RACGP

Submission on the Draft National Clinical Practice Guidelines for Dementia in Australia

4 June 2015

The Royal Australian College of General Practitioners

RACGP details

Name of organisation	Royal Australian College of General Practitioners (RACGP)
Postal Address	100 Wellington Parade East Melbourne, Victoria 3002
Legal status	Not for profit
ABN	34 000 223 807
Key contact person and contact details	Mr Stephan Groombridge, Manager, eHealth and Quality Care Policy, Practice and Innovation 03 8699 0544 stephan.groombridge@racgp.org.au

About the RACGP

The Royal Australian College of General Practitioners (RACGP) is Australia's largest professional membership body for general practitioners. With over 29,500 members across Australia, the RACGP works to support the profession through defining the standards for quality care, developing guidelines and resources, delivering education and training and advocating on behalf of general practices and general practitioners to promote the importance of a safe, quality and holistic approach to patient care.

General Comments

The RACGP welcomes the development of *Clinical practice guidelines for dementia in Australia* and appreciates the opportunity to provide comment on the consultation draft. General practitioners (GPs) play an important role in recognising, assessing, diagnosing and managing dementia, and maintaining effective and ongoing communication and coordination between the patient, carer and family with primary and specialist providers. As the main primary health care provider, the GP is the first point of contact for patients concerned with possible memory loss.

The role of GPs

We feel this role could be better recognised and supported by the guideline, especially in light of the recommendation to have continuous and comprehensive and coordinated care (For example, the guideline would benefit from comment on the availability of Medicare funded chronic disease management plans and team care arrangements). Managing multimorbidity is an example of why this role is so important and this is a core responsibility for GPs. Multimorbidity is a huge issue for this population and these issues would benefit from more focus. Most disease-specific guidelines such as those for diabetes or cardiovascular disease are based on clinical trials that excluded multimorbid patients with dementia and /or frailty. As a dementia guideline it would be helpful to have some advice on how and when to consider de-prescribing for patients with multimorbidity. There is a growing evidence base investigating the impacts of de-prescribing in residential aged care facilities.

Patient safety

Reference to patient safety is also limited in the guideline. The guideline might link to or reference state-based rules for assessing fitness to drive, home safety (for example cooking and heating), and a stepwise approach to medication safety. Medication mishap and side effects are a common cause of hospital admissions in the elderly so the guideline might include evidence for/against community pharmacy involvement in medication reviews, use of Webster packs and domiciliary care packages.

Guideline development

In regards to the guideline development process and guideline presentation, we note the guideline has used the GRADE system. This is a different system to what most NHMRC guidelines use and it means GPs will need to familiarise themselves with the GRADE terminology. This may be a barrier to the accessibility of the guideline. In addition, whilst we recognise the paucity of research evidence in the area, recommendations in the guideline are predominantly based on low level evidence or at practice point level. With practice points defined as recommendations outside the scope of the systematic review, it seems unusual that the developers have not performed further systematic reviews to ensure a better evidence base.

Comments on recommendations

Considerations for Aboriginal and Torres Strait Islander people (Rec 15-19)

Many staff working in residential care services in areas with high indigenous residents may not have English as a first language and this contributes to an already enormous cultural divide. In addition to utilising bilingual bicultural staff or professional interpreters, it is advisable that cultural awareness training be provided for staff. Some Aboriginal Medical Services (AMS) currently provide training locally to health staff in hospital and community but it is often not available for "private" organisations.

Many dementia affected remote and regional indigenous residents "lose" their history. They often have numerous medical transfers to the tertiary hospitals resulting in being placed a long way from home where no one speaks their language locally and they are isolated and suffer significantly as a result. Every resident needs their own history for carers to understand who they are. It becomes extremely challenging to address Advance Care Directives without this. Returning to Country is a spiritual necessity yet impossible for many. Using telecommunications via local nursing posts helps to link such residents to their communities. However, we recognise this can be time consuming and expensive.

There appears to be a growing set of young indigenous people with acquired brain injury and dementia who are proving to be extremely challenging as they do not fit into either local regional psychiatric or aged care services. They often need neuropsychological assessment and community intervention and then specialised age appropriate residential care - just not available regionally.

Early identification (Rec 23-25)

Earlier diagnosis allows people with dementia to plan ahead while they still have the capacity to make important decisions about their future care. In addition, they and their families can receive timely practical information, advice and support. Only through receiving a diagnosis can they get access to available drug and non-drug therapies that may improve their cognition and enhance their quality of life.

The RACGP notes that the question of the value of early diagnosis is yet to be resolved. Dementia is often not recognised early in primary care. There is frequently a delay from onset of symptoms to presentation of these symptoms to the GP, resulting from stigma and lack of recognition by the patient.[1] There may also be a delay from the presentation of symptoms to diagnosis, losing valuable opportunity for intervention. It is important that GPs recognise the possibility of dementia when people present with memory loss or other symptoms, and work to identify dementia when it is present. However the task is not simple.

Specialist assessment services (Rec 26-30)

Recommendation 26 – Some organisations recommend that all people with dementia should be referred to a specialist service. The RACGP notes that one study supported an improved outcome for carers visiting a specialist service, but did not report any such improvement for people living with dementia.[2] Referring persons with suspected dementia to specialist assessment is an aspirational recommendation given very limited availability of these services. The use of the words “should be” do not exactly match the level of evidence “EBR low”. It is better to use wording such as “if available, consider referral to specialist services”.

Diagnosis of dementia (Rec 31-41)

Recommendation 31 – In reviewing medication to identify and minimise medication use, it may be useful to reference BEERs criteria[3] or similar lists to potentially avoid inappropriate medication use. There is also opportunity to suggest simplification of medication dosing to reduce error rates/improve adherence. As an example, attention can be drawn to medications that are used for and cause incontinence, statins and other long term secondary prevention measures that might be inappropriate in the frail elderly.

Neuroimaging (Rec 47-48)

Recommendation 47 – The Guideline Adaptation Committee agreed that structural imaging was necessary to exclude cerebral pathologies and therefore this was stated in a practice point.

There is intense interest in the use of imaging for diagnosing dementia or to exclude other cerebral pathology, however no definitive test is currently available. The RACGP notes the poor quality of evidence for imaging to diagnose dementia and the lack of trials testing the outcomes of imaging to exclude other reversible causes or to subtype the dementia. In addition, the RACGP notes that imaging including CT and MRI may be difficult to obtain in rural and remote areas of Australia. Direct evidence for the relative benefits and harms of a dementia subtype diagnosis by structural imaging for patients and carers is lacking.

Information and support for the person with dementia (Rec 54-57)

The GP is well placed to inform the patient and family not only about the condition, diagnosis and prognosis but also about the consideration of legal and financial matters, available support, and care options. The RACGP notes that the evidence for education and support for people with dementia and for carers is low. However, the RACGP supports the role of the GP and practice nurse in providing education and support for people living with dementia, and their carers.

Organisation of health services (Rec 58-62)

Effective coordination of ongoing health and social care services post-diagnosis is vital for achieving appropriate support and improved quality of life for people with dementia and their carers. A wide support network including access to relevant information for managing dementia, community services, services for continuing care and end-of-life palliative care will need to be considered. The GP and practice team play a central role in the integration and coordination of care. GPs have the capacity to case manage from having experience in chronic disease management. However, the current MBS system does not support GPs to do this.

Training for staff and students (Rec 63-67)

Most of the studies for training were performed with staff in residential aged care facilities (RACFs). GPs play a different role to staff in such facilities and as such the RACGP supports specific training for GPs in identification and management of dementia. The guidelines currently do not differentiate on separate outcomes of training for GPs and aged care staff.

Promoting functional independence (Rec 68-70)

It would be helpful if GPs are able to recommend referral for training in techniques to promote independence for people living with dementia. The RACGP supports training for people living with dementia and their carers in evidence based strategies to promote independence.

Acetylcholinesterase inhibitors and memantine (Rec 71-76)

GPs are currently not able to independently prescribe anti-dementia medication. The RACGP notes the evidence regarding cholinesterase inhibitors and memantine and recommends working towards a reduction in the red tape surrounding the prescription of these medications by GPs for appropriate patients.

Recommendations 72-74 – the recommendations for use of medication for dementia are confusing as to what was being recommended or not. The confusion may arise from the grading of recommendations. Should the user of this guideline follow a recommendation designated “EBR low”? Does this designation mean there is so little evidence in favour of the recommendation that the guideline user should not follow the recommendation?

Behavioural and psychological symptoms of dementia (Rec 78-98)

Some GPs are unfamiliar with approaches to management of behaviours of concern in dementia. These behaviours cause considerable carer stress and it would be beneficial for GPs to be trained on behavioural management approaches. The Dementia Behaviour Management Advisory Service (DBMAS) in each state provides clinical support for people caring for someone with dementia who is demonstrating behavioural and psychological symptoms of dementia (BPSD) which are impacting on their care.

The RACGP notes the evidence around management of BPSD and recommends that this be incorporated in GP education, along with education about referral options. As there is limited evidence on the use of antipsychotics for BPSD, we recommend that training in behavioural management and adequate staffing be reinforced in residential aged care in order to limit the use of medications.

Recommendation 81 – it is not clear which objective tool is to be used to monitor behavioural symptoms

Recommendation 89 – if larger trials have not shown a benefit of anti-depressant medication in the absence of agitation should the guideline state "do not use SSRI for depression without agitation"?

There is lack of recommendation about the behavioural management of neuropsychiatric symptoms especially as there have been systematic reviews in this area.

The fine print mentions a website "start2talk.org.au" - this is extremely useful and should be highlighted in a tabulated list of helpful resources.

Support for carers (Rec 99-105)

GPs are often in the frontline with family and carers. GPs are well placed to offer advice to families and carers, especially in moving patients into suitable residential aged care facilities. GPs do require appropriate guidance on specific advice to provide, particularly in more advanced cases.

We acknowledge the importance of family and carer assessment, education and other multicomponent interventions and advocate for an integrated primary care approach to these activities. The general practice team needs to be aware of the available activities, able to refer into them, communicate with them and reinforce the messages being given. This will ensure that the GP's knowledge on the patient's history and family can be coordinated with the appropriate services available.

References

1. Speechly CM, Bridges-Webb C, Passmore E. The pathway to dementia diagnosis. Med J Aust. 2008;189(9):487-9
2. LoGiudice D, Waltrowicz W, Brown K, Burrows C, Ames D, Flicker L. Do memory clinics improve the quality of life of carers? A randomized pilot trial. Int J Geriatr Psychiatry 1999;14(8):626- 32
3. The American Geriatrics Society 2012 Beers Criteria Update Expert Panel. American Geriatrics Society Updated Beers Criteria for Potentially Inappropriate Medication Use in Older Adults. J Am Geriatr Soc. 2012;60(4):616-31