



What Belgian Geriatricians tell their patients with Alzheimer's disease and why: a national survey

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Abstract

To check their opinions concerning the disclosure of the diagnosis of Alzheimer's disease, a questionnaire was sent to all Belgian geriatricians. Of 309 questionnaires, 28,5 percent were returned. 54% of the responders always announce the diagnosis to their patients, 35% prefer to reveal the diagnosis only to patients with mild dementia. Doctors who announce the diagnosis to all their patients were more likely to be men and younger. Geriatricians who believe there is a benefit for the patient were more likely to be younger and to speak Dutch. The main arguments against revealing the diagnosis were the diagnostic uncertainty, the patient's right not to know and fear of provoking a depressive reaction or suicide. Other arguments used against disclosure are discussed.

Key words: Alzheimer's disease; dementia; diagnosis; disclosure; ethics; geriatricians.

Introduction

In our days, diagnosis and treatment of Alzheimer's disease (AD) are more and more based on hard scientific evidence. All over the industrialized world, physicians use stringent diagnostic criteria with high sensitivity and specificity, in which the use of classic or radionuclide imaging and other biomarkers becomes more and more important. Their pharmacological therapies are based on multi-centered randomized and placebo-controlled trials. However, between these very Cartesian stages of diagnosis and treatment, there is another, equally important stage, the one in which a doctor has to explain the results of the diagnostic procedures to the patient and often to the patient's relatives.

Interestingly, this part of the management of AD is not Cartesian at all: unlike the diagnostic evaluation and the treatment, the way in which physicians communicate the diagnosis of AD and the degree of

disclosure of this diagnosis varies widely from culture to culture, and even from physician to physician (Rice *et al.*, 1997). In Europe for instance, there seems to be a north-south gradient: in northern countries doctors tend to be more open by communicating the diagnosis directly to the patient whereas in the more southern countries doctors are more prone to dissimulate the diagnosis to the patient by limiting the disclosure principally, if not exclusively, to the patient's relatives (Gély-Nargeot *et al.*, 2003). These differences are probably based on personal beliefs, fears and suppositions, as well from the side of the physician as from the patient's relatives or caregivers and the local public opinion. The fact that AD is a mental disorder seems to be play a more important role than the often heard argument that AD is incurable and therefore announcing the diagnosis to a patient is useless and cruel: in a survey of British general practitioners, 39 percent of them always or often told their patients about their diagnosis of dementia, whereas 95 percent did the same for their terminal cancer patients (Cassilas & Donaldson, 1999).

Belgium seems to be an excellent model for the study of this supposed north-south gradient, since the northern Dutch speaking part adheres more to the Anglo-Saxon culture than the French speaking Belgians in the south of the country. In a recent nationwide survey of all Belgian neurologists and neuropsychiatrists, younger and Dutch speaking doctors tended to tell the diagnosis of AD more often directly to the patients and not only to the family than older doctors or those who speak French (Tarek-Essabiri *et al.*, 2008).

Together with neurologists and (neuro)psychiatrists, geriatricians play a key role in the diagnosis and treatment of AD in Belgium, and reimbursement of acetylcholinesterase inhibitors and memantin by the social security is only possible after diagnostic

confirmation by one of those three specialists. Therefore, we performed a nationwide survey amongst all geriatricians working in Belgium to know their attitudes concerning the disclosure of the diagnosis of AD. More precisely, we wanted to know if their opinions differ from the answers obtained from Belgian neurologists and neuropsychiatrists and if we could find the same influence of the physician's age and language on the tendency to disclose the diagnosis to the patient.

We also wanted to have more information about the suicide risk amongst AD patients after having heard the diagnosis. In our survey of Belgian neurologists and neuropsychiatrists, almost 15 percent of the participants said to have known patients who committed suicide afterwards, which seemed astonishingly high compared to the very scarce literature about this subject: Rohde has reported two cases of suicide after the disclosure of AD (Rohde *et al.*, 1995).

Methods and materials

The mailing list of our questionnaire was kindly offered by Pfizer Belgium (Ixelles, Belgium) and contained the names of 309 physicians known to work or have worked in a geriatric setting. Hundred and eighty Dutch and 129 French versions of our questionnaire were sent to their working address on September 16, 2008. Responses were accepted until November 15, 2008. On November 2, 2008, the Belgian Society for Gerontology and Geriatrics (BVGG/SBGG) was so kind to send a reminder to its members and offered the possibility to return the questionnaire by email.

The – initially – strictly anonymous questionnaire consisted of both open and multiple choice questions about the doctor's personal characteristics, his or her practical attitude and theoretical opinions concerning the announcement of the diagnosis. The questionnaire was based on and adapted from the one we used for our survey of neurologists and neuropsychiatrists, which was based on its turn on our review of the relevant literature. It was originally written in French (please see appendix A) and then translated into Dutch.

Statistical analysis of the results was done using version 6.0 of SPSS™ (Chicago, USA).

Using chi-square analysis with Yates' correction where necessary, we checked whether there was an association between the personal characteristics of the doctors and their attitude towards announcing the diagnosis of AD to the patients and their families. We made a post hoc multinomial logistic regression model to examine the relative importance of signifi-

cantly associated personal characteristics on the prediction if a responder would be likely to disclose always the diagnosis of AD and whether a responder would see a benefit in disclosing this diagnosis.

Results

DISCLOSURE OF THE DIAGNOSIS

Of the 309 questionnaires, 88 were returned, giving an overall response rate of 28.5 percent. Sixteen questionnaires were not further taken into consideration: 6 geriatricians never treated patients with AD, one did but worked abroad, the other nine had worked in a geriatric ward but were no geriatricians. This left us with 72 valid respondents. Their personal characteristics can be found in Table 1. We used Chi-square tests to compare the gender and language distributions of the responders with those of the initial mailing list. The age distribution of the respondents was compared with official data on all Belgian physicians on December 31, 2002 (National Institute for Statistics, 2002). No significant differences were found.

A little more than half of the responders (54%) said to announce always the diagnosis of AD to their patients, whereas 35% of them prefer to reveal the diagnosis only to patients with mild dementia, and only 8% never reveal the diagnosis. Relatives, on the contrary, are always informed by 89% of the doctors, and only in the case of severe dementia by all the others. Geriatricians who said to announce the diagnosis of AD to all of their patients were more likely to be men ($p = 0.008$) and younger ($p = 0.048$). Post hoc multinomial logistic regression (reference category: full disclosure, factors: gender, language, geriatrician older than 50) appeared to be a valid model (Pearson-Goodness-Of-Fit Significance = 0.450, Likelihood Ratio Test = 0.024, confidence interval 95%) with an overall correct prediction of 67.2%. To diminish the number of zero frequencies to an acceptable level the responders were split in two age groups. Although not reaching the statistical significance at the .05 level, gender was the strongest predictor of this model ($p = 0.134$), followed by age ($p = 0.186$).

Almost three quart of the responders (74%) believe there is a benefit for the patient to know his diagnosis, whereas 14 percent disagree. Those who thought there was a benefit were more likely to be younger ($p = 0.045$) and to speak Dutch ($p = 0.045$). The multinomial logistic regression model (reference category: no benefit, factors: gender, language, geriatrician older than 50, more than 10 AD patients a week) classified 84% of the responders correctly

Table 1

Personal characteristics of the 72 geriatricians who see AD patients and answered the questionnaire

		Number	%
Gender	Men	28	38,9
	Women	41	56,9
	Unknown	3	4,2
Language	Dutch	39	54,2
	French	33	45,8
Age	< 30	2	2,8
	31-40	30	41,7
	41-50	18	25,0
	51-60	16	22,2
	> 60	6	8,3
	Unknown	0	0
Weekly number of patients	< 5	12	16,7
	6 à 10	33	45,8
	> 10	26	36,1
	Unknown	1	1,4

(Pearson-Goodness-Of-Fit = 0.191, Likelihood Ratio Test = 0.036, confidence interval = 95%). The relatively strongest predictors were language ($p = 0,079$) and age ($p = 0,082$).

We asked the geriatricians who thought there was a benefit to agree or disagree with a list of arguments in favor of announcing the diagnosis. This list, which was also used in our survey amongst Belgian neurologists and neuropsychiatrists, was based on a questionnaire used in a French survey of general practitioners (Cantegreil-Kallen *et al.*, 2005) and on the common reasons for and against disclosure of the diagnosis cited in a review article of Bamford and coworkers (2004). For our physicians, the most important arguments were the patient's right to know (94%), better therapeutic compliance (83%) and the reinforcement of the confidential relationship between doctor and patient (78%). Physicians who thought there is no benefit for the patient were presented a similar list with arguments against revealing the diagnosis. They mostly agreed with the statements that the diagnosis is uncertain (90%), that the patient has the right not to know his diagnosis (80%) and that announcing the diagnosis AD could provoke a depressive reaction (80%) or suicide (70%).

TERMS USED TO DISCUSS THE DIAGNOSIS

Participants who said to announce the diagnosis to the patient preferred the term "memory disease" (59%) over "Alzheimer's disease" (48%). Contrary to the effect of age, language or gender, geriatricians who see more than 10 AD patients a week seemed to use the term more often, but this tendency did not

reach significance ($p = 0,088$). In communication with the relatives, on the contrary, "Alzheimer's disease" was the preferred choice (87%). More answers can be found in Table 2. We asked the participants whether they used other terms, but few were suggested and there was no tendency in those answers.

ASKING PERMISSION TO DISCLOSE A DIAGNOSIS

More than 55% of the participants ask their patients if they want to know the diagnosis but only 39% ask them if it can be revealed to their family. On the other hand, 18% said to ask the family if it was alright to reveal the diagnosis to the patient. We couldn't find any significant correlations between the answers on authorization prior to disclosure and the geriatrician's personal characteristics.

GIVING INFORMATION ABOUT PROGNOSIS, NEUROPSYCHIATRIC DISTURBANCES AND CAREGIVER STRESS

Seventy-one percent of the participants informed the patients about the prognosis and natural evolution of AD, whereas 94% did the same for their family. The most cited reasons for not informing patients about their prognosis were the fact that they do not ask for this kind of information (94%), fear of provoking a depressive reaction (71%) and the opinion that this kind of knowledge is useless for the patient (29%). No geriatrician's personal characteristics were significantly associated with prognosis information.

Similar differences were found concerning the information about neuropsychiatric manifestations:

Table 2

Terms used to discuss the diagnosis of AD with patients and their family

Terms used...	... for the patient		... for the family	
	N (64)	%	N (69)	%
Alzheimer's disease	31	48,4%	60	87,0%
Memory disease	38	59,4%	20	29,0%
Dementia	15	23,4%	20	29,0%
Degenerative disease	10	15,6%	8	11,6%

64% informed the patient against 97% for the family. Most cited reasons for not telling were the patient not asking for information (59%), fear of depression (45%) and the absence of neuropsychiatric troubles at the time of diagnosis (32%). Younger geriatricians tended to inform their patients more often about behavioral problems ($p = 0,031$). The vast majority (97%) of the participants talks to family about caregiver stress.

EMOTIONAL REACTIONS AFTER HEARING THE DIAGNOSIS

Participants were asked how patients and their families tend to react after having heard the diagnosis. The list of possible reactions was adapted from the OPDAL study conducted in 11 European countries ((Gély-Nargeot *et al.*, 2003) but we extended this list with other possible reactions, either based on our own clinical experience (relief, fear of stigmatization and – concerning the families – feelings of guilt for not having noticed earlier that there was a medical problem underlying the memory complaints) or to try to answer the question whether suicidal remarks or actual suicide are common. The results can be found in tables 3 and 4. We did not examine the relationship between the doctor's

characteristics and the frequency of the different emotional reactions.

SUICIDE RISK

In addition to these general questions about emotional reactions, we asked all geriatricians how many patients they had known in their own practice who committed or attempted suicide after being given the diagnosis of AD. Only one of 71 geriatricians (1,4%) reported one patient who committed suicide, and no attempts were reported.

Discussion

The major flaw of this study is the rather low response rate compared to our previous survey amongst neurologists and neuropsychiatrists, which had a response rate of 44%. Despite the fact that we accepted the offer of the BSGG to send a reminder to their members and to give them the opportunity to send their answers by email – which implied a breach of the initial anonymity –, only 88 of the 309 questionnaires (28,5%) were returned. However, our mailing list contained far more doctors than there are active geriatricians in Belgium: according to the BSGG, there are 134 geriatricians in Belgium and 165 specialists in internal medicine who took a supplementary specialization in geriatrics. If we assume that only physicians replied who are actually working as a geriatrician, this would lead to an estimated response rate of 78:134 or 58%.

The 54 percent of disclosure of the diagnosis of AD to patients, regardless of the severity of their disease is amongst the highest rates that can be found in the literature: in British, French and Dutch surveys, the percentage of general practitioners announcing the diagnosis of AD to the patient ranges from 28 to 55% (Cantegreil-Kallen *et al.*, 2005; De

Table 3

The different emotional reactions of patients after the disclosure of the diagnosis of AD and their relative frequency

N	Never	Seldom	Sometimes	Often	
Relief	63	27,0%	30,2%	38,1%	4,8%
Indifference	65	4,6%	18,5%	50,8%	26,2%
Denial/minimization	65	0,0%	4,6%	40,0%	55,4%
Anxiety/nervousness	62	0,0%	22,6%	46,8%	30,6%
Aggressiveness	63	20,6%	44,4%	30,2%	4,8%
Fear of what others might think	62	4,8%	37,1%	35,5%	22,6%
Depressive reaction	64	0,0%	31,3%	50,0%	18,8%
Suicidal remarks	64	42,2%	53,1%	4,7%	0,0%
Suicide	64	90,6%	9,4%	0,0%	0,0%

Table 4

The different emotional reactions of the patient's family after the disclosure of the diagnosis of AD and their relative frequency

	N	Never	Seldom	Sometimes	Often
Relief	62	14,5%	30,6%	35,5%	19,4%
Resignation	62	0,0%	16,1%	53,2%	30,6%
Anxiety	62	0,0%	9,7%	40,3%	50,0%
Aggressiveness	62	30,6%	40,3%	27,4%	1,6%
Denial	63	7,9%	28,6%	44,4%	19,0%
Revolt	62	16,1%	32,3%	38,7%	12,9%
Guilt	59	13,6%	37,3%	33,9%	15,3%

Lepeleire *et al.*, 2004; Downs, 2002; Vassilas & Donaldson, 1998) In a study of British geriatricians, 41% told over 80% of patients with mild dementia their diagnosis, but 77% told less than 20% of patients with severe dementia (Rice *et al.*, 1997). A Brazilian survey of geriatricians, neurologists and psychiatrists revealed that 45% of them regularly inform the patient, without significant differences between the three specialties (Raicher *et al.*, 2008). However, compared to the results of our survey of Belgian neurologists and neuropsychiatrists, of whom 68% announce the diagnosis to all of their patients, this is almost significantly lower ($p = 0,054$). At first sight, this difference seems consistent with our earlier formulated hypothesis that neurologists and neuropsychiatrists feel more "at ease" with organic degenerative diseases than other health care professionals. On the other hand, Belgian geriatricians use as easily the term "Alzheimer's disease" rather than more euphemistic descriptions, have the same opinions as the neurologists and neuropsychiatrists about the benefit of disclosure, and talk as openly about the prognosis of AD, neuropsychiatric disturbances and caregiver stress. Therefore, another hypothesis may be at the base of the observed difference: many Belgian neurologists see almost exclusively younger, outward patients in earlier stages of AD where geriatricians are more likely to encounter older, hospitalized patients in later stages.

The age of the physician seems to be one of the most important and consistent factors in predicting the disclosure attitude and opinions: younger geriatricians tend to announce the diagnosis more often to all of their patients and are more likely to see a benefit in disclosure. This is consistent with our findings for neurologists and neuropsychiatrists. The difference between younger and older physicians is likely to be a reflection of the international trend of more transparency towards patients, and more specifically those suffering from AD, as supported

by the guidelines in the current literature (Pinner & Bouman, 2002; Samuels, 2004; Downs, 1999; Mahieux, 2004; Hogan *et al.*, 2008). Since the cultural shift to a more open communication directly with the patient is a very recent evolution, and even the debate about it, it seems plausible that older doctors are less prone to change their habits and continue to work with communication models rather based on their own experience and personal convictions than on these novel guidelines.

The difference between the Dutch and the French speaking communities was less outspoken than in our previous study: although Flemish geriatricians are more likely to see a theoretical benefit in disclosure, the practical attitude of the two groups is similar.

We have no ready explanation for the observation that male geriatricians more often announce the diagnosis to all of their patients than their female colleagues. In our previous study, gender was not a significant determinant of disclosure, and we have no knowledge of other studies examining gender differences in the disclosure of dementia.

The uncertainty of the diagnosis is the most cited reason (90%) for not disclosing the diagnosis to the patient. This inaccuracy can be contested: in a study of Salmon and coworkers, the initial diagnosis of AD in 110 patients with Mini-Mental State Examination scores of more than 23 was confirmed by autopsy or disease progression in 89% of the cases. Of the twelve patients with a misdiagnosis, six had another form of dementia, five suffered from other medical conditions (depression, hypothyroidism,...) and for only one patient no medical explanation for the cognitive symptoms could be found (Salmon *et al.*, 2002). Apart from the conclusion that the risk to mistake a normal individual with memory complaints for someone suffering from AD or another dementia is quite low, one might argue that the potential inaccuracy of the diagnosis is clearly not used as an

argument against disclosure to the relatives, and assumedly neither against the initiation of appropriate treatment.

The patients' right not to know their diagnosis, cited by 80% of non-disclosers, is a valid argument against disclosure. Since 2002, Belgian law however states that the non-disclosure of a medical condition is only possible on explicit demand of the patient, and after consulting another medical professional and possibly a person of trust designated by the patient. Closer inspection learns that only 50% of the 24 geriatricians who do not systematically disclose the diagnosis to their patients ask the patient's permission prior to this decision. A part from the legal aspects, they ignore that the best way to know the patient's opinion is by asking them. In our memory clinic, we try to systematically ask all the patients before the diagnostic work-up whether they would like to know their diagnosis if we would find out they had AD. We do this preferentially in the presence of the family. In our experience, this not only helps to understand the patient's fears and expectations, but it also helps to diminish the fear of the family that diagnostic disclosure will induce catastrophic reactions, and it opens the possibility of a more open conversation on other topics as neuropsychiatric disturbances, the ability to drive or other restrictions of autonomy, and end-of-life decisions. We always note this decision in the patients' record and mention it in the letter to his or her general practitioner, not only for medicolegal reasons, but to give other caregivers an idea of what the patient already knows or not, so they can work in the same atmosphere of openness. Until now, approximately 99% of the patients have stated they wanted to know their diagnosis.

We also ask the patients if they want their family to know what's going on. Although it is understandable that a doctor would like to inform the family of AD patients, especially given their frequent lack of insight and the possibility that they might even forget the medical information that was given to them, communicating one's diagnosis to another person without the patient's explicit consent must be considered as a violation of the medical secret and can have serious legal complications for the physician, e.g. in the case of a divorce.

Finally, the fear of provoking a "reactional" depression, or even worse, suicide are the other most cited reasons (respectively 80 and 70%) for not disclosing the diagnosis to the patient. However, only 18,8 percent of the responders claim to observe often depressive reactions of their patients after the disclosure of AD and this fear is not supported by scientific data. Often, depressive thoughts are already present before the disclosure and are hence

rather a reaction to the symptoms of AD (Pinner & Bouman, 2002; Selmes & Derouesne, 2004) or might be due to serotonergic and noradrenergic alterations in the diseased brain (Zubenko *et al.*, 2003). In one study, only 6 percent of patients with mild dementia developed major depression in the year following the disclosure of the diagnosis and no catastrophic were noted (Pinner & Bouman, 2003). This is fairly low given the overall incidence of depression in AD.

In our survey of neurologists and neuropsychiatrists, 15 percent of the participants said to have observed suicide after the disclosure of the diagnosis. This seemed astonishingly high compared to the very scarce literature about this subject (Rohde *et al.*, 1995). In the current study 9,4% of the respondents claimed the same, but this time we added a more specific question: "To your knowledge, has one of your own patients committed suicide after the disclosure of the diagnosis?". To this question, only one geriatrician reported one case, and no cases of suicide attempts were reported to a similar question. This clearly proves that the suicide risk has been overrated in our previous study, as we suspected.

One argument to justify the reluctance to speak freely with the patient about eventual neuropsychiatric disturbances is the absence of neuropsychiatric troubles at the time of diagnosis. It is hard to claim that a symptom is absent if the patient has not been asked about its eventual presence. In a study of patients with the Charles Bonnet syndrome (complex visual hallucinations with full insight in cognitive intact visually impaired), 48 patients with severe visual impairment were asked if they had unusual visual experiences. Only 2 patients admitted they had had hallucinations. When the others were asked more specifically about "seeing things that are not real", 28 of the remaining patients reported episodes of hallucinations (Menon, 2005).

In conclusion, this study suggests that, much like Belgian neurologists and neuropsychiatrists, Belgian geriatricians, and especially the younger ones, feel more and more at ease with the disclosure of the diagnosis of AD. Yet, a lot of work needs to be done. We must realize that the active participation of the patient in the management of AD does not start with the disclosure of the diagnosis, but during and even before the diagnostic workup. Only by setting our own prejudices aside, we can hope that in a near future dementia will not be considered anymore as one of the last medical taboos, as proven by the reluctance to use the word "Alzheimer's disease" in the presence of our patients.

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APPENDIX A – THE FRENCH VERSION OF OUR QUESTIONNAIRE

PROFIL DU MEDECIN

Vous êtes: Neurologue
 Neuropsychiatre

Age: < 30
 31-40
 41-50
 51-60
 > 60

Sexe: Masculin
 Féminin

Vous avez terminé vos études à quelle université?

- KU
 RUG
 VUB
 ULB
 ULG
 UIA
 UCL
Autre:

Combien de patients atteints de la maladie d'Alzheimer voyez-vous par semaine?

- Je ne vois jamais ces patients
 < 5
 6 à 10
 > 10

Si vous avez répondu «Je ne vois jamais ces patients» à cette dernière question, vous ne devez pas remplir le reste du questionnaire, mais veuillez quand-même le renvoyer.

ANNONCE DU DIAGNOSTIC DE MALADIE D'ALZHEIMER

A qui annoncez-vous le diagnostic?:

- Exclusivement au patient
 Si démence légère
 Dans presque tous les cas
- Exclusivement à la famille
 Si démence sévère
 Dans presque tous les cas
- Au patient et à la famille
 Si démence légère
 Dans presque tous les cas

Trouvez-vous qu'annoncer le diagnostic de MA au patient est bénéfique?:

Oui Non

⇒ Quels sont pour vous les arguments en faveur de l'annonce du diagnostic au patient?

	OUI	NON
Le patient a le droit de savoir		
Cela renforce l'état de confiance médecin-malade		
Cela améliore la compliance		
Un diagnostic précis participe à diminuer l'anxiété		
Le diagnostic est dans la notice des médicaments		
Autre (précisez)		

⇒ Quels sont pour vous les arguments en défaveur de l'annonce du diagnostic au patient?

	OUI	NON
Le diagnostic est incertain (surtout au stade précoce)		
Il n'y a pas de traitement curatif		
Il existe un risque de réaction dépressive		
Il existe un risque de suicide		
Le patient oublie le diagnostic		
Le patient ne comprend pas la signification du diagnostic		
Il existe le «droit de non savoir»		
Autre (précisez):		

Posez-vous la question au patient s'il désire connaître ou non son diagnostic?:

Oui Non

Demandez-vous l'autorisation du patient pour révéler le diagnostic à la famille?

Oui Non

Demandez-vous l'autorisation de la famille pour révéler le diagnostic au patient?

Oui Non

Si vous choisissez d'informer le patient, quel terme préférez-vous?:

- Maladie d'Alzheimer
 Perte/ Maladie de la mémoire
 Démence
 Maladie dégénérative
 Autre

Précisez:

Si vous choisissez d'informer la famille, quel terme préférez-vous?:

- Maladie d'Alzheimer
 Perte/ Maladie de la mémoire
 Démence
 Maladie dégénérative
 Autre

Précisez:

Parlez-vous de l'évolution et du pronostic de la maladie d'Alzheimer au patient? Oui Non

⇒ Si vous avez répondu «Non», c'est parce que:

- Vous trouvez cela inutile Oui Non
 - Par crainte de réaction dépressive du patient Oui Non
 - Le patient n'a pas abordé le sujet Oui Non
 - Par manque de temps Oui Non
 - Ce sujet vous met mal à l'aise Oui Non
 - Autre (précisez)

Parlez-vous de l'évolution de la maladie d'Alzheimer et du pronostic à la famille? Oui Non

⇒ Si vous avez répondu «Non», c'est parce que:

- Vous trouvez cela inutile Oui Non
 - Par crainte de réaction dépressive de la famille Oui Non
 - La famille n'a pas abordé le sujet Oui Non
 - Par manque de temps Oui Non
 - Ce sujet vous met mal à l'aise Oui Non
 - Autre (précisez)

Parlez-vous des troubles psycho-comportementaux et thymiques liés à la maladie d'Alzheimer (agressivité, apathie, irritabilité, agitation, délires, angoisse, dépression...) au patient? Oui Non

Si vous avez répondu «non», c'est parce que...

- Vous trouvez cela inutile Oui Non

- | | | | | |
|---|--------------------------|-----|--------------------------|-----|
| - Par crainte de réaction dépressive du patient | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Le patient n'a pas abordé le sujet | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Par manque de temps | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Ce sujet vous met mal à l'aise | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Le trouble est absent | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Sujet déjà abordé par un autre médecin | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Le patient ne comprend pas | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Autre (précisez) | | | | |

Parlez-vous des troubles psycho-comportementaux et thymiques liés à la maladie d'Alzheimer (agressivité, apathie, irritabilité, agitation, délires, angoisse, dépression...) à la famille? Oui Non

Si vous avez répondu «non», c'est parce que...

- | | | | | |
|---|--------------------------|-----|--------------------------|-----|
| - Vous trouvez cela inutile | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Par crainte de réaction négative de la part de la famille | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - La famille n'a pas abordé le sujet | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Par manque de temps | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Ce sujet vous met mal à l'aise | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Le trouble est absent | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Sujet déjà abordé par un autre médecin | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Famille absente pendant les consultations | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Autre (précisez) | | | | |

Parlez-vous du stress de l'aidant à la famille? Oui Non

Si vous avez répondu «non», c'est parce que...

- | | | | | |
|---|--------------------------|-----|--------------------------|-----|
| - Vous trouvez cela inutile | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Par crainte de réaction négative de la part de la famille | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - La famille n'a pas abordé le sujet | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Par manque de temps | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Ce sujet vous met mal à l'aise | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Le problème est absent | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Sujet déjà abordé par un autre médecin | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Famille absente pendant les consultations | <input type="checkbox"/> | Oui | <input type="checkbox"/> | Non |
| - Autre (précisez) | | | | |

Quelles sont les réactions émotionnelles de vos patients à l'annonce du diagnostic de maladie d'Alzheimer?

- | | | | | | | | | |
|--|--------------------------|---------|--------------------------|---------|--------------------------|----------|--------------------------|--------|
| Soulagement | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Indifférence | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Dénégation / minimisation des troubles | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Anxiété/ nervosité | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Agressivité | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Peur du regard des autres | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Réaction dépressive | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Propos suicidaires | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Suicide | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Autre (précisez) | | | | | | | | |

Quelles sont les réactions émotionnelles des familles de vos patients à l'annonce du diagnostic de maladie d'Alzheimer?

- | | | | | | | | | |
|--|--------------------------|---------|--------------------------|---------|--------------------------|----------|--------------------------|--------|
| Soulagement | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Résignation | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Anxiété | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Agressivité | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Déni | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Révolte | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Culpabilité (ne pas avoir compris que le patient est malade) | <input type="checkbox"/> | Souvent | <input type="checkbox"/> | Parfois | <input type="checkbox"/> | Rarement | <input type="checkbox"/> | Jamais |
| Autre (précisez) | | | | | | | | |

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COORDINATION AVEC LE MEDECIN TRAITANT:

Trouvez-vous que l'annonce du diagnostic de maladie d'Alzheimer doit être faite par le médecin traitant?

- oui, car il/elle connaît le mieux le patient et son entourage
 non, car le diagnostic doit être révélé par le spécialiste qui a porté le diagnostic et qui connaît le mieux la maladie

D'habitude, vous communiquez au médecin traitant...:

- | | | |
|--|------------------------------|------------------------------|
| Le diagnostic et les bases sur lesquelles il a été établi? | <input type="checkbox"/> Oui | <input type="checkbox"/> Non |
| L'accord du patient pour communiquer le diagnostic à la famille? | <input type="checkbox"/> Oui | <input type="checkbox"/> Non |
| Les informations que vous avez données au patient et à sa famille? | <input type="checkbox"/> Oui | <input type="checkbox"/> Non |
| Leurs réactions? | <input type="checkbox"/> Oui | <input type="checkbox"/> Non |
| Autre (précisez) | | |

.....

OPINIONS ET PROPOSITIONS:

Trouvez vous que la dimension psychologique et relationnelle de l'annonce du diagnostic de maladie d'Alzheimer est négligée?

Oui Non

Précisez votre réponse.....

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