bigger steps. Before you know I was kind of holding his hand, guiding him a little bit. But he's very, he doesn't want anybody seeing me helping him you know. So, he's doing it on his own and a couple times I just dropped him off and said you know I'll find a parking place or and I'll do this or that he just jumps right out and comes in. (Mindy)

Strength.

Caregivers talked about strength changes they saw in the care recipients from being able to do more functional activities like ascending and descending stairs, to being able to get up and
down out of a chair. Linda talks about how Chuck has gotten stronger and how much he enjoyed strength exercises:

He is stronger. This year he’s been really enjoying therapy. I use to have a day or two where I can hardly get him out of bed to go to therapy. This year he has not been like that at all. The day we were in the ER until 3:00 o’clock in the morning he wanted to come to therapy the next day. I was like um I don’t think if we were in the ER until three in the morning for abdominal pain that you should probably go to therapy. So that’s been good. He’s been very motivated this semester. He likes more functional strength things like going up and down the stairs. You know he likes doing things that he can see more of an improvement in. But he likes anything that focuses on his brute strength. Like I am man, hear me roar. (Linda)

Mary reports how much better Marc is doing since going to physical therapy:

Overall, he is doing like four times better now. The activities he was doing prior to coming to the clinic are much better now, like walking. He is able to lift his leg up on a step. He is able to get up and down stairs better and he doesn’t require assistance. His hamstrings are better. (Mary)

Sheila mentions how much Luke is able to help with dressing now:

They've been working with his right arm and I see an improvement. When I'm trying to get his shirt on he is able to lift his arm up higher. I have also noticed when he sits down in his chair he is more controlled and doesn’t just flop down in the chair. (Sheila)

Tyler describes how his father was getting stronger prior contracting Covid-19

Well we have to walk with him now when he walks. We have to help him up and down the stairs. Before he got Covid-19 he was able to do that on his own. We would be there no matter what to go up and down the stairs. We’d be there if he needed help but he would do all of that by himself. Now we have to help them up and down each step. For walking we have to help him do the walking. Anywhere he goes he needs someone to be next to him and his walking is very slow, one step at a time.
Summary

The quantitative analysis although not statistically significant showed changes in perceived burden experienced by the caregiver from initial evaluation to discharge. Zarit Burden Interview scores were trending downward from the initial evaluation to discharge, then mean scores increased from discharge to one-month post discharge. It is unclear why ZBI scores worsened after physical therapy services were over. Possible explanations of why scores were trending upward after physical therapy services could be the caregiver having a perception of less support or care recipient function could have declined.

The quantitative analysis demonstrated changes in patient function scores on all outcomes except for the six-minute walk test. Independence with activities of daily living mean scores improved from initial evaluation to discharge. Balance and fall risk mean scores improved from initial evaluation to discharge indicating balance had improved. The 6MWT was the only care recipient outcome that did not reach statistical significance from initial evaluation to discharge. One reason that could have led to this finding was due to one of the participants contracting COVID-19 and regressed in function. At discharge, this patient was not able to walk as far as when she started the pro bono clinic which could have skewed the results. A statistically significant correlation was not detected between caregiver burden and care recipient function. This was not an unexpected finding. Of the 11 care recipients, six were considered completely independent with activities of daily living at the initial evaluation.

Caregiver interviews provided examples of the individual transitioning to their
role as caregiver and areas where they did not feel prepared. There was a recognition of even when there is available assistance for the caregiver-care recipient dyad it is difficult knowing who they can trust. Caregivers were able to shed light on what they found burdensome when their care recipient received physical therapy services. This study also provided examples of how care recipients benefited from physical therapy services.
CHAPTER 5: DISCUSSION

The purpose of the current study was to examine the role of physical therapy as a potential mediator to help reduce burden experienced by the caregiver. This chapter includes a discussion of both the quantitative and qualitative findings and connection of those results to the literature. This chapter highlights the implications for physical therapy, considers the limitations of the study, and provides recommendations for future research. The discussion is based on the following research questions that guided this study:

1. Does caregiver burden as measured by the Zarit Burden Interview change over time when the care recipient receives physical therapy services?
2. Does patient function improve over time in individuals receiving physical therapy services?
   Sub questions:
   - Does performance in activities of daily living (ADLs) as measured by the Barthel Index change over time in individuals receiving physical therapy services?
   - Does balance as measured by the Berg Balance scale improve over time in individuals receiving physical therapy services?
   - Does walking distance as measured by the 6 Minute Walk Test improve over time in individuals receiving physical therapy services?
3. Is there a relationship between caregiver burden and care recipient function at baseline and discharge from physical therapy services?
A sample of convenience of 12 caregivers and 11 care recipients participated in this study. A convergent mixed-methods design was used to gather quantitative and qualitative data concurrently. The quantitative analysis examined caregiver burden scores, care recipient function over time, and whether there was a connection between caregiver burden scores and patient function scores. The qualitative analysis gained insight into individual caregiver lived experiences, available assistance to reduce burden, and aspects of physical therapy that were either burdensome or beneficial. The study methods were implemented as planned. A strength of the study was to have the caregivers fill out the Zarit Burden Interview prior to interviews which allowed the primary researcher to gain better insight in their current struggles.

Semi-structured face-to-face and virtual interviews were conducted over three months. Interview data were organized into NVivo software platform. Ritchie and Spencer’s (1994) framework was used as a way to systematically organize the data and to analyze into themes. Four main themes emerged from qualitative data analysis and they include Theme 1: caregivers not feeling prepared to take on their role as caregiver; Theme 2: available assistance needed to reduce burden; Theme 3: aspects of physical therapy caregivers found burdensome; Theme 4: benefits of physical therapy. The discussion of the results will be discussed by relating the quantitative analysis to phase one and qualitative analysis to phase two understanding that the two phases were running concurrently.
Interpretation of Results

Burden and Caregiver Characteristics

This study was guided by Pearlin and colleagues (1990) Stress Process Model and results of the current study will be discussed on how they compared to the theoretical framework. Background and context related to characteristics of the caregiver. In the current study, caregivers were not from diverse backgrounds, the majority of caregivers were white females who were highly educated, and had the financial means to take care of their loved ones now and in the future. Primary stressors related directly to the needs of the patient and the assistance required by the caregiver. In the current study, caregivers provided 40+ hours of care per week assisting with dressing, bathing, brace management, and meal preparation. Caregivers were also managing care recipient cognitive and behavioral issues which created increased stress. Secondary stressors related to intrapsychic and role strains. Many of the caregivers were not only providing care for the care recipient, but they were caring for children and parents, as well as working full time. Mediators were thought to lessen the intensity of primary and secondary stressors. The purpose of the current study was to determine if physical therapy could be a mediator to help reduce burden. Caregivers reported less burden, but scores on the Zarit Burden Interview did not reflect less perceived burden.

Caregivers who scored the highest in the moderate to severe category on the ZBI will be discussed below in relation to characteristics that were found in the literature to put them at higher risk of burden. In the current study, three caregivers scored in the moderate to severe category on the ZBI at all four data collection points, and one caregiver scored in the severe category at one collection point. All caregivers scoring in the moderate to severe category were female, two of the caregivers had some college education, and two had Master’s level of
education. Three caregivers were in the 61-70 age range, while one caregiver was in the 40-50 age range. Two of the caregivers were caring for a spouse and the other two were caring for adult children. Two of the four caregivers in this range were caring for their loved one for greater than 10 years, one caregiver had been providing care for three to four years, and one caregiver had provided care for one to two years.

The link between burden and caregiver characteristics has been consistently documented in the literature. Lower educational level, female gender, number of years providing care have been found to lead to higher levels of perceived burden (Adelman et al., 2014; Pearlin et al., 1990; American Association of Retired Persons & The National Alliance for Caregiving, 2020). Results from studies examining characteristics of caregivers and higher levels of burden, however, have been mixed. Mosley and colleagues (2017) found age, gender, education level and social class were not related to increased levels of burden. The sample in the current study was representative of what was found in the literature according to female gender, and number of years providing care, but not educational level and financial resources.

Pearlin and colleagues (1990) discussed the link between caregiver statuses such as lower educational level and income leading to less opportunity for utilization of resources that ultimately leads to higher stress levels. Brandt and colleagues (2022) looked at the socioeconomic inequalities in the wellbeing of informal caregivers and found caregivers in a lower wealth quintile experienced lower life satisfaction over time. Caregivers in the present study who had a higher perceived level of burden were educated and had a household income of greater than $60,000. During the caregiver interviews, all caregivers felt they had the resources
needed to take care of their loved one. Most caregivers mentioned having the resources to rent or buy equipment that was necessary to take care of the care recipient. One caregiver mentioned researching equipment that their physical therapist thought would be beneficial and by the next physical therapy session they had bought the equipment even before trialing in their physical therapy session. The sample in this study was not representative for what was found in the literature for educational and income level.

**Assessment of Caregiver Burden**

This study revealed caregivers were not being assessed for burden when they attended medical appointments with the care recipient. Across the spectrum of health care appointments, medical providers were not consistently asking caregivers about their health or perceived burden. One of the specific aims of this study was to examine caregivers’ perceptions regarding who should be assessing for burden. The findings from this study demonstrate that caregivers would like to be asked how they are doing and coping with being a caregiver. Sullivan and Miller (2015) reported the caregiver is often overlooked in neurology practices, but state how essential the caregiver is in the management of the patient’s neurological condition. Only two of the 12 caregivers felt it was not necessary for medical providers to ask about their health. These two caregivers felt there was not enough time to focus on the needs of the patient, and asking about the caregiver would take time away from the patient’s appointment. These two caregivers felt they were healthy and the focus should be on the patient. The remaining ten caregivers felt it was important for medical providers to ask about their health and well-being. The ten caregivers that felt someone should be asking about their health stated anyone working with the caregiver-care
recipient dyad could ask about the well-being of the caregiver. Some caregivers felt the optimal provider would be the caregiver’s primary care physician since they already understand their medical history. Other caregivers felt any health care provider could ask about the caregiver including doctors, nurses, physician’s assistants, physical therapists and occupational therapists. Two caregivers mentioned they would not want the doctor to ask about their health in front of the care recipient. They felt it would make the care recipient feel bad if anything negative was said. One caregiver gave an idea of the medical provider talking with the caregiver separately from the care recipient either before or after the care recipient’s appointment.

**Care Recipient Function**

In the current study, care recipient function was assessed at the initial evaluation, midpoint (5 weeks), and at discharge (10 weeks) to monitor for changes in function over time. Capturing care recipient function at four different time points was a strength of this study. The findings of this study revealed patient function did improve over time in all assessment outcomes except the 6MWT.

**Barthel Index.**

The BI was used to assess the care recipient’s ADLs and mobility activities. The care recipients showed improvement in BI scores from the initial evaluation to the midpoint and from the initial evaluation to discharge. These findings showed care recipients required less assistance with transfers, grooming, dressing, and mobility. Qualitative analysis revealed several positive improvements in care recipients’ activities of daily living. There were reports of the care recipient being able to do more independently from donning socks and shoes, to helping make
meals, physically being able to walk longer distances, and being more confident with activities. An area caregivers consistently mentioned that was still difficult was dressing and bathing. Care recipients who continued to have difficulty were the individuals with hemiparesis of the upper extremity. It was difficult for these individuals when trying to use their hemiparetic upper extremity for daily tasks like bathing and dressing or donning socks and shoes. Hemiparesis affecting the upper extremity post-stroke has been extensively researched along with the disabling consequences (Bindawas et al., 2017; Feys et al., 2004). The findings of the current study demonstrated similar findings of continuing to require assistance from the caregiver for ADLs due to not being able to use the hemiparetic arm. Allison and colleagues (2016) performed a systematic review with the aim of identifying predictors of difficulty caring for the hemiparetic arm specifically pain, contracture, and spasticity. The authors found there were no studies that examined the construct of caring for the severely affected arm following stroke and further research needed to be conducted. The authors noted clinical implications are twofold clinicians need to intervene early in post-stroke arm care, and be prepared to help manage disability until the stroke arm stabilizes which could be months following stroke (Allison et al., 2016). Care recipients in the current study that lacked control of their hemiparetic arm was a major limiting factor in being able to complete tasks independently which resulted in needing more assistance from the caregiver.

**Berg Balance Scale.**

The BBS was an outcome measure used to assess the care recipients’ balance over time. Quantitative analysis showed there was a significant improvement in balance at two time points
from initial evaluation to midpoint and from initial evaluation to discharge. These findings demonstrate care recipients had a positive improvement in balance over the course of physical therapy. Li and colleagues (2019) described the integrated process of multiple body systems that need to work properly to give accurate input from the visual, vestibular, and somatosensory systems into the central nervous system. Individuals with neurological deficits have dysfunction of these systems that lead to balance impairments and ultimately end up leading to falls. Li and colleagues (2019) performed a systematic review to identify what rehabilitation therapies have been used to treat individuals post stroke to improve balance impairment. They found many rehabilitation therapies have been successful in treating balance impairments including whole body vibration, virtual reality, mirror therapy, balance-specific exercises, strengthening, and gait, but they go on to say more research is needed to determine comparative efficacy of different treatments (Li et al., 2019). Davies and colleagues (2016) performed research that evaluated two different types of high-frequency physical therapy balance and mobility programs in individuals with multiple sclerosis (MS). There were 32 participants total with 14 individuals in the motor adaptation cohort and 13 individuals in the therapeutic exercise cohort. The motor adaptation cohort performed 20 minutes of balance training and 20 minutes of treadmill walking and over ground walking. The therapeutic exercise cohort received 15 minutes of strength and flexibility exercises, 15 minutes of postural balance exercises, and 15 minutes of treadmill walking. They concluded that both physical therapy treatment groups showed significant improvements in postural balance and mobility. They concluded that it was the high frequency activity that led to improvements in both groups and this should be considered when developing programs for
individuals that have MS (Davies et al., 2016). Similarly, in the current study, participants were asked to rate their level of perceived exertion with verbal cues from the physical therapists and students that the individual should be working a moderately hard level during sessions to promote improvements in strength, balance and gait activities. During the qualitative analysis, caregivers discussed the progress they saw with their care recipients’ balance. Caregivers mentioned seeing differences on balance tests the first day compared to the last day and how much of an improvement they saw. Another caregiver mentioned her husband gaining a restored confidence in his balance. She reported there were times she would try to grab his arm to help him balance and he reported he did not need her help. Another caregiver mentioned having to walk him up to the therapy area in the beginning and by the end she was able to drop him off and he was able to walk up himself.

**Six Minute Walk Test.**

The 6MWT assessed distance the care recipient was able to walk in six minutes as a sub-maximal test for walking endurance and aerobic capacity. The purpose of the test was to gauge the care recipient’s functional ability, fitness level, and overall exercise tolerance. In the quantitative analysis, physical therapy intervention did not lead to any statistically significant changes in 6MWT scores over time. In this study the 6MWT was the only test used to assess gait, no other parameters were formally assessed such as stride length, swing time, cadence or stability during stance which could be better indicators of quality of gait. Bishnoi and colleagues (2022) discussed how individuals that have had a stroke or that have Parkinson’s disease (PD) often have bouts of physical therapy to specifically improve function and gait. The authors go on
to discuss the difficulty physical therapists face in terms of providing specific evidenced-based treatments to individuals with neurologic diseases with gait impairments due to the lack of evidence supporting what interventions should be used in treating gait impairments. Bishnoi and colleagues performed a systematic review that included 30 randomized controlled trials with the aim of quantifying the effect of treadmill training on gait parameters of individuals that have had a stroke or who have PD. The authors found treadmill training interventions had the greatest effect on cadence, step length, and stride length in individuals with stroke and PD (Bishnoi et al., 2022). In the current study, treadmill training was used with verbal and auditory cueing to work on gait mechanics including gait speed, step and stride length, and stability during stance. There were no objective measures taken to quantify improvement in gait mechanics. There were individuals that did not show an improvement in the 6MWT, but did demonstrate improvements with step length and stride length and were able to ambulate with a lesser assistive device such as ambulating with a cane instead of a walker.

In the qualitative analysis, caregivers mentioned several positive improvements in their care recipient’s gait mechanics and activities. Several caregivers mentioned improvement in the care recipient’s confidence with ambulation, and having to provide less support for their care recipient. Abou and colleagues (2021) performed a meta-analysis which included 53 articles looking at the effectiveness of physical therapy interventions in reducing fear of falling (FOF) in individuals with neurological conditions including MS, PD, and stroke. They reported on the economic burden that falls can have on society, and the impact it can have for individuals who have a neurologic condition. The authors linked confidence with FOF and included scales that
measured both confidence and FOF in their study. The researchers found evidence that supported physical therapy interventions when working with individuals with neurologic diseases, but those interventions looked different for individuals that had PD, MS, and stroke. The authors suggested it would be the most beneficial to decrease falls and fear of falling by designing a program that incorporates fall prevention education, and a combination of physical therapy treatments (Abou et al., 2021). In the current study, physical therapy programs were tailored to each individual care recipient and a combination of interventions were incorporated into treatment sessions such as specific balance training, body support balance training, reaching, perturbations, and dynamic balance activities. Caregivers also mentioned the improved confidence allowed care recipients to ambulate without braces and to ambulate short distances without any type of assistive device. Another caregiver mentioned the improvement they saw in gait from watching a video of gait at the initial evaluation to the end of treatment. Other caregivers gave specific examples of improvements with being able to ascend and descend stairs without assistance, being able to walk in a grocery store without the use of a motorized cart, and being able to walk outside on uneven ground.

**Caregiver Burden and Care Recipient Function**

*Zarit Burden Interview Scores.*

The Zarit Burden Interview (ZBI) was a self-report questionnaire used to measured perceived burden of the caregiver. One of the research questions of this study, asked if caregiver burden as measured by the Zarit Burden Interview changed over time when the care recipient received physical therapy services? In the quantitative analysis, this study revealed there was not
a significant change in perceived burden over the course of 10 weeks of physical therapy. Although not statistically significant, ZBI scores did decrease from the initial evaluation to discharge. There was also an increase in burden scores one month following the care recipient being discharged from physical therapy services. One explanation why ZBI scores did not remain low could be due to the length of time the caregiver had been providing care, and the number of hours a day they provide care. Most caregivers in the current study had been providing care for greater than 10 years, and reported providing care for greater than 40 hours per week. The current study only lasted 10 weeks which may not be enough time for the caregivers to feel a significant change in responsibilities that would lead to lower perceived burden. Adelman et al. (2014) performed a clinical review and found similar results with the duration in the caregiving role and hours spent caregiving and the association with higher levels of burden.

Another plausible explanation for the lack of change in ZBI scores could be due to cognition of the care recipient. Rigby and colleagues (2009) recognized the concern for the health of the caregiver following stroke. They reported on the health consequences of the caregiver, the need for assessments of the caregiver, and moving toward a patient and caregiver centered approach. They found patient cognitive level was an indicator of increased levels of caregiver burden (Rigby et al., 2009). Similarly, Jones and colleagues (2017) also found a link between caregiver burden scores and cognitive status. The authors found caregiver burden was increased in patients with Parkinson’s disease with mild cognitive impairment, and burden remained high even after controlling for assistance with ADLs, duration of the disease, patient
neuropsychiatric symptoms and motor difficulties (Jones et al., 2017). In the current study, caregiver interviews revealed they were troubled by cognitive issues in the care recipient. Caregivers reported not being able to leave the care recipient alone due to cognition and having difficulty getting out of the house to run small errands. Caregivers described changes in cognitive level of the care recipient, and how the care recipient participated in unsafe activities. The caregiver described the activity and how it resulted in the caregiver losing thousands of dollars. Another caregiver discussed the cognitive changes she was seeing in the care recipient following a stroke. She reported prior to the stroke the care recipient would never raise his voice, and since the stroke he does get angry at times and will raise his voice at her.

**Caregiver Burden and Care Recipient Function**

In the literature, there is evidence of lower care recipient function being associated with higher levels of perceived caregiver burden. One of the research questions of this study, asked if there was a relationship between caregiver burden and care recipient function at baseline and discharge from physical therapy services? The quantitative analysis failed to detect a statistically significant correlation between burden experienced by caregivers and care recipient function. One reason that could help explain why a correlation was not found was the independence level of the care recipients at the start of the study. At the initial evaluation, 54% of the care recipients were independent with activities of daily living according to the care recipient self-reported scores on the Barthel Index. Overall, the sample of care recipients were more independent and may have required less assistance from the caregiver. Kim and colleagues (2011) performed a secondary data analysis from a nationwide telephone survey administered by the National
Alliance for Caregiving using data from 307 caregivers across seven states. They wanted to gain a better understanding of what factors were related to caregiver burden. The authors found caregivers experienced higher levels of burden when the care recipient required assistance with both ADLs and IADLs. During interviews with the caregivers, many reported having to provide assistance with ADLs.

**Limitations**

There were several limitations of this study. Individuals were asked to participate in this study after they committed to receiving physical therapy services in a pro-bono clinic. This was a small, non-random sample and may not be representative of the broader population. Another limitation that was identified was the distribution of the Zarit Burden Interview. This survey was to be administered one month prior to the start of the pro-bono clinic to gain insight on how burdened the sample was prior to the start of the study, but due to scheduling, participants were not confirmed until the week before clinic start. Due to pro-bono clinic scheduling baseline caregiver burden was not assessed until the first day of the study.

Face-to-face interviews were conducted during the time the care recipient received physical therapy services which allowed feasibility of participation. The primary investigator, who was a physical therapist, was conducting the caregiver interviews which may have prevented the caregivers from giving negative feedback about physical therapy services. Another limitation was the study being conducted during a global pandemic which limited participation in the study. Participants were opting out of participating in the pro-bono clinic due to the pandemic.
Finally, characteristics of the caregivers were captured to assess connections between these characteristics and the stress process. Caregiver characteristics, available personal and social resources are important to consider when understanding how someone copes or responds to stress. The sample in this research study did not capture a disadvantaged group of caregivers. The majority of the caregivers in this study had the personal and social resources to comfortably take care of their care recipients.

**Implications for Physical Therapy Clinical Practice**

In the qualitative analysis, the majority of caregivers expressed any medical provider working with the dyad could ask information regarding the health and well-being of the caregiver. This responsibility does not need to fall on one particular provider. The patient or care recipient may see a medical provider a few times a year, but they are in the continuous care of their families. It is important to include the caregiver as part of the healthcare team and recognize when the caregiver may need assistance. As stated in the literature, the most effective healthcare team encompasses individuals from multiple disciplines working together collectively for the patient and caregiver (Sullivan & Miller, 2015). Physical therapists spend a significant amount of time with patients and their caregivers and may be the first provider to recognize when a caregiver is having difficulty, or has an unaddressed need.

An area that was repeatedly discussed in the interviews with caregivers was the home exercise program (HEP) prescribed by the physical therapist. Caregivers candidly discussed the barriers faced with having to complete the HEP with their care recipients. Barriers ranged from having the time to complete all the exercises that were prescribed, feeling inadequate when
needing to adjust exercises for the care recipient to be successful, and arguing with the care recipient to complete the exercises. When prescribing HEPs, physical therapists need to keep in mind the added stress this could place on the caregiver. One way to combat these barriers may be to have the dyad incorporate activities into their daily routine and make exercises functional.

An area that was highlighted during caregiver interviews was the expectation by the physical therapist for the caregiver to stay for each visit. While it is important for the caregiver to attend physical therapy visits to carry over activities at home this may be the only respite for the caregivers. Caregivers mentioned being reprimanded when they did not stay for physical therapy sessions. Chastising a caregiver when they do not stay for a physical therapy session may lead to resentment and a hostile relationship between the physical therapist and caregiver. It may be helpful for the physical therapist to discuss expectations with the patient and caregiver at the initial evaluation, and set specific times when it would be most beneficial for the caregiver to attend a session. Physical therapists should create a therapeutic alliance with the patient and caregiver to improve overall outcomes for the dyad.

Implications for Policy

Given the multidimensional nature of caregiver burden, it will take an interdisciplinary team to improve quality of care and outcomes for the dyad. In a clinical review of literature, it was found in a meta-analysis for cancer patients, interventions that included caregiver education, skills training, and therapeutic counseling reduced caregiver burden, but the improvements were lost with time (Adelman et al., 2014). This demonstrates the need for appropriate assessment of caregiver on an ongoing basis, and the need for an interdisciplinary approach to manage all the
different factors that are leading to increased perceived burden. A single disciplinary intervention may not have long lasting effects in the overall management of caregiver burden.

Caregiver burden is an issue that requires the attention of various entities with different backgrounds and specialties to improve outcomes for the caregiver. Policy makers should have an interest in the health of the caregiver due to the burden that could be placed on health care institutions, and federal programs such as Medicare and Medicaid. It has been estimated the annual cost of caring for an individual with Parkinson’s disease is $23 billion with 40 percent of that cost credited to informal family caregivers (Sullivan & Miller, 2015). If policy makers do not have a seat at the table to discuss options for informal caregivers it could be detrimental to the health care system. If caregivers have to give up their care duties this would lead to more individuals being institutionalized and would drive up health care costs. Due to policy changes over the past several years, there has been a shift in the way individuals are cared for with less time spent in the hospital, and more burden placed on family members to care for these individuals. In the 2020 Caregiving Report, caregivers were surveyed and were asked about national programs that would benefit caregivers (American Association of Retired Persons, 2020). Nearly 68% of caregivers felt an income tax credit would help offset the cost of care, and 65% thought a program where caregivers could earn wages for hours of provided care would be beneficial. These programs would not be successful without the support of policy makers.

**Conclusion**

The United States healthcare system will continue to face challenges as the projections of an older population over the age of 65 years continues to rise. With these projections, and the
healthcare pushing for increases in home-based care, higher demands will be placed on family caregivers. Caregiver burden has been studied extensively and the effects of caring for an individual for long periods of time are overwhelming. This study shed light on the fact that healthcare providers were not routinely screening the caregiver for burden. Caregiver burden is multidimensional and requires the efforts of an interdisciplinary team, and anyone on the team can assess the caregiver for burden. Caregivers need to be recognized as part of the healthcare team and their health is important in being able to maintain care duties.

Physical therapists spend a significant amount of time with the caregiver-care recipient dyad and are in a unique position to help the caregiver navigate through obstacles of providing care for their loved ones. Obstacles caregivers face are unique to their caregiving situation. Bringing awareness on how to access community resources, where to find new or used equipment, other treatments the care recipient might benefit from are areas that may greatly help reduce stress on the caregiver.
REFERENCES


APPENDIX A

ZARIT BURDEN INTERVIEW
Please circle the response that best describes how you feel.

**Questions:**

1. **Do you feel that your relative asks for more help than he/she needs?**
   - Never
   - Rarely
   - Sometimes
   - Quite Frequently
   - Nearly Always

2. **Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?**
   - Never
   - Rarely
   - Sometimes
   - Quite Frequently
   - Nearly Always

3. **Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?**
   - Never
   - Rarely
   - Sometimes
   - Quite Frequently
   - Nearly Always

4. **Do you feel embarrassed over your relative’s behavior?**
   - Never
   - Rarely
   - Sometimes
   - Quite Frequently
   - Nearly Always

5. **Do you feel angry when you are around your relative?**
   - Never
   - Rarely
   - Sometimes
   - Quite Frequently
   - Nearly Always

6. **Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?**
• Never
• Rarely
• Sometimes
• Quite Frequently
• Nearly Always

7 Are you afraid what the future holds for your relative?
• Never
• Rarely
• Sometimes
• Quite Frequently
• Nearly Always

8 Do you feel your relative is dependent on you?
• Never
• Rarely
• Sometimes
• Quite Frequently
• Nearly Always

9 Do you feel strained when you are around your relative?
• Never
• Rarely
• Sometimes
• Quite Frequently
• Nearly Always

10 Do you feel your health has suffered because of your involvement with your relative?
• Never
• Rarely
• Sometimes
• Quite Frequently
• Nearly Always

11 Do you feel that you don’t have as much privacy as you would like because of your relative?
• Never
• Rarely
• Sometimes
• Quite Frequently
• Nearly Always

12 Do you feel that your social life has suffered because you are caring for your relative?
  • Never
  • Rarely
  • Sometimes
  • Quite Frequently
  • Nearly Always

13 Do you feel uncomfortable about having friends over because of your relative?
  • Never
  • Rarely
  • Sometimes
  • Quite Frequently
  • Nearly Always

14 Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?
  • Never
  • Rarely
  • Sometimes
  • Quite Frequently
  • Nearly Always

15 Do you feel that you don’t have enough money to take care of your relative in addition to the rest of your expenses?
  • Never
  • Rarely
  • Sometimes
  • Quite Frequently
  • Nearly Always

16 Do you feel that you will be unable to take care of your relative much longer?
  • Never
  • Rarely
  • Sometimes
  • Quite Frequently
  • Nearly Always
17 Do you feel you have lost control of your life since your relative’s illness?
- Never
- Rarely
- Sometimes
- Quite Frequently
- Nearly Always

18 Do you wish you could leave the care of your relative to someone else?
- Never
- Rarely
- Sometimes
- Quite Frequently
- Nearly Always

19 Do you feel uncertain about what to do about your relative?
- Never
- Rarely
- Sometimes
- Quite Frequently
- Nearly Always

20 Do you feel you should be doing more for your relative?
- Never
- Rarely
- Sometimes
- Quite Frequently
- Nearly Always

21 Do you feel you could do a better job in caring for your relative?
- Never
- Rarely
- Sometimes
- Quite Frequently
- Nearly Always

22 Overall, how burdened do you feel in caring for your relative?
- Never
- Rarely
- Sometimes
- Quite Frequently
- Nearly Always
Patient number Patient first name:
Date: . . . / . . . / . . . . . . . .

ZBI Scoring:
0-20 = very little or no burden
21-40 = mild to moderate burden
41-60 = moderate to severe burden
61-88 = severe burden
APPENDIX B

DEMOGRAPHIC QUESTIONS
Please fill these questions out regarding yourself as the caregiver.

Age:
- 18-30 years
- 31-39 years
- 40-50 years
- 51-60 years
- 61-70 years
- 71-75 years
- 76-80 years
- Greater than 80 years old
- Prefer not to answer

1) Sex:
- Male
- Female
- Prefer not to answer

2) Education Level:
- Less than high school diploma/GED equivalent
- High School Diploma
- Some college, no degree
- Associates Degree
- Bachelor’s Degree
- Master’s Degree
- Doctoral Degree
- Prefer not to answer

3) Employment Status Hours/week:
- Not Currently Working
- Retired
- 1-10 hours
- 11-20 hours
- 21-30 hours
- 31-40 hours
- 40+ hours
4) If you work outside the home, how many hours do you work?
   - Do Not Work Outside the home
   - 1-9 hours
   - 10-19
   - 20-29 hours
   - 30-39 hours
   - 40+ hours
   - Prefer not to answer

5) Race:
   - White
   - African American
   - American Indian
   - Asian
   - Native Hawaiian
   - Other
   - Prefer not to answer

6) Yearly Household Income:
   - Less than $20,000
   - $20,000-$39,000
   - $40,000-$59,000
   - $60,000
   - Prefer not to answer

7) Relationship to Patient:
   - Spouse
   - Child
   - Child-n-law
   - Grandchild
   - Friend
   - Other
   - Prefer not to answer

8) Length of time you have been giving care to your loved one?
   - < 6 months
7-11 months
1-2 years
3-4 years
5-6 years
7-9 years
> 10 years
Prefer not to answer

9) How many hours per week do you give care to the care recipient?
0-9 hours
10-19 hours
20-29 hours
30-39 hours
40+ hours
Prefer not to answer

10) Do you live with the person you are caring for?
Yes
No
Prefer not to answer

11) On a scale of 0-10, with 0 being poor health and 10 being great health please rate your overall health.
0 poor health
1
2
3
4
5
6
7
8
9
10 great health
Prefer not to answer

12) Do you care for other individuals? Eg. children
☐ Yes
☐ No
☐ Prefer not to answer
APPENDIX C

INTERVIEW PROTOCOL
Participant:
Date:

This conversation will be recorded after data collection is complete the recordings will be deleted from the investigator’s computer. Everything that you say is held in confidence and is anonymous. You will receive a copy of the interview to review for accuracy and changes will be made if required.

**Caregiver Interview Questions:**

Questions related to the domains of the Zarit Burden Interview

**Physical Domain:**
1) Are there aspects of PT you feel are burdensome for you or your loved one now or in the past?
2) Are there aspects of PT you feel are beneficial now or in the past?
3) Do you and your loved one exercise regularly? If yes, how many days a week? If not, what are the barriers to not exercising?
4) Do you feel it is important for health care providers to assess for caregiver burden?
5) When you go to appointments with your loved one do the medical providers (doctors, nurses, and physical therapists) ask how you as the caregiver are doing?
6) What healthcare providers do you think should be asking caregivers about burden?
7) If you could get assistance throughout your day, what type of assistance would be the most beneficial?
8) What type of physical assistance do you have to provide for your loved one?
9) Do you feel providing physical assistance is difficult for you? If so, what is difficult?
10) How is your physical health?
11) Do you feel you can handle your own health needs? Do you have difficulty seeking care for yourself if needed?
12) What information do you feel would be beneficial related to giving care to your loved one?

13) What aspects of your role as a caregiver did you feel prepared and what aspects did you not feel prepared for?

**Psychological Domain:**
14) Do you feel you have adequate mental health resources?

**Financial Domain:**
15) Do you feel you have enough financial resources to take care of your loved one now and in the future?

**Social Domain:**
16) How often do you get to see family? How often do you get to see friends?
17) How do you feel after you see family and friends?
18) Are you able to get out into the community and do things you want to do?
19) Do you do anything to help relieve stress?
20) Do you participate in any respite care? Eg. social groups, friends/family, hobbies, support groups
APPENDIX D

BARTHEL INDEX
FEEDING
0 = unable
5 = needs help cutting, spreading butter, etc., or requires modified diet
10 = independent

BATHING
0 = dependent
5 = independent (or in shower)

GROOMING
0 = needs to help with personal care
5 = independent face/hair/teeth/shaving (implements provided)

DRESSING
0 = dependent
5 = needs help but can do about half unaided
10 = independent (including buttons, zips, laces, etc.)

BOWELS
0 = incontinent (or needs to be given enemas)
5 = occasional accident
10 = continent

BLADDER
0 = incontinent, or catheterized and unable to manage alone
5 = occasional accident
10 = continent

TOILET USE
0 = dependent
5 = needs some help, but can do something alone
10 = independent (on and off, dressing, wiping)

TRANSFERS (BED TO CHAIR AND BACK)
0 = unable, no sitting balance
5 = major help (one or two people, physical), can sit
10 = minor help (verbal or physical)
15 = independent

MOBILITY (ON LEVEL SURFACES)
0 = immobile or < 50 yards
5 = wheelchair independent, including corners, > 50 yards
10 = walks with help of one person (verbal or physical) > 50 yards
15 = independent (but may use any aid; for example, stick) > 50 yards

STAIRS
0 = unable
5 = needs help (verbal, physical, carrying aid)
10 = independent

Total (0-100)  

APPENDIX E

BERG BALANCE SCALE
Name ________________________   Date_______________
Location ______________________ Rater_______________

GENERAL INSTRUCTIONS
Please demonstrate each task and/or give instructions as written. When scoring, please record the lowest response category that applies for each item.

In most items, the subject is asked to maintain a given position for specific time. Progressively more points are deducted if the time or distance requirements are not met, if the subject’s performance warrants supervision, or if the subject touches an external support or receives assistance from the examiner. Subjects should understand that they must maintain their balance while attempting the tasks. The choices of which leg to stand on or how far to reach are left to the subject. Poor judgment will adversely influence the performance and the scoring.

Equipment required for testing are a stopwatch or watch with a second hand, and a ruler or other indicator of 2, 5, and 10 inches (5, 12.5, and 25 cm). Chairs used during testing should be of reasonable height. Either a step or a stool (of average step height) may be used for item #12.

1. SITTING TO STANDING
   INSTRUCTIONS: Please stand up. Try not to use your hands for support.
   4 able to stand without using hands and stabilize independently
   3 able to stand independently using hands
   2 able to stand using hands after several tries
   1 needs minimal aid to stand or to stabilize
   0 needs moderate or maximal assist to stand

2. STANDING UNSUPPORTED
   INSTRUCTIONS: Please stand for two minutes without holding.
   4 able to stand safely 2 minutes
   3 able to stand 2 minutes with supervision
   2 able to stand 30 seconds unsupported
   1 needs several tries to stand 30 seconds unsupported
   0 unable to stand 30 seconds unassisted

   If a subject is able to stand 2 minutes unsupported, score full points for sitting unsupported. Proceed to item #4.

3. SITTING WITH BACK UNSUPPORTED BUT FEET SUPPORTED ON FLOOR OR ON A STOOL
   INSTRUCTIONS: Please sit with arms folded for 2 minutes.
   4 able to sit safely and securely 2 minutes
   3 able to sit 2 minutes under supervision
   2 able to sit 30 seconds
1 able to sit 10 seconds
0 unable to sit without support 10 seconds

4. STANDING TO SITTING
INSTRUCTIONS: Please sit down.
4 sits safely with minimal use of hands
3 controls descent by using hands
2 uses back of legs against chair to control descent
1 sits independently but has uncontrolled descent
0 needs assistance to sit

5. TRANSFERS
INSTRUCTIONS: Arrange chairs(s) for a pivot transfer. Ask subject to transfer one way toward a seat with armrests and one way toward a seat without armrests. You may use two chairs (one with and one without armrests) or a bed and a chair.
4 able to transfer safely with minor use of hands
3 able to transfer safely definite need of hands
2 able to transfer with verbal cueing and/or supervision
1 needs one person to assist
0 needs two people to assist or supervise to be safe

6. STANDING UNSUPPORTED WITH EYES CLOSED
INSTRUCTIONS: Please close your eyes and stand still for 10 seconds.
4 able to stand 10 seconds safely
3 able to stand 10 seconds with supervision
2 able to stand 3 seconds
1 unable to keep eyes closed 3 seconds but stays steady
0 needs help to keep from falling

7. STANDING UNSUPPORTED WITH FEET TOGETHER
INSTRUCTIONS: Place your feet together and stand without holding.
4 able to place feet together independently and stand 1 minute safely
3 able to place feet together independently and stand for 1 minute with supervision
2 able to place feet together independently and to hold for 30 seconds
1 needs help to attain position but able to stand 15 seconds feet together
0 needs help to attain position and unable to hold for 15 seconds

8. REACHING FORWARD WITH OUTSTRETCHED ARM WHILE STANDING
INSTRUCTIONS: Lift arm to 90 degrees. Stretch out your fingers and reach forward as far as you can. (Examiner places a ruler at end of fingertips when arm is at 90 degrees. Fingers should not touch the ruler while reaching forward. The recorded measure is the distance forward that the finger reaches while the subject is in the most forward lean position. When possible, ask subject to use both arms when reaching to avoid rotation of the trunk.)
4 can reach forward confidently >25 cm (10 inches)
3 can reach forward > 12.5 cm safely (5 inches)
2 can reach forward > 5 cm safely (2 inches)
1 reaches forward but needs supervision
0 loses balance while trying/requires external support

9. PICK UP OBJECT FROM THE FLOOR FROM A STANDING POSITION
INSTRUCTIONS: Pick up the shoe/slipper which is placed in front of your feet.
4 able to pick up slipper safely and easily
3 able to pick up slipper but needs supervision
2 unable to pick up but reaches 2-5 cm (1-2 inches) from slipper and keeps balance independently
1 unable to pick up and needs supervision while trying
0 unable to try/needs assist to keep from losing balance or falling

10. TURNING TO LOOK BEHIND OVER LEFT AND RIGHT SHOULDERS WHILE STANDING
INSTRUCTIONS: Turn to look directly behind you over toward left shoulder. Repeat to the right.
(Examiner may pick an object to look at directly behind the subject to encourage a better twist turn.)
4 looks behind from both sides and weight shifts well
3 looks behind one side only other side shows less weight shift
2 turns sideways only but maintains balance
1 needs supervision when turning
0 needs assist to keep from losing balance or falling

11. TURN 360 DEGREES
INSTRUCTIONS: Turn completely around in a full circle. Pause. Then turn a full circle in the other direction.
4 able to turn 360 degrees safely in 4 seconds or less
3 able to turn 360 degrees safely one side only in 4 seconds or less
2 able to turn 360 degrees safely but slowly
1 needs close supervision or verbal cueing
0 needs assistance while turning

12. PLACING ALTERNATE FOOT ON STEP OR STOOL WHILE STANDING UNSUPPORTED
INSTRUCTIONS: Place each foot alternately on the step/stool. Continue until each foot has touched the step/stool four times.
4 able to stand independently and safely and complete 8 steps in 20 seconds
3 able to stand independently and complete 8 steps> 20 seconds
2 able to complete 4 steps without aid with supervision
1 able to complete >2 steps needs minimal assist
0 needs assistance to keep from falling/unable to try
13. STANDING UNSUPPORTED ONE FOOT IN FRONT
INSTRUCTIONS: (DEMONSTRATE TO SUBJECT)
Place one foot directly in front of the other. If you feel that you cannot place your foot
directly in front, try to step far enough ahead that the heel of your forward foot is ahead of
the toes of the other foot. (To score 3 points, the length of the step should exceed the length
of the other foot and the width of the stance should approximate the subject’s normal stride
width)

4 able to place foot tandem independently and hold 30 seconds
3 able to place foot ahead of other independently and hold 30 seconds
2 able to take small step independently and hold 30 seconds
1 needs help to step but can hold 15 seconds
0 loses balance while stepping or standing

14. STANDING ON ONE LEG
INSTRUCTIONS: Stand on one leg as long as you can without holding.

4 able to lift leg independently and hold >10 seconds
3 able to lift leg independently and hold 5-10 seconds
2 able to lift leg independently and hold = or >3 seconds
1 tries to lift leg unable to hold 3 seconds but remains but remains standing independently
0 unable to try or needs assist to prevent fall

TOTAL (maximum 56) ________

0-20, wheelchair bound
21-40, walking with assistance
41-56, independent
APPENDIX F

SIX MINUTE WALK TEST
**Equipment Required:**
- Stopwatch
- Measuring/trundle wheel to measure distance covered
- 30-metre stretch of unimpeded walkway
- Two cones to mark the distance that needs to be covered
- Pulse oximeter for measuring heart rate and SpO2 (optional)
- Borg Breathlessness Scale (optional)

**Set-Up:**
- Place cones at either end of the 30 meter stretch as turning points
- Have chairs set up either side and halfway along the walking stretch

**Patient Instructions:**
- The object of this test is to walk as far as possible for 6 minutes. You will walk back and forth in this hallway. Six minutes is a long time to walk, so you will be exerting yourself. You will probably get out of breath or become exhausted. You are permitted to slow down, to stop, and to rest as necessary. You may lean against the wall while resting, but resume walking as soon as you are able. You will be walking back and forth around the cones. You should pivot briskly around the cones and continue back the other way without hesitation. Now I’m going to show you. Please watch the way I turn without hesitation.

Walking Distance: ________
Rest Breaks: yes/no: ________
Number of Rest Breaks: ________
APPENDIX G

INFORMED CONSENT CAREGIVER
Study Title: Physical therapy and caregiver burden: A mixed methods design

Invitation to be part of a research study: You are invited to participate in a research study. In order to participate you must be an informal caregiver of a patient receiving physical treatment in the Clinic for Fitness and Function at Bradley University. This excludes paid caregivers, such as individuals from an official home healthcare organization. Taking part in this research project is voluntary. You must be 18 years old or older to participate.

Key information regarding this study: The purpose of this study is to explore whether physical therapy for the person you are caring for affects your feelings of burden as a caregiver. If you choose to participate you will be asked to take a two part survey that involves answering questions regarding your demographics (demographic questions are questions such as, age, gender, number of years giving care, yearly income, etc), the independence level of your loved one in activities of daily living. It also involves participating in 3-4 interviews lasting 30-45 minutes with questions regarding your experience as a caregiver related to caregiver burden.

Your participation in this study will take approximately 30-45 minutes on 3-4 separate occasions throughout the 10 weeks that your loved one is receiving physical therapy at the Clinic for Fitness and Function at Bradley University. Taking part in this research project is voluntary. You do not have to participate and can stop at any time.

Please take the time to read this entire form and ask questions before deciding to participate in this research project.

What is the purpose of this study?
The purpose of this study is to explore whether physical therapy for the person you are caring for affects your feelings of burden as a caregiver.

What will happen if you take part in this study?
If you agree to take part in this study, you will be asked to fill out a two-part survey that involves answering questions regarding your demographics, the independence level of your loved one in activities of daily living, and interviews regarding your experience of caregiver burden. Your participation in this study will take 30-45 minutes on 3-4 separate occasions while your loved one is receiving physical therapy. Your choice to participate or not participate in this study will not affect the quality of your loved one’s physical therapy treatment.

What are the risks of participating in this study?
Although unlikely, the survey could cause you to have certain uncomfortable feelings about your role as a caregiver. If you were to develop these feelings, and wished to speak with a licensed counselor, you could be referred to a facility. The activities included in this study will take approximately 30-45 minutes of your time at 3-4 different time points, at the start of physical therapy and at the end of physical therapy, and surveys will be completed on the day your loved one receives physical therapy.

Covid-19 protocols will be followed in the Clinic for Fitness and Function.

Are there any incentives for participating in the study?
There is no compensation for participating in this study. However, this study will help understand the benefit that physical therapy for an individual can affect various aspects of caregiver burden. This information can be used to improve therapy sessions to reduce caregiver burden, or identify needs in therapy to support caregivers.

**How will your information be protected?**

All reasonable efforts will be made to keep your personal information confidential. This study is anonymous and your name will be changed to a fake name to protect your identity. Only the primary investigator and student investigators will see your raw data after it has been de-identified by the primary investigator. Your information will be de-identified but linked to a master copy. The master copy will be kept separate from the data sources and will be kept in a locked file in the primary investigator’s locked office. If any of the information is shared with an external entity (such as for a presentation or publication), your name and other identifiable information will be changed or removed. In addition, data will be reported as aggregates when possible meaning the data will be reported as summaries to avoid identification of any one particular individual.

The records of this study will be kept strictly confidential. Research records will be kept in a locked file, and all electronic information will be coded and secured using a password protected file. If interviews are completed via zoom audio and video tape recordings will only be accessed by the primary investigator that will be stored on a computer that is password protected. Once the zoom meeting has been transcribed, the recording will be deleted from the computer. We will not include any information in any report we may publish that would make it possible to identify you.

**What are the costs?**

There are no costs for participation in this study.

**Whom should I call with questions or problems regarding the study?**

Questions about this study may be directed to the primary researcher investigator in charge of this study: Dr. Jamie Way at (309) 677-4534 or (309) 256-1446 or jway@fsmail.bradley.edu

**Whom should I contact with questions about my rights as a research participant?**

If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the following:

Office of Research Compliance, Integrity and Safety
Northern Illinois University
1425 W Lincoln Hwy
DeKalb, IL 60115
(815) 753-8588

Documentation of Informed Consent

Your signature below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep, along with any other printed materials deemed necessary by the study investigators.

________________________________________________           _____________________
Participant’s Signature Date
I give my consent to be audio and video recorded, as appropriate if interviews need to be conducted via zoom.

________________________________________________           _____________________
Participant’s Signature                                      Date
APPENDIX H

INORMED CONSENT PATIENT
Study Title: Physical therapy and caregiver burden: A mixed methods design

Invitation to be part of a research study: You are invited to participate in a research study. In order to participate you must be a patient receiving physical therapy treatment. Taking part in this research project is voluntary. You must be 18 years old or older to participate.

Key information regarding this study: The purpose of this study is to explore whether physical therapy can have an impact on the perceived burden experienced by the caregiver. If you choose to participate, you will be asked to take a survey with your physical therapist regarding how much assistance you require with the following activities, bathing, dressing, toileting, transfers, and continence and feeding. Your participation in this study will take approximately 15 minutes and the survey will be given on two separate occasions; once at your first physical therapy session and at your last session. Taking part in this research project is voluntary. You do not have to participate and can stop at any time.

Please take the time to read this entire form and ask questions before deciding to participate in this research project.

What is the purpose of this study?
The purpose of this study is to explore whether physical therapy can affect feelings of burden for your caregiver.

What will happen if you take part in this study?
If you agree to take part in this study, you will be asked to fill out a survey that involves answering questions regarding the assistance needed for your daily activities. Your participation in this study will take approximately 15 minutes and the survey will be given on three separate occasions; once at the first physical therapy session, at 5 weeks, and on the last session. Your choice to participate or not participate in this study will not affect the quality of your treatment in physical therapy at the Clinic For Fitness and Function at Bradley University.

What are the risks of participating in this study?
There are no anticipated risks for participating in this study. The activities included in this study are part of your physical therapy evaluation, so there is no additional time or energy required on your part. Covid-19 protocols will be followed in the Clinic for Fitness and Function.

Are there any incentives for participating in the study?
There is no compensation for participating in this study. However, this study will help understand the benefit that physical therapy for an individual can affect various aspects of the caregiver burden. This information can be used to improve therapy sessions to reduce caregiver burden, or identify needs in therapy to support caregivers.

How will your information be protected?
All reasonable efforts will be made to keep your personal information confidential. Only your physical therapist, primary investigator and student investigators will see your raw data after it has been de-identified by the primary investigator. Your information will be de-identified but linked to a master copy. The master copy will be kept separate from the data sources and will be kept in a locked file in the primary investigator’s locked office. The records of this study will be kept strictly confidential. Research
records will be kept in a locked file and all electronic information will be coded and secured using a password protected file. If any of the information is shared with an external entity (such as for a presentation or publication), your name and other identifiable information will be changed or removed. In addition, data will be reported as aggregates when possible meaning the data will be reported as summaries to avoid identification of any one particular individual.

**What are the costs?**
There are no costs for participation in this study.

**Whom should I call with questions or problems regarding the study?**
Questions about this study may be directed to the research advisor in charge of this study: Dr. Jamie Way at (309) 677-4534 or (309) 256-1446 or jway@fsmail.bradley.edu.

**Whom should I contact with questions about my rights as a research participant?**
If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the following:
Office of Research Compliance, Integrity and Safety
Northern Illinois University
1425 W Lincoln Hwy
DeKalb, IL 60115
(815) 753-8588

**Documentation of Informed Consent**
Your signature below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep, along with any other printed materials deemed necessary by the study investigators.
I agree to participate in this study

Participant’s Signature

Date