

## **Steadily decreasing prevalence of dementia in community-dwelling Japanese elderly during six-year follow-up**

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### **INTRODUCTION**

Japanese average life expectancy rose to 79.59 for men and 86.44 for women in 2009, in which aging rate was 22.7%, and is estimated to rise to 83.67 and 90.34 for men and women, respectively, in 2055, in which aging rate will rise to 40.5%. 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 drug 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 (Bureau of Social Welfare and Public Health, Tokyo, 1996; Wackerbarth SB, Johnson MM, 2002). Thus, dementia is often overlooked. Previous studies have shown that only 50% of people with dementia are diagnosed (Boise L, Camicioli R, Morgan DL, 1999) in primary care settings, and that by the time of diagnosis the demented status may have progressed to a considerable extent (Iwamoto T, Fujii H, Umahara T, et al., 2001). Many of Japanese local governments reported prevalence of dementia, which varied widely 3.0%-8.8%. Forty-five surveys were conducted during 1956–2001. Tokyo metropolis, which has a population of 13.1 million as in February 2011, conducted surveys in 1973, 1980, 1988 and 1995. Prevalence of dementia was 4.5%, 4.6%, 4.0% and 4.1% respectively. Toyama prefecture, which has a population of 1.09 million as in February 2011 and is located in the middle of Japan, facing to the Japan Sea, conducted surveys in 1982, 1985, 1990, 1996 and 2001. Prevalence was 5.6%, 4.5%, 5.7%, 4.5% and 8.8% respectively (Nakamura S, Shigeta M, Iwamoto M, et al., 2004). Wide range of prevalence could be partly due to the methods of assessment, including diagnostic criteria used. Many of previous reports in Japan showed prevalence around 5.0% and no particular tendency of increasing or decreasing could be observed. It might be partly because there were not many programs and measures against dementia initiated by municipalities before 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 on preventing dementia, promoting understanding of early symptoms of dementia and training dementia supporters in communities over the past several years. The

purpose of this study is two-fold: to clarify the changes in prevalence of dementia in City A after 2001 through a 6-year follow-up, and to discuss effectiveness of official measures and programs against dementia.

The remainder of this article is organized as follows. In the next section methods are introduced, in which baseline and follow-up data, study population, analytical methods and ethical procedures are described. In the third section results are shown, and their implications are discussed in the final section.

## **METHODS**

### **Outlines of study field**

Baseline and follow-up data were collected in City A in 2001, 2004 and 2007. City A is located in the suburbs of Shinjuku, a sub-center of Tokyo, at 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%, worked in a 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 lived in the so-called New Town, among which population aged 45 to 54 years occupies the largest proportion (Nissei Basic Research Institute, 1998). 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.

### **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 elderly aged 65 years and older living with a spouse and/or child's family. 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 (IADL), lifestyle, life satisfaction, leisure activities, socio-economic status, long-term care insurance, and others. Questionnaires of 16,462 in number were mailed 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 11,529 addressees (5,450 men and 6,079 women) responded by themselves and 1,529 by proxies (560 men and 969 women) who were all family members. 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). The 2001 survey didn't involve an item asking diseases being treated including dementia. 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.

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. Since an alternative 'dementia' was added as one of diseases being treated, addressees themselves whose demented status was mild and moderate could choose it. Survival and death of the respondents in the 2001 survey were also investigated.

In 2004, 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 2007, 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.

### Analytical methods

Among 13 items of the TMIG (Tokyo Metropolitan Institute of Gerontology) Index of Competence, some of them were modified and used for measuring the functional capacities of IADL. They were making bank deposits and/or withdrawals, filling out forms/documents such as pensions, reading books/newspapers, shopping, and food preparation. Cramer's V of food preparation in men was as low as 0.178 and omitted from the variables for multiple logistic regression analysis. Cramer's Vs of other four capacities in men varied from 0.296 (making bank deposits/withdrawals) to 0.322 (filling out forms/documents such as pensions). Those of five capacities in women varied 0.344 (reading books/newspapers) to 0.404 (making bank deposits/withdrawals) (Yamamoto C, Hoshi T, 2008).

Four capacities except 'food preparation' in men and five capacities in women were put into multiple logistic regression analysis as variables to find the levels of strength in family-caregiver's perception of the elderly demented status. With age adjusted, odds ratios (ORs) were analyzed in order to determine common variables for men and women. 'Shopping' in women was eliminated ( $p \geq 0.10$ ) in the analytical process of backward stepwise regression. ORs in cases those capacities were disordered varied from 18.852 to 1.920. In detail, in men ORs were 18.852 ( $p = 0.000$ , 95% CI: 4.489-79.168) in case the elderly couldn't fill out forms/documents such as pensions, 4.211 (0.036, 1.102-16.100) in case they couldn't make bank deposits/withdrawals, 2.379 (0.056, 1.102-16.100) in case they couldn't do shopping and 1.920 (0.043, 1.021-3.609) in case they didn't read books/newspapers. In women, ORs were 18.154 (0.000, 6.354-51.866) in case they couldn't fill out forms/documents such as pensions, 5.176 (0.000, 2.177-12.307) in case they couldn't make bank deposits/withdrawals, 2.662 (0.000, 1.539-4.606) in case they couldn't prepare food and 1.947 (0.001, 1.316-2.879) in case they didn't read books/newspapers (Yamamoto C, Hoshi T, 2008).

Cognitive scores were measured by three common capacities for men and women as clarified by multiple logistic regression analysis, i.e., making bank deposits/withdrawals, filling out forms/documents such as pensions, and reading books/newspapers, whose common intellectual elements are reading, writing and understanding Japanese characters. 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). Yamamoto and Hoshi (2010) showed that proportion of LSC in ND was equivalent to that of overlooked dementia in association with mortality and longevity with a 6-year follow-up. In brief, the number of the elderly followed was 12,143 (5,664 men and 6,479 women). 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  $85.6 \pm 8.6$  years in RD and  $84.8 \pm 8.1$  years in LSC, while it was  $79.6 \pm 7.2$  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  $90.1 \pm 6.7$  in RD and  $90.2 \pm 7.6$  in LSC, while it was  $80.2 \pm 7.5$  in HSC, which was shorter than the women's national average life expectancy 85.99 in 2007. Compared with HSC, the figures for LSC were 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.

The 2004 and 2007 data were also analyzed to clarify the proportions of LSC in ND. Prevalence of dementia was calculated by the proportions of RD and LSC in ND.

### 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.

## RESULTS

### Proportions of the recognized-demented and the lower-scoring cohort and other statistical results in the 2001, 2004 and 2007 surveys

The recognized-demented (RD) was defined as those whose family-caregivers responded as proxies due to addressee’s dementia or cognitive impairment and those who reported their own demented status. The 2001 survey didn’t involve an item asking diseases being treated including dementia, as mentioned above, and RD was totally based on family-caregivers’ assessment and perception as proxies.

In the 2001 survey, the proportions of RD were 1.1% (61/5,536) in men and 2.5% (156/6,267) in women. With subjects divided into LSC and HSC by the cut-off point, the proportions of LSC in RD were 95.1% (58/61) in men and 96.2% (150/156) in women. They were 6.3% (347/5,475) and 9.3% (570/6,111) in men and women, respectively, in ND. Sensitivity was 14.3% in men and 20.8% in women and specificity was 99.9% in both men and women (Yamamoto C, Hoshi T, 2010).

The proportions of RD in the 2004 survey were 1.2% (72/5,979) in men and 2.8% (182/6,574) in women. The proportions 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 (Yamamoto C, Hoshi T, 2011).

In the 2007 survey, the proportions of RD were 1.8% (122/6,760) in men and 3.0% (233/7,650) in women. The proportions 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% in men and 99.6% in women (Yamamoto C, Hoshi T, 2011).

### Prevalence of dementia in the 2001, 2004 and 2007 surveys

As described in analytical methods, prevalence of dementia was calculated by the proportions of RD and LSC in ND. In the 2001 survey, proportions of RD were 1.1% in men and 2.5% in women, and those of LSC in ND were 6.3% and 9.3% in men and women respectively. Thus, prevalence of dementia in 2001 was 7.4% in men and 11.8% in women. Women had 1.6 times as much as men’s prevalence. In the 2004 survey, since proportions of RD were 1.2% and 2.8% in men and women respectively and those of LSC in ND were 5.1% in men and 6.6% in women, prevalence in 2004 was 6.3% in men and 9.4% in women. Women’s prevalence was 1.5 times as much as men. In the 2007 survey, proportions of RD were 1.8% in men and 3.0% in women, and those of LSC in ND were 4.1% and 5.8% in men and women respectively. Therefore, prevalence in 2007 was 5.9% in men and 8.8% in women. Women had 1.4 times as much as men’s prevalence.

## DISCUSSION

### Steadily decreasing prevalence of dementia

As the results show, the prevalence of dementia decreased steadily over the 6 years after 2001, that is, 20.3% decrease in men and 25.4% decrease 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; distributing

the “Guidebook to Support the People with Dementia”, offering a lecture-delivering service for groups with more than five members in order to train dementia supporters, offering citizens lectures to promote understanding of dementia, and providing community people lectures on dementia in order to support people with dementia in the community. Nationwide programs resulted in training of 8,524 “Caravan mates” who serve as lecturers at “Supporters” training lectures, and 694,854 “Supporters” had been trained by the end of December 2008 (Cabinet Office, Japan, 2009). The decreasing prevalence of dementia suggests that those programs and efforts have been effective, that dementia has been better understood by community people, and that mild and moderate cognitive impairment and demented status can be improved with current drug and other therapies.

### **Significance of this study in comparison with previous dementia surveys**

As shown in the Introduction, many of Japanese local governments have reported prevalence of dementia around 5.0%, with wide range of 3.0%-8.8%. They showed no particular tendency of increasing or decreasing of prevalence. This study also showed the similar prevalence of dementia in the 2007 survey as local governments, however, this study significantly clarified the decrease of prevalence, which suggests the effectiveness of municipalities’ efforts of health promotion. The difference of prevalence in men and women was also clearly showed and women had about 1.6-1.4 times as much as men’s prevalence.

### **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 (Hoyert DL, Rosenberg HM, 1997). Previous studies have shown that remaining longevity is about 5 years after onset of dementia (Larson EB, Shadlen MF, Wang L, et al., 2004; Xie J, Brayne C, Matthews FE, et al., 2008). 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 (Ostbye T, Steenhuis R, Wolfson C, et al., 1999), 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.

### **Further efforts and action are required**

Although the prevalence of dementia has been steadily decreasing, there were still 5.9% in men and 8.8% in women who had demented status in 2007. 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 (Wackerbarth SB, Johnson MM, 2002). Yamamoto and Hoshi (2005) 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. In order to empower family caregivers to perceive demented status at an early stage, knowledge 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 daily activities. The results of this and previous studies suggest that the knowledge should provide very useful guidelines for family caregivers who play important roles as the first detector of demented status (Yamamoto C, Sato N, Hoshi T, 2005).

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- Yamamoto C, Hoshi T (2011). Steadily decreasing proportion of overlooked dementia in community-dwelling Japanese elderly: six-year follow-up in an urban population. *Bulletin of Social Medicine*, 28(1): 1-7.

## ABSTRACT

*In order to promote understanding of early symptoms of dementia, municipalities have been providing lectures on dementia and training dementia supporters in communities over the past several years. The authors have shown that proportions of overlooked dementia in an urban population were steadily decreasing during six years, i.e., 6.3% in men and 9.3% in women in 2001, 5.1% and 6.6% in 2004, and 4.1% and 5.8% in 2007 in men and women respectively (Yamamoto C, Hoshi T, 2011). The purpose of this study is two-fold; to clarify prevalence of dementia in Japanese urban elderly and the changes in prevalence with a 6-year follow-up, and to discuss effectiveness of municipalities' efforts and measures against dementia.*