Alzheimer's & Dementia 3 (2007) 404–410

# Disclosure of the diagnosis of dementia

John D. Fisk[a,*], B. Lynn Beattie[b], Martha Donnelly[c], Anna Byszewski[d], Frank J. Molnar[e]

[a] *QE II Health Sciences Centre; Departments of Psychiatry, Medicine, and Psychology, Dalhousie University, Halifax, Nova Scotia, Canada*

[b] *Division of Geriatric Medicine, Department of Medicine, UBC, Vancouver, British Columbia, Canada*

[c] *Division of Community Geriatrics, Department of Family Practice, and Division of Geriatric Psychiatry, Department of Psychiatry, UBC; and Geriatric Psychiatry Outreach Team, Vancouver Hospital, Vancouver, British Columbia, Canada*

[d] *Department of Medicine, University of Ottawa; Geriatric Day Hospital, Ottawa Hospital; and Ottawa Health Research Institute, Ottawa, Ontario, Canada*

[e] *Division of Geriatric Medicine, Department of Internal Medicine, Ottawa Hospital; Department of Medicine, University of Ottawa; Ottawa Health Research Institute; and Elisabeth Bruyere Research Institute, Ottawa, Ontario, Canada*

**Abstract** Most ethical guidelines strongly promote disclosure of a diagnosis of dementia to the affected individual, based on the principle of autonomy. Nevertheless, codes of medical ethics allow for various interpretations of this issue and surveys of clinical practice illustrate that such disclosure is by no means the rule. We argue that diagnostic disclosure for persons with dementia must be considered a process that begins when cognitive impairment is first suspected and that evolves over time as information is obtained. Whenever possible and appropriate, this process should involve not only the affected individual but also their family and/or other current or potential future care providers. Once a diagnosis is established it should be disclosed in a manner consistent with the expressed wishes of the patient, using an individualized patient-centered approach that maintains the individual's personal integrity. Diagnostic disclosure of dementia is a process that may require additional time as well as follow-up or referral to other specialists. We recommend that a progressive disclosure process be employed to address issues including: remaining diagnostic uncertainty, treatment options, future plans, financial planning, assigning power of attorney, wills and "living wills", driving privileges and the need for eventual driving cessation, available support services, and potential research participation. The potential for adverse psychological consequences to diagnostic disclosure must be assessed and these should be addressed through education and support of the patient and their family/caregivers throughout the diagnostic disclosure process. At present, few data are available regarding patients' perspectives on the diagnostic disclosure process and its consequences. This limitation and the apparent discrepancies in physician and caregiver opinions about the disclosure process, make it incumbent upon health care professionals to evaluate the diagnostic disclosure process within their practice.

© 2007 The Alzheimer's Association. All rights reserved.

*Keywords:* Alzheimer's disease; Dementia; Diagnosis; Ethics

Although various ethical guidelines for medical care exist, all with common underlying principles, few have specific recommendations regarding dementia. In 1997 the Alzheimer Society of Canada (ASC) released its Ethical Guidelines [1] document, which represented the results of a 2-year consultative process that was based on a "discourse ethics" approach previously used in developing the Fairhill Guidelines [2]. This approach used focus group discussions that included caregivers, individuals with mild Alzheimer's disease, and professionals (eg, physicians, nurses, lawyers, ethicists, and administrators) but also extended this consultation process by disseminating the information nationally for review and comment [3]. Both the Fairhill Guidelines and the ASC Ethical Guidelines addressed issues important in clinical practice and everyday life for persons with Alzheimer's disease, such as diagnostic disclosure, driving privileges, autonomy in decision making, maintaining qual-

---

*Corresponding author. Tel.: (902) 473-2581; Fax: (902) 473-7166.
E-mail address: John.Fisk@cdha.nshealth.ca

1552-5260/07/$ – see front matter © 2007 The Alzheimer's Association. All rights reserved.
doi:10.1016/j.jalz.2007.07.008

ity of life, appropriate use of restraints, and end-of-life care. The ASC Ethical Guidelines, however, also addressed genetic testing and participation in research. In 1999 the Canadian Consensus Conference on Dementia (CCCD) acknowledged the diversity and scope of ethical issues addressed by the ASC guidelines and chose to focus on discussion of diagnostic disclosures and driving privileges [4]. Revision of the ASC Ethical Guidelines through another consultative process was undertaken in 2001–2002 in response to increased awareness, earlier diagnosis, the conceptualization of mild cognitive impairment (MCI) [5], and the availability of symptomatic treatments. For the current revision of the CCCD, the topics discussed in the original document were reconsidered with a view to both updating them and adding new relevant issues. First, it was decided that because of its complexity, the issue of driving needed to be considered as a separate topic with discussions not limited to that of ethical issues. Second, it was determined that the issue of diagnostic disclosure warranted a review in light of new developments and, in particular, because of the importance of diagnostic disclosure as the starting point from which treatment and management decisions follow. For this review the PubMed and Embase databases were searched for articles with the keywords "Dementia OR Alzheimer's disease AND ethics AND diagnosis." For discussion, preference was given to publications between 1996 and 2006.

As described by Maguire [6], "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 patients' autonomy, yet consider the concerns of those who live with and care for those patients." Most ethical guidelines dealing with diagnostic disclosure to those with dementia and their family/caregivers, including those recommendations put forth in the previous CCCD, strongly promote the disclosure of a diagnosis of dementia to the affected individual, on the basis of the principle of autonomy [4]. This viewpoint is not universally held, however, and codes of medical ethics in general allow for various interpretations of the issue of diagnostic disclosure [7]. Two relatively recent systematic reviews have been undertaken by groups in the United States [8] and in the United Kingdom [9]. Both point out the need for continued discussion, research, practice guideline refinement, and education of professionals and the public about this issue. The need for a Canadian perspective on these issues is reinforced by the finding that only 4% of the articles discussing diagnostic disclosure were published in Canada [8].

We have little information about whether available practice guidelines are known by practitioners and how practitioners' experiences with dementia influence their acceptance and use of such guidelines. A review of studies of general practitioners' practices in the United States regarding diagnostic disclosure concluded that approximately half routinely withhold disclosure to the patient [8]. A survey of general practitioners in the United Kingdom identified communication about diagnosis as one of the "main difficulties" experienced by general practitioners when dealing with patients with dementia [10]. Those who reported greater difficulty with the diagnosis and management of dementia were also less likely to endorse open communications strategies for diagnostic disclosure [10]. This same association between difficulty in establishing a diagnosis and disclosing the diagnosis was also reported in an American sample of primary care physicians [11].

Although guidelines favoring diagnostic disclosure are based on the principle of patient autonomy, the arguments that have typically been put forth against diagnostic disclosure are based largely on the principle of non-maleficence (ie, the obligation to avoid harm). Justification for the emphasis on this latter principle has typically relied on (1) the lack of absolute diagnostic certainty from clinical information, (2) the absence of effective treatments of progressive dementia, (3) the questionable ability of persons with more advanced disease to understand the implications of the diagnosis, and (4) the potential for adverse psychological responses to diagnostic disclosure as their justification [12].

Diagnostic certainty, although never 100%, has improved considerably through the development of diagnostic criteria that now span a range of less prevalent forms of dementia in addition to Alzheimer's disease [13]. These criteria are unlikely to be used routinely outside specialty referral clinics, and lack of familiarity in their use among primary care physicians might contribute to uncertainty in dementia diagnosis. Nevertheless, lack of access to a diagnostic opinion from a specialty clinic and lack of certainty about a suspected diagnosis do not negate the responsibility of primary care physicians to provide "an open, honest presentation of information as it is perceived and known" [12]. Moreover, as recommended by the previous CCCD, the topic of diagnostic uncertainty itself should be discussed within the context of diagnostic disclosure (Recommendation 21) [4]. In recent years, MCI has become increasingly well-defined to the point where it can be considered as a diagnostic entity itself rather than just a risk factor for dementia [14], making it increasingly important that the same considerations for diagnostic disclosure apply to this condition. However, aside from diagnostic uncertainly, disclosure of a diagnosis of MCI is also complicated by prognostic uncertainty [15]. Explaining uncertainty to patients and family members is never a simple matter, as was evident in a qualitative study of the psychosocial impact of disclosing a diagnosis of dementia to patients and their family/caregivers by Smith and Beattie [16]. They found that family/caregivers' understanding of the clinician's uncertainty about the diagnosis was subject to their preconceived ideas about the source of their loved ones' cognitive problems. Such findings illustrate the importance of establishing a clear understanding of the perspectives of both the patient and their family/caregivers to accurately convey

Download English Version:

https://daneshyari.com/en/article/5624715

Download Persian Version:

https://daneshyari.com/article/5624715

Daneshyari.com