

The Vestibular Disorders Association (VEDA) commends the NINDS for its focus on gathering information on health disparities and inequities in neurological disorders and urges you to focus on disparities in identifying individuals with vestibular disorders.

Comments provided by VEDA staff and select medical advisors, including Drs. David E. Newman-Toker, MD, PhD and Kristen K. Steenerson, MD.

1. Identify area(s) of health disparity and/or inequity (including race/ethnic, sex/sexual orientation/gender identity, regional/geographic, age, educational attainment, or socio-economic differences) in neurological disease, treatment, care, and/or service in the U.S.
 - Missed and delayed diagnosis of stroke is the #1 vascular cause of serious harms due to diagnostic error (PMID: 31535832). The highest risk for missed stroke is patients presenting with isolated dizziness and vertigo (PMID: 28356464). The risk of misdiagnosis in this patient population falls disproportionately on women, minorities, and younger patients (PMID: 28344918).
 - Areas of health disparity are vast for individuals with vestibular disorders. Little is known regarding impact of race, socioeconomic status, sexual orientation, geography, and educational attainment on vestibular disorders. This likely stems from limited access to few professionals who treat vestibular disorders.
2. Identify determinants that help explain this/these health disparities and /or inequities.
 - Clinical factors include more atypical (e.g., dizziness without weakness) or unexpected presentations (e.g., young patients with stroke) compared to older white men. Other factors include racial, gender, and age bias.
 - For most patients, they must have the time and resources to see multiple providers before finding a dedicated vestibular professional. Many patients who have been marginalized by the system cannot continue to seek medical opinions while continuing to work, provide childcare, or perform other essential duties. These patients sacrifice their needs for survival and continue to suffer invisibly. Additionally, treatment options can range from medications to physical and occupational therapies. Therapies require time off of work and free time spent at home working on exercises in order to be effective, which can be difficult for people with constrained resources.

3. Identify evidence-based research strategies, health services, policies, and other interventions that address these disparities/inequities in neurological disease, treatment, service, or care.

- Accurate and timely stroke diagnosis in patients presenting dizziness and vertigo is possible using the eye movement-based "HINTS" approach to diagnosis, which is more accurate than even MRI with diffusion weighted images (PMID: [26444396](#)).
- Evidence-based research strategies are plentiful. First steps could include comprehensive epidemiological investigations with well-known screening questionnaires gauging burden of vestibular disease in the general population as well as targeted populations regarding race, socioeconomic status, sexual orientation, geography, educational attainment etc. An example of one questionnaire is the Dizziness Handicap Inventory, which surveys burden of dizziness in terms of physical, emotional and functional impact. This survey helps to capture burden of disease, specifics of the type of burden, and is a validated tool. Comprehensive epidemiology helps to shed light on further areas of research such as burden of specific vestibular disorders, levels of disability associated with those specific vestibular disorders, responses to treatment, and access to treatment.

4. Identify knowledge gaps about disparities/inequities in neurological conditions.

- The relative contribution of clinical factors (e.g., lower prevalence of stroke) vs. race/gender/age bias in determining disparities is unknown.
- Disparities and inequities in vestibular conditions are numerous in my expert opinion, though data is lacking. Few studies have been completed to address this question. What is known is that the general population experience dizziness and vertigo frequently, that physicians feel under-equipped to fully address patient's dizzy symptoms, that specialists wait-lists are long, diagnostic testing can be over-utilized with little impact on outcomes of patients and that helpful treatments such as physical and psychotherapies are poorly accessible. The systematic reviews completed to highlight these conclusions do not capture the underlying inequities and disparities within vulnerable populations. Additionally, most of these studies are completed outside of the United States.

5. Identify potential approaches for addressing these neurological disparities and/or inequities through ongoing or new research collaborations or interventions.

- Rapid diagnosis leading to prompt, effective therapies can be achieved through the use of remote, device-enhanced tele-consultation and has shown

early benefits (Gold, et al., 2019). Large-scale clinical trials of this approach are needed to determine their efficacy in reducing missed stroke, harms from missed stroke, and the health disparities associated with diagnostic error.

- Gold D, Peterson S, McClenney A, Tourkevich R, Brune A, Choi W, et al. Diagnostic impact of a device-enabled remote "Tele-Dizzy" consultation service [abstract]. Diagnostic Error in Medicine, 12th Annual Conference (Washington, DC). November 10-13, 2019
- Ideally, epidemiological studies of first general then specific populations using validated questionnaires would be completed in the United States. Epidemiological studies would then allow for more targeted studies to better understand which populations are at highest risk for certain conditions, for misdiagnosis, for poor access to treatment. This invaluable information would pave the way for creating treatment and access plans to help reduce the burden and chronicity of vestibular disorders as well as greatly advance our understanding of this emerging neurological science.

6. Additional comments

- Vestibular disorders refer to the connections between inner ear and brain balance centers that have been affected by specific pathologies resulting in impairment. Vestibular and balance conditions are under-diagnosed, poorly understood and disproportionately debilitating compared to similarly prevalent conditions. The conditions are for the most part benign in terms of mortality, but are generally chronic conditions that can render the affected disabled and debilitated. These conditions are generally "invisible," making their medical diagnosis, public recognition and therapeutic advances exceedingly difficult to make.