



The high prevalence of dementia and the increased availability of treatments for Alzheimer's disease and related dementias have increased the need to find optimal approaches to disclosing the diagnosis of dementia. In this article, relevant research is reviewed on physician practices and perspectives, and on older patients' and family members' preferences. Research suggests that, in general, patients and families want an accurate and clearly explained diagnosis, and that they desire guidance from the physician in understanding the course of the illness over time as well as resources that will help them to cope. Considerations in disclosing a dementia diagnosis and recommendations on how to disclose a dementia diagnosis are offered.

Key words: dementia, Alzheimer's disease, disclosure, physicians, diagnosis

Diagnosing Dementia—What to Tell the Patient and Family

Linda Boise, PhD, MPH, Director, Education/Information Transfer Core, Layton Aging & Alzheimer Disease Research Center, Oregon Health & Science University, Portland, OR, USA.

Cathleen M Connell, PhD, Professor, Department of Health Behavior and Health Education, School of Public Health; Director, Education/Information Transfer Core, Michigan Alzheimer's Disease Research Center, University of Michigan, Ann Arbor, MI, USA.

Introduction

The high prevalence of dementia,^{1,2} increased clinical understanding of Alzheimer's disease and related dementias, the availability of treatments, the increasingly earlier stage of the disease at which a diagnosis is possible, and growing public awareness have drawn attention to the need to find optimal approaches to disclosing a diagnosis of dementia. Research on factors that influence disclosure and the preferences of patients and family members, drawing on recommendations from experts in the field about how best to disclose a diagnosis of dementia, are discussed.

Although recently published clinical practice guidelines do not address the specific question of whether or not, or how, a diagnosis of dementia should be disclosed, there is an implicit assumption that diagnosis and disclosure of dementia are central components of high-quality dementia care.^{3–5} For example, the "Fairhill Guidelines for Dementia Care," state that

*"physicians should inform affected individuals and their families about the diagnosis of probable Alzheimer's disease (AD), although some physicians resist this. The communication of the diagnosis should ordinarily occur in a joint meeting with the diagnosed individual and family in order to provide the individuals with emotional support."*⁶

Similarly, the Alzheimer's Society of Canada and the U.S. Alzheimer's Association recommend that patients be informed of their diagnosis so that they can understand their symptoms, receive

treatment, learn more about their condition, seek and obtain support and assistance, and plan for the future.⁸

Why Physicians Don't Disclose

Many practicing clinicians do not subscribe to these recommendations even if they are aware of them. Available research suggests that no more than 50% of clinicians regularly disclose the diagnosis to patients with dementia.^{9–12} In one study, diagnostic uncertainty and physicians estimate of patients' wishes and emotional stability were cited as reasons for not disclosing a dementia diagnosis.⁹

Obviously, a prerequisite for disclosure is for the dementia to be recognized, evaluated, and diagnosed. Recent evidence, however, suggests that as many as 50% of cognitively impaired patients are undiagnosed.^{13–15} The restricted length of the patient's doctor visits, the subtlety of symptoms of dementia (especially in early stages),¹⁶ and the lack of follow-up to evaluate symptoms even when noted in the medical chart¹³ are cited as contributors to this underdiagnosis. The lack of follow-up is likely due in part to the perception among some clinicians that nothing can be done once dementia is diagnosed. From the perspectives of family caregivers, however, the benefits of diagnosis and disclosure are not viewed solely in terms of drug and medical treatment but also with respect to the patient's well being. Family members often report that they wish

they had known sooner that their relative had dementia because of the relief they experience when their feeling that something is wrong is met with a specific diagnosis.

Most studies conclude that the majority of patients would choose to be informed of a dementia diagnosis^{2,17–20} so that they can put their affairs in order, plan for future care, and obtain needed services.⁶ Research suggests that a patient's interest in learning his or her diagnosis may be related to age and overall mental health. Specifically, being younger and experiencing depression were related to greater interest in being diagnosed.^{20,21}

How to Disclose the Diagnosis

The manner in which any health information is communicated with the patient is critical, and this is particularly so in the case of dementia. According to caregivers, physicians need to listen to their concerns, devote more time to discussing the diagnosis and what it means, and include the patient even if he or she might not fully understand the implications of the diagnosis. Research has documented that these factors are strongly linked with caregiver satisfaction within the triadic relationship (patient-physician-caregiver) that is typical in cases of dementia.^{22,23}

Another important consideration in the disclosure process is to tailor the manner in which the information is shared to the preferences of the patient and family members. Connell and colleagues¹⁷ found that some caregivers appreciated a direct approach—having the physician come right out and tell them the results of the clinical evaluation for dementia—while others preferred a softer approach. Some caregivers found the term “Alzheimer’s disease” especially upsetting for patients. Many physicians and caregivers prefer to focus their discussion on memory problems or safety concerns rather than Alzheimer’s disease. Although this may be appropriate for the early stage of the disease or the initial doctor visits, a cautionary note is needed. Most families eventually want specific

Table 1: Disclosing the Diagnosis of Dementia—How to Tell the Family

Provide the most clinically accurate diagnosis possible.
Err on the side of disclosing rather than withholding a dementia diagnosis.
Balance discussion of cognitive deficits with the patient’s strengths and abilities.
Use the terms “mild cognitive impairment” or “MCI” with caution. If used, provide a clear explanation of their meaning and prognosis.
There are several factors to consider in disclosing the diagnosis: <ul style="list-style-type: none"> – Stage of dementia: <ul style="list-style-type: none"> Patients with severe dementia may lack the ability to understand their condition. Patients with early dementia may be the hardest to tell but they have the right to know and can benefit most from participating in decision making for future care. – Insight of the patient is necessary to understand diagnosis. – Is the patient depressed? Is the depression related to the patient’s awareness of his/her cognitive deficits? – There are cultural differences in the meaning of “cognitive impairment.”
Dose information about diagnosis, prognosis, and follow-up care: <ul style="list-style-type: none"> – At the time of diagnostic disclosure, explain the diagnosis, medication options, and address behavioural or psychiatric symptoms. – On the next visit, discuss the anticipated course of the illness over time; refer the patient to the Alzheimer’s Association. – On following visits, focus on ongoing care management and communicating information, and encourage the patient to use community resources.
Prior to conducting a clinical evaluation for dementia, assess the best way to inform the patient and family: <ul style="list-style-type: none"> – Should the patient and family be informed separately or together? – Should diagnosis and treatment recommendations be given in writing? – What terminology would be most appropriate? “Alzheimer’s disease,” “memory loss,” or “dementia”?

information about the diagnosis and its prognosis. Additionally, without a specific diagnosis of Alzheimer’s disease or other dementing illness, referrals to community-based service agencies (e.g., Alzheimer’s Association) may not be made or may not be heeded. There are benefits to offering a direct and clear disclosure and, unless there is a compelling rationale for not doing so, clinicians should communicate the specific nature of the symptoms and their cause in a sensitive and understandable way.

This does not necessarily mean telling the whole story in one sitting. In fact, several studies recommend that the

diagnosis be shared over a number of visits so that the patient and family can be eased into the bad news.^{17,24}

Whenever possible, the physician should consult with the patient and family members at the outset of the diagnostic process about their preferences for how the diagnosis should be discussed. Questions might include whether the patient wants to have a family member present when they learn the results of their evaluation or if they prefer to hear the news privately first. The clinicians may also wish to ask whether family members and patients will prefer the results of the evaluation

provided in writing or verbally and to probe their understanding and their comfort with terms such as memory loss, dementia, and Alzheimer's disease. In general, it may be best to provide the most direct and medically specific terminology while taking into consideration the reactions and comfort level of the patient and family. Direct and clear information aids in understanding; softening the diagnosis to the point of uncertainty does no service to the patient or family.

Clinicians should also recognize that many patients and families would receive the news of the diagnosis with little reaction. Silence may result from the shock of hearing the words they have dreaded to hear and may mask the true emotional impact of the diagnosis. Whatever the reason for seeming rational acceptance, it is unlikely that hearing the diagnosis of Alzheimer's disease or dementia will be received without a sobering degree of emotion. Providing information about the diagnosis with an emphasis on retained abilities and strengths puts a positive face on what might otherwise be viewed as an unacceptably depressing situation.

Giving a diagnosis to someone with mild dementia can be particularly difficult. Not only is the patient likely to have more awareness of cognitive deficits, but there also may be a high degree of uncertainty about the specific diagnosis on the part of the family and the patient as well as the clinician. In recent years, a new diagnosis referred to as Mild Cognitive Impairment (MCI) has emerged, creating an even greater challenge to timely and accurate disclosure. It is estimated that more than 50% of individuals diagnosed with MCI will progress to full dementia.²⁵ Recent studies have documented that patients' reactions to a diagnosis of MCI can be particularly variable, with some interpreting the news as an inevitable precursor to Alzheimer's disease and others as simply age-related forgetfulness. In fact, neither interpretation is accurate, and only time will reveal the ultimate course. Additional research is urgently needed to better understand

how best to disclose and monitor patients diagnosed with MCI.

Postdisclosure Information and Support

Family members and patients frequently report that they do not receive adequate information at the time of diagnosis about the nature of dementia and what they can expect to occur over the coming months, nor resources sufficient to help the patient and family plan for and cope with the disease.^{17,23,26} It is entirely possible that many patients and families simply do not hear much at the time the diagnosis is disclosed due to the emotional impact of hearing the diagnosis. This has led experts to suggest the "rule of threes."²⁷ During the initial disclosure, the goal is to explain what dementia is, what medications might be available, and to address behavioural and psychiatric symptoms. At the next visit, information can be provided about the course of the illness over time as well as what to do in the event of a crisis or emergency. In future visits, families can be encouraged to learn about and utilize community services, such as support groups and home care help, and attend to caregiver self-care and a range of potential therapies. In many cases, family members may have different understandings of the seriousness of the condition or the patient's care needs. Meeting with family members as a group, so that they all receive the same information and have the opportunity to discuss care needs, can be of great benefit. A physician referral to the Alzheimer's Society (in the U.S. the Alzheimer's Association) is highly recommended to facilitate the process of obtaining up-to-date information and available services and resources for patients and families. In some cases, family members may be more likely to contact the Alzheimer's Society if their physician made a specific referral (as opposed to expecting the family to take the initiative to make contact on their own). To the extent possible, it would be ideal if physicians (and/or members of their office staff) would follow up with the family at subsequent office visits to

make sure that they received the local support and assistance they need.

Conclusion

Diagnosing and disclosing a diagnosis of dementia requires great compassion and sensitivity. While further research is needed to provide more definitive guidelines for optimal disclosure, ethical considerations and qualitative studies of patients and family members suggest that, in most cases, direct and clear communication about the diagnosis is highly recommended. Nonetheless, clinicians should take into consideration factors that may influence their patients' preferences of whether to be informed as well as the specific words to be used, including the degree of certainty of the diagnosis, the patient's insight, and the severity of the dementia. It is also likely that there are ethnic, cultural, and racial differences in how patients and families will respond to a diagnosis of dementia, and these differences need to be better understood.^{28,29} What is clear, however, are the benefits of tailoring the disclosure to the specific needs and perspectives of the patient and family. Ideally, clinicians should seek to understand their patients' and families' preferences before undertaking a clinical evaluation, so that the resulting diagnosis can be disclosed in a way that is most beneficial. ♦

No competing financial interests declared.

References

1. Lindsay J, Sykes E, McDowell I, et al. More than the epidemiology of Alzheimer's disease: contributions of the Canadian Study of Health and Aging. *Can J Psych* 2004;49:83-91.
2. Evans DA, Funkenstein H, Albert MS, et al. Prevalence of Alzheimer's disease in a community population of older persons. *JAMA* 1989;262:2551-6.
3. Knopman DS et al. Practice parameter: diagnosis of dementia (an evidence-based review). *Neurology* 2001;56:1143-53.
4. Small GW et al. Diagnosis and treatment of Alzheimer disease and related disorders. *JAMA* 1997;278:1363-71.
5. Corey-Bloom J, Thal LJ, Galasko D, et al. Diagnosis and evaluation of dementia. *Neurology* 1995;45:211-8.
6. Post S, Whitehouse P. Fairhill guidelines in ethics in the care of people with

Diagnosing Dementia

- Alzheimer's disease: a clinical summary. *JAGS* 1995;43:1423–9.
7. Alzheimer's Association. Ethical considerations: issues in diagnostic disclosure. Fact sheet prepared by the Alzheimer's Association (ED231Z), 1997.
 8. Alzheimer's Society of Canada. Alzheimer's care: ethical guidelines, communicating the diagnosis. www.alzheimer.ca, 2001 (revised 2004); www.alzheimer.ca/english/care/ethics-communicate.htm.
 9. Vassilas CA, Donaldson J. Telling the truth: What do general practitioners say to patients with dementia or terminal cancer? *Brit J Gen Pract* 1998;48:1081–2.
 10. Clafferty RA, Brown KW, McCabe E. Under half of psychiatrists tell patients their diagnosis of Alzheimer's disease. *Br Med J* 1998;29:603.
 11. Gilliard J, Gwilliam C. Sharing the diagnosis: a survey of memory disorders clinics, their policies on informing people with dementia and their families and the support they offer. *Int J Ger Psychiatry* 1996;11:1001–3.
 12. Johnson H, Bouman WP, Pinner G. On telling the truth in Alzheimer's disease: a pilot study of current practice and attitudes. *Int Psychogeriatrics* 2000;12:221–9.
 13. Boise L, Neal MB, Kaye J. Dementia assessment in primary care: results from a study in three managed care systems. *J Ger Med Sci* 2004;59:M621–6.
 14. Camicioli R, Willert P, Lear J, et al. Dementia in rural primary care practices in Lake County, Oregon. *J Geriatr Psych Neurol* 2000;13:87–92.
 15. Callahan CM, Hendrie HC, Tierney WM. Documentation and evaluation of cognitive impairment in elderly primary care patients. *Ann Intern Med* 1995;122:422–9.
 16. Boise L, Camicioli R, Morgan DL, et al. Diagnosing dementia: perspectives of primary care physicians. *Gerontol* 1999;39:457–64.
 17. Connell CM, Boise L, Stuckey JC, et al. Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *Gerontol* 2004;44:500–7.
 18. Pinner G, Bouman WP. To tell or not to tell: on disclosing the diagnosis of dementia. *Int Psychogeriatrics* 2002;14:127–37.
 19. Marzanski M. Would you like to know what is wrong with you? On telling the truth to patients with dementia. *J Medical Ethics* 2000;26:108–13.
 20. Erde EL, Nadal EC, Scholl TO. On truth telling and the diagnosis of Alzheimer's disease. *J Fam Practice* 1988;26:401–6.
 21. Jha A, Tabet N, Orell M. To tell or not to tell—comparison of older patients' reaction to their diagnosis of dementia and depression. *Int J Ger Psychiatry* 2001;16:879–85.
 22. Beisecker AE, Chrisman SK, Wright LJ. Perceptions of family caregivers of persons with Alzheimer's disease: communication with physicians. *Am J Alz Dis* 1997:73–83.
 23. Fortinsky R. Health care triads and dementia care: integrative framework and future direction. *Aging Mental Hlth* 2001;5:S35–48.
 24. Moniz-Cook E. The therapeutic potential of memory clinics. Paper presented at the Centre for Social Research on Dementia Seminar Series, 1999.
 25. Luis CA, Loewenstein DA, Acevedo A, et al. Mild cognitive impairment: directions for future research. *Neurology* 2003;61:438–44.
 26. Haley WE, Clair JM, Saulsberry K. Family caregiver satisfaction with medical care of their demented relatives. *Gerontol* 1992;32:219–26.
 27. Wald C, Fahy M, Walker Z, et al. What to tell dementia caregivers—the rule of threes. *Int J Ger Psych* 2003;18:313–7.
 28. Connell CM, Gibson GD. Racial, ethnic, and cultural differences in dementia caregiving: review and analysis. *Gerontol* 1997;37:355–64.
 29. Janevic MJ, Connell CM. Racial, ethnic and cultural differences in the dementia caregiving experience: recent findings. *Gerontol* 2001;41:334–47.