VA | U.S. Department of Veterans Affairs

NATIONAL VA PARKINSON'S DISEASE
CONSORTIUM
Education · Collaboration · Advocacy

THE TRANSMITTER

July 2020

Article Reviews

Prepared by: Whitley Aamodt, MD, Ian Walker, MD & Eileen Hummel, MSN, CRNP– Philadelphia PADRECC

Economic Burden of PD in the United States

Although Parkinson's disease (PD) is one of the fastest growing neurological disorders worldwide, little is known about the economic burden of disease in the United States (U.S.). Study researchers used national surveys and public and private claims data to estimate the economic burden of PD in 2017 and project its probable economic impact over the next two decades. They estimated a U.S. prevalence of one million PD patients in 2017 and a total economic burden of $51.9 billion, which includes direct medical costs ($25.4 billion), productivity losses for patients and caregivers ($14.2 billion), non-medical costs such as home renovations, motor vehicle modifications, and expenditures for daily non-medical care ($7.5 billion), and disability income received ($4.8 billion). By 2037, the projected U.S. prevalence will rise to more than 1.6 million PD patients with a total economic burden of $79 billion. These results emphasize the need for new treatments and policy initiatives. Findings may also help inform decision making in PD-related resource investments and research prioritization.

NPJ Parkinsons Dis. 2020 July; 6(15); eCollection 2020.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7347582/

Tossing and Turning in Bed: Nocturnal Movements in Parkinson's disease

It is common for patients with Parkinson's disease to suffer from sleep disturbances, whether that is RBD, fragmented sleep, or nighttime hypokinesia. To determine degree of sleep impairment and its relation to overall disease severity, clinicians rely on subjective sleep diaries or costly polysomnographic monitoring. There is growing interest in the use of wearables and portable monitoring devices as a cheaper and more efficient assessment of sleep quality. The goal of this study was to examine the relationship between sleep disturbances such as nocturnal hypokinesia and the symptoms of Parkinson's disease through the use of wearable devices. The authors collected cross-sectional wearable sensor data from 304 PD patients who had participated in other clinical studies (V-TIME, PIGD, and BEAT-PD) as well as 205 age-matched healthy controls. The subjects wore accelerometers over their lower back for at least 2 nights, which measured nocturnal rest interruptions and degree of nocturnal movements. These movements were characterized as the number of positional changes and turning duration, velocity, degree, and side of turn in bed. Number of turns and turn velocity were found to decrease with disease progression while sleep fragmentation increased. PD patients <1 year from diagnosis had

similar characteristics to controls except for increased turn duration. Both cognitive function (specifically Trail Making Tests) and Non-Motor Symptoms Scale scores were inversely correlated with turning overnight. Similarly, motor symptoms of PD and LEDD (levodopa equivalent daily dose) correlated with impaired nocturnal movements. These findings lend support to the theory that nocturnal sleep disturbances increase with both motor and non-motor disease progression, in some aspects in a bidirectional manner. Furthermore, the authors suggest that wearable technology may be a valuable clinical tool in evaluating sleep quality and underlying disease severity.

Mov Disord. 2020 June; 35(6); 959-968.

A Mixed-Methods Approach to Understanding the Palliative Needs of Parkinson's Patients

Palliative care focuses on the physical, psychological, social, financial, and spiritual needs of a patient in order to improve quality of life. There has been some evidence to suggest that the standard of neurological care for Parkinson's disease (PD) may not sufficiently address all these needs and other evidence has shown that PD patients would benefit from earlier palliative care services. This mixed-methods study utilized quantitative surveys completed by PD patients, as well as general neurologists or movements disorders specialists, and qualitative interviews done with a subset of the same PD patient group. Of the 75 PD patients recruited for the quantitative survey, 49 completed the surveys fully. 23 of these PD patients also participated in the qualitative portion of the study. 50 general neurologists/movement disorders specialists completed a survey that complemented the patient survey. Patients completed a 31-item survey adapted from the Palliative Outcome Scale for Parkinson's and the Parkinson's Disease Questionnaire (PDQ)-39. The quantitative results showed that the patients perceived their psychological needs as the least addressed, while the physicians regarded spiritual needs as the least met for patients. Two major themes emerged through content analysis of the qualitative interviews that were not found in the survey results: more effective care coordination was needed and lack of healthcare education. Three secondary themes identified were the importance of support groups, importance of spirituality and religion, and the limited perception of the neurologist role in PD care. The findings support the importance of clear patient and provider communication throughout the disease course to determine and prioritize needs, as well as having palliative care involved earlier in the disease to help ensure that all identified needs are being addressed.

J Appl Gerontol. 2020 Aug; 39(8): 834-845 doi: 10.1177/0733464818776794. Epub 2018 May 22.

PMID: 29788783

https://pubmed.ncbi.nlm.nih.gov/29788783/

Committee Activities

Clinical Care Committee

- **Rotation of Committee Chair:** Leadership for the clinical care committee rotates amongst the PADRECCs. The Houston PADRECC leads the committee for July and 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. Discussion regarding COVID 19 pandemic-clinical challenges and solutions, including the need for enhanced assessment and aggressive treatment of depression using tele-technology amongst the home confined patients across the nation.

    2. Discussion about Cala Trio Device for the management of essential tremor. This device is now available upon request through the Prosthetics Service.

    3. Updates on clinical experience with newer medications – Nourianz (Adenosine Receptor antagonist), Gocovri and Imbrija Inhaler

    4. Discussion about newly approved medications including apomorphine sublingual film (KYNMOBI).

    5. Discussion about involvement with ongoing Levodopa Pump study – NeuroDerm

    6. Clinical experience with newer DBS systems including Boston Scientific's "Vercise" and Abbott's " St. Jude Medical Infinity DBS".

    7. CSP # 2015 Trial, planning and trial initiation related matters.

Education Committee

- **National VA PD Consortium Bi-Annual Meeting-** due to Covid 19 pandemic meeting is being changed to a virtual meeting. Date and additional details will follow as they are known.
- **New Partnership-VHA/PADRECC and The Parkinson's Foundation:** Goal of the partnership is to improve the care and quality of life for Veterans living with PD through collaborative education, research and services. This committee will be spearheading many of the projects planned for this partnership
- **PADRECC/EES Movement Disorder Series:** The third audioconference for FY 20 was held on May 14th, 2020 **"Web-based Resources for Parkinson's Disease Patients, Caregivers and Health Care Providers"** by Dr. John Duda, National PADRECC Director, Philadelphia PADRECC Director, and Chair of the National PD Consortium. Please see the **Dates to Remember** section below for a listing of upcoming audioconferences and mark your calendars.
- **National VA PD Newsletter:** The newsletter is currently in the editing phase and once completed will be emailed and posted on the National Website.
- **PD at Home:** Monthly PD telephone education/support group conference for patients and caregivers available nationwide on the 2nd Tuesday of each month: 10am PT, 11am MT, 12p CT, 1pm ET.
- **National Website Maintenance:** The committee performs periodic maintenance checks of the National Website to ensure information is current and up-to-date.
- **PADRECC Transmitter:** This committee continues to assemble and distribute this *e*-newsletter every other month.

- **Resources available on the National Website:**
  - **Patient Education Brochures-** https://www.parkinsons.va.gov/patients.asp
    - Exercise and Physical Activity
    - Fall Prevention
    - PD Medications
    - Motor Symptoms
    - Non-Motor Symptoms
    - Agent Orange and Toxic Exposures and PD
  - **My Parkinson's Story-**https://www.parkinsons.va.gov/patients.asp
    A series of short videos prepared by the VA PADRECCs addressing various aspects of Parkinson's disease.
  - **Suggested Education Essentials for Veterans with PD** https://www.parkinsons.va.gov/patients.asp
  - **Updated Resource Request Form-**PADRECC staff and consortium members can order bulk supply of FREE educational materials from PF and APDA. Please click on the following website link and complete the ***Resource Request Form*** and fax or email to address listed:
    https://www.parkinsons.va.gov/clinicians.asp
  - **PADRECC Pocket Card:** *Parkinson's Disease Quick Reference Guide for Imitating Therapy* is available on the National Website:
    https://www.parkinsons.va.gov/Consortium/PocketCard/PocketCard19.pdf

Philadelphia PADRECC Service Area Updates

Philadelphia PADRECC

Corporal Michael J. Crescenz VAMC

Director: John Duda, MD

Clinical Update

- **COVID 19 Pandemic Response**
  Due to the COVID 19 pandemic the Philadelphia PADRECC shifted to telemedicine for patient care (except for urgent matters) offering either telephone or video visits. Recently, visits have resumed for chemodenervation therapy and deep brain stimulation management following strict VA health and safety guidelines.

- **Expansion of Telehealth**
  - Prior to the COVID 19 pandemic the Philadelphia PADRECC had a very active Telehealth clinic servicing 25 facilities, including 2 State Veterans homes. Since the COVID 19 pandemic VA Video Connect (VVC) telehealth services into the Veteran's home have increased offering patients VVC as an alternate to in-person visits.
  - **Telemental Health**: Dr. Daniel Weintraub, in collaboration and funded by the National Telemental Health Center continues to provide initial psychiatric consult services for patients with PD and psychiatric-cognitive symptoms to the following VAMCs: Bronx, Northport, Albuquerque, San Diego,

Tampa, Ann Arbor, Dallas, Flint, Northport, Toledo and Portland (OR). In addition the following VA CBOCs have been added: Bend, White Plains, Fortworth, Sherman, Riverhead, and Pachogue. Psychiatric symptoms in patients with PD have a large impact on quality of life and managing these symptoms can be difficult and should done by a subject matter expert. Please contact Dr. Weintraub at daniel.weintraub@va.gov if you think your PD patients could benefit from such a service.

- **Accolades**

  Dr. John Duda, Philadelphia PADRECC Director was recognized with a Senior Clinician Scientist Investigator Award from the Biomedical Laboratory Research and Development Service of the Department of Veterans Affairs for his long career in VA research.

Education Update

- **National Caregivers Month**: To recognize our Veterans' caregivers, the Philadelphia PADRECC held a **Close Contact for Couples** program by Judith Sachs, a *Dance for PD® Certified Teacher in Philadelphia and is the Founder and Director of ANYONE CAN DANCE®*. This program explored ways to communicate with body, eyes and words and experiment with different ways of assisting one another. Techniques to move from bed to chair, chair to floor and down the street as partners were practiced to make movement easier and safer.
- **Patient & Caregiver Support Group Program:** This program runs from April-December and meets once a month for 1 hour to provide support and education on topics related to PD. Due to COVID 19 pandemic groups are now being held via telephone only.
- **PD 101:** This biannual patient education program was held in April in celebration of PD Awareness Month. The program was held over the telephone and provided an overview of PD symptoms, treatment and the Philadelphia PADRECC team.
- **Community Outreach:** Prior to COVID 19 pandemic, clinical staff attended several local community health fairs and presented at local support groups and professional conferences providing information on topics related to PD. Clinicians continue outreach efforts via video conferencing modalities as requested.

Research Update

- **Current Projects:** During FY 20, the Philadelphia PADRECC had **10** active research projects.

- **Clinical research:** Prior to the COVID19 administrative hold on non-essential human subjects research, recruitment was ongoing for several studies.
  - **Exercise and Recovery in Drug-Induced Parkinsonism and Parkinson Disease**

    Dr. Morley continued to enroll subjects in a 1 year randomized control trial of aerobic walking vs. normal care. The study will examine the effect of exercise on motor symptoms, non-motor symptoms, plasma biomarkers and changes in dopamine transporter imaging in earl/mid-stage PD.

  - **Understanding Physical Activity and Exercise in Parkinson Disease**

    Dr. Morley is studying physical activity habits and attitudes about exercise of people with PD. Participants are asked to complete a series of questionnaires to assess exercise and activity habits, attitudes about exercise, sleep, mood, memory, and other symptoms. Veterans were also asked to wear FitBit devices to track daily step count and activity levels. This study will examine feasibility of using wearable technology in Veterans with PD (enabling future interventional studies to increase activity levels) and investigate association between activity levels and the various clinical characteristic measured.

  - **Bacteria and Parkinson's Disease - The Role of Bitterome and Microbiome In Parkinson's Disease**

Dr. Duda, in collaboration with Dr. Noam Cohen from the ENT, continue to study how bacteria that colonize our body might contribute to the risk of PD. It has been shown that these bacteria are different in people with PD compared to people without PD. This study is trying to understand if there are genetic reasons why some people have certain types of bacteria in the hopes of developing new therapies in the future.

- **Lab Projects:**
  - **<u>Traumatic Brain Injury studies</u>**
    Dr. Duda and his colleagues, Drs. Kacy Cullen, Isaac Chen and John Wolf, from the Dept. of Neurosurgery at the University of Pennsylvania, continue studies funded by the Rehabilitation Research and Development Service to study the relationship between brain trauma and neurodegeneration. The researchers have published several studies that have shown how the brain reacts to trauma and how that could possibly lead to chronic neurodegenerative disease development. It is hoped that these studies will lead to treatments to prevent the development of these neurodegenerative diseases in Veterans and others who have suffered head injuries.
  - **Neurorestoration in Parkinson's Disease**
    Dr. Duda and his colleagues Dr. Kacy Cullen and Isaac Chen from the Center for Neurotrauma, Neurodegeneration, and Restoration (CNNR) at the Crescenz VA Medical Center, continue to investigate whether one of the main brain pathways affected in PD, the nigrostriatal pathway, can be generated in a petri dish and transplanted in animal models to reverse the motor symptoms in PD. The success of their efforts to date have led to several publications and special recognition at several different scientific meetings and additional research grants to continue these studies. The team has been successful in implanting these bioengineered pathways into a rat model of PD and are now funded to do the same in pigs, which more closely resemble what would need to be achieved to begin trying this approach in humans.
- **Upcoming Projects:**
  - **Summer/Fall 2020: VA Cooperative Study #2015 – "*Multicenter, Randomized, Double-Blind Comparator Study of Antipsychotics Pimavanserin and Quetiapine for Parkinson's Disease Psychosis (C-SAPP Study).*"**
    This is a nationwide, multicenter clinical trial comparing strategies for the management of PD related psychosis. Drs. Duda and Weintraub will be the national co-PIs and Dr. Morley will be the Philadelphia site PI.
  - **Summer/Fall 2020: *Behavioral or Solifenacin Therapy for Urinary Symptoms in Parkinson's Disease***
    The Philadelphia PADRECC (Morley, site PI) is collaborating with Dr. Camille Vaughn on her VA RR&D Merit Award study for lower urinary tract symptoms in PD. Eligible patients will be randomized to either medication or behavioral treatment (pelvic floor muscle exercises) to determine if both are equally effective in controlling frequent urination.
  - **Fall/Winter 2020: *A Multi-center, Randomized, Active-controlled, Double-blind, Double-dummy, Parallel Group Clinical Trial Investigating the Efficacy, Safety, and Tolerability of Continuous Subcutaneous ND0612 Infusion in Comparison to Oral IR-LD/CD in Subjects with Parkinson's Disease Experiencing Motor Fluctuations (BouNDless)***
    Sponsor: NeuroDerm Ltd./Syneos Health The Philadelphia PADRECC plans to be a site in this trial of a novel subcutaneous delivery system for levodopa/carbidopa.

- **Publications and other research presentations:**
  Abstracts/posters = 5 (accepted or presented)
  Manuscripts = 22 publications

Consortium Center Update

James J. Peters VAMC Update

Consortium Director: Ruth Walker, MD

With the start of the COVID-19 pandemic and the shutdown in New York State in the middle of March, Drs. Melissa Nirenberg and Ruth Walker rapidly expanded their telehealth services to care for almost all patients remotely. The only exception has been for occasional in-person clinic visits for botulinum toxin injections and DBS programming.

While there was a learning curve for most patients and family members, many have expressed great appreciation for the ability to maintain continued access to medical care without exposing themselves to potential infection risk, an issue of particular importance in our vulnerable patient population. Even as our clinic slowly reopens in the coming months, we will continue to utilize telehealth for the majority of appointments for the foreseeable future.

We were excited to schedule a James J. Peters VA Patient Awareness Day for May 27th, sponsored by the American Parkinson's Disease Foundation, and equally disappointed when we needed to postpone indefinitely due to Covid-19. We look forward to scheduling a new live event when circumstances permit, or switching to a virtual format.

Throughout the pandemic, we have continued to recruit patients for our neurodegenerative disease brain donation registry, and to pursue active research about the neuropathological and genetic substrates of movement disorders with collaborators at Mount Sinai.

Recent Publications

Feinstein E, Walker RH (2020) Treatment of secondary chorea: A review of the current literature *Tremor and Other Hyperkinetic Movements* 10(1): 22, pp. 1–14. doi: https://doi.org/10.5334/tohm.351

Martinez-Ramirez D, Walker RH, Rodriguez-Violante M, Gatto EM (in press) Rare hereditary and acquired chorea: A review of the differential diagnosis *Tremor and other Hyperkinetic Movements*

Dates to Remember

September 10, 2020

EES/PADRECC Movement Disorders Series

Topic: TBA

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

September 12, 2020 - September 16, 2020

International Congress of Parkinson's Disease and Movement Disorders

Location: Virtual Offered By: International Parkinson and Movement Disorder

www.mdscongress.org