Dementia, decision aids and general practice

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Background

As our population ages, the prevalence of dementia is rising. Given the complex care needs that accompany dementia, general practitioners (GPs) will be increasingly called upon to address a range of challenging clinical issues.

Objective

This article offers an introduction to the use of decision aids by GPs when caring for patients with dementia (or their carers). In addition, obstacles that can arise during the development of dementia-related decision aids are explored.

Discussion

A person-centred approach to people with dementia is a worthy goal. Decision aids are evidence-based tools that help patients (and carers) participate in choosing among healthcare options. Several existing high-quality, dementia-related decision aids are of relevance to the primary care setting. However, there is a need for additional research to develop decision aids which address a broader range of issues pertinent to dementia.

Up to 50% of people aged 85 years and above have dementia; Alzheimer's disease, vascular dementia, Lewy body dementia and frontotemporal dementia represent the most frequent forms.[1] It is projected that by 2050 over 1 million Australians will have dementia.[2] Accordingly, each general practitioner (GP) in Australia will see, on average, three new cases per year.[3] Despite a significant knowledge gap regarding the epidemiology of dementia in Australia, it is known that the prevalence of the condition is much higher among Aboriginal and Torres Strait Islander peoples.[4]

As aged care services become increasingly stretched, the management of patients with dementia and their attendant complex care needs will inevitably fall to GPs.[3] Fortunately, GPs are well placed to provide practical and emotional support to assist patients and their carers to come to terms with living with dementia.[5] However, a recent review of dementia management in primary care called for:[6]

- a greater focus on person-centred and customised care for patients and their carers
- an evaluation of relevant interventions or alternative models of service delivery.

It is widely recognised that patient-centred care forms the basis of general practice. This approach refers to an understanding of the whole person, an appreciation of their illness experience and a mutual agreement on problems, goals and roles.[7,8] The purpose of this paper is to highlight how dementia-related decision aids can facilitate the sharing of decisions within the primary care setting.

What are decision aids?

Identifying and making a decision about healthcare options can prove challenging for some individuals.[9] Decision aids (in the form of pamphlets, booklets, videos or web-based tools) provide structured information on the options and outcomes relevant to an individual's health. They offer evidence-based guidance on reaching an informed choice consistent with one's values and preferences.[10] Rather than replace the role of clinicians, decision aids are designed to act as adjuncts to the doctor–patient interaction. Specifically, decision aids can be used when: (i) there is more than one reasonable option, (ii) no option has a clear advantage in terms of health outcomes, or (iii) each option has benefits and harms that a patient may value differently.[9] Given the global proliferation of decision aids, guidelines informing the development of high-

quality decision aids were established by the International Patient Decision Aids Standards (IPDAS) collaboration.[10] A recent Cochrane review established that decision aids improve people's knowledge regarding options, reduce decisional conflict, stimulate people to take a more active role in decision making and facilitate risk assessment.[9]

Driving retirement

There exists a pressing need to assist people with dementia in their decision making regarding retirement from driving:

- the number of drivers with dementia on our roads is rising[11,12]
- alternative forms of transport are lacking[11]
- individuals with dementia are increasingly dependent on cars.[11]

Unfortunately, instructing a patient to retire from driving may irrevocably damage a longstanding doctor–patient relationship.[13] To mitigate this risk, a novel decision aid tailored for drivers with dementia has recently been released (refer to *Table 1*).[14] This easy-to-read booklet provides an overview of important safety issues and highlights alternative forms of transport for drivers in Australia or New Zealand. A detailed description of the complex issue of driving and dementia is beyond the scope of this article but comprehensive reviews are available elsewhere.[15–17]

Respite service choices

Respite care, a crucial component of carer support, assists people with dementia to remain living at home for as long as possible.[18] Early use of respite care enables people with dementia and their carers to continue to engage socially with others, which is an important step in combating the social isolation and stigma that often accompany a diagnosis of dementia.[18] Respite services, either at home, in a day-care centre or in a residential care facility, can temporarily reduce a carer's physical and emotional workload.[19] Yet, only 32% of individuals with dementia approved for residential respite care avail themselves of this resource within 12 months of approval.[20] With this discrepancy in mind, researchers at the University of Tasmania have developed a decision aid (the GOLD book) which explains the respite options available to patients and their carers.[19] A recent randomised trial confirmed the benefit of this relatively simple intervention.[19] Specifically, most carers found this decision aid to be useful and it provided them with needed decision support.[19] Furthermore, the trial found that use of the GOLD book led to improved carer knowledge levels and reduced decisional conflict.[19]

Use of antipsychotic medicines

Dementia is usually characterised by prominent cognitive deficits. However, non-cognitive symptoms are common and can dominate the clinical presentation.[1] Behavioural and psychiatric symptoms such as agitation, hallucinations, depression, delusions and wandering have been observed in over 60% of people with dementia.[1] Perhaps not surprisingly, antipsychotic agents are often used to treat such symptoms. Risperidone is the only antipsychotic approved for this indication in Australia.[21] Long-term use of such agents for behavioural and psychiatric symptoms, however, warrants regular clinical review and consideration of withdrawal.[22] In this context, their effectiveness is limited and vigilance is required regarding potential adverse outcomes, including higher mortality with long-term use.[1]

The Royal Australian and New Zealand College of Psychiatrists has emphasised the importance of informed consent when patients with dementia are offered antipsychotic agents.[22] More recently, a decision aid addressing the use of antipsychotic agents by people with dementia has become available online to assist patients, carers and clinicians.[23] This clinically relevant decision aid provides helpful information regarding the risks associated with antipsychotic use (eg cerebrovascular morbidity, mortality).

Feeding options in advanced dementia

For people with dementia, dysphagia can lead to malnutrition, dehydration, weight loss, functional decline, fear of eating and drinking, and decreased quality of life.[24] The prevalence of dysphagia in people over the age of 65 years who reside in long-term care facilities is 40–50% but is probably higher in those with dementia.[24,25]

A recent systematic review, examining the issue of dysphagia among people with dementia, highlighted the dearth of evidence regarding the usefulness of diagnostic tests, effect of postural changes, modification of fluid and diet consistency, behavioural management and use of medications in this population.[24] Furthermore, the placement of percutaneous endoscopic gastrostomy tubes does not lead to improved rates of aspiration pneumonia, improved quality of life or reduced rates of mortality.[24]

At times, carers and families attribute unrealistic benefits to tube feeding; consent discussions often focus unduly on procedural risks rather than potential outcomes and alternative approaches.[25] To address this clinical conundrum, a carer-centred decision aid, containing helpful information about feeding options for people with dementia, has been developed.[25] Carers are informed of the advantages and disadvantages of feeding tubes versus assisted oral feeding. This decision aid also explores the issue of end-of-life feeding for comfort and affirms the role of carers in the decision-making process.

Other dementia-related decision aids

Several other dementia-related decision aids have been developed (*Table 1*). These decision aids address a broad range of topics including

- long-term care options
- anticholinesterase use
- carer decision regarding placement
- goals of care for high-level care residents.

Given the proliferation of decision aids over the past decade, the Ottawa Hospital Research Institute has assumed the Sisyphean task of maintaining an up-to-date, publicly accessible inventory of currently available decision aids (*Table 1*).

Incorporation into primary care

In a study of 181 rural GPs in the United States, 63% felt that lack of time was the greatest barrier to their engaging in shared decision making.[26] Thus, decision aids that can be used independently at home (ie without assistance) may reduce consultation times in primary care, improve knowledge levels and enhance patient satisfaction. All four decision aids described earlier can be used in such a manner. It would suffice, for many people with dementia (or their carers), to be provided with a pertinent decision aid by a practice nurse, which can then be taken home to read. Ideally, such an approach would negate the need for lengthy office-based consultations. Further evaluation of the impact of dementia-related decision aids on primary care services/systems is an important issue worthy of future research.

Challenges in dementia-related decision aid development

The development of high-quality, clinically meaningful decision aids relies on qualitative and quantitative research methods. To date, few decision aids have been developed specifically for individuals with dementia. Unfortunately, dementia-related research is often hampered by a range of obstacles.[27] First, human research ethics committee approval of dementia-related projects is a critical, yet time-consuming, step in the research process. Second, securing informed consent from participants with dementia or their guardians is, at times, a challenging hurdle. Last, inadequate funding opportunities often preclude the conduct of promising dementia-related research projects.[27]

Conclusion

Although discussion about patient-centred care is paramount, there remains a need to 'convert the rhetoric into reality' by routinely engaging patients in decision making.[8] Clinicians (including GPs) can facilitate shared decision making by providing patients (or carers) with decision aids that raise awareness and improve understanding of treatment options and possible outcomes. Decision aids, as per the IPDAS collaboration guidelines, are useful, evidence-based tools designed to help patients/carers participate in choosing among healthcare options.[10]

Given that, in the past, people with dementia were frequently excluded from clinical research, it is refreshing to observe the rising number of decision aids tailored specifically for people with dementia. It is hoped that future research on decision aids will address the specific needs of: people with early-onset dementia; culturally and linguistically diverse (CALD) groups;[4] and individuals seeking guidance on advanced care planning, guardianship and power-of-attorney. By addressing the varied and complex needs of people with dementia and their carers, decision aids have the potential to serve as powerful tools in the provision of person-centred care.

Table 1. Resources

- Alzheimer's Australia, www.alzheimers.org.au
- National Dementia Hotline, 1800 100 500
- Ottawa Hospital Research Institute, https://decisionaid.ohri.ca/
- Driving decision aid, http://smah.uow.edu.au/nursing/adhere/drivingdementia/index.html
- Feeding options decision aid, https://decisionaid.ohri.ca/docs/das/Feeding_Options.pdf
- Respite care decision aid: Stirling C. The Gold Book for carers: guiding options for life with dementia. Hobart: University of Tasmania, 2009.

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Competing interests: None.

Provenance and peer review: Not commissioned, externally peer reviewed.

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