



An Australian Government Initiative

SCREENING AND DIAGNOSTIC ASSESSMENT OF NON-ENGLISH SPEAKING PEOPLE WITH DEMENTIA

Background Paper

Developed for Alzheimer's Australia

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Table of contents:

Background Paper..... 1

Developed for Alzheimer’s Australia 1

Terminology, abbreviations and definitions 3

Introduction..... 4

Ageing, memory loss and dementia..... 4

The context of this report..... 5

Screening / early diagnosis 6

Existing processes and tools for screening and diagnosis of dementia 8

Considerations for people of non-English speaking backgrounds..... 9

Language and culture..... 10

Use of validated and culturally appropriate screening and assessment tools 11

Communication issues in working with people with dementia 12

Communication issues – for those with dementia from non-English speaking backgrounds ... 13

Rural and remote settings..... 13

Existing guidelines and how they address the issue 14

Summary 15

References..... 16

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Terminology, abbreviations and definitions

AMTS	Abbreviated Mental Test Score
ATSI	Aboriginal and Torres Strait Islander
BPSD	Behavioural and Psychological Symptoms of Dementia
CALD	Culturally and Linguistically Diverse
CDAMS	Cognitive, Dementia and Memory Service
Incidence of people with dementia	The number of new cases diagnosed with dementia within a population over a set period of time (usually one year)
Incidence rate of people with dementia	The number of new cases diagnosed with dementia within a population over a set period of time (usually one year) as a proportion of the total population being considered
GPCog	General Practitioners Assessment of Cognition
HACC	Home and Community Care
KICA	Kimberley Indigenous Cognitive Assessment tool
MMSE	Folstein's Mini-Mental State Examination tool
NESB	Non-English Speaking Background. Although this term has more recently been superceded by the term CALD, it is broader in that it can be used to include people who do not speak English who were born overseas, as well as other groups such as Indigenous Australians who may not speak fluent English.
Older people from culturally and linguistically diverse backgrounds	“persons aged 65 or over, born overseas, in countries where English is not the main language spoken”. (AIHW, 2001, p1)
Prevalence of people with dementia	The number of people with dementia within a population at a set time point
Prevalence rate of people with dementia	The number of people with dementia within a population at a set time point as a proportion of the total population being considered
RUDAS	Rowland Universal Dementia Assessment Scale

Introduction

The "Screening and Diagnostic Assessment of non-English speaking people with dementia" *Background paper* and *Guidelines and System Recommendations* are written for staff and managers of health, community care, and residential care services. *The Background paper* (this document) is not intended as a user's manual. Rather, it describes the rationale for the *Guidelines and System Recommendations* with the aim of assisting staff and service managers to understand and accept them as part of routine practice.

Ageing, memory loss and dementia

With increasing age, some minor changes in memory are observed that are considered to be a normal part of the ageing process. However, when these mild memory changes start to impact on daily activities, they warrant screening and/or detailed assessment to determine whether the memory loss may be due to health conditions such as dementia. A key function of the health care system at this stage is the accurate early identification of those with likely dementia. The *Guidelines and System Recommendations* document that accompanies this *Background paper* provides a framework for achieving this with patients from non-English speaking backgrounds.

The term dementia encompasses a number of conditions that are characterised by short term memory loss, and impairment of other aspects of cognitive function such as language, understanding and orientation. Dementia also often impacts on other presenting symptoms such as difficulties with social and occupational functioning, and performance of activities of daily living. The most common types of dementia are:

a. Alzheimer's disease

Alzheimer's disease is the most common type of dementia, accounting for up to 60% of people with dementia (Access Economics 2006). It is characterised by some typical changes in brain tissue including neuronal degeneration, and presence of deposits of beta-amyloid plaques and neurofibrillary tangles (Hecker 2002). Onset is usually in later life, with slow, gradual progression of symptoms.

b. Vascular dementia

Vascular dementia (previously called multi-infarct dementia) is the second most common form of dementia, accounting for 20-30% of people with dementia (Access Economics 2006). It can develop from damage due to infarct or haemorrhage of important large cerebral vessels, or more commonly, to multiple small vessel infarcts, lacunes, or haemorrhage (Hecker 2002).

c. Dementia with Lewy Bodies

Dementia with Lewy Bodies accounts for around 10% of people with dementia (Access Economics 2006). It is characterised by inclusions called Lewy Bodies throughout the cerebral cortex (Hecker 2002). Clinically, Dementia with Lewy Bodies can cause fluctuations in cognitive status, some major neuro-psychiatric features (eg visual hallucinations) and some extra-pyramidal features such as muscular rigidity. It can be more rapidly progressive than other forms of dementia (Hecker 2002).

d. Other types of dementia

There are a number of other less common forms of dementia, including Fronto-Temporal Dementia (FTD) (there are more common subsets of FTD, therefore probably best not to include Picks which involves more frontal lobe symptoms such as poor problem solving and reduced abstract thinking; and sub-cortical dementia (associated with conditions such as Parkinson's disease and Huntington's disease). Younger onset dementia is another classification that refers to people under the age of 65 years with dementia.

Dementia varies in its severity, and a pathway of dementia has been described from the early mild symptoms, through to severe late stage disease (Victorian Dementia Reference Group 2004) (p 51). Three stages of the dementia pathway have been reported:

- i. Early stages on the dementia pathway. At this stage there are mild symptoms including getting lost on a familiar route, and being repetitive in speech, gradually progressing to functional difficulties including poor judgement, reduced money handling capacity, and becoming disoriented around the home.
- ii. Middle stages on the dementia pathway. More severe difficulties are evident, including word finding difficulties, presence of uncharacteristic mood swings and outbursts, and need for constant supervision. For people from non-English speaking backgrounds, skills in the use of English as a second language may deteriorate more quickly than skills in the primary language.
- iii. Late stages on the dementia pathway. At this stage, the person with dementia is dependent on others for organising all aspects of their life and care, including eating, toileting and personal care. The person with dementia may no longer talk, and may have lost their mobility.

This report focuses on the early stages of the dementia pathway, when screening and diagnosis should occur.

The context of this report

Dementia is becoming an increasingly common health problem in Australia. The number of Australians with dementia was estimated to reach over 200,000 in 2005 (approximately 1% of the population) (Access Economics 2005). In 2005, there was an estimated additional 52,000 new cases of dementia diagnosed across Australia, and this incidence of new cases is projected to increase substantially by 2050 (Access Economics 2005). As a result, the number of Australians with dementia is predicted to almost triple (to 730,000) by 2050 (Access Economics 2005). Ninety six percent of people with dementia are over the age of 60, with a marked increase in prevalence with increasing age (Victorian Dementia Reference Group 2004; Access Economics 2005).

Conservative estimates of the health related costs associated with dementia care in Australia was over \$2.5 billion for the 2000/2001 year (Victorian Dementia Reference Group 2004). Eighty four percent of these costs were associated with residential care expenditure. Of the remaining costs, approximately half were related to hospitalisation, and around 9% were for pharmaceuticals. Expenditure on health related dementia care is projected to increase from almost 1% of Gross Domestic Product (GDP) in 2002, to more than 3% by 2050 (Access Economics 2003).

In early 2005, dementia was announced as an Australian Government national health priority (Australian Health Ministers' Conference 2005). This highlights the recognition of dementia as a major health concern in Australia, and one which is projected to escalate in terms of prevalence and health costs unless a coordinated, strategic and effective approach to research, prevention, management, and service provision and support are implemented. A range of Commonwealth, State, and other stakeholder initiatives are being implemented with the goal of improving key outcomes relating to the incidence, prevalence and impact of dementia for people with dementia, those at risk of developing dementia, their carers, and the wider community.

Australia is a multi-cultural country. The rich diversity of cultural backgrounds of the Australian population provides many positive elements to Australian society. It also provides some additional challenges that need to be met.

Furthermore, Australia's population of people from CALD backgrounds is growing. As a proportion of the Australian population, those from CALD backgrounds aged over 65 years constituted 18% in 1996, and this is projected to grow to 23% by 2011 (Australian

Institute of Health and Welfare: Rowland F and Karmel R September 2004). Furthermore, the older CALD population is expected to age more quickly than the Australian born population (the proportion aged greater than 80 years will grow from 16% to 26% of the CALD population aged greater than 65 by 2011, while the proportion of the 65+ population aged more than 80 years for the Australian born population will grow from 23% to 28%) (Australian Institute of Health and Welfare: Rowland F and Karmel R September 2004). Italy, Greece, Germany, Netherlands and China are the most common birthplaces for older Australians of CALD backgrounds, although the proportion born in countries such as Lebanon, Malta, Vietnam and Croatia are all growing substantially (Australian Institute of Health and Welfare: Gibson D 2001).

Around 12% of Australians with dementia do not speak English at home (Access Economics 2006), with some variability between states (21.0% of people with dementia in the Northern Territory do not speak English at home, while 3.5% of Tasmanians with dementia do not speak English at home). Additionally, projections indicate there will be small reductions in the proportion of Australians speaking English (83.8%) and other European languages at home (7.6 to 6.0%) from 2001 to 2050, while there will be increases in the proportion of the population speaking Asian (6.0% to 8.3%) and Middle Eastern (1.8 to 2.3%) languages at home (Access Economics 2006).

There is limited data available to indicate whether the prevalence or incidence of dementia varies across ethnic groups (Manly et al. 2004; Access Economics 2006).

There is increasing evidence that people of Culturally and Linguistically Diverse (CALD) backgrounds do not access home care, health, and other services to the same level as Australians not from CALD backgrounds. For example, a study analysing Home and Community Care (HACC) data from one region in Melbourne indicated that people who spoke a language other than English at home were a third as likely to use local government HACC services than those who spoke English (Black et al. 2004). There may be a number of contributory factors to this, including the higher marriage rates and lower proportions of people from CALD backgrounds living alone (Australian Institute of Health and Welfare: Rowland F and Karmel R September 2004), or that services may not be known about, or may be viewed as culturally inappropriate. Another major barrier identified has been the limited proficiency in English by many older people from CALD backgrounds (Orb 2002). Service providers need to explore these possible contributory factors, to ensure the most culturally appropriate, culturally sensitive mix of services and procedures are available for all potential service users (Artiola et al. 1998).

Although there is limited data available, similar problems of delayed diagnosis are also considered to be present in the Aboriginal and Torres Strait Islander (ATSI) population.

Screening / early diagnosis

Many older people recognise subtle changes in their day-to-day memory, and wonder whether this might be the mild memory loss associated with ageing, or the early stages of dementia. There needs to be a range of strategies available to support people seeking early screening where there are concerns about memory loss, both to remove doubt or worry for those who do not have dementia, but also to provide early advice, management and support for those who do have early stages of dementia. Additionally, screening and early diagnosis provides an avenue for trial of the new range of medications with some potential for slowing progression of some dementias (Loy et al. 2004). For all of these reasons, screening people reporting loss of memory is a valuable approach to promote.

Despite the potential value of early screening and diagnosis of dementia, there is some evidence that people with dementia, their families and carers often delay seeking a diagnosis (Connell et al. 1996; Black et al. 2001). Factors identified that contribute to delayed screening or diagnosis include perceptions that nothing can be done, that the

memory loss was just part of the normal ageing process, and that there can be considerable stigma associated with the diagnosis of dementia.

The problem of delayed seeking of screening and diagnosis for people developing memory problems may be even greater among CALD and ATSI communities in Australia. A Melbourne study of patients presenting to a memory clinic highlighted that patients from non-English speaking backgrounds presented at a more advanced stage of dementia than those from English speaking backgrounds (LoGiudice et al. 2001). Additionally, the proportion of patients from Asian and Middle Eastern backgrounds attending the clinic were less than a third of that expected if there was proportional representation of the cultural mix of the population within the clinic's catchment area (LoGiudice et al. 2001). Similar results were reported for NSW Aged Care Assessment Programs assessment and dementia rates (Lister et al. 2006). Factors such as low proficiency in English, lack of awareness of health services available, cultural differences in perceptions and attitudes to dementia, and possibly a sense that health services are unable to provide assessment and treatment services in languages other than English, may all contribute to the low rate of presentation by people from CALD backgrounds to specialist services such as memory clinics.

Hinton and colleagues (Hinton et al. 2004) classify the causes of delays in diagnosis as multi-factorial, involving an interaction between characteristics of the patient / family, the practitioner, and the health care system. They undertook a qualitative study to investigate contributory factors to delayed dementia diagnosis in Anglo-Americans, and other cultural groups (African Americans, and Chinese Americans). They identified a number of differences between the cultural groups, including that it was far less common for Chinese American families to initiate care for dementia symptoms compared to the other groups (more commonly in the Chinese American group the initiation was triggered by health or other care staff), and that compared with the other two groups, more than double the proportion of Chinese Americans (43%) reported they had not been given a definitive diagnosis. Language barriers and discrimination were reported as two of five major categories of adverse experiences contributing to dissatisfaction among the groups in the process of obtaining a diagnosis (others being unsatisfactory diagnosis, disclosure and explanation; inadequate workup; and uncaring / insensitive attitude) (Hinton et al. 2004).

A meta-synthesis of three qualitative studies of African American, Latino and Chinese family caregivers of people with dementia about their perceptions of the onset and diagnosis of Alzheimer's disease, identified a lack of knowledge by the care-givers rather than culturally influenced beliefs as one of the major factors delaying seeking medical assessment for memory problems (Mahoney et al. 2005). Caregivers tended to seek support and advice from family prior to seeking medical assessment. Other concerns by care-givers included that some were disappointed with the initial assessment, citing dismissal of symptoms as just due to ageing. Chinese, and some Latino caregivers in this meta-synthesis were also concerned about the possibility of public disclosure of a diagnosis of dementia, and this may have limited some in seeking information about dementia, highlighting the need to emphasise measures of confidentiality among non-English speaking communities. Caregivers in these studies also reported that seeing a practitioner experienced in dementia assessment and management was more valued than seeing a practitioner of the same ethnicity. Mahoney and colleagues also highlight the need for greater knowledge of appropriate screening, assessment and referral processes by primary care practitioners (Mahoney et al. 2005).

Existing processes and tools for screening and diagnosis of dementia

Often the general practitioner is the first health professional contacted by a person concerned about their memory, or by the family of that person. As such, the general practitioner has a key role in the screening process for dementia, or to refer on to other professionals to implement this process. However, there are a number of factors which can limit early and accurate identification of cognitive impairment in the primary care setting. These include "lack of familiarity with early symptoms, lack of time and available resources, perceived complexity and lack of knowledge regarding use of available screening methods" (Borson et al. 2006) (p349). Use of a brief cognitive screen (the Mini-Cog) was shown to double the identification of cognitive impairment compared to primary care practitioners' identification based on case note review (Borson et al. 2006). These results suggest that training of primary care practitioners in the use of validated screening tools, their interpretation, and guidelines for referral and ongoing management have potential to substantially increase early diagnosis of dementia.

Health professionals other than general practitioners or other staff in community, hospital or residential facilities may recognise early and previously non-investigated signs of cognitive impairment in their patients. Where this occurs, staff have an important role both in discussing the observed signs and symptoms with the patient and their family, and in discussing recommended actions to clarify diagnosis and institute appropriate management and support as required.

Aged Care Assessment Teams are multidisciplinary teams that often have a role in screening and assessment of a range of physical, medical, psychological, social and well-being needs of older people and people with disabilities. They can have an important role in identifying early cognitive problems, and referral on for further formal assessments (Black et al. 2001). Aged Care Assessment Teams also have a key role in determining eligibility of people for residential aged care admission, or access to Community Aged Care Packages and Extended Aged Care at Home packages to support ongoing living at home.

Existing commonly used, validated screening tools for cognitive impairment include:

- The Folstein Mini-Mental State Examination (MMSE) (Folstein et al. 1975), is probably the most widely researched and utilised screening tool for cognitive impairment (Petersen et al. 2001). It is a 30 item questionnaire, commonly with a cut-off score of less than 24 used to indicate cognitive impairment.
- The Abbreviated Mental Test Score (AMTS) (Hodkinson 1972). This 10 item questionnaire is also commonly used, with a cut-off score of less than seven being used to indicate cognitive impairment.
- The Clock Drawing Test (Cahn et al. 1996). There are a number of versions of this test, and its scoring. The test evaluates the patient's ability to fill in a blank circle with the numbers and hands of a clock.
- The Min-Cog tool has been more recently developed, with the aim of overcoming some of the limitations of other cognitive screening tools (Borson et al. 2000). It consists of a three item recall task, with an elective clock drawing task. A revised scoring scale yields possible scores of 0-5 (Borson et al. 2006), with scores of 0-2 being considered in the "probably impaired" range, and scores of 3-5 in the "probably not impaired" range. It was also designed to be used to address some of the limitations of existing tools for people from CALD populations (refer to page 11).
- The General Practitioner Assessment of Cognition (GPCog) has been developed specifically for use by general practitioners in screening for cognitive impairment (Brodaty et al. 2002). Spelled Brodaty Following preliminary validation, a refined tool was developed, consisting of a nine item cognitive assessment component, and a six item informant component. Patients scoring 9 on the cognitive assessment component were considered cognitively intact, those scoring less than five were considered to have cognitive impairment, and for those with intermediate scores, the final classification was based on the informant component of the questionnaire. Those

in this intermediate range scoring three or less out of six on the informant component were considered to have cognitive impairment (Brodaty et al. 2002). Brodaty

It should be noted that all screening tools are only a preliminary stage in the diagnostic process, and as such should not be relied on to provide diagnosis. They should be used to identify those who require formal, detailed cognitive assessment to determine diagnosis and management approaches.

Patients identified as positive on one or more screening tools should be referred to specialist clinics (eg Cognitive Dementia and Memory Service [CDAMS] clinics), a neurologist, geriatrician, psychiatrist, or other qualified professional for formal cognitive assessment. This assessment may include:

- A detailed medical history from the patient, and family / friends;
- A comprehensive medical assessment to identify the extent and interaction of other medical problems that might contribute to the cognitive impairment, and to exclude reversible causes of cognitive impairment such as delirium;
- Formal cognitive function tests;
- Neuropsychological testing to clearly identify and quantify focal or general areas of cognitive impairment;
- Laboratory tests, including tests of the blood and urine to identify possible underlying problems contributing to the cognitive impairment;
- Assessment of psychological status, including assessment of depression, anxiety, and the behavioural and psychological symptoms of dementia; and
- Assessment of the patient's social network, including knowledge, stresses and coping of the carer and other family.

Following this series of assessments, formal classification of the cognitive disorder and diagnosis should be able to be made. The recommended definition of dementia (Knopman et al. 2001) is that of the Diagnostic and Statistical Manual 4th edition (DSM-IV), being "the essential feature of dementia is impairment in short- and long- term memory, associated with impairment in abstract thinking, impaired judgement, other disturbances of higher cortical function, or personality change. The disturbance is severe enough to interfere significantly with work or usual social activities or relationships with others. The diagnosis of dementia is not made if these symptoms occur in delirium...." The diagnosis should also include identification of the type of dementia.

Some of those who go through the full assessment will not meet the criteria for dementia, but may be classified as having "mild cognitive impairment", criteria which include:

- "Memory complaint, preferably corroborated by an informant;
- Objective memory impairment;
- Normal general cognitive function; and
- Intact activities of daily living" (Petersen et al. 2001).

Recognition and monitoring of patients with mild cognitive impairment is recommended, as between 6-25% of this group have been shown to progress to dementia per year (Petersen et al. 2001).

Diagnosis of mild cognitive impairment or dementia should be a basis for implementing a broad range of management and support options for the patient and their carers. Description of best practice management for people diagnosed with dementia is beyond the scope of this paper, however guidelines for management are available (see section below on Guidelines).

Considerations for people of non-English speaking backgrounds

The primary principle for screening and diagnosis of dementia in people from non-English speaking backgrounds is that all aspects of best practice as described above for screening and diagnosis within the broader community should be applied at every stage of the

assessment. Key factors that need to be superimposed over the implementation of best practice for people from non-English speaking backgrounds include:

- Access to accurate and meaningful communication and cultural understanding throughout the screening and diagnosis process. This includes understanding of both verbal and non-verbal communication; and
- Use of validated, culturally appropriate screening and assessment tools where available. Where appropriate tools are not available, the assessor needs to appreciate the potential bias of the tools used related to cultural, language and other influences.

These factors are discussed in greater detail in the following section.

Language and culture

A primary barrier to all aspects of “mainstream” Australian life, facilities and services for people from non-English speaking backgrounds is the language barrier. Therefore a strong focus of any initiative aiming to ensure equal access to quality services for older people of non-English speaking backgrounds will be on language and linguistic considerations in all aspects and levels of assessment, treatment and service provision. There is a large body of scientific evidence demonstrating that language is the main mediating mechanism between the individual and culture. Language is the principal medium of construction and transmission of personal and cultural meaning. Culture and language are inextricable from the person’s cognition, affect and behaviour, both conscious and unconscious.

For the purposes of this document, culture is not considered a unitary, fixed and impermeable entity, but rather the opposite. Culture can be considered “the basic learning about ourselves and our society which every person carries with them throughout life” (Hamilton-Smith 2001) (p 85), and which impacts on our everyday interactions and actions. It is derived from our origins and the “social heritage” of the communities in which we have lived, that is, our habits and activities, and norms and expectations and preferences are influenced by the communities in which we have lived (Hamilton-Smith 2001). As discussed above, culture is a dynamic phenomenon, and may change at varying rates for two individuals who grew up in a similar area, and migrated to another country at the same stage of their life, who then have different levels of interactions with the new culture to which they are exposed. Cultural issues may be equally relevant for second and third generation migrants whose first language is English. Practitioners working with people from non-English speaking backgrounds need to work to understand important cultural factors that could impact upon the patient – health service interaction as part of the assessment process. Particular attention and sensitivity needs to be given to issues of trauma, war experiences migration, family separation, disappearance of relatives etc.

Addressing the language barrier is an important basis for effective screening and assessment of people from non-English speaking backgrounds. To achieve this effectively requires not merely literal translation of the spoken words, but also the cultural context of what is said, and the relevance of non-spoken communication strategies as well (Manly et al. 2004; Johnstone et al. 2006). The most effective strategy is to have the assessment, including the history taking, undertaken by a competent practitioner who is fluent in the patient’s language, and is confident in practicing their profession in that language. Efforts should be made to establish and promote a model of care whereby a referral network of competent bi- and multi-lingual practitioners can be supported and readily accessed to undertake appropriate screening and assessment. Either independently or in tandem with the referring practitioner, where this is not possible, other approaches to support the diagnostic process between an English speaking practitioner and a patient of non-English speaking background include:

- use of medical interpreters. While this approach should result in good translation skills, understanding of medical terminology, and cultural awareness, there may still

be some limitations, particularly due to cultural differences between the interpreter and the patient. Gender and religious differences may be particularly important. The assessing practitioner should remain vigilant in observing the ongoing interaction between the patient / family, the interpreter, and themselves, to ensure the process progresses smoothly. Interpreter phone services are also available (for example in urgent situations where an interpreter is not able to be accessed quickly, or in some rural and remote areas), although this is a less satisfactory arrangement than having an interpreter in the room with the patient / family and the practitioner;

- use of bi/multi-lingual staff to assist with translation. While in some organisations, well trained bi/multi-lingual staff are available, there are some limitations in their use. Depending on the background and experience of the bi/multi-lingual staff, they may not have sufficient skills, sensitivities and understanding to cope with the complexities of the dementia screening process (Manly et al. 2004);
- use of family members. Family members provide an essential background which is invaluable in the dementia screening process, and as such, should be actively engaged in the process where possible. However, their role as translators is often inadequate because of potential lack of objectivity, biases based on their relationship with the patient, and lack of familiarity with medical and cognitive assessment terminology (Manly et al. 2004). There are also circumstances / cultures when use of family members such as children or adolescents may be considered inappropriate (Johnstone et al. 2005).

In situations where a competent practitioner who is fluent in the patient's language is not available, use of medical interpreters is the preferred option.

Use of validated and culturally appropriate screening and assessment tools

The National Framework for Action on Dementia 2005 Consultation Paper (Australian Health Ministers' Conference 2005) highlights the need for validated assessment tools to assess people from CALD backgrounds as a current gap. The rationale for this is multifactorial, including that several items on the most commonly used screening tools (the Abbreviated Mental Test Score [AMTS] and the Folstein Mini Mental Test Score [MMSE]) are influenced by education level, local terminology, and knowledge of local politics / government. A study by Gibbons and colleagues (2002) identified differences in MMSE items between a cohort in the United Kingdom and one in the United States of America, and considered these differences most likely due to translation artefacts in the test items (even in these two distinct cultures that share a seemingly common language). Clearly, these differences are likely to be even greater where there are difficulties with direct translation between English and other languages – for example, the MMSE item of repeating the phrase “no ifs, ands or buts” has no equivalent terminology in some languages. Manly and Espino (2004) have reviewed the available literature on this topic, and conclude that “ethnic group differences in performance on the MMSE and neuropsychological tests have shown that discrepancies between scores of different ethnic groups persist, despite equating groups on other demographics such as age, education, gender and socio-economic background” (p 99).

Teng (2002) describes the key cultural and educational factors influencing diagnosis of dementia as language, education, ecological relevance of test items, lack of appropriate test norms, and life circumstances and cultural attitudes. Again, the need for use of culturally appropriate screening and assessment tools and development of culturally appropriate norms is highlighted. Indeed, there is some evidence that cultural differences exist even within older people of the same ethnicity that may be sufficient to influence performance on cognitive assessment tasks (Manly et al. 2004). Shah and colleagues (2005) also discuss the need for other related tools, such as instruments to assess behavioural and psychological symptoms of dementia (BPSD), to be developed and validated for use with people from CALD backgrounds. Non-verbal tests can be as biased with respect to culture and education as verbal tests.

In recent years, there have been some developments to address the identified shortcomings of existing screening and assessment tools for people with dementia from non-English speaking backgrounds. These include:

- The Rowland Universal Dementia Assessment Scale (RUDAS) (Storey et al. 2004), developed by a team from the Sydney South West Area Health Service. The RUDAS consists of six primary items, and was developed to avoid items that may be subject to cultural or educational background, and also to include items to assess frontal lobe impairment (another limitation of many existing tools). Preliminary studies have shown the RUDAS to have high accuracy of identifying presence of dementia, and that the RUDAS does not appear to be influenced by language, education or gender (Rowland et al. 2006).
- The Kimberley Indigenous Cognitive Assessment tool (KICA), a cognitive assessment tool developed to address specific cultural needs of older indigenous Australians living in remote and rural areas (LoGiudice et al. 2006). The KICA comprises cognitive, informant and functional sections. Moderate to high reliability, and high sensitivity and specificity in classification of presence or absence of dementia have been demonstrated, using a cut-off score of 31 out of a possible 39.

Although these newly developed tools appear to have positive results from initial studies, they do need to be subjected to broader research and clinical application before being widely endorsed. Access and dissemination of the latest screening and assessment materials, normative data, and relevant research literature and resources to support improved screening, assessment and treatment for cognitive impairment in people from non-English speaking backgrounds could be facilitated through establishment of a national resource and documentation centre.

Communication issues in working with people with dementia

Practitioners working with patients with dementia need to pay particular attention to their communication style. These issues are equally relevant whether working with a patient who speaks the same language, or working through an interpreter. There is some evidence that there is less engagement of people from minority groups such as those from non-English speaking backgrounds, in the development of therapeutic care plans (Manly et al. 2004). This may be influenced by different understandings of health and illness models and the roles of both the patient and the practitioner.

Some of the key considerations to maximising communication between a practitioner and a patient being screened or assessed for dementia include (Crisp 2003; McPhee 2006; Mountain 2006):

Practitioner:

- check and use the patient's preferred mode of being addressed (for example, Mrs Wong, or Kim, for Mrs Kim Wong);
- obtain a personal profile of the patient, showing interest in the patient's past and current activities;
- allow adequate time for the assessment. Be aware that an assessment involving an interpreter will take nearly double the time of an assessment without an interpreter;
- ensure that the assessment time does not cause a distraction or otherwise interfere with the process or the results of the assessment. Consider possibilities such as prayer time for Muslims;
- provide support for the patient's sense of identity and worth;
- be attentive to non-verbal cues (eg agitation, frustration);
- do not raise your voice to try to enhance the patient's understanding;
- talk in a calm and reassuring manner;
- ensure you directly face the patient while speaking to them, for people with hearing impairment, this is particularly important (Note: for some cultures, eye contact is not

the norm – the practitioner needs to determine this prior to or at the commencement of the assessment);

- use short, easily comprehensible sentences;
- rephrase questions or statements if they do not appear to have been understood; and
- ensure the patient's dignity is preserved at all times.

Patient:

- ensure the patient has maximal sensory input available – appropriate glasses are worn, and hearing aid (if required) is worn and turned on;
- ensure perspectives of the patient are sought, and that the interaction is not merely between the practitioner and the carer (if one is present).

Practitioner / patient / carer interaction:

- ensure adequate engagement and time for the interaction, questions and discussion between practitioner, patient and family (Manly et al. 2004).

Environment:

- be aware of the impact of the environment on communication. If possible, avoid noisy areas and distractions. Position chairs to facilitate discussion, rather than sitting behind a desk. Avoid positioning the patient where light might be too bright (eg avoid sun-glare in a window), or where there may be insufficient light;
- avoid any décor that could be potentially intimidating such as obvious signs of religious or political beliefs. Patients should feel secure and free to express themselves.

NOTE: Details of language use and fluency may be obtained through the use of short checklists such as the Marin Short Scale (adapted).

Communication issues – for those with dementia from non-English speaking backgrounds

All of the considerations discussed in the previous section apply equally when screening or assessing a person from non-English speaking background for cognitive impairment. The challenge, when doing this through a third party such as an interpreter, is to ensure that cultural factors and sensitivities are sought and clarified early in the assessment process, and respected as the assessment progresses. Thorough assessments using an interpreter are likely to take longer, and adequate additional time should be available. Without the language cues, in order to gauge whether or not the patient is comfortable with the interpreter, it is important for the practitioner to be alert to non-verbal signals such as facial expressions and body language. Other paralinguistic cues such as volume, pitch and tone of voice, which differ from one language to another, are difficult to read accurately.

Rural and remote settings

The majority of the strategies outlined throughout this document are relevant whether the screening and diagnosis process is being undertaken in a metropolitan, or a regional / rural area. There is a need to ensure that adequate training and resources are available to support primary care practitioners in regional and rural areas to undertake the screening process effectively and to know appropriate referral pathways for further assessment procedures if indicated. An added challenge relates to the more limited availability of the specialist services such as CDAMS clinics in rural and remote areas. In Victoria, there are CDAMS clinics available within each health region, although this might still mean that some people in rural Victoria will need to travel a hundred kilometres or more to the regional clinic. Use of telemedicine can support practitioners in regional and rural areas to access specialist services. One study highlighted the potential use of a Telephone Interview of Cognitive Status (TICS) (Hogervorst et al. 2004) as a valid measure of immediate and delayed word recall, important predictors of minimal cognitive impairment. Approaches such as telephone screening, and screening procedures on the internet may be avenues to support older people and their families, particularly those in

regional and rural areas, to identify early signs of cognitive impairment suggestive of the need for comprehensive assessment.

Existing guidelines and how they address the issue

There are a number of national and international guidelines available to support best practice in dementia assessment and management. Some of these include:

- University of Newcastle upon Tyne, United Kingdom - The primary care management of dementia (1998). <http://www.ncl.ac.uk/chsr/publications/guidelines/dementia.pdf>
The American Geriatrics Society, United States of America - Clinical practice guidelines: Guidelines abstracted from the American Academy of Neurology's dementia guidelines for early detection, diagnosis and management of dementia (2003). http://www.americangeriatrics.org/products/positionpapers/aan_dementiaPF.shtml
- Alzheimer's Association & National Chronic Care Consortium, United States of America - Tools for early identification, assessment and treatment for people with Alzheimer's Disease and dementia (2001).
- American Academy of Neurology, United States of America - AAN Guideline for clinicians: Detection, diagnosis and management of dementia (2001) . http://www.aan.com/professionals/practice/pdfs/dementia_guideline.pdf
- American Medical Directors Association, United States of America - Dementia: Clinical practice guideline (2005). Summary: (available for purchase: <http://www.amda.com/info/cpg/dementia.htm>)
- Registered Nurses Association of Ontario, Canada - Nursing best practice guideline: Screening for delirium, dementia and depression in older adults (2003). http://www.rnao.org/bestpractices/PDF/BPG_DDD.pdf

Key elements of these guidelines include:

- Promotion of a healthy and active life-style to minimise or delay development of risk factors that might predispose to dementia;
- Ensure the service system has the capacity to effectively screen and diagnose minimal cognitive impairment and dementia. This includes adequate training of primary care practitioners, awareness of available screening and assessment tools and referral processes, and linkages with support services for the patient and carer;
- Accurate, easily understandable and accessible information for the community on all aspects of dementia assessment and management; and
- Services and care that are responsive to the changing needs of the patient and carer / family over time.

The guidelines above provide a sound basis for screening, diagnosis and management throughout the dementia pathway. For people from non-English speaking backgrounds, all of these principles of best practice apply equally. However, practitioners need to be aware of the issues raised throughout this background paper, and modify their practice to ensure the health care / service interaction is as efficient and effective as for those from English speaking backgrounds. The accompanying document "*Guidelines and system recommendations for practitioners, service managers and policy makers*" summarises the key elements to best practice for patients from non-English speaking backgrounds.

Additional websites / useful reading

- Multicultural Mental Health Association - www.mmha.or.au
- International Association for Cross-Cultural Psychology - www.iaccp.org
- International Test Commission - <http://www.intestcom.org/>
- International Psychogeriatric Association - www.ipa-online.org
- American Psychological Association: Standards for educational and psychological testing, 1999.

- Artiola I Fortuny L. and Mullaney H.A.: Assessing Patients whose language you do not know: Can the Absurd Be Ethical?. The Clinical Neuropsychologist 1998, Vol 12, No 1, pp. 113-126.

Summary

Effective screening of people reporting mild memory loss can result in early treatment and support for the patient and their carer / family, and may improve longer term outcomes. There are a number of barriers that currently limit screening and early diagnosis in practice, including lack of information in the community, lack of knowledge of benefits of early identification, and limited knowledge of screening, assessment and referral processes by primary care practitioners. A number of additional factors add to the delay in seeking screening and diagnosis among people from non-English speaking backgrounds. There are a range of strategies at the service system, primary care practitioner, and community levels that need to be implemented to ensure timely and effective cognitive screening for all people experiencing mild memory loss.

References

1. Access Economics (2003). The dementia epidemic: Economic burden and positive solutions for Australia.
2. Access Economics (2005). Dementia estimates and projections: Australian states and territories.
3. Access Economics (2006). Dementia in the Asia Pacific region: The epidemic is here., Report to the Asia Pacific members of Alzheimer's Disease International.
4. Access Economics (2006). Dementia prevalence and incidence among Australians who do not speak English at home., Report for Alzheimer's Australia.
5. Artiola, I., Fortuny, L. and Mullaney, H. (1998). "Assessing Patients whose language you do not know: Can the Absurd Be Ethical?." The Clinical Neuropsychologist **12**, (1): 113-126.
6. Australian Health Ministers' Conference (2005). National framework for action on dementia: 2005 Consultation paper. Canberra.
7. Australian Institute of Health and Welfare: Gibson D, B. P., Benham C and Mason F, (2001). Projections for older immigrants: People from culturally and linguistically diverse backgrounds, 1996-2026. Canberra.
8. Australian Institute of Health and Welfare: Rowland F and Karmel R (September 2004). Diversity among older Australians in capital cities 1996-2011. Canberra, Bulletin No 18, ISBN 1 74024 404 4.
9. Black, K., LoGiudice, D., Ames, D., Barber, B. and R., S. (2001). Diagnosing dementia: A reference paper. Report for the Alzheimer's Association Australia.
10. Black, K., Osborne, D. and Lindeman, M. (2004). "Access to Local Government HACC services for people speaking a language other than English at home." Australian Journal of Primary Health **10** (1): 9-15.
11. Borson, S., Scanlan, J., Brush, M., Vitaliano, P. and Dokmak, A. (2000). "The Mini-Cog: A cognitive 'vital signs' measure for dementia screening in multi-lingual elderly." International Journal of Geriatric Psychiatry **15**: 1021-7.
12. Borson, S., Scanlan, J., Watanabe, J., Tu, S. and Lessig, M. (2006). "Improving identification of cognitive impairment in primary care." International Journal of Geriatric Psychiatry **21**: 349-55.
13. Brodaty, H., Pond, D., Kemp, N., Luscombe, G., Harding, L., Berman, K. and Huppert, F. (2002). "The GPCOG: A new screening test for dementia designed for general practice." Journal of the American Geriatrics Society **50**: 530-4.
14. Cahn, D., Salmon, D. and Monsch, A. (1996). "Screening for dementia of the Alzheimer type in the community: the utility of the Clock Drawing Test." Archives of Clinical Neuropsychology **11**: 529-39.
15. Connell, C. and Gallant, M. (1996). "Spouse caregivers' attitudes toward obtaining a diagnosis of a dementing illness." Journal of the American Geriatrics Society **44**: 1003-9.
16. Crisp, J. (2003). Communication. Dementia nursing: A guide to practice. R. Hudson. Melbourne, Ausmed Publications.

17. Folstein, M., Folstein, S. and McHugh, P. (1975). "A practical method for grading the cognitive state of patients for the clinician." Journal of Psychiatric Research **12**: 189-98.
18. Gibbons, L., van Belle, G., Yang, M., Gill, C., Brayne, C., Huppert, F., Paykel, E. and Larson, E. (2002). "Cross-cultural comparison of the Mini-Mental State Examination in United Kingdom and United States participants with Alzheimer's disease." International Journal of Geriatric Psychiatry **17**: 723-8.
19. Hamilton-Smith, E. (2001). Cultural issues: Their impact on the health and care of the ageing person. Ageing at home: Practical approaches to community care. T. Cluning. Melbourne, Ausmed Publications.
20. Hecker, J. (2002). Dementia and Alzheimer's disease. Practical guide to geriatric medicine. R. Ratnaik. Sydney, The McGraw-Hill Companies Inc.
21. Hinton, L., Franz, C. and Freind, J. (2004). "Pathways to dementia diagnosis: Evidence of cross-ethnic differences." Alzheimer Disease and Associated Disorders **18**: 134-44.
22. Hodkinson, H. (1972). "Evaluation of a mental test score for assessment of mental impairment in the elderly." Age and Ageing **1**: 233-8.
23. Hogervorst, E., Bandelow, S., Hart, J. and Henderson, V. (2004). "Telephone word-list recall tested in the Rural Aging and Memory Study: Two parallel versions of the TICS-M." International Journal of Geriatric Psychiatry **19**: 875-80.
24. Johnstone, M. and Kanitsaki, O. (2005). Cultural safety and cultural competence in health care and nursing: An Australian study. Report by the Division of Nursing and Midwifery, RMIT University. Melbourne.
25. Johnstone, M. and Kanitsaki, O. (2006). "Culture, language, and patient safety: Making the link." International Journal of Quality in Health Care **18**: 383-8.
26. Knopman, D., DeKosky, S., Cummings, J., Chiu, H., Corey-Bloom, J., Relkin, N., Small, G., Miller, B. and Stevens, J. (2001). "Practice parameter: Diagnosis of dementia (an evidence based review). Report of the Quality Standards sub-committee of the American Academy of Neurology." Neurology **56**: 1143-53.
27. Lister, S. and Benson, C. (2006). "Comparative analysis of dementia and ethnicity in the New South Wales Aged Care Assessment Program : 1996 and 2001." Australasian Journal on Ageing **25**: 24-30.
28. LoGiudice, D., Hassett, A., Cook, R., Flicker, L. and Ames, D. (2001). "Equity of access to a memory clinic in Melbourne? Non-English speaking background attenders are more severely demented and have increased rates of psychiatric disorders." International Journal of Geriatric Psychiatry **16**: 327-34.
29. LoGiudice, D., Smith, K., Thomas, J., Lautenschlager, N. T., Almeida, O. P., Atkinson, D. and Flicker, L. (2006). "Kimberley Indigenous Cognitive Assessment tool (KICA): development of a cognitive assessment tool for older indigenous Australians." International Psychogeriatrics. **18** (2): 269-80 Epub 2006 Jan 11.
30. Loy, C. and Schneider, L. (2004). "Galantamine for Alzheimer's disease." Cochrane Database Syst Rev. (4): CD001747.
31. Mahoney, D., Clutterbuck, J., Neary, S. and Zhan, L. (2005). "African American, Chinese, and Latino family care-givers' impressions of the onset and diagnosis of dementia: Cross cultural similarities and differences." The Gerontologist **45**: 783-92.

32. Manly, J. and Espino, D. (2004). "Cultural influences on dementia recognition and management." Clinics of Geriatric Medicine **20**: 93-119.
33. McPhee, K. (2006). Communication. Enabling independence: A guide for rehabilitation workers. H. Mackey and S. Nancarrow. Oxford, Blackwell Publishing.
34. Mountain, G. (2006). Memory loss. Enabling independence: A guide for rehabilitation workers. H. Mackey and S. Nancarrow. Oxford, Blackwell Publications.
35. Orb, A. (2002). Health care needs of elderly migrants from culturally and linguistically diverse (CALD) backgrounds: A review of the literature. Perth, Western Australia, Curtin University of Technology.
36. Petersen, R., Stevens, J., Ganguli, M., Tangalos, E., Cummings, J. and DeKosky, S. (2001). "Practice parameter: Early detection of dementia: Mild cognitive impairment (an evidence based review). Report of the Quality Standards sub-committee of the American Academy of Neurology." Neurology **56**: 1133-42.
37. Rowland, J., Basic, D., Storey, J. and Conforti, D. (2006). "The Rowland Universal Dementia Assessment Scale (RUDAS) and the Folstein MMSE in a multi-cultural cohort of elderly persons." International Psychogeriatrics **18**: 111-20.
38. Shah, A., Dalvi, M. and Thompson, T. (2005). "Behavioural and psychological signs and symptoms of dementia across cultures: Current status and the future." International Journal of Geriatric Psychiatry **20**: 1187-95.
39. Storey, J., Rowland, J., Basic, D., Conforti, D. and Dickson, H. (2004). "The Rowland Universal Dementia Assessment Scale (RUDAS): A multicultural cognitive assessment scale." International Psychogeriatrics **16**: 13-31.
40. Teng, E. (2002). "Cultural and educational factors in the diagnosis of dementia." Alzheimer Disease and Associated Disorders **16** (Suppl 2): S77-9.
41. Victorian Dementia Reference Group (2004). Dementia framework for Victoria, 2005 and beyond: Consultation paper. Melbourne, Aged Care Branch, Department of Human Services.