

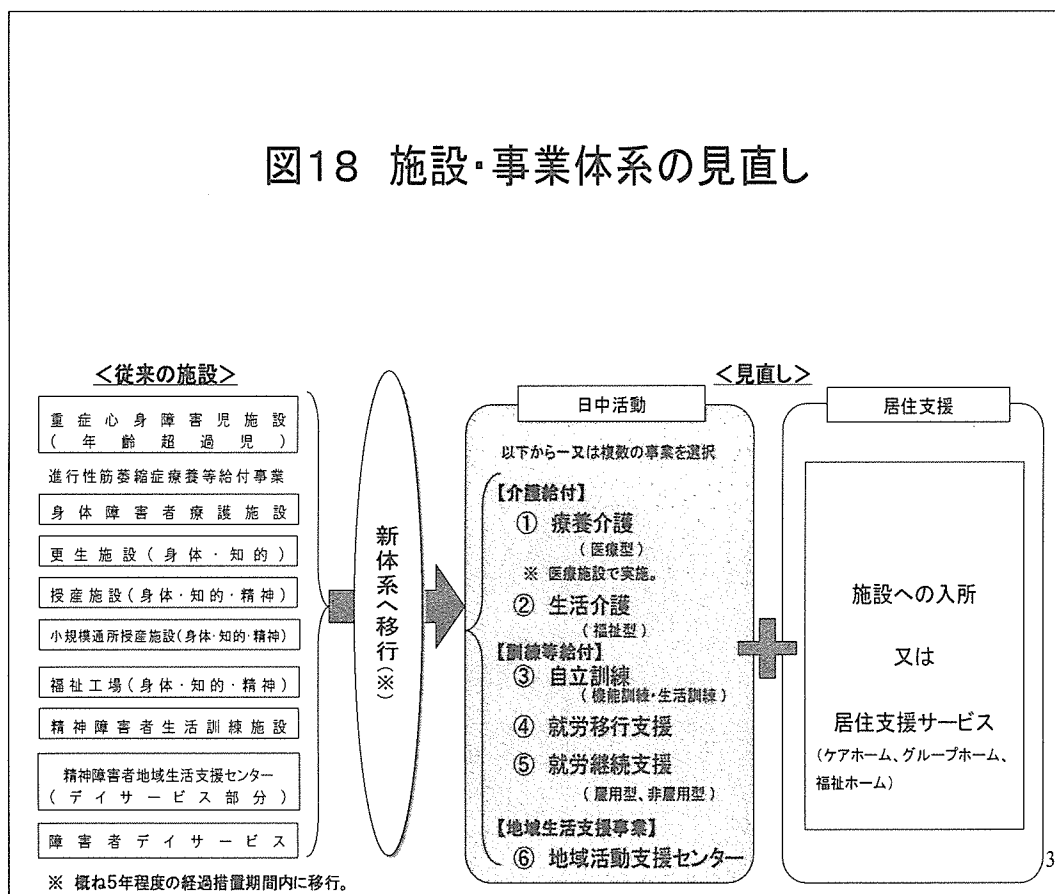
厚生労働省障害保健福祉部資料

(3) 施設・事業の見直し

障害者自立支援法において、施設・事業の見直しのねらいは以下の点にある。

- ① 障害者の状態やニーズに応じた適切な支援が効率的に行われるよう、障害種別ごとに分かれていた33種類の既存の施設・事業体系を6つの日中活動に再編する。
- ② 「地域生活支援」「就労支援」といった新たな課題に対応するため、新しい事業を制度化する。
- ③ 24時間を通じた施設の生活から、地域と交流する暮らしへの転換を図るために、日中活動の場と生活の場を分離する。
- ④ 入所期間の長期化など、本来の施設機能と利用者の実態の乖離を解消するため、一人ひとりの利用者に対して身近なところで効果的・効率的にサービスを提供できる仕組みを構築する。

図18 施設・事業体系の見直し



厚生労働省障害保健福祉部資料

8 障害者自立支援法の今後

介護保険制度における被保険者・受給者の範囲の拡大との関連で障害者自立支援法の今後について考えてみよう。

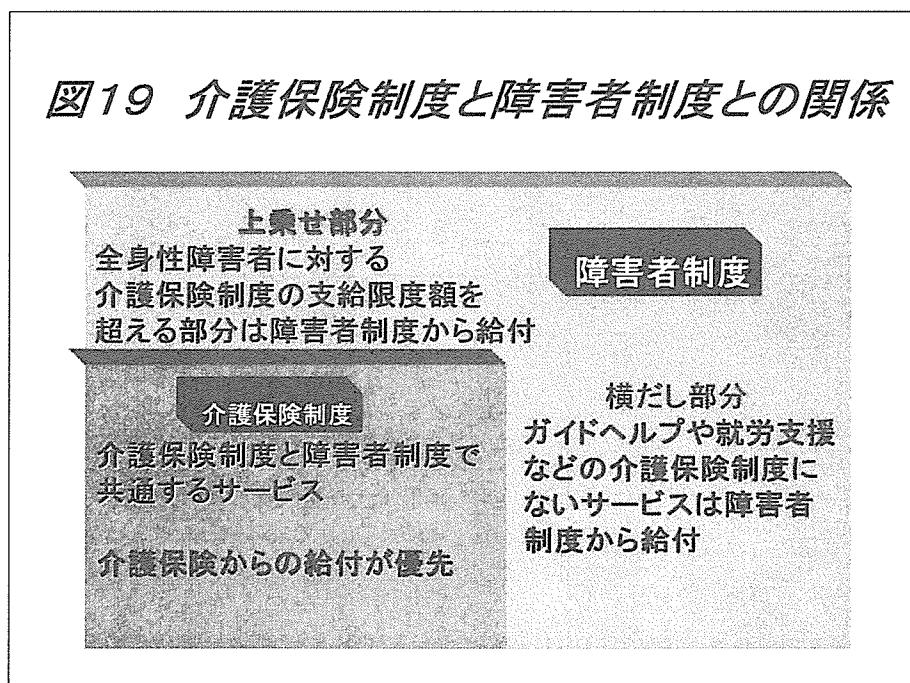
介護保険制度の被保険者・受給者の範囲の拡大を実施するとしても、障害者自立支援法のすべてが統合されるわけではない。まず、障害者自立支援法における介護給付の障害福祉サービスがどのようになるかという問題がある。介護保険制度においても、被保険者・受給者の範囲を拡大する場合、保険給付の内容をどのようにするか判断する必要がある。常識的には、介護給付のいくつかのサービスが保険給付の対象となると考えるのが妥当である。また、介護保険制度では保険給付として支給限度額が決められているのに対して、障害福祉サービスに上限が設定されていないことも大きな課題となる。現在、65歳以上の高齢障害者は介護保険制度の優先の原則から、保険給付を受けている者が多い。身体障害者においては約60%が65歳以上である。この場合、図19に示すような、介護保険制度と障害福祉制度の関係が施行されている。

介護保険制度優先の原則をもって、介護保険制度と障害福祉制度に共通するサービスは介護保険制度から提供されている。障害のある人の生活は介護保険制度からの保険給付だ

けでは生活できないので、上乘せと横だしの部分のサービスは障害福祉制度によって提供されている。上乘せのサービスとは、全身性障害者等のように長時間の介護を必要とする場合、上限設定のある介護保険制度からは提供されない可能性があるため、不足部分をカバーしようとするものである。横だし部分のサービスとは、就労支援やガイドヘルプ等の障害福祉制度独自のサービスであり、介護保険制度にはサービスである。

介護保険制度の被保険者・受給者の範囲の拡大は、慎重に検討され、国民が納得するような方向に結論を出すべきであることは言うまでもない。もし、範囲の拡大がなされたら、障害者もその範囲の中に入ることになり、障害者自立支援法は新たな制度設計を強いられることになる。障害者自立支援法における介護給付がどのように介護保険制度に組み込まれるかは結論付けられないが、訓練等給付などの就労支援等に法律のターゲットが絞り込まれる方向になってくるのではないかと思われる。そうすると、障害者自立支援法は、障害者の自立と社会経済活動を推進する性格をもつようになる。そのような観点に立てば、障害者自立支援法においては、訓練等給付の充実、相談支援体制の構築等の地域生活の支援体制の構築、障害者の所得保障問題を解決する方法を模索する必要がある。障害者の所得保障問題は、解決されないまま現在に至っており、介護保険制度にける保険料負担の問題を考えると、避けられない事柄である。

図19 介護保険制度と障害者制度との関係



厚生労働省資料

9 さいごに

介護保険制度と障害者自立支援法の将来というテーマで論述してきたが、現段階では介護保険制度における被保険者・受給者の範囲の拡大の問題が結論を得られていない。今後、

この問題に対して関係者の活発な議論がなされると思われるが、社会保障制度全体からみて、障害者の介護を保険制度でカバーするという考えが妥当か否かを考える必要がある。障害者自立支援法には、障害者の自立と社会経済活動に対する支援という大きな課題が横たわっており、この課題を解決するためにも一層の法の整備を実施することが肝要である。

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坂本洋一：「図説よくわかる障害者自立支援法」中央法規出版，2006年

社会保障審議会介護保険部会：「被保険者・受給者の範囲の拡大に関する意見」平成16年12月10日

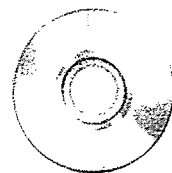
発達障害白書

日本発達障害福祉連盟 編

- ・全日本手をつなぐ育成会
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2007

年版



CD-ROM
付き

特集

岐路としての日本 制度改革の行方

日本文化科学社

なぜ伝わらないのか、どうしたら伝わるのか

なぜ伝わらないのか、どうしたら伝わるのか

成人編～知的障害を持つ人とのゆたかなコミュニケーションを求めて～

主な内容

- 1 コミュニケーションが成り立つ要件
- 2 コミュニケーションを阻害する要因
- 3 対話をする際の配慮すべき点と工夫のポイント

理解できる単語を選ぶ
連想しやすくする(体験の例示)
直接話法で話す
文節数に配慮する
時間理解が難しい
判断が変わりやすい
抽象語がわかりにくい
決定権の誤解

難しい言葉は易しく言い換える
連想しやすくする(記憶の補助)
省略した言い方と日時に注意
答えの傾向を知る
金銭管理が難しい
理由がわからない人への対応
仮定の話が難しい

4 はたらく人々

企画・監修・原案 湯汲 英史 (ゆくみ えいし)
(社) 発達協会常務理事
早稲田大学教育学部
言語聴覚士、精神保健福祉士

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(社福) さざんかの会

製作著作 アローウイン

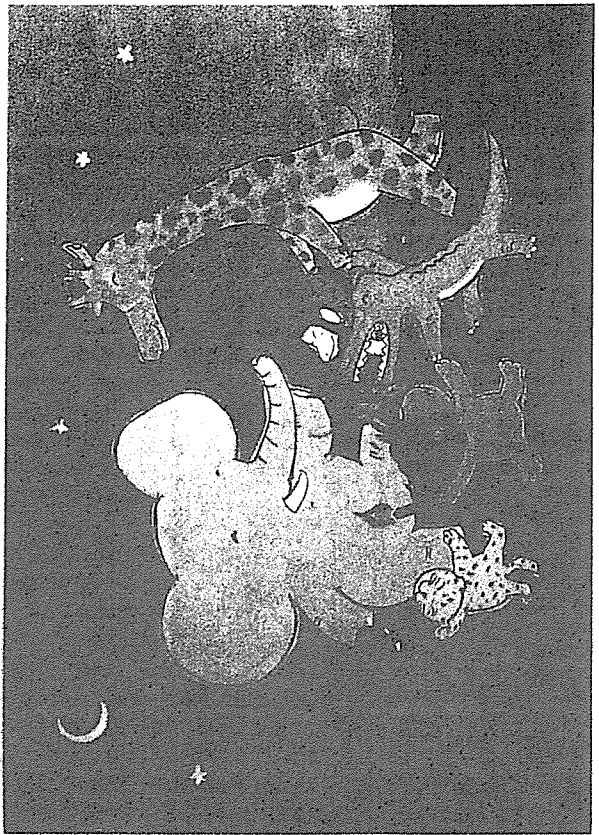
【お断り】このビデオに収録されている映像及び音声を権利者の事前の承認なしに、一部分でも複製、変更又はこれを利用して上映、ネットワークを通しての送信等をすることは禁止されています。(消費税込)

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なぜ伝わらないのか、どうしたら伝わるのか

～知的障害を持つ人とのゆたかなコミュニケーションを求めて～

成人編



成人編

VHS

uropathologies that cause dementia and peripheral neuropathy also affect the enteric nervous system. Visceral enteric neuropathies are probably common in nursing home residents and are manifested by tertiary contractions of the esophagus and diabetic gastroparesis. A review of the labeling information provided in the 2006 Physician's Desk Reference for nongeneric antimuscarinic drugs used for overactive bladder indicates that these agents are contraindicated in the presence of gastric retention. In addition, the presence of decreased gastrointestinal motility is listed as a precaution. Clinicians seldom study or quantitate gastrointestinal motility. The labeling of oxybutynin specifically recommends cautious use in the presence of gastroesophageal reflux disease. The percentage of subjects who experienced dyspepsia is listed as being from 0.9% to 5.8% greater than placebo. Trospium is considered to be an "antispasmodic" and has been shown to delay gastric emptying and to increase reflux (i.e., the fractional time of esophageal pH < 4) in healthy subjects.⁴

Regurgitated aspirated material (food, acid, or particulate material) may produce wheezing or "bronchitis," or a chemical pneumonitis, and may produce pulmonary infection if the aspirated material is colonized with bacteria. Proton pump inhibitor-induced hypochlorhydria or gastric stasis facilitate gastric colonization.⁵ The use of gastric acid-suppressive drugs is a risk factor for community-acquired pneumonia.⁶ Macro-aspiration episodes caused by gastric regurgitation often have an acute onset and may be associated with postprandial or recumbent "emesis" or gastric material on the cheek, pillow, or clothing.⁷ I believe that these episodes are relatively common and that most physicians fail to appreciate this mechanism. Aspiration that occurs in the recumbent position produces infiltrates located in the mid-lung fields, including the posterior segment of the upper lobe and apical segments of the lower lobes. One study supports the possibility that many cases of aspiration "pneumonia" may be related to aspiration of food, acid, or particulate material without infection.⁸ Protected bronchoalveolar lavage specimens were obtained within 4 hours of any antibiotic administration from 95 intubated residents admitted directly from a nursing home to an intensive care unit with risk factors for pharyngeal aspiration or reflux. In 41 of 95, clinicians failed to isolate bacteria during bronchoalveolar lavage, suggesting the presence of nonbacterial "pneumonitis." Reflux and regurgitation are also an acknowledged cause of asthmatic bronchitis and chronic cough.⁹ In one study, aspiration pneumonia accounted for more than one-third of deaths attributed to gastroesophageal reflux disease.¹⁰

It is unclear how often antimuscarinic drugs lead to pulmonary aspiration events, but in the frail elderly, I believe that this potentially lethal possibility deserves the same level of concern as that given to cognitive dysfunction.

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Author Contributions: P. J. Drinka was responsible for all aspects of the manuscript.

Sponsor's Role: None.

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ASSOCIATION BETWEEN DIASTOLIC BLOOD PRESSURE AND LOWER HEMOGLOBIN A1C AND FRONTAL BRAIN ATROPHY IN ELDERLY SUBJECTS WITH DIABETES MELLITUS

To the Editor: There is growing evidence that diabetes mellitus increases the risk of dementia for older people, and several studies have reported an association between diabetes mellitus and brain atrophy.^{1–4} Moreover, hippocampal and amygdalar atrophy in diabetes mellitus have recently been shown to be associated with insulin resistance.⁴ Because the hippocampus is a key structure for memory formation, the degree of brain atrophy of the hippocampus may partially account for neuropsychological deficits in the memory of diabetic patients. In addition to a weakened declarative memory, diabetes mellitus is often associated with impairment of cognitive speed and attention, which are frontal lobe-related brain functions,⁵ although it remains to be established whether morphometric changes occur in the frontal brain. This report concerns a preliminary study to investigate whether frontal brain atrophy (FBA) increases in elderly people with diabetes mellitus and to explore the factors leading to the development of FBA.

The enrollment for this study comprised 67 patients with type 2 diabetes mellitus (aged 60–84) treated at Kobe University Hospital and 48 healthy individuals (aged 60–86) who underwent a medical examination at the Division of Health Consultation of the Minato Health Facilities, Kobe. Diabetes mellitus was diagnosed based on information from clinical charts regarding the medical history of diabetes mellitus, blood examination results, and the presence of diabetic complications. Patients suffering from alcohol abuse, hepatic diseases, and dementia and subjects with neurological deficits due to a previous stroke were excluded.⁶ After an overnight fast, serum concentrations of blood glucose, hemoglobin A1c (HbA1c), total cholesterol, triglycerides, and high-density lipoprotein cholesterol were

Table 1. Clinical Characteristics of Controls and Subjects with Diabetes Mellitus

Characteristic	Control (n = 48)	Diabetes Mellitus (n = 67)	P-value
Age, mean \pm SE	68.7 \pm 0.9	70.0 \pm 0.8	.27*
Men, n (%)	23 (47.9)	24 (35.8)	.19 [†]
Body mass index, kg/m ² , mean \pm SE	20.6 \pm 0.4	26.2 \pm 0.4	.001*
Mini-Mental State Examination score, mean \pm SE	—	26.3 \pm 0.3	—
Duration of diabetes, years, mean \pm SE	—	18.1 \pm 1.1	—
Fasting blood glucose, mg/dL, mean \pm SE	94.9 \pm 0.9	164.8 \pm 9.6	.02*
Hemoglobin A1c, n (%), mean \pm SE	5.2 \pm 0.1	8.1 \pm 0.2	<.001*
Total cholesterol, mg/dL, mean \pm SE	198.4 \pm 4.6	214.7 \pm 5.0	.29*
Triglyceride, mg/dL, mean \pm SE	107.8 \pm 7.3	124.2 \pm 7.1	.45*
High-density lipoprotein cholesterol, mg/dL, mean \pm SE	—	63.6 \pm 2.8	—
Insulin use, n (%)	—	38 (56.7)	—
Systolic blood pressure, mmHg, mean \pm SE	110.3 \pm 1.9	135.1 \pm 2.6*	.001*
Diastolic blood pressure, mmHg, mean \pm SE	65.0 \pm 1.3	73.9 \pm 1.1*	.009*
Diabetic retinopathy, n (%)	—	44 (65.7)	—
Symptomatic nephropathy, n (%)	—	37 (55.2)	—
Persistent proteinuria, n (%)	—	21 (31.3)	—
Coronary artery disease, n (%)	—	24 (35.8)	—

*Mann-Whitney U test.

[†]Chi-square test.

SE = standard error.

determined. All computed tomography examinations were conducted using a third-generation scanner. FBA was identified with the aid of a planimeter applied to the computed tomography section as described elsewhere.⁷ Briefly, the frontal intracranial area (A) and pericerebral frontal area (B) were manually outlined, after which FBA was calculated as a percentage, expressed as (B)/(A). Statview version 5.0 was used for analysis of the data (SAS Institute, Inc., Cary, NC). Based on the hypotheses formulated in advance, .05 was selected as the level of significance.

Clinical features of control subjects and subjects with diabetes mellitus shown in Table 1 indicate that there were no differences in age, sex, or serum levels of total cholesterol, triglycerides, and high-density lipoprotein cholesterol. Serum concentrations of blood glucose and HbA1c, body mass index, and systolic/diastolic blood pressure, alternatively, were significantly higher in patients with diabetes mellitus. Five subjects had shown evidence of hypoglycemia during the preceding 6 months.⁸ Mean FBA \pm standard error of patients with diabetes mellitus was 16.8 \pm 0.5%, and that of control subjects was 15.0 \pm 0.8%, for a significant difference after adjustment for age (analysis of covariance; $P = .02$). The association between clinical variables and FBA in subjects with diabetes mellitus was tested using regression analysis, showing that FBA increased according to age (standardized $\beta = 0.21$, $P = .01$). After adjustment for age, men ($\beta = 0.22$, $P = .07$) and subjects with elevated diastolic blood pressure ($\beta = 0.37$, $P = .009$) were likely to have higher FBA, whereas HbA1c level correlated negatively with FBA ($\beta = -0.26$, $P = .05$). The other indices of diabetes mellitus did not show any significant association with FBA, although multiple regression analysis showed that age ($\beta = 0.46$, $P = .002$), diastolic blood pressure ($\beta = 0.38$, $P = .002$), and HbA1c ($\beta = -0.23$, $P = .04$) were significantly associated with FBA. Addition of other variables to the multiple regression analysis did not yield any significant correlation. Control

subjects were subjected to a similar analysis, but except for age, no significant correlation was observed (data not shown).

This study thus provides evidence that FBA increases in older people with diabetes mellitus and that age, diastolic blood pressure, and lower HbA1c levels are independent risk factors. The finding of an association between higher blood pressure and brain atrophy confirms previous results.² The second finding that HbA1c is negatively associated with FBA was unexpected. To the best of our knowledge, there have been no reports linking brain atrophy and HbA1c in elderly people with diabetes mellitus.⁹ The elderly people with diabetes mellitus in this study had a longer history of diabetes mellitus with a higher prevalence of several diabetic vascular complications than did subjects in other studies.^{1,2} It appears likely that strict blood glucose control combined with the limited cerebrovascular reserve capacity in elderly people with diabetes mellitus causes the disruption of cerebral glucose and energy metabolism homeostasis, resulting in subsequent neuronal degeneration. Because even a modest increase in the brain atrophy rate may lead to later cognitive impairment,^{7,10} the observation suggests the importance of careful management of elderly people with diabetes mellitus with regard to brain atrophy. The relationship between brain atrophy and HbA1c in elderly people with diabetes should be further examined in a prospective study.

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Author Contributions: Takashi Sakurai: study concept and design, acquisition of subjects and data, analysis and interpretation of data, and preparation of manuscript. Masako Kuranaga, Toshihiro Takata, Katsuhito Yamasaki, Hirokazu Hirai, and Hidetoshi Endo: acquisition of subjects and data and analysis. Koichi Yokono: study concept and acquisition of subjects and data.

Sponsor's Role: None.

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DIAGNOSIS OF CHRONIC KIDNEY DISEASE IN ELDERLY SUBJECTS WITH DIABETES MELLITUS

To the Editor: The prevalence of chronic kidney disease (CKD) increases in aged subjects, reaching 25% after the

age of 70 in the United States.¹ According to the National Kidney Foundation guidelines, renal function is moderately decreased when the glomerular filtration rate (GFR), predicted using the Cockcroft-Gault formula (CG) or the Modification of Diet in Renal Disease (MDRD) study equation, is lower than 60 mL/min per 1.73 m².² The MDRD equation seems more accurate,³ and MDRD-estimated GFR below 60 has been used to diagnose CKD in recent important epidemiological studies in populations without⁴ or with diabetes mellitus.⁵

Nevertheless, although the MDRD equation has been established from the results of renal-insufficient subjects, including only 6% subjects with diabetes mellitus,⁶ its superiority is questionable in these subjects. In subjects with diabetes mellitus⁷ and elderly subjects,⁸ the accuracy of the CG compares well with that of the MDRD. Because diabetic nephropathy is the first cause of renal replacement therapy after the age of 65,⁹ it is important to compare the diagnostic performances of the MDRD and CG in aged subjects with diabetes mellitus.

In 69 subjects with diabetes mellitus (39 men, 58 type 2) aged 72 and older (mean age \pm standard deviation: 76 \pm 3, range 72-83) with a wide range of renal function (serum creatinine: 54-367 μ mol/L), measured GFR (51Cr-ethylendiaminetetraacetic acid clearance) was compared with using the MDRD (4-variable version) and CG estimations using paired *t* test and correlations. The sensitivity, specificity, and diagnostic accuracy of the formulas for the diagnosis of CKD (defined as measured GFR < 60 mL/min per 1.73 m²) were assessed using nonparametric receiver operating characteristic curves. Because the performances of the equations vary according to the GFR level, comparisons were also performed after categorizing the subjects according to GFR quintiles. Results are presented as means \pm standard deviations.

The mean measured GFR was 46.5 \pm 16.9 mL/min per 1.73 m². The mean MDRD (47.1 \pm 17.9) and CG (46.7 \pm 17.9) estimations were similar, but the MDRD was better correlated to GFR (MDRD: correlation coefficient (*r*) = 0.81, CG: *r* = 0.59; *P* < .05). For the diagnosis of CKD, the sensitivity (MDRD: 98%, CG: 82%) and the specificity (MDRD: 61%, CG: 44%) were better for the MDRD, and the area under the receiver operating characteristic curve was higher (MDRD: 0.91, CG: 0.79; *P* < .05). As shown in Figure 1, both formulas overestimated GFR in the lowest GFR quintile (*P* < .005 according to paired *t* test), whereas they underestimated GFR in the highest quintile, but this was significant only for the CG (*P* < .05).

The MDRD therefore appears to be a more accurate tool than the CG for the diagnosis of CKD in aged subjects with diabetes mellitus. This advantage did not reach significance in the 52 elderly subjects (only two with diabetes mellitus) in a previous study,⁸ although misclassification of renal function was more frequent with the CG in this report. A larger study³ recruited 595 subjects aged 65 and older and found better precision with the MDRD, but the authors did not mention how many subjects were diabetic. Another study found no advantage of the MDRD over the CG in subjects with diabetes mellitus,⁷ but they were young patients with type 1 diabetes mellitus, with a high GFR (122 \pm 18). We have shown that the MDRD underestimates high GFR in such patients.¹⁰ Our work also shows

Attitudes toward disclosing the diagnosis of dementia in Japan

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ABSTRACT

Background: The rapid increase in the elderly population in Japan has triggered a debate on whether or not patients with dementia should be informed of their diagnosis. The purpose of the present study was to investigate the attitudes of people in a large city in Japan toward the disclosure of a diagnosis of dementia.

Methods: In Study 1, 2000 residents aged 40–64 and 5000 residents aged 65 and over were sampled randomly, and a structured questionnaire was sent to them by mail. In Study 2, we administered a structured interview-based questionnaire to 3949 randomly enrolled residents of Nagoya City aged 45 and over whose family member had been certified as needing long-term care.

Results: In Study 1, 79.8% of the younger respondents ($n = 710$) stated that they would prefer the disclosure of a hypothetical diagnosis of dementia, as did 75.5% of the older respondents ($n = 2162$). Furthermore, 85.1% ($n = 749$) of the younger respondents and 82.5% ($n = 2181$) of the older respondents stated that they would prefer that the patient be told his or her hypothetical diagnosis of dementia. In Study 2, in the case of care recipients without dementia, 68.3% ($n = 650$) of their family members preferred disclosure of a hypothetical diagnosis of dementia. Among the families of care recipients who had dementia, 58.4% ($n = 301$) of family members preferred disclosure.

Conclusions: The present survey of caregivers and non-caregivers in an urban city of Japan demonstrated that the desire for disclosure of a diagnosis of dementia is relatively high.

Key words: dementia, diagnosis, long-term care insurance system, adult guardianship

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Introduction

Japan has been experiencing the fastest growth of the elderly population in the world and the percentage of the population aged 65 years old and over finally exceeded 20% in 2006. A mandatory social long-term care insurance system was therefore implemented in Japan in April 2000; all people aged 65 and older are eligible to benefit from institutional and community-based services upon certification of their need for care. In 2003, more than 3.8 million people were certified to receive long-term care insurance benefits in Japan. In parallel with the introduction of long-term care insurance, the adult guardianship law came into effect to shift the system from one of enforcement to one of contract. The law is applied to a person whose mental capacity is impaired due to dementia, mental deficiency or mental illness, and is aimed at securing legal advocacy of his/her own autonomy (Nakatani, 2000).

With the increase in the elderly population, the number of people with dementia is also steadily increasing. Because patients with dementia may be unable to understand the implications of their diagnosis or make decisions on clinical, social or financial issues, their caregivers have a unique role in the process of disclosing the diagnosis of dementia. A growing national concern for older people with dementia, particularly after the introduction of the long-term care insurance system and the increase in the number of people with dementia, has triggered a debate on whether or not patients should be informed of their diagnosis.

The results of previous reports on the opinions of caregivers toward diagnostic disclosure of dementia to the care recipients were largely inconsistent (Bamford *et al.*, 2004). In Japan the results of domestic reports regarding this issue were also in disagreement (Sugiyama *et al.*, 2003; Yamashita *et al.*, 2002). In the present study we surveyed the attitudes of both caregivers and non-caregivers toward the disclosure of a diagnosis of dementia; our subjects were a population sampled in a large city in Japan.

Methods

The study consisted of two protocols, both of which were carried out in Nagoya City, which is located in the central part of Japan. Nagoya City has a population of 2 202 259 (April 2004), of whom 18.0% are 65 years of age or older. This study was developed and organized by Nagoya City and was supported by the Department of Geriatrics of Nagoya University Graduate School of Medicine. Written informed consent was obtained from all participants.

Study 1

Two thousands residents aged 40–64 and 5000 residents aged 65 and over were sampled randomly and a structured questionnaire was sent to them in December 2004. People residing in long-term care facilities and those admitted to hospitals were excluded. The questionnaire asked the participants about their background, their perceptions of dementia, level of anxiety about possible future dementia, awareness of the adult guardianship law and attitude toward the disclosure of a diagnosis of dementia. The care needs of the older participants were also surveyed. In the long-term care insurance system in Japan, all care recipients have their care needs categorized into seven levels [not eligible (independent), need support, and care need levels 1–5] depending on their physical and mental capabilities.

Study 2

We randomly enrolled 3949 residents of Nagoya City aged 45 and over who had been certified as requiring long-term care. Of these participants, 1885 were actively using at least one type of service provided by public long-term care insurance, and 2064 were not currently using any of these services. A structured interview-based questionnaire was administered to the families of the enrolled people by the investigators to evaluate the physical and mental status of the participants for determination of their care needs. Home-visit interviews were carried out between October and November 2004. The questionnaire asked about the background of the people in need of care, the awareness of the family caregiver of the adult guardianship law and the attitude of the caregiver toward the disclosure of a diagnosis of dementia. If the people in need of care were found to have dementia at the time of the questionnaire, a short memory questionnaire (SMQ; Koss *et al.*, 1993) was administered and the possibility of disclosure to the patient was investigated.

Statistical analysis

Pearson's correlation coefficients (r) were calculated for parametric data and Spearman's rank-order correlation coefficients (ρ) were calculated for non-parametric data. We used the χ^2 -test, the Kruskal–Wallis test and a one-way analysis of variance (ANOVA) for categorical comparisons of the data. Tukey's test was performed for multiple comparisons when the ANOVA showed a significant difference. Differences in the means of the SMQ among the groups were tested using the Student's t -test. A p -value of < 0.05 was considered to indicate statistical significance; all tests were two-tailed. All statistical analyses were performed on a personal computer with the statistical package SPSS 11.0 for Windows (SPSS, Inc., Chicago, IL, USA).

Results

Study 1

A total of 942 younger residents (47.1%) and 3273 (65.5%) older residents returned our questionnaire. Among the older residents, 173 were excluded because they were in hospital ($n = 53$), were residing in long-term care facilities ($n = 106$), had moved or died ($n = 5$), or the address of residence was unknown ($n = 9$). Characteristics of the respondents are shown in Table 1.

The perceptions of dementia by the respondents are shown in Table 2. Trends in answers are similar in younger and older participants. Approximately half of the participants answered that dementia is a morbid condition and more than 40% regarded dementia as a progressive disease. More than 10% of the respondents were not familiar with dementia as a disease.

Among the younger respondents, 34.1% ($n = 308$) said that they feared that they might develop dementia in the future, and 32.0% of the older

Table 1. Characteristics of responders in Study 1

	YOUNGER RESPONDENTS ($n = 942$)	OLDER RESPONDENTS ($n = 3100$)	<i>p</i> -VALUE
Gender			
Male	395 (42.3)	1403 (45.6)	< 0.042
Female	538 (57.7)	1673 (54.4)	
Age (years)			
40–49	306 (32.5)		
50–59	394 (41.9)		
60–64	241 (25.6)		
65–69		934 (30.3)	
70–79		1548 (50.3)	
80–89		541 (17.6)	
90+		57 (1.9)	
Certified care needs			
None		2548 (87.1)	
Need support		123 (4.2)	
Level 1		124 (4.2)	
Level 2		52 (1.8)	
Level 3		40 (1.4)	
Level 4		24 (0.8)	
Level 5		16 (0.5)	
Residency status			
Live by oneself	78 (8.6)	538 (20.6)	< 0.001
Live with spouse	199 (21.9)	282 (10.8)	
Other	633 (69.6)	1794 (68.6)	

Values are n (%).

Table 2. Perceptions of dementia among respondents

	YES	TEND TO YES	TEND TO NO	NO
Younger respondents				
Morbid condition	480 (67.9)	165 (23.3)	32 (4.5)	30 (4.2)
Disease of increasing frequency	466 (66.4)	181 (25.8)	35 (5.0)	20 (2.8)
Anyone may have dementia	441 (62.8)	163 (23.2)	53 (7.5)	45 (6.4)
Unfamiliar and scary disease	428 (48.0)	257 (28.8)	109 (12.2)	97 (10.9)
Familiar disease	302 (42.4)	280 (39.3)	86 (12.1)	44 (6.2)
Fatal disease	338 (38.9)	269 (30.9)	137 (15.7)	126 (14.5)
Disease unrecognized by society	303 (33.9)	360 (40.3)	129 (14.4)	102 (11.4)
Shameful disease	140 (15.7)	237 (26.7)	211 (23.7)	301 (33.9)
Untreatable disease	93 (10.4)	167 (18.7)	254 (28.4)	379 (42.4)
Older respondents				
Morbid condition	1528 (60.7)	659 (26.2)	194 (7.7)	135 (5.4)
Disease of increasing frequency	1387 (58.1)	775 (32.5)	218 (9.1)	8 (0.3)
Anyone may have dementia	1307 (50.5)	715 (27.6)	292 (11.3)	272 (10.5)
Unfamiliar and scary disease	1520 (60.5)	593 (23.6)	187 (7.4)	214 (8.5)
Familiar disease	1149 (44.9)	992 (38.8)	260 (10.2)	156 (6.1)
Fatal disease	978 (51.8)	631 (33.4)	275 (14.6)	5 (0.3)
Disease unrecognized by society	1112 (44.8)	832 (33.5)	250 (10.1)	290 (11.7)
Shameful disease	762 (31.2)	628 (25.7)	378 (15.5)	678 (27.7)
Untreatable disease	451 (18.1)	525 (21.0)	541 (21.7)	979 (39.2)

Values are *n* (%).

respondents (*n* = 927) had the same fear. Another 29.3% (*n* = 265) of younger and 28.3% (*n* = 821) of older respondents stated that they sometimes feared future dementia, while 28.1% (*n* = 254) of younger and 28.0% of older respondents (*n* = 813) rarely had this fear. Eight and a half percent (*n* = 77) of younger respondents and 11.7% of older respondents (*n* = 339) had no fear at all that they might have dementia in the future.

With regard to the adult guardianship law, 30.5% (*n* = 271) of younger respondents and 28.6% (*n* = 797) of older respondents knew about the law, but the majority of both younger (*n* = 617, 65.5%) and older respondents (*n* = 1994, 71.4%) did not know about it.

To a question assuming that the respondent would be afflicted with dementia in the future, 79.8% (*n* = 710) of younger respondents and 75.5% (*n* = 2162) of older respondents stated they would prefer to be told their diagnosis, while only 3.4% (*n* = 30) of younger respondents and 4.8% (*n* = 138) of older respondents do not wish to be told. The rest answered “don’t know.” The percentage of younger respondents who preferred disclosure was significantly higher than that of older respondents (*p* = 0.025); the reasons given for preferences regarding disclosure are shown in Table 3. Some of these reasons show a significant

Table 3. Disclosure of a diagnosis of dementia

REASONS WHY RESPONDENTS PREFER BE DISCLOSED A DIAGNOSIS OF DEMENTIA TO THEMSELVES	YOUNGER PEOPLE (<i>n</i> = 710)	OLDER PEOPLE (<i>n</i> = 2162)	<i>p</i> -VALUE
Because I have the right to know	199 (28.0)	633 (29.3)	0.279
Because I may want to consult or convey wills about the future	534 (75.2)	1292 (59.8)	< 0.001
Because telling the diagnosis would give me the option to receive treatment and rehabilitation	459 (64.6)	1297 (60.0)	0.015
Because I can accept the diagnosis and cope with problems positively	298 (42.0)	1005 (46.5)	0.020

REASONS WHY RESPONDENTS PREFER A DIAGNOSIS OF DEMENTIA NOT TO BE DISCLOSED TO THEMSELVES	YOUNGER PEOPLE (<i>n</i> = 30)	OLDER PEOPLE (<i>n</i> = 138)	<i>p</i> -VALUE
Because you cannot help having dementia when you grow old	17 (56.7)	49 (35.5)	0.004
Because there are no advantages in knowing the diagnosis due to reduced capacity for judgment	15 (50.0)	55 (39.9)	0.206
Because I may be depressed or lose hope by knowing it	21 (70.0)	58 (42.0)	0.275
Because knowing the diagnosis may exacerbate symptoms of dementia	4 (13.3)	30 (21.7)	0.219
Because it may be better untold as there is no effective remedy for reversing the condition	7 (23.3)	53 (38.4)	0.086

Values are *n* (%).

difference between younger and older respondents. However, in answer to a question assuming that a family member of the respondent has dementia, 85.1% (*n* = 749) of younger respondents and 82.5% (*n* = 2181) of older respondents stated that they would prefer that the patient be told his or her diagnosis, while only 4.7% (*n* = 41) of younger participants and 4.0% (*n* = 106) of older participants do not wish the patient to be told. The percentage of respondents who preferred telling the diagnosis of dementia to an affected family member did not differ significantly between younger and older respondents (*p* = 0.293).

The reasons given for preferences regarding the disclosure of a diagnosis of dementia to an affected family member are shown in Table 4; some of these

Table 4. Disclosure of a diagnosis of dementia to an affected family member

REASONS WHY RESPONDENTS PREFER DISCLOSURE OF A DIAGNOSIS OF DEMENTIA TO AN AFFECTED FAMILY MEMBER	YOUNGER RESPONDENTS (<i>n</i> = 749)	OLDER RESPONDENTS (<i>n</i> = 2252)	<i>p</i> -VALUE
Because he/she has the right to know	211 (28.2)	625 (27.8)	0.430
Because he/she may want to consult or convey wills about the future	612 (81.7)	1592 (70.7)	< 0.001
Because telling the diagnosis would give him/her the option to receive treatment and rehabilitation	535 (71.4)	1342 (59.6)	< 0.001
Because he/she can accept the diagnosis and cope with problems positively	259 (34.6)	849 (37.7)	0.068

REASONS WHY RESPONDENTS PREFER A DIAGNOSIS OF DEMENTIA NOT TO BE DISCLOSED TO AN AFFECTED FAMILY MEMBER	YOUNGER RESPONDENTS (<i>N</i> = 41)	OLDER RESPONDENTS (<i>N</i> = 113)	<i>p</i> -VALUE
Because he/she cannot help having dementia when he/she grows old	6 (14.6)	31 (27.4)	0.073
Because there are no advantages in knowing the diagnosis due to reduced capacity for judgment	17 (41.5)	40 (35.4)	0.307
Because he/she may be depressed or lose hope by knowing it	27 (65.9)	40 (35.4)	0.001
Because knowing the diagnosis may exacerbate symptoms of dementia	13 (31.7)	30 (26.5)	0.331
Because it may be better untold as there is no effective remedy for reversing the condition	11 (26.8)	53 (46.9)	0.019

Values are *n* (%).

reasons show a statistically significant difference between younger and older respondents.

Study 2

A total of 1444 (76.6%) family members of care recipients who were using some type of services provided by public long-term care insurance and 441 (21.4%) who did not use any service returned the questionnaire. Of the care recipients, 57.7% of the users of the care service and 53.9% of the

Table 5. Characteristics of responders in Study 2

	TOTAL <i>n</i> = 1885	WITHOUT DEMENTIA <i>n</i> = 1136 (60.2%)	WITH DEMENTIA <i>n</i> = 749 (39.8%)	<i>p</i> -VALUE
Gender (<i>n</i> = 1681, 89.2%)				
Male	617 (36.7)	371 (38.1)	246 (34.8)	0.098
Female	1064 (63.3)	604 (61.9)	460 (65.2)	
Age (years) (<i>n</i> = 1672, 88.7%)				
40–64	45 (2.7)	28 (2.9)	17 (2.4)	< 0.001
65–74	308 (18.4)	232 (23.8)	76 (10.9)	
75–84	713 (42.6)	435 (44.7)	278 (39.8)	
85+	606 (36.2)	278 (28.6)	328 (46.9)	
Residency (<i>n</i> = 1636, 86.8%)				
Live by oneself	118 (7.2)	76 (8.0)	42 (6.1)	< 0.001
Live with spouse	484 (29.6)	315 (33.2)	169 (24.6)	
Others	1034 (63.2)	559 (58.8)	475 (69.2)	
Certified level of care needs (<i>n</i> = 1678, 89.0%)				
Need support	1299 (77.4)	183 (18.7)	46 (6.6)	< 0.001
Level 1	445 (26.5)	319 (32.6)	126 (18.0)	
Level 2	341 (20.3)	193 (19.7)	148 (21.1)	
Level 3	290 (17.3)	119 (12.2)	171 (24.4)	
Level 4	222 (13.2)	8 (10.0)	24 (17.7)	
Level 5	151 (9.0)	66 (6.7)	85 (12.1)	
Duration in need of care (<i>n</i> = 1574, 83.5%)				
< 6 months	713 (45.3)	109 (12.1)	604 (89.3)	< 0.001
6 months–3 years	422 (26.8)	393 (43.8)	29 (4.3)	
> 3 years	439 (27.9)	396 (44.1)	43 (6.4)	

Values are *n* (%).

non-users were female. The percentage of people with dementia was significantly higher in the care service users (43.3%, *n* = 625) than in non-users (28.1%, *n* = 124) (*p* < 0.001). Combining the users and non-users of care service, there were significant differences with regard to age (*p* < 0.001), residency status (*p* < 0.001), certified levels of care needs (*p* < 0.001) and duration in need of care (*p* < 0.001) between the care recipients with and those without dementia (Table 5).

In the case of a diagnosis of dementia, after the exclusion of the respondents who answered “don’t know,” 79.0% (*n* = 650/823) of family members of care recipients without dementia and 58.4% (*n* = 301/515) of family members of care

Table 6. Preferences of disclosure of a diagnosis of dementia

REASONS WHY FAMILY MEMBERS OF A CARE RECIPIENT PREFER DISCLOSURE OF A DIAGNOSIS OF DEMENTIA	WITHOUT DEMENTIA (<i>n</i> = 650)	WITH DEMENTIA (<i>n</i> = 301)
Because he/she has the right to know	208 (32.5)	99 (32.9)
Because he/she may want to consult or convey wills about the future	476 (74.4)	216 (71.8)
Because telling the diagnosis would give him/her the option to receive treatment and rehabilitation	412 (64.4)	175 (58.1)
Because he/she can accept the diagnosis and cope with problems positively	347 (54.2)	156 (51.8)
Because I feel guilty about not telling the truth	136 (21.3)	52 (17.3)
Others	14 (2.2)	14 (4.7)
REASONS WHY FAMILY MEMBERS OF A CARE RECIPIENT PREFER NO DISCLOSURE OF A DIAGNOSIS OF DEMENTIA	WITHOUT DEMENTIA (<i>N</i> = 173)	WITH DEMENTIA (<i>N</i> = 214)
Because he/she cannot help having dementia when he/she grows old	56 (32.4)	119 (55.6)
Because there are no advantages in knowing the diagnosis due to reduced capacity for judgment	87 (50.3)	146 (68.2)
Because he/she may be depressed or lose hope by knowing it	73 (42.2)	48 (22.4)
Because knowing the diagnosis may exacerbate symptoms of dementia	44 (25.4)	42 (19.6)
Because it may be better untold as there is no effective remedy for reversing the condition	58 (33.5)	62 (29.0)
Others	14 (8.1)	14 (6.5)

Values are *n* (%).

recipients with dementia said that they would prefer to tell the afflicted person of the diagnosis, while 21.0% (*n* = 173/823) of the family members of the care recipients without dementia and 41.6% (*n* = 214/515) with dementia preferred not to disclose the diagnosis. There was a significant difference in the percentages of family members who wanted to disclose the diagnosis between those whose care recipient did not have dementia at the time of the questionnaire and those whose care recipient had already been diagnosed with dementia ($p < 0.001$). The reasons for preferring to disclose the diagnosis are shown in Table 6. Male family members of care recipients were significantly more likely to prefer disclosure than female family members (male 73.4%, female 68.6%, $p = 0.048$). The spouses were significantly more likely to want their care recipients to be told the diagnosis than non-spouse caregivers (74.9% vs. 66.6%, respectively, $p = 0.002$). The certified level of long-term care needs had no significant effect on disclosure preference ($p = 0.121$), nor did residence status (living alone or

living with family) ($p = 0.282$). The mean SMQ score of care recipients whose family preferred disclosure (17.6 ± 5.6 S.D.) and that of patients whose family did not prefer disclosure (17.0 ± 5.4 S.D.) did not differ significantly ($t = 1.256$, $p = 0.210$).

Of the patients whose family preferred disclosure of the diagnosis of dementia, after the exclusion of 26 patients who had not confirmed whether they were told the diagnosis or not, 62.5% (172/275) were told the diagnosis by their physicians, and 37.5% (103/275) were not told. Of the patients whose family preferred no disclosure to the patient, 64.3% (128/199) were told the diagnosis by their physicians, and 35.7% (71/199) were not told, after the exclusion of 15 patients who had not confirmed whether they were told the diagnosis or not.

Discussion

The present survey reveals that the residents of an urban area of Japan strongly favor the disclosure of a hypothetical diagnosis of dementia (Study 1), with 85.1% of younger respondents and 82.5% of older respondents expressing positive attitudes toward disclosure to their family members. In 1996, Maguire *et al.* reported that in a memory clinic in Ireland, only 17% of family members wanted disclosure to the patient of a diagnosis of dementia. This disagreement might be attributed to cultural differences. The fact that we found a willingness to disclose a diagnosis of dementia to a family member in this study population is also in contrast to the somewhat negative attitude toward disclosing a diagnosis of cancer in Japan (Elwyn *et al.*, 2002), while the trend is the opposite in western countries (Holroyd *et al.*, 2002), where people might be more sensitive to losing autonomy or human dignity by having dementia. The favorable attitudes toward diagnosis disclosure of dementia in the current study were, however, in agreement with two recent reports from western countries (Holroyd *et al.*, 2002; Pinner and Bouman, 2003) and one from Taiwan (Lin *et al.*, 2005). This may suggest that the increased public awareness of dementia in recent years has affected attitudes toward this issue irrespective of cultural differences. One recent survey performed in an island in Okinawa in Japan reported 29.9% of the caregivers were positive for disclosure (Sugiyama *et al.*, 2003), whereas another survey in an urban area in Japan showed that 71% of caregivers were in favor of disclosure (Yamashita *et al.*, 2002), which is comparable to our current results. These inconsistent results within the same country may be due to the different areas of the surveys. The attitudes in a relatively rural area in Japan might be shifting toward a more positive outlook with an increase in public awareness, but further investigation is necessary.

In the present study, the older people were less favorable to disclosure of their own hypothetical diagnosis, but no difference was found between younger and older respondents in terms of preference of disclosure of a hypothetical diagnosis to an affected family member. Although the reasons why the younger people were more favorable to disclosure of their own hypothetical diagnosis were unclear, they may have more interest in their own condition.

There was a significant difference regarding the disclosure of diagnosis between younger and older respondents in the general population and an even more striking difference between the two caregiver groups whose recipients either had or did not have dementia. Our results show that the older adults were less eager to be told of their own diagnosis and that the caregivers of patients with dementia were also less eager to tell their patients. In general, older people are more likely to have had personal experiences related to dementia than younger people, and caregivers of patients with dementia may have broader experience and knowledge of dementia, which might give them an understanding of the deeper implications of disclosure. With this deeper understanding of dementia based on actual personal experiences, caregivers of patients with dementia may become apaternalistic or reluctant to deal with the potential grief reaction of a family member, and therefore may be reluctant to disclose the diagnosis. Indeed, in a study in the U.S.A., Turnbull *et al.* (2003) found that people who had had personal experience with Alzheimer's disease (AD) were less likely to want to know themselves if they had AD than those without personal experience. In the case of patients with advanced dementia, advance planning including disclosure may have less significance. As expected, we found less favorable attitudes toward the disclosure in caregivers (Study 2) than in non-caregivers (Study 1). Although the difference in study design (questionnaires sent by mail *vs.* interview-based questionnaires) makes a direct comparison difficult, similar reasons to those given above may explain the relative reluctance of the caregivers to disclose the diagnosis of dementia.

A study conducted at a Dutch memory clinic reported that spouses were significantly more likely to want their care recipients to be told the diagnosis than non-spouse caregivers (Dautzenberg *et al.*, 2003), which is consistent with the present results.

Fahy *et al.* (2003) found that lower scores on the Mini-mental State Examination of a care recipient was a predictor of the desire of the caregivers for the diagnosis to remain undisclosed in a study performed at a U.K. clinic. In the present study, however, the mean SMQ score, which reflects the severity of dementia (Koss *et al.*, 1993), was not significantly different between the two different preference groups for disclosure, although it was slightly lower in the group that did not prefer disclosure.