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

*Guidelines and system recommendations for practitioners,
service managers and policy makers*

Developed for Alzheimer's Australia

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Authorship team:

Alzheimer's Australia-National Cross Cultural Dementia Network - Rene Grypma, Dr Sadahana Mahajani and Dr E Tam

in collaboration with

National Ageing Research Institute - Keith Hill, Jean Tinney, Leslie Dowson and Betty Haralambous (Froniditha Care Inc)

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Introduction:

These *Guidelines and System Recommendations* are intended to provide information for assessors when they are planning the dementia screening or assessment of a non-English speaking person. They apply to all elements of the screening, assessment and diagnosis process, including cognitive, neuropsychological and functional assessments. They reflect good assessment principles in general, but have been written specifically with dementia-related assessments in mind. They have also been written for service managers and policy makers. The *Guidelines and System Recommendations* document contains recommendations for resources and processes to be put into place to enable practitioners to make best use of these guidelines. A *Background paper* (Screening and diagnostic assessment of non-English speaking people with dementia: A Background paper, report for Alzheimer's Australia) provides more information supporting the rationale behind these recommendations.

The terms 'culturally competent' and 'cultural competency' are used in these guidelines as meaning that a person (clinician, interpreter), in addition to fluency in the language of the patient/client, demonstrates the ability to identify useful and culturally appropriate strategies for working with people with diverse languages and cultural backgrounds.

Part 1: Guidelines

Effective screening of people reporting mild memory loss can result in early treatment and support for the patient and their carer / family. 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 the 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, including those from non-English speaking backgrounds.

Promotion of a healthy and active lifestyle to minimise or delay development of risk factors that might predispose to dementia

There is increasing evidence that a healthy and active lifestyle can minimise or delay development of risk factors that might predispose an individual to dementia. This information needs to be promoted widely through a range of English and ethno-specific avenues to maximise awareness and uptake of these health promoting behaviours.

Guideline recommendation

Information about the potential health benefits of a healthy and active lifestyle, including reduced risk of factors that predispose an individual to dementia, should be widely promoted by all agencies involved in screening and assessment for cognitive impairment. Resources and other avenues for dissemination of information should be available in English and a range of other languages.

Promotion of the value of early screening for cognitive impairment

There are a range of reasons why early identification of dementia may be valuable for the patient, their carer / family, and the wider community. For those with concerns about their memory, early screening and assessment will either remove doubt or worry for those who do not have dementia, or provide opportunities for 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 types of dementia.

Screening is recommended for people who are expressing concern about their recent deterioration in memory, or for those whose families are noting recent memory changes. 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;
- 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.

There are a number of factors that contribute to many people not seeking screening / assessment until later stages of disease progression. Information needs to be widely available highlighting the signs that indicate that screening is suggested, and the benefits of earlier identification of cognitive impairment. Again, this information should be promoted widely through a range of English and ethno-specific avenues.

Guideline recommendation

The importance and benefits of early recognition of the presence of dementia, and avenues for early screening and assessment, need to be widely promoted and disseminated in English and a range of other languages.

Culturally competent history taking

A comprehensive history forms the foundation of the screening / assessment process. The same information should be sought from a patient from a non-English speaking background, as would be used for a patient from an English speaking background. Additionally, the assessment needs to be culturally appropriate and sensitive. Particular attention and sensitivity needs to be given to issues of trauma, war experiences migration, family separation, disappearance of relatives etc. To achieve this, it is important for the practitioner to be culturally informed, if possible, prior to the screening / assessment. While there is increasing cross-cultural awareness as part of undergraduate medical and other health practitioner training, there is a need for this to be strengthened,

and in particular, additional training provided to older practitioners who may have had little involvement in these type of programs.

Guideline recommendation

History taking when screening or assessing patients from non-English speaking backgrounds should seek the same information as from a patient from an English speaking background, and should do so in a culturally appropriate and sensitive manner. To do this effectively the practitioner needs to establish an understanding of the culturally relevant issues for each patient.

Effective communication

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 fluent English, or working through an interpreter with a patient from non-English speaking background. Some of the key considerations to maximising communication between a practitioner and a patient being screened or assessed for dementia include:

- 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;
- 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;
- provide clear information in a caring, sensitive 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;
- ensure the patient's dignity is preserved at all times;
- ensure the patient has maximal sensory input available – appropriate glasses are worn, and hearing aid (if required) is worn and turned on;
- rephrase questions or statements if they do not appear to have been understood;
- ensure perspectives of the patient are sought, and that the interaction is not merely between the practitioner and the carer (if one is present); and
- ensure adequate engagement and time for the interaction, questions and discussion between practitioner, patient and family.

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

All of the considerations discussed above 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.

Guideline recommendation

Practitioners need to utilise a range of communication strategies to maximise two way information flow during screening, assessment or management of people with cognitive impairment. When working with patients from non-English speaking backgrounds and a third party such as an interpreter, the practitioner also needs to monitor information flow to and from the interpreter, and non verbal cues.

Competent and appropriate assessors

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. 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, options 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. Where possible, aim to match the interpreter to the patient by age and gender, region / dialect, and cultural group. 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;
- 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. There are also circumstances / cultures when use of family members such as children or adolescents may be considered inappropriate.

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.

Guideline recommendation

When screening, assessing or treating a patient with cognitive impairment from a non-English speaking background, it should be undertaken using the approach that will maximise communication and cultural awareness. The best way for this to occur is through a competent practitioner who is fluent in the patient's language. Efforts should be made to establish and promote a referral network of competent bi- and multi-lingual practitioners that can be readily accessed to undertake appropriate screening and assessment.

Assessment conditions

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.

It is important to check 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.

The duration of the assessment of a person of non English speaking background is generally going to require significantly longer than the assessment of native English speakers for a number of reasons including the time taken up in translation / interpreting. The duration may be double that of an English-only assessment and appropriate provisions for breaks, or splitting a lengthy assessment in to two sessions may be appropriate.

The assessment environment should spell respect for both the assessor and the patient, while not being intimidating. Obvious signs of religious or political beliefs should be avoided by the practitioner or in the assessment room - for example a crucifix where non-Christians are a significant part of the patient group.

Guideline recommendation

Environments used for screening, assessing and treating people with cognitive impairment should be communication-friendly. Additional time should be allocated for sessions with patients from non-English speaking backgrounds, particularly when a third party such as an interpreter is used.

Use of culturally relevant screening and assessment instruments where possible

Many existing screening and assessment tools for cognitive impairment are influenced by education level, local terminology, and knowledge of local politics / government, and so may give inappropriately low scores for people of non-English speaking background. 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 short-comings of existing screening and assessment tools for people with dementia from non-English speaking backgrounds. These include:

- The Rowland Universal Dementia Assessment Scale (RUDAS), a six primary item screening tool 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).
- The Kimberley Indigenous Cognitive Assessment tool (KICA), a cognitive assessment tool developed to address specific cultural needs of older indigenous Australians in remote and rural areas.

Although these newly developed tools appear to have positive results from initial studies, there is a need for further research to validate the tools in other samples. There needs to be wide-spread promotion and training of practitioners about validated screening and assessment tools for use for people from non-English speaking backgrounds.

Guideline recommendation

Practitioners need to be aware of the limitations of some existing screening and assessment tools for cognitive impairment in their use with patients from non-English speaking backgrounds, and of emerging research validating tools that may be more appropriate for use with patients from non-English speaking backgrounds.

Part 2: System recommendations

The provision of fair access to appropriate, timely, and effective screening and assessment services for people reporting mild memory problems should be a priority for government, policy and planning staff, health service administrators, and practitioners. There should be no differences in these outcomes between people from English speaking backgrounds, and those from non-English speaking backgrounds. Currently, there are considerable limitations in aspects of the service delivery system for screening and assessing cognitive impairment for people from non-English speaking backgrounds. Key factors contributing to this include:

- Lack of knowledge among some primary care practitioners about the value of screening and early diagnosis, recommended and culturally appropriate tools, and referral pathways and ongoing management options;
- At times inappropriate planning for screening for people from non-English speaking backgrounds, such as not using a culturally appropriate interpreter, and not allowing sufficient time for an assessment with an interpreter;
- Lack of awareness among the broader community, including the non-English speaking community, about the value of early screening and diagnosis for people reporting memory problems.

System wide recommendations:

- Improved training at an undergraduate and post-graduate level of all primary care practitioners regarding the value of screening and early diagnosis, recommended and culturally appropriate tools, use of interpreters, and referral pathways and ongoing management options;
- Cross-cultural training for practitioners;
- Improved recruitment and support for bi/multi-lingual practitioners;
- Establishment and promotion of a model of care whereby a referral network of competent bi- and multi-lingual practitioners can be supported and readily accessed to undertake appropriate cognitive screening and assessment;
- Widespread promotion and access to multicultural / Transcultural Mental Health Centres;
- Establishment of a national resource and documentation centre, with the capacity to acquire, update and widely disseminate 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. Access could be via resource libraries, website, professional organisations and other avenues;
- Review of state by state variations in screening, assessment and management options for people with cognitive impairment, moving towards national best practice standards.

There is also 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. Strategies need to be explored to maximise access to appropriate specialist services in regional and rural areas, including for those of non-English speaking backgrounds.

Part 3. Resources available to support best practice

There are a number of national and international guidelines and other resources 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
- 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.

Useful additional reading

- 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

This *Guidelines and System Recommendations* document, and the accompanying *Background paper* highlight factors that can influence improved screening and early diagnosis of cognitive impairment, particularly focussing on issues to consider when working with people from non-English speaking backgrounds. The *Guidelines* can be used as a template to compare to current practice, to determine areas for improved processes to be implemented within a specific service. The ultimate goal is to achieve improved and equitable early screening and diagnosis for all people experiencing mild memory loss.