

**Caregiver Burnout Prevention at a Midwest Parkinson's Foundation**

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### **Abstract**

Parkinson's Disease is a rapidly growing neurological condition that can affect participation in everyday activities. As more individuals become diagnosed with Parkinson's Disease, the number of those caring for people with Parkinson's Disease also increases. Caregivers can become susceptible to caregiver burnout, which is a stress that accumulates over time, produces a negative outlook on caregiving, and affects many areas of one's life. Literature suggests that key areas to caregiver burnout prevention are daily care hours, education on disease, social support, and mindfulness. Through a needs assessment of a Midwest Parkinson's organization, a gap was identified between where the organization wanted to be with caregiver burnout prevention and where it was. The goal of this capstone project was to equip the organization with caregiver burnout prevention resources and strategies to promote caregiver health, well-being, and quality of life. Based on the needs assessment, two educational sessions were created and delivered to participants at three caregiver support groups over the topics of mindfulness, medication management, Lee Silverman Voice Treatment (LSVT), and respite. Program outcomes were measured via pre- and post- surveys, and this data was analyzed through independent t-tests. There was a statistically significant difference with a large effect size for mindfulness, medication management, and respite educational sessions. Outcomes suggested that caregiver confidence and satisfaction in applying burnout prevention strategies greatly increased following the educational sessions.

*Keywords:* Caregiver burnout, Parkinson's Disease, burnout prevention, occupational therapy

### **Caregiver Burnout Prevention at a Midwest Parkinson's Foundation**

Ninety thousand people aged 65 and older are diagnosed with Parkinson's Disease in North America every year. These numbers show an incidence rate that is 1.5-2.25 times greater than data from the past 20 years (Willis et al., 2022). Parkinson's Disease is a degenerative neurological condition that is often characterized by tremors, muscle stiffness, slow movements, and loss of balance. Other symptoms can include flat affect, small handwriting, difficulty eating or speaking, cognitive difficulties, and more. These symptoms can affect one's participation in activities of daily living (ADLs), instrumental activities of daily living (IADLs), work, social participation, leisure, and sleep. The rate of progression varies amongst individuals, but especially towards the later stages, those with Parkinson's Disease will need assistance from caregivers (National Institute on Aging, 2022). As the number of people diagnosed with Parkinson's Disease is increasing, the number of people caring for those with Parkinson's Disease is also rising.

Caring for a loved one with Parkinson's Disease can become a full-time job. As the disease progresses, more time is spent caregiving, and less time is devoted to other activities. If this pattern continues without intervention, it can result in caregiver burnout. Caregiver burnout is a strain felt by an individual who cares for someone with a disability, a chronic condition, or an aging family member. This stress accumulates over time, produces a negative mindset on caregiving, and affects many different areas of one's life (Ajithakumari & Hemavathy, 2022; Liu, Heffernan, & Tan, 2020). In literature, the terms caregiver burnout and caregiver burden are often used interchangeably. For the purposes of this paper, the term caregiver burnout will be utilized.

Spending time caring for another person leaves less time for other things. Not engaging in a variety of meaningful activities, or occupations, suggests occupational imbalance. If someone is spending most of their time doing one activity, such as caregiving, they are not spending time doing other activities that they enjoy. This concept of occupational imbalance can be closely related to occupational deprivation, which is when an individual is not engaging in meaningful activities for reasons beyond their control. In the case of caregiving, the tasks associated with this role can supersede engagement in all other activities (Yong et al., 2020). Taking on a caregiver role can negatively affect one's relationships, sleep, financial status, mental health, engagement in leisure activities, and quality of life (Liu, Heffernan, & Tan, 2020; Perrin et al., 2019).

Many caregivers are the sole supporter of their loved one. Scheduling alone time, asking family and friends if they can offer assistance, and seeking out respite care can help ease the burden (Ajithakumari & Hemavathy, 2022; Lee et al., 2019). Social support has also been found to have improvements on caregiver burnout and mental health (Ajithakumari & Hemavathy, 2022; Perrin et al., 2019; Tyler et al., 2020). Additionally, many caregivers of people with Parkinson's Disease do not know as much as they would like about the disease. Education on the disease and how to care for their loved one has been reported as a need for caregivers, and receiving education has had a positive effect on caregiver burnout (Ajithakumari & Hemavathy, 2022; Lee et al., 2019; Schwartz et al., 2020; Terayama et al., 2018; Weir, Danilovich, & Hoover, 2022). Lastly, mindfulness can attenuate caregiver burnout and other negative mental health symptoms (Cheung et al., 2020; Chung, Ho, & Chan, 2022; Collins & Kishita, 2019; Klietz et al., 2020).

The capstone site is a nonprofit organization that hosts exercise classes and support groups around Indiana for those with Parkinson's Disease and their caregivers. The capstone site is a resource to those affected by Parkinson's Disease in the Midwest. Caregivers who participate in support groups at this Midwest Parkinson's foundation have the benefit of engaging with others who have shared experiences. However, beyond social support and a small number of educational resources, the capstone site does not currently have other caregiver burnout prevention techniques in place. The purpose of this capstone project was to provide the capstone site with resources and strategies aimed at promoting health, wellbeing, and quality of life to ultimately prevent caregiver burnout.

### **Needs Assessment**

The student researcher conducted a needs assessment for the capstone site based on a thorough literature review, analysis of the site's website, an interview with the executive director at the site, and a conversation with the site's previous Indiana University occupational therapy capstone student. Due to the late transition to this site, the student researcher first consulted with the previous capstone student to assess the site's current state, desired state, and overall needs. At the point of their conversation, the previous capstone student had been completing her project with the site for the past 11 weeks, indicating that she had comprehensive knowledge of the site. Several weeks afterwards, the student researcher had a phone interview directly with the capstone site mentor (see Appendix A).

When asked if caregiver burnout was a relevant issue for the site, the previous capstone student identified that this was an observed need amongst caregivers for people with Parkinson's Disease at the Parkinson's organization. The previous capstone student interacted with caregivers at both exercise classes and support groups. She identified that the caregivers were constantly

available for their loved one with Parkinson's Disease. If their loved one needed assistance, they would be the one to support them. They are the sole caregiver, and they do not know how to ask for help in this caregiving role. Additionally, many of the caregivers did not have all the education about the disease and its associated symptoms (Capstone Student, personal communication, April 7, 2023). The capstone site mentor reported the same observation of caregiver needs along with mental health concerns related to apathy and incontinence. Not knowing the best ways to provide assistance to the person they care for can impact a caregiver mentally, emotionally, and physically.

After consulting with the site's previous capstone student, the student researcher went to the literature to explore caregiver burnout. The themes found in the literature about caregiver burnout closely aligned with those identified by the site's previous capstone student and site mentor, thus reinforcing the need for caregiver burnout prevention strategies at the capstone site. The literature revealed four main themes surrounding caregiver burnout for caregivers of people with Parkinson's Disease. First, many caregivers are the only person supporting their loved one, which can impact their occupational balance and mental health (Ajithakumari & Hemavathy, 2022; Cianfrocca et al., 2020; Lee et al., 2019; Sturm et al., 2019). Second, extensive knowledge and understanding about Parkinson's Disease and how to care for someone with Parkinson's Disease is not always present. Increasing this knowledge has been linked to lower levels of caregiver burnout (Armitage & Fonkem, 2023; Lee et al., 2019; Schwartz et al., 2020; Terayama et al., 2018; Weir, Danilovich, & Hoover, 2022). Next, social support and shared experiences, like those fostered through support groups, are associated with lower levels of caregiver burnout (Cianfrocca et al., 2020; Perrin et al., 2019; Tyler et al., 2020). Lastly, practicing mindfulness is a protective factor against burnout (Cheung et al., 2020; Collins & Kishita, 2019; Klietz, 2020).

The student researcher completed the gap analysis after the literature review as the information found in the literature helped inform the gap between the site's current and desired states. Consultation with the site's previous capstone student, an interview with the site mentor, and an analysis of the site's website revealed the site's current and desired states. Based on what the literature deems as best practice for preventing caregiver burnout, the student researcher examined which of these measures were already implemented by the capstone site and where there could be improvement.

### **Literature Review**

To gather more information about the current state of caregiver burnout for caregivers of people with Parkinson's Disease, the student researcher conducted a literature review. Based on the literature found by the student researcher, four main themes were identified surrounding causes of caregiver burnout as well as methods to reduce it. The first theme related to the amount of time caregivers spend caring for their loved one. When spending a large portion of one's day caring for another, it leaves little time and energy to devote to other things (Cianfrocca et al., 2020; Lee et al., 2019; Sturm et al., 2019). Utilizing respite care is a strategy aimed at decreasing daily care time, and ultimately caregiver burnout (Ajithakumari & Hemavathy, 2022). Another theme revolves around increasing knowledge about Parkinson's Disease. By having a greater understanding of the disease and its symptoms, caregivers can live with less uncertainty. Proper caregiver training provides them with the skills to best support their loved one while also protecting their own health and safety (Armitage & Fonkem, 2023; Lee et al., 2019; Sturm et al., 2019; Terayama et al., 2018; Weir, Danilovich, & Hoover, 2022). Another theme centers around social support. Caregivers need social and emotional support from other caregivers (Cianfrocca et al., 2020; Perrin et al., 2019; Sturm et al., 2019). Social support also increases resiliency, and



this ability to cope with stressors is vital when in a caregiving role (Tyler et al., 2020). Lastly, practicing mindfulness is a strategy aimed at reducing caregiver burnout (Cheung et al., 2020; Collins & Kishita, 2019; Kliez, 2020). When caring for someone with an unpredictable and progressive neurological condition like Parkinson's Disease, having strategies that one can practice themselves at any time of the day is empowering.

### **Being the Sole Caregiver**

Being the main caregiver 24/7 can be physically, mentally, and emotionally exhausting. Through qualitative interviews with neurologists, Schwartz et al. (2020) found that many neurology sessions focus almost exclusively on the patient and that there is often not enough time to address any of the caregiver's needs or concerns. Many times, these caregivers are not being checked up on by their loved one's medical team, so much so that they have even been termed "invisible patients" (Thieken & van Munster, 2021). Caregivers are not recognized by medical care teams, but they need support in navigating this new role as a caregiver.

Caregivers of people with Parkinson's Disease have also reported feeling as though they had less time for themselves, which means that they are participating less in activities that are meaningful to them (Cianfrocca et al., 2020). Spending more time caregiving daily is positively correlated with caregiver burnout (Lee et al., 2019; Soares et al., 2023). Lee et al. (2019) and Sturm et al. (2019) both found that the strongest correlate with caregiver burnout was a larger number of hours devoted to caretaking. Therefore, decreasing daily care time through respite care may be a beneficial option for caregivers of people with Parkinson's Disease. Respite care provides caregivers a break from caregiving. The duration and location of care can vary depending on one's needs. For example, respite care providers could come directly into the home for a few hours, a caregiver may drop their loved one off at a day center, or a patient could spend

a week at a skilled nursing facility (National Institute on Aging, 2017). Respite care is an option for caregivers to utilize so that they have a chance to relax and spend time doing things that are meaningful for themselves (Ajithakumari & Hemavathy, 2022). It is important to educate caregivers on how to access local respite services while addressing the guilt that can accompany using them.

### **Education**

Parkinson's Disease has both motor and nonmotor symptoms, and caregivers may not be aware of the range of possible effects. There can be changes in the way an individual conveys their emotions both through facial expressions and vocal inflections. This can cause issues in the way that a person with Parkinson's Disease communicates with their loved ones, which can be difficult for a caregiver mentally and emotionally. Some neurologists have found success in educating caregivers to read less into body language and vocal inflection and instead to explicitly ask their loved one with Parkinson's Disease about their feelings and emotions. The disease can disguise one's emotions, so it becomes necessary to make changes to the way that a caregiver communicates with a person with Parkinson's Disease (Schwartz et al., 2020).

Caregivers often need to assist their loved ones with their ADLs, which can include tasks such as eating, bathing, dressing, and going to the bathroom. These are tasks that people engage in every single day, therefore, much of a caregiver's time is spent helping their loved one with these types of activities. While caregivers can spend much time helping with ADLs, they may not have received adequate training on how to safely assist (Armitage & Fonkem, 2023; Weir, Danilovich, & Hoover, 2022). As Parkinson's Disease progresses, it makes mobility and ambulation more difficult. Moving within the home and leaving the home can take more time and energy on the caregiver's part. To prevent injury of both the caregiver and the person with

Parkinson's Disease, proper transfer training is vital. Weir, Danilovich, & Hoover (2022) conducted a systematic review about the efficacy of ambulation and mobility training for informal caregivers of people with neurological conditions, such as Parkinson's Disease. In four of the seven studies, they found educational training for caregivers to be significantly beneficial in reducing caregiver burnout (Weir, Danilovich, & Hoover, 2022).

Educating the caregiver can help relieve both caregiver burnout and reduce depressive symptoms. One educational program for caregivers of people with dementia found such results. The program included two 90-minute lectures completed over the course of two months. The content of this program included education about dementia, the progression of symptoms, types of care available, how to access care, identifying when outside care is necessary, and the experiences of other caregivers. After three months of this educational program, caregivers had a 19% decrease in depressive symptoms, whereas those in the control group had a 28% increase of depressive symptoms (Terayama et al., 2018). Lee et al. (2019) also found that less understanding of Parkinson's Disease and its associated symptoms is correlated with higher levels of caregiver burnout. Educating caregivers about the disease is crucial due to its role in combating caregiver burnout, and it has been a documented need, so it is relevant to caregivers (Sturm et al., 2019). Providing education to the caregiver of a person with Parkinson's Disease can build their competence in safely caring for their loved one. Demonstrating this competence can also build up their confidence as a caregiver (Armitage & Fonkem, 2023). Education about Parkinson's Disease is needed to help caregivers better understand what to expect, how to help, and how to protect themselves mentally, physically, and emotionally.

### **Social Support and Shared Experience**

Much of what may be helpful for caregiver burnout prevention is rooted in education, and there are many people who could benefit from it. Education alone though may not be as effective in reducing caregiver burnout. Instead, engaging in this education alongside other caregivers can be powerful. Shared experiences are unifying, and being able to share one's caregiving experiences with other caregivers is a highly sought out need for caregivers of people with Parkinson's Disease (Cianfrocca et al., 2020; Perrin et al., 2019; Sturm et al., 2019). In fact, a cross-cultural study of Parkinson's Disease caregivers from the United States and Mexico found that emotional support and social support were the two greatest needs of caregivers from the United States (Perrin et al., 2019). Caregivers of people with Parkinson's Disease who participated in a qualitative study noted that they would feel more comfortable expressing their emotions, thoughts, and fears with other caregivers (Cianfrocca et al., 2020). Being a caregiver for someone with a progressive neurological condition is an experience that cannot be truly understood by anyone who has not been through it, so joining a caregiver support group is ideal.

Social support increases one's resilience, which is one's ability to cope with stressors. Caring for a loved one with Parkinson's Disease can be stressful, so trying to find ways to bolster resilience is vital. Greater resilience has also been associated with less negative mental health symptoms. Anxiety and depressive symptoms can result when experiencing caregiver burnout, so there is a connection between resiliency, mental health, quality of life, and caregiver burnout (Tyler et al., 2020; Vatter & Leroi, 2022).

### **Mindfulness**

Caregivers can benefit from respite care, increased education, and social support. While each of these components are crucial when targeting caregiver burnout, they also each rely on

outside help and training. Practicing mindfulness is a health promotion strategy that can be independently implemented, which helps give control back to the caregiver. Research has indicated that both practicing mindfulness and having greater trait mindfulness are associated with less negative mental health symptoms (Cheung et al., 2020; Collins & Kishita, 2019; Klietz, 2020). When looking at caregivers of people with dementia, Mindfulness and Acceptance Based Interventions (i.e., acceptance and commitment therapy, dialectical behavior therapy, mindfulness-based stress reduction, and mindfulness-based cognitive therapy) have had a large effect size on depression and a moderate effect size on caregiver burnout. While this effect size decreased over time, moderate effects were still retained suggesting their efficacy as a health promotion strategy (Collins & Kishita, 2019).

Caregivers with greater psychological flexibility and mindfulness are associated with lower levels of caregiver burnout, and by intentionally practicing mindfulness, one can increase their trait mindfulness (Klietz et al., 2020). Additionally, acceptance and commitment therapy (ACT) is a mindfulness technique that revolves around psychological flexibility (Collins & Kishita, 2019). Therefore, ACT mindfulness strategies can incorporate the benefits that both psychological flexibility and mindfulness have on burnout and other negative mental health symptoms. Other evidence-based mindfulness strategies include body scans, mindful walks, yoga, meditation, and diaphragmatic breathing (Cheung et al., 2020; Collins & Kishita, 2019; Klietz et al., 2020). There has even been research to suggest benefits of creating Zentangles on well-being, but this has not been conducted directly on participants who are caregivers (Chung, Ho, & Chan, 2022).

Caregivers can practice mindfulness to help promote their own health, and they can also include their loved one for mutual benefit. An estimated one fifth of those with Parkinson's

Disease struggle with alexithymia, which is the difficulty in identifying and communicating one's feelings and emotions (Assogna et al., 2016; Norman et al., 2019). This non-motor symptom can be challenging for caregivers, but there is evidence to support the use of mindfulness-based interventions for alexithymia. Therefore, incorporating mindfulness strategies into the dyad's lifestyle may offer benefits to each of them. Once caregivers have practiced mindfulness strategies, they can add them to their toolbox for future use, whether they utilize them individually or with a loved one.

### **Gap Analysis**

#### **Current State of Site**

The capstone site hosts exercises classes and monthly support groups. They offer in-person exercise classes Monday through Friday at eight locations, and they offer a virtual exercise program that can be accessed at any time. These evidence-based exercise classes are having a positive impact on Parkinson's Disease symptoms. There are monthly support groups specifically for people with Parkinson's Disease and for those who are caregivers to people with Parkinson's Disease. Two of their caregiver-only support groups are offered in-person and one group meets virtually. These caregiver support groups allow caregivers to connect with one another and share their experiences. The capstone site also has educational resources on their website about anxiety and stress, fall prevention, palliative care, and an overview about Parkinson's Disease. Their app, iCLIMB, also has educational content about bowel and bladder care, sit to stand transfers, cognition, stretching, functional movement sequences, dance, and yoga (Indiana Parkinson Foundation, 2023).

### **Desired State of Site**

The capstone site aims to promote physical, mental, and spiritual health in people with Parkinson's Disease and their caregivers (Indiana Parkinson Foundation, 2023). Both the site mentor and a former Indiana University occupational therapy capstone student at the site have witnessed caregivers struggling mentally, physically, and emotionally in this role. In staying true to their mission statement, the capstone site would like to implement more strategies into their support groups that help promote caregivers' physical, mental, and spiritual health. The organization would like to equip caregivers with the knowledge, resources, and social support to help preserve their own health while caring for their loved ones with Parkinson's Disease.

### ***Identified Gaps***

Through consulting the literature, the capstone site's website, the previous capstone student, and the site mentor, a gap was discovered between where the site currently is and where they want to be. Currently, the Midwest Parkinson's organization provides exercise classes, support groups, and education about Parkinson's Disease. Being able to communicate with others who have shared experiences is crucial for the wellbeing of caregivers (Ajithakumari & Hemavathy, 2022; Perrin et al., 2019; Tyler et al., 2020). Additionally, more knowledge about Parkinson's Disease has also been linked to lower levels of caregiver burnout (Lee et al., 2019; Terayama et al., 2018). Measures are in place at the capstone site that help with preventing caregiver burnout, but these measures have not yet addressed safe functional ambulation and transfers, ADL training, respite care, and mindfulness, all of which are factors that can help decrease caregiver burnout (Ajithakumari & Hemavathy, 2022; Cheung et al., 2020; Collins & Kishita, 2019; Kliez et al., 2020; Lee et al., 2019; Schwartz et al., 2020; Terayama et al., 2018; Weir, Danilovich, & Hoover, 2022). Presenting caregivers with information about how to reduce

the number of hours they spend caretaking can help promote engagement in a variety of occupations. Additionally, providing more education about Parkinson's Disease and how to safely care for its symptoms can help prevent caregiver injury and promote caregivers' confidence. Caregivers also need resources to help protect their mental health daily. Increased mindfulness can prevent burnout and reduce negative symptoms, and they can be implemented independently when needed (Cheung et al., 2020; Collins & Kishita, 2019; Klietz et al., 2020). Offering this education and training to caregivers in the context of a support group at the capstone site and through their website includes all the elements of best practice to promote health and wellbeing for reduced caregiver burnout.

### **Model/Theory**

The Environment-Health-Occupation-Well Being (E-HOW) Model and Adult Learning Theory helped guide this capstone project. The E-HOW model looks at the influence that one's environment, health, and occupational participation have on quality of life and well-being, and adult learning theory looks at the way adults learn (Merriam, 2018; Pizzi & Richards, 2017). Each of the E-HOW Model components are applicable to caregiver burnout. When in a caregiving role, one experiences environmental shifts. One of the largest environmental shifts occurs socially. Relationship dynamics between friends and family can change following a loved one's diagnosis, and Cianfrocca et al. (2020), Perrin et al. (2019), and Sturm et al. (2019) stated that social support was an identified need of caregivers. The research and E-HOW model serve as reminders during the capstone to verify that burnout prevention education does not interfere with relationship building in the support groups.

Health is the next element of the E-HOW model. The relationship between caregiver burnout and health is bidirectional. Burnout affects one's health, and health circumstances can



affect the likelihood that a caregiver will develop burnout. If a caregiver's loved one has greater health needs, that leaves less time to focus on themselves. Throughout the capstone it will be crucial to have awareness of not just the caregivers' health, but each of their loved ones as well.

Greater health concerns can affect a caregiver's occupational participation, which is the last component of the E-HOW model. Caregiving responsibilities can consume a large portion of one's day which can affect a caregiver's range of occupational participation (Lee et al., 2019). Providing caregivers with ways to decrease their daily care hours during educational sessions can help promote occupational participation.

All these components have the potential to affect a caregiver's quality of life and well-being. This capstone project aims to help promote overall well-being by taking into consideration caregivers' health, environments, and occupational participation. One of the assumptions of E-HOW is that spending time doing meaningful activities is health promoting, which is a core element of occupational therapy and a focus at educational sessions.

Adult learning theory will also be utilized during this capstone experience as the population includes adults and the primary area of focus is education. For this capstone project to be successful, a thorough understanding about how adults learn needs to be at the forefront. Adult learners need to be internally motivated, and they need to know the purpose behind what they are learning. They need to be ready to learn, and they have greater motivation when that learning relates to solving a problem. Adults pull from their own unique lived experience and are self-directed independent learners (Merriam, 2018).

Adults who are a part of a caregiver support group are likely internally motivated to participate in educational sessions as joining a support group means they have already taken a step to promoting their own health. The concepts covered in the social support groups need to be

carefully selected and presented in a way that is relevant and motivating to the group members. Intentionally incorporating all these components of adult learning theory will set up a more fruitful experience for the student researcher, the caregivers, and the capstone site.

### **Project Plan and Process**

The capstone project plan was to educate the caregivers at the local Parkinson's organization about burnout prevention strategies. To accomplish this, the plan included a needs assessment of the caregivers at the site, development and delivery of educational sessions targeting burnout prevention, data collection over caregiver satisfaction and confidence in applying strategies, and creation of articles for the site's blog to ensure the sustainability of the content. Throughout the capstone experience, the student researcher met with the capstone site mentor weekly, participated in biweekly discussion posts with classmates and faculty mentor, and consulted with other caregiver professionals. The capstone project plan, goals, and objectives were monitored and adjusted based on these collaborative efforts. The student researcher's project goals and objectives supported the ACOTE focus area of education. Goals consisted of conducting a needs assessment on caregivers at the capstone site, becoming certified in Lee Silverman Voice Treatment (LSVT) Big, promoting the health, well-being, and quality of life for caregivers of people with Parkinson's Disease, and ensuring sustainability of burnout prevention content. Table 1 provides a full list of project goals and objectives.

To organize the project plan, the student researcher created a weekly project timeline. Weeks one through three focused on acclimating to the site while conducting a needs assessment on the caregivers at the site. Weeks four and five centered around developing the first educational session with weeks six through eight focused on delivering that session to caregivers and collecting data. Weeks nine and ten were devoted to analyzing the data from the first educational

session and developing the second educational session. Weeks eleven and twelve were spent delivering the second educational session and collecting data. The final two weeks of the capstone experience were dedicated to analyzing data from the second session and ensuring sustainability of the content explored in all educational sessions. To enhance the capstone project and experience, the student researcher sought out various learning opportunities. These learning experiences increased knowledge, expertise, and helped refine the project over 14 weeks.

### **Project Timeline**

#### ***Weeks One Through Three***

The first three weeks of the capstone experience were focused on acclimating to the site while conducting a needs assessment on the caregivers. The student researcher attended daily CLIMB exercise classes and four support groups to immerse into the community of the local Parkinson's organization. Up to five caregivers attended the CLIMB exercise classes, but classes were primarily attended by people with Parkinson's Disease. Therefore, exercise classes were not the optimal location for a needs assessment. However, they did offer an opportunity to learn about Parkinson's Disease and its related challenges.

Three of the four support groups attended during this period were for caregivers. Two of the monthly caregiver groups met in person and the other met virtually. Each of these support groups was held at a different location. While participants between the support groups differed, one participant attended both an in-person support group and the virtual support group. During the first support group the student researcher introduced herself, the capstone project, asked about members' challenges, and spoke about LSVT Big. Educational topics that were relevant among all three groups were respite and mindfulness. Participants of one of the in-person groups also requested more information about LSVT Big and Loud and medication management.

***Weeks Four and Five***

Once informed of the caregivers' needs, the student researcher spent the following two weeks developing the first educational session to be delivered at the following monthly caregiver support groups. The student researcher also created pre- and post-surveys to be delivered before and after the educational session. Mindfulness was chosen as the first educational session focus because it is an evidence-based strategy that caregivers can independently apply (Cheung et al., 2020; Collins & Kishita, 2019; Klietz, 2020). Therefore, after the session caregivers could start implementing it into their lives immediately. The student researcher also shared information about LSVT Big and Loud and medication management to participants at one of the in-person support groups.

***Weeks Six Through Eight***

Weeks six through eight were spent delivering the first educational session, collecting data to measure program outcomes, and making refinements of the sessions based on group needs. Prior to delivering the burnout prevention educational sessions, the student researcher distributed pre-surveys. These surveys asked about caregivers' current confidence and satisfaction in accessing and applying the soon to be covered topics. Following presentation of the educational content, the student researcher gave the caregivers a post-survey to see if their confidence in applying these burnout prevention strategies changed. By evaluating change in confidence and satisfaction, these surveys assessed the effectiveness of the educational sessions (see Appendix B for the pre- and post-survey templates).

***Weeks Nine and Ten***

The student researcher spent the ninth and tenth weeks analyzing data from the first session and creating the second session with its associated surveys. The second educational

session was focused on respite as daily care time is the number one link to caregiver burnout (Lee et al., 2019; Sturm et al., 2019). Similarly to the first session, program outcomes were measured by changes in caregiver confidence and satisfaction through pre- and post-surveys. However, the post-survey also included a free response question to gather information about additional caregiver needs.

### ***Weeks Eleven and Twelve***

Over the next two weeks the student researcher delivered the second educational session, its surveys, collected data, and prepared for project sustainability. As with the first educational session, the student researcher delivered a pre-survey to all participants before presenting the content. Following the educational session, the student researcher gave out the post-surveys. The post-survey free response section guided the student researcher's choice in topics for project sustainability.

### ***Weeks Thirteen and Fourteen***

The final two weeks of the capstone experience were dedicated to data analysis and project sustainability. The student researcher analyzed the data collected from the second educational session both individually and in conjunction with the previous data. The student researcher also spent these weeks verifying that all project materials were easily accessible to the capstone site. Additionally, the student researcher wrote research-informed articles to be uploaded to the organization's blog. Presenting burnout prevention material in another format facilitated sustainability for the capstone site, encouraged carryover, and reached more caregivers.

### **Learning Opportunities**

The student researcher was afforded a multitude of learning opportunities throughout the capstone experience. The student researcher participated in two certification training courses to enhance knowledge about Parkinson's Disease. During the first two weeks of the capstone experience, the student researcher participated in an online Lee Silverman Voice Treatment (LSVT) Big certification course, a therapy protocol for Parkinson's Disease and other neurological disorders. This was a 14.5 hour asynchronous online course with lectures and virtual practice sessions. Through this course, the student researcher learned the evidence-based LSVT Big therapy treatment protocol. Along with neuromuscular reeducation exercises, the course included cueing techniques, grading suggestions, and tips for Parkinson's related challenges.

The student researcher also participated in a CLIMB training workshop. This hybrid two-day workshop consisted of educational content delivered via lecture, discussion, and hands-on application. During this workshop the student researcher learned about common symptoms of Parkinson's Disease and muscles most affected by the disease. The program addressed different treatment options for Parkinson's Disease and exercises that address mobility, balance, coordination, joint loading, and muscle activation. An LSVT Loud certified speech therapist also lectured about speech, swallowing, and cognitive challenges with Parkinson's. The student researcher learned about warning signs for dysphagia and aspiration, and ways to grade exercises to the appropriate cognitive challenge.

While developing educational sessions for caregivers, the student researcher also participated in daily CLIMB exercise classes to be immersed in the community of the local Parkinson's organization. Attending these classes gave the student researcher a better

understanding of Parkinson's Disease, its symptoms, and proper cueing techniques. The student researcher also joined support groups for people with Parkinson's Disease. At two of these support groups, the student researcher presented occupational therapy content about hand strengthening and adaptive equipment. The student researcher also presented educational content for the first 30 minutes of four CLIMB exercise classes. One of the sessions was presented at two locations. During one of these sessions, the student researcher had the opportunity to modify for low vision accessibility.

The student researcher was also able to learn from and network with many professionals. The student researcher connected with occupational therapists, speech therapists, physical therapists, music therapists, pharmacists, nurses, neurologists, dementia care specialists, dance therapists, caregiver consultants, and personal trainers specialized in Parkinson's Disease and aging. These relationships were built through meetings, emails, exercise classes, support groups, and Parkinson's events. The student researcher also participated in an "Instagram Live" with a caregiver and a dementia care specialist about ways that caregivers can support themselves.

The student researcher sat alongside many professionals when advocating for those with Parkinson's Disease at the Indianapolis statehouse. There was a rally to help raise awareness for Parkinson's Disease and advocate for a state registry. By having registry of all those diagnosed with Parkinson's Disease, organizations could spread their resources and support to all those who need it.

### **Project Refinement**

The student researcher had to alter project plans due to various time constraints. The capstone experience would be complete by the time of the April caregiver support groups, so the student researcher would only be able to present educational content at the February and March

groups. Additionally, there were three support group meetings where a speaker was already scheduled, so the student researcher had less time to present educational content. The student researcher had to adjust educational session plans and the project timeline due to these changes. See Appendix C for the timeline of the capstone project and experience.

### **Project Implementation**

Prior to implementation, the student researcher obtained approval from the Indiana University Institutional Review Board (IRB) to conduct this non-human subjects research with the capstone site. The capstone project was conducted over 14 weeks to educate caregivers at the local Parkinson's organization on burnout prevention strategies. Three caregiver support groups participated in the two educational sessions targeting burnout prevention. Two of the groups were in person and one was held virtually. The in-person support groups were held near the northern and southern regions of central Indiana. The educational sessions were only presented at the support groups held exclusively for caregivers to ensure a safe space to talk about caregiver burnout. The February educational session covered mindfulness, medication management, and LSVT Big and Loud. The March educational session focused on respite.

### **Participants**

Any caregiver of a person with Parkinson's Disease who was attending a caregiver support group at the capstone site fit the participant inclusion criteria. The support groups were inclusive of all races, genders, ethnicities, and ages. The age range varied, but most participants were 60 and above. There were all types of caregivers in these groups: spouses, children, and close family and friends. The caregiver support groups were small, ranging from four to seven participants. The in-person support groups ranged between four to six participants, and the virtual support group ranged between three to seven participants. For the first educational



session, two participants attended both an in-person support group and the virtual support group. For the second educational session, there was no overlap in participants at virtual and in-person groups.

Participants were recruited gradually. Before the student researcher started with the capstone site, the capstone site mentor released a short biography and photo of the student researcher with the capstone project focus in their monthly newsletter. During the first three weeks of the capstone experience, the student researcher introduced herself and the capstone project to the CLIMB exercise classes and the support groups. In weeks six through eight and eleven through twelve, participants were directly recruited either by email or during the in-person support groups. All members on the virtual support group mailing list were sent an email with the link to the Qualtrics pre-survey which had the informed consent form within it. If they completed the pre-survey, they gave their consent to participate in the study. The members at the in-person support groups were each given a paper copy of the informed consent form while it was read aloud by the student researcher. The informed consent form was presented at both educational sessions as participants varied from month to month. Participants were reminded that even if they participated in the first educational session, they did not have to continue participating in the study.

### **Educational Sessions**

The student researcher led six total educational sessions, two at each support group. Each of the educational sessions were between 15 to 30 minutes of the hour-long support group. If a speaker was present at the support group, the speaker delivered their content prior to the educational session. Those educational sessions were more condensed than those without a speaker to ensure adequate time for open discussion. At the first educational session, the student

researcher gave each of the caregivers a folder with printed handouts of the information to be covered that day. The caregivers then utilized that folder to hold materials received at the following support group. The student researcher created the educational sessions based on evidence from the literature review, training from LSVT Big, and consultation with a pharmacist, dementia care specialist, eldercare navigation specialist, site mentor, and caregivers. The student researcher was intentional about incorporating elements of best practice while providing education on requested topics so that sessions were motivating and relevant.

### *Mindfulness*

Mindfulness was the first educational session focus. While having the caregivers follow along in the three-page mindfulness packet, the student researcher first defined mindfulness, gave examples of mindfulness strategies, explained the research behind mindfulness and caregiver burnout, and described how to incorporate mindfulness into one's daily routine. The student researcher then supported the caregivers through practicing a body scan guided meditation, a 5 senses strategy, and box breathing. Due to time constraints, the student researcher explained how to use Zentangles but did not practice creating them during the session. Additionally, the south-central Indiana support group did not participate in the body scan, and instead, the student researcher informed them on how to access guided meditations. Lastly, the caregivers each wrote three instances where they could practice mindfulness and chose one to implement that week. The materials needed for the session included a mindfulness packet, guided meditation information, how to scan a QR code packet, box breathing diagram, 5 Senses strategy, Zentangle how-to guide, four 3.5" by 3.5" pieces of white paper, pens, and the pre- and post-surveys.

### ***LSVT Big and Loud***

The student researcher presented briefly on LSVT Big during all three January support groups, and the participants of the south-central Indiana support group requested additional information. At the February support group, the student researcher presented a more in-depth explanation of LSVT Big and Loud. This included an overview of the LSVT Big occupational and physical therapy protocol along with the LSVT Loud speech therapy protocol. The student researcher also explained step-by-step how caregivers can find an LSVT certified clinician. Lastly, the student researcher demonstrated four exercises utilized in the LSVT Big protocol. Materials included a one-page document explaining LSVT Big and Loud and a one-page document outlining the steps to find an LSVT certified clinician.

### ***Medication Management***

The student researcher delivered medication management content during the south-central Indiana support group's February session as it was an expressed need. First, the student researcher educated caregivers about a local pharmacist-led medication consulting service, Scripts & Beyond. This service helps clients understand their medications, manage side effects, recommend cost-saving alternatives, and reach individualized health goals (Scripts & Beyond, 2024). The student researcher also shared how medications can negatively interact with foods (Zwickey, 2022). Lastly, the student researcher emphasized the importance of tracking medications and strategies to do so. This segment required a six-page document for the caregivers to reference Scripts & Beyond, nutrition considerations, and management medication strategies.

### *Respite*

To facilitate carry over of mindfulness practice, all three respite educational sessions started with a one-minute guided meditation. The north-central Indiana and virtual support groups had a speaker scheduled for those groups, so the educational session commenced once the speaker had given her presentation. The student researcher first presented a brief overview about respite. This included definition, examples, and its importance for preventing caregiver burnout. Then, the student researcher provided six ways that caregivers can find local respite centers and providers and explained how to use the day-center guide and checklist. The day-center guide and checklist were provided by the National Adult Day Services Association (NADSA: Adult Day Services, 2022). The student researcher then referenced a list of six local day centers and their addresses, hours, and costs. The student researcher also provided information about Elder Helpers, a free service where local volunteers assist older adults with tasks such as shopping, gardening, transportation, handiwork, cleaning, cooking, reading, and entertaining (Elder Helpers, n.d.).

The student researcher then provided information about two adaptive tools to help ease caregiver worries in taking respite. These tools included the PillMap, a visual medication guide, and the RAZ Memory Cell Phone, a cellphone for individuals with cognitive impairments (PillMap, 2023; RAZ Mobility, 2024). Lastly, the student researcher led an activity about making a list of tasks that they wish another individual would complete. Writing the list better equips caregivers to accept help when offered, and it may encourage them to ask for help. When friends or family offer support, caregivers can think back to the list and request assistance with one of those tasks. Materials included: a packet overviewing respite, how to find local respite guide, a condensed and expanded list of local day centers, NADSA's how-to guide in choosing a day

center, NADSA's day-center site checklist, Elder Helpers informational sheet, adaptive tool informational sheets, a blank list and word bank for the activity, pens, and the pre- and post-surveys.

### **Project Evaluation and Results**

Adequately collecting longitudinal data about caregiver burnout was a challenge due to inconsistent attendance in support groups and maintaining participant confidentiality. Therefore, the student researcher opted to administer anonymous surveys before and after each educational session to measure program outcomes. Caregiver burnout would not change immediately following one educational session, so instead of measuring burnout, these surveys measured change in caregiver confidence and satisfaction in the burnout prevention material. Questions included confidence in ability to access resources and explain content to someone, and satisfaction in ability to apply burnout prevention strategies.

Responses were based on a five-point Likert scale, and a numeric value was given to each answer choice for scoring purposes. Possible answer choices to confidence questions included: not at all confident (score of 1), slightly confident (score of 2), somewhat confident (score of 3), quite confident (score of 4), and extremely confident (score of 5). Potential answer choices to the satisfaction questions included: very dissatisfied (score of 1), somewhat dissatisfied (score of 2), neither satisfied nor dissatisfied (score of 3), somewhat satisfied (score of 4), and very satisfied (score of 5).

Once the student researcher received completed surveys, she then summed survey questions to obtain a total score for each topic. For the mindfulness surveys this included the first three questions on the pre- and post-surveys, and for respite surveys it included the first four questions on the pre- and post-surveys. Once the total scores were summed, the student

researcher input data into SPSS to calculate a pre-survey mean and a post-survey mean for each educational topic. An independent samples t-test was also performed along with Cohen's *d* effect size calculations.

### **Survey Variations Between Groups**

The surveys varied slightly between support groups. The first educational session topic for the virtual group and north-central Indiana in-person group was mindfulness, while the south-central Indiana group session topics were mindfulness, medication management, and LSVT Big and Loud. All three groups' pre-surveys consisted of four Likert style questions about mindfulness. The post-surveys had three of these four Likert style questions about mindfulness. The frequency in which a caregiver practices mindfulness will not yet have changed at the point of collecting the post data, so the student researcher modified one question. The pre-survey question asking, "How often do you currently practice mindfulness strategies at home?" was replaced with "How likely would you be to practice mindfulness strategies at home?" in the post survey. All post-surveys from the first educational session had two open-response questions. One question asked about feelings after practicing the mindfulness activity in the session, and the other asked about if there were any questions, comments, or concerns. The south-central Indiana participants' pre- and post-surveys included all the above mindfulness questions along with four Likert style questions about medication management and LSVT Big and Loud.

The second educational session centered on respite for all three caregiver support groups. Therefore, the pre- and post-surveys had the same four Likert style questions with the fifth Likert style question differing. Like the mindfulness survey, the pre-survey asked about how often the caregiver currently finds time for respite, and the post-survey asks about likelihood of utilizing respite resources and strategies. The post-survey also included three free response questions. The

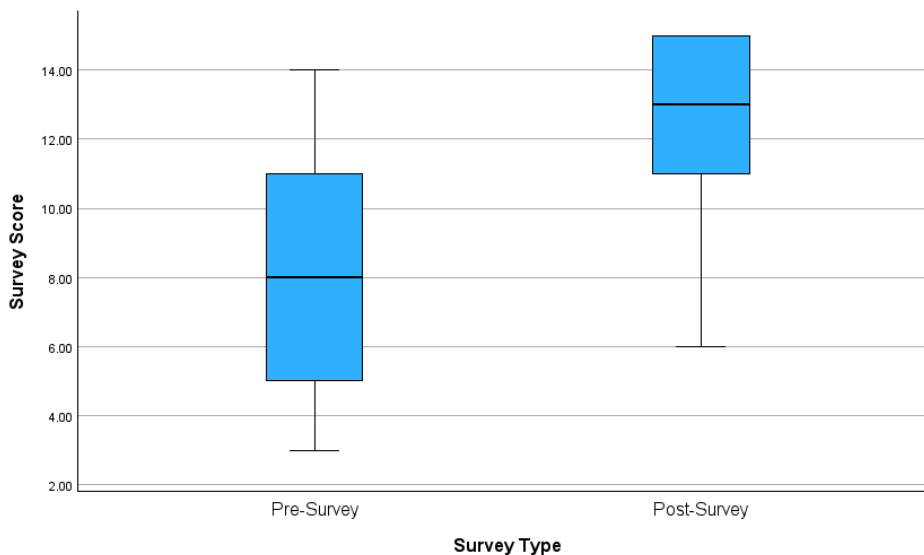
first free response question asked the number of sessions the caregiver had participated in. The second question inquired if there were additional topics that caregivers would still like to learn about, and the final question left an opportunity to note any comments, questions, or concerns.

### ***Survey Delivery***

The surveys were available in print or electronically pending the support group. The student researcher delivered the surveys in print at the in-person support groups and emailed the electronic version to potential participants at the virtual support group. For the in-person group, the surveys were delivered at the beginning of the session and collected at the end of the session. For the virtual support group, the student researcher emailed the Qualtrics pre-survey link three days before the virtual session. Once the capstone site mentor sent the follow-up email to the virtual group participants, the student researcher sent the post-survey link with documents reviewed during the educational session.

### **Results**

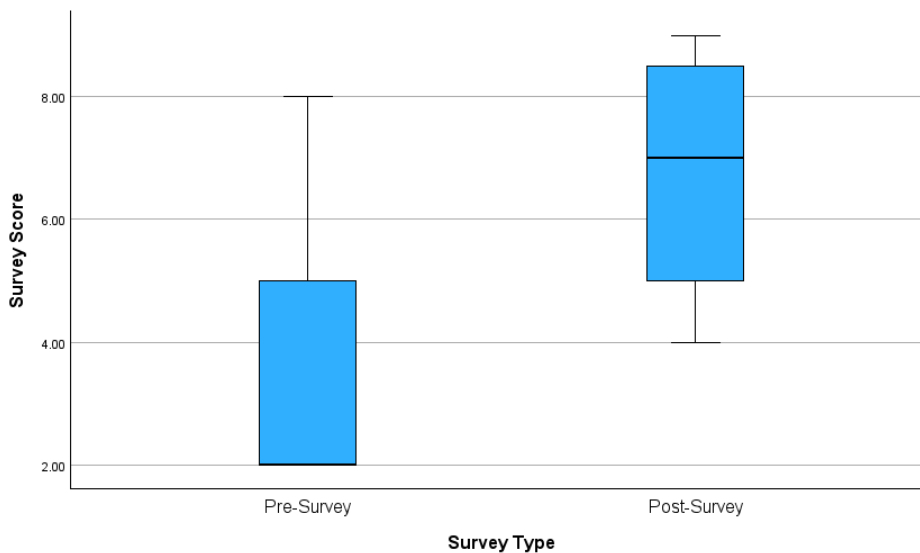
Across all three support groups, there were 19 caregivers who attended at least one educational session and eight caregivers who attended both educational sessions. There were 17 caregivers at the first educational sessions but only ten completed the mindfulness pre-survey and nine completed the mindfulness post-survey. There was a statistically significant difference ( $p = 0.005$ ) between the two groups with a large effect size (Cohen's  $d = 1.352$ ). This meant that there was a large difference between confidence and satisfaction of mindfulness knowledge before and after the educational session. Figure 1 displays the range of survey scores before the educational session (the pre-survey), and after the educational session (the post-survey). The average pre-survey score was 8.200 and the average post-survey score was 12.667, thus indicating a 54.472% increase in confidence and satisfaction.

**Figure 1***Confidence and Satisfaction with Mindfulness Knowledge*

*Note.* This figure represents caregivers' average confidence and satisfaction with mindfulness knowledge before and after an educational session about mindfulness. A participant's survey score is the sum of their responses to three questions with each question valuing 1, 2, 3, 4, or 5. The higher the value, the more confident or satisfied the participant was. Therefore, higher survey scores on this figure represent greater confidence and satisfaction with mindfulness knowledge and lower survey scores represent less confidence and satisfaction with mindfulness knowledge. The max possible score for the surveys was 15, and the lowest possible score for the surveys was 3. This represents responses from all three support groups. For the pre-survey group  $n=10$ , and for the post-survey group  $n=9$ .

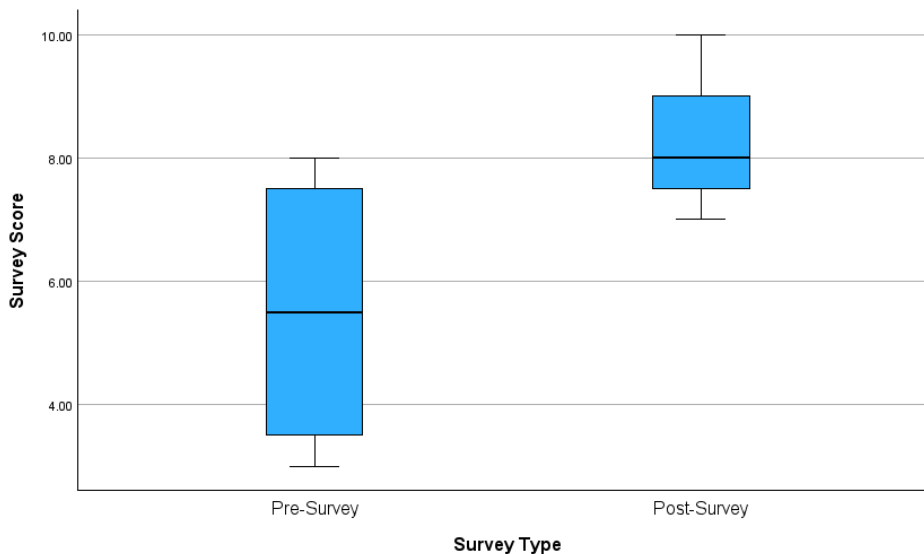
Participants from the south-central group also engaged with medication management and LSVT material at the first educational session. There were six caregivers present at the session and four completed the pre- and post-surveys for the LSVT and medication management content. There was not a statistically significant difference ( $p = 0.066$ ) between the LSVT pre-survey and post-survey scores. Figure 2 shows the range of scores on the surveys with the pre-survey average being 3.500 and the post-survey average being 6.750. This corresponds to a 92.857% increase in the average level of confidence and satisfaction in LSVT knowledge.



**Figure 2***Confidence and Satisfaction with LSVT Knowledge*

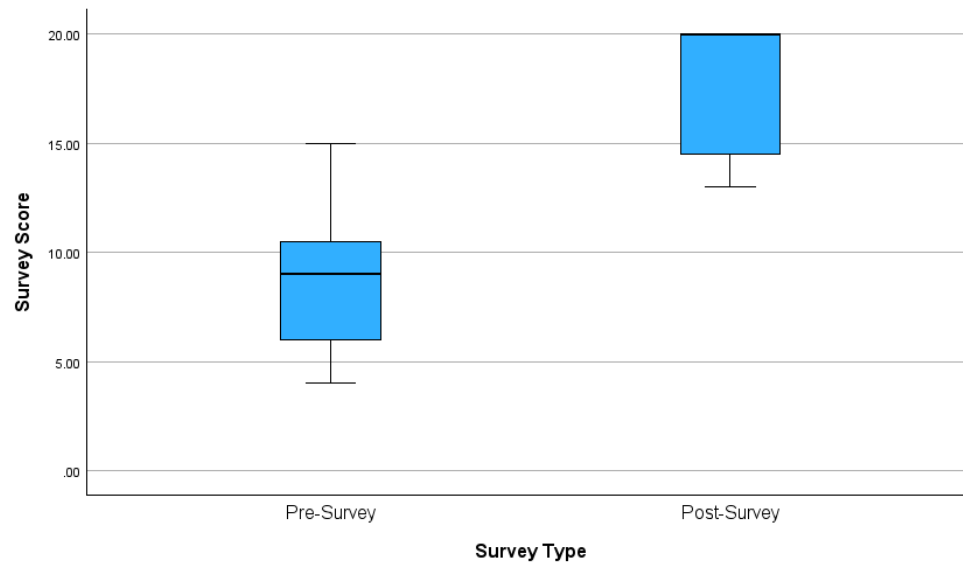
*Note.* This figure represents caregivers' average confidence and satisfaction with LSVT knowledge before and after an educational session about LSVT. A participant's survey score is the sum of their responses to two questions with each question valuing 1, 2, 3, 4, or 5. The higher the value, the more confident or satisfied the participant was. Therefore, higher survey scores on this figure represent greater confidence and satisfaction with LSVT knowledge and lower survey scores represent less confidence and satisfaction with LSVT knowledge. The max possible score for the surveys was 10, and the lowest possible score for the surveys was 2. This figure represents responses from the south-central Indiana support group. For the pre-survey group  $n=4$ , and for the post-survey group  $n=4$ .

There was a statistically significant difference ( $p = 0.044$ ) between pre- and post-survey medication management totals. This also resulted in a large effect size (Cohen's  $d = 1.444$ ), thus determining that there was a substantial increase between the confidence and satisfaction in medication management knowledge before and after the educational session. Figure 3 gives a visual representation of the medication management survey totals. The average total for the medication management pre-survey was 5.500 and 8.250 for the post-survey. The difference in means suggests a 50.000% increase in confidence and satisfaction.

**Figure 3***Confidence and Satisfaction with Medication Management Knowledge*

*Note.* This figure represents caregivers' average confidence and satisfaction with medication management knowledge before and after an educational session about medication management. A participant's survey score is the sum of their responses to two questions with each question valuing 1, 2, 3, 4, or 5. The higher the value, the more confident or satisfied the participant was. Therefore, higher survey scores on this figure represent greater confidence and satisfaction with medication management knowledge and lower survey scores represent less confidence and satisfaction with medication management knowledge. The max possible score for the surveys was 10, and the lowest possible score for the surveys was 2. This figure represents responses from the south-central Indiana support group. For the pre-survey group  $n=4$ , and for the post-survey group  $n=4$ .

There were 13 caregivers present at the second educational session. Eight of them completed the respite pre-survey and seven completed the post-survey. There was a statistically significant difference ( $p < 0.001$ ) between responses on the two surveys. The statistical difference also had a large effect size (Cohen's  $d = 2.579$ ), which means that there was a substantial difference in confidence and satisfaction of respite knowledge before and after the presentation of respite material. Figure 4 displays the array of scores on the pre- and post-surveys. The pre-survey average was 8.750, and the post-survey average was 99.184% percent larger at 17.429.

**Figure 4***Confidence and Satisfaction with Respite Knowledge*

*Note.* This figure represents caregivers' average confidence and satisfaction with respite knowledge before and after an educational session about respite. A participant's survey score is the sum of their responses to four questions with each question valuing 1, 2, 3, 4, or 5. The higher the value, the more confident or satisfied the participant was. Therefore, higher survey scores on this figure represent greater confidence and satisfaction with respite knowledge and lower survey scores represent less confidence and satisfaction with respite knowledge. The max possible score for the surveys was 20, and the lowest possible score for the surveys was 4. This represents responses from all three support groups. For the pre-survey group  $n=8$ , and for the post-survey group  $n=7$ .

### Discussion and Impact

Based on the literature review, gap analysis, and needs assessment, the student researcher found caregiver burnout to be an issue for caregivers at the capstone site. To help combat this, the student researcher created two educational sessions to teach burnout prevention techniques to caregivers. Mindfulness was prioritized during the first educational session so that caregivers could start implementing it immediately. Practicing mindfulness is associated with lower levels of caregiver burnout and negative mental health symptoms (Cheung et al., 2020; Collins & Kishita, 2019; Klietz et al., 2020). In addition to mindfulness, medication management and LSVT were requested topics by participants at one support group. Increased education about

disease and symptom management is associated with lower levels of caregiver burnout, so these topics were also addressed at the first educational session (Lee et al. 2019; Sturm et al., 2019; Terayama et al., 2018; Weir, Danilovich, & Hoover, 2022). The element most associated with caregiver burnout is daily care hours (Lee et al., 2019; Sturm et al., 2019). To emphasize the importance of rest for caregivers, respite was the focus of the second educational session.

The literature review, gap analysis, and needs assessment all suggested that education over the above burnout prevention techniques would be beneficial, but the outcome measures confirmed it. There was a large significant difference between pre- and post- educational session surveys about mindfulness, medication management, and respite. This difference shows that caregivers were not as confident and satisfied as they could be in their knowledge of burnout prevention. Increasing confidence and satisfaction equips caregivers with the skills necessary to combat burnout while empowering them to actively use said skills.

By the end of the 14-week capstone experience, the student researcher had met all projects goals and objectives. To reach these goals, sustainability of the capstone project was also considered. The student researcher configured burnout prevention materials into a new format. Burnout prevention resources were easy to access for staff at the site, and an alternative layout could reach more caregivers. This format also allowed the student researcher to educate on additional burnout prevention strategies.

### **Limitations**

While the capstone project benefitted caregivers at the local Parkinson's organization, there were limitations in the project design and findings. First, the data was based on small sample sizes. Each support group ranged from three to seven participants. Therefore, one outlier data point could skew the data set. Additionally, the participants were variable from month to

month so longitudinal data could not be collected. Of the 19 total participants, only eight of them attended both educational sessions. All those who attended the second educational session received printed resources from the first educational session. However, time did not allow for an in-person demonstration and explanation of those resources. Therefore, there was no way to ensure understanding of prior information.

There were also issues with data collection. During the first and second educational sessions, data was not collected from all caregivers at the in-person support groups. The south-central Indiana support group met during the CLIMB exercise class for people with Parkinson's Disease. To allow caregivers time to help with their loved ones' transition to and from class, the support group met for less than an hour. This contributed to a rushed wrap-up, and thus, missing surveys. Also, many participants did not complete the pre- and post-surveys from the virtual support group. Since the pre- and post- surveys were sent to everyone on the virtual support group mailing list, it was unknown if surveys were completed by those who attended the educational session. Additionally, there was no way to verify that the same participants who completed a pre-survey also completed a post-survey.

### **Impact**

Overall, the capstone project had a positive impact on the caregivers at the local Parkinson's organization, the capstone site, and the student researcher. Based on the results of the pre- and post- data, the mindfulness, medication management, and respite educational sessions had a large, positive impact on caregiver confidence and satisfaction across all groups. Following the educational sessions, caregivers were significantly more confident in their ability to access burnout prevention resources as well as their ability to apply those resources and strategies to their life. At the end of the mindfulness educational session, caregivers on average were likely to

utilize mindfulness strategies in the future. Following the respite educational session, caregivers on average were extremely likely to utilize respite strategies in the future. While burnout was not measured in this project, caregivers were educated on evidence-based burnout prevention strategies. Since caregivers reported likeliness to apply burnout prevention strategies, there is reason to believe that burnout may be positively impacted following these sessions.

On average, caregivers reported likeliness to apply mindfulness strategies, and three caregivers in the north-central Indiana support group reported having utilized one of the mindfulness strategies within the past week. One caregiver reported incorporating mindfulness while brushing her teeth. She started looking forward to this mindful moment as it had become a form of respite. Another caregiver remarked how he finds himself more present throughout his day now that he intentionally applies mindfulness strategies. This comment showcased the carryover of the strategies a month later, and the positive impact that utilizing those strategies has had on his life.

Along with the positive impact on the caregivers, the staff at the capstone site expressed sincere gratitude for the student researcher and the capstone project. Having a collection of caregiver burnout prevention resources aligns with the capstone site's mission to support the physical, mental, and spiritual health of people with Parkinson's Disease and their caregivers. A speaker who was present at two educational sessions also noted that she shared aspects of the respite session with other professionals and caregivers. This meant that these burnout prevention strategies and resources were being spread to caregivers beyond those in the community of the local Parkinson's organization. Through caregivers' comments, quantitative results, and the spread of burnout prevention resources, the capstone project was successful in promoting the health, wellbeing, and quality of life of caregivers at the capstone site.

Lastly, the student researcher was positively impacted by the capstone project and experience. This experience provided learning opportunities such as leading a support group, developing educational sessions, running an exercise class, modifying exercises, utilizing LSVT Big principles, networking, and advocating for the value of occupational therapy. Over the 14-week capstone experience, the student researcher developed abilities in leadership, public speaking, advocating, networking, time-management, empathy, cueing clients, and burnout prevention. The skills developed during this time will be useful in any occupational therapy setting.

### **Sustainability Plan**

The student researcher ensured that burnout prevention techniques were implemented into the programming at the capstone site before the end of the capstone experience. The student researcher gave the site's staff access to all digital files of the content created for educational sessions. This way, staff could make sure that caregivers new to the organization's programming had access to that material. However, without someone leading an educational session focused on those handouts, the material was not as useful to the staff at the capstone site. After a discussion with the site mentor about where this content would be most beneficial following the capstone experience, they concluded that the site's blog would be the most appropriate avenue.

The blog was an aspect of the organization's programming that the team wanted to continue developing. Presenting burnout prevention material online allowed for the content to reach a larger audience as the educational sessions had been limited to the caregivers who attended support groups. Online presentation also allowed for gradual burnout prevention education. Due to time constraints of the capstone experience, the student researcher had to prioritize content covered at educational sessions. Therefore, some burnout prevention topics

could not be addressed in the sessions. Educational sessions about burnout prevention techniques were a two-month intensive experience. Instead, fourteen blog posts would present information in manageable chunks while extending the time focused on burnout prevention. Posting content via the organization's blog reviews burnout prevention strategies for caregivers and thus can facilitate carryover. Lastly, having this material posted online also relieves the burden on staff from having to present the material themselves.

### **Conclusion**

The purpose of this capstone project was to provide a Midwest Parkinson's organization with resources and strategies aimed at promoting health, wellbeing, and quality of life to ultimately prevent caregiver burnout. The capstone project included development and delivery of two educational sessions to participants in three caregiver support groups. Following educational sessions, caregiver confidence and satisfaction in applying burnout prevention strategies greatly improved. When considering sustainability of the project, the student researcher transformed content from educational sessions to articles for the capstone site's blog. The outcomes of the educational sessions validated the positive impact of the capstone project on the site, the caregivers, and the student researcher. Sustainability efforts continue to support caregiver burnout prevention at the local Parkinson's organization.



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**Table 1***Capstone Project Goals and Objectives*

<b>Goals</b>	<b>Objectives</b>
1. The student will promote the health, well-being, and quality of life for caregivers of people with Parkinson's Disease.	1. The student will educate caregivers on Parkinson's disease, respite care, safe transfer and ADL training, and mindfulness techniques.
	2. The student will help increase caregiver self-efficacy.
2. The student will become Lee Silverman Voice Treatment (LSVT) Big certified to educate caregivers on proper ADL training for their loved ones with Parkinson's Disease.	1. The student will apply to the Horizon Fund for LSVT Big training.
	2. The student will dedicate seven hours a week for two weeks to complete the LSVT Big training.
	3. The student will pass the LSVT Big certification with a score of 84% or higher.
3. The student will perform a needs assessment on the caregivers at the capstone site.	1. The student will observe and ask questions at the capstone site's support groups and exercise classes during the first three weeks of the Capstone Experience.
	2. The student will synthesize caregiver needs based on feedback obtained during caregiver support groups.
	3. The student will create educational sessions based off caregiver needs and evidence-based burnout prevention strategies.
4. The student will facilitate sustainability of caregiver burnout education at the capstone site.	1. The student will upload all burnout prevention resources into a Google Drive folder for the capstone site.
	2. The student will write articles about burnout prevention topics for the capstone site's blog.

## Appendix A

### Interview Questions for the Capstone Site

- How many caregiver support groups are across Indiana?
- How often do the caregiver support groups meet?
- Are the caregiver support groups in-person, virtual, or both?
- Do the same people consistently come to the caregiver support groups?
- Do the caregivers who attend the CLIMB exercise classes also come to the caregiver support groups?
- What is the general meeting format of the caregiver support groups?
- Do you find caregiver burnout to be an issue for some of the caregivers who attend the caregiver support groups?
- What are some of the caregivers' challenges?
- I saw educational resources on the organization's website, is this something that you would like to be expanded?
- What are some of the features of the iCLIMB app? Are there things you would like to be expanded on this?

## Appendix B

### Pre- and Post-Survey Templates

#### Pre-Survey Template

Please circle the response that best corresponds to how you feel right now. There are no right or wrong answers, so please answer honestly.

1. How confident do you feel in your ability to apply [insert skill to be covered at the session] at home?

Not at all confident	Slightly confident	Somewhat confident	Quite confident	Extremely confident
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2. How confident do you feel in your ability to explain [insert skill to be covered at the session] to someone?

Not at all confident	Slightly confident	Somewhat confident	Quite confident	Extremely confident
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3. How satisfied are you in your ability to perform [insert skill to be covered at the session]?

Very dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Very satisfied
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4. How often do you currently utilize [insert skill to be covered at the session] at home?

Never	Rarely	Occasionally	Often	Frequently
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### Post-Survey Template

Please circle the response that best corresponds to how you feel right now. There are no right or wrong answers, so please answer honestly.

1. How confident do you feel in your ability to apply [insert skill covered at the session] at home?

Not at all confident	Slightly confident	Somewhat confident	Quite confident	Extremely confident
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2. How confident do you feel in your ability to explain [insert skill covered at the session] to someone?

Not at all confident	Slightly confident	Somewhat confident	Quite confident	Extremely confident
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3. How satisfied are you in your ability to perform [insert skill covered at the session]?

Very dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Very satisfied
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4. How likely would you be to utilize [insert skill covered at the session] at home?

Very unlikely	Unlikely	Neutral	Likely	Very likely
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5. How many educational sessions have you attended?

6. Any additional comments?



## Appendix C

# Project Timeline

