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Original article

What are the preferences of patients attending a memory clinic for disclosure of Alzheimer's disease?

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ABSTRACT

Background/aims. – This report shares and discusses the collected personal preferences of patients attending a memory clinic for disclosure of a potential Alzheimer's disease (AD) diagnosis.

Methods. – In this prospective study of outpatients attending a single memory clinic over a 6-year period (March 2004–October 2010), doctors collected their patients' wishes (willingness to be informed, motivation, presence of the family) through a standardized procedure.

Results. – Of the 1005 patients questioned throughout the study period—with a final diagnosis of dementia for 480 of them—858 (85.3%) wished to be informed of an AD diagnosis, whereas 72 (7.2%) did not and 75 (7.5%) were not sure. Older age and reduced cognitive functioning were independently associated with a preference to not be informed of a potential AD diagnosis.

Conclusion. – Our study provides evidence of the willingness of most patients to know the truth vis-à-vis AD and also offers some insight into their motivations.

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1. Introduction

Whether to disclose the diagnosis of a serious illness, such as Alzheimer's disease (AD), has long been a decision taken by physicians. This was grounded on the premise that truth can be damaging and, specifically, that disclosing such a diagnosis might destroy patients' hopes and motivations. Many physi-

cians also assume that their patients would not wish to know if they had such a negative diagnosis [1,2].

However, the recent years have seen a paradigm shift together with both a general improvement in care and wider public awareness. Patients now wish to be actively involved in decision-making when dealing with their own illness. In addition, the patient's right to know is now a well-established

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requirement in both regulatory authority and ethical guidelines. Nevertheless, in the specific case of dementia, for which treatment options are limited, balancing the obligation to tell the truth against the imperative of 'do no harm' may yet prove too delicate for many physicians.

Most of the research into truth-telling related to an AD diagnosis has included the opinions of practitioners and caregivers. Although some have assessed 'peer-group' wishes (the opinions of people of the same age), very few have reported directly questioning patients [3]. Thus, over the last 10 years, the present team undertook two studies to analyze the opinions of memory clinic practitioners [4] and patients' caregivers [5]. Based on those results and after pondering various concerns, including ethical ones, a new procedure for collecting the personal preferences of patients concerning the disclosure of their own diagnoses was introduced. Now, having collected a significant amount of data, the authors choose to share and discuss their findings.

2. Methods

2.1. Study design and population

This prospective single-centre study of outpatients attending a memory clinic in Paris, France, involved five doctors who formally questioned patients, using a standardized procedure, on their preferences for disclosure or not of a potential AD diagnosis. The study also analyzed all the data collected from March 2004 to October 2010.

2.2. Collected data

During consultations after probing for memory problems, but before any neuropsychological assessment, all patients were questioned concerning their preferences for diagnostic disclosure. The standardized series of questions was introduced with the following statement: "I will now ask you questions to which you are free not to answer if you do not so wish." This was followed by two questions: "If you ever happened to have Alzheimer's disease, or any related disorder, would you want to be told or would you rather not know about it, and why?" "Would you agree to have your family—or closest person—told of it?" Patients who wanted their family to be informed were then asked whether they preferred disclosure of their diagnosis to be made in the presence of their family or to just themselves separately. Answers were recorded on a form, which was added to the patients' medical records. However, these queries could be abandoned if the patient's responses raised concerns about the ability to cope.

Other information collected included age, gender, education level (low: <8 years; middle: secondary school; high: college or university), family history of AD, cognitive function (Mini-Mental State Examination scores; MMSE) [6], presence of a caregiver and the person who had motivated the visit and consultation. In addition, the patients' insight was evaluated on a scale of 0 (fully aware of complaint) to 3 (total loss of insight) and, if available, the final diagnosis was recorded: dementia [including AD, as per *Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) criteria*] [7]; mild

cognitive impairment (MCI; according to the definition by Petersen et al. [8]); attention disorder; organic disease; psychiatric disorder; or age-related cognitive decline (ARCD, as per the definition in DSM-IV) [7].

2.3. Statistical analysis

Patients' characteristics were analyzed according to their attitude towards disclosure of AD diagnosis (willing to be informed, not willing to be informed, not sure). Differences were tested using chi-square tests for categorical variables, and analysis of variance for continuous variables. Factors influencing their opinions on disclosure of AD diagnosis were analyzed using a polytomous (multinomial) regression model, in which patients wishing to know their AD diagnosis served as the reference. Variables introduced into the multivariate analysis were those associated with a P value <0.20 on bivariate analysis. The final model was obtained by eliminating variables not significantly associated with the dependent variable on multivariate analysis (except for age, gender and education, which were forced into the model). Patients' attitudes towards disclosure of an AD diagnosis to their families were similarly analyzed, and the reasons given to explain their position were grouped by similarity and graphically displayed. All analyses were performed using Stata 13 software (StataCorp LLC, College Station, TX, USA).

2.4. Ethics

Ethical approval was not required for this study, which was single-centred and carried out in the context of usual care. Also, as indicated by the French guidelines for diagnostic disclosure in cases of AD and related conditions: "It is recommended to assess whether the patient wishes to know the diagnosis" [9].

3. Results

Of the 1172 outpatients who attended the memory clinic over the study duration, 1005 (85.8%; 665 women and 340 men) were questioned. Patients excluded from our analyses had either difficulty in understanding ($n=36$) or speaking a foreign language ($n=19$), or suffered from severe psychiatric or behavioural disorders ($n=17$). In a few cases, the questions were either voluntarily avoided because of fears of unduly disturbing the patient ($n=63$) or because the attending physician forgot to ask ($n=32$). Only one patient refused to answer the questions.

The main characteristics of the responding patients are presented in Table 1. The final diagnosis was dementia in 480 cases (47.8%), MCI in 257 cases (25.6%), psychiatric disorder in 150 cases (14.9%) and other organic disease in 40 cases (4.0%). AD accounted for 64.4% of the dementia cases. In 78 cases (7.8%), no pathological disorder was found, and memory performances were normal (in relation to ARCD). Three-quarters of the patients arrived with a caregiver (their children as often as their spouses).

Of the patients included in our analysis, 858 (85.3%) wished to be informed of an AD diagnosis, 72 (7.2%) did not and 75

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