

“Remote Access to Care, Everywhere, for Parkinson Disease (RACE-PD)”

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Report of Findings to Date

July 21, 2015

Overview

RACE-PD is a multi-center observational study to assess the feasibility, impact, and acceptability of using telemedicine to remove barriers to care in Parkinson disease. Patients with Parkinson disease who live in New York, Maryland, Delaware, California, and Florida, and veterans with Parkinson disease living anywhere in the U.S. are recruited and seen by neurologists at approved sites. Data from one baseline survey and one virtual care visit are collected, as well as electronic surveys completed prior to the virtual care visit and 6 months after. Both participants and providers are asked to complete online surveys regarding their experience.

Background and Rationale

The Davis Phinney Foundation’s mission is “helping people living with Parkinson’s and their caregivers find new ways to live well today,” as well as giving patients the tools they need to “take charge of this disease, rather than be defined by it.” However, many patients are not able to receive the care they need to take charge of their condition and live well today. While the global burden of Parkinson disease is projected to increase 111% by 2030, access to care continues to be limited due to distance, disability, and distribution of doctors. Forty percent of Medicare beneficiaries with Parkinson disease have never seen a neurologist, and statistics show that patients who see a neurologist are less likely to fracture their hip, less likely to be hospitalized, less likely to be placed in a nursing home, and less likely to die. Many patients are not receiving the tools and advice they need to better manage their disease and improve their quality of life. We hypothesize that telemedicine consultations with a movement disorder specialist will be feasible on a national, multi-center level. We also hypothesize that these virtual visits will improve quality of care and will be acceptable, and potentially preferable, to in-person visits for individuals with Parkinson disease.

Methods

Individuals with Parkinson disease in five states are recruited and enrolled remotely. Participants complete an electronic assessment which includes a) the Parkinson disease questionnaire 39 (PDQ-39) which assesses quality of life; b) questions about time and travel; c) questions about utilization of the internet and technology; and d) demographics. Participants receive telemedicine software and a webcam if needed. The study team completes a test connection with the participant prior to a one-time virtual (video) visit with a Parkinson disease specialist. Neurologists report whether they discussed twelve common recommendations, send a consultation note to patients and their physicians if desired, and complete a satisfaction survey. Participants also complete a telemedicine satisfaction survey. Six months later, participants complete another PDQ-39 and a survey about the recommendations provided by the specialist.

Recruitment

Recruitment was delayed for 2 months in order to finish enrollment for Connect.Parkinson. In addition, there was a transition period for site coordinators at the University of California San Francisco. Recruitment efforts were continued in June 2015. We plan to complete enrollment over approximately the next 4 to 6 months. [See Figures 1 and 2, and Table 1]

Figure 1. Recruitment Efforts to Date

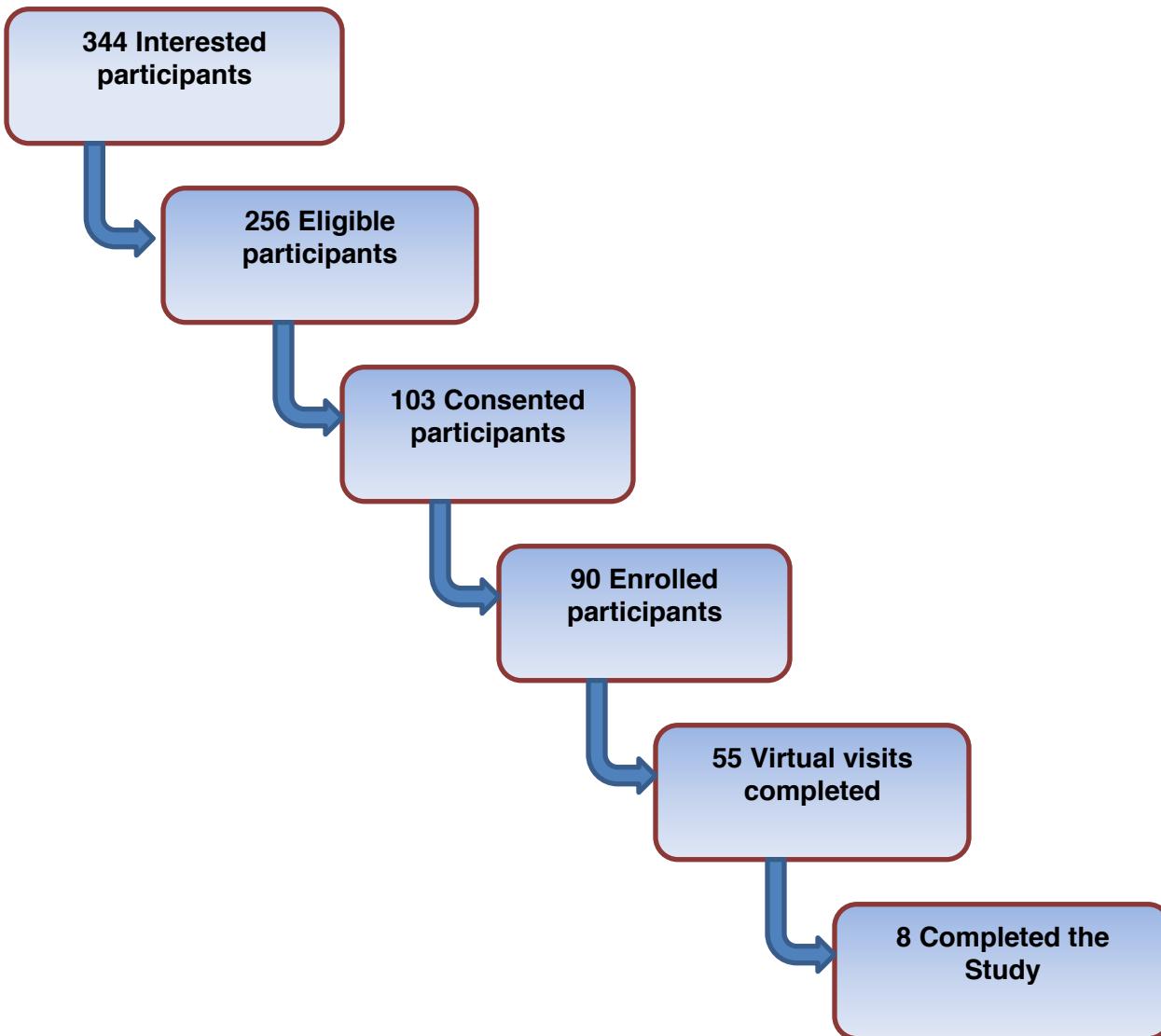


Figure 2. Geographical Distribution

Red: Interested participants

Blue: Eligible participants

Yellow: Enrolled participants

Table 1. Baseline Characteristics

Total number of patients reached through the telemedicine program	
Demographics of all participants	Average age:65
	Age range:30-88
	Locations of patients (city, state):Florida, New York, California, Delaware, Maryland
	Gender: (Male (55.6%), Female (44.4%)
	Ethnicity: White (98.8%), More than one race (1.2%)

Study Outcomes

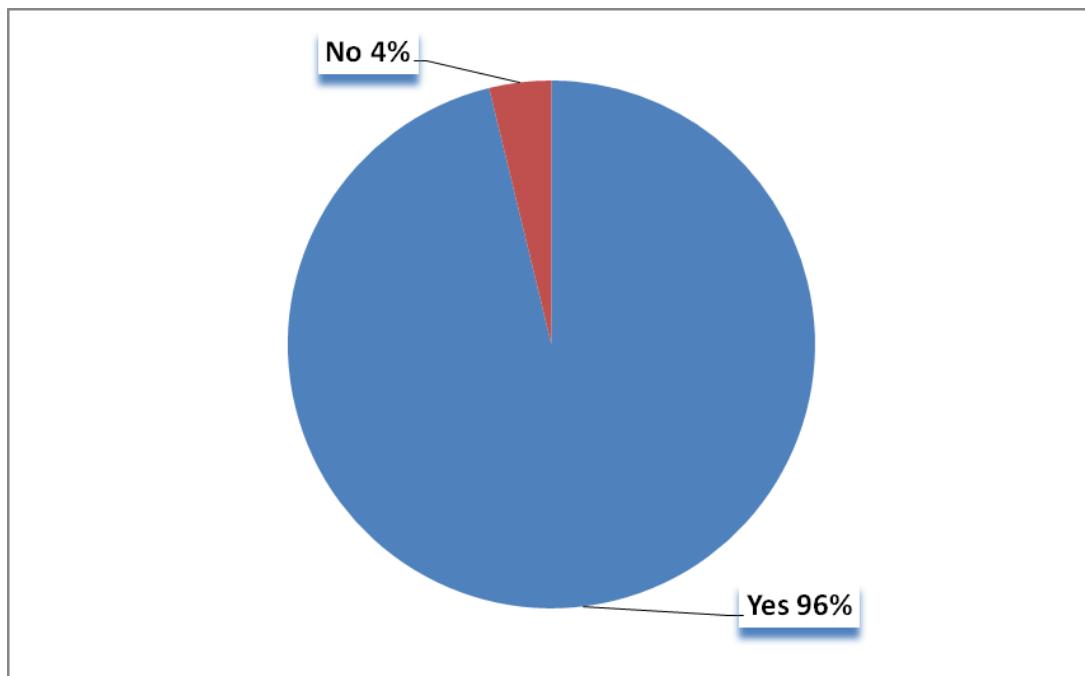
Feasibility (Specific Aim 1): *To demonstrate the feasibility of conducting remote evaluations of patients with Parkinson disease nationally.*

Primary study outcomes: The percent of telemedicine visits completed as scheduled and the percent of visits in which the investigators were satisfied or very satisfied with the care they were able to provide for Parkinson disease remotely.

Primary hypothesis 1A: At least 80% of visits will be completed as scheduled

Results: To date, 96% of visits were completed as scheduled. [See Figure 3]

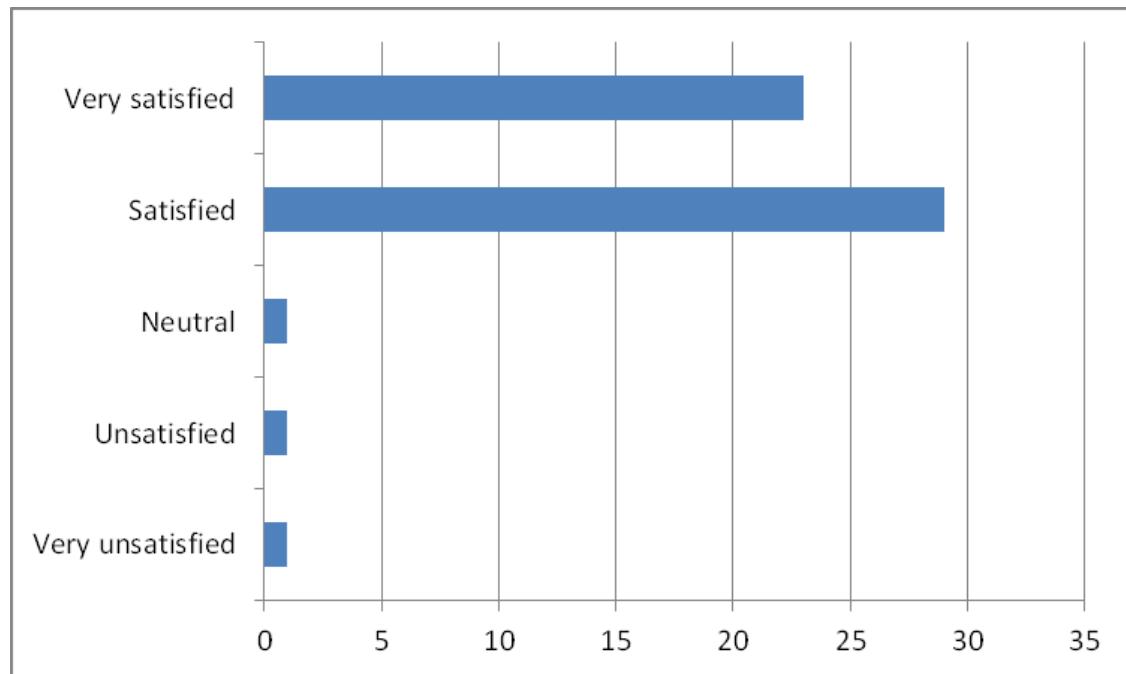
Figure 3. Percent of one-time virtual visits completed as scheduled



Primary hypothesis 1B: At least 80% of investigators will feel satisfied or very satisfied with the care they are able to provide remotely.

Results: To date, 95% of investigators feel satisfied or very satisfied with the care they are able to provide remotely. [See Figure 4] Virtual visits were delayed due to technical quality (sound and video), internet connection quality, software updates made to patients' computers or software compatibility issues. Most delays were resolved within a few minutes of cited problem.

Figure 4. Provider satisfaction with the care they are able to provide remotely (n = 55)



Selected provider feedback:

- “I thought it went well. We had a good connection and it seemed as though there were some opportunities to provide information and recommendations.”
- “Visit over an iPad (has) limited quality due to camera angle. Harder to look at someone directly in the eye.”

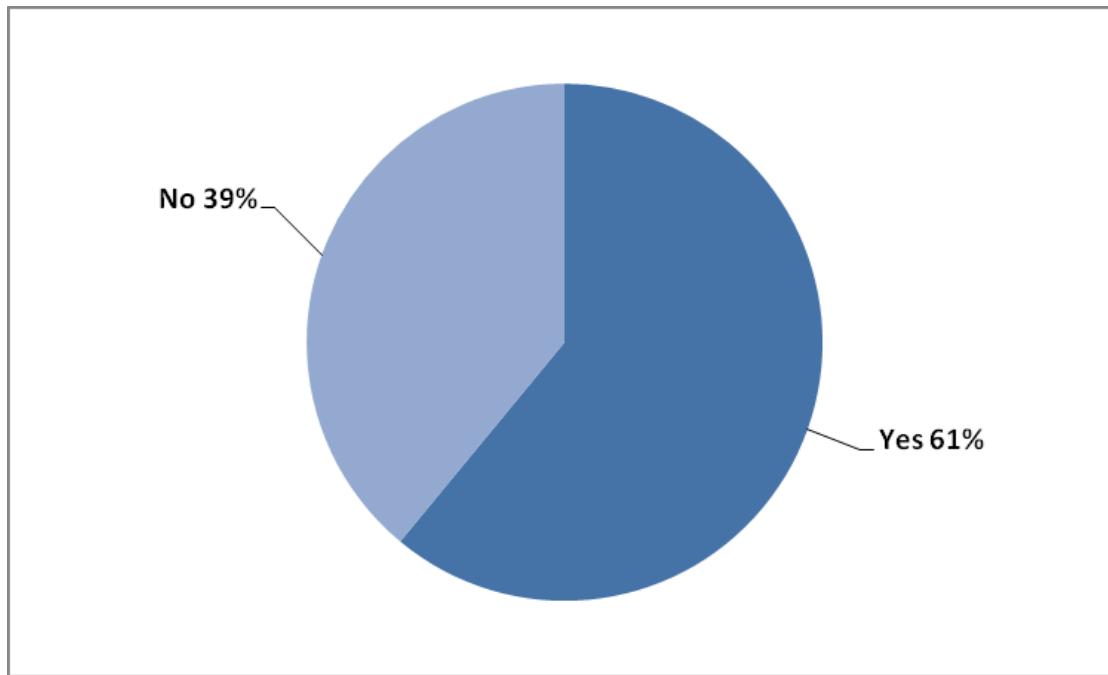
Impact (Specific Aim 2): To measure the impact of remote care on each patient's ability to improve their quality of life (QoL) and better manage their Parkinson's disease.

Primary Study outcomes: The changes in PDQ-39 prior to and 6 months after the telemedicine visit to assess change in quality of life, and adherence to recommendations provided by the physician in the visit at six months.

Primary hypothesis 2A: At least 80% of patients will have followed one or more of the recommendations provided in their virtual visit at six months. [See Figure 5].

Results: To date, 61% of patients have followed one or more recommendations provided in their virtual visit at six months. [See Figure 5].

Figure 5. Average percent of patients that have followed one or more recommendations



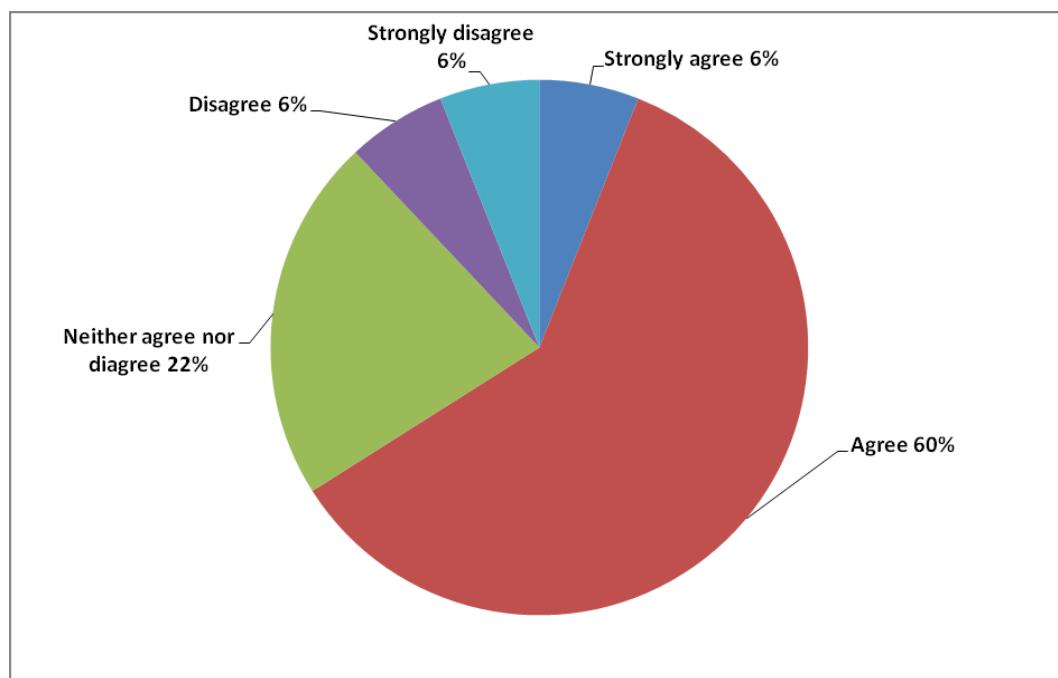
Selected patient feedback:

- “I followed the recommendations because it made dealing with Parkinson's easier.”
- “Followed recommendations received to improve my PD symptoms”
- “Aversion to taking drugs”
- “I didn't want to increase my meds at that time.”
- “I have an established relationship with [my doctor] and was not able to make the recommended changes.”

Primary hypothesis 2B: At least 50% of those who follow the recommendations will have found these recommendations to be beneficial

Results: To date, 66% of patients agree or strongly agree that the recommendations they received were beneficial. [See Figure 6]

Figure 6. Percent of patients that believe recommendations made during virtual visit were beneficial to their overall health



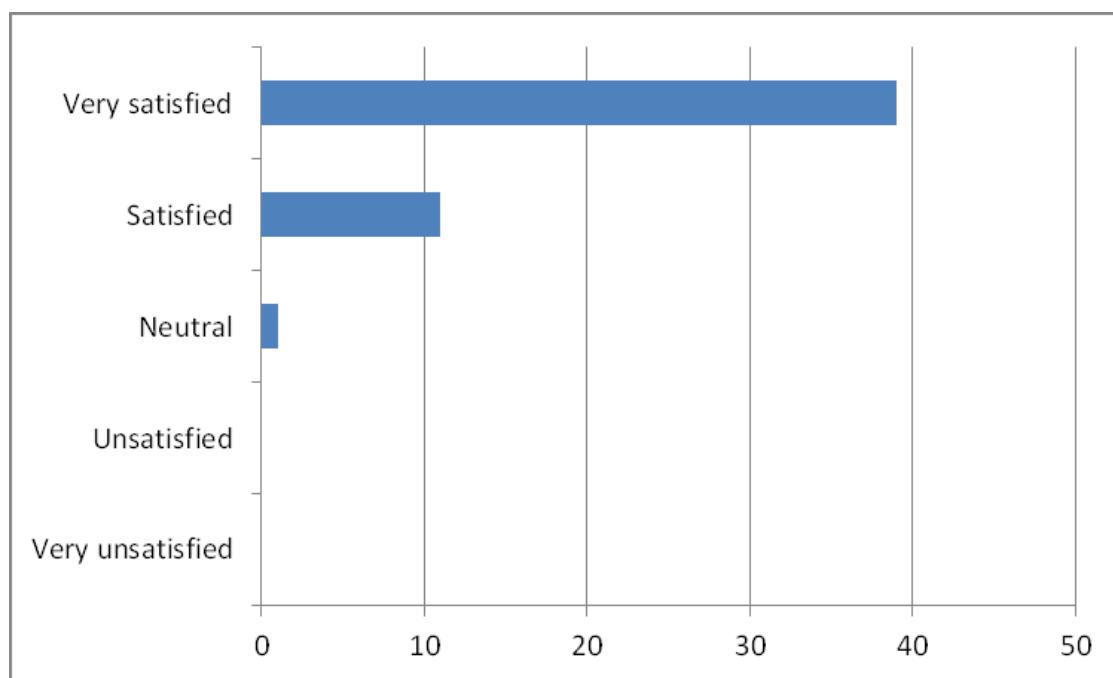
Acceptability (Specific Aim 3): To assess the long-term acceptability to patients in receiving ongoing care remotely via telemedicine.

Primary Study outcomes: Patients' satisfaction determined by the percent of those participated who stated that they are interested in receiving ongoing care for their PD via telemedicine. Time and travel to and from healthcare appointments will also be assessed.

Primary hypothesis 3A: At least 80% of patients will be interested in receiving care via telemedicine in the future.

Results: To date, 98% of patients reported that they were satisfied or very satisfied with the care they received during their virtual visit [See Figure 7] Overall, patients were satisfied with the quality, convenience, and care provided during their telemedicine virtual visit, including the decrease in travel time, and increase in time with the provider. [See Figure 8] Over 78% were interested in receiving care via virtual visits in the future and over 66% felt that their virtual visit was more comfortable than visiting their usual Parkinson disease provider.

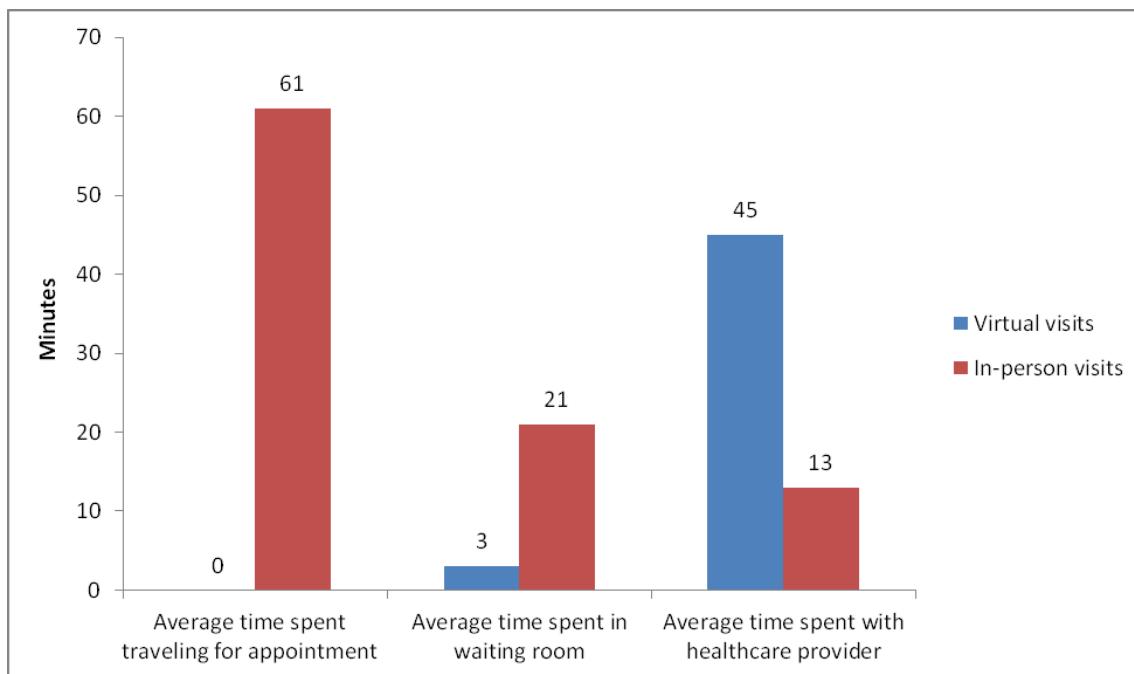
Figure 7. Patient satisfaction for care received during virtual visit (n = 51)



Selected patient feedback

- "It was very comfortable being in my own environment. The doctor was very nice."
- "I believe that using virtual visits may enable patients to see better doctors and those that aren't immediately available to them in their local communities."

Figure 8. Travel and waiting time for in-person vs. virtual visit



Summary of Results

As of July 2015, 90 individuals have enrolled, 55 have completed neurologist visits with 5 different investigators, and 8 have completed the study. 96% of visits have been completed as scheduled. 98% of participants report being “satisfied” or “very satisfied” with the care received during the virtual visits, and 79% would be interested in receiving future care via telemedicine. In addition, 33% prefer virtual visits to in-person visits and 43% are indifferent; however, 7.8% of participants were “unsatisfied” with the technical quality of the connection. 49% of participants’ PDQ-39 composite scores improved by an average of 0.7 points. Lastly, 40% “strongly agreed” or “agreed” that they received better care than visiting their usual Parkinson disease provider, and 24% “strongly disagreed” or “disagreed”.

Conclusions

Preliminary results of the RACE-PD study suggest that a program providing one-time telemedicine visits from Parkinson disease experts to individuals in their homes is feasible and satisfactory to patients. Further data will allow the evaluation of the efficacy and short term impact of this method.

List of Abstracts to date:

Ryan E. Korn, Meredith A. Achey, Christopher Beck, Denise B. Beran, et al. Preliminary results for a national case study of virtual care visits for Parkinson disease. 19th International Congress of Parkinson's Disease and Movement Disorders in San Diego, CA June 14-18, 2015.

How does this help individuals in the Parkinson's community to live well in the near future?

In alignment with Davis Phinney's mission, the RACE-PD study helps individuals in the Parkinson's community to live well in the near future by demonstrating that virtual house calls can offer people living with Parkinson's and their caregivers the care they need, the convenience they want, and the comfort they deserve. RACE-PD and other efforts such as the Connect.Parkinson Study, funded by the Patient-Centered Outcomes Research Institute (PCORI), have increasingly demonstrated the feasibility, efficacy, and utility of providing remote care to patients with Parkinson disease. Results to date from the RACE-PD study look promising and we expect that future results will support our efforts to advance care and research utilizing telemedicine to remove barriers for this care model, including licensing restrictions and lack of Medicare reimbursement.

Telemedicine, "healing from a distance", has tremendous promise and potential for Parkinson disease. Together, developments in policy and technology will enable more individuals with Parkinson disease to connect to care and participate in research. The just introduced TELE-MED Act, proposed federal legislation that would permit certain Medicare providers licensed in a state to provide telemedicine services to Medicare beneficiaries in a different state, would be a major step toward expanding access to care. In addition, state parity acts in 29 states, including New York and Delaware within the last year, have legislated reimbursement for telemedicine care. Novel applications of technology, such as wearables to provide continuous monitoring of symptoms and smartphone applications to allow wide-spread participation in research and data collection, can be paired with telemedicine to rapidly advance care and research for Parkinson disease.

In addition, the RACE-PD study presents a regional care model that has made it possible to deliver care to anyone anywhere in New York State for the period of one year. This care model can be extended and expanded to treat individuals with Parkinson disease in other regions and on a national level, with the goal of enabling anyone anywhere with Parkinson disease to receive care and participate in research. [See Figure 9]

Figure 9. Growth Horizon for Telemedicine for Parkinson Disease

