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Alzheimer's disease diagnosis disclosure in Brazil: a survey of specialized physicians' current practice and attitudes

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ABSTRACT

Background: There is little, though growing, interest in the research area of attitudes held among physicians towards disclosing the diagnosis of dementia and Alzheimer's disease (AD), or the current practice on AD disclosure. This study aimed to investigate the practice and attitudes of specialized physicians towards AD diagnosis disclosure in Brazil.

Methods: A questionnaire was devised to survey the current practice and attitudes regarding diagnosis disclosure of AD in Brazil and sent to specialized physicians (170 geriatricians, 300 neurologists and 500 psychiatrists) by electronic mail.

Results: From 970 potential respondents, 181 physicians who usually attend AD patients returned the questionnaire. There were no significant differences between the three specialties regarding the frequency with which they informed patients of their AD diagnosis ($p = 0.17$). The results revealed that only 44.8% of the physicians would regularly inform the patient of the diagnosis, although 85.6% of these use clear terminology. Despite their usual practice, 76.8% would want to know their diagnosis if they themselves were affected by AD.

Conclusions: Disclosure of AD diagnosis is not common among specialized physicians in Brazil and different factors are involved. In the clinical context, discussion on advantages of diagnosis disclosure can be useful for improving the care of AD patients and their families.

Key words: dementia, Alzheimer disease, diagnosis disclosure, bioethics

Introduction

A change of attitude toward disclosure of the diagnosis of medical conditions has become apparent in the past few decades, from an attitude of medical paternalism

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to one that takes into account patient autonomy. The best example of this shift comes from studies of cancer patients. More than 45 years ago, Oken (1961) used a questionnaire to survey the attitudes of physicians regarding diagnosis disclosure of cancer and reported that 90% of doctors adopted the practice of not disclosing the diagnosis. The same questionnaire was administered 18 years later by Novack *et al.* (1979) to doctors working in a university hospital, and 97% indicated a preference for telling a cancer patient their diagnosis. This indicates an absolute reversal of attitude such that disclosure of cancer diagnosis by physicians has become the ethical norm.

However, there is little, though growing, interest in the research area of attitudes held among physicians toward disclosing the diagnosis of dementia, especially Alzheimer's disease (AD), while little is known about the views and wishes of family caregivers and patients themselves on this subject. This issue warrants special attention in the light of the current treatment options for dementia and, even more importantly, in view of the advent of potential new AD therapies in the near future.

Diagnosis disclosure of dementia and the related ethical concerns have recently come under discussion. The American Medical Association (AMA) guidelines for the diagnosis and treatment of dementia state that the diagnosis should be given directly to the patient "if at all possible" (Guttman and Seleski, 1999). However, it has been suggested that these guidelines are inadequate to address the clinical complexities of this issue, or to cater for the cultural diversity between countries or even within the same country, especially in view of the flow of migrants with distinct social and cultural backgrounds from developing to developed countries. For example, little research has been undertaken on the impact of disclosing a diagnosis of dementia, on how to decide whether a dementia patient is competent to understand a diagnosis, or on how much information to convey.

An earlier study in Nottingham, U.K. (Johnson *et al.*, 2000) investigated current practice and attitudes among geriatricians and old age psychiatrists. The authors found that only 40% of these specialists regularly tell patients the diagnosis and 20% saw no benefit in telling the patient. However, 72.5% of the respondents stated that they would wish to know the diagnosis if they were suffering from the illness. Although physicians were aware of many benefits in disclosing, they had concerns regarding the certainty of diagnosis, the patients' insight, and the possibility of causing distress and destroying hope or motivation.

Other studies in the U.K. examining the attitudes of general practitioners, geriatricians and psychiatrists have shown similar findings (Gilliard and Gwilliam, 1996; Rice and Warner, 1994; Rice *et al.,* 1997; Clafferty *et al.*, 1998; Vassilas and Donaldson, 1998). Rice *et al.* (1997), who also surveyed geriatricians and psychiatrists, found a relationship between disclosure of diagnosis and dementia severity: patients with mild and moderate dementia were told their diagnosis more frequently than patients with severe dementia. The wide variation in practice suggests that further debate is needed on this issue (Rice *et al.*, 1997).

Another study conducted in France examined whether and how diagnosis of AD is disclosed by French general practitioners: 28% of the physicians reported having disclosed diagnosis to their patients whilst few discussed the consequences of AD and its symptoms with patients, but had a less reluctant attitude toward caregivers (Cantegreil-Kallen *et al.*, 2005).

A recent Brazilian study revealed that disclosure of AD diagnosis to patients was approved by 57.5% of 40 family caregivers, and that these rates were not correlated to socioeconomic level (Vilela and Caramelli, 2006).

Despite increasing concerns over diagnostic disclosure in AD, little is known about attitudes held among physicians toward this practice, especially in the developing world. Most people with dementia (around 60%) live in developing countries and recent projections indicate that this proportion is set to rise significantly over the next three decades (Ferri *et al.*, 2005). There is no current information or estimate regarding the number of people with dementia in Brazil. A previous population-based study found a 7.1% prevalence of dementia in individuals aged 65 years or more, with AD being responsible for 55.1% of these cases (Herrera *et al.*, 2002). Mean life expectancy is increasing rapidly in Brazil and reached 71.9 years at birth in 2005 (IBGE, 2005), indicating that dementia might affect a significant number of individuals in Brazil, which currently has a population of more than 180 million inhabitants.

In the light of this increasing interest in diagnosis and care of dementia patients, the goal of the present study was to investigate the practices and attitudes of specialized physicians concerning AD diagnosis disclosure in Brazil.

Methods

A questionnaire (see Appendix) was devised to survey the current practice and attitudes regarding diagnosis disclosure of AD in Brazil and was sent by email to 970 specialized physicians. Of these, 170 were geriatricians, 300 were neurologists and 500 were psychiatrists. They were all active members of the national medical societies of their respective specialties, and their email addresses were registered on the societies' electronic mailing lists. They were practicing in cities within all five geographic regions of Brazil.

The first part of the questionnaire requested demographic data about themselves (age, gender, involvement in university/academic activities, and their city of work) and the second part was composed of eight multiple-choice questions. The physicians were asked if they usually saw AD patients and the frequency with which they handled such cases; how often they disclosed the diagnosis of AD to the patient; which factors affected their decision to disclose; what general concerns they had regarding disclosure; the terminology employed; whether they thought most patients would want them to disclose the diagnosis of AD; and whether they would want to know their diagnosis if they were to develop AD. The SPSS program was used for data analysis (one-way ANOVA and χ^2 test).

The study was approved by the Research and Ethics Committee of the Hospital das Clínicas of the University of São Paulo School of Medicine, Brazil.

Results

From a total of 970 potential respondents, 206 physicians completed the questionnaire. The analysis included only physicians who usually attended AD patients, narrowing the total to 181 physicians and giving a response rate of 18.7%. All questionnaires were correctly completed. Table 1 shows the demographic data from the 181 respondents and the frequency of AD diagnosis disclosure.

Overall, 44.75% of respondents stated that they regularly told patients their diagnosis. There were no significant statistical differences between the three medical specialties concerning the frequency with which they told patients of their AD diagnosis ($p = 0.17$; Table 1).

Physicians' age was correlated significantly to AD disclosure. When comparing younger (20 to 39 years) with older (40 to 79 years) doctors, 32 of the former group and 49 of the latter responded that they always or usually tell the diagnosis, while 10 physicians of the younger and 36 of the older groups rarely or never tell ($p = 0.04$).

Almost all physicians who always or usually disclose the diagnosis believed that patients wanted to know their diagnosis ($p = 0.00$).

The responses relating to which factors affect physicians' decision to disclose are summarized in Figure 1. The main factor influencing disclosure in this sample was the patient's wish to be told (69.0%). Among geriatricians (80.0%) and neurologists (68.2%), relatives' views about telling the patient constituted the main deciding factor. Few respondents were influenced by the patients' financial state (13.2%). Severity of dementia was a factor that was taken into account more frequently by geriatricians and psychiatrists (77.5% and 63.0%, respectively) than by neurologists (42.0%).

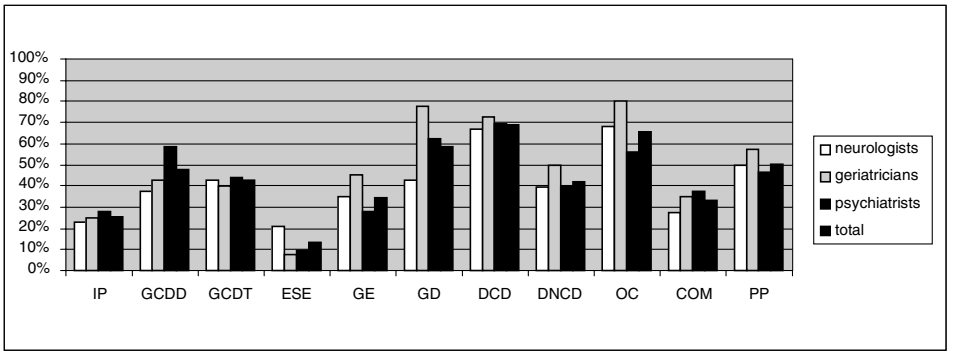

Figure 1. Factors that affect diagnosis disclosure.

IP: patient age; GCDD: degree of certainty of the diagnosis of dementia; GCDT: degree of certainty of diagnosis of type of dementia; ESE: state of patient's finances; GE: university degree; GD: severity of dementia; DCD: patient's express wish to be told; DNCD: patient's express wish not to be told; OC: relative's views about telling the patient; COM: comorbidity; PP: patient's personality.

Table 1. Main demographic features of 181 physicians grouped according to specialty and frequency of AD diagnosis disclosure

	NEUROLOGISTS N = 66	GERIATRICIANS N = 40	PSYCHIATRISTS N = 75	TOTAL N = 181	P-VALUE*
Age (years)					
Mean ± SD	45.6 ± 10.0	43.3 ± 10.0	45.7 ± 11.8	45.1 ± 10.8	**0.41**
Range	28–62	29–69	28–74	28–74	
Gender–N (%)					
Male	47 (71.2%)	22 (55.0%)	54 (72.0%)	123 (68.0%)	**0.14**
Female	19 (28.8%)	18 (45.0%)	21 (28.0%)	58 (32.0%)	
University activity–N (%)					
Yes	50 (75.8%)	33 (84.5%)	52 (69.3%)	135 (75.0%)	**0.20**
No	16 (24.2%)	7 (15.5%)	23 (30. 7%)	45 (25.0%)	
AD diagnosis disclosure–N (%)					
Always or usually	26 (39.4%)	11 (27.5%)	44 (58.7%)	81 (44.7%)	**0.17**
Rarely or never	20 (30.3%)	9 (22.5%)	17 (22.7%)	46 (25.4%)	

*χ^2 test.

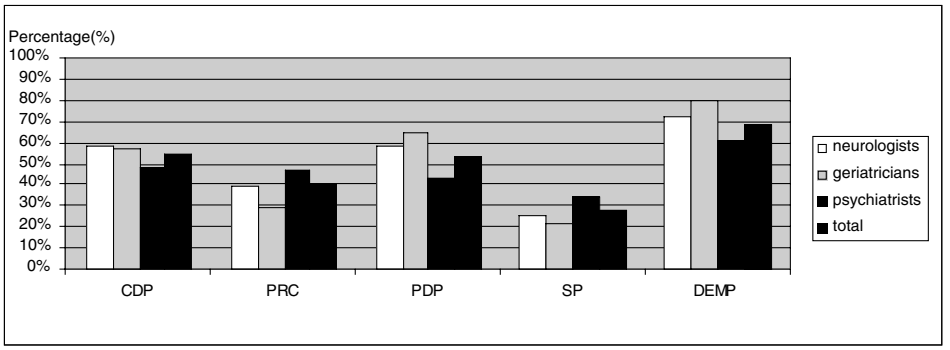

Figure 2. General concerns of physicians regarding diagnosis disclosure.
CDP: causing psychological distress; PRC: precipitating a catastrophic reaction; PDP: precipitating a depressive illness; SP: suicide of the patient; DEMP: destroying the patient's hope or motivation.

Table 2. Physicians' answers to questions 6 and 7 of the Questionnaire

	NEUROLOGISTS N (%)	GERIATRICIANS N (%)	PSYCHIATRISTS N (%)	TOTAL %
Response rates to the question: "Do you think most patients want to know their diagnosis?"				
Yes	29 (44.0%)	16 (40.0%)	41 (54.7%)	47.5%
No	21 (31.8%)	11 (27.5%)	13 (17.3%)	24.9%
Don't know	16 (24.2%)	13 (32.5%)	21 (28.0%)	27.6%
Response rates to the question: "If you were suffering from early Alzheimer's disease, would you wish to be told the diagnosis?"				
Yes	51 (77.3%)	27 (67.5%)	61 (81.3%)	76.8%
No	8 (12.1%)	6 (15.0%)	3 (4.0%)	9.4%
Don't know	7 (10.6%)	7 (17.5%)	11 (14.7%)	13.8%

Issues generally causing concern surrounding the disclosure of the diagnosis of AD to the patient are summarized in Figure 2. The main concern was the possibility of destroying the patient's hope or motivation.

The nomenclature used by the physicians was also examined: 85.6% of the respondents always used clear terminology such as AD or dementia, and the rest used a variety of terms including "memory impairment," "forgetfulness," "senility" or "sclerosis."

Respondents were asked whether they thought most patients would wish them to disclose the diagnosis of AD and whether they would wish to be told if they had early AD. Overall, 76.8% of physicians would like to know their diagnosis (if they had early AD), while only 47.5% think that the patient would like to know. These response rates are depicted in Table 2. Within the group of those who rarely or never tell patients the diagnosis (46 physicians, as shown in Table 1), 52.2% would like to know their diagnosis if they had early AD.

Discussion

There has been little research on current practice and attitudes of physicians in disclosing the diagnosis of AD, particularly in developing countries such as Brazil. In the present study, only 44.7% of physicians surveyed regularly told their patient the diagnosis, although 85.6% of these use clear terminology. Younger specialists are more likely to disclose the diagnosis of AD than their older counterparts. Despite their usual practice, 76.8% of the doctors would like to know their diagnosis if they themselves were affected, representing an inconsistent approach. Inside the group of those who rarely or never tell the patient the diagnosis (46 physicians), 52.2% would like to be told themselves.

There is marked inconsistency between the physicians' reports of their usual practice and their views on potential benefits and patients' wishes. In this study there seems to be two reasons for this: the first is the strong influence of relatives' views on telling the patient their diagnosis; the second involves protecting the patient from undue distress and a belief that hope or motivation may be reduced by non-disclosure, similar to views held with regard to cancer until some decades ago. Severity of dementia is a factor that was taken into account more frequently by geriatricians and psychiatrist than by neurologists. The questionnaire did not specifically address the reasons for this difference, which may also be due to disparities between the sample size of the three groups. It may be interesting to explore this finding in future studies.

There is now extensive literature on the wishes of patients who have cancer and the information they would like to have (Meredith *et al.*, 1996). There is some evidence from healthy adults that they would like to know if they were diagnosed with AD (Erde *et al.*, 1988). However, there are still very few studies in the literature regarding AD patients' own views on this matter and physicians are basically unsure whether patients would wish to know or not. The need for additional information is crucial since what we do not know, including the attitudes of patients and the actual emotional consequences of receiving diagnostic information, outweighs the existing body of evidence. Furthermore, the risks and benefits of being given such diagnostic information vary according to the severity of dementia. Additional research is required to provide doctors with a knowledge base for their interactions with this section of the patient population.

An additional justification for disclosing the diagnosis to the patients pertains to the decision about current and future treatment choices. These range from cholinesterase inhibitors and memantine, which have mainly symptomatic effects and may occasionally cause adverse events, to participation in clinical trials with some of the new and promising disease-modifying compounds that are currently being testing (Rogers and Friedhoff, 1996; Polinsky, 1998).

Regarding the nomenclature used, 85.6% of all physicians claimed that they employed clear terminology, such as AD or dementia. This contrasts with the findings from the U.K. study by Johnson *et al.* (2000), in which only 25% of the physicians reported this practice. In that study, the questionnaire was sent to all grades of staff working in hospitals in Nottingham, excluding pre-registration house officers. Although it is not clear how many of them had

academic affiliations, we may suppose that our study had a higher rate of academic affiliated doctors and that this difference might explain the divergence in the nomenclature employed. In addition, the fact that our study was conducted more recently, when terms like AD and dementia are more familiar to lay people, may also have contributed to this discrepancy.

It is important to point out some limitations of the present study. The sample is drawn mainly from the major cities in Brazil and may not be representative of the views and attitudes of physicians from smaller towns. Furthermore, less than 22% of the physicians who received the electronic questionnaire responded and around 10% of them declared that they did not regularly attend patients with dementia and, for this reason, they were excluded from the study. However, among the physicians who were included, there was a significant number of doctors from the three specialties, with fairly wide age ranges. As already mentioned, although they may not reflect the points of view and attitudes of physicians from smaller towns, the fact that many of them have academic positions and teaching activities is important because their opinions and practices might influence a substantial number of other colleagues.

An additional limitation is related to the fact that the study was conducted through a questionnaire survey, which relies on self-report of practice and hence does not involve objective measures. The design of the questionnaire was for descriptive use rather than for quantitative analysis. The questions were closed in order to enable a simpler analysis, but this in turn is likely to have reduced the full range of possible responses.

In conclusion, disclosure of AD diagnosis is not common practice among specialized physicians in Brazil and different factors are involved in this approach. In the clinical context, the discussion over advantages of diagnostic disclosure can be useful for improving the care of AD patients and their families.

Conflict of interest

None.

Description of authors' roles

Irina Raicher contributed to the design of the study, was responsible for the collection and analysis of the data, and for the preparation of the manuscript. Marta Maria Shimizu contributed to the collection and analysis of the data. Daniel Yasumasa Takahashi contributed to the statistical analysis and also reviewed the manuscript. Ricardo Nitrini contributed to the design of the study and also reviewed the manuscript. Paulo Caramelli was responsible for the conception and design of the study, while also contributing to the analysis of the data and to preparation of the manuscript.

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Appendix Questionnaire

Demographic data of respondent:
Age: Gender: ( ) Male ( ) Female
Year of completion of medical school:
Specialty:
Current university or academic activity: ( ) Yes ( ) No
City and state of work:

Multiple-choice questions relating to diagnosis disclosure

(1) Do you attend patients with dementia and Alzheimer's disease?
( ) Yes
( ) No
If yes, how many, on average, per year?_____

(2) Having made a diagnosis of Alzheimer's disease, how often do you tell the patient his/her diagnosis?
( ) always
( ) usually
( ) sometimes
( ) rarely
( ) never

(3) Please mark any of the following factors about an individual patient which sometimes or always affects your decision to disclose the diagnosis to him/her:
( ) patient's age
( ) degree of certainty of the diagnosis of dementia
( ) degree of certainty of diagnosis of the type of dementia
( ) state of patient's finances
( ) university degree
( ) severity of dementia
( ) patient's express wish to be told
( ) patient's express wish not to be told
( ) relative's views about telling the patient
( ) comorbidity
( ) patient's personality

(4) Please mark any factors which in general concern you about the disclosure of Alzheimer's disease to patients:
( ) causing psychological distress
( ) precipitating a catastrophic reaction
( ) precipitating a depressive illness
( ) suicide of the patient
( ) destroying the patient's hope or motivation

(5) What terminology do you use?
( ) Alzheimer's disease
( ) dementia

( ) senility
( ) sclerosis
( ) memory impairment
( ) forgetfulness
( ) other (please, specify):_____

(6) Do you think most patients want to know their diagnosis?
( ) Yes
( ) No
( ) Don't know

(7) If you were suffering from early Alzheimer disease, would you wish to be told the diagnosis?
( ) Yes
( ) No
( ) Don't know