

Guest Editorial

Telling the Diagnosis of Dementia: Consider Each Patient Individually

KEYWORDS: Alzheimer's disease; dementia; diagnosis disclosure; autonomy; paternalism

Pinner and Bouman's review article "To Tell or Not to Tell: On Disclosing the Diagnosis of Dementia" (pp. 127-137 in this issue) outlines the pros and cons of diagnosis disclosure to this diagnostic group. It is only over the past 10 years that the question of informing patients with dementia of their diagnosis has become topical, although the hard evidence for and against telling remains sparse, with much of the argument on either side being anecdotal. Paternalism is a common theme of surveys that examine the attitudes of spouse caregivers, relatives, and nonaffected older adults toward telling the diagnosis of dementia (Connell & Gallant, 1996; Erde et al., 1988; Holroyd et al., 1996; Maguire et al., 1996).

The first main review to discuss the case for and against telling the diagnosis favored informing patients of their diagnosis, but the authors cautioned that each situation should be evaluated individually (Drickamer & Lachs, 1992). The authors felt that the tendency to inform patients would increase with increased knowledge about the dementing illnesses, improved diagnostic accuracy, and greater therapeutic options. Such advances have occurred since

then, but as yet there has been no consensus on when and how to tell patients about their diagnosis.

The benefits of diagnosis disclosure appear obvious: greater patient autonomy, the opportunity for patients to become involved in decisions about their future care and treatment, the opportunity to plan for the future, the opportunity to finally put a "label" on their illness. In one study comparing older patients' reaction to their diagnosis of dementia and depression, the majority of patients with mild or severe dementia welcomed the idea of knowing their diagnosis (Jha et al., 2001).

It is understandable that our patients express mixed views on the benefits of being told their diagnosis, when there is a lack of concordance among health professionals on when, how, and whether to impart diagnostic information to patients. Fewer than half of psychiatrists regard it as their normal practice to inform patients with Alzheimer's disease of their diagnosis (Clafferty et al., 1998). Consultants in psychiatry of old age and geriatric medicine tend to inform those with mild dementia more frequently than those with more severe dementia (Rice et

al., 1997; Rice & Warner, 1994). General practitioners are significantly less likely to inform a patient with dementia of his or her diagnosis compared with terminal cancer, being mainly influenced by certainty of diagnosis, the patient's wish to be told, and the patient's emotional stability (Vassilas & Donaldson, 1998). A wide disparity exists among memory disorders clinics in the way diagnostic information is provided to patients: Fewer than half of the clinics surveyed by Gilliard and Gwilliam (1995) had guidelines for discussing diagnosis.

There is a fear among physicians and family members of patients with dementia that revelation of the diagnosis to the patient will result in a significant increase in depression, anxiety, or even suicide (Holroyd et al., 1996; Maguire et al., 1996). Although depression in dementia is well recognized, there is little evidence for a significant rise in depressive symptoms after diagnosis disclosure: Indeed the main reactions to being told the diagnosis appear to be denial or appropriate grief (Bahro et al., 1995; Rohde et al., 1995).

Depression is more likely to occur in those with retained insight. Although Jha and colleagues (2001) showed that most patients with dementia welcome information about their diagnosis, the majority of these patients also felt pessimistic once presented with this information, and those who were depressed were less favorable towards knowing their diagnosis. The same might be said of patients with any devastating diagnosis, but the solution may be to preempt and sensitively manage depressive symptoms rather than withhold the diagnosis. Patients diagnosed with dementia may also display low self-esteem, greater social isolation, and greater fear of the social stigma associated with dementia

(Husband, 2000), but such symptoms may be minimized if recognized early and managed sensitively.

Suicide is rare, though not unknown, in patients with dementia, possibly through a combination of altered insight and impaired executive function (Rohde et al., 1995). In published cases of patients with dementia who attempt or commit suicide, it is usually depression that is the primary diagnosis (Draper et al., 1998). Three percent of patients with dementia attending a memory disorders clinic report the "wish to die" and 1% exhibit suicidal ideation (Draper et al., 1998). Screening for suicide ideation at time of diagnosis should be considered in all memory disorders clinics in order to identify and support "at-risk" individuals.

As a result of diagnostic and therapeutic advances, it is likely that the dementing illnesses will continue to be diagnosed with greater accuracy at earlier stages in the disease process. This will increase the likelihood of patients being diagnosed when they have retained insight into their deficits. It will be difficult to justify withholding the diagnosis from such patients, just as it would be difficult to justify withholding the diagnosis of multiple sclerosis, motor neuron disease, or Huntington's disease from patients, conditions all regarded as progressive with few therapeutic options and associated with cognitive impairment. Patients with such neurodegenerative illnesses, however, are invariably told their diagnosis, often accompanied by backup counseling, community outreach, and emotional support.

Clinicians who diagnose patients with dementia are faced with a number of ethical dilemmas: They must be truthful, yet do no harm; they must respect patient autonomy, yet consider the concerns of

those who live with and care for those patients. These may seem like impossible contradictions, yet can be achieved if each case is considered carefully. Our primary concern should be for the well-being of the patient. Most clinicians treating patients with dementia would accept that the dementing illnesses and Alzheimer's disease in particular are a heterogeneous range of conditions. Each patient presents and progresses in a different manner. Each patient has different insight into his or her condition, different anxieties, and different home circumstances. It would seem therefore illogical to tell all patients the same information in the same manner about their illness. Patients with dementia should be afforded the opportunity to be told their diagnosis. Each case, however, should be gauged individually.

A patient's insight into his or her deficits and illness should be assessed through careful questioning, because it is likely, though not proven, that those with preserved insight are the group most likely to benefit from prophylactic monitoring for negative symptoms after diagnosis disclosure. The patient with severe dementia and markedly impaired insight is unlikely to understand the concept. This was borne out by Rice and Warner's (1994) study, which showed that psychiatrists almost never tell the patients with severe dementia their diagnosis.

WHERE DO WE GO FROM HERE?

The fear from patients, their families, and many clinicians is that diagnosis disclosure will result in increased levels

of depression, anxiety, and social isolation. In order to reduce these fears, patients with dementia should be routinely screened at the time of diagnosis for symptoms of depression, anxiety, and suicidal ideation. Patients should then be afforded the opportunity to discuss their condition and be given details of their diagnosis by a patient-led method, in which the patient is encouraged to ask about his or her illness in order to provide the amount of information relevant to that particular patient. If appropriate, written information should be provided to improve recall of information on diagnosis for the patient and carers (Patterson & Teale, 1997).

Prior to diagnosis disclosure, it should be ensured that adequate community support is available and ideally follow-up should be offered to screen for the patient's fears and anxieties. As with any chronic illness, the general practitioner should be integrally involved at all stages in the diagnostic process and should be informed what information has been given to the patient and what support is available to the patient and his or her family.

Fear is a common theme associated with diagnosis disclosure. Any fear is invariably the result of the unknown. With greater openness about cancer, combined with advances in diagnosis, management, palliation, and treatment, much of the fear and stigma surrounding the "c" word has been removed. Our hope should be that the same will happen for the dementing illnesses.

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