Secrets and lies: the dilemma of disclosing the diagnosis to an adult with dementia

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Abstract

Guidelines state that doctors should reveal the diagnosis to the carer and the person with dementia. Carers may, however, not wish the diagnosis to be disclosed. We investigated carer and patient characteristics associated with the wish for disclosure. Fifty-four per cent of 100 carers wished the diagnosis to be revealed. The only significant predictor of wish for diagnosis to be hidden was a lower Mini Mental State Examination score. Clinicians should strive for earlier diagnosis and to address carer concerns, disclose the diagnosis and thus avoid the need for secrets and lies.

Keywords: carers, dementia, disclosure, secrets

Introduction

Dementia raises unique issues about both the disclosure of the diagnosis to the patient and the carer’s role in this decision. According to international and ethical guidelines, the treatment of dementia ‘always involves... explaining the diagnosis to the older person and any carers’ [1–4]. Competent patients may decide about treatment on the basis of information about their illnesses but people with dementia may be unable to remember, understand the implications of the diagnosis and still be distressed by it [5–8]. There are only two small studies about whether patients with dementia want to know the diagnosis. They suggest that most would like to know and it may be advantageous to them [9–11]. Psychiatrists usually only disclose the diagnosis to patients with mild rather than severe dementia [12]. Two studies, one in a memory clinic (MC), the other in a community mental health team (CMHT), reported whether carers wished the diagnosis to be revealed. They found 17% and 57% of carers respectively wished the patient to be told the diagnosis [6, 13]. Our study considers whether carers wish the diagnosis disclosed when it is first made and the associates of this decision.

Methods

After local ethics committees’ permission, we identified carers from consecutive referrals from 1999–2001 from a semi-rural MC and inner city CMHTs. A carer was defined as spending ≥2 hours a day in activities related to the dementia. We asked whether they had wished the diagnosis to be revealed to the person with dementia at the time it was made and collected demographic and pathological variables.

Results

We recruited 100/104 (96.2%) of carers approached (62 from CMHTs and 38 from MCs). Fifty-four per cent [95% confidence intervals (CI) = 43.7–64.0] wanted them to be told. Table 1 shows the associations of the pathological and demographic variables with the wish to disclose. The only significant univariate association (from the variables in Table 1) of wanting disclosure was higher Mini Mental State Examination (MMSE) score (P<0.001 mean difference = 4.9; 95% CI = 2.5–7.3). Figure 1 shows the percentage of carers who wished
the diagnosis to be revealed at each MMSE score. Forward logistic regression analysis in which all the variables were entered revealed that MMSE was the only significant predictor of whether the carer wanted the diagnosis disclosed \((P<0.001; \text{odds ratio for a 1 point increase in MMSE}=1.2; 95\% \text{ CI}=1.1–1.3)\).

Discussion

More than half of carers wished their relative to be told the diagnosis and this was predicted by milder dementia. Although carers were asked retrospectively about their wish for disclosure, we do not think this resulted in bias, as the time period from diagnosis to the interview did not relate to the wish for disclosure. The carers’ perspective implied that disclosure is not necessarily ethical or beneficial.

Key point

- Earlier diagnosis and addressing the concerns of the carer about revealing the diagnosis to people with more severe dementia may allow agreement about diagnostic disclosure and avoid secrets and lies.
References


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