



An Australian Government Initiative

Strategic Directions in CALD Dementia Research in Australia



***CALD (Culturally and Linguistically Diverse groups)**

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Translating dementia research into practice



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INTRODUCTION

In 2006, one-quarter (5.3 million people) of the estimated resident population of Australia (21 million people) was born overseas as were 18 percent of those aged 65 and over (ABS, 2008). Forty percent of Australian residents had at least one parent born overseas (ABS, 2008). It is estimated that by the year 2011 there will be at least one million overseas-born older persons, with the number approaching 1.5 million by 2026 (ABS, 2002).

Persons from culturally and linguistically diverse (CALD) backgrounds are defined and grouped in many different ways for the purposes of service delivery and research. The phrase superseded by the phrase CALD in Australia was, persons from non-English speaking backgrounds (NESB) which refers to a categorisation solely on language use. Internationally the term CALD is not used, rather racial and ethnic minority groups are considered. For the purposes of this review, racial and ethnic minorities in international studies have been relabelled as persons from CALD backgrounds. While the many of the issues discussed here apply to Australian Aboriginal peoples, issues relating particularly to dementia and Australian Aboriginal people have been reviewed in a separate report. CALD subgroups have been defined by language preference – e.g. Arabic speaking, Spanish speaking (Access Economics, 2006). However these language use groups are heterogenous, a Spanish person from Spain may not be culturally similar to a Spanish speaker from Chile. CALD groups have also been defined by country of birth; however this definition excludes second generation migrants who differ from the Australian cultural majority (Khoo et al., 2002) and does not distinguish between culturally and ancestrally different groups from the one country – for example a native and Chinese Malaysians or Christian Orthodox and Jewish Russians.

The Dementia Collaborative Research Centres (DCRCs) have been conducting literature reviews and identifying gaps in knowledge in different areas relating to dementia in the context of translating research into practice. We defined topics relevant to CALD and dementia and invited experts in the field each contributed written literature reviews and a list of recommendations for future research on one or two of the topics that were circulated before a one day meeting. The topic areas were epidemiology (Brian Draper, University of NSW), community knowledge of dementia (Lee-Fay Low, University of NSW), carers (Benedict Cruysmans and Nicky Hayward-Wright, Alzheimer's Australia NSW), service delivery in the community (Georgia Zogalis, NSW Multicultural Mental Health Australia), screening and assessment (Dina LoGiudice, Royal Melbourne Hospital and NARI), medical management (Dina LoGiudice, Royal Melbourne Hospital and NARI), residential aged care (Ada Cheng, Australian Nursing Home Foundation), staff and training (Yun-Hee Jeon, Australian National University), Minority CALD (Georgia Zogalis, NSW Multicultural Mental Health Australia). Guidelines for the review were to include material relating to dementia and multicultural issues published in peer-reviewed articles and books and in the 'grey' non-peer reviewed literature (since there are relatively few peer-reviewed publications on CALD and dementia), drawing firstly on Australian research and secondarily on the international literature.

During the one-day meeting held at the DCRC at the University of New South Wales on the 17th of September, 2008, the experts gave an oral presentation, followed by group

discussion. The workshop participants reached consensus on priorities for research for each topic area, drawing on the recommendations provided by the experts.

The first part of this report that covers the nine topics relevant to CALD and dementia is based on the written literature reviews. The second part outlines challenges for CALD research followed by the key recommendations for research and this is based upon the written reviews, presentations and discussions which followed each presentation. The wording of these recommendations was subsequently refined through further work and discussion with the Alzheimer's Australia Cross-Cultural Network. The many recommendations for research proposed by workshop participants are listed in the Appendix.

EPIDEMIOLOGY

There have been no empirical studies of the incidence and prevalence of dementia in CALD groups in Australia. Access Economics were commissioned by Alzheimer's Australia to estimate the current and projected incidence and prevalence of dementia in Australians who do not speak English at home (Access Economics, 2006). They estimated that in 2005, around 12.4% of Australians with dementia (about one in eight) did not speak English at home. There was considerable variation between the states and territories, ranging from 3.5% in Tasmania to 21.0% in the Northern Territory, the latter mainly due to indigenous people. Prevalence rates were intermediate for Queensland (6.8%), Western Australia (11.5%), South Australia (12.0%), NSW (12.9%), ACT (14.7%) and Victoria (16.9%). Projections from 2001 to 2050 estimated that there would be an overall fall from 83.8% to 82.4% in the proportion of Australians who speak English. Language types are projected to shift from European to Asian & Middle Eastern languages. There is a different pattern in the projections of the proportion of the population with dementia who do not speak English with a decline expected from 12.4% in 2005 to 10.5% in 2040 before increasing again to 11.5% in 2050.

This report relied upon Australian, North American and European dementia incidence and prevalence data from 10-20 years ago projected to 2005 then superimposed upon projections from the 1986, 1991, 1996 & 2001 census data for language groups 'English', 'Other European', 'Asian', 'Middle Eastern', 'African & South American', 'Other' and 'Indigenous' languages. The resultant prevalence rates were projected to 2050.

This methodology is unlikely to produce reliable estimates for a number of reasons:

- Dementia prevalence studies often exclude subjects that cannot speak the national language so the projections are only likely to be correct if it is assumed that dementia incidence and prevalence in different CALD language groups is the same as in mainstream Australian, North American and European groups.
- The dementia incidence and prevalence data are now quite old and it might not be correct to assume that the current incidence and prevalence of dementia is the same as 10-20 years ago.
- The estimates rely on projections from census data that are also now quite old (2001).
- The census data only allow analyses into broad language groups so specific CALD populations are not examined.

- Projections to 2050 include assumptions about future immigrant group composition that might be inaccurate due to the inability to know where the future waves of immigrants might come from and whether they speak English.

It is increasingly apparent that lifestyle and environmental factors across the life cycle have a crucial contribution to the development of the dementia syndrome (Whalley, 2006). Factors that are of particular importance include education, diet, healthy and safe childhood and adolescence, physical exercise, substance misuse and socialisation. Epidemiological studies of dementia that compare ancestrally similar populations in US and Africa (Hendrie et al, 1995) and Hawaii and Japan (White et al, 1996) demonstrate the impact of migration and environment on dementia risk. Migrants have lower mortality rates than Australian non-indigenous persons, although this differs between migrant groups (Draper et al, 2005). In Mediterranean migrants to Australia, cardiovascular risk factors (some risk factors higher, some lower) and diets differ from Australian born (Powles, 2001). This suggests that the prevalence of dementia in CALD groups may differ to the English speaking population. In the USA, differences have been found in the prevalence and types of dementia in different CALD groups in the USA (Hou et al, 2006). It is unknown whether the types of dementia vary between specific CALD groups and the English speaking population and whether the clinical features and presentations of the dementia syndrome vary between specific CALD groups and the English speaking population. There are also differences in care arrangements and the effects of caregiving among different ethnic groups (see carers section below).

In summary, the currently available Australian estimates and projections for dementia prevalence and incidence in persons from CALD groups have significant limitations. An Australian prevalence and incidence study of dementia in CALD groups, including investigation of the risk factors, types of dementia and clinical features in specific CALD groups, is needed to assist in accurate planning of services. This epidemiological study could be conducted collaboratively with epidemiological studies in countries of origin of CALD groups.

COMMUNITY KNOWLEDGE OF DEMENTIA

Dementia literacy refers to a person's knowledge and beliefs regarding dementia. Dementia literacy may affect the timing and source of help-seeking, carer and community treatment of persons with dementia, and risk reduction behaviour.

There have been few qualitative studies of dementia literacy in CALD Australians. One study recruited 107 Italian Australians (age range 58-92 years) through community support groups and found that there was a low level of knowledge about the nature of Alzheimer's disease (Kinsella *et al.*, 2006). Alzheimer's Australia Victoria conducted 35 focus groups involving 383 participants in total from twelve CALD groups and found common to the CALD groups were a lack of knowledge of dementia, its symptoms and causes, stigma resulting in people being marginalized and isolated, and late diagnosis often at crisis point (Berisic, in press) .

All the international qualitative studies identified used a focus group methodology and had small sample sizes (between 3 and 39 in total) and most were conducted in

America. Poor knowledge cannot be confidently attributed to culture or race in qualitative studies as the effects of education and socioeconomic status were not controlled for (Connell and Gibson, 1997). Studies of Chinese have found that beliefs about the cause of dementia symptoms can stem from traditional beliefs systems (e.g. poor feng shui, imbalance of yin and yang, retribution for individual or family sins, possession of evil spirits) or based on personal observations or scientific research (e.g. a natural part of old age, lack of a stimulating environment, exacerbated by a move to a new environment, genetics, head injury, lifestyle) (Braun et al., 1995; Mahoney et al., 2005).

Vietnamese believe that dementia is a natural expected result of ageing, that it results from isolation and stress as a result of migration and that there is nothing that can be done for persons with dementia except to care for them, with a doctor or specialist consulted only when symptoms become very bad (Braun *et al.*, 1996). Filipinos saw dementia as a natural consequence of ageing and thought that nothing could be done; few were familiar with the term Alzheimer's disease (Braun *et al.*, 1995). South Asian Indians in India and the UK did not label symptoms of dementia with the term 'dementia' or 'Alzheimer's disease', could not distinguish the symptoms from normal ageing and tended to believe that individual and family efforts could reduce the symptoms (La Fontaine et al., 2007; Shaji et al., 2003).

Three studies of dementia literacy in non-English speaking countries that interviewed large random samples of 500 or more adults were identified. Hong Kong residents were found to have poor understanding of the symptoms of dementia with 60% thinking that dementia only affects one's memory and 25% thinking it is the same as Parkinson's disease, many thought that frequent exercise (79%), doing voluntary work (75%) and playing mahjong (70%) would help prevent dementia (Jockey Club for Positive Ageing, 2005). Only 4.4% of Sao Paulo residents applied the label dementia or Alzheimer's disease to a vignette describing mild symptoms, 46.6% described the person as having memory loss and 26.0% as ageing (Blay and Peluso, 2008). Social isolation was seen by 29.7% of respondents as the main cause of the symptoms, followed by drug use (19.2%) and a brain problem (13.1%). Japanese thought that dementia is forgetfulness due to ageing (92.3%), 37.8% thought that some types of dementia are treatable, 46% thought that some types of dementia are caused by cerebrovascular diseases and 10.6% thought that some types of dementia are hereditary (Arai et al., 2008). By comparison, the knowledge of the general Australian public on dementia symptoms was better with 82% recognising the symptoms of dementia from a vignette, over 80% believing that genetics, old age, brain disease, and stroke or mini-stroke contributed to a person getting dementia (Low and Anstey, in press).

There have only been a few quantitative studies comparing CALD knowledge regarding dementia to mainstream or White groups. Most of these were conducted in America on older samples (n between 191 and 1176). Whites/Caucasians have been consistently shown to have better knowledge of dementia than Latino, Asian, South Asian and Black groups (Roberts *et al.*, 2003) (Ayalon and Arean, 2004) (Connell *et al.*, 2007) (Purandare *et al.*, 2007). Level of education and years speaking English explained some of the differences (Ayalon and Arean, 2004).

In summary, qualitative studies suggest that some CALD migrants regard dementia as part of normal ageing and have poor knowledge and misconceptions that differ between

cultures about the disease and its causes. Comparing community based studies from non-English countries to an Australian study, suggests that on average, dementia literacy is higher in general Australian population. Studies that have compared CALD migrants to mainstream groups suggest that after adjusting for education and socioeconomic status, CALD groups have poorer knowledge than White or Caucasian groups. A limitation of this review is that only English language journals and reports were included.

To date, there has been no quantitative dementia literacy study in CALD groups in Australia. The DCRC is working towards filling this gap in the literature by conducting a population-based telephone survey of persons from Italian, Greek and Chinese backgrounds and third generation Australians. Information on the dementia literacy in other CALD groups is still needed. Further, the best approaches to improve dementia literacy in the different CALD groups is not known.

CARERS

The characteristics and circumstances of CALD carers vary widely, making them a diverse and complex group to cater for in terms of provision of information, education, emotional support and services. Differences exist not only between various groups in terms of race, ethnicity and culture, but within and across groups (Connell and Gibson, 1997; Sawrikar and Katz, 2008). The migrant experience, which includes physical and mental health, socio-economic status and personal life experience at time of migration (Orb, 2002; Kratiuk *et al.*, 1992) also needs to be taken into account when considering the welfare of CALD carers.

Qualitative research with Italian, Vietnamese and Chinese in NSW (n = 33) suggests that the dementia carer role is shared between multiple family members (Cultural & Indigenous Research Centre Australia, 2008). A Melbourne study found that carers from CALD backgrounds had a lower usage of community services and had a higher level of unmet needs compared to those from non-CALD backgrounds (Schofield, 1998). Carers from CALD backgrounds also have a lower level of access to respite care as well as reduced access to home and community-based services. Access to information about services was also significantly lower for carers from CALD backgrounds (Schofield, 1998).

Key issues have been identified that impact on the development and delivery of dementia specific information, services and support for CALD carers. The literature (Sawrikar and Katz, 2008; Cole and Gucciardo-Masci, 2003; St George Migrant Resource Centre, 2003; Dilworth-Anderson and Gibson, 2002; McMaugh, 2001; Curtin and Lilley, 2001; Lilley, 1999; Schofield, 1998; Papanicolaou and Fitch, 1996; Arkles, 1994; Kratiuk *et al.*, 1992) suggests the following key barriers:

- Poor English proficiency and low literacy in own language. This is further compounded by the use of professional and/or medical jargon (Alpi and Bibel, 2004).
- Non-identification of people from CALD backgrounds with the term 'carer' and the role of carers, and as a consequence, the unfamiliarity with the carer's status in the Australian health care system.

- Unfamiliarity with availability of services and how to access them.
- Cultural norms such as fear of community disapproval towards use of external assistance; overwhelming sense of ‘duty’ to provide support (care) and therefore feeling of guilt, shame or inadequacy if seeking outside assistance; and expectation that problems or issues are dealt with inside the family unit.
- Spouse carer’s high reliance on others to access support; especially on adult children.
- The perception that service providers or practitioners are not empathetic to issues associated with their ethnicity, which include dislocation, acculturation, identity and racism.
- Cultural stigma surrounding disability, mental illness and cognitive dysfunction.

Emotional responses such as grief, loss, guilt, anger, anxiety, helplessness, depression and fatigue; relationship problems with family or intergenerational conflict and loss of contact with social networks are compounded when these ‘hidden issues’ arise (Multicultural Mental Health Australia, 2004).

In recent Australian research, (Berisic and Nesvadba, 2008; Cultural & Indigenous Research Centre Australia, 2008) the following dementia specific issues relating to carers from a CALD background have been identified:

- Variations in perceptions of dementia, from a ‘normal part of ageing’, which was the most commonly expressed perception, to severe memory loss, or a mental illness.
- Lack of knowledge and understanding about dementia, its symptoms, causes and progression.
- The translation of the word ‘dementia’ in different languages can contribute to the lack of understanding about dementia.
- Influence of religion and culture on the level of understanding of dementia.
- Lack of understanding of dementia often results in diagnosis only being obtained at a crisis point. Seeking a diagnosis can be further delayed due to perceived stigma associated with the illness and feelings of shame.
- Linguistic and cultural isolation are compounded by dementia and the caring process (Kratiuk, et al. 1992), in particular moderate to severe dementia are associated with social isolation, community withdrawal, and in some cases marginalisation from the family unit.

Meta-analyses have shown that caregiver psychosocial interventions can reduce caregiver distress and delay institutionalisation (Brodaty *et al.*, 2003). Alzheimer’s Australia delivers the national Living with Memory Loss program for persons with dementia and their caregivers. Evaluation of the program showed that it has significant clinical impacts on the alleviation of depression in carers and a significant reduction in the amount of stress carers experienced by dementia related behaviours (Bird *et al.*, 2005).

There have been no Australian studies on the efficacy of caregiver support programs for CALD groups. A qualitative study in the UK of Black Caribbean, 10 south Asian, 12 White British suggest that specific cultural attitudes towards the caregiving role have

important implications for how carers can best be supported (Lawrence, 2008). The El Portal Latino Alzheimer's Project in Los Angeles County, USA was initiated in 1992 as a dementia-specific outreach and services program targeting Latino caregivers. The project is an inter-organizational community-based collaboration developed to provide an array of coordinated, ethnic-sensitive services to Latino dementia-affected adults and their family caregivers, using culturally specific outreach and services delivery strategies with the aim of promoting access and entry to dementia care services. The program resulted in fewer barriers to care and greater service utilisation, with Spanish-language Helpline calls increasing by 50% from the pre-program period (Aranda *et al.*, 2003). In a study of the value of telephone support groups conducted in English and Spanish 41 White and Cuban American dementia caregivers, 81% of participants found the group valuable largely because of the social and emotional support and useful information obtained from other group members. The majority of caregivers also reported that their participation had increased their knowledge and skills as caregivers (Bank *et al.*, 2006).

In summary, barriers to accessing services including language proficiency, culture, religion, family dynamics and lack of awareness of relevant services are further compounded by the stigma associated with dementia and lack of understanding and knowledge of dementia. While there are dementia specific services and support programs for people from CALD backgrounds, qualitative research has not been undertaken into appropriateness and effectiveness of these services. Additionally, there is no Australian research on how to effectively improve awareness and education, and deliver caregiver support programs to CALD carers of people with dementia. Efforts to address the needs of CALD people with dementia include ethno-specific nursing homes, cluster nursing homes (i.e. encouraging the admission of people and hiring of staff from the same cultural group) and organising specific days at day centres for different cultural groups (see below).

SERVICE DELIVERY

The under-utilization of all types of mainstream non-Government Organisations and Government services by people from CALD groups in Australia is well documented (Multicultural Mental Health Australia, 2004; Hassett and George, 2002). In rural Victoria, Home and Community Care (HACC) clients born in non-English speaking countries received 35% fewer hours of HACC service and used a smaller range of HACC services than their Australian-born counterparts (Ward *et al.*, 2005). In Eastern Sydney, Australian born clients and clients who spoke English at home had more service days as part of their Community Aged Care Package (CACP) than non-English speakers and migrants (Thomas, 2007). Patients of non-English speaking background with dementia presented at a later stage of their disease to a Melbourne memory clinic (LoGiudice *et al.*, 2001).

There are numerous factors contributing to the under-utilisation of services by persons of CALD background, however most of the Australian research that has examined service delivery is of low quality, mainly comprising uncontrolled case series and anecdotal qualitative reports.

Lack of English proficiency

English language proficiency is pivotal to the experience of persons from CALD backgrounds, as it has a marked impact on social and cultural integration, employment prospects, remuneration and access to services (Runci et al., 2005a). For persons who speak English as a second language, the onset of dementia often results in a loss of competency in English early in the course of a disease (South Western Sydney Area Health Service, 1992; Lewis and Kirchener, 1996). This increases the difficulty in obtaining assessment and services.

Lack of knowledge of or reluctance to use services

Different perceptions of symptoms of dementia in different cultural groups have already been discussed. In some cultural groups, the behaviours of a person with dementia may not be brought to the attention of medical professionals; instead, these behaviours may be normalised or self-treated (Dilworth-Anderson and Anderson, 1994).

A qualitative study of older Italian, Greek, Arabic and Chinese speakers in Eastern Sydney found that most were unaware of most types of community services (Eastern Sydney Multicultural Access Project, 2002). This may be because services may not be available in countries of origin and lack of promotion of services in their preferred language.

For some cultural groups, distrust of mainstream care providers, coupled with their own cultural perceptions and meanings of dementia, may prohibit them from seeking help outside the family (Dilworth-Anderson and Gibson, 2002).

Limited availability of culturally appropriate services

Generally mainstream services are not culturally or linguistically reflective of the needs of CALD consumers (Pensabene and Wilkinson, 1986), do not employ bilingual staff to meet the extent of demand, do not promote services to CALD groups using suitable methods and mediums and do not use community development strategies to recruit, retain and involve CALD groups.

Ethno-specific models of care that cater for specific CALD groups are the most popular (Multicultural Communities Council SA, 2007) and most utilised services by people of CALD backgrounds. Multicultural services are also well utilised by CALD groups, with brokerage models e.g. Community Aged Care Packages (CACPs) are extremely popular. Partnership services involve the partnership between mainstream and ethno-specific organisations, with the ethno-specific organisations providing the mainstream organisation with relevant skills and resources to deliver relevant services to the ethno-specific group. These services however are limited and vary inconsistently from area to area and state to state although these variations are not due to demographics or levels of need.

Difficulty accessing care

An American qualitative study on a convenience sample of Blacks, Chinese and Whites found that a higher proportion of pathways to diagnosis for Blacks were precipitated by a crisis and a higher proportion of pathways for Chinese led to a dead end than for Whites (Hinton, 2004).

Difficulty in obtaining a diagnosis of dementia may delay referral and access to care. Culturally appropriate diagnostic and screening tools are lacking for dementia, which

may result in inaccurate diagnosis of dementia in CALD groups. The Rowland Universal Dementia Assessment Scale (RUDAS) tool is culture-fair (Rowland et al., 2007), however its use by mainstream–specialist assessment services/providers such as aged care assessment teams (ACATs) and general practitioners is very limited (Cultural & Indigenous Research Centre Australia, 2008). Screening and assessment reviewed in more detail below.

ACATs are frequently reported as being inaccessible and under-utilised by older people from CALD backgrounds, the main reasons being the inappropriateness of their generic services in addressing the 'special needs' of CALD older people; the lack of bilingual/bicultural staff; the dominance of medical staff; and their use of inappropriate assessment tools (Multicultural Mental Health Australia, 2004).

In summary, lack of English proficiency, lack of knowledge of or reluctance to use services, lack of culturally appropriate services, and difficulties accessing care result in underutilisation of services by CALD groups. There has been no systematic Australian study of the pathways and barriers to accessing care, their relative importance and how to improve these pathways. This would inform the development of an appropriate model of service delivery for different CALD groups.

SCREENING AND ASSESSMENT

Screening instruments are an integral part of the case finding process for the detection of dementia, in particular for populations that are at high risk. Clinicians under-diagnose cognitive impairment if cognitive instruments are not utilised. Screening or case finding is the first stage of the diagnostic process, following which a more detailed cognitive evaluation is required (Flicker, 2005). A range of instruments can be employed at the various stages of assessment.

The majority of cognitive instruments available in developed countries have an educational and cultural bias (Parker and Philip, 2004). Prince et al for the international 10/66 consortium (2003) stated that the educational bias of some elements of tools such as the Mini-Mental State Examination (MMSE) reduce their utility for cross cultural assessments in epidemiological research, particularly in developing countries.

To develop culturally appropriate assessment tools, either existing ones have to be modified or new culturally specific tools developed. There is much research on the former, where the MMSE, for instance, has been translated into numerous languages but contextual differences often occur, even within the same culture (Ganguli and Hendrie, 2005; Chiu and Lam, 2007). Cut points often need to be changed and these modifications limit comparability between groups (Klimidis and Tokgoz). Other tools translated and assessed within multiethnic groups include the Clock Drawing Test, Mini-Cog, GPCOG and Montreal Cognitive Assessment (MoCA) (Borson et al., 1999; Parker and Philp, 2004).

If a new culturally appropriate screening tool is developed, the items must be culturally appropriate and relevant or the questions may be deemed irrelevant and responded to accordingly. It should be easily translated into different languages without loss of concept and context and not be influenced by education. Understanding of health beliefs and cultural norms is important, which assumes involvement of the local community.

A number of approaches have been suggested to ensure culture-fair, education-free instruments that have undergone translation and back translation to provide criterion and cultural equivalence. The 10/66 group has documented this process extensively in developing countries for diagnostic interview schedules such as the Geriatric Mental State schedule, Community Screening Interview -Dementia and the 10-item word list (www.alz.co.uk/1066).

In Australia there are a number of issues that add to the complexity of screening and assessment of dementia. History of migration (from few to many years ago), war experiences, different levels of acculturation for people and their families, levels of family and social supports, education (and all its meaning), literacy, language (12% Australians with dementia don't speak English at home) and the sheer number of different groups are just a few of the confounding factors (Johnstone and Kanitsaki, 2008; Access Economics, 2006).

Research in Australia on Screening

The MMSE has been translated into many languages. More recently the RUDAS (Rowland Universal Dementia Assessment Scale) was developed in Australia as a screening tool (Storey et al 2004). Its benefit is that it is easily translated without the need to change the structure or format of any item. Initial data on moderately severe clients was promising. More recently the RUDAS was reviewed in memory clinic group of 151 patients (with mild symptoms of dementia) in Melbourne and Adelaide and compared with the General Practitioner Assessment of Cognition (GPCOG) and MMSE (Rowland et al., 2007). The RUDAS was not influenced by CALD status, age or education. Sensitivity was 87.7% and specificity 90% at 23/30, with AUC was 0.94 for dementia diagnosis. Cognitive Impairment Not Dementia was also accurately assessed. This group mainly comprised of Greeks and Italians. In the same group the GPCOG was assessed. As with RUDAS it did not appear to be influenced by CALD status but was influenced by age, and the informant section appears free of bias. The GPCOG, an Australian instrument was not initially developed in a CALD group (Basic et al in press, Basic et al in press) but has been translated and validated in French and Italian populations. The RUDAS is being used to assess its utility in urban Indigenous people

Assessment and diagnosis

The assessment and diagnosis of dementia involves consideration of many domains

- cognition
- function
- behaviour

It requires the exclusion of delirium and depression and relies heavily on informant history

The lack of gold standard for diagnosis of dementia generally confounds accurate validation processes. Is it possible to develop gold standard guidelines to suit all cultural groups? Much work has been undertaken by the 10/66 programme, where documentation of a procedure for diagnostic assessment is described.

Neuropsychology is frequently utilised to assist diagnosis, but international data report that despite adjustments for age, gender and socioeconomic status, changes due to ethnicity may still persist, and some differences may occur within the same ethnic group, e.g. in USA, when matched on socioeconomic status and education, whites did better on visual naming than African Americans, and Hispanics scored less well on non verbal abstraction, category fluency and comprehension (Manly & Espino, 2004). Similar issues relate to assessment of speech disturbances in dementia.

Functional assessment appears less affected by cultural issues, but there is evidence from developing countries, particularly those in Asia and Africa, that specific adaptation may be required for different traditional societies. The different complexities of living environments, degree of family assistance and gender inequality with tasks may have an impact on functional outcome. A number of different assessment tools have been developed, for instance the Everyday Ability Scale for India and Clinician Home Based Interview to assess Function (Hendrie et al, 2006; Chiu and Lam, 2007, Ganguli and Hendrie, 2005).

An informant history is important in forming a diagnosis of dementia and the Informant Questionnaire on Cognitive Decline (IQCODE) and Psychogeriatric Assessment Scales (PAS) (both developed in Australia) have been validated in various languages and countries. However issues of differing perception of dementia, reluctance to disclose information, need to be further elucidated in the Australian setting. The utility of combining different tools to assist with assessment in different settings needs to be investigated further (Jorm, 2004).

In summary, most available screening and diagnostic instruments may be culture and education biased. The RUDAS is an Australian screening instrument designed to be language and culture fair with promising psychometric properties, however it needs further validation such as in its use by different CALD groups, in different settings (general practice, acute hospitals, community service providers) and in measuring change. Guidelines for screening CALD groups in different settings are required.

There has been limited research on the development of culturally valid measurement instruments for diagnosis. The measurement of cognitive function may not be diagnostically discriminatory in CALD groups, without norms for those individual groups. The measurement of functional change may be more useful, however instruments measuring change, collecting an informant history and excluding other conditions need to be developed and validated in an Australian context. Until these are available, it would be difficult to draw up evidence based guidelines for assessment of dementia in CALD groups in different settings.

MEDICAL MANAGEMENT

This broad area covers matters such as behaviours of concern, delirium, drug use, end of life issues and many others. Australian based CALD research on this topic is limited.

Delirium

There is a paucity of research on the presentation, detection and management of delirium in those of CALD background. A recent inpatient delirium study (Jeffs K et al,

2005) revealed high prevalence of delirium in CALD group (21%, n=98) but CALD was not found to be a significant risk factor for delirium. The report demonstrated that the diagnosis of delirium in acute setting is generally poor. However a retrospective study of delirium in hospice care in the US found significantly higher rates of delirium were documented in Caucasian patients compared with other ethnic groups suggesting the possibility of under-recognition in non-Caucasians (Irwin et al, 2008).

Drug treatments

Those of CALD background are generally not included in drug research, despite their willingness in many cases. It is not clear whether there are differential use and responses to treatment by cholinesterase inhibitors among persons with Alzheimer's disease from CALD groups, and if so what the reasons are. Similarly, differences between the use of antipsychotics amongst cultural groups are not well documented. An American study found that in Medicare beneficiaries antipsychotic medication use was 30% higher in Whites than other CALD groups (Zuckerman, 2008). A systematic review and meta-analysis in the risks of adverse reactions to drugs used in the treatment of psychoses and depression found limited evidence of ethnic differences. The findings were restricted by confounding factors and lack of data on different ethnic groups in drug trials (Ormerod et al, 2008). A review of the tolerability of SSRI antidepressants noted that pharmacogenomic research has shown differences between Asians and Caucasians. Higher rates of polymorphisms in the cytochrome p450 enzyme that is involved in drug metabolism are found in Caucasians than in Asians, while the effects of serotonin transporter gene polymorphisms upon depression outcome and adverse effects are different in Caucasians and Asians (Draper and Berman, 2008).

Behavioural and Psychological Symptoms of Dementia (BPSD)

There is some evidence internationally of cultural differences in the expression of BPSD and different cultural responses of carers. BPSD are important causes of distress, increase the risk of residential care, hospitalisation and length of stay, and often leads to chemical and physical restraint (Shah, 2007).

Most studies addressing this issue are conducted in convenience samples. A number of specific tools developed in Western settings have been adapted for other cultures, such as the Cohen Mansfield Agitation Inventory (CMAI) in Chinese, Norwegian, Dutch, Korean, Spanish, Italian and Japanese and the Neuropsychiatric Inventory in Italian, Japanese, Polish, Spanish, Belgian, Korean, Dutch, Norwegian, Greek, French and Yoruba. The Geriatric Mental State (GMS) structured interview utilised by the 10/66 research group provides a diagnostic psychiatric category. There are also a number of instruments that have been adapted and translated for screening of depression e.g. the Geriatric Depression Scale.

The 10/66 Dementia Research Group (2004) found overall levels of BPSD in community-dwelling persons with dementia in developing countries, including China, India and Latin America, to be similar to that of developed countries. Consistent with this an Australian study found that that overall rates of BPSD were similar among Chinese residents with dementia in nursing homes in Shanghai and in Chinese-specific homes in Sydney and in non-Chinese residents of mainstream Sydney nursing homes (Wu et al, in press). However a number of studies have shown differences in types of BPSD between CALD groups, e.g. delusions in Nigerians were 1/5 those of African

Americans in Indianapolis, and more common in African compared to white Americans in a dementia care centre group. Italian Alzheimer's disease patients are more irritable and agitated than Americans (Shah et al., 2005). Black and Latino community-dwelling patients with moderate to severe dementia have a higher prevalence of dementia-related behaviours than whites (Sink et al., 2004). Research limitations include small samples, use of different tools, and lack longitudinal follow-up.

Practice guidelines for the management of BPSD in CALD populations are being developed by the Dementia Behaviour Management and Assessment Service (DBMAS) in Western Australia but they have yet to be finalised and evaluated (Lynn Hedley, personal communication, 2009).

End of life issues

Cultural differences by clients and families, and health providers in response to end of life issues are documented, for example around the use of PEG (Percutaneous Endoscopic Gastrostomy) in those with dementia (Manly and Espino, 2004). There are different approaches to palliation between doctors from Netherlands and US (van der Stern et al., 2004). A systematic review of barriers to hospice use among African-Americans in the US found six main themes: traditional African-American values were in conflict with the hospice philosophy; economic factors; lack of awareness of hospice care; mistrust of the health care system; concern about family burden; and anticipated lack of minority employees (Washington et al, 2008). A study of hospitalized seriously ill US veterans of Caucasian, Hispanic and African-American background found that end-of-life treatments in patients with dementia were more likely to occur in Hispanics and African-Americans than in Caucasians particularly with regards to mechanical ventilation (Braun et al, 2008).

A recent study of Spanish-speaking subjects in the US demonstrated that perceived cultural differences in end-of-life preferences in advanced dementia were largely a function of poor comprehension that could be overcome by education using a video presentation of a person with advanced dementia (Vollandes et al, 2008). This study is a good demonstration of how apparent differences between ethnic groups might have more to do with broad issues such as education and linguistic ability than cultural background.

In summary, there is almost no Australian research on the medical management of persons from CALD backgrounds. Critical gaps include how to best assess and manage delirium, CALD access and response to drug treatment (cholinesterase inhibitors, antipsychotics and alternative medications), cultural differences in BPSD expression and management, and cultural differences in end of life issues.

RESIDENTIAL AGED CARE

In 2002, the Australian Government spent more than \$3.2 billion supporting people with dementia, with 88% of this money funding residential care placements (Access Economics, 2003). Over one-quarter of permanent residents in residential aged care facilities in Australia (27%) were born overseas, with 11% born in the United Kingdom

and Ireland and another 11% born in other areas of Europe. Almost 10% of permanent residents preferred to speak a language other than English.

Overseas born persons have lower rates of permanent residential care than Australian born. The number of Australian-born people receiving permanent care was estimated to be 55.8 per 1,000 persons aged 75–84 years and 251.6 per 1,000 aged 85 years and over. The corresponding rates for English-speaking people who were born overseas were 46.9 and 234.4 per 1,000, respectively, and the corresponding usage rates for overseas-born people whose main language was not English were 46.5 and 192.5 per 1,000, respectively (AIHW, 2008).

In 2007, there were 170,071 residential aged care places in Australia (AIHW, 2008). Mainstream nursing homes comprise of the majority of facilities, although some have voluntary ‘clusters’ of language-specific groups with provisions made to accommodate CALD needs. There are few ethno-specific nursing homes, although they are very popular with CALD groups, with very long admission waiting lists (Multicultural Mental Health Australia, 2004). In Victoria, only 80 of 868 (9%) facilities were listed as ethno-specific (DPS, 2001), and we estimated that in NSW 7.3% of residential beds are ethno-specific. In recent times, there has however been an increase in the number and language coverage of ethno-specific nursing homes and hostels (Cultural & Indigenous Research Centre Australia, 2008).

Older people prefer to reside in a facility which caters for their own cultural background (Westbrook and Legge, 1992). Mainstream residential care facilities generally fail to respond to the cultural and linguistic needs of residents from CALD backgrounds, with limited acknowledgement of their cultural and culinary needs (Pensabene and Wilkinson, 1986). Further, many CALD dementia residents have limited English proficiency. Forty percent of NSW nursing home residents and 54% of hostel residents born overseas had either only basic English language proficiency or none at all (Lazarus, 1992). Living in facilities where there are no co-residents from their CALD group, where the resident is unable to communicate in their own language is likely to be an isolating and lonely experience (Pensabene and Wilkinson, 1986; Runci et al., 2005a).

Direct care staff and health professionals who speak the resident’s language are critical for care. CALD background residents in mainstream care often do not have access to staff members who can speak their language (Runci et al., 2005a). Two studies of nursing home residents in Sydney found that 55% and 66% of residents were unable to speak to any staff members in their own non-English language (Legge and Westbrook, 1989; Patetsos and Ruddell, 1989). A more recent study of nursing home residents in Melbourne found only 56% of surveyed facilities had at least one staff member who spoke to residents in their own non-English language (Runci et al., 2005a).

Australian research led by Susannah Runci suggests that dementia patients living in ethno-specific nursing homes are better off than their counterparts in mainstream facilities (Runci et al 2005b). They found that Italian speaking residents in mainstream facilities had a significantly higher rate of prescription of daytime tranquilisers than those in Italian speaking facilities, and that residents in Italian specific facilities engaged more often in meaningful communication in the Italian language than those in

mainstream facilities. Interventions administered in Italian were more effective in reducing difficult behaviours than when administered by the same therapist in English.

The provision of ethno-specific residential care facilities to all older persons from CALD background may not be feasible (Runci et al., 2005a). Access to ethno-specific residential care is even more limited for newly arrived, geographically dispersed and smaller CALD groups (Benham and Gibson, 2000). Hence, the provision of relevant aspects of ethno-specific care within mainstream residential facilities enables the needs of a larger, more heterogenous population of persons from CALD backgrounds to be met (Runci et al., 2005a).

In summary, there is some weak evidence that ethno-specific care results in better quality of life for persons with dementia from CALD backgrounds. Appropriate models of residential care for different CALD groups within ethno-specific and mainstream homes need to be developed. To facilitate this, assessment tools need to be developed that are valid for measuring outcomes such as quality of life and quality of care for CALD dementia residents.

STAFF AND TRAINING

The cultural competence of health care workers is critical in providing care that is conducive to the needs of people with dementia and their families/carers with CALD backgrounds. The term cultural competence refers to “the awareness, knowledge, skills, practices and processes needed by individuals, professions, organisations and systems to function effectively and appropriately in culturally diverse situations in general and in particular interactions with people from different cultures” (Bean 2006, p.10). A basic tenet of cultural competence is to acknowledge that culture changes over time; and that culture is not homogenous but varies depending not only on the person’s ethnic, racial, linguistic and religious backgrounds, but also on his/her socio-economic, educational and generational status. (Zoucha & Husted 2000). Health care workers will need to learn how to communicate effectively with people in providing quality care and how to reverse the tendency to stereotype individuals from particular cultures, while at the same time being sensitive to their culturally defined needs (Chenoweth et al, 2006).

Campinha-Bacote (1994, 1999, cited in Brathwaite 2005, p.362) suggests five key elements of cultural competence necessary in the provision of effective and quality care for people with CALD backgrounds. Applied to dementia care, these elements include:

- Cultural awareness - being appreciative of and sensitive to the values, beliefs, life ways, practices, and problem solving strategies of the person with dementia’s and the care worker’s own culture.
- Cultural knowledge – having a particular knowledge on dementia in different ethnic groups, their attitudes towards dementia and the ways they manage and treat dementia
- Cultural skill - based on cultural awareness and knowledge culturally appropriate assessment of people with dementia should take place
- Cultural encounter - developing skills to communicate and interact with people with dementia and their families effectively
- Cultural desire - wanting to engage in the process of cultural competence.

No study has been identified that examines the level of cultural competence of the Australian health care workforce. However, there is clear evidence that patients and their families experience challenges because of health care workers' lack of cultural competence and lack of respect for cultural difference, leading to calls for further education and training of cultural competency for health care workers within the Australian health system (Lee 2004; NSW Health 2001; NSW Department of Ageing, Disability and Home Care, NSW DADHC, 2008). For example, nurses' inability to deal with an unfamiliar culture has been found to be the main obstacle to effective communication and care for health consumers in the CALD group, often leading to health consumers' anxiety, ethnocentrism and prejudice in the health environment (Kanitsaki 2003; Omeri 2004). A review of the international literature found that communication between doctors and CALD patients is poorer than with White patients, with differences stemming both from the behaviour of doctors and the CALD patients (Schouten and Meeuwesen, 2006).

Despite a diversity of the programs and methodological approaches, studies examining the effectiveness of different models or types of training developed to improve cultural competence of potential-students and health care professionals consistently suggest positive outcomes in terms of improving cultural competence (Brathwaite 2005). Comparisons of three timeline evaluation surveys (pre-, immediate post- and longitudinal post-) involving 515 Australian public sector employees found that training programs produced the desired outcomes at the individual, organisational and system level (Bean 2006). However no research has been identified that describes the extent to which the Australian health and education system provides learning opportunities for students and health care workers to develop cultural competence.

Health care workers from CALD backgrounds

The number of health care workers from CALD backgrounds in Australia is increasing, reflecting trends in the global movement of health care workforce, often triggered by the workforce shortages in developed countries (Hawthorne 2001; Kingma 2001; Omeri & Atkins 2002). Data from the 2006 Australian census shows that 50% of generalist medical practitioners, 42% of specialists, 47% of dental practitioners, and 27% of Nurses were born overseas, with recent arrivals more likely to be trained overseas (ABS, 2008b). There is no structured program, or model, to assist with this particular group of health care workers to develop enculturation to the workplace, nor to ensure their competence to practice as qualified health care practitioners.

One of the key challenges that Overseas Qualified Nurses (OQNs) experience is communication. This is particularly the case for those who are newly employed and those nurses from non-English speaking background (NESB) when communicating with their English speaking colleagues, patients/residents and family members. Difficulties with communication can significantly impact on the OQN's competence in providing care, working as a team member, and gaining career development, consequently experiencing mental and social isolation, homesickness and dissatisfaction with their work. Other challenges OQNs face include their lack of knowledge about the expansive nature of the Australian health system, unfamiliar care practice and work environment, particular emphases on staff rights/responsibilities and interaction mores with professional colleagues, and differences in policy directives and nursing and medical procedures. Induction or orientation programs offered to all new staff provide relatively limited information on the Australian health care system and policies (Jeon and

Chenoweth 2007). The issues and challenges that non-nursing workforce is facing are likely to be similar and could be greater for dementia/aged care workers if they do not have sufficient training in dementia care.

Since the mid 1990s, the source countries of International Medical Graduates (IMG) have become increasingly diverse, extending to countries where education and competency in the English language are variable (Charles et al., 2004). The journey of IMGs from their roles in major psychiatric hospitals overseas to the practice of psychiatry in rural Victoria, is long and often complicated from clinical, social, emotional and spiritual perspectives (Haines and Browne, 2007). Elements to be considered include the impact of the IMG's previous methods of learning, protocols and processes in their homeland, communication style and subculture from which the IMGs came, and flexibility and adaptation capacity of the IMG to acculturation processes (Haines and Browne, 2007). Numerous sources (McGrath, 2004; Postgraduate Medical Council of Victoria, 2004; Spike, 2006) have reported that IMGs receive insufficient orientation to the Australian health care system and Australian culture, and that IMGs experience many stresses in their personal lives—separation from family, inadequate employment opportunities for a spouse, and cultural isolation.

Recommendations for future research

In summary, there is no or limited research that examine the level of cultural competence of the Australian health care workforce or the effectiveness of different models/types of training designed to develop cultural competence of health care practitioners. Knowledge on the extent to which the Australian health and education system provides learning opportunities to develop cultural competence and how overseas trained health care workers make the transition to the Australian health care system is also limited.

MINORITY CALD

Older people from CALD background may suffer stress in relation to loss, past traumatic experiences, war, isolation, physical illness or disability. Nostalgia and loss of hope of returning to the homeland and increased inter-generational conflict are particular stressors in the later years of life for CALD elderly. Further, older victims of torture and trauma may experience repressed or recurring memories which become magnified in old age and the reversion to long term memories during dementia. Further, biological, psychological and social factors, including social disadvantage contribute to increased risk of isolation and depression which may mask the incidence of dementia

Refugees

Between 1951 and 2006 more than 675,000 refugee and humanitarian program entrants, including their families, have settled in Australia. Australia receives up to 13,000 people each year under the Refugee & Humanitarian program, with approximately 60% of these entrants settling in NSW & VIC. Over the last five years the proportion of refugees who come from Africa has increased. The backgrounds of refugees entering Australia in 2004-05 were as follows: Africa 66%, Middle East 29%, Europe 6%, and Asia Pacific 4% (FASSTT, 2006).

Torture and trauma survivors

A number of older people of CALD backgrounds in Australia have been the victims of dehumanising experiences, incarceration, fractured inter-personal relations (including entire family destruction) and traumatic life transitions. (Hanan and Williams 1989). Nguyen and Bowles (1999) found that between 25% and 35% of refugees admitted to Australia had experienced torture. It has been estimated that Australia has as many as 20,000 refugees still suffering the acute and chronic effects of torture and trauma. In 2004/2005 more than 11,000 survivors of torture and trauma received FASSTT (Forum of Australian Services for Survivors of Torture and Trauma) agency services.

Torture and trauma survivors and suffer from extreme levels of depression and anxiety, which manifest in sleep disorders, recurring and intrusive memories, poor self-esteem, difficulty concentrating, sadness, fear, anger, psychosomatic complaints and breakdown in family and personal relationships. Past experiences can also damage the bonds between members of refugee communities and their trust in mainstream institutions and society. A study of the effects of ageing on Holocaust survivors in Sydney (Joffe et al., 2003) found that fifty years after World War II, the traumatic effects were still evident. Survivors were functioning well socially and occupationally, however they had with increased psychological morbidity, sleep disturbances, nightmares, and higher use of anxiolytics and hypnotics; the more severe the trauma, the worse the consequences.

Trauma may increase the risk of developing dementia. A 30 month Croatian study of 538 polytraumatised refugees and displaced persons and 538 nontraumatised controls found that the risk of dementia was increased in the refugees (Folnegovic-Smalc, 1997). Persons who develop dementia often revert to long-term memories which, anecdotally, exacerbate feelings of severe stress, anxiety and flashbacks from previous negative experiences. It has been suggested that cognitive decline may disinhibit post traumatic stress disorder symptoms (Cook, 2003). Several small studies of war veterans have suggested that past trauma may be associated with more behavioural disturbance in dementia (Verma, 2001; Carlson, 2008)

Unsupported minority groups

In Australia, there are some CALD groups whose older people populations consist of the majority of their total speaking community, e.g. Estonians 70%, Latvians 67%, Lithuanians 66%, Ukrainians 57%, and Dutch 55%. Since older persons tend to be less likely to request services, these CALD groups without younger advocates may consequently be even more unsupported by the health system. Other minority CALD groups that have received little research attention include those with a mental illness and unsupported newly arrived older persons on Family Reunion schemes.

In summary, there has been little research on dementia and refugees, torture and trauma survivors and unsupported minority groups. The little evidence suggests that torture and trauma survivors may be at increased risk of dementia and behavioural disturbance.

CHALLENGES IN CONDUCTING CALD DEMENTIA RESEARCH

Research into dementia often excludes persons from CALD backgrounds, and there has been relatively little research focusing specifically on CALD groups in Australia. One reason for this research paucity is because of the challenges in conducting CALD research which include:

- Validated assessment instruments are rarely available. Hence, almost all instruments need to be validated for the CALD groups being studied.
- Cultural differences may necessitate differences in research design – CALD groups often share caregiving, hence education and support programs usually for a single caregiver may need to be broadened to include multiple family caregivers.
- It is more difficult to recruit bi- or multilingual research staff with the clinical and research skills necessary to conduct the research. All components of spoken or written interviews or surveys need to be appropriately translated and checked by a skilled translator. Use of interpreters may introduce bias as the exact translation used may vary between interviews and can up to double the length of an interview.
- Recruiting representative samples of CALD groups requires different methodologies to recruitment of representative non-CALD samples. CALD groups are less likely to participate in mainstream research (Faison et al., 2007; Olin et al., 2002); the reasons for this is are unclear.
- Multiple CALD groups need to be studied in order to draw conclusions about the generalisability or specificity of results. If multiple groups are included then methods and tools need to be appropriate for all groups studied.
- There is limited expertise on the conduct of CALD research.
- The significance of some CALD research projects can be limited, decreasing the likelihood of grant funding. CALD studies need to be designed so that they answer important questions or inform on broader issues.
- If comparisons are to be made with mainstream groups, an appropriate mainstream sample needs to be recruited, and possible confounding by education, language, culture and socioeconomic status needs to be considered.
- The above challenges increase the cost and time required to conduct the research.

SUMMARY OF KEY RECOMMENDATIONS FOR FUTURE RESEARCH

The final part of the one day meeting comprised group discussion to achieve consensus on a key research recommendation for each research area. All attendees were involved in this discussion.

1. **Epidemiology:** Conduct a longitudinal prevalence and incidence study of dementia in Australia that includes CALD persons and also examines the types of dementia, presentation and service use.
2. **Community knowledge:** Identify, develop and evaluate model/s to improve dementia literacy in the community.
3. **Carers:** Identify, develop and evaluate model/s of education to improve dementia knowledge of family and carers in a community context
4. **Service delivery:** Outline pathways and barriers to care including GPs, hospitals, community services, ACATs and residential care.
5. **Screening and Assessment:** Develop and evaluate a valid comprehensive set of CALD appropriate dementia assessment tools including assessment of function and caregiver burden. The RUDAS needs further validation in different settings and dissemination strategies developed.
6. **Medical management:** Better understanding of how being from a CALD background influences medical management and impacts on care outcomes. e.g. delirium, BPSD.
7. **Residential Aged Care:** Identify factors that improve the wellbeing of residents in aged care including comparison of mainstream, clustered and ethno-specific care
8. **Staff and training:** Establish quality evidence on the effect of the cultural competency of care workers on outcomes for persons with dementia and develop and evaluate dementia training (including training for workers from CALD backgrounds) based on this evidence.
9. **Minority CALD:** Examine the impact of refugee and refugee-like experiences on dementia prevalence and symptoms

For the above recommendations to be implemented, we need to develop a climate where research in CALD dementia will occur. ARC and NHMRC should consider making CALD research a priority area. This will be an iterative process involving research funders, policy makers, researchers, service providers and community groups. A central repository for resources and results for CALD and dementia may facilitate research.

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Appendix

Epidemiology

1. A longitudinal epidemiological study of dementia in the major CALD populations in Australia to determine incidence, prevalence, types, clinical features, and risk factors for dementia is recommended.

Community knowledge

1. A study of dementia literacy in a range of different CALD groups combining qualitative and quantitative techniques conducted with representative samples of CALD groups, the whole adult range should be included; and education, socioeconomic status and acculturation should be measured.
2. In order to plan community awareness programs, possible differences between CALD groups and within CALD groups, and the effect of demographic and acculturation variables on these differences need to be examined.

Carers

1. Research into best practice approach(es) to 'community, family and carer' awareness and education for CALD groups
2. Research into the delivery of appropriate support programs for CALD carers and persons with dementia.

Screening and assessment

1. Guidelines for screening CALD groups in different settings e.g. GP setting, acute hospitals, community service providers etc. are required.
2. The RUDAS and GP cog require further testing of validity in different settings and cultural groups.
3. Utility of screening and assessment tools over time in heterogeneous groups are also required, preferably with benefit of correlation with gold standard outcomes, including post mortem, biomarkers, neuroimaging.
4. The utility of functional decline as a surrogate measure for cognitive assessment in various CALD groups has not been determined in Australia. These measures may be useful for health workers, HACC workers etc as a possible screening tool.

Medical management

1. Research is needed to elucidate the barriers that prevent initiation of screening of dementia at a primary care level including diagnosis of depression and delirium.
2. Research into whether delirium is adequately assessed in persons of CALD backgrounds, and what are the best practice principles for management of this condition in these groups is needed.
3. Information about drug use and response to treatment (cholinesterase inhibitors, antipsychotics and alternative medications) amongst cultural groups in Australia requires further exploration to determine equity of access and response to treatment.
4. Research of the manifestations of dementia, its subtypes and behavioural and psychological symptoms in persons with dementia from different ethnic backgrounds is needed to elucidate the influences of culture and ethnicity on dementia. The development or adaptation of current tools is needed to assist with the documentation of this.

5. Elucidation of cultural differences in end life issues will play an important part in the palliation of those with dementia, in many Australian settings including hospital and residential care.

Residential care

1. Research into tools for measuring the well-being and quality of care for CALD people with dementia living in residential care settings is needed.
2. Existing tools such as Dementia Care Mapping (which is used by care practitioners and researchers to capture both the process - behaviours and outcome - well-being of care) need to be evaluated and further developed to specifically address CALD dementia residents.
3. Comparative studies among CALD residents with dementia living in clustering, multicultural and ethno-specific facilities in terms of key outcomes such as quality of life and culturally competent care practices are recommended.
4. Develop appropriate models of residential care for different CALD groups by examining international practices, cross-cultural studies and comparative studies with other countries,

Staff and Training

1. Research on developing the best cultural competency program/training for the aged and community care workers and establishing quality evidence of such program (a generic program for aged care and a more specialised program for people with dementia).
2. Establishing quality evidence regarding the impact of the health care worker's cultural competence on care outcomes is also recommended as the focus thus far has been on the outcome of training participants or recipients of the program.
3. Expanding the knowledge and understanding of the experience of CALD groups in dementia care and their health care encounters by including them in all dementia research is needed as CALD populations are often excluded in most empirical studies often due to cost, time and resource implications.
4. Development of a care/service model that effectively utilises health care workers with CALD backgrounds is also recommended.

Minority CALD

1. Empirical data on how many people of CALD background with torture and trauma experiences have dementia is needed.
2. Research into the impact of torture and trauma experiences on risk and clinical symptoms of dementia is recommended
3. Measures of risk and resilience factors amongst different CALD older people groups: e.g. larger CALD groups, refugees, recent immigrants

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