



THE TRANSMITTER

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Article Review

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High Patient Satisfaction with Telehealth in Parkinson Disease: a Randomized-Controlled Study

Video telehealth is an emerging resource for patients to obtain specialty care for Parkinson's disease (PD) both in remote settings, as well as in their own home. This dual-active arm 12-month randomized controlled trial enrolled 86 male subjects and looked at patient satisfaction, as well as clinical outcomes, travel burden, and healthcare utilization. Telehealth visits took place either at a facility nearer to the patient (satellite clinic arm) or in the patient's home (home arm). Each control group received usual, in-person care. Although overall patient satisfaction was not different between telehealth and controls, it was consistently high in all group. Greater satisfaction for telehealth was found in assessments of convenience and accessibility/distance. Clinical outcomes were similar between groups, travel burden was reduced using telehealth, and health care utilization was largely similar in both groups. As the need for PD specialty care increases, innovative patient-centered solutions to overcoming barriers to access, such as telehealth, will be invaluable to patients and may provide high patient satisfaction.

Neurol Clin Pract. 2016 June; 6(2): 241-251.

<http://www.ncbi.nlm.nih.gov/pubmed/27347441>

Clinical clusters and dopaminergic dysfunction in de-novo Parkinson disease.

Traditionally, Parkinson's disease has been classified into clinical subtypes (i.e. tremor-dominant and postural-instability-gait disorder), based on motor dysfunction. However, increasing clinical and research attention to the variety of non-motor phenotypes in PD suggests additional variability not captured by such classifications. The authors of this study queried the PPMI cohort for baseline non-motor data (cognition, apathy, mood, RBD, dysautonomia, and pain) as well as UPDRS-3 motor subscore, on 398 newly diagnosed, untreated PD patients. They then performed a non-hierarchical cluster analysis (k-means method) to define three PD subtypes based on both motor and non-motor phenotypes. They referred to the first as a "benign" subtype, with relatively low motor as well as non-motor burden. Group 2 demonstrated motor disability as well as significant apathy, hallucinations, and possibly cognitive dysfunction, while group 3 was referred to as an "intermediate" subtype, i.e. prominent motor disability but less non-motor burden. They suggest that the difference between groups 2 and 3 arises from variability in neurotransmitters other than dopamine, as non-motor symptoms are known to respond poorly to dopaminergic therapy. Although the authors acknowledge the limitations of using retrospective data and self-reported scales, they note that similar cluster definitions arose from smaller prospective studies, implying external validity. The authors intend for these subtypes to "serve as a model for future research," particularly with regard to variable clinical progression and prognosis in the PPMI study, and by extension, to patients. They conclude that non-motor phenotype clusters can and should be further refined with additional variables, such as imaging and biomarkers, and that clinically, "two main axes, motor and non-motor, should be used for subtyping PD patients" in the hopes that this will provide prognostic value for patients with PD.

Serum 25-hydroxy vitamin D concentration and risk of Parkinson's Disease

Low vitamin D levels are common among patients with Parkinson's disease (PD), and previous studies have suggested that higher levels may have protective effects against PD. This study examined serum level of 25 (OH)Vitamin D in relation to incident risk of PD using data from Atherosclerosis Risk in Communities (ARIC) study, a prospective cohort study examining diet, life style, medication use and cardiovascular risk factors (including blood markers) with 19 years of follow up. Searching ARIC data originally identified 293 potential PD subjects. The investigators then contacted these individuals and confirmed the diagnosis (via patient report and physician record review) in 106 of the participants. Concentration of ergocalciferol and cholecalciferol were measured in the samples that were archived between 1990-1992 using the gold standard liquid chromatography tandem mass spectrometry LC-MS/MS assay for 25(OH)D. No significant association was detected between serum 25(OH)D concentrations and PD incidence and lower serum concentrations of vitamin D did not increase the risk of developing PD significantly. Strengths of the study include a prospective design, long follow up, gold standard method of vitamin D assessment and clinically confirmed PD cases. The investigators' results showed no support to the hypothesis that vitamin D may protect against PD. Reverse causation may explain some of the findings from previous case control studies that had suggested this link. Since reduced mobility and therefore limit sun exposure and also dietary modifications in patients with PD due to gastrointestinal dysfunction may lead to lower levels of vitamin D.

Mov Disord. 2016 Jul;31(7):972-8. Epub 2016 Apr 19.

<http://www.ncbi.nlm.nih.gov/pubmed/?term=serum+25hydroxyvitamin+D+concentrations+in+mid-adulthood+and+parkinson's+disease+risk>

Committee Activities

Clinical Care Committee

- **Rotation of Committee Chair:** Leadership for the clinical care committee rotates amongst the PADRECCs. The Philadelphia PADRECC leads the committee for July/August. The committee meets via conference call the first Tuesday of the month at 12pm (EST)
- **Standardize and Optimize Clinical Care:** The committee continues to discuss latest research on PD, new treatment strategies and a variety of clinical issues to improve patient care and outcomes. It also serves to provide clinical support to the consortium network by focusing on measures to standardize clinical care across the PADRECC network. Recent agenda items have included discussions on:
 1. New PD treatments in the pipeline, including ND0612, which is a proprietary formulation of levodopa and carbidopa continuously administered subcutaneously and extended release Amantadine formulation. Discussions focused on reviewing the safety, tolerability and clinical efficacy data, presented at recent scientific meetings.
 2. Continued discussion focused on clinical experience sharing among the group regarding DUOPA™ (carbidopa and levodopa) enteral suspension delivered directly into the small intestine for the treatment of motor fluctuations for people with advanced Parkinson's disease and Rytary (carbidopa/levodopa IR/SA combination oral medication). Recent discussions have focused on learning optimal titrating schedules, strategies to manage complication, logistical and support issues

3. Continued experience sharing regarding the use of various Neurotoxins across the PADRECC network with the objective to improve this specialized clinical practice and develop neurotoxin selection criteria for various conditions in the Veteran population.
4. Practical aspects regarding the use of DAT scans; applications and pitfalls, including the issue of drug interference
5. Palliative Care: Review of palliative care resources and practices in the PADRECCs
6. Veteran's Choice Program: re-distribution of resources, optimal use of the program, impact on VA based sub-specialty care.
7. Consortium Sites: Strategies to improve communications, enhance educational and clinical support and develop research projects with the consortium sites.
8. National Consortium Meeting: scheduled for Sept 19th, 2016, one day ahead of WPC in Portland. Seeking poster submissions (need not be original.)
9. New MRI body scanning protocols for DBS implanted patients
10. Discussed the FDA-approved antipsychotic for PD, pimavanserin. PBM review scheduled for Fall 2016. In the interim, local P/T committee review/approval required. PADRECCs have circulated their applications to streamline individual on-boarding. Discussed likely indication and criteria for use.
11. Continued discussion of Rytary and dosing strategies. Consensus that often more than a three times/day scheduled is needed.

Education Committee

- **PADRECC/EES Movement Disorder Series:** The final audioconference for FY 2016 will be held on **September 8, 2016** "*Palliative Care and PD*" by Maya Katz, MD, Co-Director, Parkinson's Disease Palliative and Supportive Care Clinic, San Francisco PADRECC. The audioconferences are archived on the National website www.parkinsons.va.gov under the Movement Disorder Series tab. Topics and speakers for FY 2017 are being explored.
- **National Newsletter:** The newsletter is the final stages of preparation and will be ready for email distribution soon.
- **National Website Maintenance:** The committee performs monthly maintenance checks of the National Website to ensure information is current and up-to-date.
- **World Parkinson's Congress 2016-Portland:** The PADRECC & National VA PD Consortium are an organizational partner of the WPC and will have an exhibit table. Promotional materials are being developed to bring awareness of the care available at the VA for Veterans with PD and related movement disorders.
- **Education Needs Assessment:** An education needs assessment is being developed and will be disseminated to Consortium Members in order to steer future education initiatives of this committee.
- **"Mood Disorders in PD: What's New:"** This enduring material project was done in collaboration with EES and is an on-line TMS self-study program that offers CME credit for a 3 year period. This program provides VHA healthcare professionals with a broadened medical awareness of Mood Disorders in PD. The program is available on TMS:

https://www.tms.va.gov/learning/user/deeplink_redirect.jsp?linkId=ITEM_DETAILS&componentID=14771&componentTypeID=VA&revisionDate=1343926380000

- **PADRECC Transmitter:** The committee continues to assemble and distribute this e-newsletter every other month.

Philadelphia PADRECC Service Area Updates

Philadelphia PADRECC

Director: John Duda, MD

- **Telehealth and Parkinson's Disease**

Dr. Jayne Wilkinson published a PADRECC study in *Neurology: Clinical Practice* evaluating the use of telehealth in Parkinson's disease. Telehealth allows a patient to be seen by a provider using a video connection either to their home, or to a closer VAMC facility. Dr. Wilkinson found that telehealth visits were associated with a high level of overall patient satisfaction and improved satisfaction regarding convenience and accessibility, when compared with in-person visits. The study also demonstrated that telehealth resulted in financial savings related to travel and potentially impacts patient utilization of the healthcare system. Clinical outcomes for telehealth were similar to in-person visits, demonstrating that telehealth is a viable way to deliver effective care. Dr. Wilkinson continues to oversee the active clinical telehealth program at the Philadelphia PADRECC and future studies may focus directly on potential benefits to resource utilization and outcomes using telehealth in PD.

- **VA Rehabilitation R&D Career Development Award: Drug Induced Parkinsonism and PD**

Dr. Morley has recently been funded for a VA Rehabilitation R&D Service Career Development Award entitled **“Effect of exercise on recovery in drug-induced Parkinsonism and Parkinson disease.”** Subjects with suspected DIP who also have abnormal DAT-SPECT are operationally defined as having “unmasked” early PD and will be randomized to exercise (aerobic walking) or no intervention. We will examine short term effects of exercise using the UPDRS and quantitative gait testing after 8 weeks. We will also examine a potential disease modifying effect of exercise using serial DAT-SPECT and biochemical markers after 52 weeks. The results of these studies may immediately influence identification of subjects with prodromal PD, clinical management of DIP and strategies for disease-modification in PD using exercise.

- **Dopamine transporter SPECT use patterns at the Philadelphia PADRECC**

Dopamine transporter SPECT (DAT-SPECT) using 123I-Ioflupane was approved by the US FDA in 2011 for the evaluation of Parkinsonian syndromes via visualization of striatal presynaptic dopamine terminals. The studies used to support the initial approval evaluated the ability of DAT-SPECT to distinguish patients with Essential tremor and Parkinson's disease, but this technique may be useful in a variety of clinical settings. DAT-SPECT has been available at the Crescenz VAMC since October 2012. From that time until April 2016, PADRECC clinicians have ordered 50 DAT-SPECT studies for clinical purposes (just over 1 per month). While scans ordered to differentiate PD from ET accounted for 34% of studies (47% of these were abnormal), the most common indication (44%) was for the evaluation of suspected drug-induced Parkinsonism (DIP, 23% abnormal). Other indications were for the evaluation of suspected psychogenic Parkinsonism (10% of scans, 40% abnormal), dementia (8% of scans, 50% abnormal) or other secondary etiologies, such as, vascular pseudoparkinsonism (4%, 0% abnormal). The observation that nearly 1 in 4 patients with presumed drug-induced parkinsonism may have underlying neurodegeneration has led to several VA-funded research projects on the relationship of DIP to PD at the Philadelphia PADRECC.

- **Brain Wellness Clinic**

This new and innovative clinic was developed by Dr. John Duda and Heidi Watson, BSN, RN and provides patients the opportunity to focus in-depth on brain wellness. Current brain wellness risks are assessed and explored by looking at different lifestyle factors including sleep, nutrition, exercise, mindfulness/spiritual, cognitive and social interaction. During the visit, a thorough interview, several short written or web-based assessment of patients health status, and lab work (if appropriate) are completed. Clinicians discuss wellness goals important to the patient and together develop an individualized plan with realistic and achievable goals, and provide support to implement them. Patients' progress is followed either in person or through telehealth.

- **Nutrition and PD-Patient Education Program**

This patient education program was held on **April 20, 2016** to educate attendees about the benefits of a healthy lifestyle in Parkinson's disease. In a 3 hour presentation, Dr. John Duda presented information on Nutrition and PD, and led a fun and interactive cooking demonstration. Attendees had an opportunity to try the food that was prepared and ask questions regarding nutrition and other lifestyle modifications.

James J. Peters VAMC (Bronx)

Director: Ruth Walker, MD

- **Telemedicine**

The Movement Disorders telemedicine clinic based at the James J. Peters VAMC in the Bronx continues to expand. Dr. Walker sees 10 patients/month in this clinic, from 10 sites - 6 CBOCs from Long Island, one from Staten Island, one from Queens, and from the Brooklyn and Manhattan VAs. The clinic is booked up for the next 2 months. The vast majority of patients carry a diagnosis of Parkinson's disease or essential tremor. Additional diagnoses include myoclonus, progressive supranuclear palsy, and multiple system atrophy. Most patients have been seen initially in person by Dr. Walker, but if travel to the Bronx or Castle Point sites is not possible, she will consider evaluating the patient only via telemedicine.

- **DaTscan**

Our nuclear medicine facility is now up and running and is able to perform DaT scans, therefore we no longer have to refer patients out of the VA for this study

- **Deep Brain Stimulation**

A number of patients with PD or essential tremor have been referred for DBS under the Choice program from both the Bronx and Castle Point sites.

- **Hudson Valley**

Dr. Walker continues to see patients at the Castle Point site 1.5 days/week. She sees many patients with PD, some of whom have decided that they no longer need to see their community physicians. Two patients from Castle Point have undergone DBS, with excellent results. Dr. Walker also manages many patients with essential tremor, PSP, MSA, dystonia, myoclonus, Huntington's disease, and other movement disorders, who otherwise would have to travel 60 miles to the Bronx to be seen. She has just initiated a telemedicine clinic from the Castle Point VA, which covers the Hudson Valley CBOCs.

- **Dr. Walker had the following publications:**

- Sanchez E, Darvish H, Mesias R, Taghavi S, Firouzabadi SG, Walker RH, Tafakhori A, Paisán-Ruiz C (in press) **A large deletion at the *DNAJB2* locus causes autosomal recessive spinal muscular atrophy and parkinsonism** *Human mutation*

- Lupo F, Tibaldi E, Matte A, Sharma AK, Brunati AM, Alper SL, Zancaro C, Benti D, Siciliano A, Bertoldi, A, Zonti F, Storch A, Walker RH, Danek A, Bader B, Hermann A, De Franceschi L (in press) Impaired autophagy is involved in abnormalities of erythroid cells in patients with chorea-acanthocytosis *Blood*
- Walker RH (2016) Automatic behavior and communication on pramipexole *Journal of Clinical Movement Disorders* 3:9 doi: 10.1186/s40734-016-0038-7
- Walker RH (2016) Five new things: Non-Huntington's choreas *Neurology Clinical Practice* 6:150-156
- Walker RH (2016) Evolution of visual art with dopaminergic therapy *Journal of Clinical Movement Disorders* 3:6 doi:10.1186/s40734-016-0034-y
- Wang J, Bi W, Zhao W, Varghese M, Chandraratna R, Sanders M, Koch RJ, Walker RH, Ho L, Pasinetti GM (2016) A potent, selective and brain penetrable Nurr1 transactivator as a novel therapeutic agent for Parkinson's disease *Oncotarget* doi:10.18632/oncotarget.7191

Dates to Remember

September 8th, 2016

EES/PADRECC Movement Disorders Series

Topic: Palliative Care and PD

<http://www.parkinsons.va.gov/>

September 19th, 2016

National VA PD Consortium Conference

Portland, Oregon

September 20-23, 2016

4th World Parkinson Congress

Portland, Oregon

<http://www.wpc2016.org/>