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# Five-Year Community Management Rate for Dementia Patients: A Proposed Indicator for Dementia Policies

Hyuk Sung Kwon<sup>a\*</sup> Jeewon Suh<sup>b\*</sup> Mi-hee Kim<sup>c</sup> Boyoung Yoo<sup>d</sup> Minkyung Han<sup>e</sup> Im-Seok Koh<sup>b</sup> Hojin Choi<sup>a</sup>

<sup>a</sup>Department of Neurology, Hanyang University Guri Hospital, Hanyang University College of Medicine, Guri, Korea <sup>b</sup>Department of Neurology, National Medical Center, Seoul, Korea <sup>c</sup>Korean Dementia Association, Seoul, Korea <sup>d</sup>Ministry of Health and Welfare, Sejong, Korea <sup>e</sup>Department of Big Data, National Health Insurance Service, Wonju, Korea

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#### Correspondence

Hojin Choi, MD, PhD Department of Neurology, Hanyang University Guri Hospital, Hanyang University College of Medicine, 153 Gyeongchun-ro, Guri 11923, Korea Tel +82-31-560-2289 E-mail chj@hanyang.ac.kr

Im-Seok Koh, MD, PhD Department of Neurology, National Medical Center, 245 Eulji-ro, Jung-gu, Seoul 04564, Korea Tel +82-2-2260-7290 Fax +82-2-2260-7114 E-mail neukoh@gmail.com

\*These authors contributed equally to this work.

**Background and Purpose** There is no specific indicator for monitoring dementia management. We propose an auxiliary indicator called the community management rate, defined as the proportion of dementia patients who receive informal care from close caregivers or themselves within their community population. The 5-year community management rate is the percentage of dementia patients who are receiving community management at 5 years after they were diagnosed. The aim of this study was to identify how the community management rate has changed over time and how the 5-year community management rate differs according to age, sex, income, residence area, and comorbidities.

**Methods** We analyzed customized research database of the Korean National Health Insurance Services from 2003 to 2018. The 5-year community management rate was calculated annually with newly diagnosed dementia patients, and compared among subgroups according to age, sex, income, residence area, and comorbidities.

**Results** This study analyzed 549,297 patients. Among those newly diagnosed with dementia in 2003, the mean duration of community management during the 15-year follow-up was 5.98 years. The community management rate decreased rapidly from 2003 to 2006, after which it increased. A low 5-year community management rate was associated with older age, higher comorbidity burden, nonmetropolitan residence, and low income.

**Conclusions** The community management rate seems to reflect diverse patient factors. Efforts are needed to reduce the comorbidity burden and differences in the 5-year community management rate according to residence area and income. This study indicates the need for further investigations into the use of this indicator to monitor the management of dementia patients.

**Keywords** dementia; community management rate; National Health Insurance Service; policy.

# INTRODUCTION

Around 50 million people globally suffer from dementia, and the social burden is about one trillion dollars per year.<sup>1</sup> The prevalence is estimated to increase to about 152 million people by 2050.<sup>1</sup> In Korea, about 750 thousand people suffer from dementia, and this is estimated to increase to about 3 million by 2050.<sup>2</sup> The current cost of dementia in Korea is about 13 billion dollars per year,<sup>3</sup> which also is expected to increase steadily. Many governments have announced diverse public policies for responding to the rapid increase in the financial burden of managing people with dementia. Following the Korean government declaring "war on dementia" in 2008,<sup>4</sup> the National Dementia Plan (NDP) has released updated data every 5 years.<sup>5</sup>

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# **METHODS**

However, there is no specific indicator for monitoring dementia patients, and the diverse policies are typically based on population-based epidemiological data.<sup>6</sup> Since there is no disease-modifying therapy, there is need for an objective indicator that reflects the management of dementia patients and the burden on caregivers.

The cost of caring for dementia patients increases as the disease progresses.<sup>7</sup> The costs for both informal and professional care increase rapidly with increasing functional dependency.<sup>7,8</sup> As the cost of nursing facilities is supported by health insurance in Korea, health insurance can increase dramatically when patients start to receive formal care from institutions such as nursing facilities and geriatric hospitals. This indicates the importance of identifying dementia patients in the early stages and slowing its progression. Moreover, diagnosing dementia patients earlier can reduce the associated treatment costs.<sup>9</sup>

The first goal of policies for dementia is to alleviate the social burden by reducing the prevalence and incidence. In addition, policymakers should consider how to 1) perform earlier diagnoses,<sup>10</sup> 2) slow the progression of dementia with pharmacological and nonpharmacological treatments, and 3) provide support to reduce the burden on both dementia patients and caregivers. Considering those goals, we propose an auxiliary indicator called the community management rate for monitoring dementia patients after their diagnosis.

We define the community management rate as the proportion of dementia patients who receive care from caregivers or themselves within the community population; that is, not including those who are hospitalized in nursing facilities or geriatric hospitals for more than 3 months. The 5-year community management rate is the percentage of dementia patients who are receiving community management 5 years after being diagnosed. The duration of community management is from a diagnosis of dementia to long-term hospitalization (including in hospitals and nursing facilities) or death. This time period is expected to increase as dementia patients are diagnosed earlier, the progression of dementia is slowed, and the burden on caregivers providing informal care for dementia decreases. Since Korean hospitals and nursing facilities are supported by the National Health Insurance Service (NHIS), the NHIS database was used to evaluate the medical services received and calculate the community management rates during the follow-up period.

This study revealed how the community management rate has changed over time, and how the 5-year community management rate has varied according to the year of a dementia diagnosis.

# Data source

This study analyzed de-identified customized research data extracted from the National Health Insurance Database between January 1, 2003, and December 31, 2018. This database is primarily based on the Korean NHIS, which is a single government insurer that covers 97% of the Korean population; claims from the remaining 3% (who are covered by the Medical Assistance Program or the Medical Care for Patriots and Veterans Affairs Scheme) are reviewed by the NHIS. The customized database is representative of the transmission data provided by de-identifying health insurance and long-term care insurance data.11 The database provides information on healthcare utilization for both inpatients and outpatients, and includes patient demographics, diagnosis, diagnostic procedures, and prescribed medications. Diagnoses were coded using editions 5, 6, and 7 of the Korean Classification of Disease (KCD-5, -6, and -7, respectively), and a modification of the 10th revision of the International Statistical Classification of Disease and Related Health Problems (ICD-10). Data on demographics (including age, sex, income, and residence area), accompanying diagnostic codes including the Charlson Comorbidity Index (CCI), and hospitalization records were collected using the NHIS coding system.

# **Study population**

Subjects first diagnosed with dementia from 2003 to 2013 were identified in the claims data according to the appropriate KCD-5, -6, or -7 code. When a patient suspected of dementia visits a hospital, a dementia-related diagnostic code is registered in the health insurance database. This diagnostic code remains in the database, and so it can appear again when patients revisit to check the results of tests including neuropsychological assessments, laboratory tests, or neuroimaging. Therefore, dementia patients were defined as those who had a history of three or more outpatient visits or admissions with a dementia-related diagnostic code in order to reduce the false-positive rate in selecting dementia patients. For these patients, the first visit was that at which dementia was diagnosed. The dementia-related diagnostic codes were F00 (Dementia in Alzheimer disease), F01 (Vascular dementia), F02 (Dementia in other diseases classified elsewhere), F03 (Unspecified dementia), G30 (Alzheimer disease), G31.00 (Behavioral variant frontotemporal dementia), G31.01 (Semantic variant primary progressive aphasia), G31.02 (Nonfluent primary progressive aphasia), G31.03 (Logopenic primary progressive aphasia), G31.04 (Primary progressive aphasia), and G31.82 (Dementia with Lewy bodies). Subjects with any record of claims data with a dementia-related diagnostic code in 2002 were initially excluded (the washout period).

# Community management rate

We used the term "community management" to refer to patients or caregivers responsible for informal care related to a dementia diagnosis. The duration of community management is from the diagnosis of dementia to the end date of community management, which is considered to be when the patient dies or is admitted to a nursing facilities or medical institution for more than 3 months. The community management rate is the proportion of dementia patients who are receiving community management relative to the total number of dementia patients in the population.

We followed the community management rate among patients diagnosed with dementia in 2003, 2004, or 2005 (Fig. 1). The estimated community management rates were similar after 15 years among patients diagnosed with dementia in 2003, 2004, or 2005. However, using 15 years as the standard follow-up period is difficult due to its length, and so we analyzed changes and differences in the community management rate over 5-year intervals.

# **Ethical approval**

This study was approved by the Institutional Review Board of Hanyang University Guri Hospital (2020-0627). All personal information in the NHIS database was de-identified, and the need to obtain informed consent was waived.

# **Charlson Comorbidity Index**

We used the ICD-10 version of the CCI, which includes the following 17 diagnostic categories: acute myocardial infarction, congestive heart failure, peripheral vascular disease, cerebral vascular accident, dementia, pulmonary disease, con-



Fig. 1. Community management rate during follow-up of dementia patients diagnosed in 2003, 2004, and 2005.

nective-tissue disorder, peptic ulcer, mild liver disease, diabetes, diabetes with complications, paraplegia, renal disease, cancer, metastatic cancer, severe liver disease, and HIV.<sup>12</sup> Since all of the subjects in this study had dementia, the other 16 diagnostic categories were weighted to calculate the CCI. The weights and corresponding ICD-10 codes are listed in Supplementary Table 1 (in the online-only Data Supplement).

# Statistical analysis

The 5-year community management rate was calculated for patients diagnosed with dementia from 2003 to 2013. Descriptive statistics of the study population are presented. All participants were divided into groups and compared according to age (five groups: <50, 50–59, 60–69, 70–79, and ≥80 years), sex, CCI (three groups: 0, 1 or 2, and ≥3), residence area (metropolitan and nonmetropolitan), and income (quintiles). Continuous variables are expressed as mean $\pm$ SD values, and categorical variables are expressed as percentages or frequencies. The community management rate was compared using the chi-square test at 5 years after a diagnosis of dementia. All statistical analyses were performed using the SAS software (version 9.3; SAS Institute, Cary, NC, USA), and *p*<0.05 was considered statistically significant.

# RESULTS

Between 2003 and 2018, 1,756,998 patients visited medical institutions with a dementia-related code, with 941,525 of them visiting medical institutions 3 or more times. This study analyzed the 5-year community management rate in 549,297 patients (64.4% females) diagnosed with dementia from 2003 to 2013 (Fig. 2).

Demographic characteristics and comorbidities of all subjects are presented in Table 1. Among the patients newly diagnosed with dementia in 2013, the mean duration of community management during the 15 years of follow-up was 5.98 years (Table 2). Patients with younger age, lower CCI, and residence in a metropolitan area had a longer duration of community management. Dementia patients with the highest and lowest incomes had shorter durations of community management (Table 2).

The number of patients newly diagnosed with dementia increased steadily from 2003 to 2011, after which it stabilized (Fig. 3). The 5-year community management rate decreased rapidly from 2003 to 2006 (year of the dementia diagnosis), after which it increased steadily except during 2009 and 2010 (Fig. 3).

All participants were divided according to age, sex, CCI, residence area, and income. The 5-year community management rate was lower for older age (Fig. 4A) and higher co-



Fig. 2. Identification of newly diagnosed dementia patients from the database of the Korean National Health Insurance Services.

morbidity burden as determined by CCI (Fig. 4C). Females showed a lower 5-year community management rate up to 2011 (Fig. 4B). Patients living in a metropolitan area showed a higher 5-year community management rate (Fig. 4D), while those with the lowest 40% of incomes demonstrated a low 5-year community management rate (Fig. 4E).

# DISCUSSION

We have revealed changes in the community management rate over time. We also analyzed how the 5-year community management rate differs according to the year in which dementia was diagnosed and how this indicator differed according to various subgroups. The community management rate was expected to increase if patients are diagnosed earlier, the progression of the disease is delayed, or the burden of informal care decreases.

The number of newly diagnosed dementia patients in the database of the NHIS increased steadily from 2003 to 2011, after which it stabilized. This increasing trend was continued even when considering the total population or the elderly population in Korea (Supplementary Table 2 in the online-only Data Supplement). A previous study comparing an elderly cohort from 2008 and population census data from 2005 demonstrated a declining temporal trend in the incidence of all-cause dementia in Korea.<sup>13</sup> Diverse policies including mass dementia screening programs and medical expense support programs can identify and support dementia patients who are not receiving medical care. This can explain

why the number of newly diagnosed dementia patients in the NHIS database could increase even when the incidence of dementia decreased.

Following the Korean government declaring "war against dementia" in 2008, there have been announcements of three NDPs: NDP-1 (2008 to 2011), NDP-2 (2012 to 2015), and NDP-3 (2016 to 2020). These NDPs included diverse strategies for detecting early-stage dementia (mass dementia screening programs and support for dementia self-checkups), for improving the management of dementia risk factors, for expanding medical treatment support (increasing support for medical costs, expanding eligibility for long-term care insurance by adding Grade 5, provision of dementia-care information, addition of a respite care service, and designation of regional base hospitals for dementia), for expanding infrastructure (establishing a dementia management conveyance system, integrating a dementia-related database, training of healthcare professionals about dementia, enhancing dementia research, and expanding nursing facilities), for enhancing the support provided to caregivers (instigating the National Dementia Helpline, adding diverse at-home long-term care services, and improving the residential environment), and for improving awareness and overcome stigma (annual "Dementia Awareness Day," providing dementia education, implementing dementia-friendly communities and campaigns, and revising of negative legislation and social expressions of dementia).14,15

In addition to measuring the incidence and prevalence of dementia, diverse indicators were used to verify the effective-

Table 1. Demographic characteristics and comorbidities of patients diagnosed with dementia from 2003 to 2013

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	0verall (n=549,297)	2003 (n=8,333)	2004 ( <i>n</i> =12,269)	2005 ( <i>n</i> =17,918)	2006 (n=34,783)	2007 ( <i>n</i> =43,947)	2008 (n=60,229)	2009 (n=64,888)	2010 ( <i>n</i> =68,116)	2011 ( <i>n</i> =81,831)	2012 (n=80,938)	2013 (n=76,045)
Demographics												
Age (yr)	75.4±10.3	72.6±10.3	73.4±9.8	74.6±9.7	75.0±10.1	75.3±10.2	75.2±10.3	75.1±10.3	75.7±10.2	75.9±10.3	75.8±10.5	75.7±10.5
Sex, female	353,913 (64.4)	5,059 (60.7)	7,488 (61.0)	11,216 (62.6)	22,898 (65.8)	28,760 (65.4)	39,372 (65.4)	41,647 (64.2)	44,039 (64.7)	53,210 (65.0)	51,779 (64.0)	48,445 (63.7)
Income, quintiles												
<20%	78,689 (14.3)	1,201 (14.4)	1,620 (13.2)	2,720 (15.2)	3,515 (10.1)	5,195 (11.8)	7,363 (12.2)	8,087 (12.5)	10,518 (15.4)	12,994 (15.9)	13,003 (16.1)	12,473 (16.4)
20%-40%	47,233 (8.59)	827 (9.92)	1,430 (11.7)	1,587 (8.9)	2,614 (7.5)	3,368 (7.7)	4,932 (8.2)	5,580 (8.6)	5,812 (8.5)	7,235 (8.8)	7,488 (9.3)	6,360 (8.4)
40%-60%	60,784 (11.0)	1,032 (12.3)	1,491 (12.2)	2,558 (14.3)	3,003 (8.6)	4,614 (10.5)	6,463 (10.7)	7,351 (11.3)	7,662 (11.2)	9,000 (11.0)	9,015 (11.1)	8,595 (11.3)
60%-80%	89,841 (16.4)	1,935 (23.2)	2,529 (20.6)	3,427 (19.1)	4,650 (13.4)	7,025 (16.0)	9,645 (16.0)	10,673 (16.4)	10,954 (16.1)	13,345 (16.3)	13,220 (16.3)	12,438 (16.4)
>80%	168,756 (30.7)	3,237 (38.8)	5,033 (41.0)	7,026 (39.2)	8,293 (23.8)	13,052 (29.7)	17,950 (29.8)	19,495 (30.0)	20,055 (29.4)	24,871 (30.4)	25,517 (31.5)	24,227 (31.9)
No data	103,994 (18.9)	101 (1.2)	166 (1.4)	600 (3.3)	12,708 (36.5)	10,693 (24.3)	13,876 (23.0)	13,702 (21.1)	13,115 (19.3)	14,386 (17.6)	12,695 (15.7)	11,952 (15.7)
Residence area												
Metropolitan	205,329 (37.4)	3,195 (38.3)	4,473 (36.5)	6,495 (36.2)	10,796 (31.0)	14,759 (33.6)	22,068 (36.6)	24,033 (37.0)	25,608 (37.6)	32,053 (39.2)	32,054 (39.6)	29,795 (39.2)
Nonmetropolitan	343,968 (62.6)	5,138 (61.6)	7,796 (63.5)	11,423 (63.8)	23,987 (69.0)	29,188 (66.4)	38,161 (63.4)	40,855 (63.0)	42,508 (62.4)	49,778 (60.8)	48,884 (60.4)	46,250 (60.8)
CCI	3 [2–5]	3 [1–5]	3 [1-5]	3 [2–5]	3 [2-5]	3 [2-5]	3 [2–5]	3 [2-5]	3 [2–5]	3 [2–5]	3 [2-5]	3 [2-5]
Comorbidities												
Hypertension	406,517 (74.0)	5,745 (68.9)	8,692 (70.8)	12,721 (71.0)	24,998 (71.9)	32,553 (74.1)	45,119 (74.9)	48,655 (75.0)	50,858 (74.7)	60,882 (74.4)	59,928 (74.0)	56,366 (74.1)
Diabetes	244,912 (44.6)	3,378 (40.5)	5,099 (41.6)	7,394 (41.3)	14,073 (40.5)	18,773 (42.7)	26,126 (43.4)	28,758 (44.3)	30,529 (44.8)	37,151 (45.4)	37,749 (46.6)	35,882 (47.2)
Dyslipidemia	255,361 (46.5)	2,714 (32.6)	4,169 (34.0)	6,121 (34.2)	11,833 (34.0)	16,825 (38.2)	25,199 (41.8)	29,443 (45.3)	31,816 (46.7)	40,590 (49.6)	43,625 (53.8)	43,026 (56.5)
CKD	27,971 (5.1)	414 (5.0)	545 (4.4)	706 (3.9)	1,435 (4.1)	2,048 (4.7)	2,986 (5.0)	3,323 (5.12)	3,484 (5.1)	4,329 (5.3)	4,340 (5.4)	4,361 (5.7)
COPD	58,867 (10.7)	883 (10.5)	1,415 (11.5)	1,972 (11.0)	3,914 (11.2)	5,089 (11.5)	6,816 (11.3)	7,130 (10.9)	7,364 (10.8)	8,465 (10.3)	8,324 (10.2)	7,495 (9.9)
Stroke	211,938 (38.5)	3,468 (41.6)	5,068 (41.3)	7,411 (41.3)	14,082 (40.4)	17,667 (40.2)	24,088 (39.9)	25,762 (39.7)	26,303 (38.6)	30,684 (37.4)	29,817 (36.8)	27,588 (36.2)

Data are mean±SD, number (%), or median [interquartile range] values. CCI, Charlson Comorbidity Index; CKD, chronic kidney disease; COPD, chronic obstructive pulmonary disease.

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 Table 2. Duration of in-community management during the 15-year

 follow-up among the patients newly diagnosed dementia in 2013

	Duration (yr)	Number of patients
Total	5.98±5.38	8,333
Age (yr)*		
<50	13.72±3.93	237
50-59	10.83±5.67	503
60-69	8.03±5.63	2,045
70–79	5.30±4.74	3,390
≥80	2.94±3.20	2,107
Sex*		
Male	5.94±5.36	3,223
Female	5.96±5.36	5,059
CCI		
0	6.37±5.58	902
1 or 2	6.22±5.48	2,903
≥3	5.75±5.27	4,528
Residence area*		
Metropolitan	6.45±5.45	3,195
Nonmetropolitan	5.65±5.29	5,065
Income, quintiles*		
<20%	5.72±5.34	1,201
20%-40%	6.24±5.56	827
40%-60%	6.18±5.41	1,032
60%-80%	6.10±5.38	1,935
>80%	5.82±5.29	3,237

Data are mean±SD values unless otherwise noticed.

\*There were patients without data on age (n=51), sex (n=51), residence area (n=73), and income (n=101).

CCI, Charlson Comorbidity Index.

ness of the implemented policies. These indicators include the total number of screenings for dementia, the number of dementia patients exempted from calculations of health insurance (in Korea, the medical costs for severe dementia patients are reduced by applying "exempted calculation"), the budget used for dementia research and development, surveys for service satisfaction and the awareness of dementia, and the rate of using dementia support centers. While these indicators are important, there is need for an objective indicator that can reflect the original goal of dementia policies. The Ministry of Health and Welfare of Korea is preparing NDP-4 (2021 to 2025),<sup>15</sup> and various indicators are being developed to confirm the effects of diverse policies included in this plan. The community management rate was developed as an auxiliary indicator to reflect major political events. Various preemptive policies have been announced in In Korea, including expanding elderly care facilities (in 2005),<sup>16</sup> a mass dementia screening program to screen and prevent dementia (in 2007),<sup>17</sup> and standard clinical practice guidelines for dementia patients (in 2009).<sup>18</sup> As a result of policies expanding elderly care facilities,<sup>16</sup> the number of medical care facilities including nursing facilities and geriatric hospitals increased rapidly from 2004 to 2006 (Supplementary Table 2 in the online-only Data Supplement). These policies might have affected the declining temporal trend of the 5-year community management rate of dementia patients diagnosed from 2004 to 2006 (Fig. 3). In addition, the announcement of a standard clinical practice guideline for dementia patients in 2009 might have restricted the use of the diagnostic code for dementia in pa-



Fig. 3. Five-year community management rate and number of newly diagnosed dementia patients from 2003 to 2013.

# JCN Community Management Rate and Dementia



**Fig. 4.** Five-year community management rate of dementia patients stratified by age (A), sex (B), CCI (C), residence area (D), and income (E). \**p*<0.05; \*\**p*<0.01. CCI, Charlson Comorbidity Index.

tients with mild symptoms,<sup>18</sup> and hence reduced the 5-year community management rate of patients diagnosed in 2010 compared with 2009 (Fig. 3). The 5-year community management rate seems to reflect these social events.

Various policies are used to promote dementia-friendly and inclusive communities around the world.<sup>19</sup> Such communities are designed to improve negative perceptions of dementia and to promote the social inclusion of dementia patients. Interventions to overcome stigma and social exclusion are important, including since they will help dementia patients to be able to keep living in their own homes,<sup>19</sup> which is closely related to an increase in the community management rate. There is a need for effective indicators that reflect the efforts to improve the stigma and social exclusion of dementia, and the community management rate might be one such indicator.

The 5-year community management rate decreased with

the comorbidity burden according to the CCI in this study. Preventing comorbidities should increase the 5-year community management rate and reduce the social burden. Females showed a lower 5-year community management rate up to 2011, and there was no sex difference in the number of patients who were diagnosed with dementia in 2012 or 2013. Patients living in a metropolitan area showed a higher 5-year community management rate (Fig. 4D), and those with incomes in the lowest 40% demonstrated a low 5-year community management rate (Fig. 4E). These indicators reflect the demographics of dementia patients, and these differences could be due to the supporting infrastructure (i.e., day-care center, at-home long-term care services, and regional centers for dementia) and better accessibility in the metropolitan area, and greater perceived burden of informal care in the low-income group. Efforts to reduce the burden of informal care of patients and caregivers in nonmetropolitan areas and among those on low incomes should be considered in future policies in order to reduce the gaps between these subgroups.

This study had some limitations. First, we identified dementia patients using diagnostic codes and number of visits from the NHIS database, and the diagnoses could not be doublechecked by applying neuropsychological tests. Although we attempted to reduce the rate of overestimation by limiting cases to those who had three or more visits with a dementia-related diagnostic code, including the results of neuropsychological tests could have improved the accuracy. Second, data on the psychological status of patients (e.g., quality of life, mood, or emotion) could not be obtained. This information cannot be identified from claims data, and so future prospective studies should consider including interviews or questionnaires that reflect the psychological status of patients. Third, the type, compliance with, and period of medication were not analyzed. As Korean NDPs targeted all dementia patients, rather an specific types of dementia, we evaluated the community management rate for all dementia patients first and did not analyze the type of medication. Future studies of specific types of dementia and treatment modalities might yielded more detailed information.

The community management rate for Korean dementia patients could be calculated using data from the NHIS database. Since the community management rate can be affected by various factors, including the expansion of medical care facilities and the ability to perform mass screening to diagnose dementia in the early stage, we suggest using this indicator as an auxiliary indicator first and then expanding the scope of its use. Since each country has different types of infrastructure and situations related to dementia, it might be difficult to use this indicator directly. However, if the concept of the "rate of dementia patients remaining in their own community" is utilized and modified to suit the circumstances of each country, a promising indicator might be developed to help determine the direction of dementia policies.

The community management rate seems to reflect diverse social events, including policy announcements. The early diagnosis of dementia, delayed progression of dementia, and reduced informal care burden of patients and caregivers are expected to be associated with the community management rate, which makes these three indicators important references for setting new policies in the future. The present study found that the 5-year community management rate was lower for older age, higher comorbidity burden, living in a nonmetropolitan area, and lower income. Future policies should consider reducing the gaps between these subgroups. Further studies are needed into the use of this indicator for monitoring the management of dementia patients.

# **Supplementary Materials**

The online-only Data Supplement is available with this article at https://doi.org/10.3988/jcn.2022.18.1.24.

# Availability of Data and Material

The datasets generated or analyzed during the current study are available from the National Health Insurance Sharing Service at [https://nhiss.nhis. or.kr/bd/ab/bdabb006iv.do]. Upon an individual researcher's data set request, NHIS provides customized data to the researcher.

# ORCID iDs \_

Hyuk Sung Kwon
Jeewon Suh
Mi-hee Kim
Boyoung Yoo
Minkyung Han
Im-Seok Koh
Hojin Choi

https://orcid.org/0000-0002-2005-0983 https://orcid.org/0000-0003-3509-6447 https://orcid.org/0000-0002-4764-8782 https://orcid.org/0000-0002-0527-1155 https://orcid.org/0000-0002-5011-5557 https://orcid.org/0000-0002-9265-2879 https://orcid.org/0000-0002-9637-4423

#### **Author Contributions**

Conceptualization: Hyuk Sung Kwon, Jeewon Suh, Boyoung Yoo, Im-Seok Koh, Hojin Choi. Data curation: Mi-hee Kim, Minkyung Han. Formal analysis: Hyuk Sung Kwon, Mi-hee Kim, Supervision: Boyoung Yoo, Minkyung Han, Im-Seok Koh, Hojin Choi. Visualization: Hyuk Sung Kwon. Writing original draft: Hyuk Sung Kwon, Jeewon Suh. Writing—review & editing: Im-Seok Koh, Hojin Choi.

#### Conflicts of Interest \_

Hyuk Sung Kwon, an assistant editor of the *Journal of Clinical Neurology*, was not involved in the editorial evaluation or decision to publish this article. All remaining authors have declared no conflicts of interest.

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