

Disclosure of Alzheimer's disease

Senior citizens' opinions

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ABSTRACT

OBJECTIVE To determine the proportion of elderly people without dementia who would want disclosure of a diagnosis of Alzheimer's disease (AD), for themselves or for their spouses, and to verify whether the availability of medication would influence their decision.

DESIGN A cross-sectional survey with a semistructured questionnaire completed during face-to-face interviews.

SETTING Medical and surgical outpatient clinics in St Mary's Hospital Center.

PARTICIPANTS 204 subjects 65 years or older with at most mild cognitive impairment.

MAIN OUTCOME MEASURES Percentage of positive responses for disclosure of a diagnosis of AD to self or to spouse, with or without medication.

RESULTS Nearly all (98%) subjects wanted disclosure for themselves. Most (78%) wanted disclosure for their potentially afflicted spouses when medication was said to be unavailable. This proportion increased to 97%, however, if medication was available.

CONCLUSION Most participants requested honesty for themselves. Most wanted disclosure to a potentially affected spouse when medication is said to be available.

RÉSUMÉ

OBJECTIF Déterminer la proportion des personnes âgées sans démence qui, si elles étaient atteintes de la maladie d'Alzheimer (MA), voudraient qu'on leur dise, à elles ou à leurs conjoints, et vérifier si la disponibilité d'une médication influencerait leur décision.

TYPE D'ÉTUDE Enquête transversale à l'aide d'un questionnaire semi-structuré complété lors d'une rencontre avec le sujet.

CONTEXTE Cliniques externes de médecine et de chirurgie du Centre hospitalier de St. Mary.

PARTICIPANTS 204 sujets de 65 ans ou plus, sans troubles cognitifs importants.

PRINCIPAUX PARAMÈTRES ÉTUDIÉS Pourcentage des sujets souhaitant qu'on révèle un diagnostic de MA à eux ou à leurs conjoints, en présence ou en absence de médication.

RÉSULTATS Presque tous les sujets (98%) veulent être informés de leur diagnostic. En l'absence de médication, la plupart 78% souhaitent qu'on en informe le conjoint, au risque de l'affecter. Cette proportion augmente à 97% en présence d'un traitement.

CONCLUSION La plupart des sujets souhaitent être informés franchement. S'il existe une médication, la majorité veulent également qu'on le dise au conjoint, même si cela doit l'affecter.

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Cet article a fait l'objet d'une évaluation externe.

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Disclosure of a diagnosis of Alzheimer's disease (AD) and patients' wishes to be informed might draw a parallel to the history of disclosure of a diagnosis of cancer: early detection of the disease, priority given to patients' rights and autonomy, increase in public awareness, increase in treatment options, and possibility of participation in research trials might all contribute to favour truth-telling and a wish for disclosure.^{1,2}

In past years, physicians have been surveyed about their practice of informing patients and caregivers of a diagnosis of dementia.³⁻⁷ Overall, less than 50% of physicians reported they would tell the truth to their patients. Yet caregivers are almost always informed. According to some authors, the greatest barrier to disclosure by physicians is family members' reluctance to let patients know the diagnosis.^{8,9} Therefore, communicating with caregivers about disclosure of information to patients could be influenced by studies indicating that patients want to know the diagnosis.

To our knowledge, three studies of preferences addressed this issue.¹⁰⁻¹² The overall conclusions were that most people would like to be informed of a diagnosis of AD for themselves (80% to 90%),¹⁰⁻¹² but only 66% would want their spouses to know if the spouses were afflicted.¹¹ No sociodemographic variables were found to predict who would like to be informed.^{10,11}

These informative studies about patients' preferences for disclosure also exemplified limitations of

study designs. Erde et al¹⁰ interviewed adult patients (80% younger than 65) asking them to project their interest in knowing a diagnosis of AD at different ages (40, 50, up to 90) rather than their actual wish to know. Holroyd and associates¹¹ screened elderly people who lived in the same private retirement community. Marzanski¹² surveyed a small sample of patients with dementia who were asked what they recalled about what was disclosed to them without verifying their answers with collateral information. In addition, two of those studies^{10,11} were conducted before the advent of antidementia drugs, and this issue was not addressed in the third study¹²; therefore, the effect of the availability of treatment was not explored.

Aware of those limitations, we designed a survey with a large sample of elderly patients from a multiethnic Canadian population and interviewed them face-to-face using a semistructured questionnaire. Keeping in mind the findings of the other studies,¹⁰⁻¹² our main goals were to determine in our sample of elderly people without dementia the proportion who would want disclosure of a diagnosis of AD, for themselves or their spouses, and to establish whether the availability of medication would influence the decision. In addition, we explored whether sociodemographic variables could help distinguish which patients would like to be informed of a diagnosis of AD.

METHOD

We conducted a cross-sectional survey of elderly subjects attending medical and surgical outpatient clinics at St Mary's Hospital Center, a community hospital in Montreal, Que, from April 4, 2002, to May 1, 2002. The study protocol had received approval from the St Mary's Hospital Research Ethics Committee. Either the principal investigator or the research assistant approached all subjects 65 years and older. Subjects were excluded if they were unable to understand English or French and no interpreter was available or if they were unable to take part or complete the interview due to medical reasons (aphasia, deafness). Subjects who

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consented to participate were then screened with the Short Portable Mental Status Questionnaire (SPMSQ).¹³⁻¹⁵ We hoped to include in the study only subjects with at most mild cognitive impairment on the basis of the two-group analysis (intact or mildly intellectually impaired who made 0 to 4 errors and moderately or severely impaired who made 5 to 10 errors). This two-group analysis was found to be valid for discriminating between these two broad groups.¹⁴

Informed consent was obtained from each subject included in the study. Participants were then read a vignette describing progressive AD with gradual losses of cognitive function, diminishing capacities to perform activities of daily living and instrumental activities of daily living, and finally, decreasing competence to make decisions. This was followed by questions exploring wishes for disclosure of a diagnosis of AD to themselves or to their spouses, if medication were available or were not. Also, those who had spouses or children were questioned about their desire to have them informed. The medication was described as able to slow progression of disease, able to postpone institutionalization, and without severe side effects. The reasons for subjects' decisions were explored with open-ended questions. The interview was completed with questions to gather sociodemographic variables.

We conducted a pilot study with the first seven subjects to ensure inter-rater reliability. Inter-rater agreement was calculated for the SPMSQ and for the questionnaire.

A sample of 168 subjects was needed to obtain a 95% confidence interval (CI) of half-width 10% for the difference in proportion of positive responses for truth-telling by physicians for patients themselves with and without medication. We were unable to find studies in which subjects' wishes for disclosure were explored; if medication was available, a conservative value of 50% was assumed. We estimated a difference in percentage (and 95% CI) of positive responses between a wish for truth-telling about a potential diagnosis of AD:

- for patients themselves with availability of medication not mentioned versus medication stated to be available,

- for patients themselves or for potentially afflicted spouses when medication is available, and
- for a potentially afflicted spouse with medication available or medication stated to be unavailable.

When comparing responses to questions on their own diagnoses to responses about their spouses' diagnoses, subjects without spouses were removed from our analysis. The 95% CIs were adjusted to reflect the dependence of responses from the same subject. A difference of 10% or more in positive responses between questions was arbitrarily considered clinically significant. We used descriptive statistics to study the distribution of demographic characteristics of subjects. Open-ended questions were read, grouped by themes, and then compiled. To explore potential links between attitudes toward disclosure and other variables taken individually (results of SPMSQ and sociodemographic variables), we performed χ^2 tests. All data were compiled on Microsoft Access 2000; statistical analysis was performed with the SAS system.

RESULTS

In outpatient medical and surgical clinics at St Mary's Hospital Center, 268 patients aged 65 years or older were approached. Of the 236 who were eligible, 19 refused to participate and 13 interviews were interrupted and incomplete, leaving 204 participants for our study. Participation rate was 86.4%. **Table 1** shows the sociodemographic variables of our study population.

Figure 1 compares subjects' attitudes toward disclosure of a diagnosis of AD for themselves or for their spouses, with medication available or unavailable. Almost all subjects (98.0%) answered that they would prefer a diagnosis of AD to be disclosed to themselves. When the availability of medication was mentioned, this percentage increased to 99.0% (**Figure 1A**). Reasons given by participants who answered positively are listed in **Table 2**. Of participants with spouses, 96.2% wanted their spouses to be aware of the AD diagnosis. Of those who had children, 95.2% wanted them to be informed.

Table 1. Sociodemographic characteristics of study participants (n=204)

CHARACTERISTIC	N	%
Age (y)		
• 65-79	187	91.7
• 80 and older	17	8.3
Sex		
• Male	94	46.1
• Female	110	53.9
First language		
• English	69	33.8
• French	49	24.0
• Other	86	42.2
Country of birth		
• Canada	99	48.5
• Poland	14	6.9
• Italy	11	5.4
• Other	80	39.2
School attendance (y)		
• 0-6	30	14.7
• 7-12	92	45.1
• 13 or more	82	40.2
Marital status		
• Married	106	52.0
• Widowed	55	27.0
• Other (separated, divorced, single, member of a religious order)	43	21.0
Living arrangements		
• Home alone	69	33.8
• Home with spouse only	93	45.6
• Home with others (including spouse and children, children, caregiver, siblings)	29	14.2
• Senior residence, nursing home, foster home, or religious community	13	6.4
Level of independence		
• Independent (able to wash and dress themselves, walk alone without aid)	146	71.6
• Cane or walker (able to wash and dress themselves, walk alone with cane or walker)	39	19.1
• Dependent (unable to wash or dress themselves)	19	9.3
Religion		
• Catholic	113	55.4
• Protestant	38	18.6
• Other	53	26.0
Practising religion*		
• Yes	161	79.3
• No	42	20.7

*One value missing.

Table 2. Reasons subjects gave to justify wish for disclosure for themselves (n=197)

REASON FOR PREFERRING DISCLOSURE	N	%
Always want to know diagnosis	51	25.9
To prepare, to plan	52	26.4
To understand what happens, to try to help themselves	60	30.5
To look for treatment	25	12.7
Doctor's duty to tell	5	2.5
Other	4	2.0

Participants with spouses (n=106) were then asked whether they would like their spouses to be informed of a diagnosis of AD if the spouses were afflicted and there was no medication available (Figure 1B and 1C); 78.3% answered positively. The main reasons given for not wanting spouses to be aware of their diagnoses are listed in Table 3.

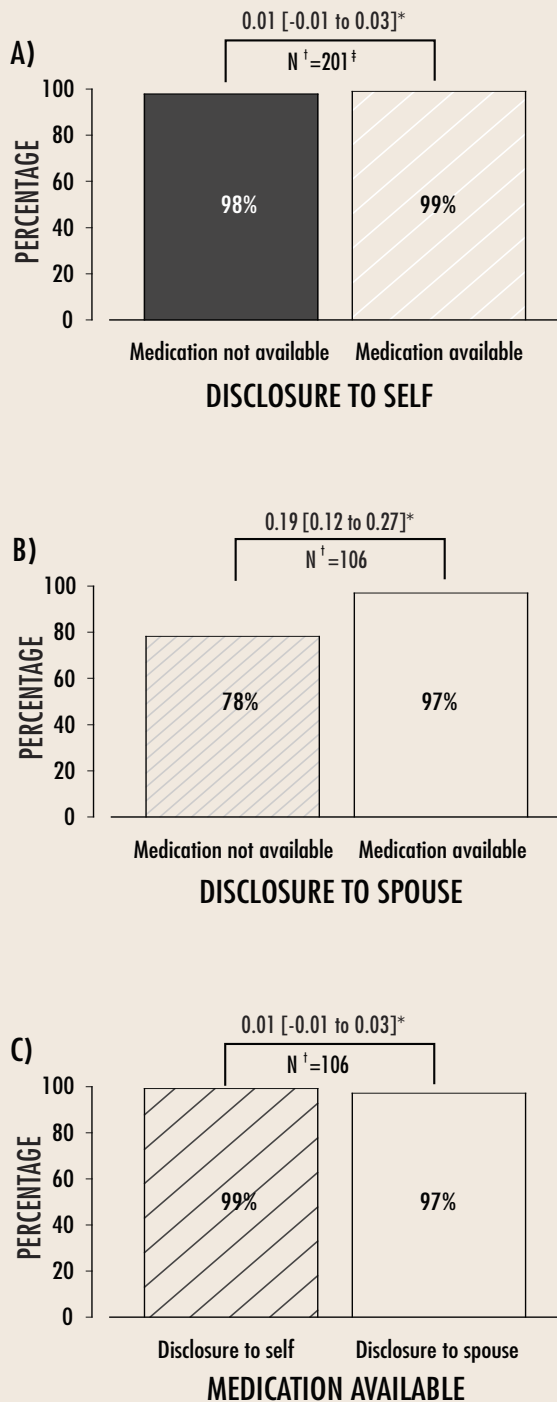
Table 3. Reasons subjects gave to justify not disclosing diagnosis to a potentially affected spouse (n=23)

REASON FOR NOT DISCLOSING DIAGNOSIS	N	%
To protect spouse from anxiety or depression	15	65.2
Spouse would not accept diagnosis	3	13.0
It would not help to tell	2	8.7
Spouse would not remember	1	4.4
Other	2	8.7

Younger subjects (65 to 69 years) were more likely to agree that their hypothetically afflicted spouses should be informed of a diagnosis of AD if no medication were available than were older subjects (difference of 13.2%, 95% CI 5.7% to 35.0%). Yet those who knew someone diagnosed with AD or dementia were less inclined (difference of 19.2%, 95% CI 4.0% to 34.2%) to accept disclosure in this situation than were those who did not know an afflicted person.

When participants were told that medication could be available, 97.2% of the sample wanted their spouses to be informed of the diagnosis (Figure 1B and 1C). The two main reasons given by those who changed their minds were that their spouses should be aware because they would have to take the medication or because they would have some hope that the medication could help.

Figure 1. Percentage of positive responses for disclosure of a diagnosis of Alzheimer's disease: to self or to spouse, with or without availability of medication



* MEAN DIFFERENCE (95% CONFIDENCE INTERVAL)

[†] NUMBER OF SUBJECTS IN THE TWO GROUPS BEING COMPARED

[‡] THREE MISSING DATA

DISCUSSION

The vast majority of subjects wanted a potential diagnosis of AD to be disclosed to them and to their spouses or children if they were to be afflicted, as already reported in the literature.^{10,11} Only 78.3% wanted a potentially afflicted spouse to be informed if medication was unavailable, a higher percentage than the 65.7% found by Holroyd and colleagues.¹¹

Most younger respondents wanted an afflicted spouse to be informed even if medication were unavailable, which parallels the actual trend toward truth-telling. Knowing others with AD or dementia had a tendency to reduce desire to inform an afflicted spouse if medication was unavailable, whereas Erde and associates¹⁰ found that acquaintances of patients diagnosed with AD wanted to be informed of their own diagnoses.

When medication is said to be available, similar proportions of participants wanted to be informed of their own diagnosis and wanted their spouses to be informed of their diagnoses. It seems that the availability of medication for AD treatment increases the desire for disclosure, as it increased the desire for disclosure about cancer.¹

When families object to disclosure, they often fear their relatives' adverse reactions. On this phenomenon the literature is scant. Rohde and co-workers¹⁶ report two suicides; Bahro and associates¹⁷ list defense mechanisms (denial, avoidance, somatization) preventing patients' acknowledgment of the disease; Husband¹⁸ suggests cognitive intervention to help patients adjust to a diagnosis of AD and to decrease the negative effects on self-esteem and quality of life. In two recent studies^{19,20} about reactions to disclosure of AD, disclosure was found to be favourable unless results were ambiguous¹⁹ and provided relief for severely demented patients who preferred to be told the truth.²⁰

Families reluctant to have physicians inform relatives of a diagnosis of AD should be educated about these study results and should be informed that nearly all elderly people would prefer that their diagnosis of AD be disclosed to them.

The Canadian Consensus Conference on Dementia,²¹ the Alzheimer's Disease Association,²² and the Fairhill guidelines²³ recommend that physicians disclose a diagnosis of AD to their patients. Authors^{1,2,21,22,24} emphasize when and how to communicate the diagnosis. It is important to verify with all patients what they want to know and how they coped with bad news in the past. Disclosure should be gradual, should occur early in the course of the disease, should respect the context of the patient-physician relationship, and (if beneficial) should be made with a significant other present. Diagnostic uncertainty, planning, and education about available comprehensive treatment should all be discussed.

This study has some limitations. First, it was conducted in a population of ambulatory elderly subjects, who were at most mildly intellectually impaired, living at home, and independent. Therefore, the results might not be generalizable to a sicker population of elderly people but could well address the clientele of primary care physicians. Second, the survey was conducted with potential patients. Therefore, how the desire to know could evolve over time remains poorly documented. Future research on disclosure of AD should focus on patients already diagnosed with AD to explore preferences and the consequences of truth-telling while honouring the golden rules of ethics.

CONCLUSION

Most elderly subjects would want to know a diagnosis of AD for themselves, and the same proportion would want a potentially affected spouse to know if medication were available. Availability of treatment options influenced at least desire for disclosure to a potentially affected spouse. ❁

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EDITOR'S KEY POINTS

- Previous studies report family physicians as reluctant to disclose a diagnosis of Alzheimer's disease (AD) to patients, but as more inclined to tell relatives.
- In this study of community-living, cognitively intact seniors in Montreal, Que, virtually all wanted to be informed of their diagnosis whether or not medication was available to treat it.
- The proportion wanting their spouses to know the diagnosis was 78% if medications were unavailable, but rose to 97% if medications were available.
- Seniors wanted to know their diagnosis to make plans and be prepared for the future, to find ways of helping themselves, and to seek treatment. In some cases they would choose not to disclose to their spouses for fear of inducing anxiety or depression.

POINTS DE REPÈRE DU RÉDACTEUR

- D'après certaines études antérieures, le médecin de famille serait peu enclin à dire à son patient qu'il souffre de la maladie d'Alzheimer (MA), mais plus porté à en avertir la famille.
- Cette étude effectuée à Montréal (PQ) chez des aînés sans trouble cognitif vivant dans leur milieu naturel révèle que presque tous veulent être informés du diagnostic, peu importe qu'il existe ou non un traitement médicamenteux contre cette maladie.
- En l'absence de traitement, 78% des sujets souhaitent que leur conjoint soit informé du diagnostic et cette proportion augmente à 97% si un médicament existe.
- Les sujets souhaitent connaître leur diagnostic afin de mieux planifier l'avenir, pour trouver des moyens de s'aider et pour chercher un traitement. Certains préfèrent ne pas le dire au conjoint de crainte de provoquer chez lui de l'anxiété ou de la dépression.

Contributors

Principal investigator **Dr Ouimet** was involved in study concept, proposal preparation, funding application, gaining ethical approval, acquiring data, drafting the article, and final approval of the version to be published. **Dr Dion** contributed to study concept, proposal preparation, funding application, gaining ethical approval, drafting the article, and final approval of the version to be published. **Dr Élie** participated in study concept, proposal preparation, funding application, gaining ethical approval, revising the article, and final approval of the version to be published. **Dr Dendukuri** was involved in study concept, analysis and interpretation of data, developing tables and figures, revising the article, and final approval of the version to be published. **Mr Belzile** contributed to analysis and interpretation of data, developing tables and figures, revision of article content, and final approval.

Competing interests

None declared

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