

原 著

# Steadily decreasing proportion of overlooked dementia in community-dwelling Japanese elderly: six-year follow-up in an urban population

## 都市部地域在宅高齢者の認知症見逃し割合は着実に減少 6年間の追跡調査より

Chisako YAMAMOTO<sup>1)</sup>, Tanji HOSHI<sup>2)</sup>

山本 千紗子<sup>1)</sup>、星 旦二<sup>2)</sup>

1) School of Nursing, Jobu University

2) Department of Urban Environment, Tokyo Metropolitan University

1) 上武大学看護学部

2) 首都大学東京都市環境学部

### Abstract

The purpose of this study is to clarify changes in the proportion of dementia that is overlooked, with a 6-year follow-up. Self-administered questionnaires were mailed in 2001, 2004 and 2007 to all people in one community aged 65 years and older living with a spouse and/or child's family. The number of subjects was 13,058 in 2001, 13,182 in 2004 and 15,084 in 2007.

Cognitive scores were measured by three capacities, making bank deposits and/or withdrawals, filling out forms/documents and reading books/newspapers, in people whose odds ratios for demented status were reported to be high with multiple logistic regression in a previous study. One point was allocated to positive answers, and the cut-off point determined by receiver operator characteristic curves was 0-1/2-3. The ratios of the lower-scoring cohort (LSC) among the non-demented (ND) were 6.3% and 9.3% in 2001, 5.1% and 6.6% in 2004, and 4.1% and 5.8% in 2007 in men and women, respectively. A previous study by Yamamoto and Hoshi suggested that the proportion of LSC in ND was equivalent to that of overlooked dementia in association with mortality and longevity. Thus, the results of this study showed that the proportion of overlooked dementia has been steadily decreasing. During the past several years, municipalities have been providing programs for early detection and prevention of dementia under nationwide measures promoted by the government. Decreases in the proportion of overlooked dementia show that while those efforts have been significant, 4.1% of men and 5.8% of women still exist whose demented status is overlooked. Further efforts and actions to detect early stages of dementia are needed to improve the quality life of the elderly.

### 抄 録

認知症見逃し割合の変化を6年間の追跡調査より明らかにすることを目的とした。2001年、2004年、2007年に65歳以上の全地域在宅高齢者に自記式質問票を郵送した。分析対象者は2001年13,058人、2004年13,182人、2007年は15,084人であった。知的能動性の測定には「預貯金の出し入れ・年金等の書類記入・新聞書物を読む」の3活動項目を用いた。多重回帰分析により、認知症状態に対するこれらのオッズ比は高いことが先行研究により明らかにされている。各活動を1点として得点化し、ROC曲線(受診者動作特性曲線)によりカットオフポイント(0-1点/2-3点)を求め、0-1点を低得点群(lower-scoring cohort; LSC)としてその割合を求めた。その結果、認知症ではない群(the non-demented; ND)における低得点群割合は、2001年が男性6.3%、女性9.3%、2004年は男性5.1%、女性6.6%、2007年は男性4.1%、女性5.8%であった。山本らの先行研究は、死亡率と寿命との関連から、NDにおけるLSCは認知症見逃し割合に相当することを明らかにしており、本研究結果は、認知症見逃し割合が着実に減少していることを示している。近年、政府や地方自治体により全国的に認知症の予防や早期発見のプログラムが提供されており、

その成果の表れと思われる。しかしなお男性 4.1%、女性 5.8%の見逃しが見られ、高齢者の晩年の QOL を高めるために認知症の早期発見に一層の努力が求められる。

Keywords: proportion of overlooked dementia, three cognitive capacities, lower-scoring cohort in the non-demented, 6-year follow-up

キーワード：認知症見逃し割合、知的能動性 3 活動、非認知症者における知的能動性低得点群、6 年間追跡調査

## 1. INTRODUCTION

The total population of Japan in 2009 was 127.51 million, a decrease of 180 thousand from the previous year, while the population of the people aged 65 years and older (elderly) reached the record number of 29.01 million. Its proportion of the national total population, i.e., the aging rate, was 22.7%. Despite of the decrease in the total population, the population of the elderly will continue to increase, exceeding 30 million in 2015, reaching 35 million in 2025, and peaking at 38.6 million in 2042, after which it is predicted to start decreasing. However, the population of the elderly between 75 and 84 years will continue rising and in 2017 will exceed the population of the elderly between 65 and 74 years. The aging rate will still continue to rise, to 40.5% in 2055, meaning that 1 in every 2.5 people will be 65 years and older<sup>1)</sup>. Along with these increases in the elderly population, the average life expectancy rose to 79.29 for men and 86.05 for women in 2008 and is estimated to rise to 83.67 and 90.34 for men and women respectively in 2055. With the world's greatest longevity, the number of people in Japan suffering from dementia is estimated to jump from 2.05 million in 2005 to 4.45 million in 2035. The increase is expected to be striking in big cities, with Saitama prefecture at the top with 3.4 times and Aichi and Osaka prefectures with 2.5 times<sup>2)</sup> as many people with dementia compared with the national average.

With drug (donepezil) and other therapies today, improvement in mild and moderate cognitive impairment and demented status are possible and the progression of the disease can possibly be prevented. Although early detection and implementation of treatment are essential, early symptoms of dementia are difficult to distinguish from senile memory disorder. It has been reported that the first consultation with a physician may be delayed for approximately two years<sup>3), 4)</sup>. Thus, dementia is often overlooked. Previous studies have shown that

only 50 % of people with dementia are diagnosed<sup>5)</sup> in primary care settings, and that by the time of diagnosis the demented status may have progressed to a considerable extent<sup>6)</sup>.

Since previous studies have not shown the extent to which demented status has been overlooked, Yamamoto and Hoshi analysed data from the 2001 Complete Survey of the Community-dwelling Elderly for City A and clarified the proportion of overlooked dementia, which was 6.3% (347/5,475) in men and 9.3% (570/6,111) in women in 2001.

Early detection and implementation of treatment are essential, as mentioned above. The government realized the significance of promoting more effective measures against dementia for "Immediate creation of a society where people can live comfortably even after suffering from dementia" and implemented the program entitled "Nationwide Caravan to Train One Million Dementia Supporters". Under these measures, municipalities have been providing lectures and making other efforts to promote understanding of early symptoms of dementia and prevent dementia, and training dementia supporters in communities over the past several years. The purpose of this study is two-folds: to clarify the changes in the proportion of overlooked dementia in City A after 2001 through a 6-year follow-up, and to discuss effectiveness of measures and programs against dementia.

## II. METHODS

### 1. Baseline and follow-up data

Baseline data from the Complete Survey of the Community-dwelling Elderly of 65 Years and Older were collected in September 2001. Self-administered questionnaires were mailed to all of the subject elderly. Responses were returned by mail by the addressees themselves or by proxies if the addressees were unable to respond for some reasons such as absence, being hospitalized, cognitive impairment

or demented status. Questionnaires consisted of 44 items such as fundamental attributes, respondents (addressee himself or herself, or proxy), family members, self-perceived health, activities of daily living, instrumental activities of daily living, lifestyle, life satisfaction, leisure activities, socio-economic status, long-term care insurance, and others.

Those whose family-caregivers responded as proxies due to the addressee's dementia or cognitive impairment and those who reported their own demented status were defined as the recognized demented (RD), and the others as the non-demented (ND).

Follow-up data were collected in September 2004 and in October 2007. Self-administered questionnaires were mailed, which consisted of the almost same items as in the 2001 survey. At the same time, survival and death of the respondents in the 2001 were investigated.

## 2. Study population

### 1) The 2001 complete survey of the community-dwelling elderly

The details of the 2001 baseline study have been described in a previous report<sup>7)</sup>. In brief, questionnaires were mailed to all of the elderly aged 65 years and older living with a spouse and/or child's family, which were 16,462 in number, and 13,195 individuals responded by mail (response rate 80.2%). After inappropriate responses were excluded, the number of analysis subjects was 13,058, among which 10,730 addressees (5,145 men and 5,585 women) responded by themselves and 1,410 by proxies (518 men and 892 women), who were all family members. The number of RD was 1,134 (408 men and 726 women). Average age and standard deviation (SD) was  $80.6 \pm 9.2$  in men and  $84.7 \pm 7.7$  in women in RD, and  $72.0 \pm 6.1$  and  $73.1 \pm 6.7$  in men and women, respectively, in ND.

### 2) Outlines of City A

City A is located in the suburbs of Shinjuku, a subcenter of Tokyo, a distance of 40-50 minutes' train ride. According to the 2005 Census, it had a population of 146,000, and consisted of 62.9 thousand households. The largest proportion, 80.0%, worked in tertiary industry, the service industry, about 58% worked in information technology, medicine, care and welfare service, education including supplementary

private schools, government and local offices, and other professions that were difficult to classify.

The aging rate in 2005 was 15.8%, which was lower than national average of 20.2%. This was probably because approximately 60% of the population lives in the so-called New Town, among which population aged 45 to 54 years occupies the largest proportion<sup>8)</sup>. The aging rate rose to 19.2% as of January 1, 2009; however, it was still lower than national average of 22.8% in 2009. City A is possibly a younger city in metropolitan Tokyo.

### 3) Follow-up surveys in 2004 and 2007

In the 2004 Survey, questionnaires were mailed to 20,938 elderly people and 13,460 responded, for a response rate 64.3%. The number of analysis subjects was 13,182 (6,235 men and 6,947 women), and the number of RD was 989 (377 men and 612 women). Average age and SD was  $78.6 \pm 8.4$  in men and  $85.1 \pm 7.1$  in women in RD, and  $72.1 \pm 6.0$  and  $73.2 \pm 6.7$  in men and women, respectively, in ND.

In the 2007 Survey, 25,316 questionnaires were mailed and 15,428 people responded, for a response rate 60.9%. The number of analysis subjects was 15,084 (7,081 men and 8,003 women), and the number of RD was 1,082 (402 men and 680 women). Average age and SD was  $78.9 \pm 8.0$  in men and  $84.5 \pm 6.9$  in women in RD, and  $72.5 \pm 6.0$  and  $73.3 \pm 6.6$  in men and women, respectively, in ND.

## 3. Analytical methods

Cognitive scores were measured by three cognitive capacities: 1) making bank deposits and/or withdrawals, 2) filling out forms/documents such as pensions, and 3) reading books/newspapers. The odds ratios of these capacities to demented status were shown to be high by multiple logistic regression analysis in a previous study<sup>9)</sup>. One point was allocated to a positive answer and scores ranged from 0 to 3 points. Areas under the receiver operator characteristic curves (AUC) were calculated and the highest AUC, i.e., the cut-off point of 0-1/2-3, was determined. The 0-1 scoring cohort was defined as the lower-scoring cohort (LSC) and the 2-3 scoring cohort as the higher-scoring cohort (HSC). The ratios

of LSC in ND in 2004 and 2007 were calculated as the proportion of overlooked dementia.

#### 4. Ethical procedures

An agreement was made between City A and the University in order to protect personal data. The University Committee on Ethical Issues approved the surveys and study. Individuals were all numbered without names, and an alternative "I don't want to answer." was provided, so that all respondents were assumed to have consented to the surveys.

### III. RESULTS

#### 1. Ratio of the lower-scoring cohort and other statistical results in the 2004 survey

With subjects divided into LSC and HSC by the cut-off point, the ratios of LSC in RD were 86.1% (62/72) in men and 94.5% (172/182) in women. They

were 5.1% (301/5,907) and 6.6% (420/6,392) in men and women, respectively, in ND. Sensitivity was 17.1% in men and 29.1% in women and specificity was 99.8% in both men and women. Thus, the results suggest the proportion of overlooked dementia in 2004 was 5.1% in men 6.6% in women (see Table 1).

#### 2. Ratio of the lower-scoring cohort and other statistical results in the 2007 survey

The ratios of LSC in RD were 74.6% (91/122) in men and 89.3% (208/233) in women. They were 4.1% (274/6,760) and 5.8% (432/7,417) in men and women, respectively, in ND. Sensitivity was 24.9% in men and 32.5% in women and specificity was 99.5% and 99.6% in men and women respectively. The proportion of overlooked dementia in 2007 is estimated to be 4.1% in men and 5.8% in women (see Table 2).

Table 1. Scores of Cognitive Capacities in Recognized-demented and Non-demented Cohorts in 2004  
n (%)

Men	Scores of Cognitive Capacities			Women	Scores of Cognitive Capacities		
	Lower Score (0-1)	Higher Score (2-3)	Total		Lower Score (0-1)	Higher Score (2-3)	Total
Recognized-demented (RD)	62 (86.1)	10 (13.9)	72 (100.0)	Recognized-demented (RD)	172 (94.5)	10 (5.5)	182 (100.0)
Non-demented (ND)	301 (5.1)	5,606 (94.9)	5,907 (100.0)	Non-demented (ND)	420 (6.6)	5,972 (93.4)	6,392 (100.0)
Total	363 (6.1)	5,616 (93.9)	5,979 (100.0)	Total	592 (9.0)	5,982 (91.0)	6,574 (100.0)

Sensitivity : 62/363=17.1%  
Specificity : 5,606/5,616=99.8%  
Positive predictive value : 62/72=86.1%  
Negative predictive value : 5,606/5,907=94.9%

Sensitivity : 172/592=29.1%  
Specificity : 5,972/5,982=99.8%  
Positive predictive value : 172/182=94.5%  
Negative predictive value : 5,972/6,392=93.4%

Note) Subjects who answered all three capacities were included in analyses.

Table 2. Scores of Cognitive Capacities in Recognized-demented and Non-demented Cohorts in 2007  
n (%)

Men	Scores of Cognitive Capacities			Women	Scores of Cognitive Capacities		
	Lower Score (0-1)	Higher Score (2-3)	Total		Lower Score (0-1)	Higher Score (2-3)	Total
Recognized-demented (RD)	91 (74.6)	31 (25.4)	122 (100.0)	Recognized-demented (RD)	208 (89.3)	25 (10.7)	233 (100.0)
Non-demented (ND)	274 (4.1)	6,486 (95.9)	6,760 (100.0)	Non-demented (ND)	432 (5.8)	6,985 (94.2)	7,417 (100.0)
Total	365 (5.3)	6,517 (94.7)	6,882 (100.0)	Total	640 (8.4)	7,010 (91.6)	7,650 (100.0)

Sensitivity : 91/365=24.9%  
Specificity : 6,486/6,517=99.5%  
Positive predictive value : 91/122=74.6%  
Negative predictive value : 6,486/6,760=95.9%

Sensitivity : 208/640=32.5%  
Specificity : 6,985/7,010=99.6%  
Positive predictive value : 208/233=89.3%  
Negative predictive value : 6,985/7,417=94.2%

Note) Subjects who answered all three capacities were included in analyses.

#### IV. DISCUSSION

##### 1. Ratios of lower-scoring cohort suggest proportion of overlooked dementia

Yamamoto and Hoshi showed in a previous study<sup>7)</sup> that the size of the lower-scoring cohort would suggest the proportion of overlooked dementia by following the elderly at the baseline for 6 years.

The number of the elderly followed was 12,143 (5,664 men and 6,479 women) and their accumulated mortality and average longevity were calculated. In men, the accumulated mortality for 6 years was 63.5% (40/63) in RD and 55.6% (193/347) in LSC, while it was 15.3% (786/5,128) in HSC. Average longevity and SD was 85.6 ± 8.6 years in RD and 84.8 ± 8.1 years in LSC, while it was 79.6 ± 7.2 years in HSC, which was almost the same as the men's national average life expectancy 79.19 in 2007. In women, accumulated mortality for 6 years was 54.0% (87/161) in RD and 45.6% (260/570) in LSC, while it was only 8.1% (447/5,541) in HSC. Average longevity and SD was 90.1 ± 6.7 in RD and 90.2 ± 7.6 in LSC, while it was 80.2 ± 7.5 in HSC, which was shorter than the women's national average life expectancy 85.99 in 2007.

Compared with HSC, the figures for LSC are clearly higher, and similar to those in RD. It is expected that the LSC elderly would have been diagnosed as demented if they had consulted with a physician at baseline, and thus LSC's demented status was overlooked. As a reference for comparison, the same analytical results as in Table 1 and 2 are shown in Table 3.

##### 2. Steadily decreasing proportion of overlooked dementia

As the results show, the proportion of overlooked dementia steadily decreased over the 6 years after 2001. Although the sensitivity in each survey has been rising, it seems to be still low. However, the specificity has been shown to be extremely high, between 99.5% and 99.9%. Decreases were 2.2 points, or 34.9%, in men and 3.5 points, or 37.6%, in women.

As described in the Introduction, the government has been promoting measures against dementia, such as the effort for "Immediate creation of a society where people can live comfortably even after suffering from dementia" and "Urgent Project for Improving the Quality of Treatment and of Life with Dementia". Under the program "Nationwide Caravan to Train One Million Dementia Supporters", municipalities have been actively promoting their own programs. Tama City has been distributing the "Guidebook to Support the People with Dementia"<sup>10)</sup> and offering a lecture-delivering service for groups with more than 5 members in order to train dementia supporters<sup>11)</sup>.

In Yokohama City, wards have been offering many programs on dementia. Izumi Ward has been offering citizens lectures to promote understanding of dementia<sup>12)</sup>, and Minami Ward has been providing community people lectures on dementia in order to support people with dementia in the community<sup>13)</sup>. Nationwide programs resulted in training of 8,514 "Caravan mates" who serve as lecturers at "Supporters" training lectures, and 694,854 "Supporters" had been trained by the end

Table 3. Scores of Cognitive Capacities in Recognized-demented and Non-demented Cohorts in 2001  
n (%)

Men	Scores of Cognitive Capacities			Women	Scores of Cognitive Capacities		
	Lower Score (0-1)	Higher Score (2-3)	Total		Lower Score (0-1)	Higher Score (2-3)	Total
Recognized-demented (RD)	58 (95.1)	3 (4.9)	61 (100.0)	Recognized-demented (RD)	150 (96.2)	6 (3.8)	156 (100.0)
Non-demented (ND)	347 (6.3)	5,128 (93.7)	5,475 (100.0)	Non-demented (ND)	570 (9.3)	5,541 (90.7)	6,111 (100.0)
Total	405 (7.3)	5,131 (92.7)	5,536 (100.0)	Total	720 (11.5)	5,547 (88.5)	6,267 (100.0)

Sensitivity : 58/405=14.3%  
Specificity : 5,128/5,131=99.9%  
Positive predictive value : 58/61=95.1%  
Negative predictive value : 5,128/5,475=93.7%

Sensitivity : 150/720=20.8%  
Specificity : 5,541/5,547=99.9%  
Positive predictive value : 150/156=96.2%  
Negative predictive value : 5,541/6,111=90.7%

Note) Subjects who answered all three capacities were included in analyses.

of December 2008<sup>14</sup>). The decreasing proportion of overlooked dementia suggests that those programs and endeavor, have been effective, that dementia has been better understood by many people, and that mild and moderate cognitive impairment and demented status can be improved with current drug and other therapies.

### 3. Significance of understanding the prognosis of dementia

Although dementia does not appear in death statistics in Japan, it was the 14th cause of death in the U.S. in 1995. Among the elderly aged 65 years and older, it was the 8th cause of death<sup>15</sup>). Previous studies have shown that remaining longevity is about 5 years after onset of dementia<sup>16,17</sup>). Knowing the prognosis of dementia is essential for the elderly themselves and also for family caregivers to make a long term care schedule and to implement early treatment<sup>18</sup>), which contributes to quality life of loved ones. In this sense, the elderly themselves and family caregivers should know that dementia shortens longevity and lowers quality of life, and that there is still a considerable proportion of overlooked dementia.

### 4. Further efforts and actions are required

Although the proportion of overlooked dementia has been steadily decreasing, there were still 4.1 % of men and 5.8% of women in 2007 whose demented status was overlooked. Further measures and education programs to detect early symptoms of dementia should be promoted in communities, since they are important for early implementation of treatment.

Studies have shown that dementia is often overlooked in primary care settings. It is understandable that physicians have difficulties diagnosing with accuracy in a short time during patient visits<sup>4</sup>). A previous study has shown that the accuracy of family caregivers' perception of dementia could be better than that of physicians since they live together with the person and spend a much longer time observing and perceiving even slight change in the person's daily activities<sup>19</sup>). In order to empower

family caregivers to perceive demented status at an early stage, knowledges and findings from research should be understood by people who live with the elderly. Cognitive decline can easily be measured by observing only three capacities: making bank deposits and/or withdrawals, filling out forms/documents such as pensions, and reading books/newspapers. This requires neither cost nor special training and skills.

Family caregivers need only to pay attention to those capacities of the elderly. The results of this and previous studies suggest that these knowledges should provide very useful guidelines for family caregivers who play important roles as the first detector of demented status<sup>19</sup>).

### References

- 1) Annual Report on the Aging Society: 2009. Section 1, Chapter 1 (report in Japanese), Cabinet Office, Japan, 2010. <http://www8.cao.go.jp/kourei/whitepaper/w-2010/zenbun/html/sl1-1-01.html>, (accessed on October 16, 2010) .
- 2) Asahi Newspaper (article in Japanese): July 6, 2008.
- 3) Report on the Investigation into Actual Conditions of the Elderly's Life and Health: 1996. Bureau of Social Welfare and Public Health, Tokyo, 1996; 24-27 (report in Japanese).
- 4) Wackerbarth SB, Johnson MM: The carrot and the stick, benefits and barriers in getting a diagnosis. *Alzheimer Disease and Associated Disorders*, 2002; 16(4): 213-220.
- 5) Boise L, Camiciolib R, Morgan DL: Diagnosing dementia: perspectives of primary care physicians. *Gerontologist*, 1999; 39(4):457-464.
- 6) Iwamoto T, Fujii H, Umahara T, et al.: Status quo and problems on dementia treatment from the viewpoint of dementia consultation (article in Japanese). *Japanese Journal of Geriatric*, 2001, 38(4):528-533.
- 7) Yamamoto C, Hoshi T: Proportion of overlooked dementia in the community-dwelling elderly: the relationship between cognitive impairment and 5.9-year survival in an urban population (article in Japanese). *Journal of Health and Welfare*

- Statistics, 2010; 57(6):18-24.
- 8) Nissei Basic Research Institute: REPORT (article in Japanese), March 1998: 2-3.
  - 9) Yamamoto C, Hoshi T: What activities are impaired when family caregivers perceive the community-dwelling elderly to be demented? Analyses of data of 10 rural towns and villages from Hokkaido to Kyushu and T City, Tokyo (article in Japanese). Health Sciences, 2008, 24(4):375-384.
  - 10) Tama City Homepage: Guidebook to support people with dementia (in Japanese). <http://www.city.tama.lg.jp/kenkou/koureisha/008624.html> (accessed on January 20, 2010).
  - 11) Tama City Homepage: Lecture to train dementia supporters (in Japanese) <http://www.city.tama.lg.jp/kenkou/koureisha/005013.html> (accessed on January 20, 2010).
  - 12) Izumi Ward Homepage: Lecture on dementia; for constructing community where everyone can live at ease "Let's promote understanding of dementia" (in Japanese). <http://www.city.yokohama.jp/me/izumi/press/21.8.11-koureishien.html> (accessed on May 2, 2010).
  - 13) Minami Ward Homepage: Enlightening lecture on dementia; understanding of dementia and supporting people with dementia in the community (in Japanese). <http://www.city.yokohama.jp/me/konan/press/press080205.html> (accessed on May 2, 2010).
  - 14) Annual Report on the Aging Society: 2009 (Summary). Cabinet Office, Japan; p.27. [http://www8.cao.go.jp/kourei/english/annualreport/2009/2009pdf\\_e.html](http://www8.cao.go.jp/kourei/english/annualreport/2009/2009pdf_e.html) (accessed on Oct. 16, 2010.)
  - 15) Hoyert DL, Rosenberg HM: Alzheimer's Disease as a cause of death in the United States. Public Health Reports, 1997; 119: 497-505.
  - 16) Larson EB, Shadlen MF, Wang L, et al.: Survival after initial diagnosis of Alzheimer Disease. Annals of Internal Medicine, 2004; 140:501-509.
  - 17) Xie J, Brayne C, Matthews FE, et al.: Survival times in people with dementia: analysis from population based cohort study with 14-year follow-up. British Medical Journal, 2008; 336: 256-262.
  - 18) Ostbye T, Steenhuis R, Wolfson C, et al.: Predictors of five-year mortality in older Canadians: the Canadian Study of Health and Aging. Journal of the American Geriatrics Society, 1999; 47(10): 1249-1254.
  - 19) Yamamoto C, Sato N, Hoshi T: Accuracy of family caregivers' perception of dementia: Comparison with dementia recognition rate of long-term care insurance and mortality reported in preceding researches, Japanese Society of Dementia Care (article in Japanese), 2005; 4(3): 496-506.

