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Nicole Schindler March 30, 2020

TeleDREAMS: Promoting Research and Advocacy Among Individuals with Parkinson's Disease and their Care Partners

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Abstract

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Significance: In Parkinson's Disease (PD), research, recruitment, and enrollment are considerable obstacles. Misperceptions about research and distrust of researchers are identified as barriers to research involvement.

Objective: Expanding on the *Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors* (DREAMS), TeleDREAMS used a telehealth model to target cognition, quality of life, health literacy, research involvement, and advocacy among individuals with PD and their care partners.

Participants: Study recruited 51 individuals (*M a*ge: 67.5 ±7.6 years; PD n=32; Care partner n=19). Eight individuals (PD n= 4; Care partner n=4) did not complete at least six modules. Results from the 43 completers (PD n=28, Care Partner n=15) are presented and compared with existing data from DREAMS (n=7) collected from earlier studies.

Measures: Tests measuring cognition, health literacy, quality of life, and depression were administered at baseline and after completion. An exit survey following completion and a follow-up survey 6-9 months after completion were administered. Within group analyses were conducted in the care partner and PD groups. Between group analyses compared PD with and without a care partner and PD participants from TeleDREAMS versus in-person DREAMS.

Results: Care partners improved from baseline to post-test on global cognition (p=0.02). The PD group improved from baseline to post-test on the Tower of London (ToL) mean first move time (p=002), the ToL time per move ratio (p=0.01), and the Short Test of Functional Health Literacy in Adults (S-TOFHLA) (p=0.03). The PD participants with care partners improved significantly more from baseline on the Test of Scientific Literacy Skills (p=0.02) and the S-TOFHLA (p=0.05) than the PD participants without care partners. TeleDREAMS PD participants improved significantly more from baseline on the ToL (p=0.02) and attrition rates were lower. Most participants reported increased advocacy engagement and changed views on research.

Conclusions: A telehealth education model may help improve cognition and health literacy in participants with PD and their care partners. If increased attendance of advocacy events and the changes in beliefs on research translates to increased research involvement in the future, then the telehealth model is important for researchers looking to increase participation.

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Introduction

Parkinson's and Research Participation, Attitudes, and Advocacy

Parkinson's disease (PD) is a progressive, neurodegenerative disorder with no cure. The number of people with PD is expected to double from 6.9 million in 2015 to 14.2 million in 2040 marking it as an important disease to target for interventions and an area of unmet need (Dorsey & Bloem, 2018). One problem with developing interventions is a lack of participation by eligible participants. In 2011, 26% of trials that newly closed were terminated due to either failed accrual or they finished with less than their desired number of participants (Carlisle, Kimmelman, Ramsay, & MacKinnon, 2015). Nearly 80% of clinical trials fail to meet their enrollment timeline ("Clinical trial delays: America's patient recruitment dilemma," 2012). These examples indicate significant challenges in participant recruitment. Failed enrollment has negative scientific and economic implications as large sample sizes are important for adequate statistical power and delayed recruitment can be costly (Johnson, 2015; Torgerson, Arlinger, Kappi, & Sjostrom, 2001). In PD research, recruitment and enrollment are considerable obstacles (Berk et al., 2017; Valadas et al., 2011). In particular, those who come from disadvantaged minority and underserved groups are even more underrepresented in research (Schneider et al., 2009).

In a qualitative evaluation among diverse older adults, misperceptions regarding clinical research, distrust of researchers, and fear of mistreatment were identified as barriers to involvement in research (Perkins et al., 2019). People with PD have indicated important barriers to research participation were: fear of potential adverse consequences, worry regarding interruptions of the current medical regimen, or concern about placebo use (Mathur, DeWitte, Robledo, Isaacs, & Stamford, 2015). In a sample of individuals participating in an event that provides insight into research activities, the willingness to participate in a clinical trial was

significantly higher for people whose knowledge about clinical tests was apparent and among those who considered clinical trials to be important (Ohmann & Deimling, 2004). Thus, potential barriers to research participation may be lessened through educating stakeholders about research involvement to facilitate understanding and communication between those conducting trials and their participants (Mathur et al., 2015).

Barriers to Research Participation: Health literacy, Cognition, and Mood

Many factors, including health literacy, cognition, and mood may impede research participation. In a cross-sectional study of individuals with PD, 30% were demonstrated to have low health literacy. Low health literacy is a trait that was significantly associated with a greater caregiver burden and hospital admissions occurring in one year (Fleisher, Shah, Fitts, & Dahodwala, 2016). Focus group discussions within minority groups identified health literacy, especially scientific health literacy, as necessary for individuals to understand the clinical research process (Evans, Lewis, & Hudson, 2012). Those with low health literacy were found to have significantly more difficulty finding clinical trials online than those with higher levels (Utami, Bickmore, Barry, & Paasche-Orlow, 2014).

Cognition and quality of life (QOL) are important for older adults with and without PD. Depressive disorders, which often negatively influence QOL, and dementia are common non-motor related complications for people with PD (Hely, Reid, Adena, Halliday, & Morris, 2008; Schrag & Taddei, 2017). A PD diagnosis and associated symptoms can majorly impact a person's psychological well-being and social functioning (Reese, 2007). Those with cognitive deficits face additional challenges to research involvement as understanding and processing information can be more difficult. Further, researchers must take additional steps to ensure that

the consent process is fair and valid (Leopore, Shuman, Wiener, & Gould, 2017). Researchers report hesitation introducing research to individuals with depression so patients with depression are not always given the option for research participation (Mason et al., 2007). Therefore, identifying an intervention that addresses health literacy, cognition, and QOL when trying to increase research participation is significant.

Care Partners of People with PD

Many PD patients are assisted by informal caregivers that provide emotional and physical support. Support from care partners can improve health outcomes for the patient they care for. A study found that older adults with a close confidant, like a family care partner, experienced less adverse outcomes than those without one (Dickens et al., 2004). At-home care helps delay nursing home placement for patients (Spillman, 2016). Further, a longitudinal study of individuals diagnosed with PD revealed that nursing home placement was associated with higher rates of mortality and a greater presence of hallucinations (Goetz & Stebbins, 1995).

The care partner's and patient's quality of life are closely linked, and positive exchanges between dyads can create closer bond formation between the care partner and the patient (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006; Yu, Cheng, & Wang, 2018). In one study, depressed PD patients with a care partner present had better recall of informed consent after one week than participants with no support person present (Teng et al., 2012). Thus, targeting care partners in research to potentially help enhance health benefits and quality of life in the person they care for is important.

Care partners have been identified as "gatekeepers" with potential to prevent or encourage a patient to become involved in research (Waite, Poland, & Charlesworth, 2019).

Without the perspectives of care partners through research, meeting both the care partner's and patient's needs is challenging (Aoun, Slatyer, Deas, & Nekolaichuk, 2017). Although limited research about care partners of individuals with PD and their beliefs about research participation is available, caregivers of individuals with Alzheimer's Disease reported barriers that often stop them from allowing their loved ones to participate in research. These reported barriers include anxiety about the planned procedures, skepticism of the research process and negative attitudes toward medical treatment (Connell, Shaw, Holmes, & Foster, 2001). The barriers impact various practical matters with regards to accomplishing study visits. For example, hesitance on the part of the care partner could lead to non-participation, especially if the care partners provide transportation for the person they care for.

Providing support for individuals with PD can be demanding and can affect the mental health of the care partners (Thommessen et al., 2002). Compared to the general population of adults, PD care partners experience more mood disorders and worse quality of life (Rajiah, Maharajan, Yeen, & Lew, 2017). A research education program targeting care partners, which would explain the intricacies and importance of the research processes, may improve care partner willingness to permit and assist the person they are caring for in research participation. Care partners, themselves, may also derive benefits from interventions and research as the diagnosis of PD can go beyond the patient and affect the lives of the people caring for him or her. Therefore, interventions that work to improve quality of life and provide education on PD may be beneficial to PD care partners.

Potential Health Education Solutions

Educational interventions targeting memory, cancer, and other illnesses and conditions have shown improvements in health outcomes (Jandorf et al., 2006; Wiegand, Troyer, Gojmerac, & Murphy, 2013). A PD and care partner specific educational intervention consisted of eight sessions focused on self-monitoring problematic behaviors, acquiring new information about the disease, and the management of stress, anxiety, and depression. The researchers found positive effects on participants moods following each session and most participants indicated that the content was useful (Simons, Thompson, Smith Pasqualini, & Members of the EduPark, 2006). Similarly, the Patient Education Program Parkinson aimed to improve health related quality of life and increase coping skills for individuals with PD and their care partners through eight informational sessions. The program showed a trend toward increased ratings on quality of life, and after the sessions, the care partners and PD participants improved on their mood (A'Campo, Wekking, Spliethoff-Kamminga, Le Cessie, & Roos, 2010). These programs highlight how educational interventions are successful in the PD-care partner community.

Few interventions have used education to help promote participation in the research process for patients. In 2008, researchers designed a successful program called the Consent Administrator Research Education Program. The intervention focused on training researchers during the informed consent process to combat negative beliefs and attitudes of participants and patients about healthcare, increase communication between researchers and participants, and increase feedback, approval, and support throughout the research process (Larson, Cohn, Meyer, & Boden-Albala, 2009). However, this intervention focused on training researchers on proper administration of information rather than attempting to improve scientific and health literacy,

cognition, and quality of life to promote research and advocacy in an older adult population contending with a neurodegenerative condition.

Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors (DREAMS) was a two-part, in-person education program. The first part of the program was an eight-week health seminar about ongoing, local research. Interested individuals who completed the first program took part in a second program which involved a training course covering the research process and research advocacy. The goals for the program were to build trust between researchers and older adults and to increase the opportunities for older adults to participate and collaborate in research (Hackney, Perkins, Dillard, & Hart). The content was derived, in part, from syllabi from Parkinson's Advocates in Research Program designed by the Parkinson's Disease Foundation (Foundation, 2017). Both programs had trends for improved attitudes toward research participation, decreased depression, and had high satisfaction ratings (Dillard et al., 2018).

Here, we evaluated an expansion of DREAMS, the Tele-DREAMS program by using a tele-health platform. TeleDREAMS uses a distance learning model for a diverse group of individuals with PD and their care partners. The PD and care partner participants read 8 modules and are measured on their health literacy, cognition, quality of life, and research activities. TeleDREAMS was designed because telerehabilitation and telemonitoring programs receive similar satisfaction ratings to in-person care, offer statistically and clinically meaningful benefits for those with chronic disease, and individuals using telehealth programs report appreciating their timely access to care (Inglis, Clark, Dierckx, Prieto-Merino, & Cleland, 2017; Johnston, Wheeler, Deuser, & Sousa, 2000). By increasing accessibility of DREAMS, more diverse and underrepresented groups can benefit from the research process training.

Hypotheses

We expect to see improvement for both participant groups (care partner and PD) in their quality of life, cognition, and health literacy and lower depression scores after the telehealth program because of the weekly interaction with students and health content. We hypothesize that individuals will participate in more research and advocacy events following their completion of the program. We expect that the tele-health/distance learning model makes the program accessible and allows for regular engagement so participants will give positive ratings for the program. We anticipate similar benefits and satisfaction ratings in both the TeleDREAMS and in-person DREAMS Team Program, but we expect lower attrition in TeleDREAMS because of the increased accessibility of the model. We anticipate greater improvement in the PD group enrolled with care partners than those enrolled without care partners because of the extra support throughout the research process.

Methods

The Emory University institutional review board reviewed and approved this protocol. All participants provided informed consent before taking part in the study.

Participants

Participants were recruited at Parkinson's community events, local churches, and within Emory's Center for Health in Aging's community outreach programs. Fifty-one participants with either PD (n=32) or care partners of those with PD (n=19) were enrolled. The sample was 54.9% male and 45.1% female and an average of 67.5 years old (SD=7.6). Eligible PD participants were diagnosed with idiopathic "definite" mild to moderate PD with unilateral onset, 3 of the 4 cardinal signs of PD (rigidity, tremor, bradykinesia, and postural instability), responded to antiparkinsonian medication, and had no other neurological disorders. All participants were able to speak, read, and understand English. Transportation was provided for those individuals who did not have their own. Forty-three participants completed at least six modules and were included in further analyses.

TeleDREAMS Program

A binder was designed by a team of five undergraduate assistants, four Doctor of Physical Therapy Students, two Medical Doctor Students, and two Master of Public Health Students. All material was reviewed by advisors. Past DREAMS research participants, considered patient stakeholder advisers, were included in the editing of the binders. The binder material was adapted lecture presentations given through the in-person DREAMS curriculum (Hart et al., 2017). Content was expanded on to make the program more PD-specific and

modified for low literacy levels. Reading level was tested using an online readability checker to ensure that the writing was at an 8th grade level or below. The binders include the following lessons and objectives:

Week 1: Introduction to Research Advocacy

- Learn what an advocate is and what it means to be an advocate.
- Describe why it is important for people with Parkinson's disease and care partners to be included in making decisions about new studies and peer-to-peer education, and the difference it can make.
- Understand the importance of, and know how to contribute to, age-related research that focuses on diverse groups of people.
- Recognize who can become an advocate (hint … you!).
- Learn strategies and work with community members to advance the interests of all people in the Parkinson's and research communities.
- Explain what it takes to support research participants and how to give them the skills they need to teach peers how to get involved.
- Understand the importance of building relationships for clinical scientific research.

Week 2: Parkinson Disease Clinical Research in the Pipeline

- What is research?
- What are the different types of research?
- How is research funded?
- What are the different types of clinical research trials and what steps do they go through?
- Why does research matter?
- What could participation in research mean for me?
- What should one consider when deciding whether or not I should participate in research?
- Where can I get more information about research participation and studies?

Week 3: Ethics and Research

- What is ethics in research?
- Why is ethics important in research?
- What factors are important for ethics in research?
- What important ethical factors are there for aging research?
- Understand the role of hope and false hope in research?
- What are the two approaches to research?
- Know what happens when unethical research is allowed to take place?
- What laws are there to prevent unethical research?

Week 4: Analysis and Evaluation of Clinical Research

- What are the major parts of a scientific research paper?

- What are the minimum and maximum?
- What is the mean or average?
- What is the mode?
- What is a p-value?
- What does *significance* mean?

Week 5: Aging and Clinical Research

- What is aging and what changes go along with aging?
- What are the different types of studies that interest you?
- How can you find clinical trials?
- What are the pros and cons of participating in clinical studies?
- How can I make a difference?

Week 6: Understanding Informed Consent and Health Literacy

- What are the definitions of health literacy?
- How does health literacy affect you?
- What is informed consent?
- How can you ensure that you are informed?
- How can you communicate health literacy to others?

Week 7: Effective Advocacy in the Clinical Research Process

- What are some of the benefits advocates bring to the clinical research process?
- What are the roles and responsibilities of a research advocate?
- What are the roles and responsibilities of a researcher?
- How can you be an effective advocate?

Week 8: Engaging Diverse Communities in Research and Getting Started as a Research Advocate

- What is a clinical trial? What is an observational study?
- Do clinical trial populations equally represent the targeted population?
- How does the lack of diversity within a clinical trial effect the safety of treatment options for the general population?
- How can you help to improve racial and ethnic diversity in clinical trial populations?

Each lesson was read weekly by participants and accompanied by a weekly phone conversation with a student. The students took notes during the conversation of answers.

Weekly Phone Call Questions

1. Have you read the weekly lesson?

2. Did you look at any of the supplemental materials?

3. What did you learn?
4. Did anything stick out as particularly interesting or new information?
5. What did you know about this topic before reading the lesson?
6. Did you learn anything you can use in your own life?
7. Is there anything else we should add to this week's module?
8. Any other comments?

Measures

Surveys were self-completed online at the participants' houses or at the assessment. Health literacy and cognitive testing were completed at Wesley Woods Health Center. Measures were administered both before and after the tele-health intervention.

Cognition

The Montreal Cognitive Assessment (MoCA) is a tool used to assess global cognition and screen individuals with mild cognitive impairment through 8 cognitive domains (Nasreddine et al., 2005). The Tower of London (ToL) is used to assess planning ability, a part of executive function (Rainville, Lepage, Gauthier, Kergoat, & Belleville, 2012). The administrator presents a card with a specific arrangement and the participants move three rings of varying sizes on three pegs to match the arrangement. The number of moves and the time it takes to complete the task are recorded.

Health Literacy

The Rapid Estimate of Adult Literacy in Medicine (REALM) is used to investigate health literacy problems in patients through the use of a 66-word recognition test (Bass, Wilson, & Griffith, 2003). The Short Test of Functional Health Literacy for Adults (S-TOFHLA) is a

comprehension test on health related information that is administered in 7-minutes (Baker, Williams, Parker, Gazmararian, & Nurss, 1999). Research literacy is measured through the Test of Scientific Literacy Skills (TOSLS), a 28-question test (Gormally, Brickman, & Lutz, 2012). To gauge baseline knowledge about the eight topics, a 20-question Advocate Literacy Test was administered.

Depression

The Beck Depression Inventory (BDI) is a self-report test used to measure the behavioral manifestation of depression (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961).

Quality of Life

Quality of life (QOL) was measured through the Short Form 12 (SF-12) which evaluates both the mental and physical parts of quality of life through two different composite scores.

Project Satisfaction

The participants' views on the program was evaluated after program completion through an exit survey with statements regarding satisfaction toward the program rated on a 5-point Likert scale (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, and 5=strongly agree).

Future Research Participation

Six to nine months following research participation, participants were called or emailed and asked several questions related to post-intervention research and advocacy activities. Nine individuals were lost to follow-up.

<u>Follow-up Survey Questions</u>

1. Have you participated in any studies since you finished the TeleDREAMS study? How many?
2. Have you engaged in any advocacy events? How many?

3. Have you attended any research or educational seminars? How many?
4. Have you given any presentations to your peers or others about any topics related to research or Parkinson's? Please describe.
5. Did participating in the DREAMS program change the way you thought about clinical research or researchers in general?
6. Do you have other comments or anything else you would like to share?

Data Analyses

Descriptive statistics were calculated for the PD and care partner groups, for participants who withdrew from the program, for PD participants with and without care partners, and for PD participants in both TeleDREAMS and existing legacy data from an in-person DREAMS program (previously described in part in Hart et al., 2017). These descriptive characteristics were compared using Fisher's exact tests for categorical variables and independent t-tests for continuous variables. Primary analyses of outcomes investigated TeleDREAMS PD and care partner groups following completion of TeleDREAMS on health literacy, quality of life, and cognitive measures using paired t-tests within groups and Cohen's *d* for effect size. Ratings in an exit survey, used to assess satisfaction for the program, were evaluated for the PD group, the care partner group, and were compared between the TeleDREAMS and in-person DREAMS groups using fisher's exact test. The change scores between pre and post evaluations on the outcome measures were calculated for the PD participants with a care partner and without a care partner and for PD participants in TeleDREAMS and in-person DREAMS. Independent t-tests were used to assess differences in change between those with and without a care partner and between those enrolled in TeleDREAMS and in-person DREAMS. Cohen's *d* effect sizes were calculated. Linear regressions adjusting for the variable of marital status was also used to assess differences between TeleDREAMS and in-person DREAMS. For the ten individuals that were

completers of the program but did not complete all measures of the post-test, the last observation carried forward method was used. The α level was set at 0.05 and per Cohen's conventions, 0.2 was small, 0.5 was moderate, and 0.8 was large for effect sizes (Cohen, 1988). All analyses were carried out using R software (version 1.2.1335).

Results

Participant Characteristics

TeleDREAMS participants: Care partners and PD

Fifty-one people (*M a*ge: 67.5 ±7.6 years; PD n=32; Care partner n=19) were recruited for the study. Eight individuals (PD n= 4; Care partner n=4) (non-completers) did not complete at least six modules. Participants in the PD group included significantly more males, a greater use of an assistive device when walking, and more comorbidities than the care partner group. The groups were similar for other baseline characteristics (Table 1A). Forty-three individuals completed six or more modules over the eight weeks, representing 15.7% attrition.

TeleDREAMS Completers versus Non-Completers

The eight non-completers were significantly older than the rest of the sample (completers) (Table 1B). Reasons given for dropping included: 1) did not see the value in the program, 2) two individuals withdrew for health reasons, 3) was too busy 4) found the reading to be too much, 5) "just not up for it," 6) two were unknown because individuals stopped answering phone calls.

PD Participants Enrolled with Care Partners versus those Enrolled Without

Of the twenty-eight PD participants who completed the program, fourteen were enrolled with a care partner and fourteen were enrolled without a care partner. Those with and without a care partner differed on marital status as those with a care partner were significantly more likely to be married than those enrolled without a care partner (Table 1C).

Participants with PD in TeleDREAMS versus In-Person DREAMS

In the in-person DREAMS program, nine individuals with PD were enrolled and seven completed the lessons with an attrition rate of 22.2%. No differences were observed between the in-person DREAMS and TeleDREAMS on the baseline characteristics (Table 1D).

Outcome Measures

Within Care Partners before and after TeleDREAMS

After completion of the TeleDREAMS program, the care partner group performed significantly better from baseline on the MoCA with a small effect size noted (Table 2a, Figure 1a).

Within PD before and after TeleDREAMS

The ToL mean first move time (scaled) and time per move ratio (scaled) significantly improved from baseline after completion of TeleDREAMS in the PD group although the effect sizes for both were small. PD performance on the S-TOFHLA also significantly improved with a small effect size (Table 2b, Figure 1b).

Satisfaction

The exit survey indicated that the participants were satisfied by the program. Mean scores showed both the PD and care partner groups reported they agreed or strongly agreed that the classes or activities enhanced their knowledge and skills about the topics (PD:21/23; Care partner:10/11) and would influence how the cared for themselves (PD:19/23; Care partner: 7/11), that they would attend future activities offered (PD:20/23; Care partner: 10/11), that they had been more mentally active (PD: 18/23; Care partner: 8/11), and that they enjoyed participating (PD:17/23; Care partner: 9/11). Participants also found the content to be useful (PD:21/23; Care partner:10/11) and high quality (PD:20/23; Care partner:11/11), and they agreed or strongly agreed that they would participate in the program if it were continued (PD:15/23; Care partner: 8/11) (Table 3a).

When investigating PD participant views in TeleDREAMS and the in-person DREAMS, participants had positive views for their respective programs. A significant difference was

observed between ratings on whether the program made the participants more mentally active with more individuals in the in-person DREAMS group reporting that they strongly agreed that they had been more mentally active. Most of both TeleDREAMS and in-person DREAMS either agreed or strongly agreed with the statement about mental activity (Table 3b).

Follow-up Survey 6-9 Months

Twenty-four participants completed the six-nine month follow up survey. Fifteen participants reported that they engaged in advocacy events and attended research or education seminars following their completion of TeleDREAMS. Nineteen individuals reported that participating in TeleDREAMS confirmed their already positive views on clinical research/researchers in general or changed the way they thought about clinical research/researchers (Table 4).

Responses to the follow-up questions reflected positive feedback. One participant stated: "It [the TeleDREAMS program] heightened my awareness for participants for research. It helped me see research from the researchers' point of view. The program provided a great overview of the entire clinical research world and then dove deep into many parts of it." Other participants commented on how the program influenced how they think about research and their future involvement saying, "TeleDREAMS encouraged me to more actively participate in research studies" and another stating, "TeleDREAMS has definitely increased my awareness, and I want to be more actively involved."

Care Partner Impact- Comparing PD Participants with and without a Care Partner

Participants enrolled with a care partner performed significantly better on the health literacy tests, the S-TOFHLA, and the TOSLS than participants enrolled without a care partner, and the effect sizes for these measures were large. Significant improvement was observed both

with and without adjusting for differences in marital status between the two groups (Table 5, Figure 2a).

In Person DREAMS and TeleDREAMS Outcomes Comparison

The TeleDREAMS group performed significantly better on the ToL time per move ratio (scaled) with a medium effect size observed. Medium effect sizes were also noted on the ToL time per move ratio (scaled), the REALM, and the S-TOFHLA (Table 6, Figure 2b).

Discussion

The TeleDREAMS program was designed to increase research participation and advocacy in individuals with PD and their care partners by expanding the DREAMS program into a telehealth model. Differences from baseline within the PD group and care partner group were seen in cognition and health literacy measures. Both the care partner and PD groups had high ratings for the program, and in follow-up, many reported that they engaged in advocacy events, attended research or education seminars, and their views on research remained positive or changed. In evaluating the PD participants who were enrolled with and without a care partner, significant differences were seen in measures of health literacy. Further, when comparing the PD participants in the in-person DREAMS program and the TeleDREAMS program, those in the TeleDREAMS program performed significantly better on the ToL and had lower attrition rates.

Completers and Non-completers

Research indicates that expository text, like the material presented in the modules, is more difficult to comprehend in older age groups (De Beni, Borella, & Carretti, 2007). Age was significantly different between completers and non-completers of the program and may have been a contributing factor for withdrawals. Other characteristics besides age likely contributed to withdrawals, e.g., health issues and other obligations.

Outcome Measure Performance:

Care Partners

Within group analysis revealed no improvement in health literacy by care partners. However, care partners had a baseline high level of health literacy. In contrast to their high

health literacy scores at baseline, the care partner group exhibited some deficits in global cognition. A cognitively normal MoCA score is greater than 26 while the average score for the care partners at the beginning of the study was only 24.2 (SD=4.8), indicating the possibility of mild cognitive impairment for some individuals in the sample, although none had a diagnosis. The care partners significantly improved on the MoCA from their original score. The findings compare with another research study that developed an intervention with social and cognitive engagement of older adults. The researchers found improvements in executive function and memory, both of which are measured in different sections of the MoCA, within a group of individuals with impaired or borderline cognition (Carlson et al., 2008).

One proposed mechanism for the improvement in MoCA score is noted in a study which found that adults taking part in sustained activities that are cognitively challenging show an increased modulation of brain activity in the medial frontal, lateral temporal, and parietal cortex-regions in comparison to individuals in low challenge environments (McDonough, Haber, Bischof, & Park, 2015). Fronto-parietal regions are often associated with general intelligence and executive function and the temporal cortex is believed to play a role in memory encoding, all of which are evaluated in the MoCA (Barbey et al., 2012; Ojemann, Schoenfield-McNeill, & Corina, 2009).

Parkinson's Disease

Within groups analysis revealed that the PD group significantly improved from baseline on functional health literacy as measured by the S-TOFHLA. The S-TOFHLA is a measure of a person's ability to understand health information through reading comprehension passages (Baker et al., 1999). TeleDREAMS placed a large emphasis on both reading health and science-related information and then articulating what was learned to a research assistant likely

contributing to increased scores. Individuals with low functional health literacy may have less knowledge about their disease and potential lifestyle modifications that would improve or stabilize their condition (Williams, Baker, Parker, & Nurss, 1998). Moreover, improvements in health literacy may be important for finding clinical trials and understanding the clinical research process (Evans et al., 2012; Utami et al., 2014). Thus, improvement in literacy levels could be important for maintaining health and increasing research participation in people with PD.

The PD participants significantly improved on the ToL from their baseline, and similar to the predicted mechanism of improvement in MoCA in the care partners, improvements may be, partly due to the increased modulation of neurons in the frontal cortex during sustained, complex situations (McDonough et al., 2015). The classic pathological findings linked to deficits in PD are dopaminergic neuronal death in the basal ganglia. Some of these neurons project to the frontal cortex, which is involved in executive function. Thus, executive function ability often decreases in individuals with PD (Cools, 2011). Results of our study showing significant improvement is meaningful, as declines are primarily observed in this population. Similar to our findings, a randomized and controlled cognitive training program in PD found that over four weeks, participants improved on many cognitive tests, including the ToL (Paris et al., 2011). Further, studies indicate that executive dysfunction and its associated behavioral challenges in individuals with PD is associated with lower quality of life scores among their care partners (Kudlicka, Clare, & Hindle, 2014; Lawson et al., 2017). Therefore, increased executive function abilities can improve the functioning of those with PD and potentially the mood of their care partner over time.

Despite literature indicating improvement in mood and quality of life through educational interventions in older adults and PD, depression scores and quality of life ratings did not show

any improvement in the PD or care partner group from baseline in our study (A'Campo et al., 2010; Dillard et al., 2018; Simons et al., 2006). Participants in our study scored above the threshold for depression on the BDI so an improvement is less likely to be observed (Jackson-Koku, 2016). Also, a major difference between these studies and the TeleDREAMS intervention is that TeleDREAMS lacked in-person socialization, and interviews with older adults indicate that the most preferred form of communication is face-to-face (Yuan, Syed, Hales, & Cotten, 2015). To maintain accessibility but observe greater socialization benefits than telephone conversations, video conferencing platforms such as FaceTime, Skype, or Zoom may be beneficial. Research indicates that video conferencing can be effective at providing care in pain management and diabetes (Burnett, Mitzner, Charness, & Rogers, 2011; Vadheim et al., 2010). Although, remote video features come with their own set of challenges as older adults self-report that they find video conferencing to not be useful (Burnett et al., 2011). Frustration that could build up from using such platforms may outweigh any benefits. Further investigation into video conferencing and its benefits and drawbacks should be considered in future TeleDREAMS studies.

The Exit and Follow-up Survey

The exit survey revealed positive ratings for the program overall, in the PD, and in the care partner group. Of particular importance, most participants agreed or strongly agreed that the classes enhanced their knowledge and skills and would influence how they will take care of themselves. The study, then, has important implications for impacting the future lives of participants. Participant willingness to attend future programs and classes for the study indicates their commitment to the goals of the study and will likely lead to stronger advocates for PD and

research. The follow-up survey also reveals promising results for the program with most participants reporting that they engaged in advocacy events, research/educational seminars, and believed that TeleDREAMS confirmed positive thoughts or changed the way that participants thought about clinical research/researchers in general.

Four individuals participated in additional research studies after completing the program. While the goal of the study was to increase research participation, six-nine months may be too short of a time period to follow-up with participants. The change in attitudes as exhibited by their exit survey and the other follow-up questions will likely have a larger impact in the long term as participants will feel more open to participating in studies in the future. The considerable number of participants who attended advocacy events was also promising as it reveals increased involvement by PD participants and their care partners. In addition, the positive comments from individuals indicate a willingness to remain involved in research. The participants should also be called over time at one year, three years, and five years following the program to further understand the impact that TeleDREAMS had on PD and care partner research participation.

Comparing PD with and without Care Partners

In comparing PD participants enrolled with and without a care partner, research indicates that individuals with a care partner have increased health benefits, remember more after an informed consent session, and have lower rates of mortality (Dickens et al., 2004; Spillman, 2016; Teng et al., 2012). The PD group performed significantly better on their performance on the health and science literacy measures of the S-TOFHLA and the TOSLS. Improvement was significant even after adjusting for differences in marital status between the two groups. Reading with a care partner may have contributed to more knowledge comprehension causing individuals

with care partners to improve from baseline. Few studies investigate partnered reading in adults, but a study investigating reading in students found that in attentive students, paired reading had a large effect on improved comprehension of material which supports our findings of increased performance of individuals with care partners on measures that require comprehension in health literacy (Mittal, Verma, Jain, Khatter, & Juyal, 2012).

Research also indicates that reading aloud can improve a range of cognitive areas including executive function in older adults. (Nouchi et al., 2012). Despite these findings and our hypothesis, the PD group with the care partners did not show any meaningful improvements over the PD group without care partners on the cognitive measures. However, scores were relatively high to begin with limiting the amount of improvement possible. The lack of significant improvement also may be because most participants read together but not aloud or read separately and discussed the material afterward together. Future studies of TeleDREAMS should investigate whether PD and care partners are reading the material together or separately to further interpret the influence of a care partner enrolled with a PD participant.

Comparing TeleDREAMS and In-person DREAMS in PD Participants

PD participants in the TeleDREAMS and the in-person DREAMS program performed similarly on most outcome measures. However, the TeleDREAMS group performed significantly better on the ToL time per move ratio (scaled) than the in-person DREAMS and effect sizes were moderately large for the ToL mean first move time (scaled) and the S-TOFHLA. While we predicted no significant difference from the in-person model, we found cognitive and health literacy comprehension benefits to TeleDREAMS in comparison to DREAMS although the sample size was small. One reason may be that in TeleDREAMS participants were able to move

at their own pace and reread any sections that they did not initially understand. They also had individualized consistent, 30-minute sustained conversations with staff assistants where they could ask questions, whereas in DREAMS, while the lectures took place directly with the faculty "expert" leading them, the question and answers were part of a group that may have received little input from the expert. Moreover, adding care partners, not evaluated in the DREAMS study, may have helped improve health literacy measures and reading comprehension in the TeleDREAMS group.

As predicted, attrition rates were higher in the in-person program than in TeleDREAMS highlighting the increased accessibility of TeleDREAMS versus an in-person model. Despite the increased accessibility of TeleDREAMS, the number of minorities between the two groups were not significantly different. Minority groups should be represented in research, but fewer minority groups are identified as having PD where the prevalence of PD in Whites is nearly 50% higher than in Asians and Blacks (Wright Willis, Evanoff, Lian, Criswell, & Racette, 2010). Study recruitment was also majorly focused on those seeking medical care at a large urban medical facility, so the pool of minority individuals with PD may not have been representative of all minorities with PD.

Importantly, both in-person DREAMS and TeleDREAMS PD groups had strong ratings for the program. However, in both DREAMS and TeleDREAMS, most participants either reported that they disagreed that they had become more physically active or that they were neutral about becoming more physically active. While the Week 5 Module: Aging and Clinical Research gives specific recommendations about physical exercise and its benefits, most of the modules do not focus on physical activity and physical activity recommendations are not given

until five weeks into the program offering an explanation for why most individuals would not have changed their activity after spending time reading the modules.

More participants in the in-person DREAMS group reported that they strongly agreed that they were more mentally active than the TeleDREAMS group after completing the program. One theory for this finding is that the in-person program included more sensory stimulation through auditory and visual senses. Sensory stimulation increases regional cerebral blood flow and may result in increased perception of mental activity (Roland, Eriksson, Stone-Elander, & Widen, 1987). The TeleDREAMS program sought to provide sensory stimulation through pictures in the modules and by providing online resources and videos through supplemental content. Although, participants may not have used these materials or had enough knowledge of computers to be able to access them. Finding new ways to engage the participants mentally will continue to be a priority in the TeleDREAMS study.

Limitations

This pilot study had several limitations. A limitation is the small sample size, especially for PD caregivers and PD participants in DREAMS, which likely means that the study is underpowered to determine some effects. Effect sizes generated from this project should overall be considered as useful for powering future studies that will more definitively test hypotheses.

Future studies evaluating TeleDREAMS could include a control group who are pretested and then post-tested 8-weeks later without an intervention. Without a non-intervention control group, we cannot state that improvements on outcome measures are not because of the practice effect as participants were tested on two occasions. Nevertheless, research indicates that the practice effect becomes smaller with increased age (Calamia, Markon, & Tranel, 2012). Because

our sample is of primarily older adults, they may be less susceptible to the practice effect. Some of the measures in the study that showed significant improvement are more resistant to the practice effect. Research on the practice effect in the MoCA indicates that at shorter time points and using alternative versions, the practice effect is not observed (Wong et al., 2018). Investigations of the practice effect in ToL found that after practice, older adults decreased their number of moves but did not improve their planning time (Lemay, Bedard, Rouleau, & Tremblay, 2004). In this study, we report improvement in the amount of time taken to make the first move indicating an improvement outside of the practice effect. We also provide between group analyses which are not affected by the practice effect.

The findings may also be subject to self-selection bias as many individuals were recruited from Parkinson's community events and within Emory's Center for Health in Aging's community outreach programs and selected whether or not they were willing to participate. Participants also may have already had positive views on research due to the communities in which they were recruited and may already be likely to participate in advocacy events and research studies. Continued recruitment of people from underserved areas that lack access to programs like TeleDREAMS is necessary to reach participants who are not already inclined to participate in research. Baseline data indicate that most of the participants are living in houses, apartments, or condominiums. However, in 2002, nearly 25% of PD patients receiving Medicare benefits lived in assisted living facilities (Safarpour et al., 2015). Future studies should target individuals in assisted living facilities as they are often not included in research and deserve the opportunity to learn research advocacy.

Conclusion

In conclusion, this research has important implications for using a telehealth education model to help improve cognition and health literacy in participants with PD and their care partners which may also help increase research involvement. If increased attendance of advocacy events and the reports of changes in beliefs on research translates to increased research involvement in the future, then the telehealth model is also important for researchers looking to increase research participation in PD and for care partners. Continuing TeleDREAMS is important for the future of research and recruitment and may increase participation in the long term.

Table 1a. Characteristics of the Sample

	Entire Sample *M (SD) /N (%)*	**Parkinson's Disease** *M (SD) /N (%)*	**Care Partner** *M (SD) /N (%)*	***P*-Values**
Sex[2]	N=51	N=32	N=19	
Female	23 (45.1%)	10 (31.3%)	13 (68.4%)	0.004*
Male	28 (54.9%)	22 (68.8%)	6 (31.6%)	
Age (years)[1]	N=51	N=32	N=19	0.51
	67.5 (7.6)	68.1 (8.3)	66.7 (6.4)	
Race[2]	N=51	N=32	N=19	
Black or African American	11 (21.6%)	7 (21.9%)	4 (21.1%)	
Asian	3 (5.9%)	1 (3.1%)	2 (10.5%)	0.34
Hispanic or Latino	2 (3.9%)	1 (3.1%)	1 (5.3%)	
White	35 (68.6%)	23 (71.9%)	12 (63.2%)	
Education (years)[1]	N=49	N=32	N=17	0.48
	16.2 (2.5)	16.1 (2.64)	16.6 (1.8)	
Employed[2]	N=50	N=32	N=18	0.26
	10 (20.0%)	5 (15.6%)	5 (25.8%)	
Marital Status[2]	N=51	N=32	N=19	
Single	3 (5.9%)	3 (9.4%)	0(0%)	
Married/Partnered	40 (78.4%)	22 (68.8%)	17 (94.4%)	0.38
Divorced	5 (9.8%)	4 (12.5%)	1 (5.6%)	
Widowed	3 (5.9%)	3 (9.4%)	0 (0%)	
Housing[2]	N=51	N=32	N=19	
House/Apartment/Condominium	49 (96.1%)	31 (96.9%)	18 (94.7%)	1
Senior Housing (independent)	2 (3.9%)	1 (3.1%)	1 (5.3%)	
Number of Falls in the Past 6-months[1]	N=51	N=32	N=19	0.12
	5.9 (26.3)	9.3(32.9)	0.1 (0.2)	
Assistive Device Use when Walking[2]	N=51	N=32	N=19	
Yes	15 (30.0%)	15 (46.9%)	0 (0%)	0.007*
No	35 (70.0%)	17 (53.1%)	18 (100%)	
Hearing Aid Use[2]	N=50	N=32	N=18	
Yes	8 (16.0%)	5 (15.6%)	3 (16.7%)	1
No	42 (84.0%)	27 (84.4%)	15 (83.3%)	
Body Mass Index (kg/m^2)[1]	N=51	N=32	N=19	0.25
	27.3 (6.2)	26.4 (5.8)	28.6 (6.8)	
Number of Comorbidities[1]	N=50	N=30	N=19	0.002*
	2.9 (2.1)	3.8 (2.4)	1.9 (1.2)	

[1]Two-tailed, independent T-Tests were used for continuous variables
[2]Fisher's exact tests were used for categorical variables
[*]P values indicate significant differences between Parkinson's Disease and Care Partner Groups at the 0.05 level

Table 1b. Characteristics of individuals whom withdrew from the TeleDREAMS program versus the rest of the sample

	Non-completers *M (SD)/ N (%)*	**Completers** *M (SD/ N (%)*	***P*-Values**
Sex[2]	N=8	N=43	0.72
Female	3 (37.5%)	20 (46.5%)	
Male	5 (62.5%)	23 (53.5%)	
Age (years)[1]	N=8	N=43	0.03*
	72.1 (5.4)	66.7 (7.7)	
Race[2]	N=8	N=43	1
Black or African American	2 (25.0%)	9 (20.9%)	
Asian	0 (0%)	3 (7.0%)	
Hispanic or Latino	0 (0%)	2 (4.7%)	
White	6 (75.0%)	29 (67.4%)	
Education (years)[1]	N=7	N=42	0.96
	16.9 (2.3)	16.1 (2.6)	
Employed[2]	N=8	N=42	
	1 (14.3%)	8 (18.6%)	0.30
Marital Status[2]	N=8	N=43	0.15
Single	0 (0%)	3 (6.8%)	
Married/Partnered	6 (75.0%)	34 (77.3%)	
Divorced	0 (0%)	5 (11.4%)	
Widowed	2 (25.0%)	1 (2.3%)	
Housing[2]	N=8	N=43	1
House/Apartment/Condominium	8 (100%)	41 (95.3%)	
Senior Housing (independent)	0 (0%)	2 (4.7%)	
Participant Type	N=8	N=43	0.45
Parkinson's Disease	4 (50.0%)	15 (34.9%)	
Care Partner	4 (50.0%)	28 (65.1%)	
Number of Falls in the Past 6-months[1]	N=8	N=43	0.16
	0.6 (1.2)	6.8 (28.6)	
Assistive Device Use when Walking[2]	N=7	N=43	1
Yes	2 (28.6%)	13 (30.2%)	
No	5 (28.6%)	30 (69.8%)	
Hearing Aid Use[2]	N=7	N=43	0.07
Yes	3 (42.9%)	5 (11.6%)	

No	4 (57.1%)	38 (88.4%)	
Number of Comorbidities[1]	N=6 2.5 (1.6)	N=43 2.7 (1.8)	0.75

[1]Two-taied, independent T-Tests were used for continuous variables
[2]Fisher's exact tests were used for categorical variables
[*]P values indicate significant differences between the group of participants that did not complete the TeleDREAMS program and the group of participants that completed at least seven sessions of the program at the 0.05 level

Table 1c. Characteristics of individuals with Parkinson's Disease enrolled with a care partner versus those enrolled without a care partner

	Parkinson's Disease with Care Partner ***(n=14) M (SD)/ N (%)***	**Parkinson's Disease without Care Partner** ***(n=14) M (SD/ N (%)***	***P*-Values**
Sex[2]			0.21
Female	2 (14.3%)	6 (42.9%)	
Male	12 (85.7%)	8 (57.1%)	
Age (years)[1]	65.5 (6.8)	69.2 (9.9)	0.26
Race[2]			0.47
Black or African American	3 (21.4%)	2 (14.3%)	
Asian	1 (7.1%)	0 (0%)	
Hispanic or Latino	1 (7.1%)	0 (0%)	
White	9 (64.3%)	12 (85.7%)	
Education (years)[1]	15.7 (3.6)	16.1 (2.0)	0.70
Employed[2]	2 (14.3%)	2 (14.3%)	1
Marital Status[2]			0.05*
Single	0 (0%)	3 (21.4%)	
Married/Partnered	13 (92.9%)	7 (50.0%)	
Divorced	0 (0%)	3 (21.4%)	
Widowed	1 (7.7%)	1 (7.1%)	
Housing[2]			1
House/Apartment/Condominium	14 (100%)	13 (92.9%)	
Senior Housing (independent)	0 (0%)	1 (7.1%)	
Number of Falls in the Past 6-months[1]	7.4 (13.8)	13.5 (48.5)	0.66
Assistive Device Use when Walking[2]			
Yes	8 (57.1%)	9 (64.3%)	0.48
No	6 (42.9%)	5 (35.7%)	
Hearing Aid Use[2]			
Yes	2 (14.3%)	2 (14.3%)	1
No	12 (85.7%)	12 (85.7%)	
Body Mass Index (kg/m^2)[1]	27.1 (5.1)	27.1 (6.7)	0.39
Number of Comorbidities[1]	3.1 (1.9)	4.1 (2.6)	0.26

[1]Two-taied, independent T-Tests were used for continuous variables
[2]Fisher's exact tests were used for categorical variables
[*]P values indicate significant differences between Parkinson's Disease participants enrolled with a care partner and those enrolled without a care partner at the 0.05 level

Table 1d. Characteristics of Parkinson's Disease Participants in TeleDREAMS and In-Person DREAMS Team Program

	TeleDREAMS *(n=28) M* (SD) /N (%)	**In-Person DREAMS Team *(n=7) M (SD) /N (%)***	***P*-Values**
Sex[2]			0.66
Female	8 (28.6%)	4 (57.1%)	
Male	20 (71.4%)	3 (42.9%)	
Age (years)[1]	67.4 (8.5)	68.1 (5.0)	0.76
Race[2]			0.17
Black or African American	5 (17.9%)	1 (57.1%)	
Asian	1 (3.6%)	0 (0%)	
Hispanic or Latino	1 (3.6%)	0 (0%)	
White	22 (75.0%)	3 (42.9%)	
Education (years)[1]	16.1 (2.9)	13.7 (2.4)	0.06
Employed[2]	4 (14.3%)	0 (0%)	0.87
Marital Status[2]			0.27
Single	3 (10.7%)	1 (14.3%)	
Married/Partnered	20 (71.4%)	3 (42.9%)	
Divorced	4 (14.3%)	3 (42.9%)	
Widowed	1 (3.6%)	0 (0%)	
Housing[2]			1
House/Apartment/Condominium	27 (96.4%)	7 (100%)	
Senior Housing (independent)	1 (3.6%)	0 (0%)	
Number of Falls in the Past 6-months[1]	10.5 (35.1)	0.3 (0.8)	0.14
Hearing Aid Use[2]			0.56
Yes	4 (14.3%)	0 (0%)	
No	24 (85.7%)	7 (100%)	
Body Mass Index (kg/m^2)[1]	27.1 (5.9)	26.6 (4.5)	0.82
Number of Comorbidities[1]	3.6 (2.3)	2.3 (1.4)	0.08

[1]Two-taied, independent T-Tests were used for continuous variables
[2]Fisher's exact tests were used for categorical variables
*P values indicate significant differences between Parkinson's Disease Participants enrolled in TeleDREAMS or the in-person DREAMS Team Program at the 0.05 significance level

Table 2a. Pretest and Post-test Values for Outcome Measures in the Care Partner TeleDREAMS Group

	N	Pre *M (SD)*	Post *M (SD)*	P-value[1]	Cohen's d
Montreal Cognitive Assessment (/30)	15	23.5 (3.6)	24.5 (3.0)	0.02*	0.30
Tower of London	15				
Total Achievement Score (scaled) (/19)		9.1 (3.4)	10.2 (4.1)	0.25	0.28
Mean First Move Time (scaled) (/19)		10.7 (3.7)	12.0 (2.4)	0.07	0.42
Time per Move Ratio (scaled) (/19)		8.6 (4.5)	9.5 (4.6)	0.10	0.20
REALM Percent Correct (%)[2]	15	95.2 (5.3)	95.4 (6.3)	0.84	0.03
S-TOFHLA Percent Correct (%)[3]	15	33.9 (3.5)	34.9 (1.6)	0.29	0.37
TOSLS Percent Correct (%)[4]	15	45.7 (6.2)	46.3 (25.2)	0.19	0.26
Advocate Literacy Percent Correct (%)	14	52.3 (21.0)	53.6 (22.3)	0.55	0.04
Beck Depression Index^ (/63)	15	6.8 (6.0)	7.2 (7.3)	0.65	0.06
Short Form-12 (/100)	15				
Mental Health Composite		46.0 (6.2)	42.9 (6.6)	0.10	0.49
Physical Health Composite		54.6 (6.8)	55.0 (6.5)	0.65	0.06

[1]Paired T-test comparing pretest and post-test values on outcome measures within the Care Partner Group
[2]Rapid Estimate Adult Literacy Measurement
[3]Short Test of Functional Health Literacy Assessment
[4]Test of Scientific Literacy Skills
[5]Center for Epidemiologic Studies Depression Scale
^Higher Scores indicate worsening function/performance; otherwise, higher scores indicate improvement
* P values indicate significant differences between pretest and post-test scores at the 0.05 level

Table 2b. Pretest and Post-test Values for Outcome Measures in Parkinson's Disease TeleDREAMS Group

	N	Pre *M (SD)*	Post *M (SD)*	P-value[1]	Cohen's D
Montreal Cognitive Assessment (/30)	28	24.2 (4.8)	24.9 (4.9)	0.07	0.14
Tower of London	28				
Total Achievement Score (scaled)		9.7 (3.6)	10.6 (3.6)	0.08	0.27
Mean First Move Time (scaled)		10.5 (4.2)	12.2 (3.3)	0.02*	0.44
Time per Move Ratio (scaled)		8.1 (4.8)	9.7 (4.0)	0.01*	0.35
REALM Percent Correct (%)[2]	28	94.3 (10.8)	94.3 (11.0)	0.91	0.005
S-TOFHLA Percent Correct (%)[3]	28	31.0 (7.6)	32.5 (7.1)	0.03*	0.21
TOSLS Percent Correct (%)[4]	26	45.6 (27.0)	47.3 (25.2)	0.49	0.06
Advocate Literacy Percent Correct (%)	25	47.1 (21.7)	55.0 (18.0)	0.32	0.39
Beck Depression Index^ (/63)	28	15.4 (11.6)	13.9 (11.5)	0.33	0.12
Short Form-12 (/100)	28				
Mental Health Composite		40.7 (8.4)	38.8 (9.7)	0.36	0.21
Physical Health Composite		40.3 (11.8)	41.4 (13.7)	0.57	0.09

[1]Paired T-test comparing pretest and post-test values on behavioral measures within the Parkinson's Disease and Care Partner Group
[2]Rapid Estimate Adult Literacy Measurement
[3]Short Test of Functional Health Literacy Assessment
[4]Test of Scientific Literacy Skills
[5]Center for Epidemiologic Studies Depression Scale
^Higher Scores indicate worsening function/performance; otherwise, higher scores indicate improvement
***** P values indicate significant differences between pretest and post-test scores at the 0.05 level

Table 3a. Exit Survey Assessing Participant Views on TeleDREAMS

	Entire Sample *(n=34) M (SD)*	**Parkinson's Disease** *(n=23) M (SD)*	**Care Partner** *(n=11) M (SD)*
The classes or activities enhanced my knowledge/skills about the topics.			
Strongly Disagree	1 (2.9%)	1 (4.3%)	0 (0%)
Disagree	0 (0%)	0 (0%)	0 (0%)
Neutral	2 (5.9%)	1 (4.3%)	1 (9.1%)
Agree	23 (67.6%)	16 (69.6%)	7 (63.6%)
Strongly Agree	8 (23.5%)	5 (21.7%)	3 (27.3%)
The classes or activities will influence how I take care of myself.			
Strongly Disagree	0 (0%)	0 (0%)	0 (0%)
Disagree	0 (0%)	0 (0%)	0 (0%)
Neutral	8 (23.5%)	4 (17.4%)	4 (36.4%)
Agree	15 (44.1%)	11 (47.8%)	4 (36.4%)
Strongly Agree	11 (32.4%)	8 (34.8%)	3 (27.3%)
The classes or activities have provided me with information I can use.			
Strongly Disagree	1 (2.9%)	1 (4.3%)	0 (0%)
Disagree	0 (0%)	0 (0%)	0 (0%)
Neutral	2 (5.9%)	1 (4.3%)	1 (9.1%)
Agree	20 (58.8%)	14 (60.9%)	6 (54.5%)
Strongly Agree	11 (32.4%)	7 (30.4%)	4 (36.4%)
The quality of the classes or activities and its content was high.			
Strongly Disagree	2 (5.9%)	2 (8.7%)	0 (0%)
Disagree	0 (0%)	0 (0%)	0 (0%)
Neutral	1 (2.9%)	1 (4.3%)	0 (0%)
Agree	17 (50.0%)	9 (39.1%)	8 (72.7%)
Strongly Agree	14 (41.2%)	11 (47.8%)	3 (27.3%)
I would attend future programs, classes and activities offered by this group.			
Strongly Disagree	1 (2.9%)	1 (4.3%)	0 (0%)
Disagree	1 (2.9%)	1 (4.3%)	0 (0%)
Neutral	3 (8.8%)	1 (4.3%)	2 (18.2%)
Agree	14 (41.2%)	9 (39.1%)	5 (45.5%)
Strongly Agree	15 (44.1%)	11 (47.8%)	4 (36.4%)
I enjoyed participating in this program.			
Strongly Disagree	1 (2.9%)	1 (4.3%)	0 (0%)
Disagree	0 (0%)	0 (0%)	0 (0%)
Neutral	7 (20.6%)	5 (21.7%)	2 (18.2%)
Agree	11 (32.4%)	6 (26.1%)	5 (45.5%)
Strongly Agree	15 (44.1%)	11 (47.8%)	4 (36.4%)
If I could, I would continue participating in this program.			

Strongly Disagree	2 (6.1%)	1 (4.5%)	1 (9.1%)
Disagree	2 (6.1%)	2 (9.1%)	0 (0%)
Neutral	6 (18.2%)	4 (18.2%)	2 (18.2%)
Agree	14 (42.4%)	9 (40.9%)	5 (45.5%)
Strongly Agree	9 (27.3%)	6 (27.3%)	3 (27.3%)
I have been more physically active.			
Strongly Disagree	1 (2.9%)	1 (4.3%)	0 (0%)
Disagree	4 (11.8%)	2 (8.7%)	2 (18.2%)
Neutral	18 (52.9%)	12 (52.2%)	6 (54.5%)
Agree	9 (26.5%)	7 (30.4%)	2 (18.2%)
Strongly Agree	2 (5.9%)	1 (4.3%)	1 (9.1%)
I have been more mentally active.			
Strongly Disagree	1 (2.9%)	1 (4.3%)	0 (0%)
Disagree	1 (2.9%)	0 (0%)	1 (9.1%)
Neutral	8 (23.5%)	4 (17.4%)	4 (36.4%)
Agree	20 (58.8%)	16 (69.6%)	4 (36.4%)
Strongly Agree	4 (11.8%)	2 (8.7%)	2 (18.2%)

Statements about TeleDREAMS and its influence on different aspects of the participants' life rated on a 5-point Likert scale (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree).

Table 3b. Exit Survey Results Assessing Parkinson's Disease Participant Views on TeleDREAMS vs. In-Person DREAMS

	TeleDREAMS ***(n=23) M (SD)***	**In-Person DREAMS** ***(n=7) M (SD)***	**P-value**[1]
The classes or activities enhanced my knowledge/skills about the topics.			
Strongly Disagree	1 (4.3%)	0 (0%)	0.38
Disagree	0 (0%)	0 (0%)	
Neutral	1 (4.3%)	0 (0%)	
Agree	16 (69.6%)	3 (42.9%)	
Strongly Agree	5 (21.7%)	4 (57.1%)	
The classes or activities will influence how I take care of myself.			
Strongly Disagree	0 (0%)	0 (0%)	0.63
Disagree	0 (0%)	0 (0%)	
Neutral	4 (17.4%)	2 (28.6%)	
Agree	11 (47.8%)	2 (28.6%)	
Strongly Agree	8 (34.8%)	2 (28.6%)	
The classes or activities have provided me with information I can use.			
Strongly Disagree	1 (4.3%)	0 (0%)	0.64
Disagree	0 (0%)	0 (0%)	
Neutral	1 (4.3%)	0 (0%)	
Agree	14 (60.9%)	3 (42.9%)	
Strongly Agree	7 (30.4%)	4 (57.1%)	
The quality of the classes or activities and its content was high.			
Strongly Disagree	2 (8.7%)	0 (0%)	1.00
Disagree	0 (0%)	0 (0%)	
Neutral	1 (4.3%)	0 (0%)	
Agree	9 (39.1%)	3 (42.9%)	
Strongly Agree	11 (47.8%)	4 (57.1%)	
I would attend future programs, classes and activities offered by this group.			
Strongly Disagree	1 (4.3%)	0 (0%)	0.85
Disagree	1 (4.3%)	0 (0%)	
Neutral	1 (4.3%)	0 (0%)	
Agree	9 (39.1%)	2 (28.6%)	
Strongly Agree	11 (47.8%)	5 (71.4%)	
I enjoyed participating in this program.			
Strongly Disagree	1 (4.3%)	0 (0%)	0.56
Disagree	0 (0%)	0 (0%)	
Neutral	5 (21.7%)	0 (0%)	
Agree	6 (26.1%)	2 (28.6%)	

Strongly Agree	11 (47.8%)	5 (71.4%)	
If I could, I would continue participating in this program.			
Strongly Disagree	1 (4.5%)	0 (0%)	0.40
Disagree	2 (9.1%)	0 (0%)	
Neutral	4 (18.2%)	0 (0%)	
Agree	9 (40.9%)	2 (28.6%)	
Strongly Agree	6 (27.3%)	5 (71.4%)	
I have been more physically active.			
Strongly Disagree	1 (4.3%)	0 (0%)	0.42
Disagree	2 (8.7%)	1 (14.3%)	
Neutral	12 (52.2%)	3 (42.9%)	
Agree	7 (30.4%)	1 (14.3%)	
Strongly Agree	1 (4.3%)	2 (28.6%)	
I have been more mentally active.			
Strongly Disagree	1 (4.3%)	0 (0%)	0.04*
Disagree	0 (0%)	1 (14.3%)	
Neutral	4 (17.4%)	1 (14.3%0	
Agree	16 (69.6%)	2 (28.6%)	
Strongly Agree	2 (8.7%)	3 (42.9%)	

Statements about TeleDREAMS and In-person DREAMS and its influence on different aspects of the participants' life rated on a 5-point Likert scale (1=strongly disagree to 5=strongly agree).
[1]Fisher's exact test comparing PD participants and TeleDREAMS and in-person DREAMS
*P values indicate significant differences at the 0.05 level

Table 4. Follow-up Survey assessing research and advocacy of participants 6-9 months following the TeleDREAMS program

	TeleDREAMS Follow-up *(n=24) N (%)*
Have you participated in any studies since you finished the TeleDREAMS study?	
Yes	4 (16.7%)
No	20 (83.3%)
Have you engaged in any advocacy events?	
Yes	15 (62.5%)
No	9 (37.5%)
Have you attended any research or educational seminars?	
Yes	15 (62.5%)
No	9 (37.5%)
Have you given any presentations to your peers or others about any topics related to your research or Parkinson's Disease?	
Yes	8 (33.3%)
No	16 (66.7%)
Did participating in the TeleDREAMS program change the way you thought about clinical research or researchers in general?	
Yes	19 (79.2%)
No	5 (20.8%)

Table 5. Change Scores comparing individuals with Parkinson's Disease with a Care Partner versus those without a Care Partner

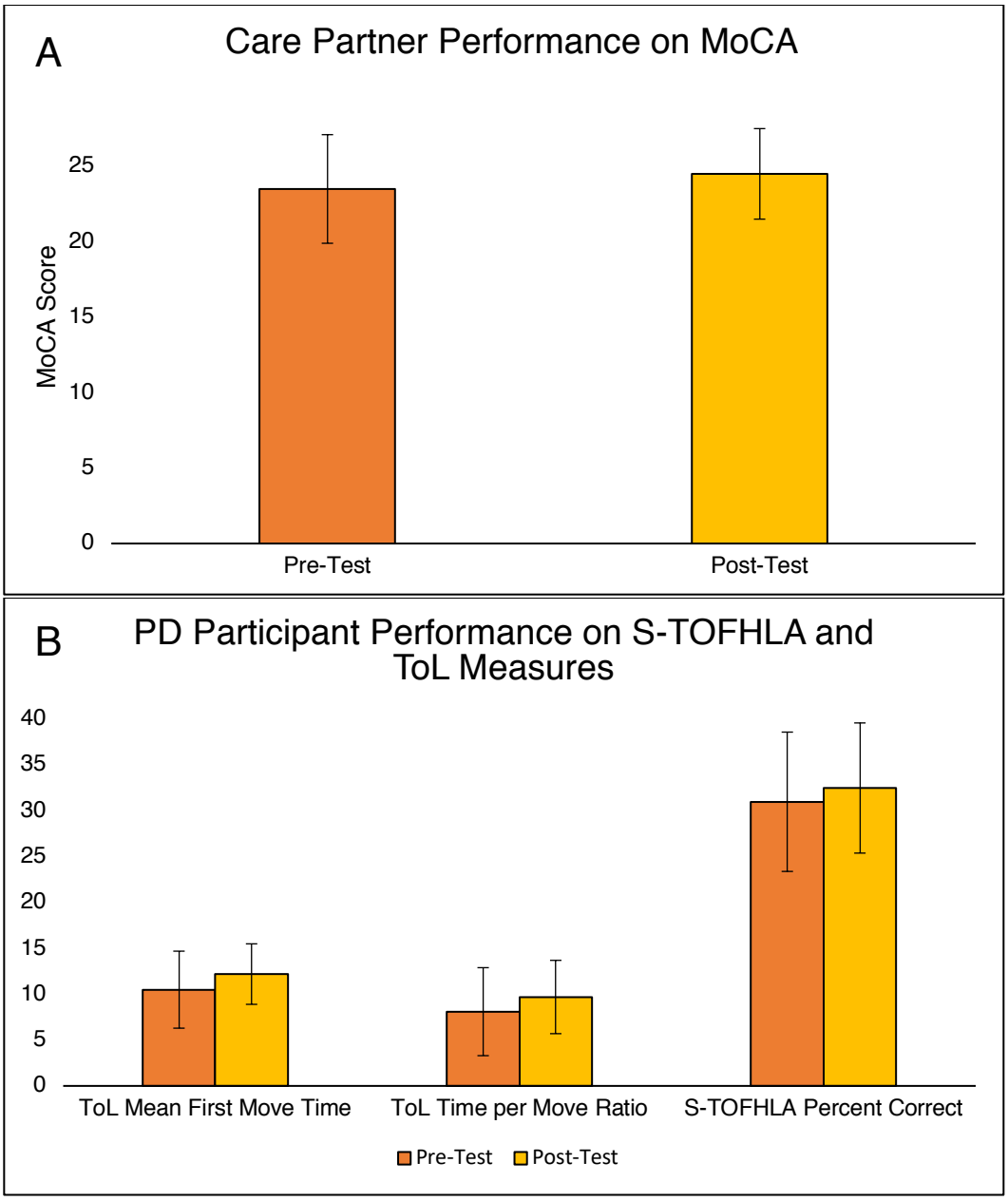
	Change[1]		*P*-value[2]	*P*-value[3]	Cohen's d
	Parkinson's Disease with Care Partner *(n=14) M (SD)*	Parkinson's Disease without Care Partner *(n=14) M (SD)*			
Montreal Cognitive Assessment (/30)	0.86 (1.06)	0.50 (1.17)	0.63	0.66	0.18
Tower of London					
Total Achievement Score (scaled)	0.36 (1.54)	1.57 (2.90)	0.26	0.28	0.43
Mean First Move Time (scaled)	2.07 (2.53)	1.29 (4.36)	0.57	0.58	0.22
Time per Move Ratio (scaled)	1.14 (2.41)	1.93 (3.58)	0.50	0.50	0.26
REALM Percent Correct (%)[3]	0.43 (1.55)	-0.32 (1.29)	0.43	0.33	0.31
S-TOFHLA Percent Correct (%)[4]	3.07 (4.46)	0 (0.78)	0.02*	0.02*	0.96
TOSLS Percent Correct (%)[5]	5.87 (10.4)	-2.81 (11.4)	0.05*	0.05*	0.79
Advocate Literacy Percent Correct (%)	-0.71 (14.0)	4.64 (9.70)	0.25	0.27	0.45
Beck Depression Index^	-1.21 (10.06)	-1.64 (4.67)	0.89	0.92	0.05
Short Form-12 (/100)					
Mental Health Composite	-3.05 (13.44)	-0.75 (7.37)	0.58	0.58	0.21
Physical Health Composite	0.67 (11.66)	1.74 (10.62)	0.80	0.76	0.10

[1]Change scores calculated by post-test minus pretest of average performance on outcome measures
[2]Independent T-test comparing change scores between PD participants enrolled with a care partner and those enrolled without a care partner
[3]Linear Regression model adjusting for marital status comparing scores between PD participants enrolled with and without a care partner
[3]Rapid Estimate Adult Literacy Measurement
[4]Short Test of Functional Health Literacy Assessment
[5]Test of Scientific Literacy Skills
[6]Center for Epidemiologic Studies Depression Scale
^Higher Scores indicate worsening function/performance; otherwise, higher scores indicate improvement
*P values indicate significant differences between the group of participants that did not complete the TeleDREAMS program and the group of participants that completed the program at the 0.05 level

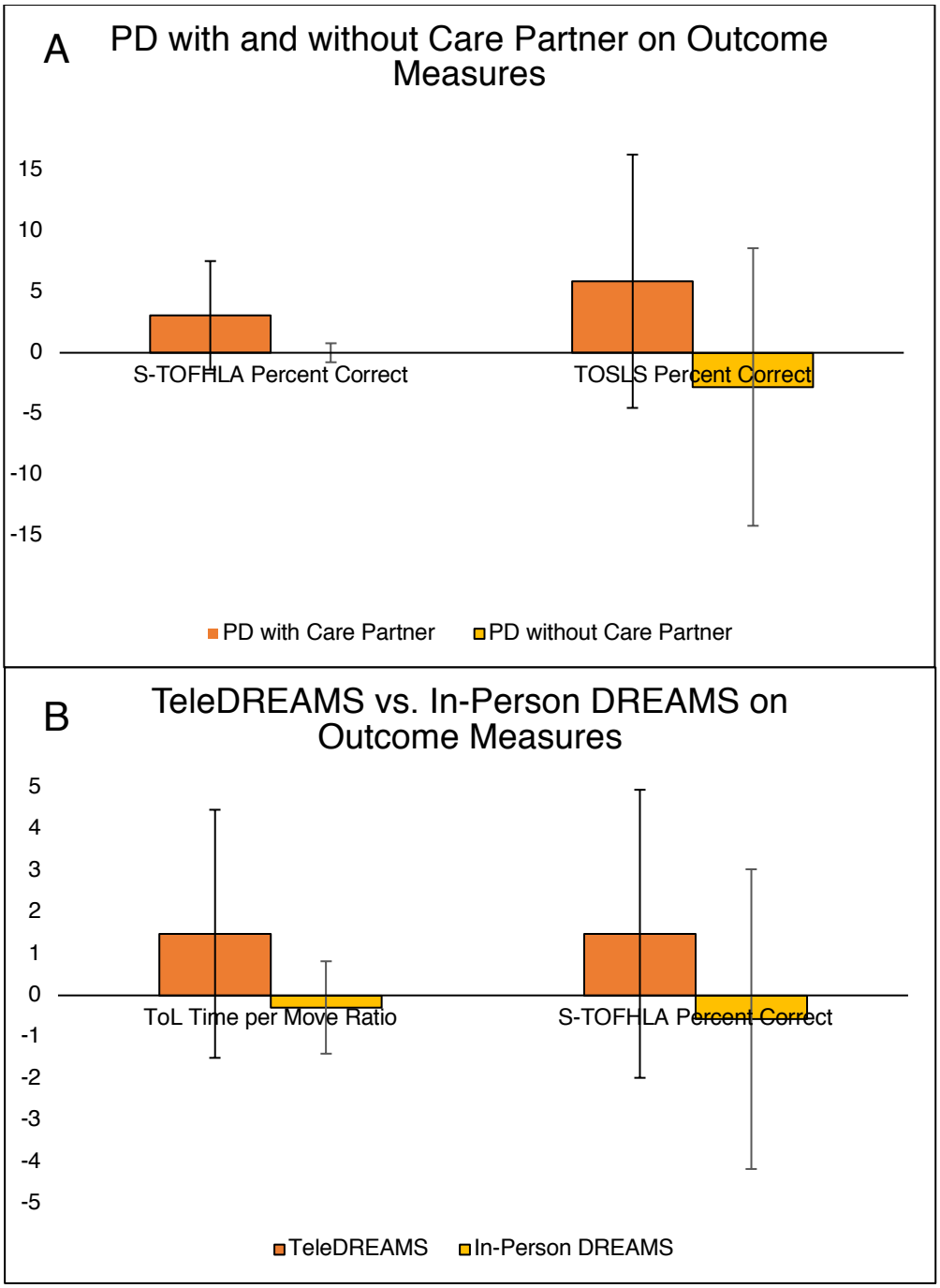
Table 6. Change Scores comparing individuals with Parkinson's Disease from TeleDREAMS and the in-person DREAMS Team Program

	Change[1]		**P-value[2]**	**Cohen's d**
	TeleDREAMS *(n=28) M (SD)*	In-Person DREAMS *(n=7) M (SD)*		
Montreal Cognitive Assessment	0.66 (1.88)	0.71 (0.95)	0.94	0.02
Tower of London				
Total Achievement Score (scaled)	0.93 (2.76)	0.71 (2.21)	0.81	0.09
Mean First Move Time (scaled)	1.62 (3.47)	-0.14 (2.19)	0.11	0.55
Time per Move Ratio (scaled)	1.48 (2.98)	-0.29 (1.11)	0.02*	0.66
REALM Percent Correct (%)[5]	0.05 (2.41)	1.30 (2.04)	0.19	0.52
S-TOFHLA Percent Correct (%)[6]	1.48 (3.46)	-0.57 (3.60)	0.20	0.60
Beck Depression Inventory^	-1.38 (7.56)	0.43 (1.51)	0.24	0.27
Short Form-12				
Mental Health Composite	1.49 (5.01)	-1.83 (10.5)	0.24	0.34
Physical Health Composite	-1.27 (4.90)	1.16 (10.76)	0.38	0.24

[1]Change scores calculated by post-test minus pretest on behavioral measures
[2]Linear regression model adjusting for education
[3]Rapid Estimate Adult Literacy Measurement
[4]Short Test of Functional Health Literacy Assessment
^Higher Scores indicate worsening function/performance; otherwise, higher scores indicate improvement
*P values indicate significant differences at the 0.05 level



Bar charts of significant differences from baseline on outcome measures in the care partner (A) and the PD (B) groups after completing the TeleDREAMS study
MoCA (/30) = Montreal Cognitive Test
ToL (/19) = Tower of London
S-TOFHLA (%) = Scientific Test of Functional Health Literacy in Adults



Bar charts of significant differences between change scores from before and after finishing the program on outcome measures between the PD group with and without a care partner (A) and the PD participants in TeleDREAMS and in-person DREAMS (B).
S-TOFHLA (%) = Scientific Test of Functional Health Literacy in Adults
ToL (/19) = Tower of London
TOSLS (%) = Test of Scientific Health Literacy Skills

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