

COMMENTARY

Attitudinal adjustment about dementia awareness and assessment: finetuning inclusion, diversity, and measurement of behavioral and psychological symptoms

Ban Ki-moon, the former secretary general of the United Nations, stated “Migration is an expression of the human aspiration for dignity, safety, and a better future. It is part of the social fabric, part of our very make-up as a human family.” Indeed, people migrate globally for many reasons, both positive and negative. Some move to a new country for better economic or educational prospects, or to reunite with family; others relocate (willingly or forcibly) to escape poverty, armed conflict/violence, religious and/or political oppression, or persecution. Irrespective of the reasons, immigrants are subjected to multiple acculturation stressors from difficult adjustments to a new country, loss of family supports, socioeconomic hardship, and experiences of discrimination (Sternberg *et al.*, 2016), all exacerbated by language and cultural barriers (Ding and Hargraves, 2009).

Migration can also interface with dementia, which is a growing concern worldwide with an expected increase in prevalence from 55 million (2021) to 78 million by 2030 to 152 million by 2050. Notably, six out of 10 persons with dementia worldwide currently live in low-and middle-income countries (LMICs) (Livingston *et al.*, 2020). However, current estimates suggest that approximately $\frac{3}{4}$ of individuals with dementia are undiagnosed, and this number may be higher for LMICs (Gauthier *et al.*, 2021). While these countries already face major social, economic, and healthcare problems, dementia is an additional and critical issue in the national and regional agendas of LMICs, posing challenges with respect to diagnosis, prognosis, care programs, and prevention (Mattap *et al.*, 2022). Adaptations of international initiatives that have proven cost-effective, in addition to development of local solutions, are strategies that can be implemented in these countries to respond to the burgeoning concern around dementia. These approaches require dedicated resources, established infrastructures, and trained clinicians with the expertise to screen and diagnose dementia, particularly for those who are recent immigrants.

As globalization, immigration, natural disasters, climate change, and conflicts have increased over the

past few decades, a growing number of persons with dementia originally from LMICs are now seen in high-income countries. In dementia research and clinical care, conflating immigrant members of ethnoracial groups and those already living in a country may lead to missing the critical role of immigration in the manifestation of dementia. Indeed, evidence suggests that immigration status may be an effect modifier in the relationship between race/ethnicity and the development of dementia. One study from the United States (US) demonstrated a higher dementia incidence among immigrant representatives of various ethnoracial groups versus their US-born counterparts, with the notable exception being US-born non-Hispanic Black participants (Moon *et al.*, 2019). Nonetheless, dementia is unlikely to be a salient concern during the immigration process or in the early formative years of settling, and attitudes toward dementia between native-born and immigrant ethnoracial groups is an underappreciated and under-researched area (Babulal *et al.*, 2019). With clinical services potentially informed by insufficient evidence in these groups, additional information to support screening and testing is required.

Zhao and colleagues have explored the issue in a study of older Chinese persons entitled Attitudes toward dementia among Chinese adults aged 50 years and older: A comparative study of immigrants living in Melbourne and non-immigrants living in Beijing (Zhao *et al.*, 2022). Mandarin language interviews were conducted with a convenience sample from community centers/activities of 25 dementia-free older persons from Beijing and 21 from Melbourne (who emigrated from China at a mean age of 55 and had been living in Australia for a mean of 12 years). Using thematic qualitative analysis, and the tripartite model of attitudes, affective (i.e. evaluations of and feelings about dementia), cognitive (i.e. knowledge and thoughts about dementia), and behavioral (i.e. intentions or actual behaviors toward dementia or persons with dementia) dimensions were explored. The qualitative coding derived 16 themes across the model including four affective, five cognitive, and seven in the behavioral domain.

Many themes were common to both groups such as feeling dementia is scary and hopeless, representing a whole-family tragedy, being associated with stigma and severe impairment, and a topic to be avoided except in jest. Both groups did express an intention to help patients with dementia, and their families, and while preferring in-home dementia care, would accept formal care. Group differences, however, were more revealing. First, the Beijing group worried more than the Melbourne group about getting dementia, which the authors proposed may arise from Beijing group concerns about the social implications of cognitive and functional decline or from the Melbourne group under-reporting their concerns so as not to trouble their children. Second, the Beijing group was more likely to believe that dementia is indeed an abnormal condition, whereas the Melbourne group denied concerns, often citing a negative family history as reassuring. Third, while the Beijing group expressed interest in dementia education and risk reduction, many in the Melbourne group denied a desire or need for more education. Similarly, while the Beijing group felt empowered to make decisions about participation in dementia-related educational activities, members of the Melbourne group were more deferential to their children and cited migration-related barriers to participation (e.g. responsibilities to grandchildren, housework, and challenges with transportation and language). This final theme on decision-making may be the most actionable difference, identifying the children of Chinese immigrants as an important access point and educational target for dementia information.

This study represents an important contribution to better understanding migration-related issues as they relate to attitudes toward dementia. The group differences emphasize the importance of migration as a variable to consider in dementia research and in the development and implementation of dementia care services, consistent with previous literature (Moon *et al.*, 2019). Findings from this study can be leveraged to better inform research and health-care services. For example, overcoming stigma is a barrier to early detection and intervention, so non-threatening culturally sensitive education can be guided by studies like this to overcome stigma.

The study is not without limitations. As the authors stated, generalizability to non-Mainland China-born individuals or to other ethnoracial groups may be the biggest concern. However, even the within-Chinese generalizability is unclear as several questions are unanswered. First, was there selection bias in the group that emigrated to Australia during this time period? Was this group similar enough to the Beijing group to allow exploration of differences based on migration status, or did the

Melbourne group differ in other ways (e.g. higher socioeconomic status, less family history of dementia, fewer worries)? Second, the sample as a whole was well-educated (~13 years), recruited from community centers and activities, and one wonders to what extent the sample represents the later-life immigrant Mandarin-speaking diaspora in Australia and elsewhere. Here, there are parallels with North American cohort studies in which participants are highly educated and may not necessarily represent the at-risk population at large.

Another limitation, common in dementia research, is reliance on the traditional cognocentric view of dementia. The major public preconceived notion about dementia relates to cognitive and functional impairment, as evidenced by the themes that emerged (e.g. becoming forgetful or incontinent). However, dementia-related behavioral and psychological symptoms (BPSD) or neuropsychiatric symptoms (NPS) are seemingly overlooked. These symptoms are almost ubiquitous in dementia and are associated with adverse outcomes such as greater caregiver burden and functional impairment, faster cognitive decline and progression to severe dementia, and a greater need for institutionalization and pharmacotherapy (Lanctôt *et al.*, 2017). BPSD are core features of dementia, often representing sequelae of the neurodegenerative process, measurement of which is an essential part of a comprehensive dementia assessment (Ismail *et al.*, 2020; Montero-Odasso *et al.*, 2020). Yet, they are not discussed here. Moreover, dementia-related changes in behavior and personality can precede cognitive changes in 59% of dementia cases, including 30% of Alzheimer's disease dementia (Babulal *et al.*, 2022; Wise *et al.*, 2019). Pre-dementia-related behavioral changes are relevant to this study. For example, participants were recruited from community centers and activities. One might speculate that this group has less apathy than a sample recruited from home or from primary care practices. Similarly, the Melbourne group described fewer worries about dementia, which could also be viewed as less anxiety. The emergence in later life of persistent apathy and anxiety/worry (and a host of other NPS) are dementia risk factors, described in the pre-dementia syndrome, mild behavioral impairment (MBI) (Ismail *et al.*, 2016). MBI has demonstrated higher rates of progression from normal cognition to mild cognitive impairment (MCI) (Ismail *et al.*, 2021) and from MCI to dementia (McGirr *et al.*, 2022), and higher burden of neurodegenerative disease changes relative to non-MBI participants (Gill *et al.*, 2021; Miao *et al.*, 2022). MBI represents an important early warning sign of dementia, sometimes observed even in advance of cognitive decline, serving as a proxy marker of neurodegenerative

disease changes. Thus, in studies on perception and attitudes toward dementia, MBI and BPSD should be incorporated explicitly into questions and into modeling. These symptoms can easily be stigmatized and considered as psychiatric disorders, escaping early detection, and thwarting efforts toward dementia prevention or mitigation.

The findings resonate with articles in the August 2022 (Volume 34;8) *International Psychogeriatrics* special issue “Geriatric Mental Health among Chinese Older Adults.” For example, health anxiety in 893 dementia- and depression-free participants from community health care centers was explored. While surprisingly common (9.53%), and being associated with the number of chronic health conditions (Yang *et al.*, 2022), one wonders to what extent this anxiety may be related to neurodegenerative disease. Longitudinal data will be informative. Elder mistreatment is another topic addressed in the special issue. One-year prevalence of elder mistreatment in persons ≥ 60 years old was determined (4%), along with findings that physical frailty, mediated by housework involvement, was associated with psychological vulnerability (anxiety, loneliness), and greater risk of mistreatment (Li *et al.*, 2022). With respect to migration effects, these psychological vulnerability factors may be important contributors to delineate differences in dementia incidence. Finally, a 3-year study in a geographically diverse sample of 3,692 community-dwelling participants found that long sleep (≥ 10 hrs/night) increased risk of cognitive impairment by 30%. While the diverse sampling was a strength of the study, which addresses ongoing issues of lack of diversity in dementia cohorts, the diversity may have provided challenges in reconciling the effects of education and language on cognitive test performance. The Zhao study is a welcome addition to this literature, reflecting the need to explore culturally specific attitudes and awareness of dementia, as a strategy to better formalize approaches for earlier detection.

As emphasized by Zhao *et al.*, stigma and negative stereotypes about dementia are informed by cultural values, traditions, and migration-related barriers. As globalization continues to unfurl, the intersectionality of multiple identities that contributes to diversity and its ever-expanding dimensions profoundly impacts perceptions and attitudes about dementia (Babulal, 2020). Imbrication of contemporary studies that adopt a cognocentric view of dementia needs to rapidly shift and include measurement of BPSD, NPS, or MBI, in addition to assessing social determinations of health (SDOH). Dementia knowledge, awareness, screening, diagnosis, and treatment are inextricable from SDOH which describes all of the conditions that may increase dementia risk over a

lifetime. It is important to assess the conditions that afford an individual the ability to play, work, live, commute, and age in place since these may contribute to health disparities and an increased risk for some populations (Balls-Berry and Babulal, 2022). The attitudes and perceptions about dementia may also shift based on a group or population’s SDOH, especially for those who are immigrants. Since the nucleus of dementia research is largely conducted in white/European, affluent, well-educated populations, there is critical need for samples that are inherently diverse and globally represented in future studies (Babulal *et al.*, 2019). Inclusion of diverse samples will provide precise prevalence estimates and incidence rates of dementia, and a much-needed enriched perspective that may include the influence of multidimensional poverty, conflict/violence, diminishing natural resources, and larger climate and geopolitical problems. The attitudes derived across the affective, cognitive, and behavioral domains from this investigation provide a launchpad for future studies to quantitatively and qualitatively explore the latent factors that contribute to attitudinal expression about dementia. This work may ultimately reduce stereotypes and stigma, increase awareness about individual risk, and also support strategies to reduce barriers to seeking care.

Conflict of interest

The authors have no conflicts of interest to declare.

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References

- Babulal, G. M.** (2020). Advancing research on diversity and disparities among aging adults. *Journal of Applied Gerontology*, 39, 455–456.

- Babulal, G. M., Chen, L., Doherty, J. M., Murphy, S. A., Johnson, A. M. and Roe, C. M.** (2022). Longitudinal changes in anger, anxiety, and fatigue are associated with cerebrospinal fluid biomarkers of Alzheimer's disease. *Journal of Alzheimer's Disease*, 87, 141–148.
- Babulal, G. M. et al.** (2019). Perspectives on ethnic and racial disparities in Alzheimer's disease and related dementias: update and areas of immediate need. *Alzheimer's & Dementia*, 15, 292–312.
- Balls-Berry, J. J. E. and Babulal, G. M.** (2022). Health disparities in dementia. *CONTINUUM: Lifelong Learning in Neurology*, 28, 872–884.
- Ding, H. and Hargraves, L.** (2009). Stress-associated poor health among adult immigrants with a language barrier in the United States. *Journal of Immigrant and Minority Health*, 11, 446–452.
- Gauthier, S., Rosa-Neto, P., Morais, J. A. and Webster, C.** (2021). *World Alzheimer Report 2021: Journey Through the Diagnosis of Dementia*. London: Alzheimer's Disease International.
- Gill, S. et al.** (2021). Neural correlates of the impulse dyscontrol domain of mild behavioral impairment. *International Journal of Geriatric Psychiatry*, 36, 1398–1406.
- Ismail, Z. et al.** (2020). Recommendations of the 5th Canadian Consensus Conference on the diagnosis and treatment of dementia. *Alzheimer's & Dementia*, 16, 1182–1195.
- Ismail, Z., McGirr, A., Gill, S., Hu, S., Forkert, N. D. and Smith, E. E.** (2021). Mild behavioral impairment and subjective cognitive decline predict cognitive and functional decline. *Journal of Alzheimer's Disease*, 80, 459–469.
- Ismail, Z. et al.** (2016). Neuropsychiatric symptoms as early manifestations of emergent dementia: provisional diagnostic criteria for mild behavioral impairment. *Alzheimer's & Dementia*, 12, 195–202.
- Lanctôt, K. L. et al.** (2017). Neuropsychiatric signs and symptoms of Alzheimer's disease: new treatment paradigms. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, 3, 440–449.
- Li, Y., Chen, H. and Peng, X.** (2022). Effect of physical frailty on elder mistreatment in a national survey: examining psychological vulnerability, housework involvement, and financial independence as mediators. *International Psychogeriatrics*, 34, 743–753.
- Livingston, G. et al.** (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, 396, 413–446.
- Mattap, S. M. et al.** (2022). The economic burden of dementia in low-and middle-income countries (LMICs): a systematic review. *BMJ Global Health*, 7, e007409.
- McGirr, A., Nathan, S., Ghahremani, M., Gill, S., Smith, E. E. and Ismail, Z.** (2022). Progression to dementia or reversion to normal cognition in mild cognitive impairment as a function of late-onset neuropsychiatric symptoms. *Neurology*, 98, e2132–e2139.
- Miao, R. et al.** (2022). Plasma beta-amyloid in mild behavioural impairment - neuropsychiatric symptoms on the Alzheimer's continuum. *Journal of Geriatric Psychiatry and Neurology*, 35, 434–441.
- Montero-Odasso, M. et al.** (2020). CCCDTD5 recommendations on early non cognitive markers of dementia: a Canadian consensus. *Alzheimer's & Dementia*, 6, e12068.
- Moon, H., Badana, A. N., Hwang, S.-Y., Sears, J. S. and Haley, W. E.** (2019). Dementia prevalence in older adults: variation by race/ethnicity and immigrant status. *The American Journal of Geriatric Psychiatry*, 27, 241–250.
- Sternberg, R. M., Nápoles, A. M., Gregorich, S., Paul, S., Lee, K. A. and Stewart, A. L.** (2016). Development of the Stress of Immigration Survey (SOIS): a field test among Mexican immigrant women. *Family and Community Health*, 39, 40–52.
- Wise, E. A., Rosenberg, P. B., Lyketsos, C. G. and Leoutsakos, J.-M.** (2019). Time course of neuropsychiatric symptoms and cognitive diagnosis in National Alzheimer's Coordinating Centers volunteers. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, 11, 333–339.
- Yang, G. et al.** (2022). Prevalence and relative factors of health anxiety of elders in community healthcare centers. *International Psychogeriatrics*, 34, 735–742.
- Zhao, M., Zhang, H., Lin, X., You, E., Wang, H. and Lautenschlager, N. T.** (2022). Attitudes towards dementia among Chinese adults aged 50 years and older: a comparative study of immigrants living in Melbourne and non-immigrants living in Beijing. *International Psychogeriatrics*, 26, 1–14.