

# Patients with dementia and their carers in general practice

**In 2004, 6.5% of Australians over 65 years of age were estimated to have dementia and the prevalence of dementia is rising as a result of our aging population.<sup>1</sup> There is evidence to show that carer wellbeing is important for the wellbeing of the patient. Increasing burden of care may lead to depression, anxiety, and more frequent physical illness in the carer,<sup>2</sup> and earlier institutionalisation of patients.<sup>3</sup>**

The general practitioner's role includes recognising early dementia, undertaking assessments to confirm the diagnosis, managing the disease, health promotion and support for both patient and carer, and follow up. We initiated a project to explore the extent to which GPs currently fulfill this role for patients with dementia still living in the community (rather than in hostels or nursing homes).

The project was approved by The Royal Australian College of General Practitioners Research and Evaluation Ethics Committee in July 2003.

## Methods

In consultation with several practising GPs and using the standards provided by the RACGPs' *Guidelines for the care of patients with dementia in general practice*,<sup>4</sup> we developed a clinical audit of five patients combined with a questionnaire for GPs to distribute to consenting carers.

General practitioners were asked to report data on five consecutive eligible patients: age and gender, dementia diagnosis and severity, comorbidities (including mental health), level of ability/disability (activities and instrumental activities of daily living),<sup>6</sup> home safety, level of communication between the GP and carer, and extent of assessment of carer health and support. The carer questionnaire focused on level of burden and was a modification of the Zarit Carer Burden Questionnaire (which gives information on health, social support, resources, behavioural management and coping).<sup>7</sup>

General practitioners were recruited in collaboration with educational programs in two divisions of general practice. As not enough carers were enlisted by the GPs,

questionnaires were sent out to carers registered with Alzheimer's Australia NSW.

## Results

Although 60 GPs expressed interest in a workshop, only 24 attended and only eight undertook an audit; four completing the full five patients and four doing 1 or 2, a total of 25 patients. Carers recruited by the GPs returned 30 questionnaires by anonymous free post to the research team. A further 108 carers approached through Alzheimer's Australia NSW submitted another 77 questionnaires, giving a total of 107 carer questionnaires.

### The patients

The patients audited were aged 72–91 years; 56% were men. The type of dementia was established in only 80%, with 40% having Alzheimer disease and 28% vascular dementia (*Table 1*). Reversible causes had been excluded for 86%. It was mild for 33%, moderate for 54% and severe for 12%. The Mini-Mental State Examination (MMSE) score was not known to the GP for 58% of the patients. There was associated depression for 38% of patients and other psychiatric problems for 20%. Only 24% of patients were receiving medication for dementia.

Comorbidity was present for 92% of patients, with 52% having three or more other conditions, the most common of which were hypertension (44%), depression (38%) and heart disease (28%). All medications had been reviewed within the past 6 months for 88% of patients.

General health assessments including vision, hearing, nutritional status, continence of bladder and bowels, and sleep patterns had each been carried out within a year for about 70% of patients, but home safety had been assessed for only 56%.

Most patients needed at least some assistance with activities of daily living; 52% with bathing and dressing, 40% with walking, 36% with toileting, and 28% with feeding. Legal matters such as driving, enduring power of attorney or guardianship, or a will had been discussed with patients or their families in less than half of cases.

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**Table 1. Dementia in patients living at home (n=25)**

Diagnosis	%	Severity	%	MMSE*	%
Alzheimer disease	40	Mild	32	12–20	21
Vascular	28	Moderate	52	21–24	17
Parkinson disease	8	Severe	12	25+	4
Other	4	Uncertain	4	Not known	58
Dementia unspecified	20				

\*MMSE = score on Mini-Mental State Examination in past 12 months

### The carers

The carer questionnaire results were not greatly different for those recruited by GPs and those recruited through Alzheimer's Australia. Most carers were female (80%), 68% spouses, 26% daughters/sons. Most (62%) had been caring for 2–5 years, 23% for over 5 years; 70% had the same GP as the patient.

The most commonly used community services were: an aged care assessment team (48%), Alzheimer's Australia (44%) (more often carers recruited from their list), respite care (30%), day care (24%) and a carer support group (24%). Services that would have been useful were not available to 23%, most commonly day care, home help, transport and respite care.

Most carers said that being a carer had affected their health (61%), and nearly all had other medical problems, including arthritis (54%), high blood pressure (47%), anxiety (44%) and depression (36%). They were afraid of the future (59%), without enough time for themselves and their own social life (45%), frequently or always burdened by caring (39%) and stressed (35%), and felt they had lost control of their lives (34%).

### Discussion

Some of the audit results raise important issues. The dementia diagnosis was not fully established for 20% of patients and the MMSE score not known by the GP for 58% of patients; this probably relates to the large amount of comorbidity being managed in these patients within the limited time available to busy practitioners. Home safety had not been assessed for 44% of patients, legal matters such as driving or guardianship had not been

considered for more than half, and for fewer than half of those with behaviour problems was there a management strategy in place. These factors point to the need for greater promotion and use of guidelines<sup>4</sup> to improve patient care and outcomes.

It was reassuring that most carers felt supported by their GP in their role of carer. It is of concern that most carers felt that being a carer affected their health, and that services that would have been useful were not available to 23%. This emphasises the need for careful monitoring of the health and coping ability of carers, and provision of support as needed.

The small numbers of GP participants means that the results are not necessarily representative, but they do provide an indication of likely important issues. The results relating to patients' age, gender and diagnosis are not greatly different from those obtained by a recent national survey of medication for dementia in 1226 patients.<sup>8</sup>

### Implications for general practice

- Dementia guidelines need to be widely promoted and used.
- Dementia severity (MMSE score) needs annual assessment.
- Home safety, driving and guardianship need to be considered.
- Carer health and needs should be assessed regularly.

### Resource

A pamphlet for carers detailing the type of support they might seek from GPs is available at [www.racgp.org.au/dementiacarer](http://www.racgp.org.au/dementiacarer) and [www.alzheimers.org.au/content.cfm?infopageid=2209](http://www.alzheimers.org.au/content.cfm?infopageid=2209).

Conflict of interest: none declared.

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