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Abstract

Objective: To analyze the chronological change in social burden of dementia in Japan for the policy implications of appropriate resource allocation and quality improvement.

Design: National population-based observational study from 2002–2014.

Setting: Five nationwide data sets from Japanese official statistics.

Method: Comprehensive Cost of Illness method (a modification of Cost of Illness method).

Main Outcome Measures: The outcome variables included (1) healthcare services (National Health Insurance), (2) nursing care services (Long-term Care Insurance), (3) Informal Care (Informal Care; unpaid care offered by family and relatives), (4) mortality cost, and (5) morbidity cost.

Results: The number of dementia increased 2.50 times from 0.42–1.05 million. While those living in homes and communities increased 3.22 times, those living in nursing care facilities increased 1.42 times. The total burden increased 2.06–2.27 times from JPY 1.84–2.42 to 3.79–5.51 trillion (JPY 1 trillion = US$ 10 billion). Regarding the total burden, the proportion of Informal Care increased

from 36.6–51.9% to 37.7–57.2%. Furthermore, the primary caretakers aged ≥70 years increased from 27.6–37.6%.

Conclusions: Owing to the promotion of "Deinstitutionalization" policy (shift of nursing care site from in-facilities to in-home and in-community), the "Elderly care by the elderly," and "Earlier diagnosis of dementia," the average cost per patient was compressed to 0.82–0.91 times from JPY 4.37–5.77 to 3.60–5.24 million. Hence, the management of Informal Care in a manner that does not exceed the acceptable limit for their caretakers, while maintaining patient safety and quality of care, is imperative.

Keywords: Cost of Illness, Social burden, Dementia, Elderly, Health Policy

Main body of text:

INTRODUCTION

Synchronous with increasing world population, the patients with dementia is also on the rise. In 2015, the estimated number of them was 46.8 million, and the total estimated worldwide cost of dementia was US $818 billion [1]. In 2015, the proportion of population >65 years of age reached 25.7% in Japan. Reflecting the growing social concern for the population aging and dementia, Japanese government started "Orange Plan" [2] in 2012 and "New Orange Plan" [3] in 2015.

Introduced in 1961, Japan's National Health Insurance, which is the universal health insurance, covers almost all medical services. However, the rising aged population resulted in an increased demand for care of the people with dementia, which eventually became a social concern in

the 1990s. In 2000, the Long-term Care Insurance (LTC Insurance) was introduced. Both National Health Insurance and LTC Insurance are social insurance systems requiring the insured people (LTC: age, 40 years) to pay premiums based on their income and co-pay 30% (Medical) or 10%–20% (LTC) of the total expenses. The price for each service is determined by the central government, and the tariff is revised every 2 (Medical) or 3 (LTC) years; the system covers the entire Japanese population uniformly. To be insured, people need to be certified to be in care or support need by their municipalities. Moreover, the category of the condition of need varies from Support Level 1–2 to Care Level 1–5 (larger figures imply a higher level of disability). Based on these levels, the maximum volume of LTC Services that can be used is determined. In 2000, 2.18 million people were certified, which in 2015 increased 2.8 times to 6.08 million [4]. LTC Services comprise In-home Services, Community-based Services, and Facility Services.

The government statistics used in this study are publicly accessible on the web (http://www.e-stat.go.jp/). Comparing Comprehensive Survey of Living Conditions in 2001 with those in 2013 revealed that the percentage of LTC Insurance insured aged 75 or older living in-home because of dementia increased from 79.9% to 89.1% of all insured with dementia. Furthermore, the percentage of their primary caretakers aged 70 or older living with them increased from 27.6% to 37.6%. These results highlighted that elderly relatives took care of their elderly relatives, signifying the progress of the so-called “Elderly care by the elderly.” In 2012, 2.18 million people worked while providing care for their relatives. According to the Employment Status Survey, the number of

workers who quit their job for caretaking increased from 79,000 in 2002 to 101,000 in 2012, which is a serious social concern [4].

Although Japanese people with mental disabilities have been admitted to psychiatric hospitals for a long time, the deinstitutionalization policy was promoted since executing “Vision for Reforming Mental Health Care and Welfare” in 2004 [5]. Likewise, for dementia, “Deinstitutionalization” (shifting the site of nursing care from in-facility to in-home and in-community) has progressed, especially after implementing the “Orange Plan” [2] in 2012 and the “New Orange Plan” [3] in 2015. However, no chronological study has investigated change in the composition of social burden. It would be important as basic data for considering clinical and policy implications for the quality assessment and improvement through appropriate resource allocation. For example, home care is the most rapidly growing segment of healthcare system but research on patient safety has been conducted within institutional settings, resulting in a significant knowledge gap for patient safety in homecare [6-8]. In Japan, there is still a few researches partly because of the lack of those basic data. Therefore, this study aims to assess the social burden of dementia in Japan from 2002 to 2014 to contribute to the medical and nursing care policy improvement in the progress of “Deinstitutionalization” policy.

METHODS

In the present study, we defined dementia as “Vascular dementia (International Classification of Diseases-10 code: F01),” “Unspecified dementia (F03),” and “Alzheimer's disease (G30).”

Table 1 summarizes the official statistics used in this study. We adopted the Comprehensive Cost of Illness (C-COI) method [9], an expanded version of the Cost of Illness (COI) method by Rice [10–12]. It has been widely used method in Japan [13–18]. While the Rice's method [10–12] included Direct cost (Medical) and Indirect costs (Morbidity cost and Mortality cost), the C-COI method also incorporated Direct cost (LTC) and Informal Care defined as unpaid care offered by family and relatives. In dementia care, it is evident that LTC and Informal Care will occupy significant portion of the total cost, and C-COI is superior to COI.

Direct cost (Medical) accounts for the medical costs directly related to the treatment, hospitalization, laboratory testing, and medications of the disease. It was calculated from the Survey of National Medical Care Insurance Services. Direct cost (LTC) was calculated as the total amount of LTC Insurance benefits, including out-of-pocket cost (10%), based on Comprehensive Survey of Living Conditions, Survey on LTC Insurance, and Survey of Institutions and Establishments for Long-term care.

Community-based Services has been newly added into LTC Insurance since 2006, of which Community-based Services (In-home) is defined as provided in-home and Community-based Services (Facility) is defined as provided in-facility.

Indirect cost consisted of the opportunity costs resulting from disease (Morbidity cost) and death (Mortality cost). Also, Informal Care was newly added to the C-COI. The following equations were applied:

Morbidity cost = Total person-days of outpatient visit × One-day labor value per person/2 + Total person-days of hospitalization × One-day labor value per person

Mortality cost = Number of deaths × Lifetime labor value per person

Informal Care = Number of primary caretaker × Average hours of caretaking × Average hourly cost of caretaker × 365 days

Total person-days of outpatient visit and Total person-days of hospitalization by sex, 5-year age group were calculated based on the Patient Survey. The labor values by sex, 5-year age group were determined based on the Basic Survey on Wage Structure and the Estimates of Monetary Valuation of Unpaid Work [19]. The Lifetime labor value per person was calculated as the sum of potential future income until their average life expectancy. The Morbidity cost was determined by assuming One-day labor value loss per inpatient and a half-day labor value loss per outpatient visit. Number of primary caretakers by sex, 5-year age group and the Average time for care a day was calculated based on the Comprehensive Survey of Living Condition.

One-day labor value per person, and Total person-days of hospitalization were calculated as follows:

One-day labor value per person = (Annual income per person + Annual monetary valuation of unpaid work per person)/365

Total person-days of hospitalization = Annual number of hospitalized patients × Average length of stay

Previous studies [1] have demonstrated that Informal Care had a large proportion of the total burden and was significantly influenced by estimation approaches. The following approaches were performed.

Case 1: Average hourly cost of caretaker 1 = Total One-day labor value per person / 8 hours / Number of primary caretakers

Case 2: Average hourly cost of caretaker 2 = (JPY 5840 + (Average hours of caretaking − 1.5) × JPY 1660) / Average hours of caretaking

Case 3: Average hourly cost of caretaker 3 = (JPY 5840 + JPY 2100 + (Average hours of caretaking − 1.5 − 1.17) × JPY 1660) / Average hours of caretaking

In Case 1, the average One-day labor value per person by sex and age groups is calculated by the Opportunity Cost Approach [13–18]. In Case 1, Average hourly cost of caretaker 1 is estimated by multiplying One-day labor value per person and Number of primary caretakers by

sex and age groups and dividing it by the total Number of primary caretakers and 8 hours (average working hours). In Cases 2 and 3, Average hourly cost of caretaker 2 and 3 are estimated by the Replacement Cost Approach using the same unit price as the fee for home nursing care covered by LTC Insurance. When body care, such as excretion and bathing, is needed, JPY 5840 is required to be paid up to the first 1.5 hours, and then JPY 830 is added every 0.5 hours (Case 2). In addition, when living assistance, such as cleaning and laundry, is needed, JPY 2100 is added up to 1.17 hours (Case 3).

The "Deinstitutionalization Rate" was defined as follows. The rise of it means an increase of the social burden in their living community and home. That is, it shows the transfer of medical and nursing care in the institutions into those in their living community and home.

Deinstitutionalization Rate = (Direct cost (Medical) of outpatient + In-home Services cost + Community-based Services + Informal Care) / (Direct cost + Informal Care)

The future labor value was adjusted to a present value using a 3% discount rate because 3% is widely used in the former studies in Japan and US, where the COI method is frequently used.

The study protocol was approved by the Ethical Committee at Toho University School of Medicine (reference number: A16019).

RESULTS

Table 2 showed the nominal GDP per capita and 2015-base Consumer price index changed a little during the study period. Therefore, our results of C-COI would be rarely affected by the price fluctuations.

The total C-COI increased 2.06–2.27 times from JPY 1.83–2.42 trillion in 2002 to JPY 3.78–5.51 trillion in 2014, of which Direct cost (Medicine) and Direct cost (LTC) increased 1.98 and 1.88 times, respectively. In addition, In-home Services increased 3.63 times, Community-based Services (In-home) 3.30 times, and Informal Care 2.24 times, whereas Facility Services and Community-based Services (Facility) increased slightly by 1.14 and 1.65 times, respectively. Consequently, “Deinstitutionalization Rate” increased from 50.3%–62.6% in 2002 to 68.6%–78.9% in 2014.

Table 3 shows that the number of people with dementia increased 2.50 times. In addition, patients with dementia living in-home and community increased 3.22 times, whereas those living in facilities remained at 1.42 times. The former average certified grade of LTC Insurance decreased from 3.0 to 2.3, but the latter increased from 3.5 to 3.8.

Table 4 shows that Average hours of caretaking decreased 0.77 times. Average hourly cost of caretaker declined 0.90 times in Case 1, but increased 1.07 times in Case 2 and 1.07 times in Case 3.

DISCUSSION

Table 5 summarizes some of the previous studies [20–28]. A review paper [29] reported that it varied considerably in the literature due to the variable number of included cost categories.

Except for Japan, there might be few countries where social burden of diseases can be calculated only by the macro data including the official statistics. Especially, most of the former studies, except for the current study, calculated Informal Care from the micro data by the bottom-up approach. Therefore, it seemed to be difficult to simply compare with the studies in Japan.

As for the studies in Japan, Sado [25] estimated it in 2014 to be JPY 10.4–15.6 trillion, which could be an overestimation. He calculated the Average hourly cost of caretaker by the Replacement Cost Approach and Lost Wage Approach. By the former approach, it was estimated to be JPY 4955/hour as the unit fee of the home-visit nursing care service by LTC Insurance. In reality, as the unit fee after 1.5 hour decreases to JPY 830/0.5 hour, we re-calculated it to be JPY 2139–2307/hour.

Wimo [24] calculated the patients with dementia in Japan to be 2.35 million and estimated the social burden to be US$ 44.9–62.4 billion in 2009. Because Wimo' study aimed at the international comparison based on the gross domestic products and average income, it abstracted Japanese socio-cultural context.

According to Prince [27], the patients with dementia in the UK in 2013 was estimated to be about 0.81 million and the total social burden was estimated JPY 3.2–5.5 trillion (£ 21.7–37.1 billion). Hurd [28] estimated that the number of the US dementia in 2010 was about 3.8 million and the total social burden was estimated at JPY 15.9–21.5 trillion (US$ 159–215 billion). Though this

study, Prince [27], and Hurd [28] estimated Informal Care in multiple methods in the different socio-economical context, it seemed to be similar social burden per person in United States (JPY 4.16–5.62 million), UK (JPY 3.97–6.79 million), and Japan (JPY 3.66–5.24 million). In contrast, the proportion of Informal Care in Japan (39%– 57%) seemed to be higher than UK (32.7%– 44%) and USA (31%– 49%). The ratios of Direct cost (LTC) to Informal Care in Japan from 2002 to 2014 were chronologically decreasing from 1.39 to 1.23. In that, it was gradually shifting from Direct cost (LTC) to Informal Care.

In Japan, local governments substantially regulated the number of beds in nursing care facilities to control expenditure, and patients with mild or moderate dementia are requested to live in their home and community. From 2002 to 2014, those living in the facility increased 1.42 times; however, those living out of facilities increased 3.22 times. Although the average certified grade of LTC Insurance increased from 3.5 to 3.8 among facility residents, it decreased from 3.0 to 2.3 among non-facility residents. Consequently, “Deinstitutionalization Rate” increased from 50.2% to 69.6%, reflecting that serious dementia prioritized using Facility Services, whereas mild or moderate dementia was supported with Informal Care, In-home Services and Community-based Services. In particular, Informal Care increased +40.3%, and In-home Services increased +25.7% regarding contribution rates (increase or decrease of each expense/increase or decrease of total C-COI × 100%), indicating that about 40.3% of the total increase could be explained only by Informal Care.

Table 4 shows that C-COI per person decreased 0.82 times in Case 1, primarily because of decrease by 0.90 times in Average hourly cost of caretaker and 0.77 times in Average hours of

caretaking. In particular, declining Average hourly cost of caretaker could be attributed to the progress of the so-called “Elderly care by the elderly” in Japan. The retirement age in Japan is at age 60, therefore the average hourly labor value sharply drops from JPY 1789/hour at age 60 to JPY 1100/hour at age 61.

Though it is certain that the ageing triggered the increasing number of dementia, a growing public awareness of the dementia issue might lead to a higher number of diagnoses by early detection. The number of articles on dementia in the five major national newspapers (Asahi, Yomiuri, Mainichi, Sankei, and Nikkei) has been increasing from 1284 articles in 2000 to 4628 articles in 2017 [30]. When applying for LTC Insurance executed since 2000, all applicants must see the physician to check up their cognitive function. Table 3 showed that the number of people with dementia in their living community and home grew rapidly while the average certified grade of LTC Insurance decreased as well as Average hours of caretaking. In institutionalized people, this trend was not as pronouncedly marked. It could be explained by the fact that the local governments substantially regulated the number of beds in nursing care facilities. In short, the increasing number of dementia in living community and home could be explained partly due to “Earlier diagnosis of dementia.”

Initially, LTC Insurance was launched because Japanese traditional family care had become unsustainable due to the trend toward nuclear families and the aging of caretakers [31]. The average number of family members per household decreased 0.5 times from 5.00 persons in 1953 to 2.49 persons in 2014 [4]. Hence, as mentioned earlier, the number of workers that has to resign for

nursing care is expected to increase. The initial purpose of LTC Insurance was to reduce the burden of the family members with public expenses. However, the proportion of Facility Services was not increasing because of financial reasons, and the proportion of In-home Services and Community-based Services was increasing. Hence, it is imperative to discuss how to balance the nursing care by LTC Insurance and Informal Care not to exceed the acceptable limit for Japanese society and each family caretaker, while maintaining the patient safety.

Limitations

This study has several limitations. An epidemiologic study in 2010 [32] estimated the number of patients with dementia to be 3.50–4.97 million. Our estimation might have underestimated the reality. Only LTC Insurance users primarily because of dementia were included in this study. People whose primary cause of disability was not dementia, but dementia played a role in disturbing their activity of daily living or mild dementia people without the LTC Services, were not included. The Hisayama Study [33], a cohort study using a small town in Kyushu (population, 8400), reported that the number of people with dementia in 2012 was about 4.61 million, of which 48% were not receiving LTC Services. A public opinion poll on dementia [34] revealed that 34% of Japanese people thought “we can live in-community with social support when dementia develops.” Hence, a further study focusing on mild dementia and dementia as a comorbidity is warranted.

This study has significance in quantitatively estimating the social burden of dementia not adequately visualized in Japan. It is necessary to shift the focus of discussion for the quality

assessment and improvement from those in institutional settings to those in home and community settings. In addition, our C-COI method would facilitate the analysis of various diseases. Hence, those C-COI applied studies could be an essential clue for better distribution of social and medical resources.

In conclusion, while the number of people with dementia increased 2.50 times from 2002 to 2014 with the population aging and the growing public awareness, the increase of the total C-COI remained 2.06–2.27 times, and cost per person was compressed by 0.82–0.91 times because of the progress of "Deinstitutionalization," "Elderly care by the elderly," and "Earlier diagnosis of dementia." Since the contribution rate of Informal Care was as high as about 40%, it is imperative to discuss how to balance LTC Insurance and Informal Care not to exceed the acceptable limit for Japanese society and Informal Caretakers, while maintaining patient safety and quality of care.

AUTHORS' CONTRIBUTIONS

SH developed the original idea and the manuscript. KM, TK, KS, and TH participated in its design and coordination. All the authors approved the final manuscript.

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Table 1. Official Japanese statistics used in the present study

Dataset year	2002	2005	2008	2011	2014
Patient survey	2002	2005	2008	2011	2014
Survey of National Medical Care Insurance Services	2002	2005	2008	2011	2014
Vital statistics	2002	2005	2008	2011	2014
Comprehensive survey of living conditions	2001	2004	2007	2010	2013
Survey on long-term care insurance	2001	2004	2007	2010	2013
Survey of institutions and establishments for long-term care	2001	2004	2007	2010	2013
Basic survey on wage structure	2002	2005	2008	2011	2014

All the above official Japanese statistics are available on the portal site of the Official Statistics of Japan (http://www.e-stat.go.jp/)

Table 2. Comprehensive Cost of Illness (C-COI) for dementia in Japan (JPY 1 million)

Year				2002	2005	2008	2011	2014
Direct cost	Direct cost (Medicine)	Outpatient		34,429	30,761	64,414	63,950	88,054
		Inpatient		141,345	152,925	270,068	227,936	260,002
	Direct cost (Long-term care)	In-home servicies		188,648	315,920	440,201	597,991	684,865
		Community-based servicies (in-home)				11,707	27,583	38,597
		Community-based servicies (facility)				113,578	148,871	186,850
		Facility servicies		745,021	848,639	775,046	858,891	846,071
Indirect cost	Morbidity cost			31,176	62,821	77,203	82,265	116,617
	Mortality cost			24,125	44,111	44,942	86,139	134,663
Informal care	Total		Case 1	672,702	837,800	1,081,385	1,297,288	1,422,871
			Case 2	1,245,433	1,719,510	2,287,619	2,729,620	3,109,699
			Case 3	1,258,562	1,739,033	2,315,028	2,763,183	3,149,452
Total C-COI	Total		Case 1	1,837,446	2,292,977	2,878,544	3,390,913	3,778,589
			Case 2	2,410,177	3,174,687	4,084,777	4,823,245	5,465,417
			Case 3	2,423,306	3,194,210	4,112,187	4,856,809	5,505,170
	Per person		Case 1	4.37	3.90	3.79	3.81	3.60
			Case 2	5.74	5.40	5.37	5.42	5.20
			Case 3	5.77	5.43	5.41	5.46	5.24
Deinstitutionalization rate (%)			Case 1	50.3%	54.2%	62.1%	66.3%	68.6%
			Case 2	62.4%	67.4%	73.6%	76.7%	78.8%
			Case 3	62.6%	67.6%	73.8%	76.8%	78.9%
Nominal gross domestic product (GDP) per capita[a]				3.91	3.96	3.82	3.70	4.08
2015-Based consumer price index[a]				97.5	96.9	98.6	96.3	99.2

[a] Nominal GDP per capita and 2015-Based consumer price index were retrieved form the Cabinet office of Japan

Table 3. Total number of patients with dementia in Japan

Year			2002	2005	2008	2011	2014
Total number of patients with dementia (persons)			420,241	588,203	760,174	890,247	1,050,608
	Living in-home and in-community		251,309	392,301	540,775	672,119	810,081
		Average certified grade of LTC insurance [a]	3.0	3.0	2.5	2.4	2.3
	Living in-facility		168,932	195,902	219,399	218,128	240,527
		Average certified grade of LTC insurance [a]	3.5	3.7	3.8	3.8	3.8

[a] 0.5 is the coefficient for the LTC insurance certification of the support needed

Table 4. Average hours of caretaking and hourly cost of the caretaker

Year		2002	2005	2008	2011	2014
Average hours of caretaking (hours/ day)		7.0	6.4	5.9	5.7	5.4
Average hourly cost of caretaker (JPY/ hour)	Case1	1,155	1,066	1,052	1,068	1,042
	Case2	2,139	2,187	2,226	2,246	2,278
	Case3	2,161	2,212	2,253	2,274	2,307

Table 5. Studies on the social burden caused by dementia

		Fukuda[20]	Fukuda[21]	Wimo[23]	Wimo[24]	Sado[25][a]	This study	Prince[27][a]	Hurd[28][a]
Target year		1999	2005	2005	2009	2014	2014	2013	2010
Country		Japan	Japan	Japan	Japan	Japan	Japan	UK	USA
Number of patients with dementia (persons)		276,000	466,000	1,809,133	2,352,632	none	1,050,608	815,827	3,824,427
Direct cost (JPY 1 million)		2,700,495	580,900	2,414,890	3,157,570	8,355,551	2,104,439	2,179,104	10,900,000
	Medical cost	409,657	580,900	none	none	1,911,446	348,056	641,791	none
	Nursing care cost	2,290,838	none	none	none	6,444,105	1,756,383	1,537,313	none
Indirect cost (JPY 1 million)		none	none	none	none	none	251,280	none	none
	Mortality cost	none	none	none	none	none	134,663	none	none
	Morbidity cost	none	none	none	none	none	116,617	none	none
Informal care cost (JPY 1 million)		none	none	1,020,370–2,359,600	1,334,180–3,085,290	2,019,000–7,236,317	1,486,341–3,149,151	1,059,701–3,358,208	5,000,000–10,600,000
	Average hourly cost (JPY 1	none	none	966	971	965–4,955	1,042–2,307	896–2,835	991–2,100
	Average hours / day	none	none	1.6 or 3.7	1.6 or 3.7	3.67	5.40	4.50	3.72
Total social burden(JPY 1 million)		2,700,495	580,900	3,435,260–4,774,490	4,491,750–6,242,860	10,374,551–15,591,868	3,842,059–5,504,870	3,238,805-5,537,313	15,900,000-21,500,000
Social burdenper person(JPY 1 million)		9.78	1.25	1.90–2.64	1.91–2.65	none	3.66–5.24	3.97–6.79	4.16–5.62

[a] Based on the data from the original article, all monetary values were re-calucurated. [JPY 1 million = US$ 10000 = £ 6700]