ORIGINAL ARTICLE

Relatives' attitudes towards informing patients about the diagnosis of Alzheimer's disease

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Objectives: To evaluate relatives' attitudes towards informing patients with Alzheimer's disease (AD) about their diagnosis.
Setting: A university hospital in Italy.
Methods: The closest relatives of each of 71 subjects diagnosed for the first time as having AD were interviewed, using a semistructured questionnaire. Spontaneous requests by relatives not to communicate issues concerning the diagnosis were also recorded.
Results: Forty three (60.6%) relatives spontaneously requested that patients not be fully informed. After being interviewed, nobody thought that the patient should be given all the information. Justifications were related to the fear of the onset or worsening of depressive symptoms in the patient.
Conclusions: In Italy relatives' opposition to informing AD patients appears to be common. Knowledge of the relatives' attitudes may be useful for clinicians but disclosure of diagnosis should be based on the clinical evaluation of the patient and on a prudent evaluation of the relationship between the patient and her/his relative caregiver.

Informing patients with Alzheimer's disease (AD) of their diagnosis is hard and is fraught with ethical issues. Physicians are reluctant to disclose AD diagnosis to their patients.[1 2] Many physicians tend to inform relatives first of the poor diagnosis and the evolution of AD, since in most cases patients are accompanied to the physician by one of their relatives. Family members often ask physicians not to inform the patient about AD: an Irish study observed that only 17% of family members wanted the AD patients to be informed.[3]

The present study was aimed at evaluating relatives' attitudes towards informing AD patients about their diagnosis in an Italian setting.

METHODS

The closest relatives of each of 71 subjects diagnosed for the first time as having AD were interviewed by NB or EP. These subjects were relatives of a series of 80 consecutive subjects clinically assessed by both the interviewers (EP or NB) in a university setting in Italy. Nine AD subjects did not have a close relative to be interviewed. In all cases relatives knew that the referral diagnosis was suspected dementia.

In AD patients, dementia severity was measured using the global deterioration scale (GDS)[4] and minimental state examination (MMSE).[5] A brief unstructured psychiatric evaluation was also part of the clinical assessment of AD patients.

Before the interview, the AD clinical course was described, with explicit reference to the progressive deterioration of mental functions and the irreversibility of this process, which at the moment continue to characterise AD. The interview was based on specific questions concerning the communication of the following issues: (i) diagnosis in terms of "Alzheimer's disease", "dementia", or "progressive memory loss"; (ii) poor prognosis—that is, loss of all the activities of daily living within 10 years at most; (iii) realistic description of possible disease features, and (iv) no disease modifying treatments. Spontaneous requests—that is, before the formal interview—by relatives not to communicate these issues were also recorded.

The presence of possible relatives' denial of AD diagnosis was investigated.

The study was designed in such a way that one of the investigators (EP), who was not responsible for communication of the final diagnosis to the patient, should imagine that he adopted a paternalistic approach towards the patient. His perceived need to employ the so called therapeutic privilege—that is, the physician's power to conceal relevant information about diagnosis because full information could be harmful for the patient's health—was also investigated in the subgroup of patients with mild dementia (GDS = 3–4).

All AD patients gave their assent to the discussion of their health problems with the chosen relative. Protection of privacy was guaranteed.

Statistical analysis for continuous variables was performed through Mann-Whitney tests, since Gaussian distribution was not assumed. Contingency tables were used to tabulate the categorial variables and the χ^2 test was used. Statistical significance was defined for p value $\leqslant 0.05$.

RESULTS

Forty three (60.6%) relatives spontaneously requested that patients should not be informed of the diagnosis using the term "Alzheimer's disease".

After being interviewed, nobody thought the patient should be given all the information. In particular, all participants stated that diagnosis in terms of "dementia", poor prognosis, and realistic description of the evolution of the disease should not be given to their relatives. As shown in table 1, the sample studied had a wide variability in terms of relatives' characteristics. Thus, this finding cannot be associated with type of family relation, age, schooling or gender, nor with the severity of dementia (see table 2).

Twenty six (36.6%) of the relatives agreed with the use of the term "Alzheimer's disease", but 17 of them, said they did not want the term "progressive memory loss" to be used, and often they added the explicit comment that "she/he does not know what Alzheimer's disease is". Thus, only nine relatives (12.7%) agreed to the diagnosis in terms of "Alzheimer's disease" being discussed with the patient, so long as the term "dementia" was not used and the description of the diagnosis was given in terms of "progressive memory loss". This

Table 1 Features of the sample of relatives studied

		Age			Schooling		
Type of relative	Gender	Mean (SD)	Median	Range	Mean (SD)	Median	Range
Children n=30 (42%)	M 13 F 17	41.2 (5.0)	41	30–54	9.5 (3.5)	8	5–18
Spouse n=34 (48%)	M 11 F 23	64.1 (7.8)	65	44–76	6.3 (3.0)	5	5–19
Others n=7 (10%)	M 1 F 6	41.3 (16.0)	41	23–65	9.7 (3.2)	8	5–13
Total n=71	M 25 F 46	52.2 (13.9)	54	23–76	8.0 (3.6)	8	5–19

Table 2 Features of the AD subjects (33 M, 38 F)

	Age	Schooling	GDS	MMSE
Mean (SD)	68.5 (7.6)	5.9 (3.6)	4.3 (0.9)	15.5 (6.4)
Median	69	5	4	15
Range	52–84	0–17	3–6	0–26

subgroup did not statistically differ from the other relatives in terms of gender distribution (M/F = 3/6 *v* 22/40); age (median = 52 *v* 54); education (median = 8 *v* 8); type of relation (children and others = 55.5% *v* 51.5%, spouses = 44.5% *v* 48.5%), or severity of AD in the patient (GDS = 4 *v* 4; MMSE = 15 *v* 15).

Twenty (28.2%) relatives considered the use of the term "progressive memory loss" to be adequate. This subgroup did not differ from the subgroup of those who refused the use of the term "progressive memory loss" for gender distribution (M/F= 6/14 *v* 19/32), age (median = 49.5 *v* 54), education (median = 8 *v* 8), type of relation (children and others = 55% *v* 51%, spouses = 45% *v* 49%, or severity of AD (GDS = 4 *v* 4; MMSE = 15.5 *v* 15).

Thirty nine (54.9%) did not want the patient to be told about the lack of disease modifying treatments. Once again, no statistically significant associations were found with these relatives' attitude (data not shown). In all but one of these 39 cases, respondents stated that the diagnosis should not be communicated either in terms of "Alzheimer's disease" or "progressive memory loss".

In all cases, justifications were related to the fear of the onset, or worsening, of depressive symptoms in the patient (reported as "depression", "hopelessness", "worthlessness", "sadness", "giving up", "losing heart" and including "thinking about suicide").

A significant degree of denial of AD diagnosis was found in 17 (23.9%) relatives.

Based on the clinical impression of one of us who assessed the 40 AD patients with mild dementia, current or previous depressive symptoms, anxiety, adjustment disorder, or other psychopathological traits where present in 20 patients (50.0%). In 15 (37.5%) of these cases, the physician saw the psychopathological features as being relevant to his use of therapeutic privilege to the detriment of patient autonomy. In contrast, only six relatives of these 40 patients agreed to communicate diagnosis in terms of both "Alzheimer's disease" and "progressive memory loss"—that is, 85% of relatives thought that concealment would be protective for the patient.

DISCUSSION

In Italy relatives' opposition to informing AD patients appears to be more common than in Ireland.[3] Relatives' opposition in our study is also greater than the approximately 35% of older persons in Charlottesville (Virginia, USA) who would not want their spouse to be told of the diagnosis of AD when interviewed about this hypothetical scenario.[6]

The prevalence of this type of opposition by relatives in Italy and Ireland contrasts with USA guidelines (obtained through a joint meeting with a group of professionals concerned with dementia and family caregivers) which state that physicians should inform affected individuals.[7] Cultural and/or social variance might explain these differences between European and USA samples. In particular the difference in attitudes may be due to the different backgrounds of those relatives who are directly concerned with Alzheimer associations or similar groups. The latter, indeed, may not be representative of the whole population of AD patients' relatives, particularly of those relatives who are facing the AD problem at the moment of initial diagnosis, such as those considered in the present study.

We observed that "lack of knowledge of the term Alzheimer's disease" was the reason given for agreement to use this diagnostic label with the patients. In particular, this concerns the fact that such a term was mentioned in informed consent worksheets for participating in randomised controlled trials. It contrasts with the opposition to the communication of the diagnosis in terms of "progressive memory loss" in 17 out of 26 cases. The term "dementia" was the most disapproved of. In everyday Italian, the word "demenza" has a derogatory significance. Among those relatives who agreed to the communication of a diagnosis (except for the use of the term "dementia"), nobody wanted details about AD to be communicated to the patient.

A possible cause of relatives' refusal to disclose diagnosis could be their denial of the diagnosis. Even given the limits of an unstructured and non-standardised assessment, however, a denial was evident only in less than one quarter of the relatives.

Another explanation could be relatives' paternalistic approach to patients, as also discussed by Maguire *et al*.[3] Over recent decades the paternalistic type of physician/patient relationship has been widely criticised.[8] Just as with physicians, paternalism on the part of relatives could have a detrimental effect on patients. Indeed, such a model presumes the existence of objective evidence leading to the determination of what is and what is not right for the patient. In other words, the relative's choice prevails over the patient's autonomy. Moreover, paternalism could be an expression of the relative's emotional difficulty in coping with the patient's psychological reaction.

Several issues related to the communication of AD diagnosis to the patient have been well covered by Drickamer and Lachs.[9] Among these, let us discuss therapeutic privilege and the right not to be informed, on the basis of the results of this study.

Therapeutic privilege is frequently used in medical practice. The risk of damaging the patient by provoking severe depression has been reported as one of the most frequent reasons amongst Italian physicians for not telling the truth.[10] Depression is often present in the early stages of AD[11] and suicide is possible (the first patient to commit suicide with the assistance of Dr Kevorkian was affected by AD) even if quite rare.[12 13] The distinction should be made, however, between suicide as a fully conscious and deliberate act, thus touching on the issue of euthanasia, and suicide as a pathological reaction to the diagnosis as a psychological stressor. Further elements to support the use of therapeutic privilege are that catastrophic reactions could be provoked by mental shock associated with communication of the diagnosis. This emotional reaction could be more severe because of the dysfunction of cognitive and emotional domains related to AD. On the other hand, a recent study in cancer patients found that disclosure of diagnosis is not associated with a worsening quality of life or emotional functioning.[14]

Our opinion is that when a physician claims therapeutic privilege and conceals relevant information about the diagnosis he/she must have available accurate and expert clinical assessment. This assessment must reveal a psychopathological condition which may worsen, due to the communication of the diagnosis, to the point of compromising the patient's self determination. It is frequent for AD patients, especially in the early stage, to be aware of their condition and sometimes "to be terrified or mortified by the knowledge of what is befalling them".[15] This is, however, a psychological reaction and it affects patient's self determination only when a psychopathological complication will raise. On the basis of our findings, to what extent can relatives' attitudes influence physicians' therapeutic privilege?

As in the Irish study,[3] so in our study, relatives' justification for not communicating the whole diagnosis was related, in all cases, to the possible onset or worsening of depressive symptoms in the patient, including suicide. In the present study, however, whereas a clinician found psychopathological traits sufficient to warrant the use of the therapeutic privilege to the detriment of patient autonomy in only 40 per cent of patients, 85 per cent of relatives did not want the diagnosis communicated using either "Alzheimer's disease" or "progressive memory loss", for fear of causing harm to the patient. This finding could be seen as illustrating that relatives' arguments for limited truth telling may not be confirmed by the clinician's assessment. It should be noted, however, that the study had the limitation that only one physician assessed the possibility of resorting to therapeutic privilege. Physicians can be influenced by this attitude of relatives and resort to the paternalistic therapeutic privilege without a more objective assessment of the patient's will, premorbid personality, and current mood. Such an assessment should be attentively balanced with warnings received from relatives. Physicians should carefully collect the patient's history by inquiring about his responses to stressful life events. This is in line with Gordon and Goldstein's conclusion in their recent review.[16] They maintained that the physician's desire to communicate honestly and directly with a patient is sometimes at variance with the equally compelling desire to concur with the patient's family's reluctance to disclose diagnosis.

We can now turn to the right not to be informed, which is laid down by Italian medical deontology.[17 18] This right seems poorly taken into consideration within Italian families. None of the relatives in our series referred to this right when justifying their preference not to communicate, wholly or partially, the diagnosis of AD. In agreement with Marzanski, this right should be respected by physicians who should not routinely disclose AD diagnosis without seeking to understand their patients' preferences.[19]

We have discussed points concerning the communication of information to the patients. Now, we turn to a fundamental issue: should a family member be told of AD diagnosis?

Actually, the physician/AD patient relationship is peculiar, since in many cases patients are examined because of a family member's request rather than because of complaints by the patients themselves. The patient's insight can be impaired at the moment of the AD diagnosis and can thus compromise the communication of disease related information, and patient autonomy. Further, a great part of the clinical assessment is based on the history collected by the family member or another close relative. From the early stage of AD, there is the need for a person to supervise the patient's activities. At a certain stage of the disease, the patient is completely dependent on a caregiver who, in most cases, is a close relative. The physician cannot do without the interaction with the relative. Thus, it is mandatory to recognise a relationship between the physician and the relative/patient dyad rather than a simple physician/patient one. Within such a relationship the communication of the diagnosis to the relative is necessary. As the Italian code of deontology states, the physician can inform third parties if the explicitly expressed consent of the patient is obtained. Among the just causes for disclosure, however, is the urgent need to protect the life or health of the person or of third parties concerned, in the event that the person in question is unable to give his or her consent by reason of it being physically impossible, inability to act or not being of sound mind. [17] Thus, it should be mandatory for the physician firstly to try to obtain from the patient the names of any persons to whom sensitive information on her/his health condition should be given. The presence of a mental disorder—for example, a persecutory ideation, as a cause of refusal to give consent to inform a family member should be excluded. Moreover, the capacity of AD sufferers to direct their lives by self determination should be assessed.

Another issue which is important for the physician when taking relatives' warnings into consideration is: does the relative operate according to the patient's will? Notwithstanding several publications, no exhaustively accepted procedure to cope with this issue has appeared. Regarding this concern, the controversies on surrogate consent may be illustrative.[20]

Among the many conclusions that can be drawn, is our suggestion that the physician's decisions should not depend upon relatives' opinions. These opinions, however, should be taken into consideration and investigated by the physician in order to explore the relationship between the patient and her/his relatives, to collect an appropriate history about the patient's premorbid and current mental status, and to appreciate the patient's preferences. The physician's decision about whether and to what extent to inform the patient should rely on a complex balance involving clinical features and the patient's preferences. Physicians should scrupulously balance the pros and cons of accepting relatives' warnings. Moreover, physicians should be prepared to counteract the emotional burden, resulting from the information communicated, on both patients and families through appropriate counselling. They should monitor the development of emotional distress or psychiatric disorders. Just as physicians are called upon to present a diagnosis, they should also formally indicate their choices in the process of informing patients and their relatives. Resources should be allocated for improving diagnosis disclosure procedures within the health care system, given that such procedures are complex and time consuming. Physicians may require training and supervision. Resources should also be allocated for planning strategies aimed at communicating AD diagnosis and proper counselling, and for evaluating their efficiency. These strategies should deal with the cognitive/behavioural features and the clinical course of AD. They should also deal with the complex interaction between the different regional cultural attitudes, legal standards, level of health information, emotional burden, and personality profiles of both consumers and physicians. The efficiency of the strategies should be assessed through outcomes concerning both emotional disturbances in the patient and his/her family, and the patient's autonomy related advantages.

A huge challenge for research in medical ethics should be to find solutions capable of harmonising the following often contrasting requirements of clinical practice: (i) respect individual choices of the patients, preserve their autonomy, and invite them to share decisions whenever possible; (ii) respect and inform patients' families who are directly affected by the detrimental effects of a poor prognosis and/or disabling disease, and (iii) improve the health of society as a whole.

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