The pathway to dementia diagnosis

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ABSTRACT

Objective: To describe the steps taken by health professionals to diagnose dementia and the timeframes for these steps, as reported by carers.

Design, setting and participants: A cross-sectional, anonymous survey was mailed or distributed by Alzheimer's Australia New South Wales, six Sydney residential aged care facilities and 13 Sydney general practitioners to 415 carers or family members of patients with dementia between May and August 2007.

Main outcome measures: First symptoms noticed and actions taken; time to first health professional consultation and diagnosis; reported actions of first health professional; satisfaction with first consultation; and use of dementia and chronic illness resources.

Results: 209 surveys were returned. Family members noticed the first symptoms of dementia at a mean of 1.9 years before the first health professional consultation about dementia, and 3.1 years before a firm diagnosis. Resource use first occurred 2.8 years after the first symptoms. Most carers (72%) were satisfied with the first consultation, which was usually with a GP (84%). Two-thirds of carers (64%) reported that the first health professional had performed a memory test.

Conclusions: Delays in presentation, diagnosis and resource use may have clinical and social implications for people with dementia and their families, in addition to the challenges of the process of obtaining a firm diagnosis.

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Dementia is the second greatest source of disability burden in Australia,[1] with around 37 000 new diagnoses made each year.[2] Early, accurate diagnosis of dementia has many benefits — treatable causes can be dealt with, interventions to slow progression can be implemented, and future planning can commence while the patient is still competent.[3] Engagement of family and carers with support services and networks can reduce carer burden[3] and in some cases delay institutionalisation.[4]

The time between onset of dementia symptoms and diagnosis is often prolonged, leading to years of uncertainty for patients and their families.[5] Overseas studies have estimated the average time from first symptoms to diagnosis, as reported by informants, to be between 1 and 3 years,[6,7] with symptoms recorded in general practitioners' medical records as early as 5 years before diagnosis.[8] Factors contributing to this delay include the insidious onset of the disease; under-recognition or uncertainty by families about the path to diagnosis; the stigma associated with dementia; and uncertainty about, a lack of knowledge about or a negative attitude to earlier diagnosis by health professionals.[5,9,10]

Identifying where diagnostic delays occur is one link in the chain towards timely diagnosis and support for patients and their carers. We aimed to describe the steps taken and delays encountered in the pathway to dementia diagnosis.

METHODS

A cross-sectional, anonymous, reply-paid survey was distributed to adult carers or significant family members (hereafter referred to as "carers") of people with dementia between May and August 2007. The survey was posted to 200 carers selected randomly from the Alzheimer's Australia New South Wales (AANSW) database of about 1900 current members, and a reminder was sent 2 weeks later. In addition, six residential aged care facilities and 13 GPs in Sydney were chosen for convenience or contacted through several Australian General Practice Networks Aged Care GP Panels. They were provided with 150 and 65 surveys, respectively, which they distributed or posted to as many known carers as possible.

The survey was developed from the literature[3,11] and included open and closed questions about the carer's and patient's demographic details; first dementia symptoms, actions, and consultations; diagnosis and use of any of a list of 22 resources (eg, support, respite and chronic illness services; medical services; advocacy organisations; and advisory services). Carers recorded the year these steps occurred.

Ethics approval was obtained from the Royal Australian College of General Practitioners National Research and Evaluation Ethics Committee.

Analysis

We performed descriptive statistics, independent t tests and χ^2 tests. $P < 0.05$ was considered significant. Missing or illogical responses were excluded from each analysis. We used SPSS for Windows, version 11.5 (SPSS Inc, Chicago Ill, USA) for all statistical analysis.

Open questions were thematically coded separately by two researchers (CMS, EP) and as a team; results for these were grouped as frequencies of the carers responding to each question.

RESULTS

We received 209 surveys: 141 recruited from the AANSW database (response rate, 71%), 59 by residential aged care facilities (40% of surveys provided) and nine by GPs (14% of surveys provided), an overall response rate of 50%.

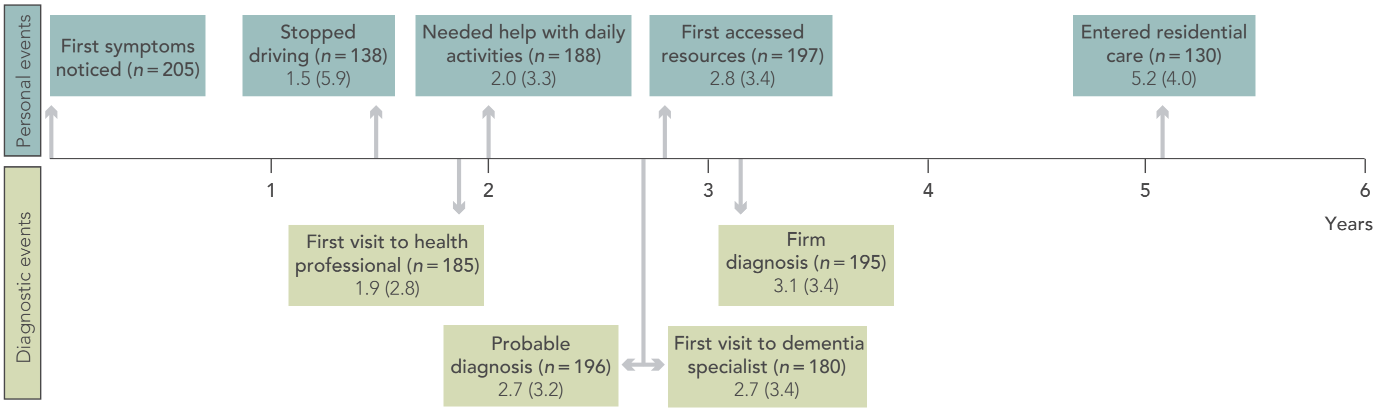
Patient characteristics

Type of dementia, sex of carer and patient, and age of carer did not significantly differ between the three groups. The mean patient age in the AANSW group was 79.8 years, 3.9 years below that of the other groups (95% CI, 1.6–6.2 years; $t = 3.4$; $P = 0.001$), and these patients were less likely to be living in residential care (30% v 74%; difference, 44% [95% CI, 31%–57%]; $\chi^2 = 36.6$; df = 1; $P < 0.001$).

The mean age of carers was 65.5 years (SD, 12.2 years); 75% were female. The mean patient age was 81.3 years (SD, 7.8 years); 62% were female. Most carers were children (45%) or spouses (43%) of patients.

Most patients (44%) lived in residential aged care facilities; the remainder lived with family (27%), in assisted living (12%) or alone (5%), and 12% had died.

1 Timeline of mean time (SD) in years for personal and diagnostic events on the pathway to dementia diagnosis



n = number of patients who had undergone this event and nominated the year it occurred in the survey.

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2 First actions taken by carers or patients after the onset of possible dementia symptoms

First action	No. (%) (*n* = 198)*
Did not take immediate action	
Attributed the problems to something else (eg, stress, normal ageing)	11 (6%)
Did nothing	11 (6%)
Carer or family covered up symptoms or compensated for patient	8 (4%)
Patient refused help	6 (3%)
Increased family involvement	
Increased family support for patient	29 (15%)
Discussed issue with family or friends	11 (6%)
Discussed issue with patient	3 (2%)
Accessed other support	
Consulted a health professional or health service	127 (64%)
Organised professional help (eg, home help, respite care, aged care)	6 (3%)
Consulted an advice line or the Internet	2 (1%)
Other†	3 (2%)

* Carers could report more than one action; 11 carers did not complete this question.
† Used natural therapies; argument between patient and carer; became anxious.

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3 Carers' reports of actions taken by the first health professional consulted

Action	No. (%)* (*n* = 206)
Conducted a memory test	132 (64%)
Referred patient	
To a dementia specialist	121 (59%)
For a blood test	96 (47%)
For a brain scan	92 (45%)
To a memory clinic	19 (9%)
Other	9 (4%)
Did nothing	20 (10%)

* Carers could report more than one action; three carers did not complete this question.

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Reported diagnoses were Alzheimer's disease (58%), vascular dementia (15%), another type of dementia (9%), a combination of types (6%) or unknown (12%).

Steps on the pathway to diagnosis

Most carers (86%) reported that either they or other family members noticed the first symptoms of dementia. In other cases, it was the patient (6%), a doctor (4%), or a friend (3%). The first symptoms noticed were memory impairment (47%), problems with everyday tasks (33%), changes in personality and behaviour (26%), changes to conversation (13%), or another symptom (8%).

Mean intervals from the time first symptoms were noticed to personal and diagnostic events are shown in Box 1. The mean time reported by carers from first symptoms to a firm diagnosis was 3.1 years. At the time of the survey, a mean of 7.8 years (SD, 5.1 years) had elapsed since symptoms had first been noticed.

The most common first actions that carers or patients took after the onset of symptoms were consulting a health professional or service (64%) and increasing family support (15%); 18% took no immediate action (Box 2).

In most cases (84%), a GP was the first health professional patients saw about their symptoms; others saw a specialist (8%) or another health professional (8%). Most carers (64%) stated that a memory test was performed by the first health professional (Box 3).

Most carers (72%) reported being satisfied with the first consultation. Reasons given by 54 carers who were not satisfied included dismissal of the problem by the health professional (33%), an unsympathetic attitude (30%), lack of information or advice (28%), misdiagnosis (19%) or inadequate investigation (13%).

Sixty-four carers nominated resources, supports or treatments they would have found helpful before diagnosis, including more information about what action to take and how to access resources (48%), an improved diagnostic process (earlier firm diagnosis, earlier referral to a dementia specialist or a more supportive doctor) (33%), and earlier access to support services or groups (25%).

DISCUSSION

The mean intervals from symptom onset to attending the first health professional about the symptoms (1.9 years), and receiving a firm diagnosis of dementia (3.1 years) are consistent with those found in overseas studies.[6-8] The consequence of this delay is a lost opportunity for earlier medical and social interventions for patients and their families, and prolonged diagnostic uncertainty. The timeline we observed suggests that levels of daily functioning were substantially impaired well before a diagnosis was made or resources were used.

The first delay in the diagnosis of dementia occurred before seeing the first health professional. Some carers arranged support in the first instance rather than seeking medical advice, but in other cases, stigma and misinterpretation of symptoms contributed to the delay. Other studies have reported that carers may be uncertain about the significance of early symptoms or may gradually adapt to the changes.[5,10]

The second delay occurred after the first health professional was consulted. Some carers reported that the first health professional did not act on symptoms or perform a memory test, and, as in other studies,[5,12,13] some carers reported that their concerns were dismissed or referral was delayed. In some cases, health professionals might not have considered dementia a likely diagnosis, may have been hesitant to suggest dementia as a possible diagnosis because of uncertainty or the stigma associated with the disease,[9] or may have believed tests would not change patient management.[14] Additionally, GPs might prefer a specialist to take on the responsibility of diagnosis and disclosure.[9,15] The complexity of the consultation itself can also contribute, given the multiple diagnoses, comorbidities, agendas and social issues to consider.[9]

Community education about early symptoms and how and when to act on them could aid earlier recognition of symptoms and, possibly, earlier presentation to a health professional.[5,16] Health professionals, especially GPs, need to be able to address the needs of patients presenting with possible dementia symptoms and their families with sensitivity and to accelerate diagnosis.[5,9,15] Acknowledgement by the health professional that a problem exists, even if uncertainty surrounds the diagnosis in the early stages, might allow families earlier access to resources and information that can assist them in their caring roles.[5,9] GPs may also wish to consider earlier referral to a dementia specialist. The Primary Dementia Collaborative Research Centre is currently investigating ways to improve dementia detection in primary care.[17]

Our study has a number of limitations that make it difficult to generalise its results to the wider community, including drawing carers from special interest groups, a low response rate (particularly from GPs), and recall bias. Carer recall may be affected by the time elapsed from first symptoms to the time of the survey and the stress of the experiences surrounding diagnosis.

As the incidence of dementia increases, it will become more important for our health system to have the tools to support earlier diagnosis to allow earlier clinical and social intervention. Studies are needed to determine how best to prompt families and health professionals to recognise and respond appropriately to the symptoms of dementia at an earlier stage.

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COMPETING INTERESTS

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