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Title:

Primary palliative care in Japan: needs estimation and projections – national database study with international comparisons

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Abstract

Objectives: We aimed to estimate the potential population that requires palliative care, clarify the relationship between this population and the rate of aging in Japan, and compare these trends with those of other countries.

Design: We used the national death registration data and population projections for Japan to estimate the population in need of palliative care using the minimal estimate method developed by Murtagh et al. Linear regression was used to create a model of mortality using sex, age at intervals of 5 years, and each major disease classification. We calculated the future population in need of palliative care until 2040 and compared the aging data to those of other countries.

Setting/Participants: All adults in Japan who died from 1980 to 2040 at intervals of 5 years.

Results: The number of people who might need palliative care from 2020 to 2040 will also increase linearly from 1,059,000 to 1,405,000. The proportion of Alzheimer's, dementia, and senility of the total need for palliative care will increase to 43.4% in 2040. The correlation coefficient between the proportion of the population in need of palliative care and the rate of aging was 0.24 in developed countries.

Conclusion: In Japan, the population requiring palliative care in 2040 will be 1.5 times that in 2015. Palliative care needs to be provided urgently for people with Alzheimer's disease, dementia, and senility. The proportion of patients in need of palliative care may not change, although the number of patients requiring such gradually increases in developed countries.

Keywords: palliative care, needs assessment, population, future estimation, Japan

What is already known on this topic

The potential population that needs palliative care are estimated in various countries, except Japan.

What this study adds

In Japan, as super-aging society, population in need of palliative care by 2040 may increase 1.5 times that in 2015. We found a positive correlation between the proportion of the population in need of palliative care and the rate of aging internationally.

How this study might affect research, practice or policy

With increasing demand for palliative care, the need to educate and train palliative care providers are emphasized.

Introduction

Palliative care aims to improve the quality of life of patients with a life-threatening illness and their families [1]. It can also help patients facing advanced chronic conditions. This includes patients with non-malignant diseases, such as dementia, heart failure, renal failure, and pulmonary diseases. However, it is challenging to expand palliative care among patients with non-malignant diseases in Japan and other countries [2]. Previous research has suggested that people with a wide range of advanced conditions and diseases may benefit from palliative care; however, there are limited reports on the proportion of potential patients in need of palliative care at the population level [3-6]. Addressing the potential need for palliative care on a population basis and predicting these numbers in the future is important for embedding palliative care in the national health policy to develop and provide appropriate services [7].

Japan is a super-aging society, and the causes of death have rapidly changed in recent decades. Approximately 1,376,000 people have died in 2019, and it is predicted to increase 1.2 times by 2040

[8]. Therefore, the need for palliative care will increase accordingly. Moreover, the prevalence of diseases and mortality patterns has changed. Specifically, the number of people with dementia have increased in the past decades and will continue to do so in the future [9]. However, there are no studies from Japan that can estimate the number of potential patients who will need palliative care using a population-based approach; moreover, there are no international comparisons.

Therefore, this study aimed to 1) estimate the potential population that needs palliative care using the standard method of Murtagh et al., [3], 2) predict the future population that needs palliative care, 3) clarify the relationship between the proportion of the population in need of palliative care and the rate of aging in Japan, and 4) compare these trends with those of other countries.

Methods

Design

We used the vital statistics provided by the Ministry of Health, Labour, and Welfare, Japan.

Data source

Death registration data (1980-2015)

We used the national death registration data to identify the causes of death for our palliative care needs estimation [10]. The data included the cause of death, sex, and age at intervals of 5 years. The cause of death was classified according to the International Statistical Classification of Diseases and Related Health Problems-ninth Revision (ICD-9) in 1980 and 1990 and the International Statistical Classification of Diseases and Related Health Problems-10th Revision (ICD-10) from 1995 to 2015. We used data from 1980 and every 5 years from 1990 to 2015.

Population and mortality (2020-2040)

The population projections data from the National Institute of Population and Social Security Research were used to calculate the population structure based on medium fertility and mortality

estimated on October 1, 2015, sex, and age at 5-year intervals [11].

Analysis

Estimation of potential population in need of palliative care

We estimated the population in need of palliative care using death registration data from 1980 to 2015 [10]. We included the number of deaths, sex, and age as specific conditions in the need for palliative care in 1980 and every 5 years from 1990 to 2015. Data with missing ages were excluded from our analysis. We used the minimal estimate method developed by Murtagh et al. to estimate the palliative care needs [3]. This method is based on the number of deaths from the condition identified as having palliative care needs. The following nine major causes of death (ICD-10 codes) were utilized: malignant neoplasms (C00-C97); heart disease (I00-I52, excluded I12 and I13); cerebrovascular disease (I60-I69); liver failure (K70-K77); respiratory disease (J06, J09-J18, J20-J22, J40-J47, and J96); renal failure (N17, N18, N28, I12, and I13); Parkinson's and neurodegenerative diseases (G10, G20, G35, G122, G903, and G231); Alzheimer's disease, dementia, and senility (F01, F03, G30, and R54); and HIV/AIDS (B20-B24) (Supplementary Table 1). We used the following web page to convert ICD-9 codes to ICD-10 codes: <http://www.icd10data.com/Convert>.

Future prediction

Based on the number of deaths because of specific conditions (Supplementary Table S1 for details of the specific conditions.), we predicted the future population in need of palliative care until 2040 as follows:

- 1) We calculated mortality based on sex, age at intervals of 5 years, and each major disease classification in 2005, 2010, and 2015.
- 2) We used linear regression to create a model of mortality with the year in 2005, 2010, and 2015.
- 3) We calculated the mortality of future patients by extrapolating the linear model.

- 4) We determined the population in need of palliative care by multiplying population projections by sex, age at intervals of 5 years, and each major disease classification every 5 years from 2020 to 2040.
- 5) The total number of patients in need of palliative care was calculated by summing the total of each age group from each major disease classification. (Supplementary Appendix 1).

Moreover, we compared our prediction with the national death prediction by the National Institute of Population and Social Security Research [8] to verify similarities in our predictions.

International comparison and association with aging

We compared the data of aging to those of other countries based on our hypothesis that aging is associated with a higher need for palliative care. We used the data on aging from 12 countries, including Belgium, Canada, Czech Republic, France, Hungary, Italy, Mexico, New Zealand, Spain (Andalusia), South Korea, Sweden, and the United States, estimated by Morin et al. [6]. We also used data from Malaysia in 2010 [12] and Brazil in 2014 [13], which were the results of the adult population aged 15 y or older using the methods of Murtagh et al. [3]. Moreover, data from Germany in 2013 [14] were also utilized, which was obtained from the whole population using the methods of Murtagh et al. We adopted the Organization for Economic Co-operation and Development data of 2014 [15] for the rate of aging in all countries except Malaysia, which was instead acquired from the Malaysian Administrative Modernization and Management Planning Unit [16].

Our estimation of aging used the death registration data from 2010 in Japan. Since open data available in Japan only targeted those who were 20 years or older, we could not compare the same age group of Morin et al., which used the data of participants aged 18 years or older. We excluded some ICD-10 codes (J06, J09-J18, and J20-J22) based on the method of Murtagh et al. and followed the methods of Morin et al [6].

We included the data of England with all ages using the methods of Murtagh et al. because

they provided only aggregated categories for the causes of death. However, the outcome of heart disease estimated by Murtagh et al. in England was lower compared to that of other countries because data were unavailable from 2006 to 2008. Therefore, we recalculated the proportion of the population in need of palliative care, substituting three times the population of heart disease in 2006 from the British Heart Foundation Statistics Database [17].

Finally, we obtained correlation coefficients by plotting the proportion of the population in need of palliative care and the rate of aging in 17 countries.

All analyses were performed using Microsoft® Excel® 2016 and SAS JMP® Pro software version 15.0 (SAS Institute Inc., Cary, NC, USA) .

Results

Estimation of the potential population in need of palliative care

The number of deaths requiring palliative care in Japan from 1980 to 2015 changed from 584,000 to 989,000 (Figure 1). In 2015, the number of deaths who needed palliative care increased 1.7 times from that of 1980. The proportion of total deaths requiring palliative care was 76.6% in 2015 (Supplementary Figure S1).

Future prediction

The number of people who will need palliative care from 2020 to 2040 will increase linearly from 1,059,000 to 1,405,000 (Figure 1). In 2020, the number of people who will need palliative care will increase by 1.3 times from that of 2020. The total number of deaths from 2020 to 2040 will rise from 1,406,000 to 1,626,000.

The proportion of the population requiring palliative care to total deaths will decrease from 79.4% in 2000 to 73.8% in 2025 (Supplementary Figure S1). We predicted the rate of the population in need of palliative care for total deaths to increase from 77.1% in 2030 to 86.4% in 2040.

The proportion of malignant neoplasms in the total need for palliative care was predicted to decrease from 38.8% to 27.0% from 2000 to 2040 (Supplementary Figure S2). The proportions of cerebrovascular and respiratory diseases decline gradually from 1995 to 2040. Moreover, the proportion of patients with Alzheimer's disease, dementia, and senility increases remarkably from 3.3% in 2000 to 43.4% in 2040.

International comparison and association with aging

We showed the proportion of the population in need of palliative care by Morin et al., in 2008 and the rate of aging in 2014 (Figure 2). The proportion of the population in need of palliative care in Japan was 77.1% in 2010, and the rate of aging in Japan was 26.0% in 2014. The Pearson product-moment correlation coefficient between the proportion of the population in need of palliative care and the rate of aging was 0.69 across 17 countries and 0.24 after excluding Brazil, Mexico, and Malaysia.

Discussion

To our knowledge, this is the first study to estimate the future population need for palliative care in Japan. We identified that the population in need of palliative care by 2040 will be 1.5 times that in 2015. The proportion of Alzheimer's, dementia, and senility will notably increase among patients who need palliative care in the future. This study had two important findings. First, our prediction of the population in need of palliative care in Japan will increase linearly. Second, the proportion of the population in need of palliative care in Japan was the same as that of other high-income countries, which are similarly affected by aging.

Our study suggests that the proportion of deaths in the need for palliative care will increase in developed countries over coming years. Many patients might feel physical and/or psychological pain in the terminal phase and require palliative care, irrespective of diagnosis [18]. Patients without cancer do not receive enough palliative care [19], although we predicted that the number of non-cancer

patients would increase because palliative care has mainly developed in the field of oncology in Japan [2]. Therefore, it is important to ensure and expand the service to non-cancer patients. The need for palliative care for Alzheimer's, dementia, and senility has increased in Japan and other countries [20]. People with dementia have difficulty expressing their pain in comparison to others; careful assessment and management is therefore more challenging. The European Association for Palliative Care (EAPC) has provided guidelines that set a proper goal for palliative care, including for those with non-cancer conditions [21]. Therefore, this framework for dementia and non-cancer patients is important for Japan and other countries.

The proportion of the population in need of palliative care in Japan was the same as that of other high-income countries, which are similarly affected by aging. In addition, we found a weak positive correlation between the proportion of the population in need of palliative care and the rate of aging, except in upper middle income countries, namely, Brazil, Mexico, and Malaysia. The proportion of the population in need of palliative care in developed countries is similar to the estimation of Gomez-Batiste et al., wherein 75% of deaths need palliative care [5]. Therefore, developed countries with similar structures of diseases need to enhance and increase palliative care to allow for the increased number of deaths from conditions needing palliative care. The implementation of palliative care will improve the wellbeing and quality of life of those with these conditions. Moreover, under the extraordinary conditions brought about by coronavirus disease 2019 (COVID-19), the number of deaths was not excessive in Japan [22]. Therefore, our prediction is unaffected by COVID-19.

Results from the present study, as well as the methods of Murtagh et al. and Morin et al., reported the needs for both primary and specialist palliative care. However, the need for primary palliative care is not the same as that for specialized palliative care [23]. Specialist palliative care is needed for patients with complex and difficult needs; therefore, a higher level of education and greater number of staff and other resources are required. We need to identify the population with the most complications and needs when allocating specialized palliative care. Therefore, screening tools, such

as the Supportive and Palliative Care Indicator Tool, might help identify patients who need specialized palliative care [24].

We adopted the most conservative method proposed by Murtagh et al. However, Morin et al. estimated the population except for some ICD-10 codes (J06: acute upper respiratory infections of multiple and unspecified sites; J09-J18: influenza and pneumonia; and J20-J22: other acute lower respiratory infections). The method of Morin et al. may be better because J06, J09-J18, and J20-J22 are acute diseases. J84, other interstitial pulmonary diseases, of ICD-10 codes might influence the population. The incidence of pneumonia might increase in the future because it is a common cause of death among older adults [10]. The disease held about 1% of the Japanese deaths in 2017, though both methods excluded interstitial pulmonary diseases. However, they would have minimal impact on the population size.

This study had several limitations. First, our projection was overestimated and/or underestimated because a simple method in our study affected the slope of the linear regression. Our regression model can be used to predict only the future 10 years. Our total death trend could be plausible because the prediction is consistent with the death trend in the population projections by the National Institute of Population and Social Security Research [11]. Second, the trend of mortality in the last 10 years might strongly affect our prediction. We calculated the mortality of patients from 2005 to 2015. The structural array generator (SAGE) analyzed the mortality characteristics in 2030 using a system that conforms to the cohort-change rate method [25]. Our results were similar for malignant neoplasm, heart disease, and cerebrovascular disease when compared with the estimation of SAGE. This rapid increase may have led to the overestimation of our results due to the higher incidence rates of dementia, senility, and age-related frailty in Japan. Third, there were minor differences in the statistical data for each country. For example, we needed to change the ICD-10 codes of Parkinson's and neurodegenerative diseases from G122, G903, and G231 to G12, G90, and G23, respectively (Supplementary Table S1). Therefore, some numbers, such as those of Parkinson's and

neurodegenerative diseases were overestimated. There were no large impacts because the proportion of Parkinson's and neurodegenerative diseases is small. Finally, our criteria excluded cases where the patients died in an accident or suffered from complications, because we used the death registration data based on the cause of death indicated in the death certificate as per the methods of Murtagh et al. [3,6,26].

Conclusions

We clarified the population in need of palliative care and the changes in each major condition: malignant neoplasms; heart disease; cerebrovascular disease; liver failure; respiratory disease; renal failure; Parkinson's and neurodegenerative diseases; Alzheimer's disease, dementia, and senility; and HIV/AIDS, in Japan. In conclusion, the number of people who need palliative care has increased in Japan by 1.5 times since 2015. The proportion of Alzheimer's, dementia, and senility of the total need for palliative care will increase remarkably from 3.3% in 2000 to 43.4% in 2040. There was a positive correlation between the proportion of the population in need of palliative care and the rate of aging.

Author contributorship

The study conception and design, material preparation, and data collection and analysis were performed by Masami Ito and Mitsunori Miyashita. The first draft of the manuscript was written by Masami Ito, and all authors commented on previous versions of the manuscript. All authors reviewed the manuscript draft and revised it critically on intellectual content. Maho Aoyama and Fliss E M Murtagh substantially contributed to the manuscript drafting. Mitsunori Miyashita supervised the conduct of this study. All authors read and approved the final manuscript.

Competing interest

The authors declare no conflict of interest.

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Data sharing

The original data used in the present study (vital statistics) are provided by the Ministry of Health, Labour, and Welfare, Japan. Other data for estimation are available upon request reasonable request to the corresponding author.

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Figure legends:

Figure 1. Population in need of palliative care in Japan from 1980 to 2040.

Figure 2. Association between the proportion of the population in need of palliative care and the rate of aging.

Supplemental materials:

Table S1. Correspondence table, converting from ICD-9 to ICD-10 codes

Appendix 1. Calculation for future predictions

Figure S1. Rate of the population in need of palliative care (total deaths)

Figure S2. Conditions of the proportion in need of palliative care (total needs)