A scoping review of the unique landscape and challenges associated with dementia in the Western Pacific region

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Summary

Dementia is a leading public health crisis that is projected to affect 152.8 million individuals by 2050, over half of whom will be living in the Western Pacific region. To determine the challenges and opportunities for capacity building in the region, this scoping review searched databases. Our findings reveal national and ethnoracial differences in the prevalence, literacy and genetic risk factors associated with dementia syndromes, underscoring the need to identify and mitigate relevant risk factors in this region. Importantly, ~80% of research was derived from higher income countries, where the establishment of patient registries and biobanks reflect increased efforts and allocation of resources towards understanding the pathogenesis of dementia. We discuss the need for increased public awareness through culturally-relevant policies, the potential to support patients and caregivers through digital strategies and development of regional networks to mitigate the growing social impact and economic burden of dementia in this region.

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Introduction

The Western Pacific is home to approximately 20% of the world's population and projected to contribute to more than half of the 152.8 million individuals estimated to be living with dementia by 2050.[1] If left unaddressed, dementia-related costs will continue to rise and significantly undermine social and economic development in this region. Recognition of this global health crisis has led to the World Health Organisation (WHO) Global Action Plan (GAP) on dementia (2017–2025), which urges governments to develop national policies to improve awareness, reduce risk factors, improve diagnosis, care and treatment for individuals living with dementia as well as to support carers and increase research.[2] However, at the time of this review, only eight of the thirty-six countries and territories in the Western Pacific region are listed as having a formal national dementia strategy (Australia, South Korea, Japan, New Zealand, Singapore, Taiwan, China and Vietnam).[3,4] National strategies would enable governments to tailor their approach of addressing dementia issues to the unique culture, demographics, and religion of each country.

Projected prevalence of dementia in the Western Pacific region

The under-developed and -funded healthcare systems in most low- and middle-income countries result in limited opportunities for capacity building around diagnosis, care, and efforts to minimise risk in people living with dementia and in their families.[5] As such, low- and middle-income countries in the Western Pacific region are expected to experience disproportionately high increases in numbers of individuals with dementia.[1] Country-level estimates predict the lowest increase to

Abbreviations: WHO, World Health Organisation; WP, Western Pacific; EOD, early onset dementia; AD, Alzheimer's disease; FTD, frontotemporal dementia; DLB, Dementia with Lewy bodies; VD, vascular dementia

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be in high-income Japan and Australia and the greatest increase to be in lower-middle income countries including Mongolia, Laos and Papau New Guinea although there are exceptions to this, as in the case of high-income Singapore due to its large aging population (Fig. 1, Table 1).[6] This trend is also observed within Greater China, where projected increases appear to be driven by the mainland rather than higher-income Hong Kong and Taiwan.[7] Importantly, projected estimates for the smaller Pacific Islands and Territories (eg. Nauru, Cook Islands, Niue, Palau, Pitcairn Island, Tuvalu) are not available, suggesting that socioeconomic factors influence the capacity and consequently, available knowledge on dementia. Although the Pacific Islands and Territories are still relatively young,[8] they already have a disproportionately large share of expensive-to-treat noncommunicable diseases by global standards, underscoring the need for governments to strategically use this opportune window to improve the overall public health system and dementia awareness to mitigate risk factors and circumvent additional strain in the future.[9]

Aims

To better understand the landscape and unique challenges faced by the diverse countries and territories within the Western Pacific region, this scoping review assesses and summarises the knowledge on dementia prevalence, literacy, genetic risk factors and clinical subtypes in the different countries and racial and ethnic populations in this region. Given the current absence of curative treatments, we also discuss the potential to develop collaborative brain bank networks to increase pathobiological knowledge relevant to the region as well as the digitisation of health as a potential area of capacity building to alleviate some of the burden associated with this growing public health challenge.

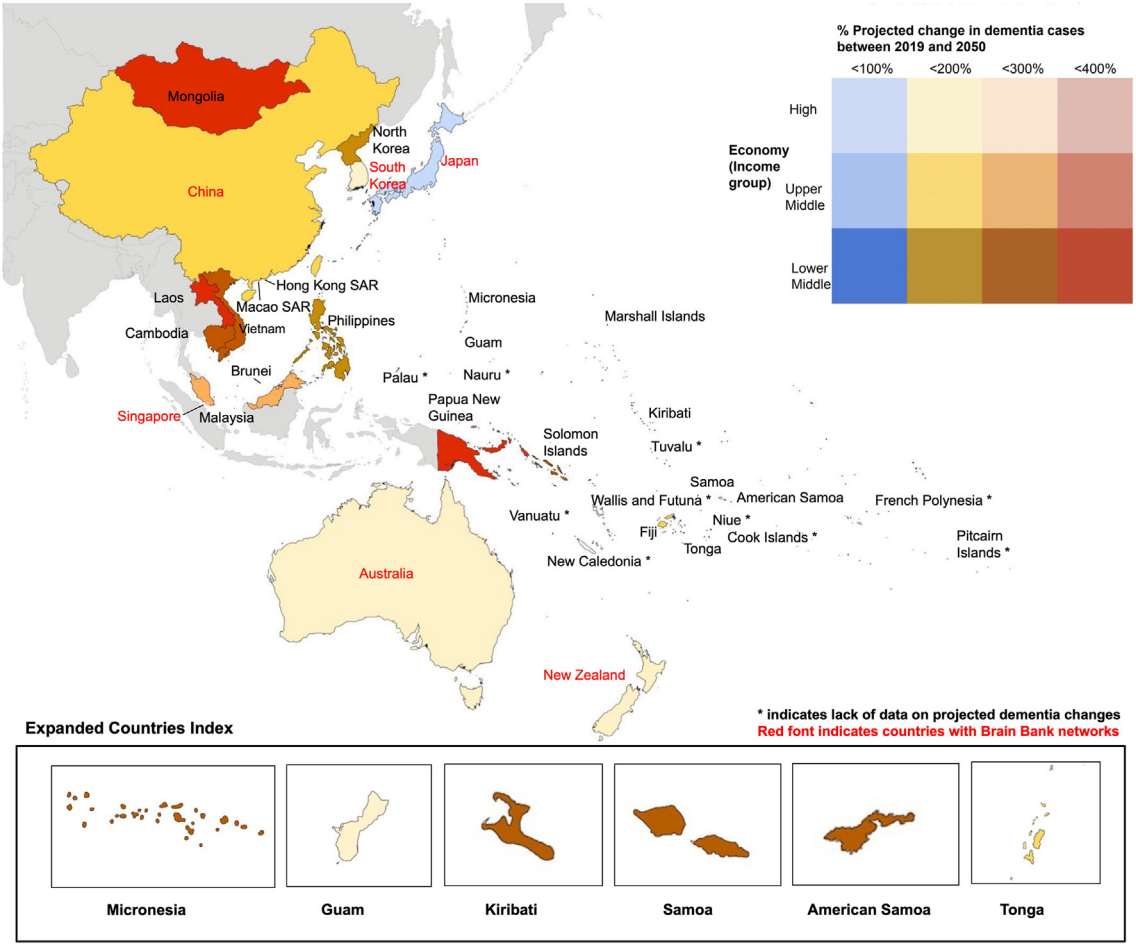

Fig. 1: The projected increase in dementia cases by 2050[6] in the different countries and economies (World Bank) within the Western Pacific region. Note: Map is adapted from the WHO Western Pacific Region map at the following URL reference: https://www.who.int/westernpacific/about/where-we-work and the insets from the WorldAtlas at https://www.worldatlas.com/. Accessed [3rd Feb 2024].

	Estimated population (world bank 2021)	Projected change in dementia cases between 2019 and 2050 (%)[6]	Economy (Income group)	Number of studies on dementia	Proportion of the total number of studies
Global		**166%**			
China	1.412 B	197%	Upper middle	6138	22.15%
Japan	125.7 M	27%	High income	7879	28.43%
Philippines	113.9 M	195%	Lower middle	68	0.25%
Vietnam	97.47 M	230%	Lower middle	98	0.35%
Korea	51.74 M South 25.97 M North	South 191% North 116%	High (south) Low (north)	2608	9.41%
Malaysia	33.57 M	249%	Upper middle	256	0.92%
Australia (PICT)	25.69 M	128%	High	7420	26.78%
Cambodia	16.59 M	276%	Lower middle	3	0.01%
Papua New Guinea (PICT)	8 M	316%	Lower middle	10	0.04%
Laos	7.425 M	351%	Lower middle	10	0.04%
Hong Kong	7.413 M	Included in China	High income	1235	4.46%
Singapore	5.454 M	356%	High income	1081	3.90%
New Zealand (PICT)	5.123 M	127%	High income	670	2.42%
Mongolia	3.348 M	389%	Lower middle	17	0.06%
Fiji (PICT)	924,610	159%	Upper middle	7	0.03%
Solomon Islands (PICT)	707,851	256%	Lower middle	1	0.00%
Macao	686,607	Included in China	High income	29	0.10%
Brunei	445,373	365%	High income	6	0.02%
Vanuatu (PICT)	319,137	174%	Not classified	1	0.00%
French Polynesia (PICT)	304,032	N/A	High income	1	0.00%
New Caledonia (PICT)	271,030	N/A	High income	3	0.01%
Samoa (PICT)	218,764	226%	Lower middle	0	0.00%
Guam	170,534	185%	High income	142	0.51%
Kiribati (PICT)	128,874	203%	Lower middle	0	0.00%
Micronesia (PICT)	113,131	222%	Lower middle	21	0.08%
Tonga (PICT)	106,017	137%	Upper middle	4	0.01%
American Samoa	45,035	226%	Lower middle	0	0.00%
Marshall islands (PICT)	42,050	285%	Not classified	1	0.00%
Palau (PICT)	18,024	N/A	Upper middle	3	0.01%
Cook islands (PICT)	17,459	N/A	Not classified	0	0.00%
Nauru (PICT)	12,511	N/A	High income	0	0.00%
Wallis and Futuna	11,469	N/A	Not classified	0	0.00%
Tuvalu (PICT)	11,204	N/A	Upper middle	0	0.00%
Niue (PICT)	1620	N/A	Not classified	0	0.00%
Pitcairn Island	67	N/A	Not classified	0	0.00%

To compare the level of knowledge on dementia, a systematic search of the available literature in PubMed was performed on the 18th July 2023 using the search terms ["dementia"] AND [each of the 36 WP countries and areas] with restrictions placed on the species "human". To compare the number of research articles on postmortem brain tissue in patients with dementia, the search terms ["dementia"] AND ["postmortem"] AND ["pathology"] AND [each of the 36 WP countries and areas] was performed with restrictions placed on the species "human". Estimated population and classification of economies into four income groups by the World Bank: low, lower-middle, upper-middle, and high income. **PICT:** Pacific Island Countries and Territories; **N/A** Not available.

Table 1: **A comparison of the number of published research on dementia in the Western Pacific region.**

Search strategy and selection criteria

Based on the World Health Organisation (WHO) Global Action Plan (GAP) on dementia (2017–2025), we sought to understand prevalence, awareness, genetic risk factors and clinical subtypes associated with dementia in the different countries and racial and ethnic populations in the Western Pacific region, as well as the potential for capacity building through the development of collaborative networks and digitisation of health. We first compared published research on dementia in the Western Pacific region by performing a systematic search of the available literature in PubMed on 18 July 2023 using the search terms ["dementia"] AND [each of the 36 WP countries and areas] with restrictions placed on the species "human". This identified a total of 27,712 publications and we listed the number of publications from each country in Table 1. This revealed that 77% of these studies were from Japan, Australia, and China (Table 1, Fig. 2), with a scarcity of published research from the Pacific Islands and Territories, as well as in

more populous Western Pacific countries which include Cambodia (population of >16 M), Papua New Guinea and Laos (population of >7 M) (Table 1, Fig. 2). Given the predominance of published research from higher income countries but the greater projected increments in dementia prevalence from lower-middle income countries (Fig. 1), we further screened studies from each country using the following search terms "dementia" and "literacy" or "awareness", "ethnoracial", "diagnosis", "genetics", "brain banks", "digitisation" to ensure representation of available data from the thirty-six diverse countries and territories within the Western Pacific region.

Dementia awareness

A lack of public awareness and understanding that dementia is a disease process, not a natural part of ageing, leads to stigmatisation and discrimination, which compounds existing barriers to diagnosis and care. This contributes to an underestimation of incident cases and results in an inaccurate representation of the true magnitude of this problem in the region. In recognition of the need to improve dementia awareness and foster a dementia-inclusive society, the WHO global Action Plan on the Public Health Response to Dementia 2017–2025 recommends all countries have at least one functioning public awareness campaign by 2025.[2] Given the rich diversity in culture and heritage in the Western Pacific region, culturally- and religiously-relevant national strategies that increase public awareness and education on dementia are needed to help dispel common misconceptions that deter diagnosis and foster a dementia-inclusive society which will in turn better support individuals living with dementia and their caregivers. For example, a study of 476 participants from Cambodia, Philippines and Fiji revealed that common misconceptions associated with dementia in these three countries include considering it to be a natural aging process; confusing dementia with depression; and believing dementia to be caused by karma.[10] One-third of people in Fiji and one-tenth of people in Cambodia and Philippines were found to have approached religious figures for help, with participants from Cambodia also turning to non-government organisations,[10] highlighting the need for greater accountability to minimise exploitation of vulnerable populations. Similarly, among racially minoritised southeast Asians living in Hong Kong, dementia was perceived as a normal aging or mental disorder associated with spiritual and psychosocial factors, with individuals having a greater reliance on families due to distrust of professional services, highlighting a greater vulnerability in underserved communities.[11] Improved dementia literacy would enable caregivers to be better equipped to advocate for and mitigate fears and communication challenges that individuals living with dementia may have with regards to approaching medical and health care professionals. It may also encourage individuals living with dementia to adopt lifestyle and behavioural changes that may slow cognitive decline,[12,13] which is particularly important given the current lack of an effective therapeutic treatment. In addition to increasing public awareness to improve earlier recognition and clinical presentation of individuals living with dementia, medical and health care professionals also need to be adequately equipped to clinically recognise and diagnose dementia. A survey of 464 final year medical undergraduates from across seven universities in Malaysia revealed a low level of dementia knowledge.[14] This underscores the need for regular review of the medical curriculum to improve the clinical recognition of individuals living with dementia and development of national dementia screening tools. In addition to being culturally- and religiously relevant, national dementia screening tools may improve diagnosis in racial and ethnic populations relevant to the region, which is important since studies have shown that clinical dementia screening tools developed in countries with predominant European ancestry are less accurate among minority racial and ethnic groups.[15]

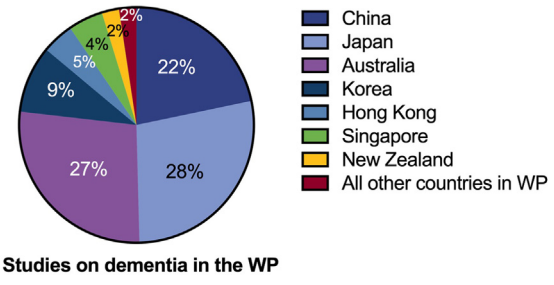

Fig. 2: The pie chart depicts the percentage of total studies published on dementia in the Western Pacific region (n = 27,712), demonstrating that these were predominantly (77%) from Japan, Australia, and China. WP: Western Pacific.

Racial and ethnic differences in dementia prevalence in the Western Pacific

The Western Pacific region is home to ethnically and racially diverse populations both within and across different countries. Racial and ethnic differences relating to dementia prevalence, presentation and survival are increasingly recognised in North America and the UK.[16–19] However, there remains significant gaps in the scientific literature on racial and ethnic diverse populations in the Western Pacific region.[6,20] Consistent with that observed in the Northern hemisphere, dementia is more prevalent in indigenous populations in Australia and Guam,[21] with First Nations Australians 3–5 times more likely to have dementia compared to the general population.[22–24] This has also been observed in New Zealand, where dementia is 58% more prevalent in Pacific Islanders (represents 8.1% of the population)

and 34% more prevalent in the Māori population (represents 16.5% of the population) compared to Europeans (which comprises 70.1%) and Asians (represents 15.1% of the population).[25] Despite representing >65% of Malaysia's multiethnic population, Malays and Bumiputeras (the indigenous population) also have a significantly higher prevalence of dementia compared to Chinese and Indians, with age, gender (female), no formal education and living in rural areas found to contribute to this higher prevalence.[26,27] Older age, female gender and lower education were also significantly associated with a higher incidence of dementia in neighbouring Singapore,[28] where the three main ethnic groups are also Chinese (74%), Malays (14%) and Indians (9%).[29] When controlled for age, gender and education, Malays and Indians in Singapore were found to have a three to four times increased likelihood of dementia but this higher prevalence could not be accounted for by cardiovascular factors, depression or activities,[28] highlighting the need to better determine risk factors relevant to different racial and ethnic groups. Given the diverse national and racial and ethnic populations and socioeconomic factors across the 36 countries and territories in the Western Pacific, this is particularly important to accelerate the development of targeted prevention and treatment strategies.

Dementia subtypes in the Western Pacific region

Consistent with that seen globally, Alzheimer's disease (AD) and vascular dementia (VD) are the two most prevalent dementia syndromes identified in population- and community-based studies within the Western Pacific region. In contrast, there have been fewer reports of Frontotemporal dementia (FTD) and Lewy body Dementia (LBD). However, it is not clear whether this is due to a lower prevalence or lower clinical recognition and misdiagnosis of these dementia syndromes, which are associated with significant behavioural and psychiatric symptoms. In Korea, FTD and LBD have been found to account for <0.3% of community-dwelling older individuals aged 60 years or above.[30] In China, FTD and LBD are aggregated as "other rare causes of dementia syndromes" with a collective prevalence of <0.1%–0.5% in population-based studies[31] and 6.8% in hospital settings.[30] A recent review of 8405 dementia medical records across nine memory clinics in China revealed that LBD represents 5.6% of all patients with dementia, but this ranged from 0.7 to 11.4 across different centres, suggesting that LBD is likely underestimated in some regions.[32]

The frequency of a clinical diagnosis of LBD has also been reported to vary between geographical regions in the UK, with this attributed to differences in diagnostic practice between clinics.[33] Of 2890 patients that attended a tertiary memory clinic in Singapore from 2010 to 2019, FTD and LBD were found to be the third most common dementia syndromes after AD and VD, each accounting for 11.1% of patients.[34] Importantly, there was a significantly greater representation of FTD in patients with an early onset (24.5% in <65 years at age of onset) compared to later onset disease (5.8% in ≥65 years at age of onset), but a significantly lower proportion of LBD in early-onset (8.3%) compared to late-onset disease (12.3%).[34] This underscores the importance of age in the interpretation of the prevalence of dementia syndromes. Similarly, a multi-site population-based study in Japan revealed that FTD is the third most common syndrome after AD and VD in individuals with early-onset dementia (EOD) (9.4%),[35] which is higher than earlier studies that identified FTD in only 3.6%,[36] indicating improvements in the clinical recognition and diagnosis of FTD in Japan. FTD is also the third most common early-onset dementia syndrome in Australia after Alzheimer's disease and vascular dementia,[37] in part through association with amyotrophic lateral sclerosis.[38,39] FTD often affects people in their early 60's and younger and both FTD and DLB can present with significant changes in behaviour including a tendency to disinhibition and changes in personality. In some cultures, there can be significant stigma related to these symptoms that prevents families and patients from seeking support and care.[40] Behavioural symptoms can differ across cultures and a reliance on the clinical presentations characteristic of patients in the West may impact the accuracy or recognition of FTD in other countries; for example, excessive eating can be observed in individuals with FTD in both Japan and the UK. However, in contrast to the significant weight gain observed in patients in the UK, a significant increase in weight is not usually reported in Japan, possibly due to a different diet and/or food culture.[41] The diagnostic criteria for language features in patients with FTD was also developed in the West and may not be as accurate in identifying language deficits in non-native English speakers.[42]

The need for improved dementia awareness to improve the recognition, diagnosis and representation of dementia prevalence in the Western Pacific region

There is a need for greater knowledge, differentiation, and awareness of these different dementia subtypes, particularly because in contrast to AD and VD, patients with FTD and DLB present with a higher frequency and diversity of behavioural symptoms in the early stages of disease, with this increasing in severity with disease progression. Similarly accurate diagnosis can inform current and future management considerations and guide prognosis. Currently, the mainstay of pharmacological treatment for AD and VAD is very different; cholinesterase inhibitors can modestly impact the

progression of AD while VAD treatment is targeted at managing vascular risk factors. Precise phenotyping will become essential in the future when disease modifying therapies targeting at underlying pathological processes become available.

The majority of individuals with FTD present with a combination of eating abnormalities, apathy, loss of empathy, stereotypical and compulsive behaviours, and psychotic symptoms[43,44]; while more than half of patients with DLB display symptoms of apathy, hallucinations, delusions and sleep disturbances.[45] Psychiatric symptoms including psychosis, depression and anxiety and apathy are also common,[44,46] adding an additional dimension to patient care needs and caregiver burden and accurate diagnosis will help clinicians identify the care needs of their patients. It is however important to note that many Western Pacific countries such as Indonesia, Bangladesh, Nepal, Pakistan, Fiji, and Philippines are underrepresented in the literature. This is further compounded by a lack of dementia syndrome subtyping or behavioural profiling in existing studies, hampering our understanding of the true dementia care needs in much of the Western Pacific Region. This ultimately reflects the multifaceted challenges faced by these nations in optimal dementia care ranging from low dementia literacy on a population level to limited dementia-specific resources and policies and initiatives from governments.

Genetic variants in the Western Pacific region

Mutations in different pathogenic genes have been associated with different clinical presentations and disease progression, highlighting the importance of understanding genetic risk factors relevant to different regions. However, over 90% of genome-wide association studies conducted to date have been in individuals of European ancestry.[47] Although race specific effects of genetic variants are increasingly recognised, studies in non-European ancestries are lacking.[48] For example, although polymorphisms in the *APOE* ϵ4 is an established genetic risk factor for Alzheimer's disease in populations of European descent, its prevalence and influence are much lower among Asian populations.[49,50] Even within Asian populations, it is less common in the Chinese and Japanese compared to Malays and Indians.[51] In Caucasian populations, a positive family history is recognised in 30–50% of patients with FTD but in countries in the Western Pacific, a positive family history has been reported in <10% of patients in Indonesia, Japan, Taiwan and the Philippines.[52] In individuals of European descent, the *C9ORF72* expansion is the most common genetic cause of FTD.[53] In contrast, in a study of 167 Chinese patients, only two *C9ORF72* carriers were identified,[54] both sharing a similar risk haplotype to European communities to keep with a single founder effect.[55] Instead, the *CHCHD10* mutation was more prevalent than the *C9ORF72* expansion in Chinese patients and compared to that in European populations.[56] The *C9ORF72* expansion was recently reported to be the most common genetic abnormality in FTD patients from Singapore and the Philippines but this was in a relatively small sample size of 60 patients from a specialist neurocognitive centre with >40% demonstrating familial disease although their ancestry was not clearly defined.[57] Although there is limited data available, the *C9ORF72* expansion has not been described in Japanese or Korean cases of FTD.[58,59] The *C9ORF72* expansion has been fairly frequently associated with amyotrophic lateral sclerosis in Taiwan[60] but there are very few cases of this expansion in patients with FTD.[61,62] The *C9ORF72* expansion is the most common genetic cause of FTD in Australia, particularly in individuals with concomitant amyotrophic lateral sclerosis.[63] Importantly, the *C9ORF72* expansion is frequently associated with psychotic symptoms and has a higher risk of being misdiagnosed as primary psychiatric disorders.[64] Psychotic symptoms, and the underlying neurobiological factors, associated with FTD are strikingly similar to those seen in other primary psychiatric disorders[44] and are a major contributor to the delayed diagnosis often experienced by patients with FTD. This delay can be reduced in a specialist centre[65] however it often requires detailed longitudinal follow up to confirm the diagnosis. This protracted process adds economic and capacity burden to the health service with implications for safety, quality and efficiency of care and would add further pressure already under-resourced services.

In addition to the *C9ORF72* expansion, mutations in the microtubule associated protein tau (*MAPT*) and *Progranulin (GRN)* genes are common genetic risk factors for FTD in European populations. However, in contrast to Australia and New Zealand where *C9ORF72* mutations are most prevalent, *MAPT* mutations are more common in Chinese, Japanese and Taiwan populations.[54,59,61,66] In contrast, pathogenic variants in these known FTD genes are rare in Korean patients but novel variants were found in the *CSF1R* and *AARS2* genes suggesting that the genetic characteristics of FTD in Korean populations are distinct not only from Caucasian populations but may also differ from other Asian populations in the Western Pacific region.[58] The *GRN* mutation accounts for approximately 14% of familial cases in Australia compared to 28% for *C9orf72*.[67] *GRN* mutations are exceedingly rare in the remaining Western Pacific regions and have been reported in only a handful of cases in Japan, China and the Philippines.[68] The prevalence in China is reported at 1.2–2.6% of all cases of FTD with no difference between sporadic and familial cases[69] and was only identified in one case out of 60 patients from Singapore and the Philippines.[57] Pathogenic variants in *Presenilin 1 (PSEN1), Amyoid Precursor Protein (APP) and Presenilin 2 (PSEN2)* are a

major risk factor for young-onset Alzheimer's disease. Approximately 20% of all cases of early onset familial AD in Korea are attributed to *PSEN1*[70] while only scattered case reports describe the presence of *PSEN2*.[71,72] *APP* is the second commonest genetic abnormality in early onset familial AD in China accounting for 15% of cases in one study[73] with a similar prevalence rate across Korea and Taiwan. In Japan, a systematic review found that mutations in the *PSEN1* gene occurred at a similar rate to other populations and led to the development of the Japanese Familial Alzheimer's Disease Database.[74] The multi-centre nationwide Chinese Familial Alzheimer's Disease Network (CFAN) was established to study and identify genes in Chinese and other ethnic groups with familial Alzheimer's disease. This large, concerted effort in 404 pedigrees identified 11 novel PSENs/APP mutations, indicating heterogeneity in AD pathogenesis between Chinese and other ethnic groups.[75] Of interest are reports of the clinical phenotype of APP, that is traditionally associated with a more rapid disease trajectory, that diverges across Western and Chinese populations with an affective prodromal period and late spastic paraparesis and ataxia in Chinese carriers.[76] The majority of genetic abnormalities for FTD and AD are inherited in an autosomal dominant manner with almost complete penetrance. These genetic findings have major implications for families and their decisions to progress to genetic testing may be influenced by cultural, ethical and socioeconomic status. The availability of testing may also vary depending on regions and may not be easily available in a clinical setting equally throughout the Western Pacific region. Genetic testing for people who do not yet have the disease but are at risk should be done in conjunction with genetic counselling and access to this service is another consideration in view of the health disparities across the Western Pacific.

Brain banks in the Western Pacific and the potential of collaborative partnerships to increase pathobiological knowledge in the region

Studies in human postmortem brain tissue have significantly advanced knowledge on the underlying pathobiology of dementia and remains the gold standard for a definitive diagnosis.[77–80] They have enabled the refinement of existing and establishment of new diagnostic criteria to improve the clinical recognition of the different pathological proteins that characterise the different dementia syndromes.[81–83] They also led to the recent discovery that the pathological TDP-43 protein is a common and distinct cause of amnestic dementia found in over 40% of individuals with advanced age and mimics Alzheimer's disease.[84,85] Importantly, recent studies have revealed that even in patients with pathologically pure Alzheimer's disease, over a third of patients are misdiagnosed during life.[86] This highlights the critical need for reliable and accessible biomarkers of disease pathogenesis to enable targeted drug development and intervention for relevant populations.[87,88] Importantly, approximately 90% of the brain banks that recruit brain tissue from patients with a neurodegenerative dementia are located in Europe and North America[89] and report under-representation from racial and ethnic groups.[90] This indicates that most of the pathobiological data on dementia is derived from individuals of European descent. The significance of this was recently highlighted in a study that identified racial and ethnic differences in neuropathology, with a significantly higher incidence of hippocampal sclerosis of a TDP-43 aetiology identified in African Americans compared to white/European Americans.[91] The extent at which racial and ethnic differences in underlying pathobiology contribute to the greater risk of clinical misdiagnosis in non-white racial and ethnic groups[15] remains to be determined but this highlights the critical need to increase awareness of the importance of brain donation in under-served racial and ethnic populations across the region. Brain banks provide an invaluable resource for improving current understanding of dementia but are expensive to establish and maintain. Within the Western Pacific, formalised brain banks collecting tissue from patients with neurodegenerative diseases have been established and are predominantly located in high-income countries: Australia, New Zealand, China, Japan, South Korea and as of 2019, Singapore, which is the first brain bank in Southeast Asia. Most of these brain banks are part of networks in the region, thereby increasing the potential for wider recruitment and research collaboration in the region. These networks include the Australian Brain Bank Network (established in 2005), the China Human Brain Bank Consortium (established in 2016),[92] the National Neuropathology Reference and Diagnostic Laboratories for Dementia (NRD) in South Korea (established in 2016)[93] and the Japan Brain Bank Net (established in 2016).[94,95] Importantly, they provide an invaluable resource to improve understanding of the pathobiology of dementia in different racial and ethnic populations that will likely be relevant not only to the region but also to underserved populations in the UK and US. However, given the high cost in establishing and maintaining brain banks, international links may be needed, particularly in lower income countries, representing a potential area of capacity building. The recent development of an X-linked Dystonia-Parkinsonism (XDP) brain banking platform in the Philippines presents a promising case study of the potential of building a brain banking platform in a low-middle income country via institutional partnerships at local, national and international levels with a shared interest and objective in studying a disease that is endemic to that region.[96]

Digitisation of health as a potential area of capacity building to support individuals living with dementia and their caregivers in the Western Pacific region

The increasing prevalence of dementia in the Western Pacific places significant physical, psychological, and socioeconomic burden on individuals living with dementia, their caregivers and community. This is amplified in low- and middle-income countries, where limited funding and infrastructure results in inadequate availability and accessibility to public health services and caregiver support. In the current absence of curative treatments, efforts to mitigate risk factors and alleviate caregiver burden are needed to address this growing public health challenge. The COVID-19 epidemic has demonstrated the incredible potential of using digital technologies to reach large communities at a national level and these health innovations have the capacity to increase equity of access to public healthcare services. Given that most of the Western Pacific region is already engaged with the digital world[97] and digital technology has the potential to empower and extend the length at which people living with dementia can continue living in their community and receive care that is aligned with their preferences, this represents an important area of capacity building that may alleviate some economic burden. For example, the inbuilt alerts to emergency services in wearable fitness trackers may encourage greater confidence and independence in individuals living with dementia to continue living in their communities and alleviate some caregiver burden. They may also promote increased levels of physical activity, which may slow disease progression. Mobile phone-based applications can also facilitate increased social engagement and support systems between individuals living with dementia as well as their caregivers to achieve greater well-being and potentially slow cognitive decline. There is no one uniform strategy particularly given the diversity in the region, and economic and societal demographics will influence national priorities for the relevant health innovations and their translation into dementia care. However, whether this takes on the form of digital decision-making tools to improve telemedicine and engagement with individuals living in isolated or remote regions or the form of smart cars that can be programmed remotely to support mobility of older individuals that are unable to drive, there is significant potential to support individuals living with dementia and their caregivers through the development and implementation of affordable and equitable regional health innovations. This represents a promising area for capacity building and that can be incorporated into culturally relevant national dementia strategies in the different countries within the Western Pacific region.

Conclusion

This scoping review demonstrates national and racial and ethnic differences in the level of knowledge, prevalence and genetic risk factors associated with different dementia syndromes in the Western Pacific region. Importantly, it reveals a growing body of research, particularly from Japan, Australia, and China, which has developed national networks to advance knowledge on dementia pathogenesis. This includes the establishment of the multi-centre nationwide Chinese Familial Alzheimer's Disease Network (CFAN) and the Japanese Familial Alzheimer's Disease Database, which represent concerted efforts to identify the pathological genes underlying dementia in Chinese and Japanese patients with familial disease.[74,75] Similarly, the establishment of Brain Bank Networks in China, South Korea, Japan, and Australia have significantly increased the capacity to improve understanding of the pathobiology of neurodegenerative diseases in this region. The knowledge gain from these countries will be relevant not only for other populations within the Western Pacific region but also for underserved populations residing in the UK and US where racial and ethnic differences in pathobiology and drug response are increasingly recognised and may impact clinical trial outcomes.[17,98] In summary, this review highlights the need for national strategies and greater collaboration in the region to increase research, improve awareness and mobilise resources to reduce risk factors and mitigate the growing social and economic impact of different dementia syndromes in the Western Pacific.

Contributors

RT conceptualised and designed the study. RT, ED and NT performed the literature review and data curation. RT wrote the manuscript with input from ED and MK. QN created the figures. All study authors approved the final paper.

Editor note

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Declaration of interests

MCK is Chair of the Brain Foundation (unpaid). The rest of the authors have no conflict of interest to report.

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