
Disclosing a Diagnosis of Alzheimer's Disease: Patient and Family Experiences

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ABSTRACT: Background: Informing patients and families about the diagnosis of Alzheimer's disease (AD) is a complex ethical and practical issue. This qualitative study explores the psychosocial impact of disclosing a diagnosis of AD on patients and family members. **Methods:** This study identified 14 patients and their accompanying family members undergoing a multidisciplinary assessment for dementia at an outpatient clinic for AD and related disorders. Of the group, three patients had probable AD and five had possible AD as per NINCDS-ADRDA criteria. Six patients were not demented as per DSM III-R criteria. Disclosure of diagnosis occurred, in a family conference, within six to eight weeks of the assessment. Data collection methods included observation of the assessment and the family conference as well as in-depth home interviews with family members and with each patient whenever feasible. The interviews were transcribed verbatim and coded for recurrent themes. **Results:** A total of 40 individuals across 14 families participated in this study. Only two families chose not to have the patient attend the family conference. The disclosure of a diagnosis of probable AD brought on an experience of relief in three families, marking the end of a lengthy period of confusion about the nature of memory problems. Patients diagnosed with possible AD and their families interpreted how indicative the diagnosis was of the presence of the disease with varying degrees of certainty depending on pre-assessment beliefs about the cause of memory problems. In the group diagnosed as not demented, four patients had complaints of forgetfulness likely related to minor depression. The disclosure of a diagnosis of no dementia did not produce the anticipated relief. Two patients continued to believe their memory problems were caused by the early onset of AD or some other "organic" problem. **Interpretation:** This study reveals that disclosure of the diagnosis of AD to patients and family members is generally beneficial but that there are variations in the understanding of the diagnostic information, particularly in instances where the assessment results are ambiguous.

RÉSUMÉ: L'annonce du diagnostic de la maladie d'Alzheimer: expériences de patients et de familles. Introduction: C'est une question éthique et pratique complexe que d'informer les patients et les familles du diagnostic de la maladie d'Alzheimer (MA). Cette étude qualitative explore l'impact psychosocial de l'annonce du diagnostic de la MA sur les patients et les membres de leur famille. **Méthodes:** Cette étude a identifié 14 patients et les membres de leur famille les accompagnant au moment de l'évaluation multidisciplinaire de la démence à une clinique externe de la MA et des maladies associées. Trois des patients du groupe avaient une MA probable et cinq avaient une MA possible selon les critères NINCDS-ADRDA. Six patients n'étaient pas déments selon les critères du DSM-III-R. L'annonce du diagnostic a été faite quatre à six semaines après l'évaluation, au moment d'une réunion de famille. Les méthodes de collecte des données incluent l'observation de l'évaluation et de la réunion de famille ainsi qu'une entrevue détaillée à domicile avec les membres de la famille et avec chaque patient si possible. Les entrevues ont été transcrites verbatim et les thèmes récurrents ont été codés. **Résultats:** Au total, 40 individus appartenant à 14 familles ont participé à cette étude. Seulement deux familles ont choisi d'exclure le patient de la réunion de famille. L'annonce du diagnostic de MA probable a procuré un soulagement à trois familles, marquant la fin d'une longue période de confusion à propos de la nature des problèmes de mémoire du patient. Les patients dont le diagnostic était une MA possible et leur famille ont interprété à quel point le diagnostic était indicatif de la présence de la maladie avec différents degrés de certitude selon leurs croyances sur la cause des problèmes de mémoire avant l'évaluation. Dans le groupe chez qui la démence était exclue, quatre patients se plaignaient d'oubli probablement reliés à une dépression mineure. L'annonce d'un diagnostic d'absence de démence n'a pas produit le soulagement anticipé. Deux patients ont persisté à croire que leurs problèmes de mémoire étaient une manifestation précoce de la MA ou d'un autre problème "organique". **Interprétation:** Cette étude révèle que l'annonce du diagnostic de la MA aux patients et aux membres de leur famille est généralement bénéfique, mais qu'il existe des variations dans la compréhension de l'information sur le diagnostic, particulièrement dans les cas où les résultats de l'évaluation sont ambigus.

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Disclosing a diagnosis of Alzheimer's disease (AD) to patients and family members is a complex event that requires the physician to consider the potential for psychosocial harm and the patient's moral and legal rights to receive the diagnosis.^{1,2} Recent evidence about disclosure practices indicates that physicians are beginning to acknowledge these rights. In a random survey of physicians in British Columbia, Bell-Irving, Donnelly and Berkowitz found that 90% of respondents made it their practice to communicate the diagnosis of dementia to the patient in some

fashion (personal communication). The authors state that disclosure can facilitate the development of a multidisciplinary

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monitoring and treatment plan that includes the patient along with caregivers and health care professionals. Another study by McCracken and associates revealed less willingness to disclose the diagnosis in a random sample of Canadian and American physicians who had an interest in geriatric medicine. They found that only 31% of respondents always disclosed the diagnosis to the patient and that 10% never disclosed the diagnosis (personal communication). Interestingly, American physicians were more likely to communicate the diagnosis than their Canadian counterparts. Respondents indicated the patient's right to know and the patient's need to plan for the future as the main factors influencing their decision. Vassilas and Donaldson³ found a similar level of reluctance to inform patients about their diagnosis of dementia in the 281 physicians they surveyed in Britain. Only 5% always told their patients of their diagnosis and only 34% often did so. In another British study, Clafferty, Brown and McCabe⁴ surveyed 246 consultant psychiatrists about their disclosure practices for a variety of disorders. In the section on disclosing a diagnosis of dementia, 27 (11%) psychiatrists avoided answering that part of the questionnaire and out of the remaining 209 who answered, only 44% replied that it was their normal practice to inform patients of their diagnosis.

Unfortunately, the literature available to physicians about the psychosocial impact of disclosure remains sketchy. A primary concern is the potential for disclosure to precipitate a severe depressive episode in the patient, thus compounding an already difficult caregiving situation for the family. Maguire and associates⁵ confirmed this to be a salient concern in families of dementia patients. The authors surveyed 100 consecutive family members accompanying patients diagnosed with AD about whether they wished the patient to be told about the diagnosis. Eighty-three family members responded that the patient should not be told of their diagnosis. The most common reason for this choice was the fear that disclosure would make the patient anxious and depressed. Paradoxically, 71 of those family members indicated that they themselves would want to be told about their diagnosis should they be diagnosed with AD in the future. Holroyd, Snustad and Chalifoux⁶ found that 80% of 156 older persons without dementia surveyed by questionnaire indicated a similar wish. Erde, Nadal and Scholl⁷ reported that 90% of 224 nondemented adult patients indicated that they would also want to be told of their diagnosis. These findings provide prospective evidence that patients want to know about their condition at the time of the assessment despite the potential for adverse psychosocial consequences.

One reason mitigating the decision to disclose is that the patient at times lacks the insight necessary to understand the condition, particularly in the later stages of AD. However, Michon and associates⁸ remark that insight is not always correlated with the severity of dementia symptoms. Some patients display anosognosia for their condition even in the early stages of cognitive decline whereas others understand the abnormality of their deficits well into the later stages of their disease. Insight into the condition may help patients in managing awkward social situations. For example, Post and Folley⁹ tell of a case where a patient whose knowledge of the diagnosis allowed him to inform friends and neighbors that his forgetfulness of them was not indicative of his unconcern but rather a symptom of AD. Another benefit is the relief experienced when finding out

the exact cause of memory problems, which may have been suspected but not formally identified until the diagnosis is disclosed. It is not unusual for physicians at the time of disclosure to hear patients and family members say that the diagnosis only confirmed what they had been suspecting all along.

One aspect of disclosure that has received little attention concerns how patients and family members understand information about the uncertainty associated with making a diagnosis in the presence of other systemic or brain diseases. The National Institute of Neurological and Communicative Disorders Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) criteria account for this uncertainty by specifying three diagnostic categories: definite, probable and possible AD.¹⁰ A definite diagnosis requires confirmation of the clinical diagnosis by autopsy.¹¹ A diagnosis of probable AD occurs when a history and neuropsychological testing confirm the presence of a progressive dementia and the physician confidently rules out systemic or brain diseases that might account for the observed cognitive deficits. The diagnosis of possible AD applies to cases where atypical variations in the onset or presentation of the dementia suggest other contributing factors to the cognitive impairment.¹² The disclosure of diagnostic uncertainty is less an issue with the diagnosis of probable AD because of its relative accuracy under the NINCDS-ADRDA criteria. However, uncertainty may be more of a concern when the diagnosis is one of possible AD as a follow-up assessment could reveal the dementia is not AD. Diagnostic uncertainty could also affect patients with cognitive impairment that do not meet the criteria for AD. If the impairment is mild, patients could be diagnosed with Cognitive Impairment, No Dementia. A recent two-year prospective study showed that 23.6% of memory-impaired individuals without dementia progressed to AD.¹³ If disclosed, the diagnosis of Cognitive Impairment, No Dementia could potentially be a source of stress to patients and families if they come to believe the diagnosis to be predictive for AD.

Overall, current information about the psychosocial impact of disclosure has been gathered from physicians and caregivers and what is known about the patient's attitude comes from prospective studies using nondemented subjects. Little is known about how disclosure is conducted by the physician and how patients and family members actually understand what is disclosed. There is no information about how understandings and reactions to disclosure might differ across the NINCDS-ADRDA categories for AD (i.e., possible versus probable AD). This study addresses these gaps in knowledge by investigating the lay understanding of diagnostic information in a sample of patients assessed for dementia and their families. It explores the psychosocial impact and interpretations of disclosure in relation to their illness circumstances and pre-assessment beliefs about memory problems.

METHODS

The study uses a qualitative design to explore the experiential aspects of disclosure of a diagnosis of dementia that have received limited attention in the literature. The conceptual framework guiding this approach differs from the traditional

tenets of verification and generalization that guide quantitative research. The intent was to undertake an in-depth exploration of the experience of disclosure from the point of view of patients and family members. This goal, along with the extensive labor involved in the use of home interviews and observation, precluded the use of a random sample. Patients with varied age and presenting intellectual and behavioral complaints and their families were purposely selected to maximize the possibility of looking at the broadest range of experiences. The advantage of this approach is that, in the words of Gubrium¹⁴ it “offers what working service providers have always at least tacitly known, that is, the importance of the case as a unit of analysis” (p. 206). Although the qualitative findings in this study stand on their own, they could also contribute to the development of hypotheses that can be verified using quantitative methods.

This study reports findings from interview data collected on 14 patients and their accompanying family members selected from an outpatient clinic for Alzheimer’s disease and related disorders (henceforth referred to as the clinic). Of the group, three patients had probable AD, five possible AD, and six were not demented. Probable and possible AD were diagnosed by NINCDS-ADRDA criteria and dementia was diagnosed by DSM III-R criteria.¹⁵ Each patient participated in a multi-disciplinary assessment at the clinic as per established protocol and underwent radiological and laboratory investigations as indicated. The clinic’s Medical Director disclosed the diagnosis to patients and family members in a family conference held within six to eight weeks of the assessment. The primary author observed the assessment and the family conference as per consent and protocol. He also conducted semistructured home interviews with each patient, whenever feasible, and with the family members who attended the assessment and/or the family conference. A total of 40 people were interviewed, once after the assessment and once more following disclosure of the diagnosis. The interviews were transcribed verbatim. The principal investigator read them, and noted in the margins salient comments that the participants mentioned about disclosure. Using inductive reasoning, the topics were grouped into abstract themes that are summarized in the results section.

RESULTS

This section summarizes key themes from the transcripts relating to the various diagnostic experiences of participants. Brief case studies illustrate these experiences.

Involvement of the patient in disclosure

The decision to include the patient in the family conference was left to the family. Only two families chose not to have the patient attend the family conference so as not to upset them with the diagnosis. In one instance, a Japanese Canadian family did not want to include their father to minimize the stigma of being diagnosed with a ‘disease of the brain’. This is in contrast to another family who insisted that the clinician disclose the diagnosis directly to the patient. Family members hoped this strategy would increase the patient’s insight and minimize her resistance to invasive caregiving tasks (i.e., overseeing finances) and acceptance of community support services (i.e., referral to an adult day centre).

Disclosing a diagnosis of probable AD

Disclosure of the diagnosis of probable AD brought on an experience of relief for the three families in this group. It marked the end of lengthy periods of uncertainty about the nature of memory problems. Family members and some patients readily accepted the disclosed diagnosis as confirming what they had been suspecting all along. In one instance, the husband of one patient even determined that his wife had AD during the assessment and readily disclosed this ‘unofficial’ diagnosis to relatives and friends. Fortunately, the investigation confirmed his diagnostic opinion. For two families, the diagnosis cleared the confusion they had experienced during prior community assessments. In one case, one daughter had brought her mother for an assessment to the family physician but was told: “What do you expect at her age (73 years)?” In the other case, the patient was diagnosed with AD by a specialist who elected not to disclose the diagnosis to either the patient or her husband, presumably to protect them from psychological harm. The husband later found out about his wife’s diagnosis from her records when she was hospitalized for an unrelated illness.

Disclosure facilitated patient care for all families. In one family, disclosure helped the caregiver request help from her siblings, some of whom, prior to the diagnosis, had attributed the patient’s memory problems to aging. Other families requested the patient be assessed by their long-term care agency. Two family members reported that knowing the diagnosis facilitated their discussion of the problems experienced by the patient with friends and co-workers. The widespread awareness of AD encountered by these family members related in part to the high public profile of the disease.

Disclosing a diagnosis of possible AD

There were five patients and their families who were told of a diagnosis of possible AD. Disclosing this diagnosis was akin to a negotiation process. Family members tended to ask numerous questions during the Medical Director’s discussion of test results, in attempts to confirm the presence of AD. Those questions occasionally challenged the Director in her attempts to convey a competent diagnostic impression while discussing legitimate diagnostic uncertainties that could only be clarified by longitudinal follow-up. There were marked differences in the way patients and their families interpreted how indicative the diagnosis was of the actual presence of AD. Two families interpreted the uncertain nature of the diagnosis as evidence confirming their beliefs that a prior medical condition, and not dementia, caused the patient’s memory problems. In one case, this was pneumonia and in the other, it was the side-effects of a medication prescribed following by-pass surgery.

In contrast, three families believed the patient to suffer from AD prior to the assessment. They interpreted the diagnosis as confirming the presence of the disease in a more definite way than warranted by the assessment results. Some family members described the patient as someone with AD to other relatives. One family member even requested a long-term care assessment against the patient’s wishes. Only two members reported being uncertain about the nature of their relative’s condition but attributed their confusion to their inability to understand the Medical Director’s diagnostic opinion.

Disclosing a diagnosis of no dementia

The median age for the six patients who were told they likely did not have AD was 49 years as compared to 85 years for patients diagnosed with probable or possible AD. Two patients were siblings who were participating in an interprovincial pedigree study at the time of the assessment. They were assessed to establish a baseline measure for cognitive functioning and neither expected the assessment to reveal any impairment. The other four patients came in with complaints of forgetfulness that had caused them some embarrassment at work and in social situations. They complained mostly of a sporadic inability to recall the names of friends or work colleagues and of temporarily forgetting how to perform particular procedures at work. For example, one woman mentioned that her inability to remember certain key sequences for her cash register made her feel “really stupid”, especially when there were long line-ups of customers. Another woman, an elementary school teacher, described panicking when she forgot about having sent one of her pupils to the principal’s office and was reminded of her actions by the class when she noticed the pupil’s absence.

Three patients in this group had received treatment for depression in the community but expressed dissatisfaction with their treatment. They believed their memory problems would be better explained as the early symptoms of AD or some form of “organic” problem than by a psychiatric condition. All three obtained a referral to the clinic after persistent complaints about forgetfulness, which they reported as being inadequately attended by their family physician or psychiatrist. One patient reported that her psychiatrist did not think an assessment was necessary but agreed to a referral in order to put to rest her concern about having AD.

Paradoxically, disclosure of a diagnosis of no dementia did not produce the expected relief and even provoked a mild crisis for two of the patients. One patient felt that the absence of a diagnosis was evidence that the clinic team had not taken her complaints seriously. The patient revealed that she was considering a head trauma she suffered as a child as an alternate explanation for her memory problems. In the other case, the clinic’s psychologist successfully dealt with the patient’s concerns about a diagnosis of no dementia by suggesting that her occasional episodes of forgetfulness were better accounted for by the stressful life events she recently had experienced. This approach resulted in the adoption by the patient of strategies to manage her stress.

Disclosing assessment results

One challenge for the physician is deciding how much information to give patients and families about the results of the assessment. Providing too much information could overwhelm some patients and families and give them the impression that the condition is more severe than indicated by test results. On the other hand, others may want to know every detail and providing them with insufficient information could lead them to conclude that the assessment was incomplete and perhaps to request a second opinion. The disclosure protocol at the clinic included discussion of all significant test results with family members and with patients in a family conference. In a pilot survey of family satisfaction with the conference, Francoeur found that 80% of family members were satisfied with how the Medical Director

explained their relative’s condition (personal communication). Of the remaining respondents, 10% said they were somewhat satisfied and only 10% said they were somewhat dissatisfied. On the question of how helpful the conference was in assisting them to understand the problems experienced by their relatives, 80% of respondents replied that it was very helpful or helpful while 20% found it somewhat helpful.

This study provides further information about what contributes to family satisfaction with the conference. In the post-family conference interviews, few family members could recall details about disclosed test results. Rather, they said that the discussion of those results mostly reassured them about the thoroughness of the assessment. There was an exception with patients in the no-dementia group who became interested in the test results as they attempted to understand why the assessment did not confirm their experience of memory problems. This suggests that family and patient satisfaction about disclosure of test results does not necessarily relate to the clinical significance of that information.

INTERPRETATION AND RECOMMENDATIONS

Disclosing a diagnosis of AD is a complex and multi-factorial process. Communicating a diagnosis of probable AD to patients and family members seems less likely to result in misinterpretation of diagnostic information and may help by dispelling misunderstandings about the origins of cognitive decline. However, the diagnosis of possible AD, while useful in dementia research, can be confusing to patients and family members when disclosed in a clinical context. Specifically, the diagnosis can result in determinate interpretations that could be problematic if a follow-up assessment reveals the diagnosis to be not AD but some other dementia such as Pick’s disease or dementia with Lewy bodies. Family members may need to explain the new diagnosis to friends and relatives after telling everyone that the patient had AD. They could also experience difficulty in finding information about these less frequently diagnosed dementias and be restricted in their access to some support services.

The findings presented in this study are not generalizable to larger populations but nevertheless suggest a number of recommendations to guide disclosure:

- Involving the patient in the disclosure along with family members is recommended unless there are extenuating circumstances. This involvement respects the patient’s right to know and family members may be reassured by the knowledge that the patient possibly has gained some insight from participating in the disclosure.
- The physician should disclose the diagnosis as specifically as possible and the disclosure should include discussion of test results, prognosis, treatment options, advance planning, and support services.
- The physician should disclose a diagnosis of possible AD with care to prevent patients and families from misinterpreting the uncertainty associated with this diagnosis. In some cases where the cognitive impairment remains mild, the interpretation of a possible diagnosis as unlikely to be AD could help ward off a sense of hopelessness that would otherwise result from a more definite interpretation. In more

severe cases, allowing families to perceive the diagnosis with greater certainty than perhaps warranted by the assessment may assist their efforts to secure appropriate support services. The physician needs to make patients and family members aware of the potential for a diagnosis of possible AD to change at a future assessment.

- Awareness of the psychosocial circumstances leading to the assessment in patients with cognitive complaints but not meeting criteria for dementia can facilitate the physician's handling of disclosure in cases where forgetfulness may be associated with the diagnosis of depression.

CONCLUSION

While each case should be considered individually, this study shows that disclosure of the diagnosis of AD can help patients and families to understand troublesome memory problems and to initiate plans for the management of the illness. This study also demonstrates that preassessment expectations about the diagnosis and particular illness circumstances can mediate the interpretation of diagnostic information. The Alzheimer Society of Canada¹⁶ has published an 'Information Sheet' that recommends establishing a plan for disclosure that takes into account patients' and family members' expectations of what the assessment will reveal. The findings about diagnostic communication in this study may be helpful in the implementation of this clinical practice, particularly in situations where the physician is confronted with the task of disclosing an ambiguous diagnosis. Finally, the study underlines the need to further investigate the psychosocial factors that are involved in the lay interpretation of diagnostic information and the uncertainty associated with the assessment of dementia disorders.

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