

#### NATIONAL VA PARKINSON'S DISEASE

CONSORTIUM

 $Education \cdot Collaboration \cdot Advocacy$ 

# THE TRANSMITTER

March 2024

## **Article Reviews**

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### Soft robotic apparel to avert freezing of gait in Parkinson's disease

The dopamine deficiency in Parkinson's disease (PD) contributes to the reduced automaticity of movements. This can manifest as freezing of gait (FoG), a gait disturbance characterized by episodic absence of forward movement despite the intention to walk. This is often described as a feeling of feet being 'stuck' to the floor, and may impact as many as 80% of people with PD. Dopaminergic medication and deep brain stimulation sometimes yield modest yet transient benefits. Behavioral interventions, such as cueing strategies using auditory, visual or vibrotactile stimuli can help; however, their usefulness remains largely limited, as cueing fails to elicit consistent immediate effects to alleviate freezing and also the high dependence on cognitive processing makes cueing an impractical compensatory strategy as it can interfere with daily activities. The origins of FoG are poorly understood but what is consistently observed is a marked reduction in stride length and cadence (number of gait cycles) that leads to reduced gait speed. Wearable robotic elements have shown useful in improving movement in other neurological disorders such as stroke and spinal cord injury. In this paper, the author applied a soft robotic exoskeleton which can measure wearer movement and trigger assistance of hip flexion to trigger lower limb movement. A single individual with PD taking carbidopa-levodopa and treatment resistant FoG was tested with and without the exoskeleton. Without the exoskeleton, the participant exhibited freezing 30% of the time; with it, this reduced to 0% and total distance traveled improved by 50%. They next re-tried this in a real-world setting, walking several blocks on a busy Boston street. There was a reduction in freezing time from 63% to 6%, and distance traveled increased from 217m to 361m in 6 minutes. No deleterious effects were observed. This is an exciting proof-ofconcept study in a single individual where further studies involving more participants and with different settings are surely needed.

Kim J, Porciuncula F, Yang HD, et al. Soft robotic apparel to avert freezing of gait in Parkinson's disease. *Nat Med*. Jan 2024;30(1):177-185. doi:10.1038/s41591-023-02731-8

### Gender Differences in Task Specific Dystonia: What Can we Learn from Musician's Dystonia

It has been repeatedly shown that musician's dystonia has a higher proportion of male patients (4:1). This has previously been thought to be related to higher genetic susceptibility related to biologic gender differences. Other risk factors include positive family history (also associated with a younger age of onset), later age when taking up the instrument, over-practice, and sudden increase in practicing times. Other task specific dystonias and musician's dystonia have been found to have a male preponderance, but also an average younger age of onset in females.

This group in Germany created one of the largest cohorts of data through a mailed out questionnaire to 633 expert-diagnosed patients with musician's dystonia. 367 responded (55.7% response rate). Data collected included demographics (age, sex, etc.), musical training (university training, professional career), practice habits at different stages of life, course of their musician's dystonia, and family history (FH) for movement disorders. They looked at differences between male and female participants regarding cumulative practice time until the age of 20 and afterwards, age of onset of musician's dystonia, age at start of instrumental playing, distribution of instrumental groups, and distribution of family history for movement disorders. They performed a subgroup analysis on pianists and violinists as they have a younger age of onset, increased ability to practice multiple hours per day (as compared to wind instruments due to embouchure fatigue, for example), and more equal gender distribution. For the non-normally distributed data, they performed a Wilcoxon test. For categorical variables, they performed a chi-square test. To assess the impact of family history and gender on age of onset and cumulative as well as average practice time until MD onset, they used an ANOVA with post-hoc tests.

21.6% of the patients included were female, fitting with previous ratios. Most did not have a positive family history, but the proportion was higher in women compared to men (24.4% vs 10.8%, p=0.002). Median age of onset was 30 in women and 35 in men, a significant difference (p=0.004).

Age at beginning of instrumental playing was lower in women than in men (7.5 vs 9.0, p<0.001) Cumulative practice time until the age of 20 was higher in women than in men (8766 vs 6574h, p=0.03). Average practice time per year until onset of MD did not differ significantly between men and women. Subgroup analysis using ANOVA (FH+/- and M/F) showed that younger age of onset was associated with positive family history, but not for gender (p=0.03, p=0.768). They also looked at average mean playing time differences until onset in the same groups and found a trend towards higher mean and cumulative playing time in those without family history (p=0.08, p=0.057).

The results suggest that difference in gender prevalence for musician's dystonia is not related to increased genetic susceptibility in males, but may be related to differences in asymmetric distributions of practice time. Women tended to start the instrument at a younger age and have a more linear progression of practice hours. Men tended to have a sharper increase in practice hours around the age of typically entering university or professional play. This supports the previously seen associations with repetitive movement and over practicing being a key risk factor in developing musician's dystonia. They suggested this information could be used to develop healthier practice habits in children to help avoid

this disabling disease. They also discussed a higher risk seen in previous studies in brass instrument players may be related to a lower variability of muscle action of the embouchure. These support an underlying pathophysiology of repetitive actions done more closely together in time.

Doll-Lee, J., Passarotto, E., Altenmüller, E. and Lee, A. (2024), Gender Differences in Task Specific Dystonia: What Can we Learn from Musician's Dystonia? Mov Disord Clin Pract. https://doi.org/10.1002/mdc3.14015

#### Sleep disorders in Parkinson's disease, an Early and Multiple problem

Sleep changes in PD are a known phenomenon contributing to reduced quality of life for patients and caregivers. In later stages of Parkinson's Disease (PD) sleep disturbances are sometimes attributed to "off" motor symptoms such as bradykinesia, dystonia, and tremor, however, sleep disturbances in early PD where motor fluctuations are less common are not as well know. Sleep disorders outside of REM Behavior Disorder (RBD) are often overlooked in clinical practice or taken in isolation rather than considered in combination with one another.

This group of researchers out of Paris, France, in conjunction with the Parkinson's Foundation, aimed to determine prevalence and possible combination of various sleep disorders in early Parkinson's Disease. Of the 162 PD participants, sleep disorders were very frequent (71%) and almost half of the PD cohort had at least two types of sleep disorders. Insomnia was found to be the most common sleep disorder (41%) followed by definite REM Behavior Disorder (RBD) (25%), Excessive Daytime Sleepiness (EDS) (25%), and Restless Leg Syndrome (RLS) (16%). Interestingly, sleep disorders increased with longer disease duration and dysautonomia. An ordinal logistic regression was used to determine factors of association with these sleep conditions. Female gender, shortened sleep time, and RLS were associated insomnia. Dysautonomia and advanced age was associated with RBD. Lastly, psychiatric/mood symptoms and use of dopamine agonists was associated with EDS.

Certain sleep disorders, such as REM Behavior Disorder, when present at later stages of PD are associated with impaired cognition and motor severity. It remains unclear if presence of these sleep disorders in early stages of PD influence cognition and motor severity down the line. This retrospective cohort study provides a good description on the prevalence and associated factors of sleep disorders in early stages of PD and lays groundwork for further investigation of the effect of sleep disturbance long term in PD. As clinicians we screen for abnormal movements during sleep, in particular REM Behavior Disorder, however, other sleep disorders such as insomnia, restless leg and excessive daytime sleepiness are often overlooked. These are conditions which negatively affect quality of life and if addressed early and in combination may result in better patient outcomes long-term.

Dodet, P., Houot, M., Leu-Semenescu, S. *et al.* Sleep disorders in Parkinson's disease, an early and multiple problem. *npj Parkinsons Dis.* **10**, 46 (2024). <a href="https://doi.org/10.1038/s41531-024-00642-0">https://doi.org/10.1038/s41531-024-00642-0</a>

## **Committee Activities**

#### **Clinical Care Committee**

- Rotation of Committee Chair: Leadership for the clinical care committee rotates amongst the PADRECCs. The San Francisco PADRECC leads the committee for March/April. 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 treatment strategies, new medications and other procedures, and other clinical issues to improve patient care and outcomes across the national PADRECCs service area. It also serves to provide clinical support to the PADRECC Associated Sites by focusing on procedures and measures to standardize clinical care across the PADRECC network.
- Recent agenda items have included:
  - 1. Future planning to enhance clinical service provision at PADRECCs : Suggestions and Strategies
  - 2. Discussion of new therapies in the pipeline and possible use in the VA in the future
  - 3. Discussion of DBS management and surgical programs at the PADRECCs
  - 4. Role of MRI guided focused ultrasound thalamotomy in the management of essential tremor and Parkinson's disease

#### **Education Committee**

- PADRECC/EES Movement Disorder Series-Webinars: knowledge-based webinars to provide VHA healthcare professionals with current practice standards and emerging trends in the treatment of Parkinson's disease and other movement disorders. CEs are typically provided for the <a href="mailto:live">live</a> webinars. Check out the following link for a list of past webinars and if you are interested in receiving a recording of a past webinar please email <a href="mailto:Gretchen.glenn@va.gov">Gretchen.glenn@va.gov</a> and list the date/topic of interest: <a href="https://www.parkinsons.va.gov/Consortium/Presentations/Audio Conference/MDS.asp">https://www.parkinsons.va.gov/Consortium/Presentations/Audio Conference/MDS.asp</a>
- Patient and Care Partner Webinars: coordinating several webinars in recognition of Essential Tremor and Parkinson's Disease Awareness Months
  - o Essential Tremor: Understanding and treating Essential Tremor- March 21, 2024
  - o **PD 101-** April, 2, 2024
  - o Mental Health Issues in PD- April 10, 2024
- Parkinson's Disease Rehab-Community of Practice on Microsoft Teams- collaboration with rehabilitation subject matter experts across the VA with interest in PD to develop this COP to address and enhance rehabilitation care for Veterans with PD and similar conditions. The goal of the platform is to share evidence-based knowledge to inform PD-specific rehabilitation practices, provide access to up-to-date resources, program success and opportunities for improvement. All are welcome to join:

https://teams.microsoft.com/l/channel/19%3a NAJNcVxoyd5XB0M UnwK4Ym7vi8C971TC0xqer

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- 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.