

Progressing dementia risk reduction initiatives for culturally and linguistically diverse older adults in Australia

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Abstract

Objectives: Dementia is a global public health concern, with approximately 487,500 Australians living with this condition. As an incurable disease, collaborative public health approaches are at the forefront for risk reduction of dementia. In Australia, nearly one in three individuals older than 65 years belong to culturally and linguistically diverse populations (CALD), yet dementia prevention approaches within CALD communities remain limited. Current health services and education require a targeted multidimensional and multicultural approach for dementia prevention interventions.

Methods: Recent recognition of gaps in CALD dementia awareness and accessibility has instigated a range of initiatives that address language disparities and dementia literacy within Australia's older population. While these have created pockets of dementia awareness and health promotion, a 'whole of community' and government approach is needed to decrease the recognised modifiable risk factors of dementia.

Results: This work serves to identify effective methods to promote dementia risk factor reduction using behaviour change techniques through five key recommendations specific for CALD communities. These suggestions are covered by the need for federal funds to be allocated to specific culturally inclusive initiatives highlighted under primary care, public health, research and community sectors.

Conclusions: Key recommendations are created to address language disparities and dementia literacy in Australia's older population to aid healthy brain ageing for CALD older adults.

KEYWORDS

culturally and linguistically diverse adults, dementia, health policy, health services

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1 | INTRODUCTION

Dementia is a significant global public health concern and currently affects over 55 million individuals worldwide, with a yearly increase of 10 million new cases.¹ The severity of dementia's burden is further highlighted by being the seventh leading cause of death and its causal impact on the disability and dependency of older adults, caregivers and on health and aged care systems.¹ Dementia rates in Australia exceeds global trends; it is the second leading cause of death nationally and the leading cause of death in females, with an estimated 487,500 Australians living with dementia in 2022.² As a cure is not available yet, a collaborative public health approach targeting dementia prevention is advocated for the general public³ and rural communities.⁴ Recent reports have suggested that as much as 40% of dementia risk is attributable to lifestyle factors, and a focus on the possibilities and importance of considering lifestyle factors for dementia prevention is key.⁵ As such, multidomain trials exploring education, physical activity, nutrition and cognitive exercise interventions can serve as protective factors of cognitive ageing.⁶ However, sociocultural factors also need to be addressed for dementia prevention to account for the diverse older population in Australia.⁷

Australia's multicultural population plays an important role in dementia trends and statistics. Many of Australia's residents speak a variety of languages and were born, or are children to those born, overseas and are identified as culturally and linguistically diverse (CALD) populations.⁸ The latest census data report that 45% of Australians identified as CALD, 21% speak a language other than English and that 1 in 3 individuals older than 65 years belong to a CALD population (approximately 1.3 million people).⁸ Critically, over a quarter (28%) of older CALD individuals have dementia and have lower primary care presentation for dementia (e.g. visiting a General Practitioner [GP]) compared with individuals from English-speaking backgrounds, highlighting the need for targeted awareness and understanding of dementia and its risk factors.⁹ Further compounding these issues is the phenomenon of CALD people experiencing dementia who revert to their first language.¹⁰

Many multicultural communities have a perception that memory loss and associated cognitive decline are a part of normal ageing and that dementia is a mental illness of 'craziness' which instigates stigma towards diagnosis and seeking help.¹¹ The lack of understanding of dementia, its symptoms and preventative measures has a negative impact on participating in research, gaining positive social support, actively seeking help and undertaking early measures of good health.⁸ Furthermore, these negative perceptions of dementia within CALD communities strengthen the cycle of stigma and inaccessibility to

Policy Impact

This work highlights the need to address dementia in culturally and linguistically diverse populations (CALD) in Australia. By pinpointing existing interventions and gaps in dementia research in CALD populations, we aim to build on public health approaches specific to these communities to reduce dementia risk. Five key recommendations are created to address language disparities and dementia literacy in Australia's older population.

culturally sensitive education causing late diagnosis and delayed treatments.

Culturally and linguistically diverse populations are largely excluded in existing dementia research targeting diagnosis, intervention and prevention.^{12,13} Unfortunately, while racial and ethnic disparities and lack of participation in prior dementia prevention programs were common, the lack of evidence regarding effective CALD-inclusive dementia interventions causes inequitable care and poor evidence-based practice and policy.¹⁴ To our knowledge, multidomain lifestyle dementia prevention interventions have largely been implemented in Western countries (e.g. POINTER trial), with very little representation in other multicultural countries. Recruitment mechanisms, such as the 'Step Up for Dementia Research' platform, currently cater to English-speaking volunteers thereby limiting engagement with CALD populations. An immediate change needs to occur, and even more so within multicultural Australia. Currently, an average 44% of active Australian dementia trials exclude participants without English proficiency, and only 11% of trials include CALD participants who meet English proficiency.¹³ There are several key challenges in executing dementia prevention for CALD groups. Firstly, recruitment and engagement are difficult due to issues in funding, resourcing and existing stigma. Secondly, there is a lack of culturally sensitive clinical evaluation. Neuropsychological assessments are critical for monitoring cognitive change and guiding treatments, and are core in determining the efficacy and effectiveness of clinical trials, but these were developed originally among Western, English-speaking populations. Although some efforts have been made to develop more sensitive tools (e.g. the Rowland Universal Dementia Assessment Scale – RUDAS) to assess individuals from diverse ethnic and racial groups, additional instruments and normative data are required.

Furthermore, previous multidomain lifestyle interventions targeting dementia risk reduction highlight modifiable factors such as diet, education and physical activity;

yet, these factors vary among cultures according to cultural norms and socio-economic standing.⁶ Current modifiable dementia risk factors are also not well understood for multi-ethnic population groups and thus dementia prevention interventions that are applicable and generalisable to CALD populations have yet to be provided.

In addition, the perceptions and needs of the CALD population regarding dementia care and services may have a further impact on how CALD communities perceive dementia as a condition. Indeed, access to dementia care has been found to affect caregivers in their ability to plan, negotiate and manage services. CALD caregivers struggle with making informed decisions due to limited English and health literacy.¹⁵ While a variety of government-funded community organisations are available for CALD communities to support dementia awareness and enhance communication using preferred language cards and informative resources,¹⁶ there appears to be no proactive method to reach CALD communities directly. Instead, individuals and caregivers are approaching services independently, and this has limited reach, since many are unaware of the resources available to them.

This article serves to promote practical initiatives to enact the CALD dementia research action plan¹⁰ and to prioritise effective ways to promote dementia risk reduction behaviours in CALD communities. We present five key recommendations for a CALD-inclusive public health approach targeting dementia risk reduction that could be achieved now, taking into account challenges and barriers (Figure 1).

2 | FEDERAL AND STATE GOVERNMENT-LED INITIATIVES

Federal and State Governments can expand existing investment in aged care services and local health districts by restructuring programs and activities to focus on brain

health and reduce cognitive decline risk. As CALD older adults and communities often have delayed presentation and consultation in the health-care system, a strengthened community approach is required—initial steps could focus on integrating culturally delivered home aged care packages for older people, through employing bilingual administrators and addressing the unique cultural values and traditional health beliefs of older adults within services associated with dementia risk reduction. For instance, culturally competent care such as physical fitness and social support activities can be delivered in the language of choice at Day Centres, or by reaching out to individuals at home in order to overcome accessibility issues.

Federal funding can also be used to create and market risk-reduction awareness videos and information booklets. State health care should lead the creation of a CALD Dementia Taskforce which includes health-care members, local health districts, health promotion officers, policy officers, dementia specialists and GPs to educate community leaders, cultural events organisers, bicultural support workers and local religious leaders regarding dementia literacy. Relaying health information in native speech and respective cultural norms would overcome cultural and language barriers.

Funding can be used in dementia research to increase the inclusion of CALD populations in study criteria through allowing services for certified interpreters' and/or bicultural workers' involvement and engagement while ensuring they uphold protocols. Funding can create further translation options for Australia's multicultural populations, such as interpreters, digitally translated surveys and printed information in different languages.

3 | PRIMARY CARE-LED INITIATIVES

Within primary care, culturally supportive GP clinics can further reduce the stigma of 'old-age retardation and

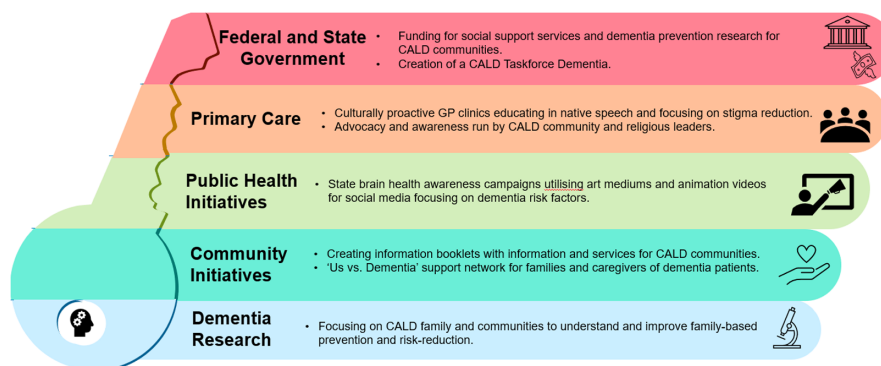


FIGURE 1 Key recommendations supporting dementia risk reduction initiatives for culturally and linguistically diverse (CALD) older adults and communities

crazy disease' through proactively informing patients and caregivers, in native speech, that dementia is not a characteristic of ageing and that they disagree with negative cultural attitudes. Older adults often approach their GP as their first point of contact: it is important to equip GPs with information to assist individuals to navigate through the health-care system and receive first-hand information on modifiable dementia risk factors.¹⁷ GPs from CALD backgrounds also have the advantage of understanding cultural beliefs and in delivering information and support through long-standing relationships without language and cultural barriers.¹⁷ They are also in the best position to initiate a whole-of-family approach in recommending dementia risk reduction strategies, as well as early detection involving active participation of family members.¹⁵ This approach has the potential to work in many cultural groups that have a shared, collectivist view in looking after older family members. While there is limited formal evaluation of existing primary health-care initiatives in Australia for dementia services to CALD groups, research evidence strongly suggests the need for bilingual community-based navigators to assist CALD individuals in accessing health services.¹⁸ Additionally, exploratory research in Victoria highlighted the importance of using a cultural exchange model to uncover the barriers and facilitators to seeking dementia care services among older people from CALD backgrounds.¹⁹ In some countries, such as New Zealand, a primary health-care program such as 'Your Local Doctor' was created to assist CALD communities and new immigrants to transition to a new health-care system, enabling access to health-care services and to drive enrolment with a local doctor in general practice.²⁰ Furthermore, health-care professionals in multicultural communities have a well-respected stature that families and older people from CALD backgrounds trust, which is crucial in tackling the social stigma associated with dementia by providing appropriate information to CALD communities.⁷

4 | PUBLIC HEALTH INITIATIVES

Targeting dementia risk across the lifespan, and particularly in older age, is necessary. Employing behaviour change techniques to modify dementia risk and/or delay onset is an essential step in health promotion and public health.³ State brain health awareness campaigns should use innovative forms that transcend cultural and ethnic disparities. One suggestion is that communication using art mediums (e.g. murals, film, dance) could be delivered in high-density traffic spots (e.g. GP waiting rooms, bus stops, aged care homes, libraries)²¹ frequented by cultural groups. A recent initiative addressing widespread

awareness in multicultural communities (*Moving Pictures*) shows excellent promise. This multimedia program co-produced by individuals from CALD backgrounds targeting dementia detection and diagnosis, care navigation and the caregivers' journey, has created 15 short films across five languages.²² This program has been exceptionally successful in addressing simplified dementia facts for CALD communities through visual stimuli; the films have been defined as 'boundary crossers' of language and understanding.²² Currently, *Moving Pictures* is developing dementia prevention awareness in CALD communities, with feedback and evaluations underway on the efficacy of information understanding and delivery in order to encourage behavioural changes. Crucial to their success is the involvement of CALD care service providers and families affected by dementia in the research design, implementation and dissemination processes. Engaging with key community leaders, CALD people with dementia and bilingual health-care workers facilitates knowledge exchange and raises awareness between trusted peers rather than service-based information from professionals.²³⁻²⁶

5 | COMMUNITY-LED INITIATIVES

Dementia awareness strategies should include the creation of information booklets with key culturally appropriate and relevant information. These should include support services for CALD communities with a focus on available community-based support activities and highlighting important information, for instance, local social groups incorporating physical activities for older adults, educating risk factors as well as promoting strategies to maintain cognitive function, and they should be presented in multiple languages. Booklets can also provide recipes and diet guidelines that cater to healthier versions of cultural foods. GP clinics can be a point of distribution during clinic visits and can encourage sign-ups for home packages at 50 and 65 years of age.

Community members could further help champion and advocate raising awareness in CALD communities and focus on building social acceptance in their social groups. Community leaders can approach priests and religious leaders as key navigators in CALD communities with a dementia stigma reduction plan to be included in weekly sessions to ensure wide reach. These initiatives strengthen a framework which combines education, making contact within the community and challenging unhelpful attitudes in order to reduce stigma.²³

Understanding that families are the main support system, instigating a network of 'Us vs. Dementia' that aims to build awareness and support for families and caregivers

for a whole-of-community approach is proposed. This network, involving community leaders, CALD Taskforce, Local Health Districts, patients, dementia-friendly families and caregivers, actively focuses on dementia-related psychosocial support and education for the entire support system of CALD dementia patients. It is crucial to acknowledge the important role families play in the care of CALD populations belonging to collectivist cultures: family and caregivers need dementia education and an awareness of potential risk factors in order to increase early presentation for diagnosis and its subsequent management. In order to provide families with the understanding and personal support they need to care for those living with dementia, there is a need to encourage community cohesion around dementia-friendly lifestyles, develop positive attitudes towards dementia, and enable supportive physical and emotional environments within the home and support services.

6 | OVERCOMING THE CHALLENGES

These recommendations do not come without challenges. Receiving additional government funding requires approval, and lobbying is generally required for further monetary aid from the Commonwealth Health Budget. However, funding policy advocacy to achieve healthy ageing and reductions in the health burden for CALD groups is possible, and lobbying the leaders who are committed to this cause is necessary.

A current challenge with GP clinics is their being unable to accommodate language preferences, thus alternative means of communication are required. This can be done through matching language information pamphlets and perhaps watching *Moving Pictures* (or other forthcoming campaigns) during the GP visit, as it reduces the need for translation.

Challenges related to brain health awareness campaigns can include inadequate collaborations, resulting in outdated ideas and lack of public engagement. This can be overcome by focusing on innovative media that speak to multicultural communities, for example, design from multi-ethnic art students from community organisations, and social marketing through popular social media forms targeting appropriate groups (e.g. WeChat for Chinese users). Community-led initiatives often suffer from a lack of appropriate involvement, as bringing patients, families and caregivers together with dementia organisations can be difficult due to busy schedules or engagement hesitancy. There are, however, helpful dementia organisations with large volunteer bases, and approaching these groups to build upon broader networks can help to launch the 'Us vs. Dementia' network.

7 | CONCLUSIONS

Our recommendations for dementia research are to focus on cultural, family and community research to better understand and improve family-based prevention and risk-reduction of dementia. We need the results of research analysing current community and family lifestyles, assessing the level of perceived education and understanding of dementia, its risk-factors, and the support required to create health promotion initiatives and intervention strategies. Further focusing on types of proactive engagement in dementia prevention activities that can be culturally accepted and incorporated in day-to-day activities is pivotal to ensuring the effectiveness and sustainability of the results of such dementia research.

Implementation of these recommendations has the potential to increase awareness, accessibility and support for CALD communities regarding dementia risk reduction. A whole-of-community and collaborative public health approach is essential for these recommendations to have their desired effect on the needs of Australian CALD communities.

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CONFLICTS OF INTEREST

Dr Jed Montayre and Dr Joyce Siette are Associate Editors for the Australasian Journal on Ageing. There are no other conflicts of interest.

DATA AVAILABILITY STATEMENT

Not applicable.

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