







Estimated prevalence of underdiagnosed dementia in a multiethnic community-based study

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ABSTRACT

Dementia frequently goes undetected in community settings, particularly among socially disadvantaged populations. Here, we estimated the prevalence of underdiagnosed dementia across diverse sociodemographic determinants of health in the Health and Aging Brain Study–Health Disparities (HABS-HD), a community-based cohort of adults recruited through community outreach in Fort Worth, Texas. We estimated age-specific probabilities of underdiagnosis using Poisson regression models with a log link, including age and sex as covariates. Robust (sandwich) variance estimators were used to obtain standard errors and 95% confidence intervals (CI). Group differences or trends for continuous measures were assessed using robust variance estimates. The prevalence of underdiagnosed dementia was higher among individuals without physician access (98.1% vs. 78.1%, $p < .0001$), non-English speakers (97.9% vs. 76.8%, $p < .0001$), and the uninsured (91.5% vs. 79.5%, $p = .03$). Black and Hispanic participants also showed higher prevalence (85.8% and 90.9%) compared to non-Hispanic White participants (64.9%; $p = .02$ and $p = .002$, respectively). Each additional year of education was associated with a 2.5% lower risk of underdiagnosis ($p < .0001$). No differences were observed by sex, marital status, income or social support. Our results highlight that several sociodemographic factors contribute to the likelihood of living with undiagnosed dementia.

1. Introduction

Dementia often goes undetected in community settings, and emerging evidence suggests this may disproportionately affect socially disadvantaged populations, including those from lower socioeconomic groups, with limited healthcare access, and marginalized racial or ethnic backgrounds [1,2]. Underdiagnosis can delay treatment, reduce access to services, and exacerbate disparities in outcomes [3]. Here, we estimated the prevalence of underdiagnosed dementia in a diverse, community-based cohort across various sociodemographic

determinants of health.

2. Methods

2.1. Participants

The Health & Aging Brain Study – Health Disparities (HABS-HD) study is a single-site community-based study of aging and dementia conducted at the University of North Texas Health Science Center in Fort Worth, Texas. Participants are recruited from the community, without a

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specific focus on individuals with cognitive decline, representing a diverse range of cognitive function. Inclusion criteria for the study required participants to be aged 50 years or older, self-identify as Hispanic, non-Hispanic White or Black, be able to provide a reliable informant, be fluent in English or Spanish and be able to complete all study procedures. Exclusion criteria included a history of type 1 diabetes, current urinary tract infection or uncontrolled inflammatory conditions, a cancer diagnosis or chemotherapy/radiation treatment in the past 12 months, active mental illness affecting cognition (except depression or anxiety), recent traumatic brain injury with loss of consciousness, current alcohol or substance abuse, severe medical conditions that could impact cognition, or any condition/device preventing MRI or PET scanning [4]. For the current analysis, 3838 participants completed a baseline visit, of whom 2974 had available medical history regarding prior dementia diagnoses. Among these, 2839 participants had complete demographic assessments. From this subset, 170 participants met criteria for dementia based on our study assessment. Ethnicity and race are self-identified, and participants may choose to receive their interview either in English or Spanish. The HABS-HD study was approved by the Institutional Review Board University of North Texas Health Science Center. All participants or their caregivers provided informed written consent to participate in the study.

2.2. Clinical assessment

The main outcome of this cross-sectional study was all-cause dementia, including Alzheimer's disease, vascular dementia, and mixed dementia, following standardized criteria used in Alzheimer's disease studies and clinical practice, as described elsewhere [4]. Cognitive impairment not meeting criteria for dementia was not included as an outcome. Briefly, clinical diagnoses were determined using an algorithm combining Clinical Dementia Rating scores, test performance and expert review, with neuropsychologist input for any discrepancies. Medical records, registries, or electronic health records were not available; therefore, prior diagnoses were determined solely based on participant self-report. Participants were asked whether a physician had ever diagnosed them with dementia. Underdiagnosed dementia was defined as participants who met the cognitive criteria for dementia based on the study assessment but had not received a prior clinical diagnosis.

2.3. Sociodemographic categories

Participants were characterized across multiple sociodemographic categories, including gender, race/ethnicity, primary language, marital status, educational level, insurance status, income, social support and access to a physician. Gender, marital status and ethnicity were self-reported. Primary language was categorized as English versus non-English, based on participants' self-reported languages (i.e., participants classified as non-English speakers reported that they did not speak English at all). Educational level was measured as total years of formal education completed. Insurance status was derived from multiple HABS-HD variables, including Medicaid, Medicare, other public insurance, private insurance, or no insurance. Participants reporting any form of coverage were classified as insured, while those reporting no coverage were classified as uninsured. Access to a physician was defined based on participants' self-report of having a regular healthcare provider. Income was the self-reported current total annual household income. Finally, social support was assessed using a validated questionnaire measuring the functional components of support [5]. Higher scores on this scale indicate greater social support.

2.4. Statistical methods

This study was designed as a descriptive, prevalence-focused analysis rather than a prediction-oriented modeling study. By quantifying the population burden of underdiagnosed dementia and identifying groups

disproportionately affected, this approach provides insights into diagnostic disparities that are directly relevant for public health and clinical planning, even without generating individual-level predictions. First, we calculated the proportion of participants who were accurately diagnosed versus those with underdiagnosed dementia across different socio-demographic categories. We then estimated age-specific probabilities of underdiagnosis using Poisson regression models with a log link, adjusting for age and sex and separately including each demographic or social factor. Age and sex were included as baseline covariates, while the sociodemographic factors were examined in separate models rather than simultaneously, in order to avoid overfitting and maintain precision given the modest sample size. For continuous measures (i.e., years of education, social support score, income), predicted probabilities were calculated across the observed range of each variable while holding age and sex at reference or mean values. Robust (sandwich) variance estimators were used to obtain standard errors and 95 % confidence intervals (CI). Normality of continuous predictors was assessed using the Shapiro–Wilk test and was not met for any variable (all $p < .0001$). Predicted probabilities and their corresponding CIs were derived using the delta method. Group differences or trends for continuous measures were assessed using robust variance estimates. To assess the robustness of our findings to potential unmeasured confounding, we calculated e-values for each estimated risk ratio. E-values quantify how strong an unmeasured confounder would need to be, in terms of its association with both the exposure and the outcome, to fully explain away the observed effect. All analyses were conducted using R v.2024.04.2 [6].

3. Results

This study included 170 participants (mean age: 68.7 ± 10.2 [range: 50.2–91.8], 52.4 % female) who received a diagnosis of dementia from the HABS-HD team, along with documented history of a prior dementia diagnosis made by an external physician. Demographic characteristics of the sample with subgroup-specific prevalence of underdiagnosis are listed in Table 1.

Fig. 1 shows how the prevalence of underdiagnosed dementia varies with age across categorical sociodemographic and social factors, as well as continuous measures including education, income, and social support, in this community-based cohort. The estimated prevalence of underdiagnosed dementia was 98.1 % (95 % CI: 65.8 % – 100 %) for those without access to a physician, compared to 78.1 % (95 % CI: 64.9 % – 94.0 %) for those with access ($p < .0001$; Fig. 1E). Among non-English speakers, prevalence was 97.9 % (95 % CI: 69.8 % – 100 %), significantly higher than the 76.8 % (95 % CI: 63.4 % – 93.1 %) observed in English speakers ($p < .0001$; Fig. 1G). By insurance status, prevalence was 79.5 % (95 % CI: 66.3 % – 95.4 %) among insured individuals versus 91.5 % (95 % CI: 58.0 % – 100 %) among the uninsured ($p = .04$; Fig. 1H). Racial disparities were observed, with Black participants showing a prevalence of 85.8 % (95 % CI: 63.2 % – 100 %) and Hispanic participants 90.9 % (95 % CI: 70.7 % – 100 %), both significantly higher than Non-Hispanic White participants at 64.9 % (95 % CI: 46.5 % – 90.7 %) ($p = .02$ and $p = .002$, respectively; Fig. 1F). No significant differences were detected by sex or marital status. Overall, the prevalence of underdiagnosed dementia declined as age increased.

For continuous measures, we examined the associations of education, income, and social support with underdiagnosis, adjusting for age and sex. For education, each additional year of education was associated with a 2.5 % lower risk of underdiagnosis (RR = 0.975, 95 % CI: 0.964–0.987, $p < .001$). There was a trend toward lower underdiagnosis with higher income, but it was not statistically significant (RR per \$10,000 increase = 0.985, 95 % CI: 0.962–1.007, $p = .18$). There was no significant association between social support and underdiagnosis (RR per 1-point increase = 1.006, 95 % CI: 0.995–1.016, $p = .30$).

We quantified the robustness of the observed associations to potential unmeasured confounding using e-values. Speaking English versus not speaking English had an e-value of 1.86 for the point estimate (CI e-

Table 1
Demographic and clinical characteristics of the study cohort, with subgroup-specific prevalence of underdiagnosis.

| | Accurately diagnosed n = 32 | Underdiagnosed n = 138 | All n = 170 |
|---------------------------------|--------------------------------|---------------------------|-----------------|
| Age, mean (SD), y | 71.3 (9.76) | 68.1 (10.3) | 68.7 (10.2) |
| Sex, no. (%) | | | |
| Female | 19 (21.3) | 70 (78.7) | 89 |
| Male | 13 (16.0) | 68 (84.0) | 81 |
| Ethnicity, no. (%) | | | |
| Black | 7 (14.3) | 42 (85.7) | 49 |
| Non-Hispanic White | 19 (35.2) | 35 (64.8) | 54 |
| Hispanic White | 6 (9.0) | 61 (91.0) | 67 |
| Education, mean (SD), y | 13.9 (3.09) | 10.9 (4.87) | 11.5 (4.73) |
| CDR SoB, mean (SD) | 6.63 (3.00) | 3.65 (2.28) | 4.21 (2.69) |
| MMSE, mean (SD) | 20.6 (6.85) | 22.6 (5.06) | 22.2 (5.48) |
| APOE ε4 allele, no. (%) | | | |
| Non-carrier | 19 (19.8) | 77 (80.2) | 96 |
| Heterozygote | 7 (14.0) | 43 (86.0) | 50 |
| Homozygote | 3 (25.0) | 9 (75.0) | 12 |
| Missing | 3 (25.0) | 9 (75.0) | 12 |
| Language spoken, no. (%) | | | |
| English speaker | 1 (2.90) | 34 (97.1) | 35 |
| Non-english speaker | 31 (23.0) | 104 (77) | 135 |
| Marital status, no. (%) | | | |
| Married | 16 (18.4) | 71 (81.6) | 87 |
| Previously/never married | 16 (19.3) | 67 (80.7) | 83 |
| Income, mean (SD), US dollars | 46,700 (52,600) | 32,400 (45,300) | 35,100 (46,900) |
| Social support score, mean (SD) | 36.1 (8.20) | 37.5 (7.02) | 37.3 (7.25) |
| Insurance, no. (%) | | | |
| Insured | 31 (20.9) | 117 (79.1) | 148 |
| Uninsured | 1 (4.5) | 21 (95.5) | 22 |
| Access to a physician, no. (%) | | | |
| Yes | 32 (22.1) | 113 (77.9) | 145 |
| No | 0 (0) | 25 (100) | 25 |

Abbreviations: SD, standard deviation; CDR SoB, Clinical Dementia Rating – Sum of Boxes; MMSE, Mini-Mental State Examination; APOE ε4, apolipoprotein E epsilon.

value 1.55), suggesting that a moderately strong unmeasured confounder would be needed to fully explain away the association. For ethnicity, Black versus White participants had a point estimate e-value of 1.97 (CI e-value 1.28), and Hispanic versus White participants had a point estimate e-value of 2.15 (CI e-value 1.53), indicating slightly stronger robustness for these comparisons. For insurance status and access to a physician, the confidence intervals included the null, yielding CI e-values of 1.00, and point estimate e-values of 1.57 and 1.82, respectively. Education had the smallest e-values, with a point estimate of 1.19 (CI e-value 1.13). Overall, these e-values suggest that the observed associations could be explained by moderately strong unmeasured confounding.

4. Discussion

In this study, we examined the prevalence of undiagnosed dementia within a diverse, community-based cohort and explored how it relates to sociodemographic factors and social determinants of health. Our findings suggest that beyond age, several sociodemographic factors substantially contribute to the likelihood of living with undiagnosed dementia. Individuals with limited access to a physician, no health insurance, language barriers or belonging to racial and ethnic minority groups were more likely to have undiagnosed dementia, pointing to persistent gaps in detection that disproportionately affect already underserved populations. These disparities are concerning because they not only delay diagnosis but may also reduce access to essential

healthcare resources, appropriate treatment, supportive services, and interventions that can improve quality of life and slow disease progression [7], further exacerbating challenges faced by individuals living with dementia. Furthermore, undiagnosed dementia can place additional burdens on caregivers and families, particularly in communities where social support networks are limited.

These findings are consistent with prior studies reporting substantial rates of undiagnosed or delayed dementia diagnoses, particularly among individuals facing social and structural barriers to care [8]. Previous population-based studies have shown that limited healthcare access, lower socioeconomic status, and language or cultural barriers are associated with reduced likelihood of receiving a formal dementia diagnosis, even in the presence of cognitive impairment [9–11]. Our results align with this literature by reinforcing the role of access to care and social determinants in shaping diagnostic disparities. However, some variables commonly associated with undiagnosed dementia, such as gender and income, were not significant in our analyses. This may be partly due to the relatively small sample size, which limits precision and results in wider confidence intervals, making it more difficult to detect modest effects. Additionally, social determinants in our cohort are highly interrelated, so the observed variance may be largely attributed to these correlated factors rather than to gender or income alone. Consequently, non-significant findings for these variables should be interpreted cautiously, as they do not necessarily indicate a lack of effect in the broader population.

An important consideration is that these findings should be interpreted within the context of the US healthcare system. In settings with universal healthcare coverage, barriers related to insurance status and access to primary care may be less pronounced, potentially reducing some sources of underdiagnosis observed in this study. However, evidence from other countries suggests that disparities in dementia detection may still persist [12], driven by social determinants of health. Thus, while the specific contributors to underdiagnosis may differ across healthcare systems, social and structural determinants of health are likely to remain important influences on dementia recognition. Future studies conducted in non-US settings will be essential to determine how healthcare system organization modifies these associations and to identify context-specific strategies to improve equitable dementia diagnosis.

In addition, several emerging health-related factors such as visual impairment, resting heart rate, and social isolation have been increasingly linked to dementia risk [13–17]. Future research could explore whether these factors also contribute to the likelihood of living with undiagnosed dementia, potentially shaping disparities in detection alongside the sociodemographic and structural determinants examined in the present study.

Addressing these inequities will require multifaceted strategies. First, consistent with our finding that individuals with limited access to physicians were more likely to have undiagnosed dementia, particular attention should be given to improving both general access to physicians and the tools they have for efficient cognitive assessment [18]. Expanding the availability of digital cognitive assessment platforms [19] can help identify individuals at risk more rapidly and systematically, supporting primary care providers in detecting dementia early, even in busy clinical settings. Second, reflecting our finding that participants with limited English proficiency had higher rates of underdiagnosis, culturally and linguistically tailored diagnostic services could ensure that assessments are accessible and accurate for individuals from diverse backgrounds, overcoming language and cultural barriers [20]. These services may include the use of trained interpreters, translated testing materials, and culturally adapted cognitive tests that account for educational and linguistic differences. By providing assessments that are both understandable and culturally relevant, healthcare providers can more accurately detect cognitive impairment, reducing the risk of misdiagnosis or underdiagnosis among individuals who face language, cultural or educational barriers to care. Additionally, culturally sensitive

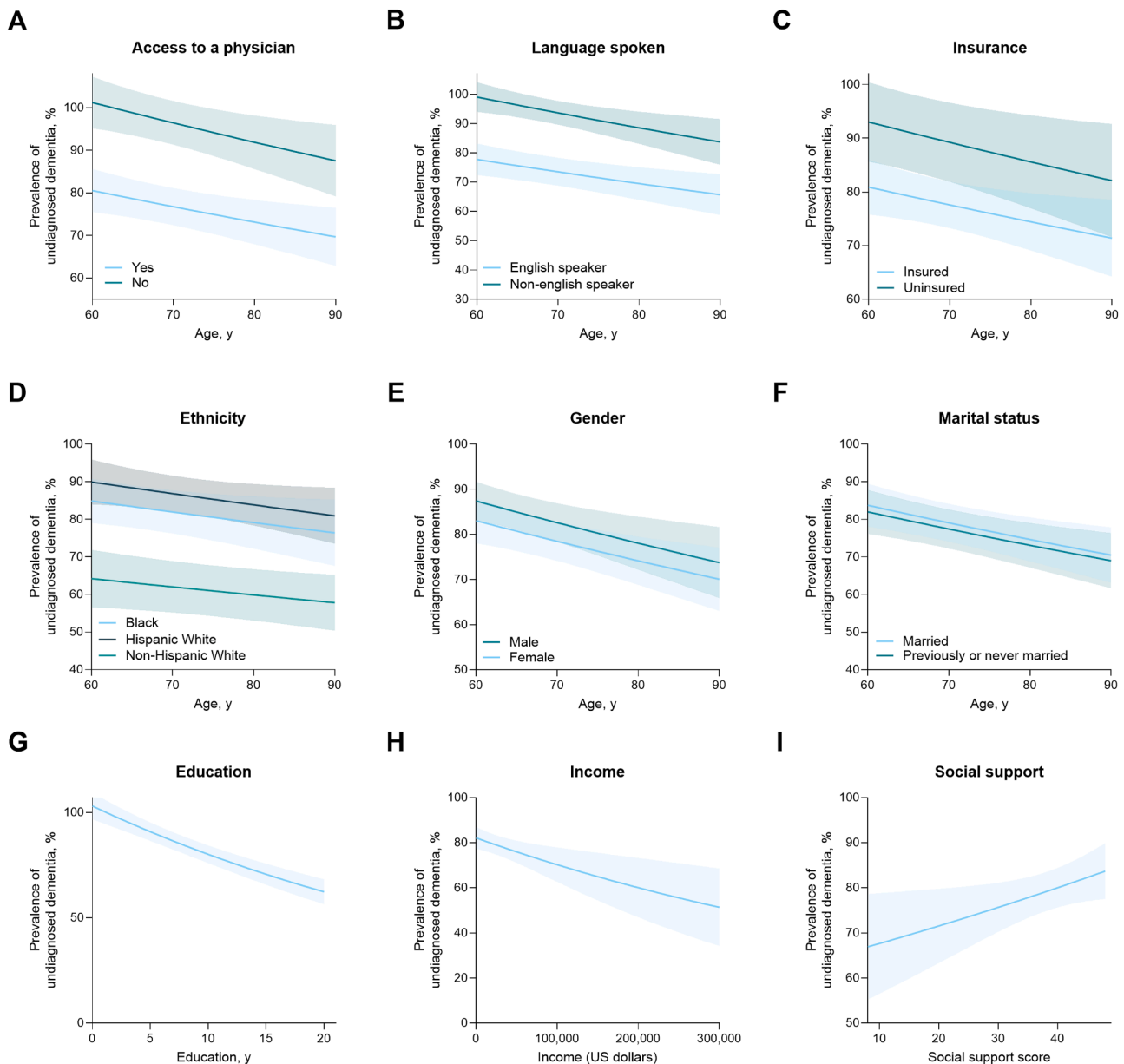


Fig. 1. Estimated prevalence of underdiagnosed cognitive impairment by age and by (A) education level, (B) gender, (C) social support, (D) income, (E) access to a physician, (F) ethnicity, (G) language spoken, (H) insurance coverage and (I) marital status, with standard errors based on the jackknife method.

services can help build trust between patients and providers, encouraging engagement with healthcare systems and facilitating timely follow-up and management. In the same line of thought, African Americans aged 64 years and older experience an estimated 27 cases of all-cause dementia per 1000 person-years, compared with 19 cases per 1000 person-years for White Americans [21,22]. Despite this higher prevalence, our findings indicate that Black individuals are disproportionately underdiagnosed. Education for healthcare providers about social determinants of health could improve recognition of at-risk populations and reduce implicit biases in diagnostic practices. Finally, in line with our observation that participants without health insurance or with limited access to physicians were more likely to be underdiagnosed, community-based outreach programs can help reach individuals who may not regularly interact with healthcare services, particularly those facing structural barriers such as limited access to physicians or lack of health insurance. These programs can raise awareness about cognitive health, provide education on the early signs of dementia, and encourage timely evaluation. By bringing screening

and resources directly into communities through local centers, faith-based organizations, or mobile clinics, outreach initiatives can help reduce gaps in diagnosis and ensure that underserved populations are connected to appropriate care and follow-up services. In summary, by implementing such measures, healthcare systems can work toward more equitable identification of dementia, ensuring that all individuals with cognitive concerns, regardless of socioeconomic status, language, or race and ethnicity, have timely access to diagnosis and appropriate support.

Several limitations should be considered when interpreting these findings. First, the study was conducted at a single site in Fort Worth, Texas, within the context of the US healthcare system, which may limit the generalizability of results to other regions or populations. Second, the sample size ($n = 170$) is relatively modest, which may reduce statistical power to detect differences for some subgroups and reduced the precision of certain prevalence estimates, as reflected by wider confidence intervals; however, the study was designed as a descriptive, prevalence-focused analysis, and the resulting estimates remain

informative for characterizing diagnostic disparities and identifying populations at higher risk of undiagnosed dementia. Third, underdiagnosis was assessed based on self-reported prior physician diagnoses, which may be subject to recall bias or misreporting. An additional consideration is that our study population was selected based on pre-defined inclusion criteria, with participants motivated to take part in research. This may introduce selection bias, meaning that the prevalence estimates of undiagnosed dementia observed in this cohort might not fully reflect rates in the broader community. As such, caution is warranted when generalizing these findings to other populations, even within the same region, and future studies with more representative samples are needed to confirm the observed patterns of disparities in dementia diagnosis. Another limitation of our study is the relatively low e-values observed across variables, which indicates that the associations are potentially sensitive to unmeasured confounding. However, this likely reflects the fact that these socioeconomic and healthcare-related factors are intrinsically related. For example, individuals who are less educated are also more likely to have lower income, reduced access to a physician, and so on. As a result, a single unmeasured confounder could plausibly influence multiple observed associations, leading to modest E-values. Nonetheless, reporting these values provides a quantitative assessment of the sensitivity of our findings to unmeasured confounding and highlights the complex, interconnected nature of these social determinants of undiagnosed dementia. Finally, although clinical assessments followed standardized protocols, cultural, linguistic, and educational factors may have influenced neuropsychological test performance, potentially affecting the classification of dementia.

Data statement

Data from the HABS-HD study can be accessed from <https://ida.loni.usc.edu>.

Disclosure

L. Trudel reports no disclosures relevant to the manuscript. J. Therriault has served as a consultant for the Neurotorium Educational Platform and as a medical writer for Alzheon Inc, both outside of the scope of the present work. A.C. Macedo, K.L. Meeker, M.N. Braskie and A.W. Toga report no disclosures relevant to the manuscript. S. Gauthier serves on scientific advisory boards for Alzheon, AmyriAD, Advantage, Eisai Canada, Enigma USA, Lilly Canada, Medesis, Lundbeck Foundation, Novo-Nordisk Canada, Okutsa, and TauRx. H. P. Vitali serves on the scientific advisory boards for NovoNordisk, Eisai, and Lilly, and received honoraria from IntelGenx Corp. S.E. O'Bryant reports no disclosures relevant to the manuscript. P. Rosa-Neto has served on scientific advisory boards and/or as a consultant for Roche, Novo Nordisk, Eisai and Cerveau Technologies, outside of the scope of the present work.

Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this work, the authors utilized ChatGPT to identify errors in R scripts. All content generated or modified with the tool was subsequently reviewed and edited by the authors, who take full responsibility for the final content of the publication.

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CRediT authorship contribution statement

Lydia Trudel: Writing – review & editing, Writing – original draft, Formal analysis, Data curation, Conceptualization. **Joseph Therriault:** Writing – review & editing, Data curation, Conceptualization. **Arthur C. Macedo:** Writing – review & editing. **Meredith N. Braskie:** Writing – review & editing, Data curation. **Karin L. Meeker:** Writing – review & editing, Data curation. **Arthur W. Toga:** Writing – review & editing, Data curation. **Serge Gauthier:** Writing – review & editing, Supervision. **Paolo Vitali:** Writing – review & editing, Supervision. **Sid E. O'Bryant:** Writing – review & editing, Supervision, Project administration, Investigation, Funding acquisition. **Pedro Rosa-Neto:** Writing – review & editing, Supervision, Funding acquisition.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

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