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RESEARCH LETTER

Determination of driving cessation for older adults with dementia in Japan

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INTRODUCTION

It is estimated that in Japan there are approximately 0.35 million people with dementia who continue to drive (Arai Y and Arai A, 2005). With the amendment to Section 103 of the Road Traffic Act in 2002, dementia is now included as a reason for license revocation (Arai, 2006; Arai *et al.*, 2006). However, it has been argued that the implementation of the Act leaves much to be desired. Arai (2006), from interviews with licensing officers, revealed problems with the Act: (1) there is no clear definition of 'dementia'; (2) is it right for the authority to deprive people in an early stage of dementia of self-sustainability?; and (3) little description is provided as to how to assess such people in terms of 'fitness to drive'. In particular, it remains to be defined who in practice ultimately makes the decision regarding driving cessation of older adults with dementia (Arai *et al.*, 2007).

OBJECTIVES

The present study investigated: (1) who plays a major role in deciding driving cessation of older adults with dementia (hereinafter 'patients'); (2) what are the

current practices of family caregivers regarding attempts for driving cessation of patients; and (3) what are the necessary requirements for enabling the cessation of driving.

METHODS

The study subjects were 79 pairs of family caregivers and consecutive outpatients from June 2004 to March 2006 at Ehime University Hospital that satisfied the diagnostic criteria for dementia.

The median age of patients was 74 years. Forty-three were male and 36 were female. Diagnoses were as follows: Alzheimer's disease ($n = 51$); Vascular dementia ($n = 8$); Dementia with Lewy bodies ($n = 9$); Frontotemporal lobar degeneration ($n = 5$); and others ($n = 6$). The median age of the family caregivers was 68.5 years. Twenty were male and 59 were female. Relationships of caregivers to patients were; wife ($n = 42$); husband ($n = 20$); daughter ($n = 8$); daughter-in-law ($n = 7$); and others ($n = 2$).

Patients were assessed according to the Mini-Mental State Examination (median MMSE = 22), the Neuropsychiatric Inventory (median NPI = 9), and the Clinical Dementia Rating (median CDR = 1). Family caregivers completed a self-administered questionnaire that included details of the patient's driving habits and plans for driving cessation.

RESULTS

(1) Whereas 54% ($n = 20$) of family caregivers answered (to the question 'who should determine whether or not

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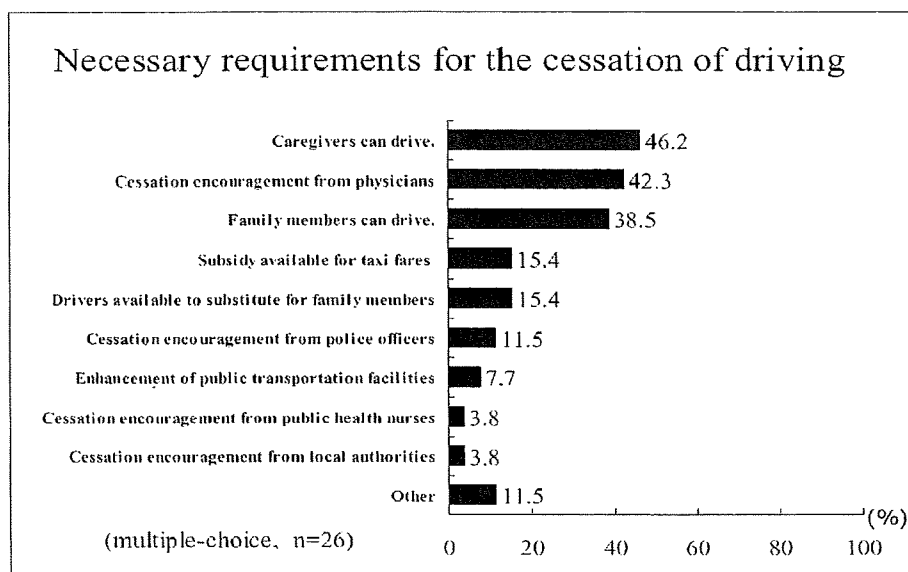


Figure 1. Necessary requirements for the cessation of driving.

the patient continues to drive?'; multiple-choice, $n = 37$) that the patients themselves should determine whether to cease driving, in nearly half (47.6%, $n = 10$) of the driving cessation cases ($n = 21$), the family caregivers actually made the decision.

(2) Of those family caregivers who doubted the driving ability of their patients ($n = 18$), only half attempted to encourage that patients to cease driving ($n = 9$). That is to say, nearly half of the patients continued to drive.

(3) Availability of family caregivers (46.2%) or other family members (38.5%) who can drive instead of the patient and encouragement from physicians (42.3%) were raised as essential to facilitate cessation of driving (multiple-choice, $n = 26$; Figure 1). The need for public support such as the availability of a subsidy for taxi fares was also raised (15.4%), along with the enhancement of public transportation facilities (7.7%).

DISCUSSION

We found a discrepancy between the results obtained and the desire that patients' intention should be respected in regard to driving cessation. Moreover, our findings regarding the necessary requirements for enabling the cessation of driving clearly indicated that

the decisions made in practice were highly situation-dependent. Therefore, issues such as institutionalising the availability of transportation alternatives, or more broadly, sustainable urban planning, should be matters of policy in order not to place the entire responsibility on patients or family members as a matter of 'self-help'.

CONFLICT OF INTEREST

None.

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Differences in perceptions regarding driving between young and old drivers and non-drivers in Japan

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Objective: The issue of driving cessation for dementia patients is one of the urgent public health priorities in Japan and is often complicated, with family or social barriers yet to be sufficiently addressed. Because the possibility of dementia or family caregiving can befall anyone, we focused on the disparity in people's perceptions of driving as possible barriers. The present study aimed to assess perceptions of driving among the general public and examine differences in perceptions based on age and driving status.

Methods: A survey was conducted in a sample of the general public aged 40 and over in Japan. Respondents were 1010 people who received a self-administered questionnaire that included questions regarding perceptions about driving and sociodemographic factors.

Results: The drivers that participated in this study tended to highly agree that 'driving is a "right" which we all deserve', compared with the non-drivers. The most common reason for reluctance to stop driving among drivers was the possible loss of personal mobility. Apart from transportation, older drivers were more likely than younger drivers to value the qualitative aspects of driving, for example, driving was viewed as 'a motivating factor in my life'.

Conclusions: These disparities in the general public's perceptions about driving may be possible family or social barriers to driving cessation in the case of drivers with dementia. Our findings also suggest that when addressing the need for driving retirement, not only mobility but also the qualitative aspects of driving be paid more attention. Copyright © 2010 John Wiley & Sons, Ltd.

Key words: older drivers; driving cessation; perception; general public; dementia

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Introduction

The number of older drivers has been increasing dramatically as Japan's population ages. People aged 65 and older account for 21% (27 million) of the total population in Japan. The number of licensed drivers over 65 ('older drivers') exceeded 11 million in 2007, accounting for 14% of the total drivers of all ages. The number of drivers in the older population is about 40% which is much lower than the 80% in the younger population under age 60 who drive. However, automobiles are nonetheless a practical form of

transportation for older people, and driving can play a key role in maintaining independence.

Given that advanced age is associated with a higher risk of chronic diseases as well as physical, sensory and cognitive impairments, older drivers are considered to be vulnerable to having motor vehicle crashes (Anstey *et al.*, 2005). Indeed, during 2008 in Japan, the traffic accident rate was estimated at 863 cases per 100 thousand older drivers, the third highest after 1685 cases in the 16–24 age group and 1036 cases in the 25–29 age group (Traffic accidents situation, National Police Agency (NPA), 2009). Moreover, the accident

1 rate among drivers under age 65 tended to decrease in
2 the past decade, whereas that among older drivers
3 remained at a high level.

4 Thus, the Japanese government has enforced a traffic
5 safety campaign targeting older drivers and has paid
6 special attention to older drivers suffering from
7 dementia, who are considered a high-risk group. In
8 2002, Section 103 of the Road Traffic Act was amended.
9 In the amended Act, dementia was included as a reason
10 for license revocation, stating that if a driver is found to
11 be 'demented', his/her driving license shall be revoked
12 (Arai Y and Arai A, 2005; Arai Y, 2006). Such efforts
13 can lead to raising the national profile of driving and
14 dementia. However, there are several challenges related
15 to implementation of the Act. It is not easy to identify
16 drivers who suffer from dementia without guidelines and
17 mandatory reports from physicians. In addition, without
18 a clear consensus regarding the progressive decline of
19 cognitive functions, it is difficult to decide when drivers
20 should stop driving (Arai, 2006; Hirono, 2006). This has
21 raised concern that many drivers may continue to drive
22 after onset of dementia, as reported in previous
23 studies (Odenheimer, 1993; Dobbs *et al.*, 2002; Adler
24 and Kuskowski, 2003; Herrmann *et al.*, 2006).

25 The NPA reported that nationwide only 192 drivers
26 had their driver's licenses revoked due to dementia
27 over the last four years since the law was amended.
28 Moreover, the most common reason for license
29 revocation was 'concerns of family members' (133
30 cases), which was followed by 'police activity' (e.g.,
31 handling a traffic accident) (59 cases) ('Older drivers:
32 introduction of cognitive assessments' (Japanese), *The*
33 *Daily Police News*, 20 October 2006). Our previous
34 study regarding family caregivers of current and
35 former drivers who had dementia ($n = 21$) showed
36 that a primary reason for driving cessation among
37 former drivers was because 'family caregivers dis-
38 covered the patient was driving dangerously' (48%),
39 followed by 'patients and family caregivers were
40 persuaded by physicians' (14%), 'traffic accidents'
41 (14%), and 'other' (2%) (Arai A *et al.*, 2006). Cotrell
42 and Wild (1999) demonstrated that either the patient
43 or caregiver was responsible for decisions regarding
44 driving status in most cases of those with Alzheimer's
45 disease (AD) who stopped driving. Similarly, Perkin-
46 son *et al.* (2005) reported from focus-group interviews
47 that most of the stakeholders with respect to driving by
48 persons with AD believed that family members had
49 primary responsibility for identifying and dealing with
50 unsafe drivers. Thus, family members of dementia
51 patients play a pivotal role in decision-making
52 regarding patients' driving and in supporting the
53 eventual goal of driving cessation.

54 However, the decision of driving cessation is often
55 complicated for longtime drivers, and even more so for
56 those with dementia and their family caregivers for a
57 number of reasons: (1) rejection by drivers due to the
58 symptoms of dementia such as memory impairment or
59 unawareness of deficits; (2) rejection by drivers due to
60 a strong need to drive, i.e., because it is a necessary
61 form of transportation; and (3) conflicts between
62 drivers and their family members due to different
63 perceptions about driving such as opinions as to what
64 driving means to the person who is driving. These
65 reasons, including ones which are not necessarily
66 related to dementia, can hinder driving cessation from
67 occurring at the most appropriate time, jeopardizing
68 personal and public safety.

69 Although much of the literature has focused on
70 examining the medical and non-medical predictors of
71 driving cessation in older adults with dementia
72 (Wackerbarth and Johnson, 1999; Adler and Kus-
73 kowski, 2003; Carr *et al.*, 2005; Herrmann *et al.*, 2006),
74 little is known about what kinds of difficulties exist
75 between dementia patients and family members with
76 respect to patients' driving cessation. As Carr *et al.*
77 (2006) have suggested, research is needed regarding
78 family or social barriers that may delay driving
79 cessation in older adults with dementia.

80 The family or social barriers might be, in part, the
81 result of disparities of perceptions regarding driving
82 between dementia drivers and family members.
83 Different perceptions about driving may cause family
84 conflicts, posing possible barriers to achieving driving
85 retirement at the most appropriate time. Furthermore,
86 family caregiving can befall anyone; most individuals
87 are susceptible to the possibility of suffering dementia
88 or becoming family caregivers. It is thus important to
89 explore perceptions among the general public, with the
90 expectation that the findings would provide implica-
91 tions for drivers with dementia and their family
92 caregivers. In addition, it can be useful information to
93 allow the public to better understand and get involved
94 in addressing issues of driving and dementia. We
95 therefore aimed to explore the perceptions of driving in
96 a sample of the general population and examine the
97 differences of perceptions from age and driving status
98 viewpoints.

99 Design and methods

100 In October 2007, we conducted a survey among the
101 general public aged 40 and over in Japan. Participants
102 were selected from a research panel organized by Social
103 Survey Research Information (SSRI) Co., Ltd. The

1 panelists, who were recruited from the general
 2 population and were willing to participate in surveys,
 3 included 31 050 persons aged 40 or over. Each person
 4 eligible for this panel was competent in reading and
 5 answering a series of self-administered questionnaires
 6 distributed by the SSRI; therefore, the quality of this
 7 research panel was assured and responses were valid
 8 and reliable. All panelists lived independently in
 9 communities. If we found that more than one panelist
 10 resided in the same household, we limited participa-
 11 tion to only one member from that household. Of the
 12 1191 who agreed to participate in this study, 1010 were
 13 randomly selected to fit into predetermined categories
 14 by a quota sampling method (Moser and Kalton,
 15 1989). This quota sampling method has been used in
 16 previous studies (Arai Y *et al.*, 2005; Arai Y *et al.*,
 17 2008). The quota controls used in the present study
 18 were gender, age group, driving license status, and
 19 place of residence (urban: population \geq 500 000,
 20 suburban: 100 000 to < 500 000 or rural: < 100 000)
 21 based on Japan's national statistics. Although there
 22 were similar distributions of most of the socio-
 23 demographic characteristics compared with Japanese
 24 population statistics, there was a slightly higher
 25 proportion of study participants who lived in a
 26 household with two or more generations, had higher
 27 education, or were or used to be administrative
 28 workers.

29 Each subject received a self-administered question-
 30 naire that requested information about sociodemo-
 31 graphic factors (e.g., education, annual household
 32 income, employment status, and living arrangement),
 33 driving status (drivers: those who had a driver's license
 34 and frequently drove, and those who had a driver's
 35 license and rarely drove; non-drivers: those who did
 36 not have a driver's license), and perceptions related to
 37 driving.

38 **Perceptions about driving**

39 We asked all participants including drivers and non-
 40 drivers to identify how they perceived 'driving' using
 41 the following question based on a previous study by
 42 Perkinson *et al.* (2005): 'Do you think that driving is a
 43 "right" which we all deserve'? We also asked only the
 44 frequent drivers (i.e., those who had a driver's license
 45 and frequently drove) about possible barriers to
 46 driving cessation using the following question:
 47 'Assuming you have to stop driving, what would be
 48 the reasons, if any, for your reluctance to do so?'

49 The former question was answered by a four-point
 50 Likert scale (agree, agree somewhat, disagree some-
 51 what, disagree), while the latter was a multiple choice
 52 question in which participants chose all the answers
 53 that applied from 15 items created by the authors (a
 54 psychiatrist and public health specialist: YA and AA).

55 what, disagree), while the latter was a multiple choice
 56 question in which participants chose all the answers
 57 that applied from 15 items created by the authors (a
 58 psychiatrist and public health specialist: YA and AA).

59 **Statistical analyses**

60 Multiple logistic regression models were used to
 61 compare the older group (65+ years) and younger
 62 group (40–64 years), and the drivers and non-drivers,
 63 on their perceptions of driving, adjusting for potential
 64 confounding factors such as age group/driving status,
 65 gender, place of residence, education, annual house-
 66 hold income, living arrangement, and employment
 67 status. The associations between the probability of each
 68 reason for feeling reluctant to stop driving and the age
 69 group were evaluated by calculating the crude odds
 70 ratios (ORs) and the ORs adjusted for potential
 71 confounding factors, including gender, place of
 72 residence, education, annual household income, living
 73 arrangement, and employment status using the logistic
 74 regression models. All calculations were performed
 75 using SAS version 9.1.3 for Windows (SAS Institute
 76 Inc., Cary, NC).

77 **Results**

78 Table 1 shows the characteristics of the respondents
 79 ($n = 1010$) by age group and driving status. Most of the
 80 older drivers were men; further, the older age group
 81 had fewer years of education and lower annual
 82 household incomes than the younger age group. The
 83 younger drivers were more likely to be employed and
 84 lived in households with two or more generations
 85 present. The younger participants also tended to live in
 86 urban areas. Most of the drivers in both age groups
 87 frequently drove.

88 Regarding how the participants perceived 'driving',
 89 the largest number of older drivers agreed that 'driving
 90 is a "right" which we all deserve' (Table 2). Perceptions
 91 of driving did not significantly differ between the age
 92 groups. However, we found that the drivers tended to
 93 regard 'driving' as a deserved right compared with the
 94 non-drivers after controlling for potential confoun-
 95 ders.

96 As shown in Table 3, 'It would be difficult for me to
 97 go out' (65.8% of the total) was the most common
 98 reason given for reluctance to stop driving among the
 99 frequent drivers, followed by 'It would be difficult for
 100 my family members to go out' (43.0%), 'Loss of
 101 something I enjoy' (29.2%), and 'A driver's license is
 102 difficult to get' (29.2%).

Table 1 Characteristics of participants by age group and driving status

	Older (65+ years)		Younger (40–64 years)	
	Drivers (n = 192)	Non-drivers (n = 258)	Drivers (n = 451)	Non-drivers (n = 109)
Men, n (%)	136 (70.8)	89 (34.5)	251 (55.7)	29 (26.6)
Age, mean (SD)	72.9 (5.3)	75.5 (6.1)	48.0 (6.5)	52.9 (8.0)
Education, n (%) ^a				
<10 years	49 (25.9)	78 (30.4)	12 (2.7)	8 (7.4)
10–13 years	74 (39.2)	134 (52.1)	148 (32.9)	55 (50.9)
13+ years	66 (34.9)	45 (17.5)	290 (64.4)	45 (41.7)
Annual household income (thousands of Yen), n (%) ^b				
<4000	75 (42.4)	103 (43.3)	47 (11.0)	33 (31.7)
4000–8000	69 (39.0)	103 (43.3)	185 (43.4)	46 (42.2)
8000+	33 (18.6)	32 (13.5)	194 (45.5)	25 (24.0)
Employed, n (%)	53 (27.6)	25 (9.7)	355 (78.7)	54 (49.5)
Living arrangement, n (%) ^c				
Alone	10 (5.4)	27 (11.1)	7 (1.6)	6 (5.7)
Couple	95 (50.8)	84 (34.4)	56 (12.8)	34 (32.4)
Two or more generations in household	82 (43.9)	133 (54.5)	374 (85.6)	65 (61.9)
Place of residence, n (%) ^d				
Urban	58 (30.7)	84 (34.6)	249 (55.6)	51 (49.5)
Suburban	56 (29.6)	71 (29.2)	103 (23.0)	27 (26.2)
Rural	75 (39.7)	88 (36.2)	96 (21.4)	25 (24.3)
Frequently driving, n (%)	145 (75.5)	na	372 (82.5)	na

Missing data: six data points (a), 65 data points (b), 37 data points (c), and 27 data points (d).

useful as an ID card' (27.2%). The reason 'Loss of a motivating factor in my life' was significantly more common, among the older drivers than among the younger drivers, even after adjusting for potential confounders. Moreover, compared with the younger drivers, the older drivers appeared to be concerned about 'Loss of something I enjoy' ($p = 0.05$) and 'Loss of a hobby' ($p = 0.08$) after driving cessation, although these reasons were not significant.

Discussion

The present study clearly demonstrated the disparities in perceptions about driving in a sample of the Japanese general public.

Perceptions about driving varied according to the respondent's driving status. Irrespective of age group, drivers tended to believe that driving was a deserved right, whereas non-drivers were less likely to think so. Further research is needed regarding why the difference in perceptions existed. These different perceptions are nonetheless thought to be a cause of possible conflicts among family members or stakeholders; those drivers who perceive driving as a right may firmly refuse to give up driving or even rigidly adhere to continuing to drive. These results also indicate that drivers and non-drivers may have a different understanding of 'driving'. Therefore, it is necessary for the general population, irrespective of driving status, to promote a more precise recognition of current driving license regula-

Table 2 Perceptions of driving among the general public

	Older (65+ years)		Younger (40–64 years)		<i>p</i> value ^b (adjusted for potential confounding variables)	
	Drivers (n = 192)	Non-drivers (n = 257) ^a	Drivers (n = 449) ^a	Non-drivers (n = 109)	Older vs. younger	Drivers vs. non-drivers
'Driving is a "right" which we all deserve'					0.7462	0.0009
Agree/Agree somewhat, n (%)	147 (76.6)	146 (56.8)	311 (69.3)	72 (66.1)		
Disagree somewhat/Disagree, n (%)	45 (23.4)	111 (43.2)	138 (30.7)	37 (33.9)		

^aOne missing data point for the older non-drivers and two missing data points for the younger non-drivers.

^bCalculated by multiple logistic regression model including age group/driving status, gender, place of residence, education, annual household income, living arrangement, and employment status.

Table 3 Possible reasons for reluctance to stop driving among frequent drivers (multiple answers)

Reason	Older drivers (65+ years, n = 144) ^a	Younger drivers (40–64 years, n = 370) ^a	Older vs. younger drivers	
	n (%)	n (%)	Crude OR	Adjusted OR ^b
I am not reluctant to stop driving	22 (15.3)	51 (13.8)	1.13	1.64
It would be difficult for me to go out	90 (62.5)	248 (67.0)	0.82	0.88
It would be difficult for my family members to go out	59 (41.0)	162 (43.8)	0.89	0.87
Loss of something I enjoy	56 (38.9)	94 (25.4)	1.87*	1.81
Loss of independent living	39 (27.1)	81 (21.9)	1.33	1.10
A driver's license is useful as an ID card	38 (26.4)	102 (27.6)	0.94	1.16
Loss of a motivating factor in my life	28 (19.4)	30 (8.1)	2.74*	4.93*
Loss of a way to relax	21 (14.6)	43 (11.6)	1.30	1.85
Loss of a hobby	20 (13.9)	32 (8.7)	1.70	2.44
Loss of a sense of self	20 (13.9)	43 (11.6)	1.23	0.91
I want to keep my driver's license	18 (12.5)	38 (10.3)	1.25	0.77
Loss of my dignity	15 (10.4)	29 (7.8)	1.37	1.31
Loss of something I commit to regularly	14 (9.7)	22 (6.0)	1.70	2.02
Loss of an opportunity to be alone	8 (5.6)	22 (6.0)	0.93	2.06
I don't know how to return my license	0 (0.0)	0 (0.0)	—	—

^aOne missing data point for the older drivers and two missing data points for the younger drivers.

^bOdds ratio (OR) was adjusted for gender, place of residence, education, annual household income, living arrangement, and employment status by multiple logistic regression model.

**p* < 0.05.

tions to close the perception gap and for the sake of public safety.

Our study also showed that among the frequent drivers in both older and younger groups, most of the reasons for reluctance to stop driving were related to the possible loss of personal mobility (shown in Table 3). Our finding partly supports Freund's view (Freund and Szinovacz, 2002) in which decisions to stop driving were associated not only with competence but also with the availability of alternate transportation opportunities. In addition, a previous study regarding family caregivers of dementia patients by Mizuno *et al.* (2008) showed that family caregivers cited alternative transportation, and in particular the availability of family caregivers or other family members who could drive instead of the patient, as essential to facilitate the cessation of driving. It has also been reported that the availability of transportation services was a key factor in allowing older people to keep attending social activities and maintain autonomy (Roper and Mulley, 1996; Dickerson *et al.*, 2007; O'Neill, 2007). It is clear that alternate transportation is needed to facilitate the smooth transition to another form of transportation after driving retirement and prevent older people from experiencing restricted mobility. Although availability of a mass transit system varies between rural and urban areas in Japan, a bus or community bus (one that circles around the area) has been developed as a practical form of transportation to enhance the mobility of the residents and is expected to support

those who have stopped driving as well as their family members.

We found a significant difference between the older and younger age groups with respect to the reasons for reluctance to stop driving. The older drivers were more likely to value the qualitative aspects of driving, for example, driving as 'a motivating factor in my life', 'something I enjoy', and consider a 'hobby'. It appears that driving is regarded not only as a mode of transportation but also as a meaningful activity for older drivers. This might be related to the findings of another study in which 93% of drivers diagnosed with dementia (*n* = 43) thought that driving was important to their quality of life (Adler and Kuskowski, 2003). Both practical and qualitative aspects of driving can be important factors in maintaining independence among older people.

These noticeable reasons for reluctance to stop driving may be related to the negative consequences of driving cessation among older people or people with dementia cited in previous reports: increased depressive symptoms (Marottoli *et al.*, 1997; Fonda *et al.*, 2001; Ragland *et al.*, 2005), decreased out-of-home activity levels (Marottoli *et al.*, 2000), difficulties in accessing social and recreational services (Taylor and Tripodes, 2001), and increased risk for entry into a nursing home (Freeman *et al.*, 2006). We therefore suggest that more attention be devoted to not only the problem of decreased mobility but also alternatives to the qualitative aspects of driving. One possible

alternative would be to increase opportunities for participating in leisure, physical, and social activities and social services, which could help older people find something else to 'motivate them in their lives', 'enjoy', and have as a 'hobby' after driving retirement. Moreover, to seek appropriate alternatives for individuals, family members, and stakeholders should communicate with the older drivers early in the process of driving cessation to try to better understand what 'driving activity' means for them.

The limitations of this study should be noted. Although our study sample was selected from a research panel based on national statistics using a quota sampling method, a certain amount of selection bias was unavoidable. In addition, we categorized the respondents into two groups of driving status: drivers and non-drivers. However, we did not know if the non-drivers group included former drivers who had returned a driver's license and stopped driving. A self-administered questionnaire, as used in this study, can represent another information bias. Perceptions about driving were not sufficiently explored by the closed-ended format in the questionnaire; thus, the results should be carefully interpreted. We did not take into account in the analyses whether the licensed drivers had other drivers to provide transportation. Instead, we used living arrangement as a confounding factor related to the availability of alternate drivers that could be controlled in the analyses.

Despite these limitations, our findings provide useful insights into the possible family or social barriers to driving cessation in the case of drivers with dementia. As observed in the present study, the disparities in perceptions about driving may cause conflicts among stakeholders with respect to when dementia patients should have their licenses revoked. It is thus important to facilitate general public involvement in considering the public health issue of driving and dementia, closing the perception gap and developing strategies to better address the difficulties related to driving cessation as a whole society. Moreover, in addition to practicable transportation alternatives, the qualitative aspects of driving should also be paid more attention when preparing alternatives. In this way, the goal of more effectively meeting the needs of retiring drivers while also allowing them to maintain autonomy can be more easily achieved.

Conflict of interest

None known.

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Key points

- The drivers among the general public that participated in this study tended to highly agree that 'driving is a "right" which we all deserve', compared with the non-drivers.
- The most common reason given for reluctance to stop driving among frequent drivers was the loss of personal mobility; further, older drivers were more likely than younger drivers to value the qualitative aspects of driving.
- Disparities in the general public's perceptions about driving may present possible family or social barriers to driving cessation in the case of drivers with dementia.
- It is suggested that not only mobility but also the qualitative aspects of driving be paid more attention when developing alternatives to driving.

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What do we know about dementia?: a survey on knowledge about dementia in the general public of Japan

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SUMMARY

Objective The importance of early detection of dementia has been highlighted in recent years by the medical and scientific community; however, delays often occur between the recognition of signs or symptoms and a decision by the patient or family to seek professional help. Such delays may be caused by a lack of knowledge about dementia among patients and family members. The aim of this study was to determine the understanding of dementia among the general public.

Methods We conducted a survey in Japan that asked 11 questions regarding knowledge of 'general' information, 'symptoms', and 'biomedical' issues related to dementia. A quota sampling method was used to select 2,500 participants, 2,115 of who were eligible for the analyses.

Results The average number of correct responses among females was significantly greater than that among the males. A multiple comparisons test demonstrated that middle-aged women were more knowledgeable than younger and older respondents. It was revealed that there was a lack of knowledge on biomedical aspects of dementia, i.e. cause, treatment, and prognosis along with a misunderstanding of dementia as senescence forgetfulness among the general public.

Conclusions There appeared to be gaps in knowledge on dementia among the general public, which may prevent caregivers from planning upcoming social and financial challenges. Correct information needs to be given by health professionals and care staff. Educational initiatives planned for the general public could be useful, and should target those groups, men and non-middle aged women who have lower knowledge. Copyright © 2008 John Wiley & Sons, Ltd.

KEY WORDS — dementia; knowledge; awareness; health education; survey; help-seeking behaviour

INTRODUCTION

The importance of early detection of dementia has been highlighted in recent years by the medical and scientific community; however, delays often occur between the recognition of signs (or symptoms) and a decision by the patient or family to seek professional help. Such delays may be caused by barriers such as a lack of knowledge about dementia among patients and family members (Boise *et al.*, 1999; Werner, 2003). Thus, to encourage patients and family members to

seek help at an early stage, awareness of dementia and/or the levels of understanding of dementia among the general public should be raised. A greater public awareness is vital for future health care practices and policy development (Yeo *et al.*, 2007).

Much of the focus of research on knowledge of dementia has been on family members (Graham *et al.*, 1997; Werner, 2001; Proctor *et al.*, 2002; Spitznagel *et al.*, 2006), rather than the general public (Steckenrider, 1993; Werner, 2003). Among the relatively few studies that have investigated the general public's level of knowledge about dementia, samples have tended to be small and non-representative. Another limitation of previous studies is that they have mainly been conducted among Caucasians in Europe and North America. Differences in the level of knowledge of dementia, however, may be derived from ethnicity,

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nationality and culture (Ayalon and Arean, 2004; Purandare *et al.*, 2007). The present study was aimed at elucidating with a larger sample the extent of the Japanese general public's knowledge about dementia. Given that the prevalence of dementia among older people in Japan is predicted to peak at around 10.5% in the year 2035 (Arai and Ikegami, 1998), it appeared timely to investigate the level of understanding about dementia in this population.

METHODS

Design and participants

In July 2006 we conducted a survey that asked 11 questions regarding knowledge of dementia. The survey was conducted by the same method as had been undertaken in a similar earlier survey by the authors (Arai *et al.*, 2005). Briefly, participants were selected from a panel organized by the Social Survey Research Information (SSRI) Co., Ltd in Japan. For the panel consisting of 65,750 persons from the general population and aged 20 years or more, 2,500 were selected by a quota sampling method (Moser and Kalton, 1989). Each subject received a self-administered questionnaire that sought information including gender, age (in 5-year intervals), and items related to dementia knowledge.

Dementia knowledge

The questionnaire about dementia in the present study (See Table 2) consisted of 11 items covering 'general' information (questions 1, 2, 3, 4), 'symptoms' (questions 5, 7, 8), and 'biomedical' issues including treatment and prognosis (questions 6, 9, 10, 11). We constructed the questionnaire in several steps. First, a list of question items was generated based on face validity. Some of these items were selected from previous studies (Dieckmann *et al.*, 1988; Gilleard and Groom, 1994; Graham *et al.*, 1997) whilst the others were written by the authors (psychiatrist and public health specialist: YA and AA). Second, the list was reviewed by a psychiatrist and several public health specialists for wording and coverage of the knowledge area. The items used a true-false format.

In developing the items, we used a criterion-referenced rather than a norm-referenced strategy. A criterion-referenced strategy draws test items from an existing body of knowledge, in this case, concerning dementia. The items drawn from a diverse body of knowledge would not be expected to form a scale or have high internal reliability. They are judged instead

on how well they represent knowledge in the area. This approach is more sensitive than a norm-referenced strategy for identifying people's knowledge of content in a specific area (Isaac and Michael, 1982; Dieckmann *et al.*, 1988).

Statistical analysis

The analysis looked at the overall level of knowledge and the effects of gender and age on knowledge. Participants' age was classified into three categories: 20–39 years, 40–64, and 65+. This classification was used because age 40 and age 65 years old have significant meaning in the Long-Term Care (LTC) insurance program in Japan (Ministry of Health, Labour and Welfare, 1999; Arai *et al.*, 2003). Specifically, those who are aged 40 start to pay monthly premiums and those who are 65 years or older are entitled to receive care services under the LTC insurance program in Japan. To evaluate the effects of gender and age on knowledge, a two-way analysis of variance (ANOVA) with Tukey-Kramer multiple comparisons tests was conducted. We also looked at the effects of age and gender on the proportions of correct responses to each of the 11-item dementia knowledge test using Chi-square tests. The criterion for statistical significance was $p < 0.05$ for all analyses. All calculations were performed using SAS version 9.1.3 for Windows (SAS Institute Inc., Cary NC).

RESULTS

Of the 2,500 subjects, 2,161 returned the questionnaire and 2,115 were eligible for the analyses; 747 aged 20–39 years, 795 aged 40–64, and 573 aged 65+.

Table 1 shows the average number of correct responses to questions related to knowledge of dementia. Of the 11 items, the average number of correct responses was 6.8 (SD = 1.61) in total respondents. The two-way ANOVA demonstrated that there were main effects of gender and age on correct responses on dementia knowledge. The average number of correct responses among the females was significantly greater (7.0; SD = 1.58) than among the males (6.7; SD = 1.63). Among the age groups, the Tukey-Kramer multiple comparisons test for least-squares mean of the correct responses showed that the middle-aged respondents had a higher mean correct than in other age groups. Also, there was a significant interaction between gender and age, which meant that the effect of gender was not constant across three-age groups; the multiple comparisons analysis showed that

Table 1. Correct responses reflecting dementia knowledge

	<i>n</i>	No. of correct responses ^a	SD ^b	<i>p</i> -value ^c
Total	2115	6.9	1.61	
Gender				<0.0001
Male	991	6.7	1.63	
Female	1124	7.0	1.58	
Age				0.0012
20–39	747	6.7	1.65	
40–64	795	7.0	1.52	
65+	573	6.8	1.66	
Interaction between gender and age				0.0463
Male, 20–39	326	6.6	1.73	
Male, 40–64	394	6.8	1.54	
Male, 65+	271	6.8	1.62	
Female, 20–39	421	6.9	1.57	
Female, 40–64	401	7.3	1.47	
Female, 65+	302	6.8	1.69	

^aArithmetic mean of correct responses.

^bStandard deviation of the arithmetic means of correct responses.

^cSignificance tests for main effects for both gender and age and for interaction between them by two-way ANOVA.

middle-aged women (40–64 years) were significantly more knowledgeable compared to younger (20–39) and older (65+) men and women.

Table 2 shows the proportions of correct answers to each item in terms of dementia knowledge among total respondents. We obtained several interesting findings. First, the proportions of correct responses to items related to 'biomedical aspects of dementia' tended to be low. For example, only 10% of the respondents knew that dementia could shorten one's life expectancy after the onset (Question 11) and only 40% knew that some types of dementia were treatable (Question 6). Second, respondents were less likely to have information regarding the causes of dementia such as vascular dementia and hereditary types (Questions 9 and 10). Third, the proportions of correct responses to the items related to 'general knowledge' and 'symptoms' tended to be moderate to high. However, to our surprise, nearly 20% of the respondents still believe that senescence forgetfulness progresses with advancing age (Question 4). Fourth, females showed age-group disparities in the proportions of correct responses to most items, irrespective of the knowledge categories ('general': Questions 1, 2, and 4; 'symptoms': Questions 5 and 7; 'biomedical': Question 9). Middle-aged (40–64 years) women appeared to be more knowledgeable compared to younger (20–39) or older (65+) age groups. On the other hand, in males, we found differences of the proportions of correct responses among the age-groups in only a few items (Questions 2 and 10).

DISCUSSION

The present study showed that females appeared to have more knowledge about dementia than did males among the Japanese general public. In particular, in terms of age and gender, middle-aged women seemed to know much more than other groups.

Few prior studies have indicated a gender difference with regard to the extent of dementia knowledge. On the other hand, the relation between age and knowledge on dementia has been found to be inconsistent in previous studies; many of these studies targeted those who are aged 45 years or older without including younger people (Steckenrider, 1993; Werner, 2003; Ayalon and Arean, 2004). In Werner's study, advancing age was constantly associated with lower knowledge about Alzheimer's disease (AD) among community-dwelling people who did not have a close relative diagnosed with AD; likewise, in Steckenrider's study, older people knew less about AD among general public. In contrast, a study conducted by Ayalon and Arean did not show any significant effect of age on the extent of knowledge about AD among patients recruited from primary-care clinics.

Our study targeted the general public, and included younger people as well as middle-aged and older ones. The findings suggested that the relation of age and the level of dementia knowledge was not linear. Instead, our study highlighted the highest level of knowledge about dementia among middle-aged women. Two factors may account for these findings. First, as

Table 2. Proportions of correct responses to questions related to dementia knowledge by age group and gender among the general public

Knowledge category	No. Question	True/False	Correct responses (%)			
			Total (n = 2,115)	Male	Female	
			20-39 (n = 326)	40-64 (n = 394)	65+ (n = 401)	65+ (n = 302)
General	1	Dementia is forgetfulness due to aging. Everyone will have a dementia with advancing age	91.7	91.4	89.7	89.1**
General	2	Dementia is a disease affecting the brain. Not everyone will suffer dementia.	68.4	75.9	67.5*	74.2**
General	3	Risk of dementia increases with age.	70.9	69.3	72.0	69.9
General	4	Senescence forgetfulness progresses with advancing age, resulted in the patients are unable to recognize their families.	78.5	80.0	79.3	79.1*
Symptoms	5	Dementia is defined as a reduction of cognitive abilities including understanding and judgement, as well as memory loss.	65.6	70.8	72.7	67.6**
Biomedical (treatment)	6	Some type of the dementia is treatable.	29.8	33.8	38.0	43.1
Symptoms	7	People suffering dementia become unable to perform familiar tasks at once.	95.7	98.2	95.6	95.7**
Symptoms	8	People suffering dementia become unable to recognize time, place, and person at once.	93.6	96.2	94.5	94.4
Biomedical (cause)	9	Some type of the dementia is caused by cerebrovascular diseases.	38.3	45.9	46.1	47.7**
Biomedical (cause)	10	Some type of the dementia is hereditary.	12.6	7.1	10.3*	12.6
Biomedical (prognosis)	11	Dementia shortens the life expectancy after onset.	12.0	8.4	12.2	10.3

Differences among the age groups by gender were examined using Chi-square test.

* $p < 0.05$.** $p < 0.01$.