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

THE TRANSMITTER

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Article Reviews

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Compensation Strategies for Gait Impairments in Parkinson's Disease

Gait disorders in Parkinson disease (PD) are among the most disabling symptoms of the disease because they significantly limit mobility and often result in falls and fall associated injuries. Patients with Parkinson disease use a wide variety of strategies to compensate for their gait impairments. Examples include walking while rhythmically bouncing a ball, crossing the legs when walking, or stepping over an inverted cane.

This review discusses the implications of the various compensation strategies for the management of gait impairment in Parkinson disease. 59 unique compensation strategies were identified from several hundred video recordings of patients who spontaneously informed clinicians about the use of self-invented tricks and aids to improve their mobility. These compensation strategies may contribute to understanding their underlying mechanisms and help to develop focused rehabilitation techniques. These compensation strategies may also help patients by allowing them to select a strategy that best matches their needs and preferences and health care professionals by permitting them to incorporate these into their therapeutic arsenal. In this observation, the overarching working mechanisms involved an allocation of attention to gait, the introduction of goal directedness, and the use of motor programs that are less automatized than those used for normal walking. They found that these compensation strategies seem to appeal to processes that refer to earlier phases of motor learning process rather than to a reliance on final consolidation.

JAMA Neurol. 2019;76(6):718-725. doi:10.1001/jamaneurol.2019.0033 Published online March 25, 2019.

To watch videos of unique compensation strategies: https://edhub.ama-assn.org/jn-learning/video-player/17400996?utm_source=silverchair&utm_campaign=jama_network&utm_content=video&cmp=1&utm_medium=email

Istradefylline for the treatment of Parkinson's disease: is it a promising strategy?

Istradefylline (ISD) is a new drug developed for the treatment of Parkinson's disease (PD). It is an adenosine receptor A_{2A} antagonists that will represent an important option for patients with advanced PD where it has demonstrated efficacy in decreasing daily OFF time and is well tolerated. ISD has been marketed in Japan since May 2013. This review summarizes the evidences that have emerged from clinical studies demonstrating the efficacy of ISD in advanced parkinsonian patients, potential role in treating non-motor symptoms (NMS) and cognitive decline, and its putative role as neuroprotective agent. This Expert opinion suggest that ISD might represent an alternative option for patients with advanced PD. The reduction of OFF time highlighted in pivotal trials is comparable to that obtained with different levodopa adjunct therapies. The low profile of side effects makes ISD a more suitable drug for advanced patients whose illness is complicated by depression or cognitive impairment. Future studies are warranted to investigate the possible effects of this drug to delay the occurrence of dyskinesia and to impact significantly on NMS.

Expert Opin Pharmacother. 2018 Nov;19(16):1821-1828. doi: 10.1080/14656566.2018.1524876. Epub 2018 Oct 11.

Effects of Deep Brain Stimulation on Postural Trunk Deformities: A Systematic Review.
Axial postural deformities including camptocormia, Pisa syndrome, retroflexion (opisthotonus) and neck anteroflexion (anterocollis) often complicate Parkinson's disease (PD). These deformities are difficult to treat, and their progression is associated with significant disability, particularly in patients with PD. Deep brain stimulation (DBS) effects on postural deformities are poorly explored. The aim of this systematic review was to evaluate the quality of evidence and summarize the effectiveness and/or harms of DBS for the management of postural trunk deformities. Five patient groups were identified in the 35 studies with individual data available: (1) parkinsonian camptocormia (n = 96): 89 patients underwent subthalamic (STN) and 7 globus pallidus pars interna (GPi) DBS. Camptocormia was the indication in 3 patients. The study concluded that Low-quality level of evidence suggests that dystonic camptocormia and opisthotonus improve after GPi-DBS. Parkinsonian camptocormia, Pisa syndrome, and anterocollis have variable responses, and their dystonic features should be further explored

Mov Disord Clin Pract. 2019 Oct 1;6(8):627-638. doi: 10.1002/mdc3.12829. eCollection 2019 Nov.

Committee Activities

Clinical Care Committee

- **Rotation of Committee Chair:** Leadership for the clinical care committee rotates amongst the PADRECCs. The Southeast PADRECC leads the committee for January. 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. Updates on clinical experience with newer medications – Nourianz (Adenosine Receptor antagonist), Gocovri and Imbrija Inhaler
  2. Discussion about involvement with ongoing Pump study – NeuroDerm
  3. Continued discussions about use of Duopa advantages vs disadvantages
  4. Clinical experience with Boston Scientific DBS

Education Committee

- **PADRECC/EES Movement Disorder Series:** The first audioconference for FY 20 was held on January 9th, 2020 **"Ophthalmic Manifestations of Movement Disorders"** by Dr. Ali Hamedani, University of Pennsylvania. The audioconferences are now available on VA TRAIN so non-VA clinicians can participate and receive CME credit. Please see the **Dates to Remember** section below for a listing of upcoming audioconferences and mark your calendars.
- **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. Monthly flyers are emailed to all Consortium Members, please advertise to your PD patients.
- **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
  - **PADRECC Support Group Listings** 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

Southeast PADRECC Service Area Updates

Director: Dr. Jessica Lehosit

Clinical/Education News

- **Telehealth Update:**
  The Richmond PADRECC continues to expand telehealth services to those veterans unable to travel to the Richmond PADRECC for face to face clinical visits. 544 veterans were seen via TH in Fiscal 2019. We continue to expand our TH services and are currently projected to increase by 10-15% for this fiscal year.

  The Richmond PADRECC continues to expand access to care through VA Video Connect visits to patients homes.

- **Rehabilitation Services**
  The Richmond PADRECC, in collaboration with the department of Physical Medicine and Rehabilitation, held its second annual education awareness event "Give Parkinson's Disease the Shake Down" during Parkinson's Awareness month in April. Therapists from various rehabilitation disciplines including physical therapy, occupational therapy, speech therapy, kinesiotherapy, recreational therapy and music therapy offered hand's on demonstrations to conference participants. Participants, who were mostly people with Parkinson's disease and their family care-partners, rotated through each station where they had time to interact with the therapists, ask questions and learn about each therapy and its interventions (adaptive tools, compensatory swallowing techniques, canes, walkers, painting, playing drums and walking to a rhythm/beat). The event was well attended and open to veterans and to the community. The event was led by Dr Abu Qutubuddin MD, MBBS PADRECC Associate Director of Rehabilitation and Debra Dellinger Nurse Practitioner Richmond PADRECC. The 3rd annual "Shake Down" is scheduled for April 17, 2020.

- **Virginia APDA (American Parkinson Disease Association) Education Day**
  PADRECC team members, Miriam Hirsch RN, BSN DBS coordinator and Debra Dellinger RN, MS, Nurse Practitioner along with members of the Virginia APDA community sponsored the annual PD Parkinson Disease Education Community Day with over 300 people in attendance. The Richmond PADRECC staff helped to plan this event and were guest speakers.

Neurosurgery/DBS update & Research:

- The Richmond PADRECC is home to robust DBS telehealth and face-to-face clinics and provides on average, 4-5 DBS surgeries per month including lead placements and DBS battery changes. This number continues to grow with the addition of our new neurosurgeon, Dr. Paul Koch. He joined the Richmond PADRECC team in 2018 and performs DBS and other surgeries here and at Virginia Commonwealth University (VCU) Health System in Richmond. He is an assistant professor at VCU School of Medicine. He completed his residency training at the University of Pennsylvania, and a fellowship in Stereotactic and Functional Neurosurgery at Emory University. Dr. Koch's clinical interests include the surgical treatment of epilepsy, stereotactic therapies for movement disorders and other conditions, including deep brain stimulation and lesioning, and the treatment of pain through open and neuromodulatory therapies. He also has a strong interest in traumatic brain injury, both the acute management and the long-term cognitive sequelae, including the development of post-traumatic epilepsy.

- Dr. Kathryn Holloway, neurosurgical director of the Richmond PADRECC for the past 18 years, continues to perform DBS at the Richmond VAMC but is now able to focus more time to the many DBS related research projects she is involved in. One such project includes data obtained from the Cooperative Studies Program (CSP) #468 Study: A comparison of Best Medical Therapy to Deep Brain Stimulation of Subthalamic Nucleus and Globus Pallidus for the Treatment of Parkinson's Disease. This was the largest randomized comparison of DBS implantation sites in PD and significantly shaped the discussion around DBS target selection. All six PADRECCs participated in this study along with six private sector surgical centers. For this project, Dr. Holloway is investigating the differences in surgical targeting of these two brain nuclei and its clinical relevance. The findings of this study may further influence choice of stimulation site.

- The Richmond PADRECC and VCU are a combined site for the Registry for the Advancement of DBS in Parkinson's disease (RADPD) funded by the Michael J Fox Foundation. This is the first, nationwide data registry for DBS, with the purpose of gathering the same information, from multiple clinical sites, about patients with PD who are undergoing DBS treatment. Analysis of this information may help identify DBS best practices, side effects of DBS therapy (and how to prevent or manage them), and the cost-effectiveness of different procedures in DBS treatment.

- Dr. Mark Baron's laboratory studies in animal models of movement disorders are advancing our understanding of the pathophysiology and subcircuits responsible for individual movement disorders, including Parkinson's disease and dystonia. By separately inducing these two conditions with highly focused motor territory lesions in the GPe in rats and reconstructing multi-synaptic anterograde tracer labeling from these sites to the cortex, the investigators are demonstrating that PD and dystonia originate from similar pathology along two distinct motor subcircuits. From these findings, abnormal signaling along the basal ganglia-primary motor cortex subcircuit is suggested to be principally responsible for Parkinson's disease and along the supplementary motor cortex subcircuit for dystonia. In addition to publishing this work, the investigators will be shortly submitting their anticipated landmark rewriting of the longstanding basal ganglia thalamocortical pathways. Dr. Baron's laboratory work is supported by a BLR&D Merit Review award, which was renewed in January 2019.

Awards

- Southeast PADRECC Movement Disorder Neurologist, Dr. Mark Baron and PADRECC research director, George Gitchel PhD were the recipients of the 2019 Virginia Commonwealth University Inventor of the Year Award for their work on the RightEye System which is an Eye tracking technology to help with differential diagnosis of Movement Disorders. Recently, the technology was awarded a US patent, and the RightEye test was granted FDA Breakthrough Device Designation as a screening tool for Parkinson's disease.

Collaboration

- Southeast PADRECC continues to have a psychiatrist available weekly to see PADRECC patients for face to face or Telehealth appointments
- Southeast PADRECC has also expanded to include rotation through the PADRECC for Pharmacy residents.

Southeast Consortium Center Updates

Durham, NC

Consortium Director: Burton Scott, MD, PhD

The Durham Consortium Center provides care for about 100 veterans with Parkinson's disease (PD). Our PD clinics meet 10 times a month and are staffed by two movement disorders neurologists, Dr. Burton Scott and Dr. Jeff Cooney, in addition to Anna Cotton, PA and a variety of Duke Neurology residents who rotate through the clinic. Physical therapy, occupational therapy, speech therapy, and social work support are available at our facility. The VA neurosurgeons, Dr. Dennis Turner and Dr. Nandan Lad perform about 6 Deep Brain Stimulation (DBS) surgeries at the Durham VAMC per year, and about 100 DBS surgeries per year at Duke University Medical Center across the street from the VA. Initial DBS programming is performed by Dr. Turner's group, and maintenance programming is done in our movement disorders clinics. Dr. Cooney works with the neurosurgeons for DBS-planning and is in the operating room during DBS surgeries. In addition, Veterans are offered the opportunity to participate in multiple Parkinson's disease clinical trials at Duke University if they choose to, including trials sponsored by Biogen, Biotie, and the Parkinson Study Group.

Dates to Remember

March 12, 2020

EES/PADRECC Movement Disorders Series

Topic: Exercise and Physical Activity in the Management of PD

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

April 25- May 1, 2020

American Academy of Neurology Annual Meeting

Toronto, Canada

https://www.aan.com/conferences-community/annual-meeting/

May 14, 2020

EES/PADRECC Movement Disorders Series

Topic: To be Determined

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

September 10, 2020

EES/PADRECC Movement Disorders Series

Topic: Palliative Care Needs in Parkinson's Disease

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

September 12, 2020

National VA PD Consortium Meeting

Philadelphia, PA

September 13-17, 2020

International Parkinson and Movement Disorder Society Congress

Philadelphia, PA