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Dementia – who cares?

A comparison of community needs and primary care services

Background

Health professionals have varying levels of knowledge about, and interest in, providing dementia services. This article compares patient experiences in dealing with dementia with the perceived role of health care providers in providing dementia care.

Method

Qualitative data from interviews of patients with dementia and their carers was compared with quantitative data from health professional surveys, where health professionals described their knowledge of dementia and their attitudes toward, and roles in, management.

Results

Patients often notice dementia symptoms before their general practitioner and seek diagnosis and support. Not all GPs wish to provide dementia services and many are unaware of the benefits of early diagnosis and dementia care guidelines. Dementia forums attract older health professionals, suggesting younger members are less engaged in dementia care. Older patients tend to consult with older GPs, but older GPs are less aware of dementia diagnosis and management guidelines.

Discussion

Patients turn to their GP for help with dementia but may find most benefit from the assistance and advice of people who have already negotiated the pathways to care. Health professionals who fail to investigate patients presenting with dementia symptoms can delay diagnosis, denying patients and carers early intervention that could improve quality of life for both patient and carer.

■ Although there is clear evidence that early diagnosis of dementia is beneficial to patients, their carers,^{1,2} and the health system,³ this diagnosis is often delayed, resulting in less than optimal management that impacts on the quality of life of the sufferers.⁴ The symptoms of dementia may develop slowly and may remain untreated until a crisis arises, so the general practitioner needs to be alert to the warning signs if the diagnosis is to be made in a routine consultation.⁵ Symptoms suggestive of dementia do not always trigger further investigation, so the diagnosis may remain unconfirmed.⁶ Many doctors feel that unlike other diagnoses, for which a range of treatments are known to be beneficial, little can be done to help those with dementia.⁷ General practitioners may lack training in dementia, especially older GPs whose training preceded modern treatments for the disease.⁸ Nurses and GPs who receive dementia education may increase case finding activities,⁹ working together as a team to achieve an initial diagnosis and applying evidence based strategies in ongoing management.¹⁰ General practitioners are likely to be more actively involved in dementia care when they have access to specialist dementia services and support.⁷

There are a range of cognitive tests that assist screening for dementia in the at risk elderly population, including the widely used Mini Mental State Examination (MMSE). However, there are barriers to applying these tests, including the range of symptoms that can feature early in the disease, a reluctance to identify these symptoms as due to dementia – a diagnosis that for some carries a stigma – and, for all patients, the prospect of declining independence.^{11,12} The tests themselves have lower sensitivity and specificity early in the disease, and many physicians lack confidence in making a clinical diagnosis.^{6,13} However, listening to family and carers can alert the GP to a possible diagnosis of dementia in a patient otherwise well practised in the art of consultation.¹⁴ An abbreviated test such as the Mini-Cog – which requires the patient to recall three items and complete a clock drawing test – has 95% specificity and

97% sensitivity, and can help GPs overcome the time constraints associated with the longer MMSE.¹⁵ Physicians may be reluctant to test for a disease where the diagnosis is less than certain and where discussion with the patient is likely to create anxiety for both clinician and patient.⁶ General practitioners may not be aware of dementia care guidelines or may not recognise the benefits of applying them.¹⁶ Primary health care providers such as the GP and community nurse are well positioned to identify dementia in their patients,¹⁷ and to direct patients to agencies that may be better able to meet their dementia needs.¹⁸

This article compares qualitative data on health services from consumer interviews with quantitative survey data from the GPs and other primary health care professionals providing the services in the community. The interviews were conducted in Mackay, a regional city in Queensland; surveys were distributed to GPs and other health professionals in Mackay and Townsville, a city 400 kilometres north of Mackay. The experiences and expectations of patients and the knowledge, perceived role and current practice of health practitioners looking after dementia patients and their carers give a picture of both met and unmet needs in community dementia care. Patients with dementia, both community dwelling and in residential care, depend upon their GP for primary care management and referral to support and tertiary services. The patients in this study were identified through their GP.

This project received ethical approval from the ethics committees of The Royal Australian College of General Practitioners (RACGP) and James Cook University, Townsville, Queensland.

Method

Twenty patients with a confirmed diagnosis of dementia were identified by their GPs, who suggested the patient or a key family member as the contact point to invite to participate in the study. Twenty nondirected interviews were conducted. The interviews focused on the patients, and discussed issues that had in the past, or might in future, lead to their admission to a care facility. Thirty-seven people, consisting of patients, family and carers, contributed to the interviews. The interview group size ranged from one to five members and was determined by the key family contact. The transcribed interviews provided a range of qualitative data that included experiences with health services and expectations of care from health professionals. Of the sample interviewed, all patients had at some stage been cared for at home, although a greater proportion (12/20) had already been admitted to a care facility. Analysis was by the qualitative method of immersion crystallisation, where the transcribed interviews were examined many times to identify themes that best described the participants' experiences.¹⁹ Applying the method of grounded theory, we were able to generate theories from the interview data, validating participant experiences by turning them into scientific evidence.²⁰ We discuss emergent theories related to provision of health services for people with dementia and their carers, which lead to the conclusion that these people's needs may, at times, be unmet.

Quantitative data was obtained from a one page survey distributed at three dementia forums (n=59) and by post to GPs in Mackay and Townsville (n=55). The survey was designed to be brief, with simple questions and multichoice answers to facilitate response. The data collected included the demographics of health professionals, the dementia services they provided, and their attitude to, and knowledge of, dementia. The responses were entered on SPSS software for analysis.

Results

Qualitative analysis of interviews produced a wide range of data, including descriptions of patient and carer experiences with the health system when seeking dementia diagnosis, advice and management. The cases consisted of patients aged 70–99 years at the time of interview, with a predominance of females to males of 16/4. The informants consisted of patients, spouses, children and their partners, and a niece, all of whom had at some stage been involved in providing care for the patient with dementia (*Table 1*). All patients living at home were included in the interviews, although their contribution varied from 100% (an interview with a single woman living alone) to a few words (an interview with five family members). A more detailed description and discussion of the participants and the wide range of themes arising from the interviews has been previously published.²¹

Themes relating to patient and carer experiences with the health system are outlined in *Table 2*. Thirteen of the interviews talked in overall positive terms about the GP's management of dementia, while seven expressed negative impressions. The positive experiences related to timely intervention, advice and investigations leading to appropriate diagnosis and management. The negative experiences related to delays in acknowledging symptoms and attributing them to dementia; inadequate or absent management strategies; and delayed or absent referral to support agencies.

Support services were discussed by all carers still looking after patients at home (8/8), but by only a quarter (3/12) of those whose family member was in residential care. A small number (3/20) described how they had received no assistance until a friend suggested they needed help. One commented on the excellent help provided by home visiting nursing services – with the exception of public holidays, when the agency concerned provided none. This patient spent 4 days over Easter with no support while the family took a well earned break, expecting nursing visits to continue. The patient was on no medication, and agency policy was to provide nursing services on public holidays only for dispensing medication. Negative experiences with nutrition and hydration in all (13/13) cases related to patients who at the time were self caring but were also receiving support services in the earlier stages of dementia. These services did not address the impact of declining memory and impaired compliance on regular eating and drinking.

A prompt diagnosis explaining symptoms was obtained in a quarter of the cases (5/20). The majority of cases (15/20) reported delays in diagnosis, with a time interval of 1–8 years reported

between first presentation of symptoms to the GP and eventual diagnosis. A small number (2/20) were incorrectly told by their GP that the patient did not have dementia.

Less than a quarter of interviews (4/20) contained specific comments on the GPs' knowledge of, and attitude to, dementia, with two negative and two positive comments.

Access to the dementia medication, acetylcholine esterase inhibitors, was raised in four interviews. Two very distressed carers related their failed efforts to obtain a prescription from either a GP or specialist. They had pinned their hopes on this new wonder drug, which they thought might offer some improvement in symptoms for

their loved one. Both patients had MMSE results below 10, denying them access to government subsidised medication; however they were not offered a private prescription, despite their pleas and investment in private consultations and investigations, which suggest that the family would have been prepared to pay. Mention of other medications in the interview had negative connotations, with nine interviews relating to medication compliance and adverse effects while the patient was still community dwelling. The adverse effects related to decreased cognition due to sedatives and/or problems with alcohol abuse.

The survey results produced quantitative data from a range of health professionals.

Table 1. Interview participant details

Residency	Patient gender and age	Informant(s)*	Months of home care
In care	Female, 88 years	Daughter (only child)	18
In care	Female, 99 years	Daughter and her husband	36
In care	Female, 81 years	Son	3
In care	Female, 77 years	Daughter	24
In care	Female, 86 years	Widowed daughter (only child)	36
In care	Female, 84 years	Husband and daughter	12
At home	Female, 77 years	Patient, husband, two daughters, son-in-law	36
At home	Male, 81 years	Patient and wife	96
In care	Female, 91 years	Niece	6
In care	Female, 75 years	Husband	30
In care	Female, 85 years	Son and his wife	36
In care	Female, 70 years	Daughter and her husband	48
In care	Male, 95 years	Daughter	60
In care	Female, 94 years	Daughter	120
At home	Male, 88 years	Patient and wife	24
At home	Female, 89 years	Patient, husband and daughter	24
At home	Female, 86 years	Patient, daughter and GP	84
At home	Female, 78 years	Patient (single woman, no siblings)	36
At home	Female, 82 years	Patient, son and his wife	36
At home	Male, 84 years	Patient, wife and daughter	36

* All provided care at home

Table 2. Interview themes related to health services

Emergent themes	Total responses	Positive	Negative
Health professional management of dementia	20	13	7
Timely diagnosis responding to symptoms	20	5	15
Accurate diagnosis	7	5	2
Access to support in the home	11	6	5
Access to acetylcholine esterase inhibitor medication (for dementia)	4	2	2
Adverse medication interactions/compliance problems	9	0	9
Access to adequate nutrition and hydration	13	0	13
GP knowledge of dementia	4	2	2

The sample surveyed (n=114) consisted of five groups (Table 3):

- a dementia forum run by the Townsville Division of General Practice (n=32), with 50% response (16/32) consisting of four GPs, two psychologists and 10 nurses
- an open dementia forum at Townsville General Hospital (n=59) with 49% response (29/59) consisting of no GPs and 59% (17/29) nurses
- surveys posted to GPs in Mackay (n=100) with just under 50% response (47/100)
- a postal survey to GPs in Townsville (n=170) with eight responses
- a dementia workshop in Proserpine (n=14) with 14 responses.

Of all the respondents, 53% were GPs and 33% were nurses, with the remainder other health care providers.

Experience in practice

We collected data on the time respondents had been in practice to provide a measure of experience; we also collected data on the date of respondents' initial professional training. Of all the respondents, only 8% were in their first 5 years of practice; 56% had been practising for more than 20 years. Of GPs attending dementia forums, all five (100%) had been practising for more than 20 years. Of the GPs who responded to the postal survey, 55/60 (92%) had been in practice more than 10 years and 47% for more than 20 years (Table 3, 4).

Proportion of practice population over 65 years of age

Over a third (37%) of all GPs surveyed estimated 20% of their practice populations to be over 65 years of age; 12% estimated

that 20% of their practice population was over 75 years of age. The figures for GPs who had been practising more than 20 years were 39% and 21% respectively (Table 5).

Knowledge, attitudes and beliefs

Most respondents indicated that the incidence of dementia increased with age, but there was variation in the values selected, with 24% indicating an incidence of <5% under 75 years of age and a further 5% indicating the same incidence of <5% in those over 75 years of age.

We collected data on the preference of health professionals to look after patients with dementia. Of all the survey respondents answering this question, 15/72 (21%) preferred not to, as did 14/40 (35%) of the GPs replying to the postal survey. Of all the participants who had been practising for over 20 years, 9/38 (24%) preferred not to manage patients with dementia. These nine were all GPs, of whom one had attended a dementia forum (Table 6).

Of all the respondents answering the question, 'is early diagnosis of dementia harmful to the patient?' 16/109 (15%) answered 'yes'; more than half of these respondents (9/16) had been practising for more than 20 years (Table 7).

Of those respondents answering the question: 'Is there a cure for dementia?' 9/112 (8%) of respondents answered 'yes'; a majority of these (7/9) had been in practice more than 20 years. Five were GPs (Table 7).

Of health professionals who considered that their duties included specialist referral, only three said they would never refer dementia patients; two out of these three had been in practice more than

Table 3. Survey participants

Source of participants	Total attendees	Total responses	GP responses	Nurse responses	Other health professionals	Participants in practice >20 years
Mackay GP postal drop	100	47	47	0	0	26/55 (47%)
Townsville GP postal drop	170	8	8	0	0	(GP postal survey)
Townsville GP division dementia forum	32	16	4	10	2	38/59 (64%)
Townsville hospital dementia forum	59	29	0	17 (58%)	12 (42%)	(dementia forums)
Proserpine dementia forum	21	14	1	12	1	
Total	375	114	60 (53%)	39 (34%)	15 (13%)	64 (56%)

Table 4. GP survey and dementia forum participants' years in practice vs. patient population over 75 years of age

Source of GPs	GP years in practice				Subtotal	Total
	<5 years	5–10 years	10–20 years	>20 years		
Mackay GP postal survey	3	7	15	22	47	55
Townsville GP postal survey	2	0	2	4	8	(postal)
Townsville GP division dementia forum	0	0	0	4	4	5
Townsville hospital dementia forum	0	0	0	0	0	(dementia forums)
Proserpine dementia forum	0	0	0	1	1	
20% patients >75 years	(1)	(0)	(1)	(6)	(7)	
Total	6	7	17	30	60	60

20 years. However, 24/83 (29%) always referred and 56/83 (67%) sometimes referred. These responses were spread over all practitioner time in practice (Table 7).

Discussion

The sample of consumers interviewed covered an age range typical of our older population and their carers. The contribution by patients with dementia is important and reduces the possibility of underestimating unmet needs.²² The contribution by carers may be influenced by their own health problems, a topic not discussed in this article; however carer health also impacts on the overall needs of the patient, reflecting a service need rather than creating bias.^{23,24}

The themes relating to health services that arose from the nondirected interviews reflected issues that were important to the participants, whose responses ranged from gratitude to despair. Patients and carers expressed the distress caused by their GP's failure to initiate timely investigations to explain symptoms, or to offer advice on appropriate support – a finding consistent with other studies.²⁵ While all carers welcomed offers of support, some only gained this support when another member of the community informed them of their entitlement. Patients and carers were accepting of a diagnosis of dementia, but some GPs were reluctant or unable to provide this. The paucity of comments on GP dementia knowledge suggests that patients trust their GPs and assume that the GPs are informed. The problems for patients in accessing dementia medication may reflect their exposure to media promotion of this new medication at the time, and the difficulties for GPs in negotiating the

government conditions for obtaining a subsidy for the medication. Current evidence suggests that a negative approach to treatment of dementia is not best practice,³ but our results suggest that some GPs may be unaware of this. Management of medication for dementia patients living in the community was problematic for many families.

Our survey samples comprised groups of health professionals who had chosen to attend dementia forums (a majority being GPs, with the next largest group being nurses) and another group of GPs in usual practice, who completed a postal survey. The length of time in practice of all survey respondents reflects our aging workforce,²⁶ with the greatest proportion of respondents in practice over 20 years. This group was also more highly represented at dementia forums, possibly reflecting personal as well as professional interest. All practitioners provided services for patients over 65 years of age, with a higher proportion of older practitioners caring for patients over 75 years of age.

A significant proportion of health professionals, mainly GPs, preferred not to manage patients with dementia. Unless these health professionals refer dementia patients to other colleagues who have an interest in dementia, care may be less than optimal, especially as patients consult more frequently with GPs as they age.⁷ The one GP attending the dementia forum who reported a preference not to manage patients with dementia was possibly attending to complete his accreditation requirements that were due the following month, rather than out of clinical interest. Serial studies of the attitude of health professionals to dementia has shown that attitude can improve with time,⁷ and that the inevitable, increasing exposure of GPs to our aging population may shift GP preferences, especially if resources for referral are available. Other studies show that GPs who have limited access to specialist support for managing dementia patients may be poorly motivated to initiate care;⁶ this is the case in Mackay, where there are no resident geriatricians. Lack of awareness of both the benefits of early diagnosis and the absence of a cure for dementia was more common in practitioners who had been in practice more than 20 years, confirming the findings of other researchers.²⁷ Practitioners who had been in practice for many years were also more likely to have a practice population in the older age group, so it is possible that older patients attending older practitioners have less access to appropriate dementia care.

Conclusion

Patients turn to their GP when faced with symptoms of dementia; however not all GPs wish to provide dementia services and many are unaware of dementia care guidelines and the benefits of early diagnosis. Patients need to know where to go for help when faced with this diagnosis. They may find the most benefit from the assistance and advice of people who have already received support and negotiated the pathways to care. Health professionals who fail to investigate patients presenting with dementia symptoms can delay diagnosis, denying patients and carers early intervention that could improve the quality of life for both patient and carer.

Table 5. Percentage patients >75 years vs. GP years in practice

Percent of patient population >75 years of age	GP years in practice				Total
	<5 years	5–10 years	10–20 years	>20 years	
<5%	2	3	3	5	13
6–10%	1	3	7	7	18
10–20%	3	1	5	10	19
>20%	0	0	1	6	7
Missing	0	0	1	2	3
Total	6	7	17	30	60

Table 6. Health professionals who do not wish to look after dementia patients

Survey group	Do not wish to look after dementia patients			
	Yes	No	Not applicable or missing	Total
All participants	15	72	27	114
GP postal survey	14	40	1	55
All attendees of dementia forums	1	33	25	59
Participants in practice >20 years	9	38	15	62
GPs in practice >20 years	9	20	1	30

Table 7. Health professionals' years in practice vs. beliefs and practice

		Health professional years in practice				Totals
		<5 years	5–10 years	10–20 years	>20 years	
Belief that early diagnosis is harmful	No	9	12	20	52	93 (85%)
	Yes	2	2	3	9	16 (15%)
Belief in dementia cure	No	11	15	22	55	103 (92%)
	Yes	0	0	2	7	9 (8%)
Referring dementia patients	Never	1	0	0	2	3 (3%)
	Always	1	6	8	9	24 (29%)
	Sometimes	6	3	14	33	56 (67%)

Recommendations

Although patients may first seek help for dementia from their GP, knowledge of all primary care providers, including community nurses, should improve the outcomes for patients with early dementia.¹⁷ Improved community and health professional awareness of the benefits of early diagnosis and support for dementia sufferers could lead to earlier presentation and appropriate response, reducing barriers to service utilisation. Health professionals have an ethical obligation to respond to the needs of patients with dementia and their carers; referral to other agencies should be considered, especially if the health professional's clinical interests lie elsewhere.

Conflict of interest: none declared.

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