

VA

U.S. Department of Veterans Affairs

Veterans Health Administration
Parkinson's Disease Research,
Education & Clinical Centers**NATIONAL VA PARKINSON'S DISEASE****C O N S O R T I U M***Education · Collaboration · Advocacy*

THE TRANSMITTER

November 2023

Article Reviews

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Disparities in Huntington Disease Severity: Analysis Using the ENROLL-HD Dataset

Health disparities are well-documented in many common neurologic diseases. This study aims to describe racial and ethnic disparities in Huntington's disease using the ENROLL-HD dataset by looking at baseline disease severity as measured by the total functional capacity (TFC) scores. ENROLL-HD is an international, longitudinal, observational study of patients with Huntington's disease. In this study, the authors analyzed available data from 4,717 North American participants in the study with a CAG repeat length of ≥ 36 . Categorization of race/ethnicity was based on participants' self-identification. The authors found that 89.5% of participants in this cohort identified as white, 3.4% as Hispanic or Latino, and 2.3% as African American/Black. Multivariate regression models revealed that Black participants and those with less than a high school level of education had a lower TFC score (more advanced disease) at baseline compared to white participants. Furthermore, those with some form of higher education or professional degree had a higher TFC score (less advanced disease). This study corroborates health disparities that have been seen in more common neurologic diseases, and emphasizes the importance of further studying the role that social determinants of health may play in Huntington's disease.

Mendizabal A, Singh AP, Perlman S, Brown A, Bordelon Y. Disparities in Huntington Disease Severity: Analysis Using the ENROLL-HD Dataset. Neurol Clin Pract. 2023 Dec;13(6):e200200. doi: 10.1212/CPJ.0000000000200200. Epub 2023 Oct 2. PMID: 37795504; PMCID: PMC10547468.

Reach of Palliative Care for Parkinson Disease: Results From a Large National Survey of Patients and Care Partners

Patients with Parkinson's disease (PD) and their caregivers have high palliative care needs as a result of progressively disabling motor and non-motor symptoms. The authors of this study define palliative care as an approach that goes beyond diagnosis and treatment to address complex symptomatology, psychosocial, and spiritual needs of patients and their caregivers, and defining personalized goals of treatment. The objective of this study is to describe the current extent to which patients and their

caregivers feel their palliative care needs are being met, their perceptions regarding clinical communication, and their knowledge of palliative care. The authors administered a survey to over 12,000 patients who had consented to receiving surveys from the Parkinson's Foundation, and received 1,882 responses (1,266 from people with PD, and 616 from care partners; response rate 14.5%). While the majority reported that their neurologists asked about non-motor symptoms, 50% reported that pain as a specific symptom was never managed or only managed if they brought it up. Furthermore, their emotional and spiritual needs (55%), care partner's well-being (57%), and advanced care planning (79%) were never addressed or only addressed if they brought it up. Most reported being knowledgeable about palliative care (85%), and 64% felt that the quality of clinical communication was open and honest. These results highlight the gaps in care experienced by people with PD and their caregivers. The authors propose opportunities to address these gaps through clinician education, and also by advocating for institutional support to implement models of care that may facilitate the implementation of palliative care in routine neurologic care for people with Parkinson's disease.

Seshadri S, Dini M, Macchi Z, Auinger P, Norton SA, Holtrop JS, Kluger BM. Reach of Palliative Care for Parkinson Disease: Results From a Large National Survey of Patients and Care Partners. Neurol Clin Pract. 2023 Dec;13(6):e200214. doi: 10.1212/CPJ.0000000000200214. Epub 2023 Oct 16. PMID: 37854173; PMCID: PMC10581080.

The Impact of Sex-Specific Survival on the Incidence of Dementia in Parkinson's Disease

Older age and higher disease severity are well-documented risk factors for the development of dementia in Parkinson's disease. Several studies have suggested that men may have a higher risk and prevalence of Parkinson's disease dementia (PDD), though as a result of higher life expectancy, the authors of this study aimed to examine the impact of sex differences in survival after initial Parkinson's disease (PD) diagnosis on the risk of subsequently developing PDD. They examined a random sample of German health claims data and identified new PD cases who were followed-up for a PDD diagnosis or death between the years 2006 and 2017. Two thousand one hundred ninety-five (2195) new PD cases were identified, 602 of whom died before receiving a diagnosis of dementia, and 750 of whom developed PDD by the end of 2017. Men did have a higher adjusted risk of PDD compared to women, though when accounting for death the risk was not significantly different. Sex-specific analyses showed that age and disease severity significantly affected PDD risk in women, but not in men. These findings suggest that men with PD may die before receiving a dementia diagnosis, whereas women with PD survive at higher rates, regardless of their age at onset and disease severity. The authors provide a thoughtful discussion of the implications of their findings. First, that clinical trial design for potential disease modifying therapies will need to take these sex differences into account and should conduct sex-stratified analyses. And second, that men and women may have different risk factors for dementia, suggesting that sex-specific tailored approaches to treatment and counseling may be warranted.

Fink A, Dodel R, Georges D, Doblhammer G. The Impact of Sex-Specific Survival on the Incidence of Dementia in Parkinson's Disease. Mov Disord. 2023 Nov;38(11):2041-2052. doi: 10.1002/mds.29596. Epub 2023 Sep 1. PMID: 37658585.

Committee Activities

Clinical Care Committee

- **Rotation of Committee Chair:** Leadership for the clinical care committee rotates amongst the PADRECCs. The Northwest PADRECC leads the committee for November/December. 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 consortium network 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 live 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 Gretchen.glenn@va.gov and list the date/topic of interest: https://www.parkinsons.va.gov/Consortium/Presentations/Audio_Conference/MDS.asp
- **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_UnwK4Ym7vi8C971TC0xqerdfds1%40thread.tacv2/General?groupId=bf9f6fc8-06da-401e-99c5-6dd0b47494ee&tenantId=e95f1b23-abaf-45ee-821d-b7ab251ab3bf
- **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.