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Descriptive epidemiology of dementia in the US

Using routine data to uncover underlying trends presents challenges

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Population estimates of dementia have, in recent decades, become of national interest to policy makers, politicians and the wider community. In a linked study (doi:10.1136/bmj-2024-083034), Blass and colleagues report estimates of the incidence and prevalence of dementia in the US Medicare fee-for-service health insurance system for people aged 66 years and over.[1] Consistent with findings from cross-generational cohort studies,[2 3] they found that age standardised incidence of dementia declined from 3.5% in 2015 to 2.8% in 2021 and prevalence increased from 10.5% to 11.8% owing to population ageing. Clear differences existed between subgroups by race/ethnicity and deprivation, but interpreting these differences is not simple using this dataset alone.

Studies that rely on routine data have both strengths and limitations. These include the nature, availability, and configuration of services, who accesses them and how, and how these are recorded, as well as how all can vary across time and between specific communities. This can drive numbers in different directions. The study is based on Medicare fee-for-service claims and does not include Medicare Advantage plans. Medicare Advantage and fee-for-service are two distinct types of Medicare coverage, differing in their structure, benefits, costs to beneficiaries, quality metrics, and healthcare utilisation patterns and in the demographics, socioeconomic status, and health profiles of their enrollees.[4-7] Non-uniform enrolment and retention of beneficiaries in Medicare fee-for-service by income, race/ethnicity, and underlying health conditions make interpretation of the findings less than straightforward. At face value, the narrowing gap in incidence of dementia by race/ethnicity may suggest that inequalities are decreasing. Contrarily, it could be driven, wholly or in part, by growing disparities in access to healthcare. By 2021, 43% of Medicare beneficiaries, up from 31% in 2015, had enrolled in or switched to Medicare Advantage. People who switched were more likely to be from Hispanic or black minorities and to be in the lower strata of income and education within those groups.[4-7] Compared with their white counterparts, black and Hispanic Medicare Advantage beneficiaries had fourfold to fivefold higher rates of enrolment in special needs plans, indicating severe chronic disease or institutional care.[4] These disparities suggest that black and Hispanic beneficiaries who were at higher risk of dementia were more likely to opt out of fee-for-service during the study period. This shift may account for, or overestimate, the narrowing gap in dementia incidence by race/ethnicity. Hispanic beneficiaries had the highest and fastest growing enrolment in Medicare Advantage and special needs plans,[4-7] which might explain the lower incidence of dementia in those of them who remained with fee-for-service compared with their white counterparts in 2021.

As the marginalised minorities are under-represented in Medicare fee-for-service, true inequalities by area deprivation index are likely to be larger than those reported. Better health monitoring, greater awareness, and diagnosis at an earlier stage could also drive numbers up for the more advantaged groups, further masking socioeconomic inequalities. The geographical variation in estimates of incidence/prevalence is likewise compounded by factors such as regional clustering of the under-represented groups[4 5] and differences in access, quality of care, and attitudes towards diagnosis and treatment. Without accounting for these factors, estimates derived from routine data and insurance claims cannot be taken at face value. Even then, uncovering the true underlying trends is not easy. In addition to the challenges mentioned above, the covid-19 pandemic affected survival and life expectancy and could drive estimates down. Although the decline in age standardised incidence is consistent with other reports, the magnitudes are less reliable for population level estimates. Further sensitivity analyses could explore such questions.

An important policy implication is to ensure that under-representation of marginalised groups in data does not create blind spots that lead to further marginalisation in provision of services for those in greatest need. Dementia estimates have been reported in a range of data sources,[2 3] including routine data, geographically representative cohorts, volunteer cohorts, and national panels such as the Health and Retirement Study. Numbers of people estimated to be living with dementia are now sensitive metrics. Estimates are used globally or nationally for forward planning in almost every proposal for research funding from policy to molecule and to justify investment into the search for a range of potential benefits—from upstream prevention, risk reduction, and effective treatments for proposed underlying causes, to symptomatic approaches, carer research, and later stage support and care. This study highlights a further need. Routine data are subject to diagnostic fashions. Robust descriptive dementia epidemiology requires sustained attention to how we estimate dementia in ageing populations, anchoring through population representative studies and deep dives into unrepresented populations. Comparisons across time must be made using stable methods, along with understanding changes in the biological underpinning of expressed dementia (including protective factors).

The implications of the findings added to those already published, for the US and beyond, are clear. Decline in the occurrence of dementia is not experienced universally. Disadvantage matters, and the need to tackle life course inequalities and inequities for ethnic minorities and socially deprived communities is vital. All the risk factors identified in the Lancet Commission are associated with clustering in such communities.[8] The findings highlight not just the need for improvement in services for people living with dementia in communities where higher incidence and prevalence might be expected, but also the need to implement policies for improvement in risk factor profiles across populations from early life onwards. Politicians and many others are calling for early detection without clear evidence of benefit. Reducing life course inequalities is probably the greatest intervention that any society can do to push morbidity from its risk factors and the syndromal presentation back as close to late life death as possible.

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