Dementia in general practice: the practical consequences of a more positive approach to diagnosis

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SUMMARY. General practitioners are often reluctant to administer brief cognitive tests, and to question the relatives of patients who appear to be demented, for fear of causing distress. Diagnoses of dementia are therefore often based on guesswork, and non-demented patients may be rated as cognitively impaired in error. A randomly selected sample of 174 general practice patients aged 80 years and over were asked to complete a simple test of orientation and information in order to assess the usefulness and acceptability of such a procedure. If patients scored 10 points or less out of 12, a relative or other knowledgeable informant was questioned about their changes in mental state and behaviour. Assessments proved acceptable to patients, relatives and doctors; diagnoses were revised in 29 cases; and practical initiatives were proposed in 15 cases. Open discussions with patients and their families proved innocuous and have much to commend them.

Keywords: dementia; cognitive status; diagnostic techniques; differential diagnosis; elderly.

Introduction

DEMENTIA is commonly incurable but it can be managed, just as diabetes mellitus, rheumatoid arthritis and macular degeneration are managed. If management techniques are to prove successful, diagnoses should be based on the history and a mental state examination; dementia should be distinguished from depression and acute confusional states; uncommon but treatable forms of dementia should be identified and corrected; patients with established dementia should be helped to perform at their optimal level; and families should be given whatever support and practical advice they need.

Dementia cannot be managed, however, if doctors fail to detect it. Despite the fact that general practitioners in recent studies in the United Kingdom and western Europe successfully recognized the majority of the cases of dementia in their care much remains to be done.[1-3] In a Cambridge research project, general practitioners' assessments of cognitive status were based as much on guesswork as hard, substantial evidence; few used tests of memory and orientation, and some deaf, dysphasic or depressed elderly people were labelled as 'demented' or 'possibly demented' in error.[1] In addition, general practitioners postponed taking action until relatives or neighbours insisted that something be done.

Doctors who wish to take an assertive approach to the diagnosis and management of dementia face an uphill battle. Demented elderly people rarely present for help of their own accord and their families are often reluctant to trouble doctors with a problem which many of them see as part of the normal ageing process. In the Cambridge study, less than half of those who cared for a markedly disabled spouse or parent had ever raised the question of dementia with their general practitioner but when they did, and the doctor responded with interest and concern, they were deeply appreciative.[1] Despite this it would be rash to propose that doctors take the initiative until their concerns have been answered. Brief cognitive tests and an interview with a relative or other knowledgeable informant about changes in memory, judgement and behaviour might cause grievous offence; large numbers of false positive diagnoses could lead to fruitless, expensive investigations; and efforts to sharpen the diagnostic process might produce little useful return.

The aims of this study were to test the acceptability and usefulness of a simple procedure to detect the presence and severity of dementia in primary care, and to determine, if possible, whether a deliberate search for dementia will do more harm than good.

Method

A method was devised which fulfilled the following requirements. Assessment procedures should be brief, require a minimum of training and should prove acceptable to patients, relatives and doctors; the cognitive test selected should be capable of detecting marked degrees of dementia with a high degree of accuracy; and depression, acute confusional states and other treatable conditions should be discounted by means of an interview with a relative or other knowledgeable informant.

In 1990 patients aged 80 years and over who were resident in the community were selected at random from the family practitioner committee lists of seven members of the Fenland General Practice Research Group who were general practitioners in urban and rural Cambridgeshire. The selected patients were then interviewed by their general practitioner during specially arranged appointments using a protocol which enquired into mood, general complaints and medications and concluded with the information–orientation scale taken from the Clifton assessment procedures of the elderly.[4] Doctors were asked to note if deafness,

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Submitted: 21 January 1992; accepted: 10 June 1992.

visual impairment, dysphasia and so on made interview difficult.

The information–orientation scale consists of 12 basic questions (orientation to time and place; the name of the prime minister; the name of the president of the United States of America; the colours of the British flag), scoring one point each. The scale takes only two to three minutes to administer and was designed to detect dementias which are associated with clinically significant forgetfulness, inertia, physical dependency and disturbed behaviour.[4] In order to produce sufficient cognitive test failures to assess the usefulness of the procedure the usual cut-off point of seven points used to denote 'severe cognitive impairment' was increased to 10.[4] Questions missed because of deafness, dysphasia or refusal were scored as zero.

When patients scored 10 or less out of a maximum score of 12 points on the scale, questions were put to a relative or other knowledgeable informant about changes in patients' memory, intellect, behaviour and everyday skills and about the duration and course of symptoms. Informants were interviewed at the time, if they were present, and if not by telephone or at a separate visit. Questions which addressed criteria for dementia, acute confusional states and depression contained in the third revised edition of the *Diagnostic and statistical manual of mental disorders*[5] were selected from the Cambridge examination for mental disorders of the elderly.[6]

Doctors were asked to rate patients' cognitive function on a three point scale: not demented, possibly demented or definitely demented. Ratings were made at the following times: prior to the interview with the patient; after the initial discussion about mood, general complaints and medications; after the cognitive test; and after the informant interview if this was required. This was to determine which if any of these steps produced a change in assessment. The doctors were also asked to rate whether the cognitive test and informant interview had contributed usefully to their knowledge of each patient and then, if the patient was judged to be demented, to list what actions they wished to take. The doctors rated the usefulness of the exercise on a scale of one (a waste of time) to four (extremely useful). They were also asked if they made regular use of cognitive tests in assessments of patients aged 75 years and over, or if they planned to incorporate them in future assessments. Finally the doctors wrote a brief description of each patient and interview.

Patients and informants were asked about their response to being questioned in this way and to the assessment being carried out annually. However, since patients and relatives might be reluctant to criticize their doctors, even when invited to do so, general practitioners were asked to make additional ratings of patients' and informants' responses to the interview on the basis of their demeanour and casual comments.

Before the study began, the doctors attended a one-hour training meeting and read a 10-page training manual which described the procedures involved in the project and included a brief discussion of dementia and its differential diagnosis.

Results

The seven general practitioners involved in the study were members or fellows of the Royal College of General Practitioners and had worked in their current posts for between three and 17 years. All had experience in geriatric medicine at postgraduate level but only one had comparable experience in psychogeriatrics. Three of the seven doctors had contributed to a study of the epidemiology and natural history of dementia conducted several years previously.[1,7,8] However, all but three of the patients who had been noted to be demented in that study had since died or moved to residential care. These three patients were included in this study; they were so markedly disabled that mistaken assessments were highly unlikely.

The doctors were asked to attempt 25 assessments but pressure of work meant that the numbers of patients interviewed ranged from 17 to 41 with a mean of 25. Twenty eight of the 220 patients whose names were selected were usually seen by a colleague or had died, moved away or been admitted to a residential home. Of the remaining 192 patients 174 agreed to be interviewed (90.6%). Five refused assessment, six were too ill to be interviewed, four could not be contacted and three were excluded for other reasons (a lengthy psychiatric history, recent bereavement and intense hypochondriasis).

The age of the 174 patients ranged from 80 years to 99 years with a mean of 84.9 years; 67.8% were women, 66.1% were widowed and 51.1% lived alone. Most had been registered with their practice for many years (mean 11.5 years, range one year to 56 years) and all but five had consulted their doctor in the previous 12 months. The mean number of consultations during this period was 7.3 with a range of zero to 46.

Thirty nine of the 174 patients (22.4%) scored 10 or less out of the maximum score of 12 points on the information–orientation scale and 15 (8.6%) scored seven points or less. An informant was identified and interviewed for all but one of the 39 subjects who scored 10 points or less.

A comparison between the doctors' ratings before and after assessment is presented in Table 1. Doctors modified their ratings for 12 of the 38 patients who scored 10 or less on the scale and for whom an informant was identified. They changed their rating from not demented to possibly or definitely demented in four cases but none of these patients was severely demented, judging from their scores on the screening test (scores of eight, nine, 10 and 10, respectively) and their informants' comments. For the 135 patients who scored 11 or 12 points on the scale, initial and final assessments were in total agreement in 118 cases. The most striking finding was that 15 patients, previously thought to be possibly or definitely demented, were regraded as not demented. Two were profoundly deaf, six were depressed (of whom two had been prescribed antidepressant medication) and three were exceptionally frail. The patient whose rating was revised from definitely demented to not demented was actually dysphasic.

Table 2 shows the number and direction of revisions after each of the three stages of the assessment. The initial discussion led to changes in ratings for eight of 174 patients (4.6%), most commonly in a downward direction from possibly demented to not demented. Cognitive testing led to changes in rating for a further 15 patients (8.6%), mostly in a downward direction. Following informant interviews concerning 38 patients the rating was

Table 1. Doctors' ratings before and after assessment for the 38 patients who scored 10 points or less on the screening test and for whom an informant was interviewed and for the 135 patients who scored 11 or 12.

	Final rating (no. of patients)		
Initial rating	Not demented	Possibly demented	Definitely demented
Patients scoring 10 or less			
Not demented	4	1	3
Possibly demented	0	6	7
Definitely demented	0	1	16
Patients scoring 11 or 12			
Not demented	115	1	0
Possibly demented	14	3	0
Definitely demented	1	1	0

Table 2. Contribution of initial discussion, cognitive test and informant interview to doctors' ratings.

	No. of changes in ratings					
	Upward revision			Downward revision		
Change following:	Not to possibly demented	Not to definitely demented	Possibly to definitely demented	Definitely to possibly demented	Definitely to not demented	Possibly to not demented
Initial discussion (n = 174)	1	0	0	1	0	6
Cognitive test (n = 174)	2	0	2	1	1	9
Informant interview (n = 38)	0	0	8	0	0	1

n = total number of patients.

changed in nine cases (23.7%), all but one from possibly to definitely demented.

The doctors felt that the cognitive test made a useful contribution to their knowledge for 46 of the 174 patients assessed (26.4%) and a major contribution in another 15 cases (8.6%). The informant interview was rated as making a useful contribution for nine of the 38 patients for whom this step was carried out and a major contribution in another 15 cases. New initiatives were proposed for six of the 13 patients who were rated as possibly demented at the end of the exercise and for nine of the 26 who were rated as definitely demented. These included more regular visits (three patients), greater support to families (four), referral to social services or visits by community psychiatric nurses or health visitors (six), respite admission (one) and physical investigations or treatment (three).

In response to the question, 'How useful did you find the cognitive test?', one doctor gave a rating of two on the four point scale, five gave a rating of three and one a rating of four (extremely useful). In response to the question, 'How useful did you find the informant interview?', two gave a rating of two, three gave a rating of three and two a rating of four. While two of the doctors had used formal tests of memory and orientation when circumstances suggested that a patient was demented, the remaining five had relied on personal observations and the reports provided by relatives. When asked if they planned to incorporate cognitive tests into future annual assessments, five stated that they wished to apply them more frequently but only three thought it appropriate to administer such tests each year.

The assessment proved acceptable to patients and relatives in so far as this could be judged. Only one patient, a demented woman, objected to the interview and to having the same procedure applied each year. Doctors felt that three patients found the cognitive test 'a bit unpleasant' but none of the informants who were interviewed objected to being questioned either currently or in the future.

Discussion

One critic of regular surveillance thought it likely that elderly people would resent 'this new and unsolicited intrusion of their privacy'.[9] The results of this study suggest that this is not the case as only one of the 174 patients assessed objected to the procedure. Little evidence of dissatisfaction among patients was detected and none of the relatives who were interviewed raised any objections. The screening test seemed highly acceptable. Unsolicited visits may be seen as an expression of care and concern but it remains to be determined whether this favourable response persists as patients become accustomed to the notion of an annual assessment.

The interview with patients, which covered general complaints, depression and cognition, could be completed within an estimated 10 to 15 minutes and the informant interview in another five minutes although it took longer if patients or relatives wished to discuss their concerns in detail. This is a substantial investment for general practitioners given that they care for an average of 100 patients aged 75 years and over[9] whose mental, physical and social well being must be reviewed each year under the conditions of the new general practitioner contract.[10]

Research projects usually entail some compromise between clinical and academic interests. It was not intended that the study protocol be applied as part of annual assessments of elderly patients although doctors could do so if they wished. The use of a higher than usual cut-off point on the information-orientation test followed from the need to generate sufficient informant interviews to comment on the usefulness and acceptability of this particular procedure. As a result, mildly demented patients were almost certainly identified by the study and the results must be seen in this context. Early dementia causes little distress to families and results in substantially fewer demands on medical and social services than more advanced degrees of disability.[7,11,12] A cut-off point of eight or nine would be preferable in day to day practice.

Review of the doctors' protocols suggested that their final ratings of possible and definite dementia were adequately substantiated but mistakes will be made if general practitioners interpret impaired cognition and the description by relatives of forgetfulness and disorientation as *prima facie* evidence of dementia. Even the briefest assessment procedures provide a wealth of information which must be interpreted carefully, and further medical and psychiatric investigations will be required in a proportion of cases.

A mental state examination and informant history are essential if delirium, depression and other causes of reversible cognitive impairment are to be detected and treated. The accounts of relatives or other knowledgeable informants are especially important since confused elderly people cannot provide accurate information about their current level of function, recent illnesses and injuries, and the medications they take each day. All previous investigators have been loathe to question relatives for fear that they will dismiss the subtle, gradually progressive manifestations of dementia as part of 'normal old age' and so fail to report them, but informants' responses in a recent community survey correlated to a highly statistically significant degree with other, independent measures of cognitive and behavioural abnormalities.[13]

In this study the initial discussion resulted in six patients who had previously been rated as possibly demented being reclassified as not demented and the cognitive test resulted in a further nine such revisions. Mistaken attributions of possible dementia are probably innocuous although the possibility exists that patients wrongly judged to be possibly demented may be treated less vigorously in consequence owing to dementia's poor prognosis. If this were true, small numbers of elderly people may be investigated less intensively or referred to specialist medical or surgical services less frequently than would normally be the case.

The informant interview resulted in eight patients who were

previously rated as possibly demented being reclassified as definitely demented. This is an impressive yield, considering that interviews were required for only 39 of the 174 patients. Recent research makes it plain that families value the opportunity to discuss their concerns with general practitioners, although most will not do so unless doctors take the initiative or until the family's resources are stretched to breaking point.[1] In a lengthy intervention study most of the relatives interviewed had limited expectations of what could be done to help them.[8] Indeed, their expectations were sometimes so low that a proportion had failed to apply for the financial benefits and practical assistance to which they were entitled. There is nothing to suggest, therefore, that an open approach in dealing with relatives will result in a massive influx of strident and unrealistic demands for assistance.

The knowledge doctors gained as a result of the surveillance programme led to their proposing new, practical initiatives for 15 of the 39 patients who were labelled at the end of the exercise as being possibly or definitely demented. These initiatives consisted for the most part of more regular follow up and the provision of greater support for families. They were therefore practicable, relatively inexpensive and likely to be welcomed by relatives. The exercise appeared to be justified, therefore, but it remains to be seen whether screening for dementia needs to be repeated each year. While five of the seven doctors stated that they planned to employ brief cognitive tests more frequently, only three wished to administer cognitive tests on a routine basis. This decision seems entirely reasonable. Dementia usually develops in a slow, insidious fashion and the number of new cases arising each year in a typical general practice will be far too small to warrant the administration of cognitive tests each year to every patient aged 75 years and over.

The findings of this study show that cognitive tests, when combined with informant histories could help to sharpen diagnoses and promote good community care. A detailed review of all elderly patients may be useful from time to time but formal investigations should be restricted to instances in which a doctor or nurse has reason to suspect that a patient suffers from an organic mental disorder. In cases such as these, a combination of a brief cognitive test and an informant interview, if scores are low, is a powerful and acceptable clinical tool.

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Acknowledgements

Dr O'Connor was supported by the Charles Wolfson Charitable Trust. Dr K Morgan, University of Nottingham, kindly supplied data relating to scores on the information–orientation scale in a previous survey. Copies of the protocol used for interviewing the informants are available on request from Professor O'Connor.

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