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MEDIA RELEASE

BRINGING ETHNIC DIVERSITY TO DEMENTIA RESEARCH

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THE current body of research on dementia does not reflect the ethnic and cultural diversity of the Australian population, leaving people from culturally and linguistically diverse (CALD) backgrounds receiving inequitable dementia care, according to the authors of a Perspective published today by the Medical Journal of Australia.

The authors, led by Lee-Fay Low, Associate Professor in Ageing and Health at the University of Sydney, found in their searches of Australian dementia research that CALD people were under-represented.

“Of the 15 published dementia clinical trials published between 2016 and 2018, two studies reported that 33.3% and 31.6% of participants were from non-Australian backgrounds, and three studies reported that 7.1%, 12.5% and 57.0% of participants spoke English as a second language. The remaining ten studies did not report ethnicity-related data,” they wrote.

“We also searched the Australian New Zealand Clinical Trials Registry and ClinicalTrials.gov and found that 42 of the 94 currently registered active dementia clinical trials in Australia (44.7%) excluded patients not fluent in English. A systematic review of 96 international randomised controlled clinical trials to improve cognition related to dementia (total of 37 278 participants) found that of the 39 trials (39.4%) reporting ethnicity, pooled data showed that only 11.4% (95% CI, 7.5–15.9%) of participants were non-Caucasian.”

Low and colleagues wrote that Australian dementia research was contributing to international gains in early detection and lifestyle-related risk reductions, through initiatives such as the Australian Imaging, Biomarkers and Lifestyle (AIBL) prospective risk identification study with over 1000 participants, the Maintain Your Brain online dementia risk-reduction trial with a target of 8500 participants, and the Australian Dementia Network (ADNeT) dementia registry and memory clinic network.

“Given that one in three older people in this country are from a CALD background, it is important that these initiatives focus on achieving ethnic or cultural diversities in their samples, and support the participation of people with low English proficiency,” they wrote.

“At the very least, data collected on CALD variables, such as country of birth, years lived in Australia, proficiency in English and language spoken at home, must be considered in the analyses and subsequent publications.

“We believe that across all Australian dementia research, overall CALD participation should be around 30%, proportional to the total CALD population in Australia of people aged 65 years and over.”

The authors proposed four strategies that may increase CALD participation in research:

- recognising diversity as a priority — grant funders should require applicants to address how they will support the inclusion of CALD populations or at least justify their exclusion;
- funding the additional costs of translation or interpreters;
- leveraging existing datasets to study ethnic and cultural differences in dementia; and
- support from academic publications in encouraging reporting of variables relating to ethnicity or culture, and ethnicity-specific analysis, where appropriate.

“Finally, we might be able to increase uptake of research opportunities by CALD participants through ensuring that research questions are relevant to them, increasing awareness of dementia, and ensuring accessibility of materials, such as cultural relevance, language and level of literacy,” Low and colleagues concluded.

“Through such strategies, Australian dementia research, and Australian medical research more broadly, can more accurately reflect the ethnic and cultural diversity of the Australian population.”

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