

On Truth Telling and the Diagnosis of Alzheimer's Disease

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Whether to inform patients that they have Alzheimer's disease can be a vexing issue. Two approaches to medical ethics may be used to address this issue: one takes a strong rights-oriented position; the other takes a best-outcome position. The interests that patients have in knowing relate to both schools of thought. The authors surveyed 224 adult patients who were waiting to see their physicians. The findings showed that over 90 percent of patients want to be told of the diagnosis. Reasons for wanting to be told included making plans for care, obtaining a second opinion, and settling family matters. No demographic markers could be used to predict who would not be told. Even though several patients indicated that reading a case description made them feel suicidal, reactions to not being told are generally negative. Following either ethical approach leads to the conclusion that patients ought to be told. Subjects' interests in whom else should be told were also recorded, raising questions of confidentiality.

Whether a physician should or should not inform a patient of a grim diagnosis is a classical issue in medical ethics. Two schools of thought address this dilemma.¹ One contends that competent patients have a moral right (approaching an absolute right) to know the diagnosis. Persons holding this position are known as *deontologists*. The other school contends that a patient should be told the diagnosis only if knowing is more likely to benefit the patient. Those who take this position are known as *consequentialists*.

The deontologists hold that, as a moral right, the information belongs to (competent) patients regardless of the consequences of telling them,^{2,3} that being told is a patient's right, which should be respected. In short, this right should be honored if the physicians' experience in general is that telling patients results in sad consequences or even if a particular physician expects the consequences of telling to be detrimental to a particular patient. The consequentialists insist that the proper decision about truth telling depends on the details of each situation.⁴ Such a

decision is called *clinical*, implying that an experienced physician should decide by predicting which course of action might produce the best results.

Early in the progress of Alzheimer's disease, there is a stage when the diagnosis can be made and the patient is still able to understand the prognosis. Should such patients be told at this time? The answer depends in part on what people say they would want to know. A survey was conducted to assess whether patients would declare an interest in being informed of the diagnosis of Alzheimer's disease; the findings bear upon both schools of thought.

METHODS

Given the bearing of patients' interests on both approaches, having scientific understanding of such interests would be valuable. Thus in the winter of 1985-86, a consecutive series of ambulatory patients aged over 21 years were asked to respond to a self-administered questionnaire. Prospective subjects were approached while waiting to obtain medical care from one of two practices (either a family practice or general internal medicine practice) in southern New Jersey. The questionnaire first elicited demographic data (Table 1), then it offered a description of a patient with possible Alzheimer's disease, presenile dementia, or senile dementia, and next it posed a number of questions

Submitted, revised, December 23, 1987.

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TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF SUBJECTS (n = 224)

Characteristic	Percent
Age group	
<50	43.7
50-64	37.8
≥65	18.5
Sex	
Male	40.0
Female	60.0
Marital status	
Married	66.1
Never married	12.2
Divorced or separated	11.3
Widowed	10.4
Number of children	
None	8.0
1	15.0
≥2	77.0
Ethnicity	
White	96.9
Non-white	3.1
Religion	
Catholic	46.3
Protestant	40.2
Jewish	6.1
Other	7.4
Self-reported health status	
Current	
Good-excellent	73.9
Fair-poor	26.1
Lifetime	
Good-excellent	86.1
Fair-poor	13.9

that probed for subjects' reactions and interests. The description that the subjects read is as follows:

At age 54, John Smith has a disease that is changing him. He has trouble remembering and is no longer able to add and subtract. He is becoming increasingly moody. Often he is extremely angry with his wife and children for no reason. Because of this, his family takes him to the doctor. His doctor asks him special questions to find out if he is one of the few people who have a disease of the brain that gets worse with time and has no treatment. John's doctor finds him to have all the early signs of the disease. In time John will not be able to drive anymore or find his way when he is outside of the house. In time he will not be able to dress or bathe himself. His mind and body will gradually fall apart. Some years later, he will stop using the toilet; he will stop talking. He will be like a newborn baby, curled up in bed, wearing an adult diaper, unable to feed himself. After a while, he will die.

His family will have a very difficult time while John is sick.

TABLE 2. SUBJECTS' REACTIONS TO A HYPOTHETICAL DIAGNOSIS OF DEMENTIA (n = 224)

Item	Percent
Wishing to know	91.9
Reasons for (interests in) wishing to know*	
Advanced planning	94.2
Second opinion	62.3
Settle family matters, etc	36.2
Travel, vacation	15.7
Reactions to story*	
Frightened	24.6
Upset	17.9
Neutral	2.9
Depressed	14.3
Suicidal	17.4
Interested	53.6
Happy	0.9
Others to tell if not the patient*	
Spouse	87.0
Adult children	81.8
Friend	41.8
No one	31.9
Knows someone with dementia-like symptoms	30.5

* More than one response per subject is possible

After the early stages, they will be unable to leave him alone because he will wander off. Money will be a problem because of all the medical bills. His family will not be able to afford to put him in a nursing home. They will feel burdened by his continued existence. There is no help that his doctor can offer. No medicine or operation can slow the disease or stop its course.

The above account was followed by the statement, "This is a description of a patient who could have Alzheimer's disease, presenile dementia, or senile dementia."

Data were analyzed using the *z* test (with continuity correction) for differences in rates and proportions.⁵

RESULTS

Subjects were asked whether they would want to be told that their physician thought they had such a disease; they were also asked how they thought they would feel about being told at various ages. The vast majority indicated that they wanted to be told under both current and hypothetical conditions (Table 2). When asked to project their interest in knowing at the ages of 40, 50, or 60 years, 97.5 percent indicated they would want to know. When projecting to 70, 80, or 90 years of age, 87.5 percent indicated they would want to know.

Subjects were given options for the reasons why they might want to be told they had Alzheimer's disease. Reasons commonly used in discussions on ethics were available on the questionnaire. Those wanting to know indicated that advanced planning for finances or personal care was of high interest (94.2 percent). Almost two thirds (62.3 percent) indicated an interest in obtaining a second opinion to confirm the diagnosis. Approximately one third indicated an interest in settling affairs with family and friends. Relatively few (15.6 percent) expressed an interest related to wanting to travel or take a vacation.

No demographic differences marked those who wanted to know the diagnosis from those few who did not. Age, sex, religion, race, current state of health, sense of health over one's lifetime, number of children, occupation, and marital status cannot be used as indicators that a patient would rather not be told. There are, however, demographic differences at specific ages in the proportion of those who would want to know whether they had dementia. More wanted to be told if the disease were diagnosed at 40 to 60 years than they did if it were diagnosed at 70 to 90 years (97.5 percent vs 85.7 percent, $P < .05$). Those wishing to know of a diagnosis made in middle age (40 to 60 years) were more likely to be white (97 vs 85.7 percent, $P < .05$) and were somewhat more likely to have a friend or acquaintance with dementia-like symptoms when compared with patients not expressing an interest (30 percent vs 0 percent, $P = .08$).

When subjects were asked to predict whether they would want to be told they had dementia if the disease were diagnosed when they were 70 to 90 years of age, more of those who were over 65 years at the time of survey replied in the affirmative (27.1 vs 3.7 percent, $P < .01$). This difference is noteworthy, if only to illuminate social prejudices about the aged. Those wanting to be told their diagnosis were less likely to be divorced (10.7 vs 21.4 percent, $P < .01$) than those not wanting to know. Those wanting to know also were more likely to know someone who possibly had dementia (31 vs 14.8 percent, $P = .072$) than those who did not want to know.

Subjects were also asked to report how they felt after reading the account of the patient. A few admitted to strong reactions such as feeling depressed (14.3 percent) or suicidal (2.9 percent). The majority declared an interest in the patient, in the story, and in the symptoms manifested. One wrote a note, and one returned the form to a clerk; both indicated being very upset by the story.

Those wanting to know the diagnosis were more likely to reply that not being told would make them angry (70.9 vs 29.1 percent, $P < .05$) or that they would feel deceived (79.1 vs 20.9 percent, $P < .001$). Subjects who wanted to know were also more likely to want their spouse to be told should the physician decide to withhold the information from them (89.3 vs 20.9 percent, $P < .001$).

The final item on the questionnaire posed the general

moral question of whether patients suspected of having dementia should be told. The vast majority (91.9 percent) responded in the affirmative.

DISCUSSION

From the point of view of ethical theory, patients' interests relate to both schools of thought about truth telling. An important feature of the rights-oriented or deontological position is that it enables and entitles competent persons to choose. For example, the right to marry is the right to marry any of the many eligible persons. This choice includes the option of waiving the right altogether (the right to marry is the right to not marry). Accordingly, a credible interpretation of the right to know one's diagnosis includes a right to refuse to be informed. People are most likely to choose not to be informed, that is, to waive their right to know, when they have no interest in the information to which they are entitled. Furthermore, people are likely to choose not to be informed when they find the information fearful or unpleasant. Thus, a patient would most likely choose to remain uninformed when he or she has no interest in knowing or is interested in avoiding the suffering from knowing a grim diagnosis, just as such a patient might waive the right to vote because of a bad storm. In these ways, then, the patient's interests and desires are relevant to the rights-oriented approach to the physician-patient relationship. Persons having a diagnosis of Alzheimer's disease should not automatically be considered incompetent.⁶

Patients' interests and desires also bear upon the position of the benefit-oriented or consequentialist school. On one hand, because clinicians are restricted to what they observe, clinical experience is insufficient grounds by which to justify withholding a diagnosis from a patient. Clinicians' access to well-rounded understanding of situations can be limited, especially when patients do not disclose their confusion, fears, sense of loss, and individual preferences. On the other hand, clinical experience might lead to proposing a rule against withholding a diagnosis from a competent patient. Such a rule might be as directive as rules reflecting the rights-oriented approach. The justification for such a rule would be as follows: In a great percentage of cases, the observed results of withholding are worse than the imagined effects of telling, and there is no way to tell when nondisclosure will work out well. (An argument for such a rule can be found in the medical literature as early as 1909; tuberculosis and cancer are the prime examples discussed at that time.⁷) Whatever the message from clinical experience, then, decision making on the clinical model is handicapped by not knowing a patient's desire to know the diagnosis. Good clinical decisions take such interests into account.⁸

The questionnaire solicited information about respondents' interests and feelings that would not be readily apparent to clinicians (nor, perhaps, to family members). Subjects identified and expressed many reasons for wanting to know and many feelings about how they would react to being deprived of such knowledge.

The results of the questionnaire bear directly on confidentiality as well. Almost one third (31.9 percent) reported they would want no one told if they were not told themselves, 12.1 percent indicated they would not want their spouse told, and 18.2 percent indicated they would not want adult children told. Finally, the moral belief of the subjects is captured in that they reported in overwhelming numbers that they feel such patients should be told.

The issue of telling someone profoundly bad news has vexed those involved in medical decision making for many years. Changes in attitudes about informing patients of cancer have, over a 20-year period, been remarkable.⁹ Communication about other diseases has resisted this trend. In one study, 83 percent of patients who were suffering from multiple sclerosis wanted to be told, although 25 percent had to discover it on their own.¹⁰ Even before the recent possibility of early diagnosis of Huntington's disease, the question of whether to tell carriers of their status prior to the onset of symptoms received a great deal of attention.¹¹ One physician noted with anguish that victims of epilepsy are both lied to and encouraged to lie about their condition to employers and drivers license bureaus.¹² Although what physicians think about disclosing the diagnosis to Alzheimer's disease is unknown, this study provides a sample of what patients want.

Since the completion of this survey, a book about the management of dementia has been published for family members, patients, and care givers.¹³ Without citing any

data, the authors claim that most people want to be told about their diagnosis. Valuable suggestions for coping with the disease and for preparing for its course are provided. They show that many social and psychological interventions and actions can be undertaken. Patients' interests in knowing should not be considered pointless. Further, because most patients want to know whether they are thought to have Alzheimer's disease, it is possible to assume that most would not waive their right to be informed. Under the theory of either school of thought, therefore, patients should be told.

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Commentary

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Since the guest editorial "Empirical Studies of Ethics in Family Medicine"¹ appeared five years ago in this journal, the number of empirical studies on medical-ethical issues has increased dramatically. As in other areas, quantity of research does not necessarily indicate quality; indeed, at a recent national meeting on human values in

medicine, a panel discussion was devoted specifically to the question of how to tell good from bad empirical research in ethics. The present study of truth telling and Alzheimer's disease gives us an opportunity to review some of the conceptual and methodological concerns that arise in this field.

TABLE 1. CATEGORIES AND EXAMPLES OF EMPIRICAL STUDIES THAT MAY PERTAIN TO ETHICAL ISSUES

Category of Research	Example
Survey of ethical opinion	How family physicians approach common ethical problems ⁵
Survey of clinical practices	How physicians decide on cardiopulmonary resuscitation ⁶
Measures of ethically significant variables	Reduced ability of elderly to comprehend typical medical facts ⁷
Tests of empirical assumptions in ethical argument	How well family members' decisions match the elderly's own wishes

Research in family medicine ought ideally to address problems that arise commonly in the practice of that specialty. The foregoing study by Erde et al seems to fit this requirement. In particular, we note that truth telling and information disclosure are reported by family physicians to be among the most commonly encountered ethical problems.² But an empirical study on an ethical issue has several additional requirements—the ethical principles involved must be properly conceptualized, and the precise relationship between the empirical results and the ethical “ought” question must be clearly understood.¹ Much of the flawed research on medical ethics fails on one or another of these grounds. For instance, a good deal of the early research on informed consent was useless because it was based on the assumption that the patient's ability to recall at a later date the facts that the physician had told him was a valid test of whether informed consent had occurred.³ It takes little imagination to realize that the extent to which a person knowledgeably participates in a decision today—which is what really is at issue in informed consent—may bear little relation to whether he or she can recall certain facts when quizzed a week or a month from now.

In Table 1⁴ are listed various sorts of empirical studies that may pertain to ethical issues. At first glance it might seem that the study by Erde et al falls under the first category, and simply records patients' opinions about the truthful disclosure of the diagnosis of Alzheimer's. If this were so, the study would still be an improvement over earlier work that surveyed physicians' attitudes toward truth telling with little concern for what patients wished.^{8,9} A closer look, however, reveals that the authors have larger goals in mind, and that their study is intended to be one of the fourth type.

Erde et al hold that the interests of the patient are relevant to the obligation to tell the truth, no matter which of the two common philosophical stances on truth telling

one adopts—stances that have been termed the benefit principle and the autonomy principle.¹⁰ Roughly speaking, under the benefit principle, the patient should be told the truth if and only if it would be in the patient's best interest to be told. Under the autonomy principle, as Erde et al conceive it, the patient should be told if and only if he or she expresses an interest in being told. Under either principle, the authors conclude, the ethically significant variable is the patient's interest in being told the diagnosis, and so the researchers set out to determine what interest people have in being told the diagnosis of Alzheimer's.

Have Erde et al met the requirements for empirical ethics research? First, have they clearly explained the link between the empirical results and the relevant ethical principles or issues? On this question, the study is problematic. On their analysis, the ethically relevant variable is the individual patient's interest; but what they have measured is patients' attitudes and preferences toward a hypothetical scenario. The translation from the measured variable to the ethically relevant variable is especially difficult if one favors the benefit principle. Our expressed preferences and our best interests often fail to correspond—or else who would smoke, eat high-cholesterol foods, and avoid exercise? Indeed, the traditional paternalistic argument has always been that the physician, experienced at the bedside, knows the true interests of the patient with regard to disclosure of “bad news” much better than the patient himself does, no matter what the patient may say he wants.

To make expressed preferences correspond more closely with real best interests, important stipulations must be made. For instance, the preference must be as informed as possible. A skeptic could reasonably claim that patients who do not have Alzheimer's disease might state a speculative wish to know the diagnosis, whereas people who have actually developed the disease, and who would have to cope with the devastating news, might have very different preferences. The preferences of this study's subjects might bear little relation to the best interests of actual Alzheimer's patients.

The reader should next ask whether the researchers have properly conceptualized the relevant ethical principles. There is some room for disagreement on this score as well. In discussing the autonomy principle, the authors assert that this principle implies a right to request not to be told the truth, a right equal in force to the right to be told the truth. Contrary to the impression they create, there have been serious objections against this view on the grounds that refusing information is inconsistent with the exercise of autonomy,¹¹ or that refusals of information typically arise from compromised capacities for autonomy.¹² One way to appreciate the potential force of this problem is to imagine that the research results had been radically different, with most of the subjects claiming they

would not want to be told. If the authors remained true to their ethical assumptions, they would have to recommend that, out of respect for their autonomy, patients should not be told their diagnosis. Many people would think it a peculiar, even perverse, respect for autonomy that deliberately discouraged patient deliberation and decision making.

When we take their ethical analysis at face value, there are difficulties in understanding how to justify the recommendation they make in favor of the practice of telling patients their diagnosis. Their research shows that there are persons who express an interest in not being told but that there are no reliable markers to identify these individuals. If so, then their unqualified recommendation is subject to the same sort of criticism that they level at the best-interests model: it would impose a rule of thumb that is too crude to distinguish those patients who would benefit from those who would be harmed. Given their empirical findings, the crude rule they recommend ignores the presumed rights of some patients not to be told the truth. To be consistent with both their ethical analysis and their empirical findings, must not they recommend asking each patient, "Would you like me to tell you what you've got, and what the prognosis would be?" One family physician has advocated that this eliciting of preferences be made part of the standard intake interview, in the form of a "value history."¹³

We have argued that the study by these authors is defective in several important respects. In closing, however, we want to note that the findings of Erde et al do succeed in undermining certain more limited ethical arguments that a physician might entertain. It would, for instance, be very hard after reading this study to suggest either of the following:

1. "If patients were told frankly how devastating and depressing Alzheimer's disease is, they would tell us right away never to break the news to them if they developed it."

2. "I can decide whom to tell and whom not to tell based on individualized clinical judgment; I can always tell the difference between those who would wish to be told and those who would not."

Indeed, the main virtue of this study may be to repeat the finding that physicians who do wish to adhere to their patients' preferences had better ask what those preferences

are because physicians, in most such matters, turn out to be poor guessers.

Ethical problems occur commonly in family medicine and, when they do occur, may be among the most vexing of clinical challenges. While it is seldom, if ever, true that an empirical study will clearly point the way to a single, ethically correct course of action, it is often true that our understanding of common ethical problems will be enhanced by thoughtful and well-designed empirical studies. While many conceptual and methodological pitfalls lie in wait for the investigator, the potential payoff is so great that studies of this type should be encouraged.

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