Addressing the nuances of racial disparities in deep brain stimulation

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There is a growing body of evidence suggesting that deep brain stimulation (DBS) is a safe and effective treatment, and it can even increase life expectancy for people with Parkinson's Disease (PD).[1] DBS treatment can, therefore, be vital for a significant proportion of the population. Promoting access to, the use of, and innovation in DBS technologies is commendable in many instances and aligns with Articles 4 and 25 of the United Nations Convention on the Rights of Persons with Disabilities, which obliges states to promote research, development, and distribution of new technologies and devices.[2] As such, understanding disparities in DBS access is essential, particularly the factors contributing to the lack of access for particular cohorts.

Sarica et al.[3] found that African American status was identified as the sole factor negatively associated with the use of DBS across all three primary indications (PD, Essential Tremor, and dystonia). These findings reflect existing disparities in diagnostic rates of PD within this population.[4] The authors propose several potential explanations for this phenomenon. They suggest that it is possible that a greater proportion of African American patients prefer to receive care from neurologists, who may have a lower tendency to suggest DBS surgery as a treatment option. However, further evidence is needed before concluding that disparities result from preferences rather than a lack of options, as many individuals from disadvantaged communities might not have access to any medical treatment, let alone expensive DBS treatments. Given racial disparities in medical school student populations, there might be less Afro-American individuals having the opportunity to train for DBS surgery. This raises a follow-up question: do African American PD patients tend to consult with African American doctors who, as it turns out, may have less opportunities for medical and consultancy training in offering DBS? Do the current disparities boil down to a structural gap in medical training?

Another question arises: Once medical doctors from underrepresented communities receive adequate training on DBS, will the potential accompanying increase in DBS procedures lead to additional burden on minorities, if limited affordable care and follow-up resources are provided post-surgery? PD is a progressive disease, ultimately resulting in the debilitation of most people with PD. Managing follow-up visits for programming is typically more challenging for people with PD and their caregivers compared to those with Essential Tremor. Emerging literature indicates that long-term DBS use (more than 25 years) for PD extends the acute stage of the disease, which can further extend the need for caregivers, potentially leading to increased caregiver burden and associated ethical tensions.[5] In the absence of proper and affordable resources for long-term care, could DBS lead to additional vulnerabilities, burden, and harms to disadvantaged minorities?

It is critical that prospective patients are provided with sufficient details on the short- and long-term risks of DBS treatment, and on the availability of resources to minimise these risks, to ensure they can give proper informed consent. While some of these potential risks are well understood, others remain difficult to comprehend and predict. Moreover, some physical and psychological harms are acute and can be minimised by adjusting the stimulation parameters, while others are more pressing and persisting. Given the disparities in DBS utilisation of African Americans, coupled with racial stigma that may prevent Black people from seeking help for behavioural disorders,[6] there could be limited knowledge on the psychological, relational, and social effects of DBS on certain populations. Thus, the question of whether or not DBS may induce post-operative personality changes[7,8] may deter prospective patients from accepting DBS treatment, especially if there is limited information on their prevalence for particular populations and on the availability of resources to mitigate or address them.

Closing the gap in DBS access is important to ensure that all people with PD and their carers maintain the best possible quality of life while navigating the disease trajectory. However, it is equally important to underscore that DBS implantation is just part of the therapy, and that access to follow-ups is also crucial, especially when undesirable psychologic sequelae arise. Collection of data on these sequelae is also crucial to provide people from minority and disadvantaged backgrounds more comprehensive information on their risks, and their options to mitigate them. Finally, the study of Sarica

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et al. should serve as a challenge not just for improving access to DBS, but also for the need to conduct further research to better understand how intersectional disadvantaged identities[9] can further lead to access disparities; how gender, racial, and other demographic disparities also manifest in clinical trials that extend the use of DBS to other conditions, such as dementia[10]; and how these disparities exist and persist at a global level.

Contributors

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Declaration of interests

None.

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References

1 Lau B, Meier N, Serra G, et al. Axial symptoms predict mortality in Parkinson's disease patients with subthalamic stimulation. *Neurology*. 2019;92(22):e2559–e2570. https://doi.org/10.1212/WNL.0000000000007562.

2 United Nations General Assembly. *A/RES/61/106*. 2006.

3 Sarica C, Conner CR, Yamamoto K, et al. Trends and disparities in deep brain stimulation utilization in the United States: a nationwide inpatient sample analysis from 1993 to 2017. *Lancet Reg Health Am*. 2023. https://doi.org/10.1016/j.lana.2023.100599.

4 Bailey M, Anderson S, Hall DA. Parkinson's disease in African Americans: a review of the current literature. *J Parkinsons Dis*. 2020;10(3):831–841.

5 Gilbert F, Lancelot M. Incoming ethical issues for deep brain stimulation: when long-term treatment leads to a "new form of disease". *J Med Ethics*. 2021;47:20–25. https://doi.org/10.1136/medethics-2019-106052.

6 Yu Y, Matlin SL, Crusto CA, Hunter B, Tebes JK. Double stigma and help-seeking barriers among Blacks with a behavioral health disorder. *Psychiatr Rehabil J*. 2022;45(2):183–191. https://doi.org/10.1037/prj0000507.

7 Gilbert F, Viaña JNM, Ineichen C. Deflating the "DBS causes personality changes" bubble. *Neuroethics*. 2021;14:1–17. https://doi.org/10.1007/s12152-018-9373-8.

8 Gilbert F, Goddard E, Viaña JMN, Carter A, Horne M. "I miss being me": phenomenological effects of deep brain stimulation. *Am J Bioethics Neurosci*. 2017;8(2):96–109. https://doi.org/10.1080/21507740.2017.1320319.

9 Wemrell M, Karlsson N, Perez Vicente R, et al. An intersectional analysis providing more precise information on inequities in self-rated health. *Int J Equity Health*. 2021;20:54. https://doi.org/10.1186/s12939-020-01368-0.

10 Viaña JNM, Vickers JC, Cook MJ, Gilbert F. Currents of memory: recent progress, translational challenges, and ethical considerations in fornix deep brain stimulation trials for Alzheimer's disease. *Neurobiol Aging*. 2017;56:202–210. https://doi.org/10.1016/j.neurobiolaging.2017.03.001.