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GP management of dementia

A consumer perspective

■ **As the population ages, the general practitioner is likely to have an increasingly important role in diagnosing and managing dementia.¹ Many people in the community dealing with dementia have little help until a diagnosis is made, and their experiences produce a profile of their met and unmet needs.² A nondirected interview technique elicits a wide range of themes from individual life phenomena, with each person attributing their own meaning to events and experiences.³ Open ended discussion can produce unexpected information that is outside the experience of the researcher but relevant to the people being studied,⁴ reflecting the unique nature of each person's experience with dementia.⁵ Patients expect their GP to know about dementia and look to their GP for help with the disease,⁶ but these expectations may not always be matched by the doctor's knowledge about dementia or their perceived role in dementia care.⁷**

Patients and their families benefit from support in the early stages of the disease, particularly when the patient is physically well and active and the family is adjusting to possible different roles.⁸ Both family and doctor can overlook the benefit of early intervention, increasing the burden of care for the family that contributes to early admission.^{9,6}

A standard tool for diagnosing and measuring the severity of dementia in general practice is the Mini Mental State Examination (MMSE), but this may have poor sensitivity and specificity for some patients early in the disease or due to cultural and educational factors.¹⁰ Nearly half of the GPs in a United Kingdom study believed early diagnosis of dementia was not beneficial, and two-thirds did not offer memory tests when the patient complained of memory problems.¹¹ Autopsy studies show that the diagnosis is made before death in 3% of mild and 24% of moderate to severe cases, and pathological changes may occur years before the first symptoms.¹² Medical records can document signs of dementia up to 4 years before a formal diagnosis is made.¹³ Present research suggests early intervention can modify the

course of the disease, and may delay onset in people with potentially treatable risk factors for the disease.¹⁴

The dementia specific medications acetylcholine-esterase inhibitors are designed to delay cognitive decline. Media coverage in 2001 promoting this new treatment coincided with interviews for this study, giving hope to people dealing with dementia. However, the medical profession's lack of awareness of the value of this medication, together with government regulations restricting medication subsidy, made access to this treatment difficult. The inevitable cognitive decline associated with dementia affects the quality of life of both patient and carers, creating an ethical dilemma when treatment is denied.¹⁵

The participants in this study resided in Mackay, a regional city in Queensland, where GPs provide a range of services in the absence of dementia specialist services. In major centres, referral by the GP to a dementia specialist service may be the preferred pathway to dementia diagnosis and care.

Ethics approval for this study was granted from the ethics committees of The Royal Australian College of General Practitioners and Otago University, New Zealand.

Method

This ethnographic study was conducted by a researcher with personal experience of dementia in their own family and a cohort of people already diagnosed with dementia, together with their families and carers. Thirty patients with a diagnosis of dementia were identified by 11 GPs. Twenty-two patients were women and eight men; with 20 participating in the study. Those excluded included one patient who died before the interview, two with a GP who did not wish to participate, two whose GP did not respond to an invitation to participate, four whose next of kin lived elsewhere, and one family that declined to participate. The invitation to participate was extended to a key person in the family, identified by the patient's GP. The final sample studied consisted of 16 women and four men, of whom 11 women and one man were in residential care. The mean age of admitted patients was 85 years; for community dwelling patients the mean age was 83 years.

No restriction was placed on the number of family members participating in the interviews, and the patient with dementia was included when the family felt this was appropriate, acknowledging the meaningful contribution of a person suffering from dementia.¹⁶

All participants chose to be interviewed in their homes, with interviews lasting 1–2 hours using a nondirected technique to encourage free discussion around the topic of admission to a care facility. Interviews were recorded and later transcribed and analysed using the qualitative method of immersion crystallisation whereby the transcribed interviews were examined many times, identifying statements that matched themes best describing the participants' experiences.¹⁷

Results

A total of 20 interviews were conducted with 37 participants, eight of whom were patients.

GP themes

Thirteen interviews contained positive statements about their GP's dealing with dementia; seven described negative experiences, with interviewees indicating that they had expected more help from their GP than they received. General practitioner themes were further explored under the headings of diagnosis, cognitive testing, dementia knowledge, carer support, treatment and medication compliance. The interviews demonstrated how GPs' management of a dementia patient can impact on all members of the family.

'The GP never told dad. I begged him to tell him. The doctor was God. It had to come from his mouth before he would do it. If only the GP had been more upfront and said "looks like you are in for a hard time now and you should do something".' (A daughter).

Diagnosis

All 20 interviews discussed dementia diagnosis, with the GP playing a varied role. Prompt diagnosis in response to symptoms was described in five of the 20 cases. Four of these diagnoses were made by a GP and one by a psychiatrist providing private care for a chronically depressed patient. Fifteen of the 20 cases reported delays in diagnosis, with a time interval of 1–8 years reported between first presentation of symptoms to the GP and diagnosis.

Three patients were aware that something was wrong, but only one was offered investigations by the GP to confirm the diagnosis.

'She told her doctor she was forgetting things and he did a memory test and sent her for a brain scan.' (A daughter).

'She would cry and say "there is something wrong with me, I wish the doctor could fix me up." I had been taking her to the doctor and he said there was nothing wrong.' (A husband).

In eight of the 20 cases, respondents described how the carer made the diagnosis, with two being frustrated when the diagnosis was initially refuted by the GP. Four cases discussed the stress of dealing with symptoms and behaviour that had no explanation before diagnosis, and another four accepted symptoms as part of aging without mention of distress.

The carers demonstrated insight into the difficulties in making a diagnosis of dementia, discussing lifestyle issues that contributed to memory problems. In almost half (n=9) of the groups, cognitive problems were made worse by the side effects of medication (especially sedatives), in two-thirds (n=13) by irregular food and fluid intake, and in one, alcohol abuse contributed to symptoms.

Cognitive testing

Three interviews described problems in patient cooperation with the MMSE. They described how evasive actions were taken by the patient to avoid answering questions that could highlight their shortcomings, producing inappropriately low scores; one patient scored 1 out of 30 while still functioning at home. In four interviews, carers felt the score did not accurately measure cognition, scoring too low to meet the qualifying score of 12–24 for subsidised dementia medication.

Dementia knowledge

General practitioners' knowledge and attitude toward dementia was mentioned in only four interviews. Two positive comments welcomed GPs' ability to offer prompt diagnosis and access to support. Two negative comments reflected attitudes of other health professionals toward GPs, whereby health providers working in specific dementia services attributed difficulties in accessing help to GPs' lack of knowledge about dementia.

'I asked why the doctor didn't tell me about that and she said that the doctors don't know. Most of them don't know.' (A daughter).

Carer support

Large portions of all interviews focused on issues relating to carer support, discussing relief from help received and the frustration of being unable to access help. Many positive comments demonstrated that the most reliable, up-to-date source of information about dementia support services came from other carers who had firsthand knowledge of the pitfalls and benefits, and not from the GP. A quarter (n=5) of the interviews produced negative comments about services received, demonstrating the strong recall and impact of negative experiences.

'Not a damned thing happened for us. That was the hard part because she got no help. You didn't know what help there was.' (A daughter).

'We had gone away for 5 days and when we returned she had on the same clothes and she was dirty, and meals on wheels hadn't been and what was in the fridge was still there. I asked if it was usual to leave people over the holiday periods. She didn't have to have medication so their role was to make sure people got tablets, not that they got fed.' (A daughter-in-law).

Treatment

Only two out of 20 patients received acetylcholine-esterase inhibitors. Four of the carers recalled their doctor discussing dementia

medication, but no prescription was given as the dementia was 'too bad'. Nearly half (n=9) of the carers said this treatment option had not been discussed with them. Only two participants actively sought acetylcholine-esterase inhibitors, both for a family member living at home, but were denied a prescription by GPs who felt this treatment was inappropriate. No interviews mentioned the offer of a private prescription from the GP.

Medication compliance

Medication compliance was raised by nearly half of the cases (n=9). This was a major problem when the patient was self caring – complicating management of behaviour when supervision was either absent or sporadic.

Discussion

Population studied

The patients in this study are representative of the older age group more likely to be diagnosed with dementia. Women outnumbered men, as found in older populations. Three of the four men were managed at home, reflecting the higher availability of carers for men, often the spouse, and the smaller proportion of men in residential care.¹⁸

Diagnosis

A delayed diagnosis was common, increasing patient and family stress. The diagnosis was often missed in routine consultations in which the patient was well practiced in their role.^{11,19} Some experts suggest that a diagnosis of dementia is less likely if the patient complains that something is wrong,²⁰ but the present study confirms that patients may be aware of their own dementia and the importance of GPs listening to them. Relatives and carers can accurately identify cognitive problems, and their concerns can alert the doctor to the need for investigation.²⁰ Knowing that a medical condition was causing symptoms turned the diagnosis of dementia into a useful tool that could initiate appropriate intervention and support.²⁰ Dementia guidelines developed for GPs by The Royal Australian College of General Practitioners recommend case finding in at risk populations so that the diagnosis can be made early in the disease.²¹ There may be value in regularly testing cognitive function in the elderly at risk of dementia, to establish a baseline and to document changes; this would enable early intervention and provide an opportunity for the patient to have input into future management plans.²⁰

Cognitive testing

In Australia a specialist can commence acetylcholine-esterase inhibitors for dementia when the MMSE score falls between 12 and 24 out of a maximum 30. However, the accuracy of this test was questioned by families who felt the score was too low due to the patient's lack of engagement or inability to perform some tasks. This raises the question of the value of MMSE for diagnosing and monitoring changes in dementia. Standard tests all give poor to good classification accuracy, but the use of more than one test improves the

rigour of the measurement.²² The General Practitioner Assessment of Cognition (GPCOG) test has been designed for use in general practice, combining objective data from family and care givers with questions directed to the patient resulting in 0.85 sensitivity and 0.86 specificity for dementia diagnosis.²³ However this test is not recognised as a measure for access to medication.

Dementia knowledge

The paucity of comments about GPs' knowledge of dementia may indicate that most patients trusted their GP to be informed about the disease, accepting the service offered. This study reflected previous findings that deficiencies in GP knowledge about dementia can delay diagnoses and lead to less than optimal support and management.²⁴ Responsive GP dementia services received positive comments, while negative comments were received when GPs failed to identify the disease or arrange support. Carers appreciated a diagnosis that explained what was happening, even when the prognosis was difficult.

Carer support

Patients expected their GP to offer appropriate care and access to dementia support, but many found that other people and agencies dealing with dementia were better informed about support services and were a reliable source of accurate information. Many elderly people lack the information needed to access support and value a GP who can inform them.²

Treatment

Media coverage heralding the government subsidy for acetylcholine-esterase inhibitors generated discussion of this treatment option in all interviews. Families hoped this new drug would provide the treatment they were looking for to help their loved ones, but difficulty in accessing this medication raised issues about GPs' attitude to dementia and awareness of recent improved management practices. No GP offered a private prescription when the patient failed to meet the requirements for government subsidy. Studies show that any improvement in symptoms – even for a short period – is worthwhile, both for patient and carer, and may delay the need for residential care.²⁵

Medication compliance

This study confirmed that elderly people, especially those with dementia, can have problems with medication compliance, compounding disease management.²⁶ In recent years we have seen the introduction of medication packaging and home medication reviews, but these have not had the expected impact on improved medication compliance and patient care.²⁷ A better outcome may be achieved if GPs rationalised medication to essential items so that compliance was improved.²⁸

Conclusion

Our findings indicate that the problems encountered by patients with dementia and their carers could be reduced if GPs were more alert to

the possibility of dementia in older patients, better informed about support systems, and if they implemented effective management plans. General practitioners are highly skilled in making diagnoses from patients' stories, but contributions from both the patient and carer may be needed to suggest early dementia, and further cognitive testing and investigation necessary to confirm a diagnosis. With the population aging and dementia prevalence increasing, GPs are well placed to initiate early support, sustaining a reasonable quality of life for patients for longer, and reducing the burden of care and costs to the health system.

Conflict of interest: none declared.

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