

The role of carers in the information process in dementia

Rahul Rao

The role of carers is explored in the process beginning with the early detection of changes in cognitive function through to the diagnosis of dementia. Carers were not always aware of early cognitive decline before other family and friends. Forty-five per cent of initial diagnoses were made by GPs. In over 50% of cases, the sufferer had not been told their diagnosis by health professionals or carers. A quarter of carers wanted more information about dementia even after referral to specialist services. The importance of early referral and provision of sufficient comprehensive information about dementia are discussed.

The role of carers in the early detection of changes in cognitive function of people with dementia, as well as their attitudes to the diagnostic process and its sequelae, have not been subject to close examination. The most commonly reported part of this process has been that of the psychiatrist's role in communicating the diagnosis of dementia (Rice & Warner, 1994).

Caring for someone with dementia is associated with depression in 30–50% of cases (Coope *et al.*, 1995). The early detection of cognitive impairment, adequate information about dementia from health professionals, and subsequent mobilisation of appropriate services may therefore reduce morbidity in the mental health of sufferers and carers and be seen as examples of 'good practice' (Wattis, 1996).

This study aimed to explore three particular areas: the involvement of carers in the initial detection of dementia, their attitudes towards the way in which the diagnosis was communicated, and attitudes towards sharing the diagnosis with the sufferer.

The study

A questionnaire was sent to the carers of all those people having a case-note diagnosis of Alzheimer's disease on the caseload of an old age psychiatry community team. All case notes met DSM-III-R criteria for primary degenerative dementia of the Alzheimer type, and all dementia sufferers had scores on the Mini-Mental State Examination (Folstein *et al.*, 1975) of 23 or less. The questionnaire included questions concerning

the initial detection of memory problems by the carer or other people (and their response to this), the initial diagnosis by a health professional (including what was communicated, to whom and whether or not this was understandable), whether the diagnosis was shared with the sufferer and concerns about this, and whether this changed the carer's understanding of the disorder. Provision was also made for any comments that carers wished to make. The study was carried out between April and September 1995. Relationships between categorical variables were analysed using the chi-squared (χ^2) statistic, with Bonferroni and Yates' corrections applied appropriately.

Findings

Fifty-eight questionnaires were sent out and 49 (84%) were returned. Ages of dementia sufferers ranged from 65 to 94 years (s.d.=6); 22 (45%) were men and 27 (55%) women. Thirty carers were female and 19 were male. All men were married and living with their spouse; women whose carers were not their spouse (daughter ($n=7$) or sister ($n=1$)) all lived alone and were widowed.

Responses to questionnaire items are shown in Table 1. Twenty-two of the 49 carers (45%) reported that the initial diagnosis of dementia was made by a general practitioner and 23 (47%) by a psychiatrist. In four (8%) cases, the carer could not recollect who had first made the diagnosis.

Other people were more likely than the carer to think that memory problems were related to dementia/Alzheimer's disease, yet less than half those who noticed memory problems had reported these to the carer at the time. In less than a third of cases was the sufferer told that there was something wrong at the time by anyone who was aware of the memory problems.

The diagnosis was commonly told only to the carer. 'Dementia' was the commonest word to be used, followed by the terms 'Alzheimer's disease' and 'memory loss'. An explanation of the term dementia/Alzheimer's disease and of the prognosis/course of the disorder was communicated

Table 1. Carers' attitudes to the information process in the diagnosis of dementia

	Number of cases (%)
Initial detection of cognitive changes	
Carer first to notice memory problems	36 (74)
Other people (who had noticed memory problems) reported these problems to carer	20 (41)
Other people (who had noticed memory problems) thought memory problems caused by Alzheimer's disease ¹	25 (51)
Diagnosis of dementia	
Initial diagnosis made by psychiatrist	23 (47)
Initial diagnosis told to sufferer	18 (37)
Words 'dementia'/'Alzheimer's disease' used	32 (65)
Meaning of term dementia explained in understandable way ²	28 (57)
Prognosis explained in understandable way ³	28 (57)
Carer shared diagnosis with sufferer	19 (39)
Diagnosis helped to change way carer understood the condition	29 (59)
Information about dementia	
Adequate amount given ⁴	38 (78)
Still wished for more information	18 (27)

1. More likely for other people than carers $\chi^2=6.3$, d.f. 1, $P=0.01$.

2. More likely for psychiatrists than GPs $\chi^2=7.0$, d.f. 1, $P=0.008$.

3. More likely for psychiatrists than GPs $\chi^2=20.5$, d.f. 1, $P=0.001$.

4. More likely for psychiatrists than GPs $\chi^2=4.9$, d.f. 1, $P=0.03$.

in less than two-thirds of cases. Psychiatrists were more likely to explain the meaning of dementia/Alzheimer's disease in an understandable way than general practitioners. Psychiatrists were also more likely to explain the likely course of the disorder in an understandable way. Most carers thought that about the right amount of information was given and most did not require further information. Psychiatrists were more likely than GPs to provide adequate information. Most carers thought that the diagnosis had changed their understanding of the memory problems.

Fewer than half the carers had shared the diagnosis with the sufferer. Different reasons were given, such as the sufferer not being able to understand the significance of the word 'dementia', worries over emotional reactions at being told, thinking that the sufferer would forget being told, and reporting that the sufferer thinks that memory problems are part of 'old age'. Of the spontaneous comments made by carers, the most frequent reflected overall satisfaction with the services they now received. However, most of the other comments related to the importance of earlier diagnoses in helping to mobilise services and provide a better understanding of dementia (including provision of written information and attendance at carers groups).

Comment

The point at which carers of those with cognitive decline bring this concern to the notice of health

professionals may be influenced by several factors. One may be the assumption that memory problems are an invariable consequence of advancing age (Rao *et al.*, 1997). As memory problems were first noticed by other people in 26% of cases in this study, and this was frequently not reported to the carer at the time, this may have delayed the carer seeking help. Many carers would have liked a diagnosis made earlier which may have resulted in earlier access to appropriate services.

The study has methodological limitations. It is possible that carers whose questionnaires were not received represented a biased group in terms of satisfaction with aspects of diagnosis/service provision; there may also have been bias in recall of events surrounding the initial diagnosis. Although the questionnaire was confidential and required no personal information from carers, responses could have been influenced by concerns that other health professionals may have access to these questionnaires.

A considerable proportion of initial diagnoses were made by GPs. One study has shown that less than 50% of GPs use standardised tests for this purpose (Mackenzie, 1992). A clearer explanation of the nature of dementia (described not solely in terms of 'memory problems') and its possible effects on others can also lead to greater carer satisfaction. The time period between initial diagnosis by a GP and referral to the old age service is not known from this study.

Sharing the diagnosis of dementia with the sufferer remains an ethical dilemma. Given the stigma the diagnosis still carries, the task may be

made more difficult for the carer (Drichamer & Lachs, 1992). In this study, it was not commonplace to share the diagnosis with the sufferer; indeed, a high proportion of psychiatrists still opt to limit this discussion to carers (Brodaty *et al.*, 1990). Although the current level of information provided by the community team appeared to be adequate in about two-thirds of cases, a sizeable proportion of carers wished for more information.

Early diagnosis of dementia and appropriate referral to specialist services can benefit both carers and dementia sufferers (Sperlinger & Furst, 1994). However, the involvement of GPs in the process requires close liaison with old age psychiatrists if this is to be achieved at an earlier stage in the disorder. How information about dementia is communicated to carers and their views on sharing the diagnosis with the sufferer should also be taken into account when evaluating services, and may help to reduce the burden of care.

Acknowledgement

I wish to thank Dr Martin Smith for his help in questionnaire design.

References

- BRODATY, H., GRIFFIN, D. & HADZI-PAVLOVIC, D. (1990) A survey of dementia carers, doctors' communications, problem behaviours and institutional care. *Australia and New Zealand Journal of Psychiatry*, **24**, 362-370.
- COOPE, B., BALLARD, C., SAAD, K., *et al* (1995) The prevalence of depression in the carers of dementia sufferers. *International Journal of Geriatric Psychiatry*, **10**, 237-242.
- FOLSTEIN, M. F., FOLSTEIN, S. E. & MCHUGH, P. R. (1975) 'Mini Mental State'. A practical method for grading the cognitive state of patients for the clinician. *Psychiatric Research*, **12**, 189-198.
- DRICHAMER, M. D. & LACHS, M. S. (1992) Should patients with Alzheimer's disease be told their diagnosis? *New England Journal of Medicine*, **326**, 947-951.
- MACKENZIE, D. M. (1992) Screening of the mental state of the over-75s in the community: what are GPs doing? *Psychiatric Bulletin*, **16**, 146-147.
- RICE, K. & WARNER, N. (1994) Breaking bad news: what do psychiatrists tell their patients about their illness? *International Journal of Geriatric Psychiatry*, **9**, 467-471.
- RAO, R., DENING, T. R., BRAYNE, C., *et al* (1997) Suicidal thinking in community residents over eighty. *International Journal of Geriatric Psychiatry* (in press).
- SPEHLINGER, D. & FURST, M. (1994) The service experiences of people with presenile dementia: a study of carers in one London borough. *International Journal of Geriatric Psychiatry*, **9**, 47-50.
- WATTS, J. (1996) Caring for older people: what an old age psychiatrist does. *British Medical Journal*, **313**, 101-104.
- Rahul Rao, Senior Registrar in Old Age Psychiatry, Maudsley Hospital, London SE5 8AZ