Do age-standardised dementia incidence rates really increase in England and Wales?

Yuntao Chen and colleagues analysed data from the English Longitudinal Study of Ageing (ELSA) across 2002–2018, revealing a U-shaped trend in dementia occurrence.[1] Their findings indicate that age-specific dementia rates initially declined from 2002, and began to rise around 2008. However, a commentary by Nichols and Lee raised the possibility that the upward trend might be due to methodological issues.[2]

Given the substantial societal implications, especially for care services, it is essential that we gain a better understanding of these time trends. An increase in age-standardised incidence rates would exacerbate the public health challenges arising from population ageing. Projections based on the upward trend suggest that by 2040, the number of people with dementia in England and Wales could be 40% higher than previously estimated.[1]

Chen and colleagues used an algorithmic dementia diagnosis developed by Ahmadi-Abhari (the first author of this Correspondence) and colleagues.[3] Dementia was ascertained on the basis of the following three criteria: an impairment in cognitive function, characterised by low scores in at least two of the three cognitive domains tested, coupled with functional impairment (cases of transient cognitive or functional impairments were excluded from the definition); a doctor diagnosis of dementia; or cognitive decline reported by an informant.[4] To estimate trends in age-standardised incidence, Chen and colleagues used seven subcohorts with 4 years of follow-up from waves 1 to 3 (years 2002–06) to waves 7 to 9 (2014–18).[1]

One concern is that the tests used to measure cognitive function in ELSA were not exactly the same throughout the study period.[2,5] Unlike in other waves, the verbal fluency test was not in the 2012 battery. Chen and colleagues imputed the missing test score using information from the 2010 and 2014 assessments for the participants with available data. This approach might not entirely mitigate bias because individuals with cognitive decline are less likely to continue participating in the study compared with those who do not have cognitive decline. The absence of the verbal fluency test could therefore lead to an underestimation of dementia incidence in the 2008–12 and 2010–14 subcohorts, but an overestimation in the 2012–16 subcohorts.

Another potential source of bias arises from wave 9 in 2018, which marks the final data collection point available in ELSA. Due to the absence of subsequent data, individuals with transient cognitive and functional impairments cannot be identified and excluded from dementia cases at this wave. Consequently, this could lead to an overestimation of incident dementia in the 2014–18 subcohort.

Taken together, these potential biases, resulting in an underestimation of dementia incidence around 2012 and an overestimation in the subsequent years, could create a spurious U-shaped calendar trend.

To mitigate these drawbacks, one approach is to exclude data from 2012 and 2018 and switch to 2-year follow-up periods instead of 4-year intervals. This analysis, relying on consistent dementia assessments, shows a declining dementia trend without reversal (appendix figure A), which persists after excluding doctor-diagnosed dementia from the case definition (appendix figure B).

Doctor diagnosis of dementia is influenced by evolving diagnostic practices. If the reported upward trend in dementia incidence were accurate, we would anticipate a more substantial increase in doctor-diagnosed cases compared with algorithmic definitions. However, what we observe is a mildly rising trend over time, consistent with a combined effect of non-increasing dementia incidence and improved diagnostic practices (appendix figure B).

Another approach to administer a fully consistent definition is to rely solely on the tests for two cognitive domains available across all ELSA waves (memory and orientation to time, coupled with functional impairment) and informant data. Although this results in a less comprehensive dementia definition, it enables us to use data from all ELSA waves. Also, with this approach we found no evidence of an upward trend in dementia incidence since 2008 (appendix figure A).

Finally, we assessed whether our analyses replicate Chen and colleagues' results on a U-shape trend when using inconsistent dementia definitions. It appears that this is indeed the case, supporting the validity of our findings (appendix figure C).

In summary, the inconsistent administration of cognitive tests in ELSA could explain the observed upward trend suggested by Chen and colleagues. According to analyses based on a consistent dementia definition, dementia incidence followed a more favourable trend in England and Wales.

Further research is needed to fully explore the nature of changes in dementia incidence in the UK and elsewhere, based on multiple data sources and approaches. The number of people with dementia increases globally as the elderly population grows.[6] If age-standardised incidence rates are also on the rise, the growth in the number of dementia cases will exceed expectations driven by population ageing. Conversely, if age-standardised incidence rates decline, the increase will be less pronounced.

See Online for appendix

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