

Truth-telling and the diagnosis of dementia

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The change of attitude towards disclosure of the diagnosis of medical conditions, most notably cancer, has been dramatic in the past 40 years. However, the progression of openness towards patients suffering from Alzheimer's disease or other dementias may be less apparent.

Most of the research on truth-telling in relation to diagnosis is held in the cancer literature. In the 1960s, an early study of physicians' attitudes towards disclosure of the diagnosis of cancer showed that 90% of doctors had a policy of not revealing the diagnosis (Oken, 1961). The study was repeated nearly 20 years later and a major shift was found in medical attitudes, with 98% of doctors reported as having a policy of telling patients the truth (Novack *et al*, 1979).

Little is known about the attitudes held among psychiatrists and physicians towards disclosing the diagnosis of dementia, or about what is the current practice. Similarly, there is little evidence as to what carers or indeed patients themselves wish to know with regard to their diagnosis. With the advent of potential treatment options for Alzheimer's disease, the issues surrounding early diagnosis and prognosis have come to the fore in the psychiatry of old age. Consequently, an intrinsic part of our clinical practice must be questioned: that of disclosure of the diagnosis of dementia. The advantages and disadvantages of disclosure of such a diagnosis and the ethical issues involved are discussed.

'TRUTH-TELLING' AND DEMENTIA: PRACTITIONERS' ATTITUDES AND PRACTICE

There may be parallel issues to consider between cancer and dementia, for example, with the advent of new drug therapies and increased public awareness, but there are also notable differences. In dementia, the illness is intrinsically altering the patient's

cognition, ability to make judgements and have insight, thus affecting the patient's very being. This makes the issue of disclosure rather different from other physical illnesses.

There is a small but growing research interest in the area of disclosure of the diagnosis of dementia. A recent study examined current practice and attitudes among geriatricians and psychiatrists of old age. The results suggested that only 40% of health-care specialists of the elderly regularly tell patients the diagnosis and 20% see no benefit in telling the patient. However, 72.5% of the respondents would wish to know themselves if they were suffering from the illness (Johnson *et al*, 2000). Other studies examining the practice of general practitioners, geriatricians and psychiatrists have shown similar findings (Gilliard & Gwilliam, 1996; Rice *et al*, 1997; Clafferty *et al*, 1998; Vassilas & Donaldson, 1998).

VIEWS OF CARERS, PATIENTS AND THEIR PEER GROUP

The view of carers' on information given by health professionals is sparse. A recent study has examined the views of relatives of sufferers of Alzheimer's disease: 83% of carers expressed a wish that their relative should not be told (Maguire *et al*, 1996). Despite this, 71% of the same carers indicated that they themselves would like to be told if they were developing the illness. A similar, although smaller, survey reported different findings: 57% of first-degree relatives wished the sufferer to be informed (Barnes, 1997). Reasons for this included: relatives not wishing to hide information from their loved ones; that they would probably work it out anyway; and making preparations for their future.

Much less is known about patients' preferences. One may gain some insight into the views of elderly patients with dementia by examining the views of other elderly

peer groups. One such study found that 90% would have wished to be told of the diagnosis, their reasons mainly being in order to make plans for care, obtain a second opinion and settle family matters (Erde *et al*, 1988). More recent studies have shown similar findings (Holroyd *et al*, 1996; further details available from the author upon request).

The question of what patients with a diagnosis of dementia would wish to be told remains largely unknown. The Fairhill guidelines (Post & Whitehouse, 1995) report a series of meetings involving the testimonies of patients and care-givers about ethical aspects of dementia care and they are firmly of the view that the patient with mild dementia should be told of the diagnosis. However, there is no direct research evidence obtaining views on being given a diagnosis of dementia involving the patients themselves. One might argue that this lack of research activity is due to the ethical difficulties of including patients with dementia in such research. This would seem more palatable than the possibility that this is just one further reflection of the medical profession's paternalistic 'we know best' attitude.

TO TELL OR NOT TO TELL? - ISSUES AGAINST AND REASONS FOR DISCLOSURE

The moral doctrine of diagnosis disclosure is derived from a respect for the patient's autonomy as well as beneficence. Considering the principle of respect for autonomy (the ability to self-govern and make one's own decisions) and the principle of non-maleficence (the obligation not to inflict harm intentionally), one finds that these two goals are not necessarily incompatible but often lead to different decisions about what information is given.

The rationale for withholding information rests on preventing harm. It can be argued that truth-telling has become a moral absolute, the patient's right to know being paramount; but if taken literally, it is easy to imagine the potential harm in some cases. One must remember that non-maleficence must be ensured in disclosure (Charlton, 1998). Although there is no evidence of long-term psychological damage, physicians have stated various concerns, including the fear of destroying hope and concern about specific detrimental outcomes such as depressive illness,

suicide or catastrophic reaction (Watts *et al*, 1992; Markle, 1993; Rohde *et al*, 1995).

Other reasons that give rise to concern for disclosure include the difficulties of accurate diagnosis. However, there are clear and accurate diagnostic criteria for Alzheimer's disease (ICD-10; World Health Organization, 1992). Drickamer & Lachs (1992) state that although the histological diagnosis is often uncertain in life, we still have the option of being 'truthful' with our patients, making an honest presentation of the information as it is perceived and known. Positive reasons for disclosure range from "the patients' right to know" and facilitation of future planning to "taking that once in a lifetime holiday". It may assist in persuading the patient to accept help and in managing social needs. It enables the issue of driving safety to be addressed (Johnson & Bouman, 1997). With advanced medical directives, personal affairs such as power of attorney, making wills, choice in future care and living wills may be established. Being told the diagnosis may aid the issue of psychological adjustment, allowing patients to share their anxieties. Disclosing the diagnosis can assist access to the new cognitive enhancers, such as donepezil and rivastigmine. With the development of new drug treatments, disclosure allows patients to consent to participation in clinical trials when they still have the capacity to consent. Currently most research relies on relatives to give proxy consent, although this is currently being challenged as legally unacceptable (Ross, 1996).

WHEN AND HOW TO TELL

In the early stages of dementia, while the individual is still competent, it can be argued that a patient needs to know the diagnosis to enable choice, autonomy and future planning. In the late stages of disease the truth will neither benefit nor harm, and disclosure is merely futile. Moody (1995) wrote, "What sense really does it make to speak of *telling* the truth when the truth can only be *heard*, and then promptly forgotten". But there is more of a dilemma in the cases where some understanding remains. It is difficult to find the right time when the diagnosis is clear enough but the patient's capacity to make use of the information is intact enough.

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When having to deliver such bad news, sensitivity, flexibility and discretion are required. Disclosure should not be a one-off event and must be seen as an ongoing, dynamic process and a fundamental part of the care of a patient with dementia. Many doctors hold the fear of causing distress by telling the truth about the diagnosis, but in turn it could be considered an intrinsic part of our work to address the distress and be there for the patient, even if they do not take the diagnosis well.

There is an extensive literature now on the wishes of patients who suffer from cancer and the information that they would like to have (Meredith *et al*, 1996). There is some evidence from healthy adults that they would like to know if they had a diagnosis of Alzheimer's disease. However, medical practitioners, relatives and carers appear more reluctant to disclose diagnostic information to a patient suffering from dementia. This reluctance appears to be operating on a mechanism of a wish to protect, but from what? There is little evidence that patients will suffer any long-term harm following disclosure. There are no studies specifically investigating patients' views on this matter and doctors really are unsure whether patients would wish to know or not. This has to be an important area for further research, to enable our therapeutic alliance with our patients to be strengthened. It is not a question of whether to tell the truth or not; we must be truthful to our patients. When and how are the questions that need to be explored, with the help, of course, of our patients.

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