

**THE IMPACT OF TREATMENT MODALITY AND PSYCHOSOCIAL
FACTORS ON INFORMAL CAREGIVERS OF PEOPLE WITH
PARKINSON DISEASE**

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To my family, who love and support me unconditionally, 143.

To my friends, who I know are very happy I can no longer use “I really can’t, I have to work on my thesis” as a reason to stay at home.

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ABSTRACT

Parkinson disease (PD) is a degenerative neurological disorder that impacts a great number of individuals in the United States and often results in significant changes to speech and voice, as well as increased reliance on informal caregivers. Relevant literature has shown that caring for a person with PD can have a negative impact on caregivers but has not explored the relationship between perceived impact of life events or relationship satisfaction and caregiver quality of life (CGQOL), or the impact that therapy delivery paradigm can have on these psychosocial factors and on caregivers of people with PD. The current study examined the psychosocial factors associated with caring for someone who has PD and the effect of therapy delivery paradigm on these factors through regression and mediation analyses. Results indicated that caregiver burden, caregiver depression, and perceived impact of life events (PILES), were significantly associated with CGQOL post-treatment, but quality of life pre-treatment and treatment modality were not significant. Although no evidence of mediation was found in this study, change in PILES scores from pre- to post-treatment was significantly associated with caregivers' ratings of patient self-efficacy for communication post-treatment, while caregiver burden pre-treatment and self-efficacy for people with disabilities pre-treatment were significantly associated with caregivers' rating of self-efficacy for people with disabilities post-treatment. Collectively, results from this study suggest that focusing on the psychosocial impact of caregiving is an integral part of the treatment process for any provider working with people with PD. Ensuring that caregivers receive the support and education needed to effectively manage the psychosocial factors associated with caregiving will lead to higher quality of care for the patient, as well as better patient outcomes in therapy, and in their daily lives.

INTRODUCTION

Parkinson disease (PD) is a degenerative neurological condition that is characterized by deficits in both limb motor function and speech. It has been estimated that there were 680,000 individuals in the United States ages 45 years or older with PD in 2010, and that the number of patients will rise to approximately 930,000 in 2020 and 1,238,000 in 2030 based on census population projections (Marras et al., 2018). People with PD often experience decreased speed of movement, tremors, and difficulties with speech and voice. Of the almost 700,000 individuals with PD in the United States, researchers estimate that 89% have voice disorders and over 45% have articulation disorders, including hypophonia and hypokinetic dysarthria (Logemann & Fisher, 1981). These patients frequently experience decreased vocal pitch and loudness, hoarse or breathy vocal quality, imprecise or slurred articulation, and vocal tremor. Their rate of speech is also altered, ranging from abnormally slow to abnormally fast (Sapienza & Hoffman, 2018).

Despite these clear communication issues, only 3-4% of patients receive speech treatment (Ramig et al., 2008). In many cases, travel distance and unequal distribution of healthcare providers with the knowledge necessary to treat people with PD limit access to care. However, telemedicine, or the use of technology to deliver care at long distances, can allow patients to overcome barriers related to receiving treatment. While this seems like the perfect solution, various healthcare policies, including limited reimbursement for telemedicine services, are slowing the implementation and growth of telemedicine-centered care models for patients with PD (Achey et al., 2014). Studies that examine the benefits and drawbacks of telemedicine are critical for developing more targeted telemedicine policies and reimbursement strategies.

Telemedicine

The availability and use of telemedicine platforms as a model of service delivery for people with PD has increased in recent years. Achey et al. (2014) surveyed prominent neurology departments in 2012 and found that over 85% had implemented telemedicine programs or planned to do so within the year. These platforms allow patients to overcome common barriers to treatment like mobility issues and travel distance to specialists. While the clinical use of telemedicine is increasing, particularly in response to the COVID-19 crisis, the literature on the subject is not expanding at the same rate—a database search of the terms ‘telemedicine’ and ‘Parkinson disease’ led Achey et al. (2014) to 53 relevant articles, with only 9 relating to actual service delivery to patients. Six years later, entering the same search criteria on PubMed leads to 144 articles, with only 14 relating to service delivery. A majority of these articles make the same claims—that the telemedicine services for people with PD is promising option in terms of both treatment outcomes and technological feasibility, but many providers have been slow to implement telemedicine services (Dorsey et al., 2010, Dorsey et al., 2013, Mammen et al., 2018). Achey et al.’s (2014) review on the past, present, and future of telemedicine for people with PD makes many of the same claims. Namely, while telemedicine services are an effective option for people with PD, policies surrounding insurance and limited reimbursement for these services has slowed the adoption of this model of service delivery. Providing therapeutic treatment via telemedicine platforms has been found to be as effective at increasing vocal intensity as face to face voice treatment for people with PD (Tindall et al., 2008). Tindall et al. (2008) examined the effectiveness of providing voice therapy via videophones to people with PD daily for a four-week period and compared outcomes to traditional treatment delivered face-to-face. Participants achieved post-treatment improvements in vocal intensity that were similar to improvements seen in participants who received face-to-face treatment. Following treatment, participants were given the Telemedicine Satisfaction

Questionnaire, created by Yip et al. (2003). Results of this questionnaire indicated that participants were highly satisfied with the videophone service delivery model and the decreased travel time to receive services (Tindall et al., 2008).

People with PD and their caregivers in Dorsey et al.'s 2010 study reported high degrees of satisfaction with the telemedicine platform used to provide services. They believed that telemedicine decreased travel burden and increased their access to high quality PD specialists and claimed that telemedicine was an improvement as compared to previous face-to-face experiences. Participants felt that the providers listened to their concerns and did not rush them through the appointment despite technological difficulties related to poor signal or difficulty hearing their provider (Dorsey et al, 2010). These findings are indicative of the potential that telemedicine has to expand access to specialist care for people with PD and provide treatment outcomes that are comparable to those seen in face-to-face treatment.

Effects on Care Partners

With the costs of skilled care for older patients rising rapidly, many families are turning away from expensive long-term care facilities or home health aides and are assuming the role of primary caregiver for parents, spouses, or family members (Martinez-Martin et al., 2012). Many of these caregivers do not have the education or ability to provide long-term care, and often experience a variety of psychosocial effects due to the burden of providing care to a person with PD (Peterson et al., 2016, Martinez-Martin et al., 2012). These effects take a mental and physical toll on caregivers, which can negatively impact their effectiveness as a care partner in treatment, and the overall quality of care the patient is receiving (Mosley et al., 2017). Caregivers report issues with mental health, increased caregiver burden, and reduced quality of life through both formal and informal measures, including surveys and scales that are specific to PD caregivers,

similar measures that can be applied to the general population, short- and long-term clinical observations, and interviews with caregivers (Martinez-Martin et al., 2012, Zarit et al, 1986).

Caregiver burden can look different from person to person but is typically described in relevant literature as the extent to which caregivers feel that providing care for the patient has a negative effect on their physical, financial, social, and mental state (Zarit et al., 1986). Protective factors like frequent breaks, high self-esteem and resilience, and family support can shield some caregivers from the negative impact that mental health issues, economic strain, and reduced relationship status can have on the caregiver's perception of burden and quality of life (Martinez-Martin et al., 2012). As the disease progresses, the burden of caring for a person with PD increases, with related increases in morbidity and mortality for patients, and increases in disability for patients and caregivers (Hassan et al., 2012). Results from the PDQ-39 and Multidimensional Caregiver Strain Index (MCSI) analyzed in Hassan et al.'s 2012 suggest that at ten years of disease and beyond, patients experience an overall reduction in quality of life in all domains assessed by the PDQ-39, and caregivers experience an overall increase in burden in all domains assessed by the MCSI. Hassan et al., (2012) conclude by stating that improvements in strategies to relieve caregiver burden and increases in caregiver access to in-home support are necessary to allow patients to remain in their homes throughout the disease progression.

Several studies have shown that mental health issues can increase caregiver burden and reduce overall quality of life for both patients and caregivers. Mental health issues, like depression and anxiety, in people with PD are commonly associated with increased caregiver burden and decreased quality of life for caregivers (Schrag et al, 2005). Patients with anxiety often rely excessively on the caregiver for support and supervision, and depression in people with PD can decrease the amount of relationship reciprocity and the patient's motivation to participate in treatment or activities of daily living (Mosley et al., 2017). Depression, unlike other mental health

issues, often goes undiagnosed for a prolonged period of time in people with PD, because some common symptoms of depression, like flat affect, fatigue, decreased appetite, and insomnia, are frequently mistaken for a normal part of the progression of PD (Dissanayaka et al., 2011). Oldenkamp et al. (2016) found that caregivers of patients with higher rates of comorbidity or significantly lower motor abilities more often experienced mental health issues that were disruptive to their daily life. Apathy is also common in people with PD and has been associated with both increased cognitive impairment and dementia in patients and decreased quality of life for caregivers (Fitts et al., 2015, Martinez-Martin et al., 2012).

While relevant literature explains the negative relationship between caring for a person with PD and overall caregiver and patient quality of life, these studies have not explored the relationship between perceived impact of life events or relationship satisfaction and quality of life. They also have not explored the impact that therapy delivery paradigm can have on these psychosocial factors and on caregivers of people with PD. There is a potential for telemedicine therapy to increase or decrease caregiver burden and other psychosocial factors. There are added burdens associated with telemedicine care, including setting up the technology necessary to participate and related technological difficulties. However, there is also a possibility that factors like decreased time and travel burden associated with telemedicine could benefit caregivers who are used to traveling long distances for their care receiver's specialty medical care. Understanding the effect that treatment modality can have on a caregiver's physical and emotional state is an integral part of understanding how this impact can influence treatment outcomes for the person they are caring for, even if the patient is not experiencing negative psychosocial effects themselves. This research seeks to assess the psychosocial effects associated with caring for someone who has PD, including apathy, depression, quality of life, self-efficacy, communication participation, and caregiver burden, and the effect of therapy delivery paradigm on these psychosocial factors.

PURPOSE

The purpose of this study was to investigate the impact of therapy delivery paradigm on psychosocial factors associated with caregiving (i.e., depression, caregiver burden, and relationship satisfaction), and whether those factors, in turn, affect caregivers' quality of life. Using an implementation study design, we aimed to examine two questions.

1. What impact does therapy delivery paradigm (either traditional or telemedicine) have on the psychosocial factors associated with caregiving? In this case, the literature does not provide enough evidence to support a directional hypothesis. We will examine this in two ways.
 - a. ANOVAs will be used to understand if there is an effect of treatment modality in pre- to post-treatment change in the caregiver-related psychosocial variables.
 - b. A regression analysis will be used to determine whether treatment modality, caregiver-related psychosocial variables (perceived impact of life events, depression, relationship satisfaction, and caregiver burden), and quality of life at pre-treatment predicted caregivers' quality of life post-treatment.
2. How do caregiver ratings of patient apathy, self-efficacy for communication, and self-efficacy of people with disabilities mediate the relationship between caregiver-related psychosocial variables and caregiver quality of life?
 - a. A mediation analysis will be used to determine whether patient-related psychosocial variables (caregiver ratings of patient apathy, self-efficacy for communication, and self-efficacy of people with disabilities) mediated the relationship between caregiver-related psychosocial variables and caregiver quality of life.

- b. We hypothesized that negative perceptions of their care partners (patient apathy, self-efficacy for communication, and self-efficacy for disabilities) would lead to reduced ratings of caregiver quality of life.

METHODS

One hundred and five (105) people with PD were screened for participation in this study, and 40 were excluded from the study for a variety of reasons (see Figure 1). Of the 65 pairs enrolled, 34 chose to receive traditional face-to-face treatment with a speech-language pathologist (SLP) using the SpeechVive device, and 31 elected to receive treatment with an SLP using the SpeechVive device through a telemedicine platform developed for use with the device by SpeechVive, Inc. Each of the SLPs completed their own assessments to determine the scope and duration of treatment and number and frequency of sessions to best serve each patient. Participants with PD used the SpeechVive for 3 months and then were given the option to purchase the device (at the post-session). If they chose to purchase the device, they continued to use it for the next 3 months. If they chose not to purchase the device, they did not use the device for the second 3 months. All participants were invited to participate in all post-testing sessions and their device status was recorded for each. Participants were tested at 4 time points: pre-session, mid-session (1.5 months after pre-session), post-session (3 months after pre-session) and 3-month post-session (6 months after pre-session). Participant attrition occurred throughout the study for a variety of reasons (see figure 1), with 50 pairs completing the study to the post-session (3 months after pre) and 48 pairs completing the 3-month-post-session (6 months after the initial pre-session). Figure 1 describes criteria for initial exclusion and reasons for participant attrition from the study in greater detail.

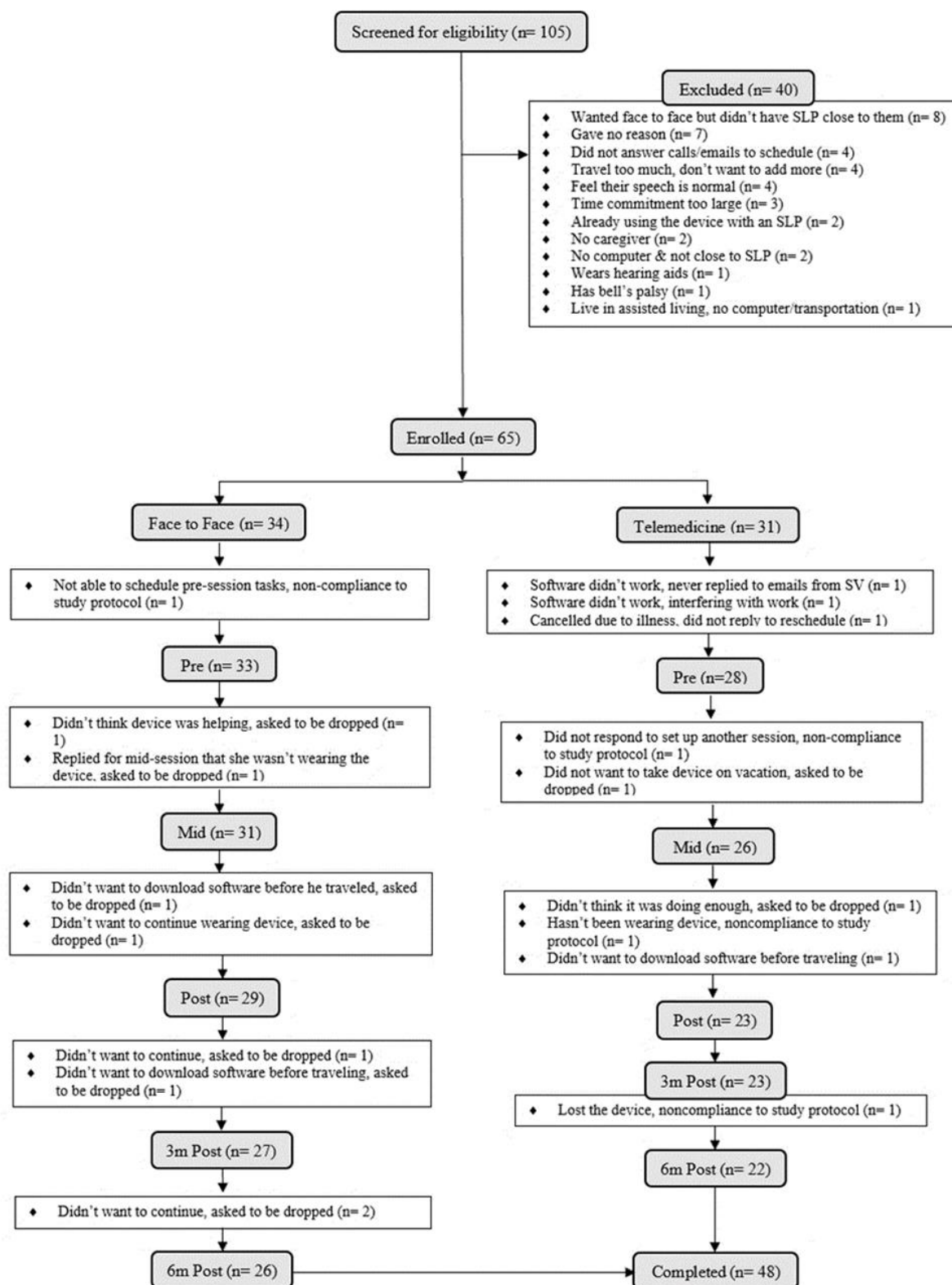


Figure 1 – CONSORT flow diagram of patient enrollment and participation

Data Collection

Participants were given specific instructions on how to complete all surveys through the secure web-based application Research Electronic Data Capture (REDCap). A PowerPoint containing instructions on how to access, complete, and submit all surveys electronically was emailed to participants. For patients who had difficulty with the online platform, additional assistance and paper versions of the surveys were made available.

Caregiver-Related Surveys

- **Caregiver Burden (CBI)**
 - Purpose: Assessment of caregiver burden
 - Length: 12 items
 - Example Items: “Do you feel angry when you are around your care receiver? Do you feel uncertain about what to do about your care receiver?”
 - Scoring: Never (0) – Nearly Always (4)
 - Higher score = Higher levels of burden
- **Depression (CG-D)**
 - Purpose: Used to identify depression in older adults
 - Length: 15 items
 - Example Items: “Do you often feel helpless?” “Do you feel that your life is empty?”
 - Scoring: Changed for each question, for some yes (1), No (0); for others yes (0), no (1). >5 suggests depression, >10 almost always depression
 - Higher score = Higher levels of depression
- **Perceived Impact of Life Events (PILES)**
 - Purpose: Examines what domains participant is perceiving gains/losses in associated with life events. Participants were directed to consider the diagnosis of PD as the life event when answering these questions.
 - Length: 29 items
 - Example Items: Meaning in life, time spent with friends, financial security, level of social acceptance
 - Scoring: Extreme Loss (1) – Extreme Gain (7)
 - Higher scores = Higher perceived gains in domains assessed
- **Relationship Satisfaction (REL)**
 - Purpose: Assesses the satisfaction of the patient-caregiver relationship
 - Length: 5 items
 - Example Items: “You have a good relationship.” “Your relationship is strong.”

- Scoring: Strongly Disagree (0) – Strongly Agree (5)
 - Higher scores = Stronger relationship
- **Quality of Life (CGQOL)**
 - Purpose: Assess the quality of life of caregivers of people with PD
 - Length: 46 items
 - Example Items: “Does the regular everyday care and attention to your care receiver make you depressed?” “Have you continued at your former place of work after your care receiver fell ill?”
 - Scoring: Each item scored differently
 - Higher score = higher quality of life

Patient-Related Surveys

- **Apathy (P-AP)**
 - Purpose: Recommended as a tool to measure the severity of apathetic symptoms in Parkinson disease
 - Length: 14 items
 - Example Items: “Are you interested in learning new things?” “Do you have plans and goals for the future?”
 - Scoring: Not at all (0) to a lot (3)
 - Higher score = Less apathy
- **Self-Efficacy**
 - Communication (SEC)
 - Purpose: Assess the care receiver’s communication participation
 - Length: 10 items
 - Example Items: “Does their condition interfere with...talking with people they know? Communicating when they need to say something quickly?”
 - Scoring: Very Much (0) – Not at all (3)
 - Higher score = Higher levels of self-efficacy for communication
 - People with Disabilities (SEP)
 - Purpose: Assess the care receiver’s self-efficacy for daily life activities
 - Length: 6 items
 - Example Items: “You can keep your care receiver’s PD from being the center of your life...from interfering with the things you want to do?”
 - Scoring: Not at All (1) – Completely (5)
 - Higher score = Higher levels of self-efficacy

This research sought to assess 1) the psychosocial effects associated with caring for someone who has PD, including depression, quality of life, communication participation, and caregiver burden, and 2) the effect of therapy delivery paradigm on these psychosocial factors. Survey data was collected from caregivers at three different time points: pre-session, post-session, 3-month post session. These surveys are listed in Table 1 below. Appendix A displays what surveys caregivers were asked to complete, and how many of these surveys each participant completed at each time point: pre-treatment, post-treatment, and 3-months post-treatment.

Table 1– RedCap Surveys: Caregivers.

Apathy Scale*** <i>Starkstein et al., 1992</i>	Relationship Satisfaction <i>Norton, 1983</i>
Zarit Burden Interview <i>Bedard et al., 2001</i>	Self-Efficacy of Communication*** <i>Baylor et al., 2013</i>
Geriatric Depression Scale <i>Sheikh et al., 1986</i>	Self-Efficacy for People with Disabilities*** <i>Amtmann et al., 2012</i>
Perceived Impact of Life Events Scale <i>Servaty-Sieb, 2014</i>	Scale of Quality of Life of Caregivers <i>Glozman et al., 1998</i>

***Indicates caregivers were asked to respond about their care receiver

Statistical Analysis

Before any data could be analyzed, missing data from survey responses were replaced. Each survey had varying degrees of missing responses, which can be found in Appendix A. In total, 18.4% of survey responses from the telehealth group had missing data, and 12.4% of face to face group responses had missing data. On a question-by-question basis for each participant, missing responses were replaced with the average response on the survey for the participant on that survey instrument. T-tests were used to determine if there were significant differences across the treatment modality groups at baseline. Then, a correlation matrix was computed to determine how the caregiver-related and patient-related psychosocial variables were correlated.

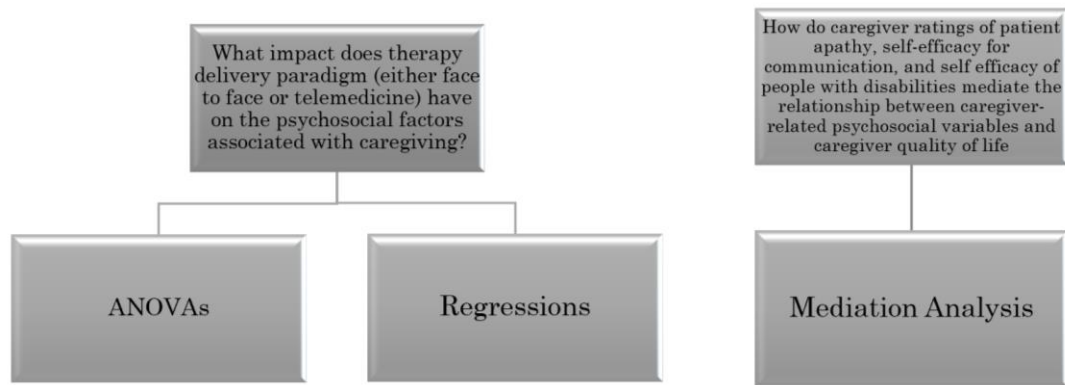


Figure 2 – Conceptual model for research questions and associated statistical analyses

A regression analysis was used to determine whether treatment modality, caregiver-related psychosocial variables (perceived impact of life events, depression, relationship satisfaction, and caregiver burden), and quality of life at pre-treatment predicted caregivers' quality of life post-treatment. In these models, the pre-treatment value for quality of life, treatment modality, and the pre-treatment values for the caregiver-related psychosocial variables were included. To develop a prediction model that only used predictors related to quality of life post-treatment, models were run individually, adding the change (pre- to post-treatment) for one psychosocial variable at a time. Exploring the model in this way, limited the noise added to the model by predictors unrelated to quality of life post-treatment, a critical given the sample size. Then a full model was run including all psychosocial variables where the $p < .10$ (pre-treatment and pre- to post-treatment change), plus treatment modality and quality of life pre-treatment.

A mediation analysis was used to determine whether patient-related psychosocial variables (caregiver ratings of patient apathy, self-efficacy for communication, and self-efficacy of people with disabilities) mediated the relationship between caregiver-related psychosocial variables and caregiver quality of life. Variables that were significant in the final model of the regression analysis were included in the mediation models. As with the regression analysis, models were run with

each individual patient-related psychosocial variable, adding the pre-treatment value and the change between pre- and post-treatment one variable at a time.

RESULTS

Means, standard deviations, and minimum and maximum values are presented for each variable and each treatment modality group in Table 2 and for pre- and post-treatment in Table 3.

Table 2 – Means, standard deviations (SD), min, and max values for each survey instrument by treatment modality

Measure	Group	Obs.	Mean	SD	Min	Max
Caregiver Quality of Life	Face-to-face	58	154.35	16.79	96.2	193
	Telemedicine	47	152.45	12.02	121.5	195
Caregiver Burden	Face-to-face	57	9.10	8.49	0	33
	Telemedicine	48	10.51	8.93	0	29
Caregiver Depression	Face-to-face	60	1.48	2.10	0	10
	Telemedicine	50	1.69	1.70	0	7
Caregiver Perceived Impact of Life Events	Face-to-face	58	106.03	21.10	57	167
	Telemedicine	47	103.18	22.13	56	171
Caregiver Relationship Satisfaction	Face-to-face	58	22.91	4.17	0	25
	Telemedicine	47	21.17	6.31	0	25
Caregiver Rating of Patient Apathy	Face-to-face	58	10.69	6.70	0	27
	Telemedicine	47	10.50	7.63	1	31.1
Caregiver Rating of Patient Communication	Face-to-face	58	14.64	7.83	0	28
	Telemedicine	50	13.03	8.74	0	30
Caregiver Rating of Patient Self-Efficacy for Daily Activities	Face-to-face	58	18.27	5.48	6	28
	Telemedicine	49	18.58	5.70	8	30

Table 3 – Means, standard deviations (SD), minimum, and maximum values for each survey instrument pre- and post-treatment

Measure	Time	Obs.	Mean	SD	Min	Max
Caregiver Quality of Life	Pre-treatment	57	154.63	14.85	96.2	193
	Post-treatment	48	152.17	14.79	112	195
Caregiver Burden	Pre-treatment	58	9.60	8.25	0	33
	Post-treatment	47	9.90	9.24	0	31
Caregiver Depression	Pre-treatment	62	1.58	1.98	0	10
	Post-treatment	48	1.58	1.87	0	8
Caregiver Perceived Impact of Life Events	Pre-treatment	57	105.11	20.46	57	167
	Post-treatment	48	104.33	22.90	23.4	171
Caregiver Relationship Satisfaction	Pre-treatment	57	21.89	6.11	0	25
	Post-treatment	48	22.42	4.14	0	25
Caregiver Rating of Patient Apathy	Pre-treatment	57	9.52	6.20	0	28
	Post-treatment	48	11.87	7.89	0	31.1
Caregiver Rating of Patient Communication	Pre-treatment	59	13.44	7.51	0	30
	Post-treatment	49	14.49	9.12	0	30
Caregiver Rating of Patient Self-Efficacy for Daily Activities	Pre-treatment	59	17.96	5.45	6	29
	Post-treatment	48	18.96	5.69	8	30

Baseline Group Differences

There were no significant differences between the two treatment modality groups at baseline on any of the measurements. Results from this analysis can be found in Appendix B.

Effects of Treatment Group and Time

There were no significant group, time, or group by time effects for the following variables in the mixed ANOVA: Caregiver burden, depression, PILES, relationship satisfaction, quality of life, or self-efficacy. Time was a significant factor in the mixed ANOVA for apathy. ($F= 6.84$, $p=.012$), but there was no significant effect of group or group by time. Caregiver ratings of patient apathy increased from pre- to post-treatment indicating that caregivers rated their care receivers as more apathetic post-treatment.

Table 4 – Results for all psychosocial factors from the mixed ANOVAs;

	Group		Time		Group*Time	
	F	P	F	P	F	P
AP	0.00	0.982	6.84	0.012*	0.05	0.825
CBI	0.09	0.769	0.00	0.967	0.01	0.915
CG-D	0.24	0.626	0.21	0.646	0.63	0.431
PILES	0.56	0.459	0.05	0.826	0.17	0.685
REL	32.51	0.119	0.05	0.832	0.04	0.840
QOL	0.40	0.531	0.76	0.387	0.55	0.463
SEC	0.60	0.440	0.90	0.348	0.41	0.525
SEP	0.00	0.961	1.25	0.269	0.85	0.363

*Indicates statistical significance

Abbreviations: AP, Patient Apathy; CBI, Caregiver Burden Index; CG-D, Caregiver Depression; PILES, Perceived Impact of Life Events Scale; REL, Relationship Satisfaction; QOL, Caregiver Quality of Life; SEC, Patient Self Efficacy for Communication; SEP, Patient Self Efficacy for People with Disabilities.

Correlations Between All Variables

Significant correlations were identified between a number of measures, and correlations for all psychosocial variables other than caregiver quality of life can be found in Appendix C.

Quality of life pre-treatment was moderately, positively correlated with quality of life post-treatment, moderately, negatively correlated with caregiver burden pre-treatment, and weakly, negatively correlated with caregiver burden post-treatment. **Quality of life post-treatment** was moderately, negatively correlated with caregiver burden pre- and post-treatment, weakly, negatively correlated with caregiver depression post-treatment, moderately positively correlated with PILES post-treatment, and moderately, positively correlated with relationship satisfaction post-treatment.

Relationship Between Caregiver Psychosocial Variables and Quality of Life

As previously discussed, this study is part of a larger implementation study examining the efficacy of SpeechVive treatment through a telemedicine platform. In the caregiver data set discussed here, there were no significant effects of treatment modality. Therefore, to maximize the

power of regression and mediation models, this study combined the data from both groups. However, we included treatment modality in these models as a dependent variable to allow for the model to demonstrate any significant effects of treatment modality on quality of life.

The full model included treatment modality, quality of life pre-treatment, caregiver burden pre-treatment, caregiver depression pre-treatment, change in depression, PILES pre-treatment, and change in PILES (see Table 4). See Appendix D for the interim models which were used to develop the full model. Higher caregiver burden pre-treatment ($\beta = -.29$, $p = .035$), higher caregiver depression pre-treatment ($\beta = -.29$, $p = .048$) and increases in caregiver depression from pre-to post-treatment ($\beta = -.39$, $p = .006$) were associated with lower quality of life post-treatment. Additionally, higher PILES scores pre-treatment ($\beta = .30$, $p = .028$) and increases in PILES scores ($\beta = .29$, $p = .031$) were associated with higher caregiver quality of life post-treatment. For the PILES, higher scores are indicative of perceived gains in the life domains assessed. However, treatment modality ($\beta = .10$, $p = .144$) and quality of life ($\beta = .14$, $p = .141$) pre-treatment did not significantly predict quality of life post-treatment. The full model accounted for 59.5% of the variance in post-treatment quality of life.

Table 5 – Regression analysis full model,

Variable	Coef.	SE	Z	P
CBI Pre	-0.286	0.135	-2.11	0.035*
CG-D Pre	-0.290	0.147	-1.98	0.048*
CG-D Change	-0.378	0.137	-2.75	0.006*
PILES Pre	0.304	0.138	2.20	0.028*
PILES Change	0.289	0.134	2.15	0.031*
QOL Pre	0.135	0.141	0.96	0.338
Treatment Modality	0.097	0.144	0.85	0.394

*indicates significant at $p < .05$, standardized coefficients are reported here

Abbreviations: CBI, Caregiver Burden Index; CG-D, Caregiver Depression; PILES, Perceived Impact of Life Events Scale; QOL, Caregiver Quality of Life

Effect of Patient-Related Psychosocial Variables on Quality of Life

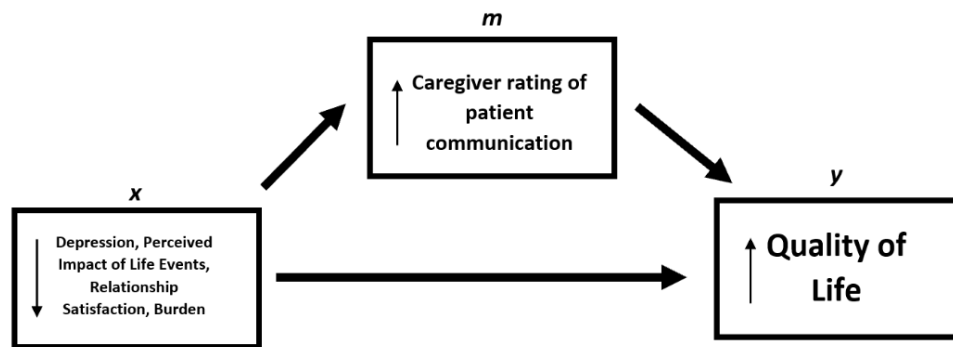


Figure 3 – Conceptual model for mediation analysis using self-efficacy for communication as mediator

Caregiver ratings of patient self-efficacy of communication did not mediate the relationship between the caregiver-related psychosocial variables and quality of life because they were not significantly related to quality of life (pre-treatment: $\beta = -.07$, $p = .699$; post-treatment: $\beta = .14$, $p = .770$). Adding self-efficacy for communication to the model did not substantially change the predictors of quality of life post-treatment (see Table 5). Increases in PILES scores from pre- to post-treatment ($\beta = .22$, $p = .04$) were significantly associated with higher caregivers' ratings of patient self-efficacy for communication post-treatment.

Table 6 – Mediation results with Self-efficacy for Communication (SEC) post-treatment as mediator

Variable	SEC Post-Treatment				QOL Post-Treatment			
	Coef.	SE	Z	P	Coef.	SE	Z	P
SEC Pre	0.667	0.090	7.41	0.000	-0.070	0.181	-0.39	0.699
SEC Post					0.137	0.141	0.98	0.770
CBI Pre	-0.007	0.118	-0.06	0.954	-0.339	0.154	-2.20	0.028*
CG-D Pre	-0.204	0.108	-1.90	0.058	-0.267	0.155	-1.73	0.084
CG-D Change	-0.070	0.107	-0.66	0.511	-0.365	0.137	-2.67	0.008*
PILES Pre	0.167	0.112	1.50	0.133	0.323	0.143	2.26	0.024*
PILES Change	0.220	0.107	2.05	0.040*	0.300	0.140	2.13	0.033*
QOL Pre					0.137	0.141	0.98	0.329

*indicates significant at $p < .05$, standardized coefficients are reported here

Abbreviations: CBI, Caregiver Burden Index; CG-D, Caregiver Depression; PILES, Perceived Impact of Life Events Scale; QOL, Caregiver Quality of Life; SEC, Patient Self Efficacy for Communication

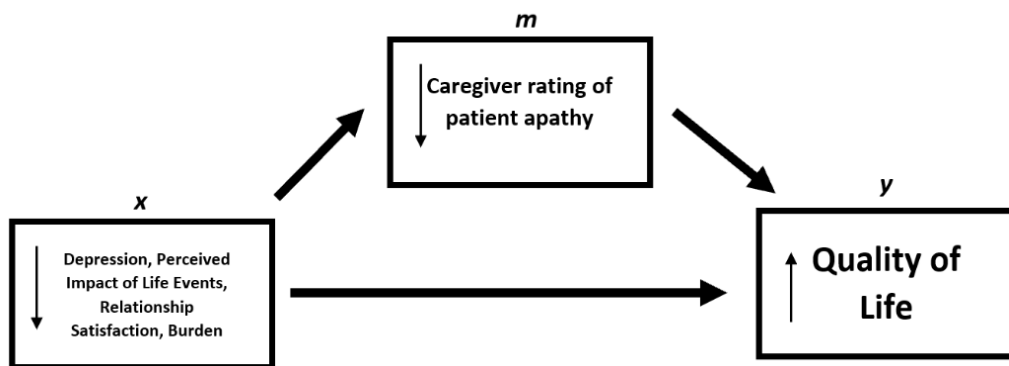


Figure 4 – Conceptual model for mediation analysis using apathy as mediator

Caregiver ratings of patient apathy did not mediate the relationship between the caregiver-related psychosocial variables and quality of life because they were not related to quality of life (pre-treatment: $\beta = -.06$, $p = .741$; post-treatment: $\beta = .15$, $p = .412$). Adding apathy into the model did not substantially change the predictors of quality of life post-treatment (see Table 6). No psychosocial variables significantly predicted caregivers' ratings of patient apathy post-treatment.

Table 7 – Mediation results with Apathy post-treatment as mediator

Variable	Apathy Post-Treatment				QOL Post-Treatment			
	Coef.	SE	Z	P	Coef.	SE	Z	P
AP Pre	0.704	0.078	9.00	0.000*	-0.059	0.178	-0.33	0.741
AP Post					0.150	0.183	0.82	0.412
CBI Pre	0.100	0.108	0.92	0.356	-0.307	0.144	-2.14	0.033*
CG-D Pre	0.020	0.123	0.16	0.871	-0.300	0.151	-1.96	0.051
CG-D Change	0.130	0.122	1.07	0.283	-0.370	0.140	-2.65	0.008*
PILES Pre	-0.023	0.115	-0.20	0.842	0.323	0.141	2.28	0.022*
PILES Change	-0.162	0.108	-1.50	0.134	0.304	0.138	2.20	0.028*
QOL Pre					0.130	0.143	0.90	0.366

*indicates significant at $p < .05$, standardized coefficients reported here

Abbreviations: AP, Patient apathy; CBI, Caregiver Burden Index; CG-D, Caregiver Depression; PILES, Perceived Impact of Life Events Scale; QOL, Caregiver Quality of Life

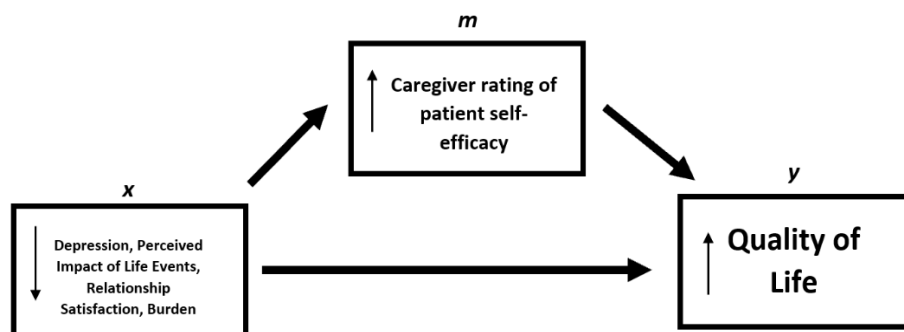


Figure 5 – Conceptual model for mediation analysis using self-efficacy for people with disabilities as mediator

Caregiver ratings of self-efficacy for people with disabilities did not mediate the relationship between the caregiver-related psychosocial variables and quality of life because they were not related to quality of life (pre-treatment: $\beta = -.09$, $p = .311$; post-treatment: $\beta = -.13$, $p = .547$). Adding self-efficacy for people with disabilities into the model did not substantially change the predictors of quality of life post-treatment (see Table 7). Lower ratings of caregiver burden pre-treatment ($\beta = -.37$, $p = .007$) and higher self-efficacy for people with disabilities pre-treatment ($\beta = .35$, $p = .003$) were significantly associated with higher caregivers' rating of self-efficacy for people with disabilities post-treatment.

Table 8 – Mediation results with Self-efficacy for People with Disabilities (SEP) post-treatment as mediator,

Variable	SEP Post-Treatment				QOL Post-Treatment			
	Coef.	SE	Z	P	Coef.	SE	Z	P
SEP Pre	0.345	0.116	2.97	0.003*	-0.087	0.144	-0.60	0.311
SEP Post					-0.134	0.132	-1.01	0.547
CBI Pre	-0.370	0.137	-2.70	0.007*	-0.357	0.147	-2.43	0.015*
CG-D Pre	-0.120	0.140	-0.85	0.394	-0.282	0.144	-1.96	0.050*
CG-D Change	-0.193	0.123	-1.46	0.144	-0.377	0.137	-2.75	0.006*
PILES Pre	0.052	0.142	0.36	0.715	0.344	0.138	2.49	0.013*
PILES Change	0.172	0.134	1.39	0.198	0.301	0.135	2.22	0.026*
QOL Pre	0.037	0.136	0.27	0.787	0.129	0.139	0.93	0.355

*indicates significant at $p < .05$, standardized coefficients reported here

Abbreviations: CBI, Caregiver Burden Index; CG-D, Caregiver Depression; PILES, Perceived Impact of Life Events Scale; QOL, Caregiver Quality of Life; SEP, Patient Self Efficacy for People with Disabilities

DISCUSSION

Caring for a person with PD throughout the disease process puts an incredible amount of stress on the caregiver in several domains, including their physical, mental, social, and financial states. Review of the current literature regarding caregivers of people with PD revealed a negative relationship between caring for a person with PD and depression, caregiver burden, and overall caregiver quality of life. While this information gives insight into some of the issues facing caregivers of people with PD, several gaps remain. This study examined the impact of treatment modality on psychosocial factors associated with caregiving. We have included novel scales that we hypothesized would be important factors in caregiver quality of life including the perceived impact of life events and a measure of relationship satisfaction. Lastly, we considered the relationship between caregiver perceptions of patient abilities and caregiver quality of life.

The current study used group statistics, mixed ANOVAs, and regression analyses to determine the impact that treatment modality, whether face-to-face or telemedicine, had on the psychosocial factors associated with caregiving. There were no changes in caregiver psychosocial variables as a result of treatment modality. Treatment modality was not a significant factor in any of the regression models, suggesting that face-to-face treatment and telehealth treatment do not impact caregiver quality of life in different ways. Virtual speech-language pathology services have begun and will continue to expand, especially given the current global health crisis. There were no significant differences in caregiver burden between treatment groups at any of the time points studied, suggesting that treatment modality neither increases nor decreases caregiver burden. This is noteworthy, as it shows that the added burden of setting up and troubleshooting associated with telemedicine did not lead to significant increases in caregiver burden. Knowing this, providers can feel more confident that their choice of treatment modality will likely not have a negative impact

on the quality of life of caregivers. However, results also indicated that telehealth services did not positively impact the caregiver's quality of life or decrease their levels of caregiver burden as some providers might expect. This is worth noting, as it suggests that while telehealth does not negatively impact caregivers, providers must do more than offer telehealth visits as an option in an attempt to significantly alleviate burden on their patients' caregivers.

Relevant literature has suggested that mental health issues such as depression can have a major impact on a caregiver's quality of life throughout the progression of disease. Results from the regression model indicated that caregiver depression significantly predicted quality of life post-treatment. As caregiver depression increases, caregiver quality of life decreases. In this study, this negative relationship existed with both caregiver depression pre-treatment and change in caregiver depression from pre- to post-treatment. This provides a basis for taking the mental health of caregivers into consideration during the treatment process, as it is likely that substantial increases in caregiver depression would have a negative impact on both their ability to participate in the therapeutic process and the quality of care that they are able to provide to their care partner (Rush Smith, et al., 2011). These results underline the importance on being aware of the caregiver's mental state and providing referrals to mental health professionals and mental health resources as appropriate throughout the treatment process in order to achieve better outcomes for both patients and caregivers.

The relationship between a caregiver's quality of life and the perceived impact of life events (measured using the PILES) as related to their care partner's PD has not yet been explored in relevant literature, but it was hypothesized that a higher perceived negative impact of PD would result in a lower quality of life for caregivers. Results indicate that PILES scores pre-treatment and change in PILES scores from pre- to post-treatment significantly predicted caregiver quality of life. As PILES scores increased, caregiver quality of life also increased. Higher PILES scores are

indicative of perceived gains in a variety of domains, including meaning in life, financial security, and level of social acceptance, among others, whereas lower scores are indicative of higher perceived losses in these same areas. Of all the psychosocial factors studied, change in PILES scores from pre- to post-treatment was the only factor that loaded significantly on the patient-related variable of self-efficacy for communication in the mediation analysis. This indicates that as a caregiver's perception of their care receiver's ability to participate in communicative exchanges increased, they saw related increases in perceived gains assessed in the PILES. This may be because the PILES includes areas such as quality of romantic relationship, happiness, and appreciation for life. It is likely that as a caregiver observes their care receiver participating more fully in communication in their daily life, they would see similar gains in these areas, and others involving social participation and relationships. These results highlight the widespread impact that caring for a person with PD can have on a person's life, and the importance of checking in with caregivers to determine the level of support they require in order to continue providing a high quality of care. It is expected that a diagnosis of PD, and the associated burden of care it places on a spouse or family member might significantly impact the caregiver's quality of life and the relationship satisfaction between caregiver and care receiver, but these factors were not significantly linked in the results of this study. Discussing the impact caregiving can have on these different areas of a person's life is an important part of the therapeutic process and will allow providers to suggest appropriate resources and make referrals to any other disciplines they deem necessary based on the situation.

In relevant literature, caregiver burden is described as a complicated, multidimensional concept that has been shown to vary person to person depending on a number of factors, including their physical, financial, social, and mental states. Caregiving often creates what Mosley et al. (2017) call an "invisible patient" in the patient-provider-caregiver system, in that although

caregivers are experiencing significant amounts of strain and burnout, their health and well-being are typically not a priority for the provider, as they are not the patient being treated. When the wellness of caregivers is overlooked throughout the treatment process, it decreases the caregiver's effectiveness and negatively impacts their ability to remain an informal partner in treatment provision (Mosley et al., 2017). The survey selected to measure caregiver burden assessed a variety of areas where caregivers are most often impacted, such as anger, privacy, stress, personal health, and more, in an attempt to capture the most complete picture of the burden of care experienced by each participant. Results indicate that higher levels of caregiver burden pre-treatment significantly predicted quality of life. As caregiver burden increased, quality of life decreased. While caregiver burden pre-treatment significantly drove quality of life, caregiver burden pre- to post-treatment was not significant. This is consistent with findings in relevant literature that suggest caregiver burden does not typically decrease without external support that allows the caregiver to adapt to their informal role, reducing their level of burden (Liu et al., 2020). While speech-language pathology intervention can often provide benefits in speech and language abilities of patients that can lead to perceived improvements in patient quality of life, the field does not often focus on activities of daily living (ADLs) like cooking a meal, cleaning a house, or other physical activities a caregiver is typically responsible for. Therefore, while a patient may be better able to participate in communication and some daily activities from pre- to post-treatment, these improvements may not relieve the physical strain felt by the caregiver who is responsible for major ADLs, causing caregiver burden to remain static. Caregiver burden was also the only caregiver-related psychosocial factor that loaded significantly on self-efficacy for people with disabilities post-treatment. The scale used to assess self-efficacy of people with disabilities focused on the level to which caregivers perceived their care receiver's PD impacted their daily lives. Amtmann et al., (2012) suggested that self-efficacy influences the course of action an individual chooses, as well

as the levels of effort expended, stress experienced, and perseverance in the face of difficulties. They also suggest that self-efficacy strongly predicts health-related behaviors and can impact the experience of chronic illness. This supports our interpretation that caregiver burden is related to how well caregivers perceive their care receivers to be self-efficient in a number of areas, including social interaction, issues related to their PD, and ADLs. From the standpoint of healthcare providers, finding ways to provide impactful treatment for the person with PD while not placing an increased burden on caregivers is paramount, as it has been shown that inability to recognize and manage caregiver burden can lead to premature institutionalization of the care receiver (Mosley et al., 2017). Overall, results suggest that providing formal support for caregivers is necessary to ensure that the selected treatment program is not increasing levels of caregiver burden, so caregivers are able to provide the highest quality of care possible to their care receivers, while still taking care of themselves.

LIMITATIONS

There were a number of limitations to this study that are worth noting. First, the study design did not allow for a control group, as ethical concerns prevent researchers from withholding treatment in order to obtain a true control group. Instead, the two groups in this study were both given the same form of treatment, with the difference being modality of treatment. Since this study was an implementation study, the people with PD and their care partners chose the treatment modality they preferred. It is possible that this freedom led participants to choose a treatment modality they already felt comfortable with and knew they would experience the least amount of strain from, impacting the perceived effects that treatment modality had on the psychosocial variables studied. The relatively small sample size of this study for the regression and moderation analyses is also a limitation, as it could lead to the results of the study not being representative of the population being studied as a whole. It would have also been beneficial to have the age of the caregiver partners when completing statistical analysis to determine if this played a role in the psychosocial factors or quality of life across time, but this information was not collected during the initial data collection phase prior to treatment.

SUMMARY

Results from the current study showed that many of the psychosocial factors associated with caring for a person with PD significantly impact caregiver quality of life, including caregiver burden, caregiver depression, and perceived impact of PD. Treatment modality did not significantly impact caregiver quality of life, suggesting that moving therapy to telemedicine delivery does not have a significant positive or negative impact on the quality of life of caregivers. Higher caregiver ratings of patient self-efficacy for communication were associated with in ratings of gains in the perceived impact of PD on their lives. Higher caregiver ratings of patient self-efficacy with ADLs were associated with lower ratings of caregiver burden. Overall, results from this study highlighted the significant effects psychosocial impact can have on caregivers of people with PD which are likely to negatively impact the quality of care that they are able to provide to their care partner (Rush Smith, et al., 2011). It has also been documented that in order to improve caregiver quality of life and quality of care, caregivers should be given access to educational programs that provide information customized for people with PD (Lee et al., 2019). Given information found in relevant literature and the results of the current study, it is evident that focusing on the psychosocial impact of caregiving is an integral part of the treatment process for any provider working with people with PD. While the

caregiver is not the person providers are directly treating, it is important to recognize that caregivers are providing the majority of care outside of a provider's office. Ensuring that they have the support and education they need to manage the stresses and strains associated with caregiving will lead to higher quality of care for the patient, which will likely lead to better patient outcomes both in therapy and in the home.

APPENDIX A. SURVEYS

Table 9 – Caregiver survey completion across time

	AP	CBI	D	PILES	REL	SEC	SEP	QOL
MPD001								
MPD002								
MPD003								
MPD004								
MPD005								
MPD006								
MPD007								
MPD008								
FPD009								
FPD010								
MPD011								
FPD012								
FPD013								
MPD014								
FPD015								
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MPD058								
FPD060								
FPD061								
MPD062								
MPD063								
MPD064								
MPD065								
MPD066								
MPD067								
FPD068								
MPD069								
MPD070								
MPD071								
MPD073								

Key
Completed survey
Did not complete survey
Participant dropped from study

APPENDIX B. BASELINE GROUP DIFFERENCES

Table 10 –Baseline group differences, t-test results

Variable	Group	Observations	Mean	SE	SD	Pr (T > t)
QOL Pre	Face to face	31	156.4	3.219	17.92	0.329
	Telehealth	26	152.5	1.966	10.02	
	Difference		3.896			
	Combined	57	154.6	1.968	14.86	
QOL Post	Face to face	27	152	2.959	15.37	0.928
	Telehealth	21	152.4	3.139	14.39	
	Difference		-0.395			
	Combined	48	152.2	2.135	14.79	
CG-D Pre	Face to face	33	1.550	0.411	2.363	0.913
	Telehealth	28	1.607	0.274	1.449	
	Difference		-0.057			
	Combined	61	1.577	0.254	1.981	
CG-D Post	Face to face	27	1.4	0.339	1.762	0.457
	Telehealth	21	1.810	0.440	2.015	
	Difference		-0.410			
	Combined	48	1.579	0.270	1.868	
CBI Pre	Face to face	31	8.871	1.491	8.302	0.474
	Telehealth	26	10.46	1.623	8.276	
	Difference		-1.591			
	Combined	57	9.596	1.093	8.255	
CBI Post	Face to face	27	9.370	1.702	8.845	0.660
	Telehealth	21	10.57	2.159	9.892	
	Difference		-1.201			
	Combined	48	9.896	1.333	9.235	
PILES Post	Face to face	27	105.9	4.482	23.29	0.608
	Telehealth	21	102.4	4.975	22.80	
	Difference		3.471			
	Combined	48	104.3	3.305	22.90	
REL Pre	Face to face	31	22.77	0.925	5.149	0.239
	Telehealth	26	20.85	1.382	7.047	
	Difference		1.928			
	Combined	57	21.89	0.809	6.108	
REL Post	Face to face	27	23.07	0.525	2.731	0.215
	Telehealth	21	21.57	1.178	5.400	
	Difference		1.503			
	Combined	48	22.42	0.597	4.135	
AP Pre	Face to face	31	9.742	1.050	5.848	0.770
	Telehealth	25	9.248	1.345	6.724	
	Difference		0.494			
	Combined	56	9.521	0.829	6.200	

Table 10 continued

AP Post	Face to Face	27	11.78	1.450	7.535	0.931
	Telehealth	21	11.98	1.858	8.512	
	Difference		-0.203			
	Combined	48	11.87	1.139	7.890	
SEP Pre	Face to face	32	17.91	0.996	5.636	0.932
	Telehealth	27	18.03	1.025	5.324	
	Difference		-0.123			
	Combined	59	17.96	0.709	5.449	
SEP Post	Face to face	27	18.70	1.032	5.362	0.730
	Telehealth	21	19.29	1.356	6.214	
	Difference		-0.582			
	Combined	48	18.96	0.822	5.694	
SEC Pre	Face to face	32	14.47	1.257	7.112	0.253
	Telehealth	27	12.21	1.522	7.910	
	Difference		2.258			
	Combined	59	13.44	0.977	7.508	
SEC Post	Face to face	27	14.85	1.681	8.724	0.762
	Telehealth	22	14.04	2.081	9.761	
	Difference		0.806			
	Combined	49	14.49	1.303	9.120	

APPENDIX C. CORRELATIONS

Table 11 – Correlations between psychosocial variables

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. QOL Pre	1.000															
2. QOL Post	0.347 0.016	1.000														
3. CBI Pre	-0.453 0.001	-0.431 0.002	1.000													
4. CBI Post	-0.290 0.046	-0.352 0.014	0.835 0.000	1.000												
5. D Pre	-0.227 0.092	-0.238 0.108	0.276 0.039	0.335 0.021	1.000											
6. D Post	-0.173 0.239	-0.318 0.028	-0.015 0.920	0.131 0.375	0.537 0.000	1.000										
7. PILES Pre	0.243 0.070	0.250 0.087	-0.217 0.105	-0.043 0.773	0.084 0.539	0.071 0.632	1.000									
8. PILES Post	0.119 0.422	0.422 0.003	-0.392 0.006	-0.475 0.001	-0.103 0.491	-0.030 0.840	0.395 0.006	1.000								
9. REL Pre	0.166 0.218	0.207 0.158	-0.339 0.010	-0.253 0.082	0.005 0.970	0.123 0.404	0.065 0.630	0.318 0.028	1.000							
10. REL Post	0.167 0.218	0.375 0.009	-0.445 0.002	-0.495 0.000	-0.351 0.015	-0.142 0.337	0.098 0.508	0.481 0.001	0.495 0.000	1.000						
11. AP Pre	-0.121 0.375	-0.206 0.160	0.377 0.004	0.393 0.006	0.211 0.121	0.170 0.249	-0.151 0.267	-0.243 0.096	0.064 0.641	-0.351 0.015	1.000					
12. AP Post	-0.092 0.532	-0.180 0.220	0.370 0.010	0.489 0.000	0.196 0.187	0.210 0.151	-0.117 0.428	-0.316 0.029	-0.051 0.732	-0.337 0.019	0.765 0.000	1.000				
13. SEC Pre	0.124 0.259	0.178 0.228	-0.470 0.000	-0.436 0.002	-0.035 0.797	0.051 0.731	0.236 0.077	0.289 0.047	0.056 0.681	0.183 0.213	-0.195 0.149	-0.291 0.045	1.000			
14. SEC Post	0.187 0.197	0.239 0.103	-0.486 0.000	-0.552 0.000	-0.195 0.185	-0.120 0.416	0.161 0.271	0.419 0.003	0.034 0.818	0.357 0.013	-0.326 0.022	-0.410 0.004	0.733 0.000	1.000		
15. SEP Pre	0.135 0.316	0.022 0.881	-0.256 0.055	-0.290 0.046	-0.197 0.423	0.005 0.971	0.155 0.250	0.212 0.148	0.154 0.253	0.020 0.894	0.105 0.440	-0.055 0.712	0.000 0.100	0.090 0.540	1.000	
16. SEP Post	0.239 0.102	0.224 0.125	-0.510 0.000	-0.657 0.000	-0.187 0.209	-0.167 0.256	0.134 0.364	0.350 0.015	0.063 0.673	0.416 0.003	-0.263 0.071	-0.309 0.032	0.359 0.012	0.563 0.000	0.455 0.001	1.000

APPENDIX D. REGRESSION ANALYSIS

For the model that included change in caregiver depression, caregiver depression pre-treatment, change in caregiver depression, and caregiver burden all significantly predicted quality of life post-treatment. Both caregiver depression pre-treatment and change in caregiver depression were included in the full model.

Table 12 – Regression with depression pre-treatment and change in depression

Variable	Coef.	SE	Z	P
Treatment Modality	0.084	0.117	0.72	0.474
QOL Pre	0.078	0.143	0.54	0.588
CG-D Pre	-0.341	0.149	-2.29	0.022*
CG-D Change	-0.396	0.140	-2.83	0.005*
PILES Pre	0.169	0.128	1.32	0.188
REL Pre	0.141	0.144	0.98	0.328
CBI Pre	-0.347	0.136	-2.56	0.011*

*indicates significant at $p < .05$, standardized coefficients reported here

Abbreviations: CBI, Caregiver Burden Index; CG-D, Caregiver Depression; PILES, Perceived Impact of Life Events Scale; REL, Relationship Satisfaction; QOL, Caregiver Quality of Life

For the model that included change in caregiver ratings of perceived impact of life events (PILES), PILES pre-treatment, PILES change, and caregiver burden significantly predicted quality of life post-treatment. Both PILES pre-treatment and PILES change were included in the full model.

Table 13 – Regression with PILES pre-treatment and change in PILES

Variable	Coef.	SE	Z	P
Treatment Modality	0.069	0.121	0.56	0.572
QOL Pre	0.169	0.149	1.14	0.255
CG-D Pre	-0.109	0.145	-0.76	0.450
PILES Pre	0.323	0.148	2.18	0.029*
PILES Change	0.300	0.150	2.00	0.046*
REL Pre	0.028	0.156	0.18	0.856
CBI Pre	-0.189	0.146	-1.30	0.001*

*indicates significant at $p < .05$, standardized coefficients are reported here

Abbreviations: CBI, Caregiver Burden Index; CG-D, Caregiver Depression; PILES, Perceived Impact of Life Events Scale; QOL, Caregiver Quality of Life

For the model that included change in relationship satisfaction, no variables significantly predicted quality of life post-treatment. Relationship satisfaction pre-treatment and change in relationship satisfaction were not significant so they were not included in the full model.

Table 14 – Regression with relationship satisfaction pre-treatment and change in relationship satisfaction

Variable	Coef.	SE	Z	P
Treatment Modality	0.080	0.125	0.64	0.523
QOL Pre	0.160	0.150	1.07	0.285
CG-D Pre	-0.053	0.156	-0.34	0.735
PILES Pre	0.152	0.137	1.11	0.269
REL Pre	0.341	0.218	1.56	0.118
REL Change	0.303	0.204	1.48	0.139
CBI Pre	-0.212	0.148	-1.43	0.153

*indicates significant at $p < .05$, standardized coefficients reported here

Abbreviations: CBI, Caregiver Burden Index; CG-D, Caregiver Depression; PILES, Perceived Impact of Life Events Scale; REL, Relationship Satisfaction; QOL, Caregiver Quality of Life

For the model that included change in caregiver burden, no variables significantly predicted quality of life post-treatment. Change in caregiver burden was not significant so it was not included in the full model.

Table 15 – Regression with caregiver burden pre-treatment and change in caregiver burden

	Coef.	SE	Z	P
Treatment Modality	0.051	0.126	0.41	0.683
QOL Pre	0.123	0.155	0.79	0.428
CG-D Pre	-0.136	0.149	-0.91	0.361
PILES Pre	0.187	0.140	1.34	0.180
REL Pre	0.106	0.156	0.68	0.496
CBI Pre	-0.271	0.144	-1.88	0.060
CBI Change	-0.033	0.134	-0.24	0.807

*indicates significant at $p < .05$, standardized coefficients reported here

Abbreviations: CBI, Caregiver Burden Index; CG-D, Caregiver Depression; PILES, Perceived Impact of Life Events Scale; REL, Relationship Satisfaction; QOL, Caregiver Quality of Life

REFERENCES

- Achey, M., Aldred, J. L., Aljehani, N., Bloem, B. R., Biglan, K. M., Chan, P., Cubo, E., Ray Dorsey, E., Goetz, C. G., Guttman, M., Hassan, A., Khandhar, S. M., Mari, Z., Spindler, M., Tanner, C. M., van den Haak, P., Walker, R., Wilkinson, J. R., & on behalf of the International Parkinson and Movement Disorder Society Telemedicine Task Force. (2014). The past, present, and future of telemedicine for Parkinson's disease: Telemedicine for Parkinson's disease. *Movement Disorders*, 29(7), 871–883.
- Amtmann, D., Bamer, A. M., Cook, K. F., Askew, R. L., Noonan, V. K., & Brockway, J. A. (2012). University of Washington self-efficacy scale: A new self-efficacy scale for people with disabilities. *Archives of Physical Medicine and Rehabilitation*, 93(10), 1757-1765.
- Baylor, C., Yorkston, K., Eadie, T., Kim, J., Chung, H., & Amtmann, D. (2013). Communicative participation item bank (CPIB): Item bank calibration and development of a disorder-generic short form. *Journal of Speech Language and Hearing Research*, 56(4), 1190-1208.
- Bedard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist*, 41(5), 652-657.
- Boersma, P. & Weenink, D. (2020). Praat: doing phonetics by computer [Computer program]. Version 6.1.13, retrieved 19 April 2020 from <http://www.praat.org>
- Dissanayaka, Nadeeka N.W., Sellbach, A., Silburn, P. A., O'Sullivan, J. D., Marsh, R., Mellick, G. D. (2011). Factors associated with depression in Parkinson's disease. *Journal of Affective Disorders*, 132(1-2), 82-88.
- Dorsey, E. R., Deuel, L. M., Voss, T. S., Finnigan, K., George, B. P., Eason, S., Miller, D., Reminick, J. I., Appler, A., Polanowicz, J., Viti, L., Smith, S., Joseph, A., & Biglan, K. M. (2010). Increasing access to specialty care: A pilot, randomized controlled trial of telemedicine for Parkinson's disease. *Movement Disorders*, 25(11), 1652–1659.
- Dorsey, E. R., Venkataraman, V., Grana, M. J., Bull, M. T., George, B. P., Boyd, C. M., Beck, C. A., Rajan, B., Seidmann, A., & Biglan, K. M. (2013). Randomized controlled clinical trial of "virtual house calls" for Parkinson disease. *JAMA neurology*, 70(5), 565–570.
- Fitts, W., Weintraub, D., Massimo, L., Chahine, L., Chen-Plotkin, A., Duda, J. E., Hurtig, H. I., Rick, J., Trojanowski, J. Q., Dahodwala, N. (2015). Caregiver report of apathy predicts dementia in Parkinson's disease. *Parkinsonism and Related Disorders* 21(8), 992-995.
- Glozman, J. M., Bicheva, K. G., & Fedorova, N. V. (1998). Scale of quality of life of care-givers (SQLC). *Journal of Neurology*, 245(1), S39-S41.

- Hassan, A., Wu, S. S., Schmidt, P., Malaty, I. A., Dai, Y. F., Miyasaki, J. M., Okun, M. S. (2012). What are the issues facing Parkinson's disease patients at ten years of disease and beyond?: Data from the NPF-QII study. *Parkinsonism and Related Disorders*, 18, S10-S14.
- Lee, J., Kim, S. H., Kim, Y., Kim, Y. L., Sohn, Y. (2019). Quality of life of caregivers of individuals with Parkinson's disease. *Rehabilitation Nursing* 44(6), 338-348.
- Liu, Z., Heffernan, C., Tan, J. (2020). Caregiver burden: A concept analysis. *International Journal of Nursing Sciences*, 7(4), 438-445.
- Logemann, J. A., & Fisher, H. B. (1981). Vocal tract control in Parkinson's disease: phonetic feature analysis of misarticulations. *The Journal of speech and hearing disorders*, 46(4), 348-352.
- Mammen, J. R., Elson, M. J., Java, J. J., Beck, C. A., Beran, D. B., Biglan, K. M., Boyd, C. M., Schmidt, P. N., Simone, R., Willis, A. W., & Dorsey, E. R. (2018). Patient and Physician Perceptions of Virtual Visits for Parkinson's Disease: A Qualitative Study. *Telemedicine journal and e-health: the official journal of the American Telemedicine Association*, 24(4), 255-267.
- Marras, C., Beck, J. C., Bower, J. H., Roberts, E., Ritz, B., Ross, G. W., Abbott, R. D., Savica, R., Van Den Eeden, S. K., Willis, A. W., & Tanner, C. (2018). Prevalence of Parkinson's disease across North America. *Npj Parkinson's Disease*, 4(1), 21.
- Martinez-Martin, P., Rodriguez-Blazquez, C., & Forjaz, M. J. (2012). Quality of life and burden in caregivers for patients with Parkinson's disease: Concepts, assessment and related factors. *Expert Review of Pharmacoeconomics & Outcomes Research*, 12(2), 221-230.
- Mosley, P. E., Moodie, R., & Dissanayaka, N. (2017). Caregiver Burden in Parkinson Disease: A Critical Review of Recent Literature. *Journal of Geriatric Psychiatry and Neurology*, 30(5), 235-252.
- Norton, R. (1983). Measuring marital quality: A critical look at the dependent variable. *Journal of Marriage and the Family*, 45(1), 141-151.
- Oldenkamp, M., Hagedoorn, M., Slaets, J., Stolk, R., Wittek, R., & Smidt, N. (2016). Subjective burden among spousal and adult-child informal caregivers of older adults: Results from a longitudinal cohort study. *BMC Geriatrics*, 16(1), 208.
- Peterson, K., Hahn, H., Lee, A., Madison, C., & Atri, A. (2016). In the Information Age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers' education needs, barriers, and preferences. *BMC Geriatrics*, 16(1), 164.

- Ramig, L. O., Fox, C., & Sapis, S. (2008). Speech treatment for Parkinson's disease. *Neurotherapeutics* 8(2), 299–311.
- Rush Smith, G., Williamson, G. M., Miller, L. S., & Schulz, R. (2011) Depression and quality of informal care: A longitudinal investigation of caregiving stressors. *Psychol Aging*, 26(3), 584-591.
- Schrag, A., Hovris, A., Morley, D., Quinn, N., & Jahanshahi, M. (2006). Caregiver-burden in parkinson's disease is closely associated with psychiatric symptoms, falls, and disability. *Parkinsonism & Related Disorders*, 12(1), 35–41.
- Servaty-Seib, H. L. (2014). Using a gain/loss framework to measure impact: The perceived impact of life event scale. *Journal of Loss and Trauma*, 19(4), 331-354.
- Sheikh J.I., Yesavage J.A. (1986). Geriatric depression scale (GDS): Recent evidence and development of a shorter version. *Clin Gerontol* 1986;165–173.
- Starkstein, S. E., Mayberg, H. S., Preziosi, T. J., Andrezejewski, Leiguarda, & Robinson, R. G. (1992). Reliability, validity, and clinical correlates of apathy in Parkinson's disease. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 4(2), 134-139.
- Tindall, L. R., Huebner, R. A., Stemple, J. C., Kleinert, H. L. (2008). Videophone-delivered voice therapy: A comparative analysis of outcomes to traditional delivery for adults with parkinson's disease. *Telemedicine and e-Health*, 14(10), 1071-1077
- Zarit, S. H., Todd, P. A., MSG, Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *The Gerontological Society of America*, 26(3), 260-266.