Disclosure of diagnosis of Alzheimer's disease in French general practice

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Abstract

Most practitioners find disclosing the diagnosis of Alzheimer's disease (AD) to an individual with dementia very difficult. Literature results show a wide variability in attitudes and clinical practice, and diagnosis seems to be more often disclosed to caregivers than to patients. The objective of this study was to examine whether and how diagnosis of AD is disclosed in French general practice and which issues are addressed with the patient.

A questionnaire was sent via mail to 1,629 general practitioners (GPs), 1,105 belonging to the Sentinel's network and 524 specially recruited doctors practicing in the Rhône-Alpes region.

A total of 631 questionnaires were returned (response rate, 39 percent), of which 616 were eligible for analysis. Twenty-eight percent of GPs reported having disclosed the diagnosis to the patient (25 percent mentioned "Alzheimer's disease"), whereas 88 percent considered it their role to announce the diagnosis to the patient. Regarding the type of information provided to the patient, only 25 percent discussed the nature of the illness, 23 percent behavioral problems, and 47 percent depression, mainly for psychological reasons (63 percent). Stress was discussed with 79 percent of the caregivers.

We concluded that GPs do not discuss the consequences of AD and symptoms (e.g., behavioral disorders) with patients, mainly for psychological reasons, whereas they have a less-reluctant attitude toward caregivers. As the GP has the weighty task of providing appropriate community care and psychological support to the patient, it is of utmost importance to reflect on how disclosure of diagnosis can be facilitated.

Key words: Alzheimer's disease, diagnosis, disclosure, patient information

Introduction

Disclosure of Alzheimer's disease (AD) is a complex clinical and practical issue. The majority of studies on disclosure of diagnosis show wide variability in attitudes and practices. A systematic review on disclosure in dementia by Bamford resumes 59 evidence-based studies examining frequency of disclosure and emotional consequences for patients and caregivers, as well as attitudes

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Table 1. Topics discussed with the patient

	Explanation of AD			Behavioral problems			Depression		
	Response			Response			Response		
	Not discussed	No	Yes	Not discussed	No	Yes	Not discussed	No	Yes
n (percent)	4 (0.7)	422 (74.3)	142 (25.0)	4 (0.7)	435 (76.6)	129 (22.7)	9 (1.6)	294 (51.8)	265 (46.7)

and practices of professionals.[1] The review demonstrates a large variability as to opinion and clinical practice.

The practitioner has an ambiguous position, as he is the messenger of a traumatic event and the one who has to find a solution for the problem. He has to choose the right time at which to tell the truth and find the appropriate words. Most practitioners find disclosing AD to the patient very difficult. Consequently, diagnosis seems to be more often disclosed to caregivers than to patients,[2,3] especially in general practice.[4,5] The embarrassment of the general practitioner (GP) toward the person diagnosed with AD is reflected by the expressions used. "Alzheimer's disease" seems to be significantly more pronounced in the presence of caregivers, whereas "memory problems" seems to be used in disclosing the diagnosis to the patient.[6]

Disclosure of AD is still an effortful task. Bamford's review reports that 28 to 58 percent of GPs consider openly discussing dementia with the patient a difficult task that demands a lot of time and energy. Twenty to 53 percent of practitioners think the same way regarding disclosure of dementia to relatives.[4] They even consider disclosure as one of the most difficult aspects of dementia management in general practice, probably because GPs have a lot of difficulty in accepting this kind of diagnosis.[7]

This contributes to the current and as of yet unresolved debate about the value and potential benefit of disclosure. A main argument against disclosure is the risk of causing harm. Indeed, there is some evidence of negative consequences of disclosure for the patient. The most common negative reactions seem to be denial or minimization of deficits, low self-esteem, self-stigmatization, fear of others finding out and associated social embarrassment, fear of not being listened to, and fear of long-term dependency needs. Some study results emphasize somatic problems, depressive mood, and social withdrawal.[8,9]

Interestingly, no long-term damage has been evidenced, and risks of major depression and suicide have been overestimated.[10] The literature shows even positive reactions to disclosure such as experiences of relief because of the understanding of the problem and dissipation of doubt and uncertainty.[8,9] Conversely, not telling the truth, or telling it in a vague way, seems to produce anxiety and confusion.

Evidence on relatives' reaction on disclosure of dementia is not consistent, as reactions of denial and anxiety and experiences of resignation and relief have all been described.[11] Interestingly, 50 percent of relatives consider themselves as not having been informed sufficiently on dementia.[3] Caregivers complain about lack of information on prognosis and lack of consideration of the emotional aspects by the physician. The type of information relatives want to be told varies with time, but at time of disclosure, caregivers desire information about the nature of the illness, behavioral symptoms, and prognosis.[11-13]

Patients' lack of insight and understanding represents another argument against disclosure of diagnosis. This idea supposes that disclosure makes sense only if the

Table 2. Topics discussed with the caregiver

	Explanation of AD			Behavioral problems			Caregiver stress			Depression		
	Response			Response			Response			Response		
	Not discussed	No	Yes	Not discussed	No	Yes	Not discussed	No	Yes	Not discussed	No	Yes
n (percent)	10 (1.8)	48 (8.5)	510 (89.8)	17 (3.0)	81 (14.3)	470 (82.7)	6 (1.1)	112 (19.7)	450 (79.2)	16 (2.8)	69 (12.1)	483 (85.0)

Table 3. Topics not discussed with the patient

Reason	Explanation of AD	Behavioral problems	Depression	Caregiver stress
Unprofitable/nothing to offer	37	38	42	–
Psychological reasons	63	53	43	–
Issue not addressed by patient	43	35	30	–
Lack of patient insight	12	70	8	–
Lack of time	4	2	6	–
GP embarrassment	9	6	5	–

Numbers given are percentages.

patient still has the ability to understand the importance and consequences of his illness. The capacity of understanding seems to depend on severity of the disease. Nevertheless, relatives and professionals risk underestimating a patient's comprehension. Study results demonstrate that 30 to 61 percent of patients are still able to understand their condition and are willing to openly discuss the diagnosis.[8,14,15]

Methods

We wanted to know whether and how diagnosis of AD is disclosed in French general practice and which issues were addressed with patient and relatives. In December 2004, a questionnaire focusing on the management of the last patient with AD seen by the practitioner was sent by mail to 1,629 French GPs—1,105 belonging to the Sentinel's network and 524 specially recruited doctors practicing in the Rhône-Alpes region. A total of 631 questionnaires were returned (response rate 39 percent), of which 616 were eligible for analysis.

Results

Twenty-eight percent of the respondents reported having disclosed diagnosis (68 percent had established the diagnosis themselves, and 19 percent had announced a diagnosis established by a specialist). Eighty-eight percent of GPs considered it their role to announce the diagnosis to the patient. All thought it was the GP's role to inform the caregiver.

Sixty percent had not announced diagnosis because a specialist had done it. The remaining 12 percent reported not having communicated a diagnosis at all. Among those who had communicated the diagnosis to the patient, 25 percent used the term "Alzheimer's disease." When diagnosis was disclosed to the family, GPs spoke about "Alzheimer's disease" in 87 percent of cases.

Regarding the type of information provided (Tables 1 and 2), 25 percent of GPs explained the nature of the illness, prognosis, and risk factors to the patient, and 90 percent explained these to the family. Respondents reported having addressed the issue of behavioral problems with 23 percent of the patients and 83 percent of patient caregivers.

Depression was discussed with 47 percent of the patients and 85 percent of the caregivers. Stress was discussed with 79 percent of the caregivers. Ninety-seven percent of the respondents thought that depression should be discussed with the patient, and 99 percent thought it should be with the caregiver. Almost all GPs (98 percent) felt it was their role to discuss caregivers' stress.

The possibilities of psychosocial care and support had been spontaneously explained by 65 percent of GPs. Only 6 percent of patients had addressed the issue, versus 48 percent of relatives. In 15 percent of cases, the topic had not been discussed at all.

The topics listed in Tables 3 and 4 (reasons why a topic had not been discussed) had multiple choices in the survey, and the sum of their percentage may be over 100.

Reported reasons of not having discussed the nature of AD with the patient were psychological reasons (63 percent), subject not having been initiated by the patient (43 percent), GP conviction of having nothing to offer (37 percent), patient lack of insight (12 percent), GP embarrassment (9 percent), and lack of time (4 percent).

Reported reasons of not having discussed the nature

Table 4. Topics not discussed with the caregiver

Reason	Explanation of AD	Behavioral problems	Depression	Caregiver stress
No caregiver	33	33	33	33
Issue not addressed by caregiver	25	33	33	40
Unprofitable/nothing to offer	6	19	19	19
Psychological reasons	13	14	10	18
Explanation given by specialist	13	–	–	–
Lack of time	6	4	7	8
GP embarrassment	6	4	2	3

Numbers given are percentages.

of AD with the caregiver were, besides the reason that 33 percent of the patients had no family caregiver, subject not having been initiated by the caregiver (25 percent), psychological reasons (13 percent), explanation already given by the specialist (13 percent), embarrassment (6 percent), conviction of having nothing to offer (6 percent), and lack of time (6 percent).

GPs did not discuss behavioral problems with the patient for psychological reasons (53 percent), because the patient had not tackled the issue (35 percent), because they considered it unprofitable (38 percent), because of embarrassment (6 percent), or because of lack of time (2 percent).

Reported reasons of not having discussed behavioral problems with the caregiver were, besides the reason that 33 percent of the patients had no family caregiver, the subject not having been initiated by the caregiver (33 percent), feeling of having nothing to offer/that it is unprofitable (19 percent), psychological reasons (14 percent), embarrassment (4 percent), and lack of time (4 percent).

Depression had not been discussed with the patient for psychological reasons (43 percent), because it was considered unprofitable (42 percent), because the patient had not spontaneously mentioned it (30 percent), because of embarrassment (5 percent), because of lack of patient insight (8 percent), or because of lack of time (6 percent).

Patient depression had not been discussed with the caregiver because the latter had not addressed the issue (33 percent), the GP considered it unprofitable (19 percent), because of psychological reasons (10 percent), because of lack of time (7 percent), or because of embarrassment (2 percent).

Caregiver stress was not addressed because the caregiver had not mentioned it (40 percent), because the GP considered it unprofitable (19 percent), for psychological reasons (18 percent), because of lack of time (8 percent), or because of embarrassment (3 percent).

Discussion

GP attitudes toward patient and caregiver differ: they do not systematically give a differential diagnosis to the individual with AD, whereas the caregiver seems to be fully informed. This result is in accordance with the literature.[5] There are few studies that evaluate patients' opinions, but existing results show that at least individuals with mild dementia seem to want to know the diagnosis.[14,16]

Generally, GPs do not discuss consequences of AD and symptoms (e.g., behavioral disorders) with patients, mainly for psychological reasons, whereas they have a less-reluctant attitude toward caregivers. Only depression seems to be more easily discussed (by one-half of the GPs). The availability of antidepressants may be a valuable explanation for a less-reluctant attitude toward demented patients.

Regarding the reasons why a topic is not tackled with a caregiver, the most frequently reported reason is because the latter did not address the issue spontaneously.

The results also show a discrepancy between doctor practice and opinion: nine out of 10 doctors consider it their role to explain the illness and its consequences and symptoms to the patient, but only one out of four tackles the issue. This is probably related to the feeling of having nothing to offer to a person with AD.

Conclusion

As the GP has the weighty task of providing appropriate community care and adequate psychological support to patient and family caregivers, it is of utmost importance to reflect on how disclosure of diagnosis can be facilitated. These results show a reluctant attitude toward patients, although AD management has become more patient centered, considering the patient as a psychologically autonomous person having mental and relational abilities, who has the right to know and who can still decide on issues regarding personal life and treatment and care options. In this light, knowing his/her condition allows the patient to establish a relation of confidence with his family practitioner, which may facilitate future care. When it is a specialist who is in charge of disclosure, the general practitioner should be informed of the way patient and caregiver reacted to have a good understanding of emotions, needs, and desires of the patient and his/her caregiver.

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