DISCLOSURE OF THE DIAGNOSIS OF ALZHEIMER'S DISEASE

Caregivers' opinions in a Brazilian Sample

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Abstract – Background: Disclosure of the diagnosis of Alzheimer's disease (AD) remains a contentious issue, and has been little studied in developing countries. **Objective:** To investigate the influence of socio-demographic factors and the experience of being a caregiver on opinion about disclosing AD diagnosis to the patient in a Brazilian sample. **Method:** Caregivers of 50 AD patients together with 50 control participants that did not have the experience of being a caregiver of AD patient were interviewed using a structured questionnaire. **Results:** Most of the participants (73.0%) endorsed disclosure of the diagnosis, while caregivers were less prone to disclose (58.0%) than controls (88.0%; p=0.0007). Logistic regression confirmed that only the experience of being a caregiver was associated with a lesser tendency for disclosure endorsement. **Conclusion:** The majority of participants was in favor of disclosing the diagnosis, but caregivers were less willing to disclose the diagnosis to the AD patient.

KEY WORDS: Alzheimer's disease, diagnosis, disclosure, caregiver, dementia.

A revelação do diagnóstico de doença de Alzheimer: opiniões de cuidadores em uma amostra brasileira

Resumo – Fundamento: A revelação do diagnóstico de doença de Alzheimer (DA) tem sido tema polêmico e pouco estudado em países em desenvolvimento. **Objetivo:** Investigar a influência de fatores sócio-demográficos e a experiência de ter sido cuidador na opinião sobre a revelação do diagnóstico em uma amostra brasileira. **Método:** Cuidadores de 50 pacientes com DA e 50 indivíduos controle que não tinham tido experiência como cuidadores de pacientes com DA foram entrevistados com o uso de um questionário estruturado. **Resultados:** A maioria dos participantes (73,0%) manifestou-se a favor da revelação diagnóstico aos pacientes, mas cuidadores foram menos favoráveis (58,0%) que controles (88,0%; p=0,0007). Regressão logística demonstrou que apenas a experiência como cuidador foi associada com menor tendência a apoiar a revelação do diagnóstico. **Conclusão:** A maioria dos participantes foi a favor da revelação do diagnóstico ao paciente, mas aqueles com experiência como cuidadores de pacientes com DA foram menos favoráveis.

PALAVRAS-CHAVE: doença de Alzheimer, diagnóstico, revelação, cuidador, demência.

The population worldwide has undergone an aging process that has led to an increasing prevalence of chronic illnesses, such as Alzheimer's disease (AD)[1-3]. Therefore, the ethical issues concerning this disease, which impairs not only patient quality of life, but also of those around them, have come to the fore[4-7]. AD is a progressive neurological illness causing the decline of the patient's cognitive abilities, including memory, judgment, orientation and attention, eventually rendering them fully dependent on external care. Psychiatric symptoms, mainly depression and agitation, are also very frequent. AD onset commonly occurs at the age of 65 years onwards and entails a significant shortening of the patient's lifespan[8,9]. In so far as AD is a degenerative disease bearing a somber prognosis, the disclosure of the diagnosis to the patients represents a polemic issue for their families[10-13]. Studies investigating the question of disclosure have found differing results. In Ireland, from a cohort of 100 relatives of AD pa-

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tients, only 17 relatives stated the patient should be told the diagnosis of this disease, whereas the remaining 83 stated patients should not be told. The main rationale behind the latter stance was that depression would accrue in the patient should their diagnosis be disclosed to them. However, 71 relatives said they would rather the diagnosis of the disease be disclosed to them should they be AD suffers, where the majority stated they had the right to know so as to enable them to make the proper arrangements for the future in order to ease the coming burden on their families[14].

Contrasting with the results from Ireland, a study in England showed that 57% of the first degree relatives of AD patients wanted the diagnosis to be disclosed to their ill relative[15]. In another study in the US, disclosure of the diagnosis of AD correlated with the knowledge people had of the disease. In this study, about half of the 57 relatives, members of community societies which provided assistance to families of patients with dementia, stated they were not given enough information about the disease. Most relatives believed the patients should be told of their disease diagnosis and prognosis by the physician, despite the fact that half of the relatives informed that patients had reacted badly to the disclosure and that only one-third of the relatives had felt the disclosure had been of any use to the patient[16]. In Italy, semi-structured interviews were given to the closest relatives of 71 patients with recent diagnosis of AD. Forty three (60.6%) relatives spontaneously declared their wish for patients not to be informed of the diagnosis. Following the interview, all interviewees felt the patient should not be told of the diagnosis, fearing bringing on or worsening depressive symptoms for the patients[17]. This result is similar to that found in Ireland by Conor et al., showing that this fear of the emotional impact on the patient following disease diagnosis disclosure is prevalent among patient relatives[14]. To date, few studies have been carried out on disclosure of the diagnosis of dementia in Brazil and in Latin America[18-20]. In Brazil, caregivers of 20 AD patients followed in a public university hospital were compared with caregivers of 20 patients treated in a private clinic, looking for possible differences in the wish to disclose. Less than half (42.5%) of all the caregivers favored disclosure of the diagnosis to the patient, and there was no influence of the socioeconomic status in their opinion. However, the study in question did not investigate the influence of schooling or knowledge of AD[18]. In another recent study conducted in Brazil by our group, a letter was sent to neurologists, psychiatrists and geriatricians asking whether they usually disclose the diagnosis to their patients. Among 181 physicians who answered, 44.7% informed that they regularly provide the diagnosis to AD patients[20].

This study had the objectives of investigating the opinion of a Brazilian sample of participants on the disclosure of AD diagnosis, searching for the influence of socio-demographic factors, mainly schooling, and of the experience of being a caregiver on the wish to disclose the diagnosis to a relative afflicted by AD, and to provide data for comparisons with other studies carried out in different countries.

METHOD

The caregivers of patients with the diagnosis of probable AD, according to the National Institute of Neurological and Communicative Disorders and Stroke – Alzheimer Disease and Related Disorders Association (NINCDS-ADRDA) criteria[21] followed by members of the Behavioral and Cognitive Neurology Group Unit of the Hospital das Clínicas of the University of São Paulo School of Medicine, in Brazil, and a equivalent number of participants without AD cases in their families were interviewed. The structured questionnaire used in Japan by Mimura[22] comprising 14 questions related to caregivers' opinions on the disclosure of AD diagnosis was translated into Portuguese by both a physician and a student of Medicine who were fluent in both Portuguese and Japanese. Subsequently, all arising disagreements in translations were resolved through a consensus between the two physicians. Another questionnaire was created to evaluate the general knowledge on AD symptoms and course of the disease. The questionnaires were made up of multiple choice tests. The Brazilian ABIPEME (Brazilian Association of Market Research Institute) questionnaire was also applied to assess the socioeconomic status of the interviewees. After this, an informative text on AD, containing an explanation of disease symptoms and course, was read to each interviewee after which, they were questioned again on disclosure of diagnosis to the patient.

The influence of schooling, age, gender, and socioeconomic status on the wish to disclosure of diagnosis was assessed. It was evaluated whether the wish for or against disclosing would be modified after having received more information on the disease, and whether the existence of a real patient with AD in the family would interfere with the interviewee's standpoint.

The knowledge of AD was probed and whether this bore any influence on schooling. The interviewees' own wish on the disclosure of the diagnosis to them should they themselves have AD was also verified.

The study was also intended to make a qualitative analysis of the interviewee's answers to the open questions on the disclosure of the diagnosis and to this end the answers of the caregivers and controls were assessed separately.

The data were stored in a Microsoft Excel Table. Categorical data were tested for the independence between the categories and statistical analyses were carried out with the Fisher exact test for 2 × 2 contingency tables, and the two-sided exact test[23] for bigger contingency tables. Student *t* test was used for comparison of the mean values for continuous variables. As in the multivariate analyses, logistic regression was performed in order to verify the factors interfering with the wish to disclose the diagnosis. The statistical software ®SPSS version 10.0.1 (SPSS Inc), ®Minitab 15 (State College, Pennsylvania, USA, 1983) were used. The value of significance accepted was 0.05.

The study was approved by the Ethics and Research Committee of the institution, and the questionnaires were applied after reading out and signing of the informed consent.

RESULTS

We were able to interview 50 caregivers (of 50 patients with AD) and 50 participants without AD cases in their families, comprising 34 men and 66 women, with mean age of 57.97 years (SD=11.53) and mean schooling of 8.93 years (SD=4.77), with a median of 10 years of schooling.

When all interviewees were jointly assessed, 73% were in favor of disclosing the diagnosis to an AD patient. Age, gender and socioeconomic level did not influence this

Table 1. Influence of education (years of schooling), age, gender and socioeconomic level on the wish of disclosing AD diagnosis to a patient.

	Disclosure of the diagnosis to the patient			
	Yes	No	Total	p
Education				0.028
<10 years	39 (82.98%)	8 (17.02%)	47	
≥10 years	34 (64.15%)	19 (35.85%)	53	
Age				0.113
<56 years	30 (68.18%)	14 (31.82%)	44	
≥56 years	43 (76.79%)	13 (23.21%)	56	
Gender				0.214
Men	27 (79.41%)	7 (20.59%)	34	
Women	46 (69.70%)	20 (30.30%)	66	
*Socioeconomic level				0.214
A	10	8	18	
B	25	10	35	
C	29	8	37	
D	9	1	10	
E	0	0	0	

*If by collapsing categories A and B and categories C, D and E two categories are built, the p-value for Fisher exact test for 2 × 2 contigency table is 0.046.

Table 2. Demographic characteristics of caregivers and control subjects.

	Caregivers	Control subjects	p
Education (years of schooling)			0.017
Mean (standard-deviation)	10.06 (4.80)	7.80 (4.51)	
Median	11	8	
Range	0–16	0–17	
Age			0.144
Mean (standard-deviation)	59.66 (13.17)	56.28 (9.44)	
Median	57	56	
Range	21–85	32–75	
Gender			0.2053
Men	14 (28.00%)	20 (40.00%)	
Women	36 (72.00%)	30 (60.00%)	
Socioeconomic level			0.131
A	12 (24.00%)	6 (12.00%)	
B	20 (40.00%)	15 (30.00%)	
C	15 (30.00%)	22 (44.00%)	
D	3 (6.00%)	7 (14.00%)	
E	0	0	

Table 3. Relatives caregivers and controls' opinion on disclosure of the diagnosis, and care for the patient (questionnaire originally proposed in Japan, by Mimura et al).

	Caregivers	Control group	p
Main justification for disclosing the diagnosis to the patient:			0.351
It is a right of the patient to know his diagnosis	15 (51.72%)	25 (56.82%)	
The patient can overcome the setback of knowing the diagnosis of his disease	1 (3.45%)	6 (13.64%)	
It is necessary to start with the medication	10 (34.48%)	9 (20.45%)	
The patient already knows the diagnosis of his disease	1 (3.45%)	3 (6.82%)	
Others	2 (6.90%)	1 (2.27%)	
Main justification for not disclosing the diagnosis to the patient:			0.131
The patient can become depressed or shocked after knowing the diagnosis	13 (61.91%)	2 (33.33%)	
The patient is not able to understand the meaning of the diagnosis	7 (33.33%)	2 (33.33%)	
Knowing the diagnosis has no meaning	1 (4.76%)	0	
The patient is afraid of getting the AD	0	1 (16.67%)	
Others	0	1 (16.67%)	
Main justification for the will of having the diagnosis of his illness disclosed to himself.			0.989
Would like to know the treatments and information about the disease	23 (51.11%)	23 (46.94%)	
To be informed of the diagnosis is one's right	16 (35.56%)	18 (36.73%)	
To get prepared for the aging	5 (11.11%)	6 (12.25%)	
Would like to settle the issues related to assets legacy in advance	1 (2.22%)	1 (2.04%)	
Others	0	1 (2.04%)	
Main justification for the will of not having the diagnosis of his illness disclosed to himself.			0.833
Would get depressed or shocked after knowing the diagnosis	4 (80.00%)	1 (100%)	
Knowing the diagnosis has no meaning	1 (20.00%)	0	
Where would you like to be cared?			0.159
In a institutuion	23 (28.95%)	23 (46.00%)	
At home	27 (71.05%)	27 (54.00%)	
By whom?			0.171
Relative	14 (36.84%)	17 (34.00%)	
Professional	24 (63.16%)	33 (66.00%)	
What is your marital status?			0.169
Married	36 (72.00%)	31 (62.00%)	
Single	7 (14.00%)	6 (12.00%)	
Widow	5 (10.00%)	4 (8.00%)	
Divorced	2 (4.00%)	9 (18.00%)	
What is your source of revenue?			0.689
Do paidwork daily	12 (24.00%)	12 (24.00%)	
Do paidwork sometimes	7 (14.00%)	4 (8.00%)	
Do not do paidwork	31 (62.00%)	34 (68.00%)	

opinion, while higher schooling was associated with a stronger wish of not revealing the diagnosis (Table 1).

Table 2 shows the demographic characteristics of the sample when divided into caregivers and controls. Age, gender and socioeconomic level did no differ between the groups, but caregivers had higher schooling than controls. Among the caregivers, 58% decided on disclosing the diagnosis to the AD patient, whereas among the controls, the number rose to 88% (p=0.0007). Other socio-demographic variables, including schooling, were not associated with any trend towards disclosure or non-disclosure of the diagnosis to the patient. When the socioeconomical level were divided into only two levels, those in the lower level where more prone to disclose the diagnosis than those in the upper level (p=0.046).

Reading of the informative text did not modify the results (p=0.68 among the caregivers and p=0.40 among the controls).

Logistic regression showed that only the real experience as a caregiver (β= –1.670 (0.521); odds ratio= 0.188; 95% CI, 0.680-0.523; p=0.001) was associated with the wish for non-disclosure of the diagnosis compared with the hypothetical situation, while schooling, age, gender and socioeconomic level were not associated.

In the caregiver group, 90% of the interviewees would like to have the diagnosis revealed to them should they

Table 4. Opinion on the prognosis of Alzheimer's disease.

	Caregivers	Control group	p
Course of the disease:			<0.001
Think there is cure.	9 (18.00%)	26 (52.00%)	
Think that gets worse as time goes by.	40 (80.00%)	18 (36.00%)	
Think that AD does not get worse along the time but the patient keeps having symptoms.	1 (2.00%)	6 (12.00%)	
The AD patient in your opinion:			0.064
Will be able to keep his daily activities normally in the future.	2 (4.00%)	7 (14.00%)	
Will get wholly dependent on other people to do his daily activities.	48 (96.00%)	43 (86.00%)	

have AD, and 98% of the controls expressed the same wish (p=0.092) (Table 3). AD was considered a reversible disease by 18% of the caregivers and by 52% of the subjects without AD cases in the family (p=0.0003), whereas 48% of caregivers and 82% of the control group thought the disease did not shorten the patient's lifespan (p= 0.159) (Table 4).

DISCUSSION

The main finding of this study was that the majority of the interviewed subjects opted to disclose the diagnosis to the patient with AD. This finding contrasts with results found in Ireland[14] and Italy[17], yet is similar to those reported in the USA[16] and England[15].

However, caregivers were less likely than controls to disclose the AD diagnosis, 42% of them stating that the diagnosis should not be disclosed to their ill relative. On the other hand, the degree of schooling did not bear any relationship with the wish to reveal the diagnosis. These results suggest that the factor truly determinant of the wish to prevent the patient from knowing the diagnosis of their own disease is the real life experience as a caregiver, whereby people who did not experience AD cases in their own families held a view which differs from that of caregivers of AD patients. The impact of personal experience with AD in reducing the attitude toward disclosing the diagnosis had been previously reported in elderly American subjects[24].

In this study we expected people with higher schooling and even from the upper socioeconomic levels to exhibit behavior more akin to that seen in developed countries, approving the disclosure of the diagnosis to the patient with AD. We found the opposite: in the univariate analysis participants with higher educational level and from the upper socioeconomic level were less willing to disclose the diagnosis to the diseased relative. Nevertheless, in the logistic regression, only the experience of being a caregiver was associated with the wish of not disclosing the diagnosis. It is upheld here the somewhat trivial understanding that culture bears greater influence than schooling and that conducts coming from the experience acquired in other countries should not be defined for our milieu. Furthermore, use of generalizations such as a prevailing Catholic religion, such as in Ireland and Italy or "Latin origin" to infer trends in our population proved inappropriate in this case.

Caregivers had better knowledge about AD and even so showed greater tendency to spare the patient the disclosure of this diagnosis compared with those without cases of AD in their families. This finding is important, reflecting that revealing the diagnosis in our milieu, does not depend on knowledge about the disease. On the contrary, greater theoretical knowledge and real-life experience increased the trend towards not disclosing it. However, the finding that more than half of the caregivers thought the AD diagnosis should be disclosed to the patient represents an important fact to be considered by the doctor in decision-making in our context.

There are limitations in this study. The number of caregivers probably was small for reaching a more definitive conclusion on the importance of socio-demographic factors. On the other hand, we did not investigate the importance of the severity of the disease on the wish to reveal the diagnosis. In a study, the only factor that was associated with the wish of not telling the diagnosis was a score in the Mini-Mental State Examination below 17[25]. It is probable that for mild AD, or even for mild cognitive impairment, the wish to disclose the diagnosis in an Brazilian sample would be different than those reported herein.

The main justifications for not disclosing the diagnosis to the patient were the fear of worsening or leading to depression and the knowledge that due to the cognitive deficits brought about by AD itself they would unable to grasp the meaning of the diagnosis. Nevertheless, most of the people interviewed in this study would want their own diagnosis revealed to them should they suffer from AD. This somewhat conflicting aspect, had already been noted in studies carried out in Italy[17] and Ireland[14], as well as by specialized physicians interviewed in our previous study in Brazil[20]. This may reflect differences in schooling, or even culture, between the over-65 year-old generation and their offspring.

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