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Clinical audits demonstrate that there are gaps between research evidence and what occurs in current clinical practice for people with dementia. Studies conducted in Australia suggest that: health and aged care professionals do not receive sufficient training in dementia care [1]; few people with dementia have advance care plans [2] and the number of people in residential aged care facilities prescribed antipsychotics is high [3]. The lack of access to specialist services in rural and remote areas of Australia creates further challenges in delivering consistent evidence based care for people with dementia [4]. Community dwelling people with dementia also report substantial unmet needs, with one study conducted in the United States finding approximately half of those surveyed reported the need for home safety evaluation, general health and medical care, meaningful activities, and advance care planning [75]. Most carers surveyed reported that they needed more education about dementia [5]. These evidence practice gaps demonstrate opportunities to improve the quality and safety of health and aged care services for people with dementia and their carers in Australia.

One approach commonly used to improve the quality of care is the development of Clinical Practice Guidelines. Guidelines synthesise the latest, highest quality research and provide this information in a usable format for clinicians [6]. The research evidence is considered by a Committee comprising clinical experts, end users and consumers. The committee form recommendations for clinical practice based on available evidence. Australia's National Health and Medical Research Council (NHMRC) standards for clinical practice guidelines include 54 mandatory requirements that must be met in order for Clinical Practice Guidelines to be considered trustworthy [7].

In December, 2015, the NHMRC approved the first Clinical Practice Guidelines and Principles of Care for People with Dementia. The Guidelines were developed using ADAPTE methodology in which high quality existing international Guidelines are adapted for use in a local context [8]. The UK's National Institute for Health and Care Excellence (NICE) Guidelines for dementia, which were published in 2006, were identified as being the most recent, high quality Guidelines and thus were the foundation Guidelines adapted for the Australian context [9]. An evidence update (involving 17 systematic reviews) was completed to ensure that relevant evidence published subsequent to the NICE Guidelines was included. In addition, a dedicated search for literature involving people with dementia of Aboriginal and Torres Strait Islander or culturally and linguistically diverse backgrounds in Australia was undertaken.

The Clinical Practice Guidelines for Dementia in Australia are intended primarily for medical practitioners, nursing and allied health professionals and aged care workers. The Guidelines contain 109 recommendations which are relevant to care provided in community, residential and hospital settings. Of these recommendations, 29 were evidence based recommendations, seven were classified as consensus based recommendations and 73 were practice points.

The main implications for policy and practice associated with the Guidelines are detailed below.

### **Implications for policy**

Several of the recommendations within the Guidelines indicate areas of care that require greater consistency, improvements in service provision or increased access to services. For example, the Guidelines recommend that people with a possible diagnosis of dementia should be offered referral to memory assessment specialists or services for a comprehensive assessment. Specialist assessment was recommended in view of evidence suggesting improved outcomes for carers after attending a memory assessment service [10]. An international study conducted in the Netherlands found that there were no differences in costs between memory clinic and primary care management [11]. However, there are often long waiting lists in urban areas for these services and access to memory assessment specialists in rural and remote areas is limited. Nevertheless the Guideline Adaptation Committee felt that all Australians should have access to such services to improve the quality of dementia care. Policy makers should consider ways of overcoming barriers to accessing such services.

Commonwealth government funded Home Care Packages provide people with formal supports to remain in their own home and are usually overseen by a health or aged care professional who takes on the role of care coordinator. The number of care packages available is limited and there are often long waiting lists to access such packages. The Guidelines recommend that people with dementia have access to a care coordinator from the time of diagnosis. Care coordination is associated with reduced carer impact and is highly valued by care recipients [12]. The recommendation for care coordination does not conflict with the recent move towards consumer directed care packages, rather it emphasises the importance of the person with dementia and their carer having a key contact person.

Recent times have seen a move towards care aligned with active ageing and restorative care philosophies [13]. Most people live with a diagnosis of dementia for years and minimising functional decline can enable the person to participate in valued activities for longer and delay the need to move to residential care. The Clinical Practice Guidelines recommend that exercise should be strongly encouraged and that people living in the community should have access to occupational therapy interventions that aim to promote independence and maximise engagement in activities. Policymakers should review existing services and ensure that people with dementia have the opportunity to access exercise programs and occupational therapy programs for people with dementia.

Families are often the first people to notice the symptoms of dementia. The Clinical Practice Guidelines emphasise the importance of involving carers in all aspects of care including during the process of diagnosis. It is recommended that carers have access to programs that are tailored and delivered in the home. The content should include: individualised strategies and building carer skills to overcome specific problems, training in communicating effectively, support and information regarding coping strategies and training in the use of

meaningful and enjoyable activities to engage the person with dementia. The availability of these types of tailored programs is currently limited.

Finally, the Guidelines suggest that medical practitioners consider prescribing cognitive enhancing medications for indications that are not currently listed on the Pharmaceutical Benefits Scheme. Recent evidence suggests beneficial effects of acetylcholinesterase inhibitors on cognition and activities of daily living in people with Dementia with Lewy Bodies, Parkinson's Disease dementia and vascular dementia [14-18]. Hence, it is recommended that prescription of these agents is considered following open discussion with the person with dementia of the potential benefits, side effects and out of pocket costs.

### **Implications for practice:**

Research studies consistently find a delay between onset of symptoms and diagnosis [19]. Yet, there is a strong argument for timely diagnosis in order for the person and their family to plan ahead [20]. The Clinical Practice Guidelines recommend that symptoms are explored when first reported and are not dismissed as 'part of ageing'. Testing in primary care settings should include: history taking, cognitive and mental state examination with a validated instrument, physical examination, medication review, consideration of other causes and a basic dementia screen including blood tests. People with a possible diagnosis of dementia should be offered referral to memory assessment specialists or services. While structural imaging (via CT or MRI) is recommended in most people to exclude other cerebral pathologies, routine testing for biomarkers is considered to be premature. Adherence to the recommendations for the process of diagnosis will lead to greater consistency in the process across Australia. This will ensure that the tests thought to be beneficial are routinely conducted and that the costs and burden associated with unnecessary testing are reduced.

While the NICE Guidelines provided little guidance regarding the way in which medical practitioners should communicate the diagnosis of dementia, there was lengthy discussion within the Guideline Adaptation Committee regarding this aspect of care. The Committee agreed that communication should be clear and that medical practitioners should not withhold information based on their own discomfort in conveying the diagnosis. Difficult scenarios, such as the rare occasion when the person states they do not wish to know the diagnosis, should be managed carefully; the person's wish not to know should be respected; however, the family may require support to manage this situation and consequences (e.g., driving cessation) should be addressed.

One of the most effective ways of improving the quality and safety of dementia care is building the skills of health and aged care professionals to provide person centred care and communicate effectively with the person with dementia and their carer. High quality studies have shown that training is associated with reduced anxiety, agitation and distress in the person with dementia (e.g., [21]). Training programs that have been shown to be effective are comprehensive, take place over a number of training sessions and are interactive in nature (e.g., incorporate role play and case based training). Health and aged care professionals

should also use language consistent with Alzheimer's Australia guide to dementia friendly language.

Symptoms of dementia such as anxiety, agitation and depression can be distressing for the person with dementia and their carers and can be difficult to manage. The importance of preventing symptoms with person-centred care is highlighted in the Guidelines, as is undertaking an assessment of presenting symptoms and using non-pharmacological strategies in the first instance. The Guidelines recommend a trial of SSRI antidepressants for people with agitation, while noting that the efficacy of antidepressants for the treatment of depression in people with dementia is uncertain. Antipsychotics are not usually recommended unless the person has severe symptoms causing distress to themselves or others and non-pharmacological approaches have failed. There was little evidence identified regarding the use of intra-muscular agents in emergency situations such as violence, aggression or extreme agitation. The Committee recommended that as circumstances vary between settings, local evidence based guidelines should be developed addressing management strategies and appropriate use of parenteral medications.

Finally, the Guidelines formed eight specific recommendations regarding care involving people from Aboriginal and Torres Strait Islander or culturally and linguistically diverse backgrounds. These recommendations reflect the need to involve appropriate representatives in new initiatives specifically for these client groups, to involve bilingual, bicultural workers and interpreters in care (particularly during assessment, communicating the diagnosis and gaining consent) and to ensure that care plans are culturally appropriate. The KICA and RUDAS cognitive assessment tools are recommended as options for use in certain circumstances.

In summary, the Guidelines identify a number of key areas in which there is scope to improve the safety and quality of care. The Guidelines and the National Framework for Action on Dementia should be used to guide dementia care in Australia over the next five years.

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