

# Telling the truth: what do general practitioners say to patients with dementia or terminal cancer?

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## SUMMARY

*A questionnaire was sent to all general practitioners (GPs) in Cambridgeshire asking them about their practice in telling patients with dementia or terminal cancer their diagnosis. Although the majority of GPs would always or often tell patients of a diagnosis of terminal cancer, this was not the case in dementia; uncertainty of diagnosis was cited as the most important factor in not giving the diagnosis. The implications of these findings are discussed in the light of the GP's role in dementia and the development of new anti-Alzheimer's drugs.*

**Keywords:** dementia; diagnosis; questionnaires; communication.

## Introduction

ATTITUDES to talking about a patient's diagnosis with the patient have changed in recent years. Physicians now discuss frankly diagnoses such as terminal cancer.<sup>1</sup> Although dementia affects 1 in 12 of the population over the age of 65 years and the consequences of the illness are profound, there is little information about the way this condition is discussed with sufferers. Because dementia is so common, general practitioners will often be responsible for making the diagnosis. We wished to find out the practice of GPs in discussing the diagnosis of dementia and terminal cancer.

## Method

A questionnaire was devised which asked GPs what they said to patients suffering from dementia or terminal cancer and also requested some information about the GP. It was piloted with 10 GPs and subsequently revised. A list of practising GPs in Cambridgeshire was obtained from the family health services authority. Each GP on the list was sent a copy of the questionnaire. Three hundred and seventy two questionnaires were sent out and a reminder was issued if the questionnaire had not been returned within four weeks. Chi-square tests were used to calculate differences in responses.

## Results

Two hundred and sixty one replies were received after the first posting and a further 24 after the second; 281 were fully completed (76% of the total sent out), 195 (69%) of the GPs were male and 86 (31%) were female. Sixty one (22%) of the GPs had

been in practice for more than 20 years, 102 (36%) for between 10 and 20 years, and 118 (42%) for less than 10 years. When the GPs were asked to indicate on a five-point scale if they agreed with the statement 'I feel confident when making the diagnosis of dementia', 206 (73%) agreed or strongly agreed, while the remaining 75 (27%) were undecided, disagreed, or strongly disagreed. We then asked, again using a five-point scale, if the GPs would inform a patient of the diagnosis if the patient was suffering from dementia or terminal cancer. Table 1 sets out their replies. GPs were significantly more likely to tell patients the diagnosis in the case of cancer ( $\chi^2 = 204$ ,  $df = 4$ ,  $P < 0.001$ ). Similarly, they were much more likely to give patients the prognosis for cancer than for dementia ( $\chi^2 = 198$ ,  $df = 4$ ,  $P < 0.001$ ). Of 10 factors that influenced their decision to tell patients of their diagnosis of dementia, GPs rated the three most important as certainty of diagnosis (153 GPs, 54%), the patient's wish to be told (113 GPs, 40%), and the patient's emotional stability (90 GPs, 32%).

## Discussion

A good response rate to the questionnaires was achieved, though practice among Cambridgeshire GPs may be different from elsewhere in the country. GPs are reluctant to disclose the diagnosis of dementia with patients (only 39% always or often did so), and this reflects the unwillingness of consultant psychiatrists to do so.<sup>2</sup> They appear to have no problems with disclosing a diagnosis of terminal cancer to their patients (95% always or often did so). There are advantages and disadvantages to discussing the diagnosis of dementia with a patient.<sup>1</sup>

We believe that in many cases there would be benefits in disclosing the diagnosis, including better planning for the future so that, for example, power of attorney, wills and long-term care could be sorted out in advance. GPs viewed problems with certainty of diagnosis as a major factor in discussing the diagnosis with dementia sufferers, but despite this the majority of GPs in our study felt confident in making a diagnosis of dementia.

One survey in the United States found that 90% of patients of all ages would wish to know their diagnosis if they were ever to develop dementia;<sup>3</sup> certainly in the United Kingdom cancer patients want to be told their diagnosis and prognosis,<sup>4</sup> and GPs' practice appears to reflect this. Public awareness of dementia will increase, spurred on by developments such as Ronald Reagan's public announcement in 1994 that he had Alzheimer's disease, and the fact that the anti-Alzheimer's drug donepezil is already available in the UK, with many more such drugs likely to be on the market soon. This may mean that patients with dementia will present earlier with a consequently greater understanding of their own problems. If patients are to be told their diagnosis, this must be done sensitively and with respect for the patient's wishes. GPs are in a unique position to recognize cognitive decline, and (by virtue of the sheer numbers of patients with dementia) will continue to play a key role in identifying the illness.<sup>5</sup> The use of simple protocols should improve their diagnostic ability in dementia.<sup>6</sup>

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**Table 1.** Number of GPs who would inform their patients of their diagnosis and prognosis (percentages in brackets).

Frequency with which GPs (n = 281) inform their patients	Diagnosis of dementia	Diagnosis of terminal cancer	Prognosis of dementia	Prognosis of terminal cancer
Always	14 (5.0)	76 (27.0)	14 (5.0)	72 (25.6)
Often	96 (34.2)	190 (67.6)	87 (31.0)	186 (66.2)
Occasionally	116 (41.3)	12 (4.3)	114 (40.6)	19 (6.8)
Very rarely	48 (17.1)	3 (1.0)	55 (19.6)	4 (1.4)
Never	7 (2.5)	0 (0)	11 (3.9)	0 (0)

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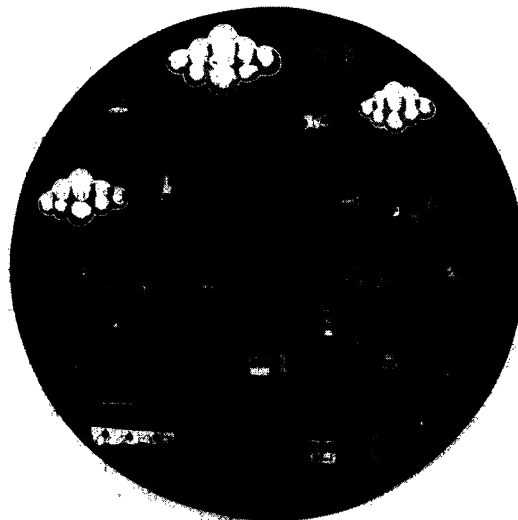
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