COMMENTARY

Racial and Ethnic Disparities in Parkinson Disease

A Call to Action

Whitley W. Aamodt, MD, MPH, Allison W. Willis, MD, MS, and Nabila Dahodwala, MD, MS

Neurology: Clinical Practice 2023;13:e200138. doi:10.1212/CPJ.0000000000200138

Correspondence
Dr. Aamodt
whitley.aamodt@
pennmedicine.upenn.edu

Abstract

Health disparities are pervasive in the United States. In the field of Parkinson disease (PD), profound racial and ethnic disparities exist in diagnosis, treatment, and research participation, leading to differential health outcomes and lack of generalizable research data. Racial and ethnic disparities not only limit our understanding of this complex heterogeneous disorder but also hamper our ability to provide new evidence-based care for America's most vulnerable populations. In this report, we summarize findings from our comprehensive white paper for the Michael J. Fox Foundation that reviews the current state of knowledge on racial and ethnic disparities in PD care in the following areas: epidemiology, etiology, phenotype and diagnosis, treatment, and research. We also identify knowledge gaps and necessary policy changes to ensure equitable, high-value care for all persons with PD. These strategies are designed to help identify and reduce health disparities among persons with PD and may serve as a model for other neurologic diseases.

Almost 2 decades have passed since the Institute of Medicine (now called the National Academy of Medicine) published its landmark report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care.*[1] Unfortunately, health status and healthcare disparities remain pervasive in medicine, particularly in the field of Parkinson disease (PD). The Michael J. Fox Foundation commissioned a comprehensive white paper to better understand the current state of knowledge on racial and ethnic disparities in PD and identify knowledge gaps and necessary policy changes to ensure equal high-value care for all persons with PD. We highlight the main findings from this report (eAppendix 1, lww.com/CPJ/A404).

Background and Definitions

The broad term *health disparities* indicates differences in health conditions that exist among specific population groups and limit their ability to achieve their full health potential. *Health status disparities* are group differences in the incidence, prevalence, morbidity, and mortality of health conditions, while *healthcare disparities* are group differences in healthcare access, quality, and outcomes. There is often implied overlap between the term health disparity and *health inequity*, which indicates an immoral or unjust difference in health care. We use the term health disparities, given its more common usage in the United States, though health inequity is implied as part of its definition.[2]

Race and ethnicity are overlapping concepts that are often used synonymously. While *race* refers to physical differences that groups consider socially significant, *ethnicity* refers to shared cultural characteristics such as language, ancestry, practices, or beliefs.[3] Healthcare disparities are often described by race and ethnicity but can exist in the delivery of care based on age, sex, sexual orientation or gender identity, disability, socioeconomic status, or geographical location. In this summary, we describe racial and ethnic disparities among individuals in the following racial/ethnic groups: Asian, Black, Latino, Native American, and White.

Department of Neurology (WWA, AWW, ND); and Translational Center of Excellence for Neuroepidemiology and Neurology Outcomes Research (WWA, AWW), University of Pennsylvania, Philadelphia, PA.

Funding information and disclosures are provided at the end of the article. Full disclosure form information provided by the authors is available with the full text of this article at Neurology.org/cp.

The relationship between race, ethnicity, and health is complex. Race is a social construct, and racism, racial segregation, and racial discrimination directly affect the ability of minoritized groups to access and receive quality health care. In the United States, race and ethnicity are closely associated with socioeconomic status (SES) and may serve as a proxy for other social and environmental factors. These factors, often called *social determinants of health*, have a profound impact on health and health outcomes and include variables such as education, housing, access to transportation, proximity to quality care, and exposure to racism and other discriminatory health practices, among others. It is essential that health policymakers and community leaders understand the intricate relationship between race, ethnicity, SES, and social determinants of health to identify and eliminate racial and ethnic disparities at the individual, community, state, and national levels.

Structural racism and racist cultural beliefs contribute to stereotyping, mistrust, and unconscious bias among patients and medical care providers. *Bias* has been used to describe both implicit/explicit stereotypes and prejudice in health care. In 1 systematic review exploring implicit racial/ethnic bias among healthcare professionals in 15 studies, low to moderate levels of implicit racial/ethnic bias were found in all studies but 1.[4] Most healthcare providers demonstrated positive attitudes toward White patients and negative attitudes toward persons of color, and this *implicit* bias associates with *explicit* actions, such as inappropriate treatment decisions, negative patient-provider interactions, and poor treatment adherence, resulting in worse patient health outcomes.[4] In PD, there are profound racial/ethnic disparities in diagnosis, treatment, health outcomes, and research participation, which we will review in detail.

Epidemiology

Studies suggest that the frequency and risk of PD varies by race and ethnicity.[5] Most studies report the greatest prevalence and incidence of PD in White individuals, followed by Latino, Asian, Black, and Native American individuals who have the lowest reported rates of disease (Table 1). Although European ancestral groups have been reported to have the highest prevalence of monogenic risk factors or genetic traits associated with early-onset PD, several factors limit our ability to clearly understand whether there is any association between ancestry or social risk factors with polygenic or late-onset PD. Typical case ascertainment methods have relied on clinical records from academic medical centers that are disproportionately accessed by persons with high income, advanced education, and quality primary care. The current PD diagnostic criteria are drawn from such cohorts. PD epidemiology studies (both medical record based and administrative data based) may therefore be limited in their ability to capture or reflect PD occurring in persons who experience complications from comorbid diseases (e.g., diabetes, cerebrovascular disease) or have language, insurance, geographical, or socioeconomic barriers to receiving a PD diagnosis. Second, PD diagnosis in persons from minoritized groups may be missed or delayed in those exhibiting typical symptoms. In the only door-to-door population-based study of PD prevalence in the United States, investigators found that Black individuals were twice as likely to be previously undiagnosed with parkinsonism as White individuals,[6] which may reflect provider bias, differences in health literacy, mistrust of the healthcare system, or other barriers to care access that contribute to measurable differences in disease prevalence. Given that age is the greatest risk factor of PD, differences in life expectancy can also affect observed differences in prevalence. Finally, while several studies have compared Black-White differences in rates of PD, few studies have investigated prevalence and incidence among persons of Asian, Latino, and Native American descent. Major knowledge gaps remain about whether observed racial/ethnic differences in PD prevalence and incidence reflect ancestral differences in monogenic or polygenic risk, socially determined differences in environmental exposures, receipt of quality or unbiased care, or shortfalls in current research scope and study design/methods.

Etiology

While researchers are still uncovering the genetic and environmental underpinnings of PD, several studies point to different genetic factors that may increase PD risk. Specific genes implicated in PD are *SNCA*, *PRKN*, *PINK1*, *DJ-1*, *GBA*, and *LRRK2*, among others. The *LRRK2* G2019S variant is the most common known cause of genetic PD. While this variant occurs more frequently in people of Basque, Ashkenazi Jewish, and North African origin, different *LRRK2* variants may be more common risk alleles for PD in Latino and East Asian individuals.[7,8] Another study showed that people with melanoma, which is strongly linked to red hair, fair skin, and polymorphisms in the melanocortin 1 receptor gene, are at a higher risk of PD.[9] This study suggests that White individuals may have a higher genetic risk of PD than persons of color, which could explain the higher prevalence.

Unfortunately, many early studies exploring PD genetics included only White patients, such as the landmark twins study based on the National Academy of Sciences/National Research Council World War II Veteran Twins Registry.[10] Although several more recent kindred and genetic studies have investigated PD risk in diverse populations, sample sizes are overall small. For example, 1 study described PD in a large Native American family with 4 affected family members over 2 generations,[11] and a more recent multicenter study of young-onset PD included 12/956 (1.3%) Black and 77/956 (8.1%) Latino participants in its cohort.[12] Another study evaluated known genetic alterations in Black patients from sub-Saharan African, but enrolled only 39 participants.[13] To date, there is limited data from multiethnic genome-wide association studies in the United States. However, the Global Parkinson's Genetics Program aims to study the genetic risk of PD with a focus on recruitment from underrepresented groups through partnerships with the Latin American

Table 1 Prevalence and Incidence of Parkinson Disease by Racial and Ethnic Group in the United States

Study year	Sample	White	Asian	Black	Latino	Native American/ Alaska native
Prevalence[a]						
1972	Louisiana, clinic based	121–128	—	9–31	—	—
1974	Louisiana, hospital based	147	—	22	—	—
1985	Mississippi, population based	353	—	338	—	—
1995	New York, community registry	116	—	57	—	—
2010	National, Medicare beneficiaries	1672	1139	1036	1543	
2012	National, Indian Health Service	—	—	—	—	356
Incidence[b]						
1995	New York, community registry	11.8–13.3	—	—	—	—
2003	California, health system	13.6	11.3	10.2	16	—
2009	Pennsylvania, Medicaid beneficiaries	54	—	23	40	—
2010	National, Medicare beneficiaries	452	339	362	476	—
2015	National, Indian Health Service	—	—	—	—	36
2017	National, survey data	197	—	135	—	—

[a] Prevalence reported per 100,000.
[b] Incidence reported per 100,000 person-years.
Data are summarized from epidemiologic studies presented in the Michael J. Fox Foundation's white paper entitled "Health Disparities in Parkinson's Disease: Improving Care for America's Most Vulnerable Populations" (eAppendix 1, lww.com/CPJ/A404).

Research Consortium on the Genetics of Parkinson's Disease and Black and African American Connections to PD.

The role of environmental risk factors in the etiology of PD is arguably greater than genetic risk. PD is more common among Black Americans than Nigerians[14] and men of Japanese or Okinawan descent residing in the United States compared with those residing in Asia.[15] PD risk is also associated with living in rural communities, pesticide exposure, and heavy metal exposure, but most studies do not report data by race/ethnicity.[16] One study of 89 persons with PD (53 White, 31 Latino, and 5 Black individuals) found that rural living, area farming, and well water consumption were associated with PD in Black patients only.[17] Unfortunately, limited data on racial/ethnic differences in rural residence and associated exposures preclude any firm conclusions about disparities in environmental risk factors.

PD risk is also elevated among United States Veterans. Exposure to Agent Orange during the Vietnam War is associated with an increased risk of PD. Although Black individuals were more likely than White individuals to be drafted for Vietnam,[18] little is known about how this disparity may translate into increased rates of PD occurrence. Contamination of the water supply with trichloroethylene and perchloroethylene at Camp LeJeune, a military base in North Carolina, has also been associated with an increased PD risk. Finally, military service is associated with a higher risk of traumatic brain injury (TBI), which can lead to PD. One study of patients with TBI found that patients with comorbid TBI and PD were more likely to be Black or Latino.[19]

Several unanswered questions about the etiology of PD remain. Does ancestry/genetic variation by race/ethnicity contribute to differences in PD risk or the heterogeneity of PD symptoms? Are there racial/ethnic differences in rural, environmental, or occupational exposures that contribute to differences in overall PD risk or symptoms?

Diagnosis and Phenotype

PD is underrecognized and underdiagnosed in people of color.[6,20] Several hypotheses may explain these findings and include the following: (1) higher rates of comorbid cognitive impairment that can reduce awareness of PD symptoms[21]; (2) racial/ethnic differences in healthcare-seeking behaviors[22]; (3) underrecognition of PD signs and symptoms by treating providers; and (4) inadequate PD diagnostic criteria that were based primarily on the evaluation of White patients and do not represent the full diversity of PD phenotypes.

To identify the true reasons for underrecognition of PD, it is necessary to know whether there are racial/ethnic differences in symptoms. Prodromal symptoms often herald the diagnosis of PD and include olfactory impairment, constipation, mood changes, and REM sleep behavior disorder. One community-based study on the prevalence of olfactory impairment found that hyposmia was more common among Black (22.3%) than White

(10.4%) individuals.[23] However, another study found that the association between hyposmia and PD risk was stronger among White (hazard ratio [HR] 4.9, 95% CI 2.3–10.5) than Black (HR 2.5, 95% CI 0.8–8.1) individuals.[24] Studies comparing motor and nonmotor symptoms across racial/ethnic groups are limited in number. However, some suggest that Black patients with PD may have worse motor symptoms than White patients.[25] From these data, it is unclear why PD would be underrecognized in underrepresented groups based on symptoms alone.

Delays in diagnosis may partly account for worse motor symptoms among Black patients with PD compared with White patients.[20] In 1 study of Veterans with newly diagnosed PD, Black patients presented for care at more advanced stages of disease but self-reported disability at the same level of motor impairment as White patients. Furthermore, there is evidence of missed diagnoses.[6] Unfortunately, there has been little funded research on the mechanisms that drive these diagnostic delays. One community-based study of PD knowledge and healthcare-seeking behavior identified overall low PD literacy among underrepresented groups and several racial/ethnic differences in reasons for not seeking care.[22] Specifically, Black individuals reported lack of insurance, religious concerns, and mistrust as barriers to care, while Chinese Americans reported language barriers and lack of knowledge on where to seek treatment. Both groups are also subject to explicit bias and receipt of lower quality care from healthcare providers.

Understanding the diversity of PD symptoms is critical to reducing disparities in diagnosis and treatment. Specifically, we need to know whether there are racial/ethnic differences in PD symptoms at onset or differences in the recognition of these symptoms. Should PD diagnostic criteria be revised to be more inclusive? Are there racial/ethnic differences in PD progression? How might comorbid disease, cultural factors, or patient preferences contribute to racial/ethnic differences in symptoms or the recognition of these symptoms?

Treatment

After PD diagnosis, there are profound disparities in access to care, care delivery, and the receipt of medical, surgical, rehabilitative, and palliative therapies (Table 2). While only 58% of people with PD are seen by a neurologist, non-White patients are even less likely to receive neurologic care.[30] These disparities in PD treatment ultimately lead to worse outcomes. Individuals who do not receive care from a neurologist are more likely to have hip fractures, visit the ED, be hospitalized and placed in skilled nursing facilities, and, ultimately, die.[30]

PD experts have long advocated for the implementation of telehealth services to increase access to care for those that live far from specialty centers or have limited ability to travel due to cost, disability, or accompaniment by a care partner. Furthermore, telehealth for PD management is feasible and has high reported satisfaction among persons with PD and providers.[33] Although participants in PD telehealth studies have been largely White, college educated, and under the care of a movement disorders specialist, recent data obtained after the COVID-19–related expansion of telehealth coverage showed that residents living in the most disadvantaged neighborhoods had the highest odds of using telehealth for at least 1 outpatient visit.[34] Furthermore, integrated centers of care such as the Veterans Health Administration Parkinson's Disease Research, Education, and Clinical Centers offer tablets to facilitate home telehealth visits for individuals who do not have access to digital technology or Internet services.

Cultural competency among providers, particularly in cross-cultural communication strategies, is essential to reduce bias and improve overall health outcomes. Little is known about the effect of cultural competency training programs on persons with PD. However, to address barriers related to language differences, the University of Rochester started a Spanish language neurology clinic, which has increased access for Latino patients with PD.

When examined in more depth, underlying differences in social determinants of health may also explain partly the observed treatment disparities. For example, minority-serving hospitals are less likely to perform deep brain stimulation (DBS) surgery regardless of patient race (odds ratio [OR] 0.76, 95% CI 0.66–0.87), and high neighborhood SES is associated with higher odds of DBS surgery (OR 1.42, 95% CI 1.33–1.53).[29]

We still need to understand racial/ethnic and socioeconomic barriers to specialty care and develop effective interventions to reduce inequities. How can we improve access to neurologic specialty care for non-White patients with PD? How can we improve care delivery for diverse groups, including English translation and telehealth services? How can we reduce PD treatment disparities and improve outcomes?

Research

A major shortcoming in our knowledge of PD is that most funded, published research is based on studies of White patients. In a review of 239 PD studies over 22 years, only 17% reported data on race and ethnicity. These studies enrolled a total of 7,481 participants, and only 8% were non-White.[35] In another analysis of PD trials of neuropsychiatric symptoms, only 11 of 63 studies reported data on race and ethnicity, and fewer than 1% of participants were Black or Latino.[36] There are numerous proposed barriers to more diverse representation among research participants (Figure). Despite these barriers, a survey of PD patients found no racial difference in willingness to participate in clinical research.[37]

There have been prior initiatives to improve diversity in PD clinical trials. One randomized recruitment intervention tested partial funding for a recruitment coordinator and improved PD education for primary care providers in underrepresented communities. Unfortunately, this trial was stopped early because of lack of efficacy.[38] A more recent cluster randomized trial tested a trust-based continuous quality improvement intervention that was tailored to each

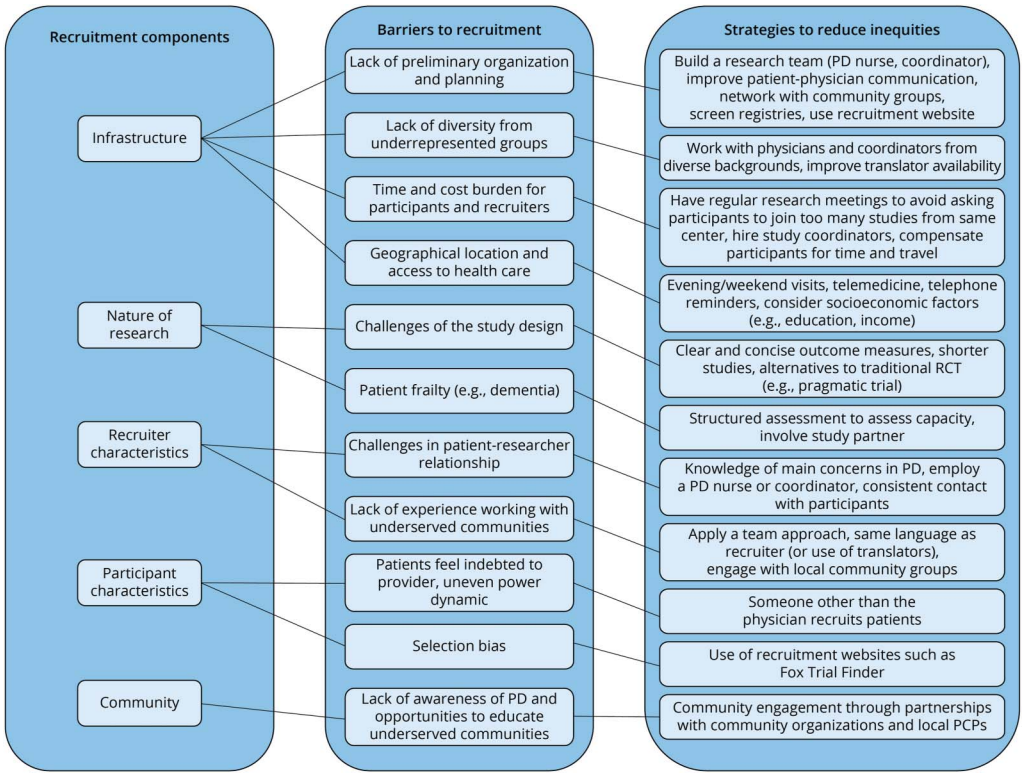
Table 2 Treatment Disparities Among Minoritized vs White Persons With PD

	Medications	Rehabilitation services	Surgery	Neurology specialty care
Black	• OR 0.24 (0.09, 0.64) of starting PD treatment after new diagnosis[26] • OR 0.80 (0.69, 0.93) of receiving PD medications with prevalent PD[27]	• OR 0.63 (0.59, 0.67) of receiving physical or occupational therapy[28] • OR 0.63 (0.59, 0.67) of receiving speech therapy[28]	• OR 0.20 (0.16, 0.25) of receiving DBS surgery[29]	• OR 0.67 (0.62, 0.71) of seeing a neurologist if a Black woman[30] • OR 0.68 (0.63, 0.73) of seeing a neurologist if a Black man[30]
Latino	• OR 1.11 (1.00, 1.23) of being coprescribed cholinesterase inhibitor for dementia and anticholinergic drug (frank prescribing area)[31]	• OR 0.91 (0.85, 0.98) of receiving speech therapy[28]		• OR 0.79 ([0.63, 0.98) of seeing a neurologist if a Latino woman[30]
Asian		• OR 1.31 (1.21, 1.41) of receiving physical or occupational therapy[28]	• OR 0.55 (0.44, 0.70) of receiving DBS surgery[29]	• OR 0.85 (0.75, 0.95) of seeing a neurologist if an Asian woman[30]
Native American	• OR 0.62 (0.51, 0.74) of being prescribed cognitive enhancing medication[31]	—	—	—
Non-White	• Veterans 15% less likely to be titrated to therapeutic range with dopamine agonists[32] • OR 0.75 (0.39, 0.89) for Veterans to receive antidepressant therapy for depression[32]	—	—	• OR 0.83 (0.79, 0.87) of seeing a neurologist[30]

Abbreviation: DBS = deep brain stimulation.
Brackets denote 95% confidence intervals.

study site and included improved patient navigation and initiatives to reduce instrumental barriers to research participation (e.g., cost and transportation).[39] This trial was successful in meeting its goal of 10% minority subject enrollment. Currently, the Michael J. Fox Foundation and the Community Access, Recruitment and Engagement Research

Figure Recruitment Barriers and Strategies to Reduce Inequities in Parkinson Disease Clinical Trials



PCP = primary care provider; PD = Parkinson disease; RCT = randomized controlled trial. Schematic adapted from Picillo et al.[43] with permission from Elsevier.

Center at Massachusetts General Hospital have partnered on a study called Fostering Inclusivity in Research Engagement for Underrepresented Populations in PD to learn more on how to engage more diverse communities in PD research.[40]

The lack of diversity in clinical trials has important implications. First, our understanding of this complex heterogeneous disorder remains limited. Second, the lack of generalizable data from clinical trials will hamper our ability to provide evidence-based personalized care, further exacerbating healthcare disparities. To improve care, we need to learn about the most effective ways to improve diversity in clinical trials. Are there unique strategies for diverse PD recruitment and retention?

Action, Advocacy, and Health Policy

In the preceding sections, we highlighted knowledge gaps surrounding the epidemiology, etiology, diagnosis, treatment, and study of PD in diverse populations. Although research exploring racial and ethnic disparities in PD has grown in the past decade, healthcare disparities remain pervasive at all levels of PD care. To confront these disparities, we must recognize them, understand their underlying causes, identify modifiable risk factors, and develop interventions and policies to improve care for all persons with PD, which could be applied to other neurologic diseases as well. Using PD as a model, we propose the following health policy action steps.

Develop a National Plan for PD

The prevalence of PD is rising. Policies to improve PD diagnosis and treatment should be implemented at a population level to confront and reduce inequities in care. To ensure timely diagnosis, public health campaigns are needed to improve awareness and recognition of PD symptoms. To identify at-risk populations, a national registry should be created to collect epidemiologic data and determine geographic trends in PD incidence and prevalence. PD registries currently exist in select states only (e.g., California and Nebraska) and clusters may cross state lines. In addition, government insurance programs such as Medicare should guarantee coverage for specialty drugs and advanced therapies regardless of patient income. Lastly, racism and discrimination are powerful forces that prevent minority groups from receiving necessary care and should be acknowledged. Because implicit bias, structural racism, and patient mistrust in the healthcare system are barriers to developing national health policies, the initiatives outlined further may also serve as incremental steps toward achieving a national PD plan.

Establish an Advisory Council Within the Department of Health and Human Services on PD Care, Services, and Research

In the process of developing a national agenda, an advisory council should help set the standard for PD care and oversee collaborative efforts between government agencies, private foundations, healthcare systems, and grassroots organizations to reduce health disparities in PD. An advisory council could also coordinate efforts across federal research agencies, ensure the proper allocation of funding for PD-related research and health initiatives, and catalyze private sector research through tax credits and the efficient dissemination of results from federally funded studies to private sector organizations that are developing interventions to combat racial disparities. Finally, this council could help recruit and invest in PD workforce from minority and immigrant-serving communities to improve engagement among persons of color.

Invest in Community, Patient, Family, and Provider PD Education

There is a pressing need for greater community awareness of PD symptoms to ensure timely diagnosis and treatment. Public health campaigns at the local, state, and national levels are needed to educate the public and healthcare providers on recognizing (and screening for) common prodromal, motor, and nonmotor symptoms. Improved translation services in clinical settings will help promote health-seeking behaviors among non-English speaking patients. In communities without a practicing neurologist or PD specialist, continuing medical education courses could also teach general practitioners about the nuances of PD diagnosis and treatment and could be offered virtually or in-person at professional conferences.

Invest in PD Disparities Research

Because research participation in PD trials disproportionately occurs among White individuals, we must also develop innovative strategies for diverse clinical trial recruitment to strengthen the science underlying PD etiology and treatment. Grant proposals that address PD health disparities and encourage diverse research participation should be prioritized in the review process. Additional research money is also needed to ensure these projects are funded. Financial incentives, such as student loan forgiveness, could be awarded to research teams that enroll a certain percentage of research participants from different racial/ethnic groups. Conversely, if pharmaceutical companies or other study groups fail to enroll minorities, they could face harsher penalties, such as withheld approval from the United States Food and Drug Administration for study drugs.[41]

Invest in the Care of Military Service Personnel and Veterans at an Elevated Risk of PD

Non-White populations were disproportionately recruited for military service during the Vietnam War, which may place Veterans from racial and ethnic minority groups at an elevated risk of PD through unique exposures (e.g., Agent Orange, trichloroethylene and perchloroethylene, and TBI). To reduce racial disparities and improve health outcomes, we must invest in the care of active service members and Veterans. Environmental exposures to chemicals and other contaminants should be limited when possible, and annual screening for PD should be offered free of charge to those with and without formal service connection.

Support Nationwide Teleneurology Initiatives and Insurance Reimbursement

There is a national shortage of neurologists in the United States, and many persons with PD do not have access to neurology specialty care. To improve care access in underserved and rural communities, teleneurology initiatives are needed. State and national laws should be implemented to allow neurologists and PD specialists to conduct virtual visits with all patients regardless of their state of residence. Insurance reimbursement for virtual visits should also be commiserate with in-person visits to avoid deincentivizing or penalizing providers for expanding care coverage to those most in need.

Racial and ethnic disparities are pervasive in PD and increasingly important not only because racial and ethnic minority groups will represent half of the United States population by 2040 but because all Americans should have equitable access to health care regardless of their age, race/ethnicity, sex, gender identity, geographic location, or financial resources.[42] Despite growing interest in the field of health disparities, numerous questions remain. How do we improve PD recognition and diagnosis among members of racial and ethnic minority groups? How do we design and conduct studies to understand modifiable risk factors more common in underrepresented communities? How do we develop interventions and policies to improve affordability and access to care? To reduce racial and ethnic disparities in PD, we must first recognize them and understand their underlying causes, a primary focus of ongoing research that will inform future interventions. Strategies to reduce inequities and improve neurologic care are a public health priority for America's most vulnerable populations.

Study Funding

This work was supported by the Michael J. Fox Foundation, NIH (T32 NS061779), and the 2022 American Academy of Neurology Clinical Research Training Scholarship in Neurodisparities funded by the Hearst Foundation, Eisai, and the American Brain Foundation in collaboration with the American Academy of Neurology Institute.

Disclosure

W.W. Aamodt serves as the Section Editor of the *Neurology* Resident & Fellow Section and receives research support from the American Academy of Neurology Institute; A.W. Willis reports no disclosures relevant to the manuscript; N. Dahodwala receives research support from the Michael J. Fox Foundation. Full disclosure form information provided by the authors is available with the full text of this article at Neurology.org/cp.

Publication History

Received by *Neurology: Clinical Practice* August 29, 2022. Accepted in final form December 1, 2022. Submitted and externally peer reviewed. The handling editor was Associate Editor John P. Ney, MD, MPH.

Appendix Authors

Name	Location	Contribution
Whitley W. Aamodt, MD, MPH	Department of Neurology, Translational Center of Excellence for Neuroepidemiology and Neurology Outcomes Research, University of Pennsylvania, Philadelphia, PA	Drafting/revision of the article for content, including medical writing for content; major role in the acquisition of data; study concept or design; and analysis or interpretation of data
Allison W. Willis, MD, MS	Department of Neurology, Translational Center of Excellence for Neuroepidemiology and Neurology Outcomes Research, University of Pennsylvania, Philadelphia, PA	Drafting/revision of the article for content, including medical writing for content; analysis or interpretation of data
Nabila Dahodwala, MD, MS	Department of Neurology, Translational Center of Excellence for Neuroepidemiology and Neurology Outcomes Research, University of Pennsylvania, Philadelphia, PA	Drafting/revision of the article for content, including medical writing for content; study concept or design; and analysis or interpretation of data

References

1. Institute of Medicine (US). Committee on understanding and eliminating racial and ethnic disparities in health care. In: Smedley BD, Stith AY, Nelson AR, editors. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. National Academies Press (US); 2003.
2. Isaac LA, Laveist TA. *Defining Health and Health Care Disparities and Examining Disparities across the Life Span*. John Wiley & Sons, Inc; 2013.
3. Bhopal R. Glossary of terms relating to ethnicity and race: for reflection and debate. *J Epidemiol Community Health*. 2004;58(6):441-445. doi:10.1136/jech.2003.013466
4. Hall WJ, Chapman MV, Lee KM, et al. Implicit racial/ethnic bias among health care professionals and its influence on health care outcomes: a systematic review. *Am J Public Health*. 2015;105(12):e60-e76. doi:10.2105/AJPH.2015.302903
5. Bailey M, Anderson S, Hall DA. Parkinson's disease in African Americans: a review of the current literature. *J Parkinson's Dis*. 2020;10(3):831-841. doi:10.3233/JPD-191823
6. Schoenberg BS, Anderson DW, Haerer AF. Prevalence of Parkinson's disease in the biracial population of Copiah County, Mississippi. *Neurology*. 1985;35(6):841-845. doi:10.1212/wnl.35.6.841
7. Romero-Gutiérrez E, Vázquez-Cárdenas P, Moreno-Macías H, Salas-Pacheco J, Tusié-Luna T, Arias-Carrión O. Differences in MTHFR and LRRK2 variant's association with sporadic Parkinson's disease in Mexican Mestizos correlated to Native American ancestry. *Npj Parkinson's Dis*. 2021;7(1):13. doi:10.1038/s41531-021-00157-y
8. Abbas MM, Xu Z, Tan LCS. Epidemiology of Parkinson's disease-east versus west. *Mov Disord Clin Pract*. 2018;5(1):14-28. doi:10.1002/mdc3.12568
9. Gao X, Simon KC, Han J, Schwarzschild MA, Ascherio A. Genetic determinants of hair color and Parkinson's disease risk. *Ann Neurol*. 2009;65(1):76-82. doi:10.1002/ana.21535
10. Tanner CM, Ottman R, Goldman SM, et al. Parkinson disease in twins: an etiologic study. *JAMA* 1999;281(4):341-346. doi:10.1001/jama.281.4.341
11. Denson MA, Wszolek ZK. Familial parkinsonism: our experience and review. *Parkinsonism Relat Disord* 1995;1(1):35-46. doi:10.1016/1353-8020(95)00010-4
12. Alcalay RN, Caccappolo E, Mejia-Santana H, et al. Frequency of known mutations in early-onset Parkinson disease: implication for genetic counseling: the consortium on risk for early onset Parkinson disease study. *Arch Neurol*. 2010;67(9):1116-1122. doi:10.1001/archneurol.2010.194
13. Yonova-Doing E, Atadzhanov M, Quadri M, et al. Analysis of LRRK2, SNCA, Parkin, PINK1, and DJ-1 in Zambian patients with Parkinson's disease. *Parkinsonism Relat Disord*. 2012;18(5):567-571. doi:10.1016/j.parkreldis.2012.02.018
14. Schoenberg BS, Osuntokun BO, G Adeuja AO, et al. Comparison of the prevalence of Parkinson's disease in black populations in the rural United States and in rural Nigeria: door-to-door community studies. *Neurology*. 1988;38(4):645-646. doi:10.1212/wnl.38.4.645
15. Morens DM, Davis JW, Grandinetti A, Ross GW, Popper JS, White LR. Epidemiologic observations on Parkinson's disease: incidence and mortality in a prospective study of middle-aged men. *Neurology*. 1996;46(4):1044-1050. doi. 10.1212/wnl.46.4.1044
16. Bellou V, Belbasis L, Tzoulaki I, Evangelou E, Ioannidis JPA. Environmental risk factors and Parkinson's disease: an umbrella review of meta-analyses. *Parkinsonism Relat Disord*. 2016;23:1-9. doi:10.1016/j.parkreldis.2015.12.008
17. Kamel F, Tanner C, Umbach D, et al. Pesticide exposure and self-reported Parkinson's disease in the agricultural health study. *Am J Epidemiol* 2006;165(4):364-374. doi:10.1093/aje/kwk024

18. Goodwin GF *"Black and White in Vietnam"*. The New York Times; 2017. ISSN 0362-4331. Retrieved 2021-11-23.
19. *Disabilities That Are Proximately Due to, or Aggravated by, Service-Connected Disease or Injury*, D.O.V. Affairs; 1979, Amended 2001, 2006, 2013.
20. Dahodwala N, Karlawish J, Siderowf A, Duda JE, Mandell DS. Delayed Parkinson's disease diagnosis among African-Americans: the role of reporting of disability. *Neuroepidemiology*. 2011;36(3):150-154. doi:10.1159/000324935
21. Seltzer B, Vasterling JJ, Mathias CW, Brennan A. Clinical and neuropsychological correlates of impaired awareness of deficits in Alzheimer disease and Parkinson disease: a comparative study. *Neuropsychiatry Neuropsychol Behav Neurol.* 2001;14(2):122-129.
22. Pan S, Stutzbach J, Reichwein S, Lee BK, Dahodwala N. Knowledge and attitudes about Parkinson's disease among a diverse group of older adults. *J Cross-cult Gerontol.* 2014;29(3):339-352. doi:10.1007/s10823-014-9233-x
23. Dong J, Pinto JM, Guo X, et al. The prevalence of anosmia and associated factors among U.S. Black and white older adults. *J Gerontol Ser A*. 2017;72(8):1080-1086. doi:10.1093/gerona/glx081
24. Chen H, Shrestha S, Huang X, et al. Olfaction and incident Parkinson disease in US white and black older adults. *Neurology*. 2017;89(14):1441-1447. doi:10.1212/WNL.0000000000004382
25. Bailey M, Anderson S, Stebbins G, et al. Comparison of motor, non-motor, and quality of life phenotype in Black and White patients with Parkinson's disease. *Parkinsonism Relat Disord.* 2022;96:18-21. doi:10.1016/j.parkreldis.2022.01.018
26. Dahodwala N, Xie M, Noll E, Siderowf A, Mandell DS. Treatment disparities in Parkinson's disease. *Ann Neurol.* 2009;66(2):142-145. doi:10.1002/ana.21774
27. Dahodwala N, Willis AW, Li P, Doshi JA. Prevalence and correlates of anti-Parkinson drug use in a nationally representative sample. *Mov Disord Clin Pract.* 2017;4(3):335-341. doi:10.1002/mdc3.12422
28. Fullard ME, Thibault DP, Hill A, et al. Utilization of rehabilitation therapy services in Parkinson disease in the United States. *Neurology*. 2017;89(11):1162-1169. doi:10.1212/WNL.0000000000004355
29. Willis AW, Schootman M, Kung N, Wang XY, Perlmutter JS, Racette BA. Disparities in deep brain stimulation surgery among insured elders with Parkinson disease. *Neurology*. 2014;82(2):163-171. doi:10.1212/WNL.0000000000000017
30. Willis AW, Schootman M, Evanoff BA, Perlmutter JS, Racette BA. Neurologist care in Parkinson disease: a utilization, outcomes, and survival study. *Neurology*. 2011;77(9):851-857. doi:10.1212/WNL.0b013e31822c9123
31. Mantri S, Fullard M, Gray SL, et al. Patterns of dementia treatment and frank prescribing errors in older adults with Parkinson disease. *JAMA Neurol.* 2019;76(1):41-49. doi:10.1001/jamaneurol.2018.2820
32. Cheng EM, Siderowf AD, Swarztrauber K, et al. Disparities of care in veterans with Parkinson's disease. *Parkinsonism Relat Disord.* 2008;14(1):8-14. doi:10.1016/j.parkreldis.2007.05.001
33. Beck CA, Beran DB, Biglan KM, et al. National randomized controlled trial of virtual house calls for Parkinson disease. *Neurology*. 2017;89(11):1152-1161. doi:10.1212/WNL.0000000000004357
34. Bose S, Dun C, Zhang GQ, Walsh C, Makary MA, Hicks CW. Medicare beneficiaries in disadvantaged neighborhoods increased telemedicine use during the COVID-19 pandemic. *Health Aff* 2022;41(5):635-642. doi:10.1377/hlthaff.2021.01706
35. Schneider MG, Swearingen CJ, Shulman LM, Ye J, Baumgarten M, Tilley BC. Minority enrollment in Parkinson's disease clinical trials. *Parkinsonism Relat Disord.* 2009;15(4):258-262. doi:10.1016/j.parkreldis.2008.06.005
36. Di Luca DG, Sambursky JA, Margolesky J, et al. Minority enrollment in Parkinson's disease clinical trials: meta-analysis and systematic review of studies evaluating treatment of neuropsychiatric symptoms. *J Parkinson's Dis.* 2020;10(4):1709-1716. doi:10.3233/JPD-202045
37. Wendler D, Kington R, Madans J, et al. Are racial and ethnic minorities less willing to participate in health research? *Plos Med* 2005;3(2):e19. doi:10.1371/journal.pmed.0030019
38. Tilley BC, Mainous AG, Elm JJ, et al. A randomized recruitment intervention trial in Parkinson's disease to increase participant diversity: early stopping for lack of efficacy. *Clin Trials*. 2012;9(2):188-197. doi:10.1177/1740774512436881
39. Berk S, Greco BL, Biglan K, et al. Increasing efficiency of recruitment in early Parkinson's disease trials: a case study examination of the STEADY-PD III trial. *J Parkinson's Dis.* 2017;7(4):685-693. doi:10.3233/JPD-171199
40. *The Michael J. Fox Foundation and Massachusetts General Hospital Announce Initiative to Engage Underrepresented Populations in Parkinson's Research*. Updated October 9, 2019. [Cited 2021 August 8]; Available from: Www.Michaeljfox.Org/Publication/Michael-j-Fox-Foundation-and-Massachusetts-General-Hospital-Announce-Initiative-Engage.
41. Ojukwu DI, Andruska KM, Halpern CH. Lessons from george floyd: racial inequalities in the treatment of Parkinson's disease. *Mov Disord.* 2021;36(3):599-603. doi:10.1002/mds.28388
42. Saadi A, Himmelstein DU, Woolhandler S, Mejia NI. Racial disparities in neurologic health care access and utilization in the United States. *Neurology*. 2017;88(24):2268-2275. doi:10.1212/WNL.0000000000004025
43. Picillo M, Kou N, Barone P, Fasano A. Recruitment strategies and patient selection in clinical trials for Parkinson's disease: going viral and keeping science and ethics at the highest standards. *Parkinsonism Relat Disord.* 2015;21(9):1041-1048. doi:10.1016/j.parkreldis.2015.07.018

How to cite this article: Aamodt WW, Willis AW, Dahodwala N. Racial and ethnic disparities in parkinson disease: a call to action. *Neurol Clin Pract.* 2023;13(2):e200138. doi:10.1212/CPJ.0000000000200138.