

ORIGINAL ARTICLE

SOCIAL RESEARCH, PLANNING AND PRACTICE

Awareness-raising activities for community residents about decision-making regarding end-of-life care: A nationwide survey in Japan municipalities

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Aim: The purpose of the present study was to clarify the current state of awareness-raising activities to educate residents about decision-making regarding end-of-life care using a nationwide survey of municipalities in Japan.

Methods: A cross-sectional questionnaire-based survey of all municipalities in Japan ($n = 1741$) was carried out. We asked one representative from each municipality whether or not there were ongoing municipality-led activities to raise awareness and educate the community about end-of-life care decisions. A logistic regression analysis was carried out to examine the regional characteristics associated with running municipality-led awareness-raising activities. Additionally, we investigated the creation and contents of awareness-raising materials targeting residents.

Results: The questionnaire was completed by 1145 municipalities (valid response rate 65.8%). We found that 39.4% of the municipalities surveyed were currently running or planning activities about end-of-life care. Municipalities with active public awareness campaigns had a significantly higher financial capability index than inactive municipalities. Awareness-raising materials targeting residents were created in 134 of the municipalities. The most frequently mentioned components of the materials were the importance of articulating one's intentions with regard to end-of-life care services in advance, sharing those feelings with the family and revisiting them repeatedly (73.9%), and the explanation of home healthcare and long-term care services (47.7%).

Conclusions: The present findings suggest that cities with tight budgets are unable to carry out activities to raise awareness and educate residents about end-of-life care. Thus, it is important to pursue the implementation of further national-level initiatives and funding support for municipalities. *Geriatr Gerontol Int* 2019; ●●: ●●–●●.

Keywords: aging, awareness, end-of-life care, municipality.

Introduction

The global population is aging, and Japan is experiencing the world's highest aging rate. Often referred to as an aging society, as deaths exceed births in ever greater numbers, Japanese society is approaching a new status: hyper-aged and death-ridden. In 2017, approximately 1.34 million Japanese citizens died;¹ in 2025, at which point every member of the baby-boom generation will be aged at least 75 years, this figure is estimated to reach 1.52 million, twice the number of births for the same year.² These social trends have caused growing public interest in end-of-life care. According to a 2017 survey carried out by the Ministry of Health, Labour and Welfare (MHLW), approximately 60% of respondents reported having thought about what medical or nursing care they might need in the last years of their lives.³

Legal frameworks in the USA and UK recognize advance directives (AD), documents in which a person specifies what kinds of medical procedures or care they wish to receive (or refuse) in the future should their decision-making capacity become impaired. In Japan, AD are not legally binding and lack a uniform format. Nearly three-quarters (73.7%) of respondents in a 2004

survey of middle-aged and older adults residing in Tokyo wanted to verbally communicate their wishes about treatment strategies, yet just 20.3% had actually written an AD.⁴

In 2006, a doctor at a hospital in Toyama Prefecture was reported to have removed life-sustaining respirators from several terminal patients between 2000 and 2005.⁵ In the following year, the national government issued formal guidelines to help clarify best practices and objectives for end-stage medical care (Guidelines for Medical Decision-Making Processes in the Final Stages of Life).⁶ These guidelines emphasize the importance of not only AD, but also a discussion process between the patient, their family and healthcare providers. In one government-run investigation in 2013, however, 55.9% of respondents still had not discussed with their family the procedures and treatments they wished (or did not wish) to receive in their final years.⁷ In 2016, a survey of older adults who had been visited by a doctor at home found that 32% planned to leave their care decisions to their doctor or family, whereas a mere 1.9% had written an AD.⁸ These research findings suggest the need to raise awareness and better educate the public about the decision-making regarding end-of-life care.

In recent years, widespread aging and increasing deaths have already prompted some efforts in municipalities all over Japan, such as seminars for residents, and creating and distributing leaflets, pamphlets and other educational materials; some initiatives are even covered in newspapers or other media. However, no studies have investigated these awareness-raising activities to educate the public about the decision-making regarding end-of-life care; therefore, they are still poorly understood as to their extent and content nationwide.

The purpose of the present study was to clarify the current state of awareness-raising activities to educate residents about decision-making regarding end-of-life care, and investigate the creation and contents of leaflets, pamphlets and other materials for residents by carrying out a nationwide survey of all municipalities in Japan.

Methods

Participants

We aimed to carry out a cross-sectional survey of all municipalities – cities, towns, villages and special wards – in Japan ($n = 1741$) from February to March 2017. Initial requests were issued by the MHLW to all of Japan's prefectural offices ($n = 47$), which sent a questionnaire to all municipalities in their respective jurisdiction. Surveys were completed by a representative working in a relevant department of long-term care in each municipality. This survey was approved by the Promotion office of Home Health Care, Ministry of Health, Labour and Welfare. The representative working in the relevant department in each municipality was informed about the research purpose, methods and academic research use through written documents. Returning the survey was interpreted as giving consent to participate.

Questionnaire

All survey items were discussed by a research committee composed of medical and nursing researchers, legal scholars, doctors and nurses routinely involved in end-of-life care, and government policymakers.

Respondents were first asked whether or not there were any ongoing municipality-led activities to raise awareness and educate the community about decision-making regarding end-of-life care. If so, they were asked to identify the nature of those initiatives – creating educational materials, holding seminars and so on – as well as the contents of any media prepared in conjunction.

Survey items regarding the educational materials were as follows:

- Target age group (years): <40, 40–64, 65–74, ≥75
- Method of distribution: by post, in person, in stands (i.e. in a public location where anyone is free to take them), as handouts for seminars (courses, etc.) designed for residents, other
- Place of distribution: residents' homes, medical facilities, pharmacies, visiting nurse agency, homecare services agency, public health centers, public information counter, other
- Staff explanation: Do recipients have the material's contents explained to them? If so, by whom?

Survey items regarding the specific topics presented in the educational materials were as follows. Respondents were asked to select all applicable responses.

- Importance of articulating one's preferred location of care and treatment in advance, sharing those feelings with family and revisiting them repeatedly
- Changes in mental/physical state one can expect at the end of life
- Meaning of the term "life-sustaining treatment"
- Objective, procedure and so on of life-sustaining treatment: artificial respiration, endotracheal intubation, cardiac massage, artificial nutrition, and hydration (e.g. by gastrostomy tube, parenteral nutrition), other
- Home healthcare or long-term care services (e.g. details of visiting care, visiting nursing etc.; public insurance framework for home care; expenses/burden etc.)
- Other

The last set of questions included whether each municipality actually recorded residents' wishes regarding end-of-life care using a standard AD-like form (template etc.) that residents could complete themselves. If so, respondents were asked to specifically note which of the following data were collected to share with medical institutions and other relevant parties as required:

- Personal wishes about life-sustaining treatment in general
- Personal wishes about individual life-sustaining treatments, such as artificial respiration, endotracheal intubation, cardiac massage, and artificial nutrition and hydration (e.g. by gastrostomy tube, parenteral nutrition)
- Personal wishes and feelings about palliative and end-of-life care in general excluding life-sustaining treatment: preferences/priorities, specific objections and so on (Do they want to fight a disease to the very end? Do they want an ambulance called even if their condition worsens? Do they want to keep medical procedures to a minimum? Do they want to continue to make all decisions about treatment options by themselves? etc.)
- Official designation of a surrogate to make decisions related to their treatment plan on their behalf, if they are unable to
- Where they want to receive end-of-life care; where they want to die
- Emergency contact (family member, other relatives, medical facility etc.)
- Date signed
- Signature (own)
- Signature (surrogate)
- Other

Statistical analysis

The dependent variable was the existence of ongoing or planned activities to raise awareness and educate residents about decision-making regarding end-of-life care (Yes = "active," No = "inactive"). The independent variables were drawn from population-level data obtained from a government-published portal site for Japanese government statistics (current as of 1/1/2014):⁹ total population; percentage of residents aged ≥65; percentage of deaths at home; number of hospital or clinic beds per 1000 residents; percentage of residents certified to require long-term-care; financial capability index (FCI); rate of population change; and percentage of solitary-living older adults.

First, a bivariate analysis was run between active/inactive status and each of the independent variables to identify those with significant associations. Next, a multivariable logistic regression analysis was carried out introducing all significant variables with P -value <0.1 into the model after checking them for multicollinearity. The

Table 1 Characteristics of municipalities active/inactive in awareness campaigns about decision-making regarding end-of-life care

	Active (<i>n</i> = 451)				Inactive (<i>n</i> = 694)				<i>P</i> -value [†]
	<i>n</i>	Median	25–75 percentile		<i>n</i>	Median	25–75 percentile		
Total population	451	42 100	17 822	– 100 639	694	23 652	8712	– 56 512	<0.0001
Percentage of population aged ≥65 years	451	28.1	24.1	– 32.4	694	29.2	24.9	– 34.0	0.0157
Percentage of deaths at home	449	11.6	8.8	– 14.1	683	10.4	8.0	– 13.2	0.0003
No. hospital or clinic beds per 1000 residents	451	11.1	6.4	– 17.3	694	10.5	4.1	– 17.8	0.0430
Percentage of residents certified to require long-term-care	451	56.6	49.5	– 63.9	694	56.8	49.1	– 63.1	0.6688
Financial capability index	442	0.53	0.34	– 0.76	689	0.43	0.25	– 0.68	<0.0001
Rate of population change (%)	451	–0.34	–0.65	– 0.06	694	–0.42	–0.78	– –0.07	0.0061
Percentage of solitary-living older adults	451	11.4	9.3	– 14.4	694	11.9	9.4	– 15.4	0.0859

Total *n* = 1145. [†]Wilcoxon rank sum test.

model goodness-of-fit was assessed using the Hosmer–Lemeshow test. Statistical significance was set at 5%. In addition, the contents of educational materials were analyzed using descriptive statistics. SAS (version 9.4; SAS Institute, Cary, NC, USA) was used for all analyses.

Results

The questionnaire was distributed to all 1741 municipalities in Japan and returned by 1158; however, 13 did not answer the main question and were excluded from the analysis. The final sample was thus 1145 (valid response rate 65.8%). Of these, representatives from 443 (38.7%) affirmed their municipality was currently running activities to raise awareness and educate residents about decision-making regarding end-of-life care, and those from another eight (0.7%) municipalities claimed they had such efforts in the planning stage. In contrast, 694 (60.6%) municipalities did not have any such initiatives. Of the active municipalities, 99 (8.7% of total sample) both held events (e.g. seminars) and created educational materials, 317 (27.7% of total sample) only held events, and 35 (3.1% of total sample) only created materials.

Characteristics of municipalities running awareness campaigns about decision-making processes regarding end-of-life care

For the first bivariate analysis, as aforementioned, municipalities were classified into two groups: “active” (*n* = 451), comprising municipalities currently running (*n* = 443) or planning (*n* = 8) activities to raise awareness and educate residents about decision-making regarding end-of-life care; and “inactive” (*n* = 694), not running or planning such activities. Next, logistic regression analysis was carried out between active/inactive and the variables showing significant (*P* < 0.10) associations in the bivariate analysis (total population, percentage of population aged ≥65 years, percentage of deaths at home, number of hospital or clinic beds per 1000 residents, FCI, rate of population change and percentage of solitary-living older adults; Table 1). The final stepwise logistic regression model showed that active municipalities had a significantly higher FCI than inactive municipalities (OR 1.871, 95% CI 1.146–3.054; Table 2).

Characteristics of active municipalities that created educational materials

In total, of the 451 active municipalities, 109 reported creating leaflets, pamphlets or other media to raise awareness and educate

residents about decision-making processes regarding end-of-life care, and another 25 stated being in the process of doing so. Once again, bivariate analyses were carried out with the independent variables above and creating such educational materials as the dependent variable: “active” (already created/currently in preparation; *n* = 134) or “inactive” (*n* = 317). Next, logistic regression analysis was carried out between active/inactive and the variables showing significant (*P* < 0.10) associations in the bivariate analysis (total population, percentage of population aged ≥65 years, percentage of deaths at home, FCI and percentage of solitary-living older adults; Table 3). The final stepwise logistic regression model showed that active municipalities that created materials had a significantly lower percentage of older residents than inactive municipalities (OR 0.958, 95% CI 0.925–0.991; Table 4).

Contents of materials created by municipalities

Table 5 details the contents of materials prepared by the municipalities. Most municipalities (73.5%) reported that their materials lacked a target age group. The most common method of distribution was as handouts for seminars (courses etc.) designed for residents (75.8%), followed by distribution in person (48.5%) and in stands (45.5%). More than two-thirds (66.9%) of representatives claimed that residents were given some form of explanation along with the materials, with the “explainer” most commonly being a doctor or nurse (*n* = 77, 46.4%).

The most frequently mentioned components were the importance of articulating one’s intentions with regard to end-of-life care services in advance, sharing those feelings with family and revisiting them repeatedly (73.9%), and the explanation of home healthcare and long-term care services (47.7%).

Most municipalities (71.1%) claimed to provide people with a standard AD-like form they could fill in themselves. The most frequently recorded information on these forms was the place where

Table 2 Characteristics of municipalities active in awareness campaigns about decision-making regarding end-of-life care: results of the multivariable logistic regression

	Odds ratio	95% Confidence interval
Total population	1.000	1.000–1.000
Percentage of deaths at home	1.020	0.994–1.047
Financial capability index	1.871	1.146–3.054

Total *n* = 1118. Hosmer–Lemeshow goodness-of-fit test: $\chi^2 = 4.6436$, *P* = 0.7949.

Table 3 Characteristics of active municipalities creating/not creating educational materials

	Active (<i>n</i> = 134)			Inactive (<i>n</i> = 317)			<i>P</i> -value [†]
	<i>n</i>	Median	25–75 percentile	<i>n</i>	Median	25–75 percentile	
Total population	134	50 112.5	23 927 – 102 082	317	37 909	15 475 – 99 724	0.0372
Percentage of population aged ≥65 years	134	27.5	23.8 – 31.3	317	28.4	24.1 – 33.5	0.0443
Percentage of deaths at home	133	11.9	9.5 – 14.4	316	11.2	8.6 – 14.0	0.0841
No. hospital or clinic beds per 1000 residents	134	12.2	7.5 – 16.8	317	10.6	5.9 – 17.8	0.3006
Percentage of residents certified to require long-term-care	134	56.7	48.0 – 63.8	317	56.6	50.0 – 64.0	0.4893
Financial capability index	133	0.58	0.40 – 0.77	309	0.52	0.32 – 0.76	0.0912
Rate of population change (%)	134	−0.29	−0.59 – 0.08	317	−0.37	−0.68 – 0.02	0.2903
Percentage of solitary-living older adults	134	10.9	9.1 – 13.2	317	11.5	9.4 – 14.9	0.0409

Total *n* = 451. [†]Wilcoxon rank sum test.

Table 4 Characteristics of active municipalities creating educational materials: results of the multivariable logistic regression

	Odds ratio	95% Confidence interval
Proportion of older adults (in total population)	0.958	0.925–0.991

Total *n* = 440. Hosmer–Lemeshow goodness-of-fit test: $\chi^2 = 11.9692$, *P* = 0.1526.

individuals wanted to receive end-of-life care/pass away (53.1%), followed by emergency contact information (50.0%), date signed (46.1%), personal wishes/feelings about end-of-life care in general (excluding life-sustaining treatment; 43.0%) and personal wishes about life-sustaining treatment in general (39.1%). However, 29.9% of municipalities said their forms had no field for residents to record their intentions about end-of-life care.

Discussion

The present analysis found that 39.4% of the Japanese municipalities surveyed were currently running (or planning to run) activities to raise public awareness and educate residents about decision-making regarding end-of-life care, with higher FCI being predictive of active status.

FCI is a standard indicator used to track the economic strength of ordinance-designated cities in Japan, calculated by dividing a reference income by a given town's expenses. Whereas a value of 1.0 would indicate a perfect balance between revenue and expenditures, values <1.0 mean that expenditures exceed revenue, necessitating subsidies in the form of local allocation tax grants. According to the Ministry of International Affairs and Communications' fiscal-year 2017 survey, just 80 (4.6%) of Japan's 1741 municipalities have an FCI >1.0, with the majority facing difficult economic conditions.¹⁰

Although many local programs are centrally controlled in Japan, the activities to raise awareness and educate residents about decision-making regarding end-of-life care are part of a national program over which municipalities have a large degree of choice. However, research has shown the effects of a municipality's financial strength on its ability to carry out local public health programs: cities with lower FCI have less funds available to subsidize child healthcare costs,¹¹ school expenses¹² and preventive vaccinations;¹³

lower FCI was also associated with low rates of cancer screenings among residents.¹⁴ These findings suggest that cities with tight budgets have to prioritize public health initiatives required by law, leaving them unable to carry out non-compulsory programs, such as activities to raise awareness and educate residents about decision-making regarding end-of-life care. Furthermore, in a position statement on end-of-life care for senior citizens published in 2012 by the Japan Society of Geriatric Medicine, the authors emphasized the need for financial assistance in order to realize end-of-life care in its ideal form.¹⁵ Therefore, national-level initiatives and funding designated to municipalities are necessary to raise awareness and educate residents about decision-making regarding end-of-life care.

Leaflets, pamphlets or other awareness-raising materials targeting residents were created in just 134 municipalities (11.7% of the total sample). These municipalities showed a lower percentage of older adults in their populations. Municipalities with high aging rates might prioritize allocating resources to other projects and measures targeting older adults who require long-term care or have dementia, leaving them unable to pursue activities to raise awareness and educate residents about decision-making regarding end-of-life care.

Approximately 70% of educational materials were accompanied by an explanation from an expert, such as a doctor or nurse, at the time of distribution, which most often communicated to recipients the importance of articulating one's intentions with regard to end-of-life care services (facilities, treatments etc.) in advance, sharing those feelings with family and revisiting them repeatedly. Based on these findings, we can surmise that these educational materials essentially conformed to the MHLW Guidelines for Medical Decision-Making Processes in the Final Stages of Life, which emphasize the importance of a discussion process between patients, family members and healthcare providers. In contrast, public awareness of this practice seems hardly widespread, with just 39.5% of respondents of a MHLW nationwide survey in 2017 reporting having talked about medical or nursing care for end of life with a family member or health/long-term provider.³

Some limitations to the present study should be acknowledged. First, two-thirds (65.8%) of the total 1741 municipalities participated in the survey, and there were smaller numbers of non-responders than responders. According to the present results, the median total population size of "active" municipalities was significantly larger than that of "inactive" municipalities in either bivariate analysis; however, there was no significant association between active/inactive status and the total population in either

Table 5 Contents of materials created by municipalities

	<i>n</i>	%
Target age group (years), MA (<i>n</i> = 134)		
<40	2	1.5
40–64	8	5.9
65–74	38	27.9
≥75 years	29	21.3
Undetermined	100	73.5
Method of distribution, MA (<i>n</i> = 134)		
By post	11	8.3
In person	64	48.5
In stands	60	45.5
As handouts for seminars	100	75.8
Other	29	22.0
Place of distribution, MA (<i>n</i> = 134)		
Residents' homes	26	27.1
Medical facilities	56	58.3
Pharmacies	31	32.3
Visiting nurse agency	37	38.5
Home care services agency	43	44.8
Public health center	46	47.9
Public information counter	61	63.5
Other	26	27.1
Staff explanations (<i>n</i> = 134)		
No	43	33.1
Yes	87	66.9
By whom (MA)		
Municipal officer	47	28.3
Physician/nurse	77	46.4
Other	42	25.3
Contents of materials created by municipalities, MA (<i>n</i> = 130)		
Importance of articulating one's preferred location of care and treatment in advance, sharing those feelings with family, and revisiting them repeatedly	96	73.9
Changes in mental/physical state one can expect at the end of life	33	25.4
Meaning of the term "life-sustaining treatment"	35	26.9
Objective, procedure etc. of life-sustaining treatment: artificial respiration, endotracheal intubation, cardiac massage, artificial nutrition and hydration, other	35	26.9
Home healthcare or long-term care services	62	47.7
Other	27	20.8
Entry field (<i>n</i> = 130)		
Without entry field	37	29.9
With entry field	91	71.1
Contents of entry field (MA)		
Personal wishes about life-sustaining treatment in general	50	39.1
Personal wishes for individual life-sustaining treatments	47	36.7
Personal wishes and feelings about palliative and end-of-life	55	43.0

(Continues)

Table 5 Continued

	<i>n</i>	%
care in general, excluding life-sustaining treatment: preferences/priorities, specific objections etc.		
Official designation of a surrogate to make decisions related to their treatment plan on their behalf if they are unable to	43	33.6
Where they want to receive end-of-life care; where they want to die	68	53.1
Emergency contact	64	50.0
Date signed	59	46.1
Signature (own)	49	38.3
Signature (surrogate)	11	8.6
Other	26	20.3

MA, multiple answer.

multivariable analysis. Considering these results, smaller municipalities might have been underrepresented in the multivariable analyses. Second, new MHLW guidelines were released to municipal officials in 2018.¹⁶ The committee for revisions to the guidelines proposed more initiatives at the national level to provide more opportunities for citizens to start considering end-of-life care. These included establishing official "awareness" days, holding topical events on those dates, and setting up portal sites so that residents can access information related to decision-making support and end-of-life medical and nursing care, and educational websites. As a result, active municipalities might have increased from 2017 owing to the implementation of these national-level initiatives. It is expected that the present findings can be applied as a baseline for any future research aimed at verifying the effects of these new government initiatives started in 2019.

In summary, the present study used a nationwide survey of municipalities in Japan to provide new data showing that just 39.4% of municipalities were currently running awareness-raising activities about decision-making regarding end-of-life care. Furthermore, we found that municipalities with active public awareness campaigns about end-of-life care had a significantly higher FCI than inactive municipalities. Low financial municipalities might be able to promote awareness-raising activities for community residents with financial help from the national government. In addition, we clarified that awareness-raising materials targeting residents were created in 134 municipalities, as well as the contents of such materials. We believe that these findings contribute significantly to policy planning.

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Disclosure statement

The authors declare no conflict of interest.

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