Referral patterns and diagnosis in presenile alzheimers disease: implications for general practice

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SUMMARY

Background. *Presenile dementia of alzheimer type is a rare condition, and a report drawn from a large population may be useful to general practitioners.*

Aim. *A study was undertaken in the Northern Regional Health Authority area to investigate general practitioner referral practice, hospital investigations and diagnosis in cases of presenile alzheimers disease.*

Method. *Reviews of 186 sets of case notes of patients diagnosed between 1985 and 1989, and follow-up interviews with the principal carer in a subsample of 73 surviving patients were undertaken.*

Results. *In 63% of cases, formal diagnosis of presenile alzheimers disease was made by a neurologist, in 27% of cases by a psychiatrist and in 9% by a physician. Symptoms of depression had been noted in 45 patients (24%) and 21 had been prescribed antidepressant drugs prior to specialist referral. Computerized tomography scans were requested significantly more frequently by neurologists than other specialists and lumbar puncture was virtually only done by neurologists, but there were no significant differences between specialists regarding other clinical investigations. Domiciliary care or day centre attendance were more likely to be arranged at hospital discharge by psychiatrists than other specialists, but at follow-up interview no differences in community care provision were found according to initial specialty. Interviews with relatives of surviving patients revealed that at initial contact with general practitioners 48% of patients were unaware that they had any problem. Only 13 relatives (18%) felt they had been given sufficient information at diagnosis concerning the chronic and progressive nature of the disease, and at follow up 26% remained unaware of the existence of the Alzheimer's Disease Society.*

Conclusion. *These results reinforce the importance of the role of general practitioners in arranging and coordinating appropriate support for patients and their relatives, in providing continuity of care and in advising the families of the existence of voluntary organizations.*

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Introduction

ALZHEIMERS disease has a characteristic neuropathology but is diagnosed clinically by exclusion of other possible causes of dementia. Although originally described as a presenile dementia, the great majority of these cases occur in those aged 65 years and over. However, because of their rarity and the ominous prognosis, presenile cases present special problems of diagnosis and management. The annual incidence of presenile dementia of alzheimer type has been estimated at 7.2 per 100 000 of the population and the prevalence at 34.6 per 100 000 in the 45 to 64 years age group.[1] Individual general practitioners will have had little experience of this rare condition, and a report drawn from a large population may be useful.

Method

Cases of presenile alzheimers disease in the Northern Regional Health Authority area diagnosed between 1985 and 1989 were identified from their *International classification of diseases* (9th revision) hospital inpatient codes and through enquiry among community services, including general practice, as fully described elsewhere.[1] Hospital case notes were used to provide clinical details and information concerning referral pattern, investigations undertaken and subsequent support. Surviving patients with a close relative willing to participate were followed up and the relative interviewed to confirm diagnosis[2] and for additional information concerning early symptoms,[3] pathways to diagnosis and current domiciliary support.

Differences between subgroups were examined for stastical significance using the chi square test.

Results

Hospital diagnosis

A total of 186 cases of presenile alzheimers disease were identified (47.3% men, 52.7% women). The age range of the cases was 45–64 years, with a mean of 59.1 years (standard deviation 4.1 years). Those patients previously referred to a specialist for symptoms of dementia, and the type of specialist making the diagnosis of presenile alzheimers disease, are shown in Table 1. According to the case notes two thirds of patients (67.2%) had not previously been seen by a consultant for symptoms of dementia. In 63.4% of all cases, the diagnosis was made by a neurologist. Psychiatrists were significantly more likely to carry out domiciliary visits prior to patients' hospital attendance than were physicians or neurologists (nine, 17.6%, versus six, 4.4%, respectively, $\chi^2 = 8.7$, 1 df, $P<0.05$). The time between symptom onset and final diagnosis was similar in the three specialties; overall, 90 patients (48.4%) were diagnosed in hospital within 12 months of symptom onset and 142 (76.3%) within two years.

A total of 45 patients (24.2%) had symptoms of depression, 21

Table 1. Cross tabulation of diagnostic specialty, by previous referral for symptoms of dementia.

Diagnosed by:	No. of patients not previously seen by consultant	No. of patients seen previously by consultant			Total no. of patients
		Neurologist	Psychiatrist	Physician	
Neurologist	68	–	28	22	118
Psychiatrist	40	3	–	8	51
Physician	17	0	0	–	17
Total	125	3	28	30	186

of whom (46.7%) had been prescribed antidepressants prior to hospital referral. There was no evidence from the hospital records that the presence of depressive symptoms or their treatment had delayed the making of the final diagnosis of presenile alzheimers disease, although the effectiveness of such treatment could not be assessed. Anxiety was recorded more often in the notes of patients diagnosed by psychiatrists (13, 25.5%), than by neurologists or physicians (12, 8.9%) (χ^2= 8.8, 1 df, P<0.05). Changes in patient behaviour were also more frequently recorded by psychiatrists (29 cases, 56.9%) than by neurologists and physicians (46, 34.1%) (χ^2= 7.9, 1 df, P<0.01). For all other reported clinical features, including depression, there were no significant differences between specialties.

Laboratory investigations and special tests carried out and support arrangements made at time of discharge by the different specialists are shown in Table 2, together with the percentage of tests reported to be within normal limits. Neurologists were significantly more likely to arrange for their patients to have a computerized tomography scan or lumbar puncture compared with other specialists. Psychiatrists were more likely than neurologists or physicians to arrange for patients to receive domiciliary services or day centre/day hospital care. Few computerized tomography scan results or psychometric test results were within the normal range. The computerized tomography scans revealed no focal lesions; most scans showed various degrees of generalized atrophy.

Relatives' recollections at follow up

The mean time between diagnosis and follow-up interview with the relatives of 73 surviving patients was 4.2 years (standard deviation (SD) 1.1 years). This subsample was not significantly different from the remainder with regard to sex, age at diagnosis, diagnostic specialty or length of survival, but were drawn from the more recent years of the original cohort. In 68 cases (93.2%), memory impairment was one of the earliest features noted by relatives; depression had been noted in only 11 cases (15.1%). Other common early features were confusion or disorientation (53 cases), lack of energy (46) and aphasia (19). Examples of behaviour that indicated early dysfunction included setting the table for members of the family who had left home some years previously, driving round a roundabout the wrong way, and not being able to find a parked car after a shopping trip.

At first medical consultation, 35 patients (47.9%) were unaware of any problem, and the decision to seek medical advice, which in 70 cases (95.9%) involved a consultation with a general practitioner, was made by only 11 patients (15.1%). The majority of patients (62) required persuasion to seek medical opinion and this frequently involved subterfuge on the part of relatives and general practitioners. In 10 cases, problems and difficulties in the workplace resulted in an employer suggesting (and in one case insisting on) a medical consultation.

Eleven relatives believed they were not given a diagnosis of the patients' illness at hospital following completion of the diagnostic assessment, and only 13 (17.8%) considered that they had been given sufficient information or advice about the prognosis. Relatives were more likely to have been told of supportive domiciliary services by psychiatrists (nine, 52.9%) than by neurologists or physicians (five, 9.1%, χ^2= 15.6, 2 df, P<0.01). Likewise, eight relatives who saw psychiatrists (47.1%) had been

Table 2. Investigations undertaken during the diagnosis of presenile alzheimers disease (and percentage of tests with normal results) and follow-up arrangements made by the specialists.

	% of patients having test/service arranged by consultant making diagnosis				
	Neurologist (n = 118)	Psychiatrist (n = 51)	Physician (n = 17)	Total (n = 186)	% of total tests in normal range
Test					
CT scan	*99.2*	*52.9*	*58.8*	*82.8* ***	*13.0*
Lumbar puncture	*62.7*	*2.0*	*5.9*	*40.9* ***	*98.7*
Thyroid function	*72.9*	*76.5*	*52.9*	*72.0*	*97.8*
Folic acid and vitamin B_{12}	*72.0*	*72.5*	*76.5*	*72.6*	*99.3*
Liver function	*52.5*	*45.1*	*70.6*	*52.2*	*95.9*
EEG	*52.5*	*56.9*	*41.2*	*52.7*	*32.7*
Psychometric test	*48.3*	*60.8*	*52.9*	*52.2*	*3.1*
Service					
Outpatient appointment	*51.7*	*56.9*	*58.8*	*53.8*	–
Domiciliary service	*1.7*	*47.1*	*5.9*	*14.5* ***	–
Day centre/day hospital	*1.7*	*51.0*	*0*	*15.1* ***	–

n = number of patients in group. CT = computerized tomography. EEG = electroencephalography. Overall difference between specialties, χ^2: *** P<0.001.

told of self help organizations such as the Alzheimer's Disease Society compared with 10 (18.2%) seen by neurologists or physicians (χ^2= 5.6, 2 df, P<0.05).

At the time of interview, 19 relatives (26.0%) remained unaware of the help available from the Alzheimer's Disease Society. Fifty nine patients (80.8%) were receiving, or if in hospital had been receiving, a social security attendance allowance, and 45 (61.6%) were attending or had attended a day centre. Uptake of services in the longer term was not related to the original specialty of diagnosis.

Discussion

Studies of psychiatric referrals have described the difficulties in diagnosing presenile dementia in its early stages, particularly in distinguishing it from depression.[4,5] In this study depression was recorded in the case notes as a symptom in 24% of patients and treated with antidepressant medication in 11% prior to a hospital visit. This points to the existence of some early uncertainty about the diagnosis, as does the fact that many patients were seen by consultants from more than one specialty. However, unlike a previous study in the 1970s, the presence of depression did not appear to be associated with delay in the diagnosis of dementia.[6] Notwithstanding, almost a quarter of all patients were not diagnosed in hospital within two years of the onset of their symptoms.

In suspected presenile alzheimers disease, the main use of laboratory tests is to exclude reversible dementias associated with potentially treatable conditions, and the results were within normal limits in nearly all cases. Computerized tomography scans are carried out to detect conditions with focal brain pathology, including stroke[7] and none of the scans in this sample revealed focal lesions; 13% were reported as normal, the remainder showing some generalized atrophy. The virtual restriction of lumbar puncture to neurologists probably reflects current practice, whereby lumbar puncture remains a routine part of neurological investigations but is considered less relevant in psychiatry. The lower rate of scanning requested by psychiatrists and physicians compared with neurologists may reflect difficulties in access to a scanner rather than diagnostic complacency, and some of the referrals from psychiatrists to neurologists may have been made for this reason.

Survival rates for presenile alzheimers disease indicate that early death is uncommon.[8] Five year survival following diagnosis has been reported as 69% of that of the general population matched for age and sex, with a median survival time after symptom onset of nine years.[1] About one third of patients with any type of presenile dementia die at home or in a residential home,[9] the remainder in hospital.

Given the dissatisfaction expressed by many relatives about the amount of information provided about the illness at the hospital consultation when diagnosis was made, family doctors may wish to discuss prognosis with relatives, as well as the availability of different types of care and social security benefits.

From this study, it appears that general practitioners cannot assume that the diagnosis of dementia after thorough investigation in hospital necessarily results in patients and relatives being fully informed of the diagnosis and likely prognosis. Since community services were seldom arranged at hospital visits, the continuity of follow up and the counselling and support of newly diagnosed cases of presenile alzheimers disease and their families, together with the coordination of appropriate community care and support, clearly remain in the province of the general practitioner.

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