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ORIGINAL ARTICLE

Practices and opinions about disclosure of the diagnosis of Alzheimer's disease to patients with MCI or dementia: a survey among Belgian medical experts in the field of dementia

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Abstract

Previous surveys revealed that only a minority of clinicians routinely disclosed the diagnosis of Alzheimer's disease (AD) to their patients. Many health professionals fear that the disclosure could be harmful to the patient. Recent advances in the development of biomarkers and new diagnostic criteria allow for an earlier diagnosis of AD at the mild cognitive impairment (MCI) stage. The Belgian Dementia Council, a group of Belgian experts in the field of dementia, performed a survey among its 44 members about their opinions and practices regarding disclosure of the diagnosis of AD, including MCI due to AD, and its consequences. Twenty-six respondents declared that they often or always disclose the diagnosis of AD to patients with dementia and to patients with MCI when AD CSF biomarkers are abnormal. The majority observed that the disclosure of AD is rarely or never harmful to the patients. Their patients and their caregivers rarely or never demonstrated animosity towards the clinicians following disclosure of the diagnosis of AD. These results should reassure clinicians about the safety of AD diagnosis disclosure in most cases whether the patient is at the MCI or the dementia stage.

Keywords Alzheimer disease · Mild cognitive impairment · Diagnosis · Disclosure

Introduction

About 10 years ago, two surveys revealed that only 68% of Belgian neurologists [1] and 54% of Belgian geriatricians [2] always disclosed a diagnosis of Alzheimer's disease (AD) to their patients despite several international guidelines that recommended the disclosure of the diagnosis to the patient in most cases [3–5]. Moreover, the proportion of patients fully informed of the exact diagnosis is even lower because clinicians often used euphemistic terms like "memory disease" or vague terms like "neurodegenerative disease". Only 40.8% of the 216 neurologists and 48% of the 88 geriatricians who answered these surveys used the term AD with their patients while more than 80% used it to discuss the diagnosis with the caregivers. An older survey performed in 2002 among 521 general practitioners in Flanders revealed that only 36% usually or always disclosed the diagnosis to their patients with dementia and that only 20% used the term AD [6]. These results were concordant with practice and opinions of physicians from various countries [7]. One of the main reasons for not disclosing the diagnosis was the fear to be harmful or cause depression. Second, a diagnosis of clinically probable AD has limited specificity to predict a neuropathological diagnosis of AD [8]. This uncertainty may have led clinicians to be vague about the exact diagnosis. In recent years, our knowledge of the natural history of AD has improved. Recent advances in the development of biomarkers and the introduction of new diagnostic criteria in 2011 and 2014 enable an earlier and more reliable diagnosis of AD at a mild cognitive impairment (MCI) stage and possibly at a presymptomatic stage in some cases (usually not in clinical practice but rather in a research setting) [9, 10]. Public awareness about AD has increased as well. According to a recent review, 90% of the general population wish to be

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informed if they would suffer from AD [11]. Of a consecutive series of 67 patients with amnestic MCI, 61% wished to participate in an additional amyloid PET study to receive more information about possible AD [12]. This evolution raises new ethical and practical challenges in daily practice for the clinicians who take care of MCI patients [13]. Many health care professionals still believe or fear that the disclosure of AD to the patients is or could be harmful.

The Belgian Dementia Council (BeDeCo) is a national scientific non-profit organization of experts in the field of dementia and cognitive disorders. BeDeCo includes neurologists, geriatricians, old age psychiatrists, general practitioners, and government representatives. The topic of the potential harm of AD diagnostic disclosure was discussed during a regular meeting of BeDeCo attended by 16 of its members on the 11th of March 2019. Considering the gradual introduction of biomarkers in the diagnostic workup of AD from its earliest symptomatic stages (prodromal AD or MCI due to AD according to the new diagnostic criteria [14]) during the last decade, it was decided to perform a new survey about opinions and practices among BeDeCo members regarding the disclosure of the diagnosis of AD and its consequences, not only to patients with dementia but also to patients with MCI. We hypothesize that if this survey provides evidence that disclosing the diagnosis of AD is more beneficial than harmful, it could be helpful to the patients, their caregivers and their treating physicians to prevent unnecessary worry about the disclosure process.

Methods

A non-systematic and unpublished review of the literature was performed by the first author, and this topic was discussed during a regular meeting of BeDeCo. The draft of the questionnaire was written by the first author to cover a broad range of issues concerning AD diagnosis disclosure encountered in daily practice and then reviewed and amended by the members of the executive board of BeDeCo (JCB, SE, BE and OD). The validity and the reliability of the survey were not evaluated formally. After approval of the final version (in English), the survey was created with the LimeSurvey software and stored on a protected local server of the UCLouvain. Apart for usual demographic data of the respondents, the 10-min survey included 23 forced-choice questions on a 5-point Likert-type scale organized into five sections: personal practice of disclosure, consequences of disclosure for the patient, personal opinion about harm or benefit of disclosure, consequence for the caregiver and personal preference if suffering from AD. A text version of the survey can be found in the Supplementary Material. An invitation letter and a link to complete the survey were sent by email to all the 44 members of BeDeCo on the 1st of June 2019. Two reminders were sent by email to all BeDeCo members, one in July 2019, one in August 2019. The survey ended on the 1st of September 2019. Answers were collected anonymously. Descriptive statistics were used for reporting the results. Statistical analysis through correlation analysis between demographic data and answers to questions is not relevant due to the small sample size. As no patient was involved in the study, the opinion of an ethics committee was not required.

Results

Participants

The survey was completed by 26 (59%) of the 44 BeDeCo members of whom 5 (19%) where female and 21 (81%) were male. Their main occupation was general practitioner: 1 (3.8%), geriatrician: 4 (15.4%), neurologist: 19 (73%) and psychiatrist: 2 (7.7%). They worked in Flanders: 11 (42.3%), Brussels: 8 (30.7%) or Wallonia: 7 (26.9%). The mean age of the participants was 49.6 (SD 12.4, range 25–72). They had a mean of 21.3 years (SD 10.9, range 1–40) of experience in the field of dementia. All participants had access to and experience with the use of CSF biomarkers in their practice.

Practice of disclosure

All the respondents declared that they often (15%) or always (85%) disclose the diagnosis of AD to their patients with AD dementia whereas 77% of them often or always disclose the diagnosis of AD to MCI patients as well. More than 60% of the clinicians recommend AD CSF biomarker analysis to their MCI patients. Nearly all the respondents disclose the diagnosis of AD to their MCI patients when CSF biomarkers are abnormal. In contrast, 38% of clinicians never or rarely disclose a diagnosis of AD to MCI patients when biomarkers are not available. Detailed results are presented in Table 1.

Consequence of disclosure for the patient

Two-thirds of the clinicians rarely or never observed harmful consequences related to the disclosure of the diagnosis for AD in case of dementia and 58% reported the same findings in case of MCI. About one-third of the respondents reported that the disclosure of AD is sometimes harmful, both in patients with MCI and dementia. Only 12% of respondents observed that the disclosure of AD to MCI patients is often harmful. More than 90% of clinicians reported that their patients with dementia or AD rarely or never blame their physician or regret having been told their diagnosis. The patients sometimes blame the clinician or regret that they have not been informed of their diagnosis of AD according

Table 1 Questions about practice of disclosure

Questions	(Nearly) never	Rarely	Sometimes	Often	(Nearly) always
Do you disclose the diagnosis of AD to your patients with dementia?	0	0	0	4 (15%)	22 (85%)
Do you disclose the diagnosis of AD to your patients with MCI?	1 (4%)	1 (4%)	4 (15%)	5 (19%)	15 (58%)
Do you advise your patients with MCI/dementia to undergo lumbar puncture for diagnosis of AD?	1 (4%)	2 (8%)	7 (27%)	11 (42%)	5 (19%)
Do you disclose the diagnosis of AD in MCI when biomarkers are available (and positive)?	0	0	0	3 (12%)	23 (88%)
Do you disclose the diagnosis of AD in MCI when biomarkers are not available?	5 (19%)	5 (19%)	4 (15%)	8 (31%)	4 (15%)
Do you disclose the diagnosis of other diseases than AD to your patients with dementia?	0	0	1 (4%)	4 (15%)	21 (81%)
Do you disclose the diagnosis of other diseases than AD to your patients with MCI?	0	1 (4%)	9 (35%)	6 (23%)	10 (38%)

to 19% of the clinicians in case of dementia and 15% of clinicians in case of MCI. Detailed results are presented in Table 2.

Personal opinion about harm or benefit of disclosure

All the respondents partially or completely disagreed with the assertion that disclosing the diagnosis of AD to patients with dementia is more harmful than beneficial. In addition, 88% had the same opinion about the disclosure of AD in MCI. All the respondents partially (23%) or completely (77%) agreed that if a patient suffers from AD, it is better for her/him to be informed. Detailed results are presented in Table 3.

Consequence for the caregiver

The disclosure of AD to the patient is rarely or never harmful to the caregiver according to 84% of the respondents in case of dementia and according to 69% of the respondents in case of MCI. Only one respondent reported that disclosing the diagnosis of AD to the patient is often harmful to the caregiver. About 90% of the respondents reported that the caregivers rarely or never blame them for having disclosed the diagnosis of AD to the patients with dementia or MCI. Detailed results are presented in Table 4.

Personal preference if suffering from AD

At last, 24 (92%) of the participants declared that if they had AD, they would want to be informed of the diagnosis, irrespective of the disease stage. Only two (8%) were uncertain and no one declared he or she would not want to be informed.

Table 2 Questions about the consequences of disclosure for the patient

Questions	(Nearly) never	Rarely	Sometimes	Often	(Nearly) always
In your daily practice, do you observe that disclosing the diagnosis of AD to your patient with dementia is harmful to her/him?	7 (27%)	10 (38%)	9 (35%)	0	0
In your daily practice, do you observe that disclosing the diagnosis of AD to your patient with MCI is harmful to her/him?	6 (23%)	9 (35%)	8 (31%)	3 (12%)	0
Do your patients with dementia blame you for being informed of the diagnosis of AD or regret that they have been informed?	16 (61%)	9 (35%)	1 (4%)	0	0
Do your patients with MCI blame you for being informed of the diagnosis of AD or regret that they have been informed?	15 (58%)	9 (35%)	2 (8%)	0	0
Do your patients with dementia blame you for not being informed of the diagnosis of AD or regret that they have not been informed?	14 (54%)	7 (27%)	5 (19%)	0	0
Do your patients with MCI blame you for not being informed of the diagnosis of AD or regret that they have not been informed?	17 (65%)	5 (19%)	4 (15%)	0	0

Table 3 Questions about personal opinion of the clinician about the disclosure

Questions	Completely agree	Partially agree	No opinion	Partially disagree	Completely disagree
Disclosing the diagnosis of AD to patients with dementia is more harmful than beneficial. What is your opinion?	0	0	0	7 (27%)	19 (73%)
Disclosing the diagnosis of AD to patients with MCI is more harmful than beneficial. What is your opinion?	0	1 (4%)	2 (8%)	11 (42%)	12 (46%)
If a patient has AD, it is better for her/him to be informed than not knowing. What is your opinion?	20 (77%)	6 (23%)	0	0	0

Table 4 Questions about caregiver point of view

Questions	(Nearly) never	Rarely	Sometimes	Often	(Nearly) always
In your daily practice, do you observe that disclosing the diagnosis of AD to your patient with dementia is harmful to her/his caregiver(s)?	10 (38%)	12 (46%)	3 (12%)	1 (4%)	0
In your daily practice, do you observe that disclosing the diagnosis of AD to your patient with MCI is harmful to her/his caregiver(s)?	9 (35%)	9 (35%)	7 (27%)	1 (4%)	0
Do the caregiver(s) of your patients with dementia blame you for having disclosed the diagnosis of AD to the patient?	8 (31%)	16 (61%)	2 (8%)	0	0
Do the caregiver(s) of your patients with MCI blame you for having disclosed the diagnosis of AD to the patient?	13 (50%)	10 (38%)	3 (12%)	0	0
Do the caregiver(s) of your patients with dementia blame you for not having disclosed the diagnosis of AD to the patient?	19 (73%)	4 (15%)	2 (8%)	1 (4%)	0
Do the caregiver(s) of your patients with MCI blame you for not having disclosed the diagnosis of AD to the patient?	20 (77%)	5 (19%)	1 (4%)	0	0

Discussion

All the members of a group of Belgian experts in the field of dementia declare that they often or always disclose the diagnosis of AD to patients with dementia. This finding differs from previous studies. Indeed, a systematic review published in 2019 showed that the proportion of general practitioners or specialists who routinely or always tell their patients with dementia their diagnosis was on average only 43% and ranged between 7 and 78% while 96% disclosed the diagnosis to the family of the patients [7]. In the same review, it appeared that the term AD was used by only 14–41% of the physicians when communicating with their patients. However, our present results are similar to those of a recent survey performed among 54 dementia specialists in Denmark which reported that 100% of them often or almost always disclose a diagnosis to their patients with dementia, 91% routinely use the term dementia and 94% often or almost always disclose the specific disease (AD, vascular dementia, Lewy body dementia, etc.) responsible for the cognitive impairment [15].

All the respondents of our survey also declare that they often or always disclose the diagnosis of AD to patients with MCI when AD cerebrospinal fluid (CSF) biomarkers are positive whereas less than half of the responders often or always disclose a diagnosis of AD to MCI patients when biomarkers are unavailable. In our study, the use of AD CSF biomarkers seems thus valuable to raise confidence in the clinical diagnosis. However, current medical practice in Europe is quite heterogeneous concerning the disclosure of AD at the MCI stage. In the previously cited Danish study, 69% of the respondents declared that they almost always or often inform the patient about the aetiology of MCI, but the paper gave no information about the use of AD CSF biomarkers in the diagnostic and disclosure processes [15]. In a recent survey of 102 members of the European Academy of Neurology (EAN) and the European Alzheimer's Disease Consortium (EADC) from 25 countries, only 45% of them reported they describe MCI to their patients as "possibly early AD" and 69% discuss the risk of AD with MCI patients [16]. In the same study, for those patients meeting the research criteria for prodromal AD or MCI due to AD [8, 9], 70% of the respondents always disclosed the diagnosis with various terms, the more common being "possible early AD" or "early AD". In a sample of 108 German health professionals with specialization in dementia and AD, 41% (51% in

university hospitals versus 36% in general hospitals) of the respondents usually disclosed a diagnosis of AD to patients with MCI and pathological CSF biomarkers and 88% of them informed the patients about the risk of future dementia. Whereas only 3% of the responders disclosed a diagnosis of AD to patients with MCI when biomarkers were unavailable [17]. The rate of disclosure of AD-MCI was thus quite lower than in our sample but again, these results highlight the growing influence and potential added value of AD CSF biomarkers in the diagnostic process of MCI. Of note, patients accepting to undergo a lumbar puncture (LP) are more likely those who want to know their diagnosis after discussion of the first results and the benefit/harm ratio of the result of biomarker analysis. In the group of MCI patients without biomarker analysis, patients might have refused the LP because they did not want to know their diagnosis. Our survey may thus suffer from a selection bias, as neurologists may disclose more often the diagnosis of AD to patients who are willing to know their diagnosis. Some co-authors from University centres with access to amyloid-PET (a technique allowing confirming an AD diagnosis at the MCI or dementia stage without LP) observe that some patients refuse both LP and amyloid-PET probably because they do not want to know while others who fear the LP consent to amyloid-PET.

There is a long-lasting debate in favour or against disclosure of the diagnosis of AD to the patient whatever the stage of the disease. The more common arguments in favour of the disclosure are the right to know (principle of autonomy) and the opportunity to plan for the future including advance care planning. The more common arguments against disclosure are the fear of psychological harm (depression, anxiety, catastrophic reaction, suicide, etc.) and stigmatization [7]. We did not ask the BeDeCo members about the reasons why they disclose or not the diagnosis. One reason for not disclosing could be the anosognosia of the patient. Although it was not addressed in this survey, we can speculate that anosognosia could influence the diagnostic process of AD. Recent research demonstrated an early decline in awareness of memory deficit leading to anosognosia in some MCI patients several years before they reach the dementia stage [18]. The majority of the respondents observed that the disclosure of AD is rarely or never harmful. Only one-third observed that it is sometimes harmful to the patient, which is concordant with previous research. Prospective studies about the consequence of the disclosure of the diagnosis showed that an increase of depressive or anxious symptoms was rare and that the disclosure was safe in the large majority of patients with mild or moderate dementia [19, 20]. A recent systematic review concluded that disclosing pathological amyloid PET results to cognitively normal individuals or patients with MCI had a low risk of psychological harm [21] even when the MCI patients were told that a positive scan means "very early stage of AD" and high risk of worsening [12].

According to the vast majority of BeDeCo members who completed the survey, their patients rarely or never blame them or regret that they have been informed of their AD diagnosis. It is not surprising as 84% of individuals with cognitive impairment consider full disclosure of dementia preferable [11]. In a large study with a sample of 1005 patients attending a memory clinic between 2004 and 2010 (of whom 480 had dementia), 85.3% wished to be informed of an AD diagnosis while only 7% did not and 7.5% were uncertain [22]. Nearly all the BeDeCo members disagree that disclosing the diagnosis of AD is more harmful than beneficial and all of them believe it is better for the patient to be informed, even at the MCI stage. That is probably why nearly all of them would want to be informed themselves if they suffered from AD. The opinion expressed in older surveys by general practitioners is, however, quite different. They frequently considered that revealing the diagnosis of dementia was not beneficial and not helpful [7]. But the opinion of BeDeCo members about the benefit of diagnosis is quite similar to that of the previously described group of European specialists as 84% of them agreed somewhat or strongly that a diagnosis of prodromal AD or MCI due to AD was helpful for patients and family (to plan for the future, to engage in risk reduction activities, to include patients in clinical trials or to plan follow-up) and only 18% strongly or somewhat agreed that "diagnosing causes unnecessary worry for the patients" [16]. We would also note that to the best of our knowledge, no study evaluated if not disclosing the diagnosis of AD to the patient could also be harmful.

Most of the BeDeCo members declared that the disclosure of the diagnosis to the patients is rarely or never harmful to the caregivers and it seems very rare that the caregivers blame the doctors for having told the diagnosis of AD to the patients. Similarly, in a retrospective survey of 107 AD dementia patients and their caregivers, 94% of caregivers declared that the patient had the right to know his diagnosis, 85% thought that the disclosure of the diagnosis of AD could be useful and only 4% would prefer not to disclose the diagnosis to the patient [23].

This study has several limitations. It reflects the opinion and practice of only 59% of a small group of Belgian experts in the field of dementia and is, therefore, not representative of the whole medical community. We can expect that the expertise of the participants in the present survey gives them confidence in their diagnosis and care. They probably have a higher motivation for early diagnosis. However, the opinion of experts has a low level of scientific evidence. Their actual practice has not been objectified by an independent investigator. Some questions proposed in the survey such as "Do you observe that disclosing the diagnosis of AD to your patient with dementia is harmful?" are rather

vague and could be interpreted in different ways by different respondents. The respondents were neither asked on which data they relied on to answer this kind of questions nor how they organized the follow-up of their patients after disclosure of the diagnosis. They were not asked why they decided to disclose or not to disclose the diagnosis to the patient and whether they disclosed it to the caregiver. Nevertheless, we believe that these results are valuable as they reflect recent trends in the changing landscape of AD diagnosis. The experience of BeDeCo members should reassure clinicians about the safety and the usefulness of AD diagnosis disclosure in most cases whether the patient is at the MCI or the dementia stage. There are not yet Belgian or European guidelines concerning the disclosure of a diagnosis of MCI in a clinical setting. In a research setting, the IDT CRP recommendations for amyloid PET disclosure consist of extensively informing the patients (I) so they can make an informed decision (D). After testing (T), the patients have to confirm if they still wish to receive the information (C). Finally, the result is returned (R) and post-guidance is planned (P) [24]. We also refer to the guidelines of the American Academy of Neurology that recommend clinicians to discuss diagnosis, prognosis, long-term planning and biomarker research with MCI patients even if they acknowledge that the disclosure of the diagnosis must be balanced with the potential harm such as anxiety [25, 26]. The disclosure of a diagnosis of AD is only the first step of an ongoing and patient tailored process. Not all the information has to be given at the same time and follow-up visits should be planned to allow discussion about prognosis, lifestyle change, advance care planning, treatment and participation in research.

In conclusion, our results add evidence to recommend the disclosure of the diagnosis of AD, including at the MCI stage, when positive biomarkers are available. These data can increase the confidence of clinicians to disclose the diagnosis of AD in its earliest symptomatic stages. Unjustified fears about AD disclosure should not deprive patients of the right to be timely and properly informed of the diagnosis.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethics approval Not applicable as no patient was involved in the study.

Consent to participate All respondents of the survey participated freely and anonymously.

Availability of data and material The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

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