

## Preference of middle-aged Japanese regarding place to receive end-of-life care: a case study of parents of nursing students

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**Abstract Objectives:** This study was performed to assess the preference of middle-aged Japanese regarding end-of-life care.

**Methods:** A structured, self-administered questionnaire survey regarding preference of place to receive end-of-life care was performed among parents of nursing school students by postal mail.

**Results:** A total of 64 (61.5%) participants returned the questionnaire. Some of the major concerns regarding home-based end-of-life care were being a burden on their family and whether their family would accept care at home at the end of their life. The majority of the participants wanted more information regarding financial support system and availability of medical and care institutions and care support services to receive home-based end-of-life care, regardless of the extent of their pre-existing knowledge regarding end-of-life care, and participants with little or no prior knowledge of the end-of-life care were less likely to appreciate the importance of family support system.

**Conclusions:** These results suggest that ignorance about end-of-life care produces a narrower range of choices and limits decision making regarding such care, even though most participants would prefer to receive end-of-life care at home.

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**Key Words** : end-of-life, good death, home care, institutional care, family support

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### Introduction

Where to die and what type of care to receive at the end of life are important issues for all people in every country.<sup>1</sup> End-of-life care is linked with “good death,” and there is increasing discussion about its definition and components.<sup>2-7</sup> In general, people wish to be free of physical and psychological pain and to retain both their dignity and autonomy until the end. However, the definition of a good death may also depend on sociocultural background.

According to the annual report of the Ministry of Health, Labour, and Welfare of Japan, 82.3% of Japanese people who died in 2006 did so at hospital or in medical facilities, while 3.1% died in nursing homes, and 12.2% died at home. A study regarding end-of-life care conducted by the Japanese Ministry of Health, Labour, and Welfare in 2003 indicated that 49% of physicians, 41% of nurses, and 38% of care workers preferred to receive home-based end-of-life care than institution-based care, while

the general population preferred end-of-life care at institutions (hospital, 38%; nursing home, 25%) than at home (23%). Previous studies in Japan suggested that gender, availability of home medical treatment, nursing and care services, hospital beds in local areas, and family support influenced people’s decision-making regarding terminal care,<sup>8</sup> and also played role in determining what kind of terminal care people actually received.<sup>9-11</sup>

This study was performed to gain insight into the preference and state of readiness among middle-aged Japanese regarding their end-of-life care. Our findings provide background information for healthcare professionals to administer better care to their patients and support them in attaining the ideal end of life.

### Methods

A structured questionnaire was administered to middle-aged parents of nursing students in September 2008. A total of 104 students agreed to pass the informed

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consent sheet and the questionnaire in sealed envelopes to their parents. They were however asked not to elaborate on the contents of the questionnaire to their parents to ensure that participation was voluntary. The students were divided into two groups so as to collect approximately the same number of male and female participants. Thus, the first group was asked to deliver the consent sheet and the questionnaire to their male parents, while the second group to their female parents. Parents were asked to complete the informed consent sheet and return it along with the anonymous questionnaire by postal mail.

The questionnaire was prepared based on the findings of a literature review.<sup>2,4,9-11</sup> Occupations of the respondents were categorized into healthcare providers, including physicians, nurses, and other care workers, and non-healthcare providers. The questionnaire consisted of questions on sociodemographic characteristics, preference regarding place to receive end-of-life care, knowledge regarding home-based end-of-life care, and knowledge and conditions necessary to make decisions about end-of-life care. "End of life" was defined as the terminal stage where one suffers from critical disease or conditions and requires assistance in activities of daily life due to disability.

The level of knowledge regarding home-based end-of-life care was rated on a 4-point scale: "I know about it very well," "I know something about it," "I do not know much about it but I have heard about it," and "I have never heard about it." The first two categories were considered as "having knowledge regarding end-of-life care," while the latter two categories were considered as "not having knowledge regarding end-of-life care."

Fisher's exact test and Mantel-Haenszel test were performed to analyze the associations between sociodemographic characteristics and preferences regarding place to receive end-of-life care, as well as information participants regarded as necessary for them to make decisions regarding end-of life care.

The study protocol was approved by the Ethics Committee of the Graduate School of Biomedical Sciences, Nagasaki University. All the participants were informed about the objective of the study, were assured confidentiality and ethical consideration, and were asked for voluntary participation upon written document.

## Results

A total of 64 (61.5%) participants returned the questionnaire. All participants were in their 40s or 50s, and were defined as middle-aged for the purposes of this

study. Eleven participants were excluded from the analysis due to missing data. Thus, the data from a total of 53 participants (14 men and 39 women) was analyzed. Table 1 shows the sociodemographic characteristics of the participants.

Only four respondents considered home as an ideal place for the end of their life, including their death. On the other hand, 41 respondents did not wish to receive end-of-life care at home throughout their terminal stage. Of them, 34 respondents wished to be cared for at home and then moved to a hospital, and 7 respondents wished to be cared for at hospital and then moved to home, and 8 respondents preferred to die at hospital and/or care institution. Regardless of their preference of place to receive end-of-life care, a total of 11 (20.8%) respondents preferred to die at home. In other words, several participants, although preferred to die at home, nevertheless chose places other than their homes to receive end-of-life care (Data not shown).

As shown in Table 2, preference for at-home care under any circumstances was not associated with any of the measured sociodemographic characteristics. Twenty five respondents (47.2%) thought that it was possible to receive end-of-life care at home. Occupation, that is being a medical health professional ( $p = 0.006$ , Fisher's exact test), was significantly associated with participants thinking it is feasible to realize home-based end-of-life care.

The main reasons behind the perceived difficulty over home-based end-of-life care were "too much burden on the family (43.4%)," "appropriate medical care is available at hospital (24.5%)," and "appropriate emergency care is possible at hospital (28.3%)." Twenty-five (47.2%) respondents reported having good or some knowledge about end-of-life care at home (Table 1). There was a significant difference in the perceived difficulty over home-based end-of-life care between those who did and did not have such knowledge (odds ratio: 3.750; 95% confidence interval: 1.193, 11.792;  $p < 0.05$ ).

Table 1 shows the information all the participants sought in making decisions about end-of-life care, which included financial support (66.0%) and availability of medical and nursing facilities and care support services (58.5%). There was no significant difference between people with and without knowledge regarding the contents of information they sought (Table 3).

**Table 1.** Characteristics of the respondents and distribution of respondents' preference regarding end-of-life care ( $n = 53$ )

	<i>n</i>	%
Sex		
Male	14	26.4
Female	39	73.6
Age		
40 – 49	15	28.3
50 – 59	38	73.6
Working status		
Currently working	43	81.1
Retired	10	18.9
Occupation		
Healthcare provider/Medical health professional	25	47.2
Non-healthcare provider/Non-medical health professional	28	52.8
Preference regarding end-of-life care		
Home throughout	4	7.5
Home, then hospital	34	64.2
Hospital, then home	7	13.2
Hospital throughout	7	13.2
Nursing home	1	1.9
Feasibility of dying at home		
Possible	5	9.4
Possible depending on conditions	20	37.7
Difficult	24	45.3
Don't know	4	7.5
Knowledge required to make decisions about end of life care		
Financial support (medical and nursing care insurance)	35	66.0
Availability of medical and care institutions and care support services	31	58.5
How to make decisions about medical treatment and care	5	9.4
Palliative care	22	41.5
Support system for family	18	34.0
Advantages and disadvantages of end-of-life care at home	14	26.4
Advantages and disadvantages of end-of-life care at hospital	7	13.2
Others	4	7.5
Reasons for the perceived difficulty over home-based end-of-life care		
Too much burden on the family	23	43.4
Preconception that appropriate medical care is available at hospital	13	24.5
Preconception that appropriate emergency care is possible at hospital	15	28.3
Inadequate housing structure to receive home-based care	4	7.5
There is no home doctor	1	1.9
Lack of knowledge among family members regarding patient care	3	5.7
There is no family who can take care	2	3.8
Economic condition	2	3.8

**Table 2.** Sociodemographic factors and preference for end-of-life care at home and feasibility of dying at home ( $n = 53$ )

	Preference for end-of-life care at home			Feasibility of dying at home		
	<i>n</i>	%	<i>p</i> -value	<i>n</i>	%	<i>p</i> -value
Sex						
Male	11	78.6	0.422	9	64.3	0.212
Female	34	87.2		16	41.0	
Age						
40 – 49	12	80.0	0.673	6	40.0	0.556
50 – 59	33	86.8		19	50.0	
Working status						
Currently working	38	88.4	0.163	22	51.2	0.302
Retired	7	70.0		3	30.0	
Occupation						
Healthcare provider	24	96.0	0.053	17	68.0	0.006
Non-healthcare provider	21	75.0		8	28.6	

Fisher's exact test was performed.

Preference for end-of-life care at home included "at home throughout," "at home in the beginning, then hospital when necessary," and "at the hospital/nursing home in the beginning, then at home at the end."

**Table 3.** Knowledge required to make a decision about end-of-life care ( $n = 53$ )

	With knowledge regarding end-of-life care ( $n = 23$ )		Without knowledge regarding end-of-life care ( $n = 30$ )		Odds ratio	$p$ -value
	$n$	%	$n$	%		
Financial support (medical and nursing care insurance)	15	65.2	20	66.7	1.067	0.857
Availability of medical and care institutions and care support services	14	60.9	17	56.7	0.841	0.979
Way to make a decision about medical treatment and care	2	8.7	3	10.0	1.167	0.756
Palliative care	11	47.8	11	36.7	0.632	0.596
Support system for family	11	47.8	7	23.3	0.332	0.119
Advantages and disadvantages of end-of-life care at home	4	17.4	10	33.3	2.375	0.327
Advantages and disadvantages of end-of-life care at hospital	0	0.0	7	23.3	-	-

Mantel–Haenszel analysis was performed to examine the association between impression and knowledge regarding end-of-life care. Participants were allowed to choose more than one category.

### Discussion

Non-medical health professionals were more likely to perceive home-based end-of-life care as difficult. Participants requested information regarding financial support systems and availability of medical and care institutions and care support services to realize end-of-life care at home regardless of their knowledge regarding end-of-life care.

This study had several limitations. First, the sample size was too small to perform statistical analysis with appropriate statistical power. Second, since the respondents were the parents of students in a health-related institution, and were therefore more likely to work as medical health professionals than the general population. This distribution of study participants' background can affect generalization of the results of this study among middle-aged Japanese people. Third, the gender ratio of the participants was unbalanced. On the other hand, the results of this study regarding preferred place to receive end-of-life care according to occupation were consistent with those previously reported studies,<sup>12</sup> and offered additional, more detailed understanding of the attitudes of middle-aged Japanese toward end-of-life care.

The percentage of the participants in this study who expressed preference to die at home was 20.8%, which was slightly higher than the national average of 12.2% according to the 2006 report of the Ministry of Health, Labour, and Welfare of Japan. On the other hand, 96.0% of the participants reported preference for remaining at home at some point during the end of life, which was higher than that among physicians, nurses, and care workers reported by the Ministry of Health, Labour, and Welfare of Japan in 2003 (50%).

The term "good-quality care" however is to a certain extent subjective, and the evaluation of quality of care by patients and their family, and the kind of care they

see as ideal may be influenced by various factors including seriousness of the patient's condition, stress related to family role as caregivers, and place of death.<sup>13</sup> Thus, in this study, one of the major factors which influenced the participants' preference of place to receive end-of-life care was the perceived burden on their family. On the other hand, sexual difference was also observed, as more women tended to prefer to die at home but nevertheless, more women tended to think of this option as unfeasible. Similarly, Grande *et al.* also concluded that women were less likely to die at home because men were probably less capable of acting as caregivers.<sup>14</sup> From a different perspective, a study from Korea showed that cancer patients and their family were more likely to prefer receiving end-of-life care at home if they had access to appropriate support.<sup>15</sup>

Furthermore, in order for people to make informed decisions about end-of-life care, they should be equipped with appropriate and adequate knowledge regarding medical/healthcare services, including insurance system, palliative care, and support for families as caregivers, prior to entering the stage when they actually require such care. Without such knowledge, it is likely that when actually faced their end of life, people's choice will be influenced by immediate concerns for their family and their preexisting knowledge, however limited it may be, regarding end-of-life care.

The findings of this study suggest that people without knowledge about end-of-life care may not be aware of the sort information they ought to have to make appropriate decisions. It is important to provide adequate and appropriate information and suitable medical/healthcare support to facilitate ideal end-of-life care for all. Even with family support and appropriate information and knowledge about end-of-life care, it may still be difficult to attain ideal end-of-life care at home if medical/

healthcare resources are scarce within the community.

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### References

- 1) Singer PA, Bowman KW. Quality care at the end of life. *BMJ* 2002, 324(7349): 1291-1292.
- 2) Long SG. Cultural scripts for a good death in Japan and the United States: similarities and differences. *Soc Sci Med* 2004, 58(5): 913-928.
- 3) Rietjens JA, van der Heide A, Onwuteaka-philipsen BD, van der Maas PJ, van der Wal G. Preferences of the Dutch general public for a good death and associations with attitudes towards end-of-life decision-making. *Palliat Med* 2006, 20(7): 685-692.
- 4) Hattori K, McCubbin MA, Ishida DN. Concept analysis of good death in the Japanese community. *J Nurs Scholarsh* 2006, 38(2): 165-170.
- 5) Cheng SY, Hu WY, Liu WJ, Yao CA, Chen CY, Chiu TY. Good death study of elderly patients with terminal cancer in Taiwan. *Palliat Med* 2008, 22(5): 626-632.
- 6) Gibson MC, Gutmanis I, Clarke H, Wiltshire D, Feron A, Gorman E. Staff opinion about the components of a good death in long-term care. *Int J Palliat Nurs* 2008, 14(8): 374-381.
- 7) De Jong ID, Clarke LE. What is a good death? Stories from palliative care. *J Palliat Care* 2009, 25(1): 61-67.
- 8) Choi J, Miyashita M, Hirai K, Sato K, Morita T, Tsuneto S, Shima Y. Preference of place for end-of-life cancer care and death among bereaved Japanese families who experienced home hospice

- care and death of a loved one. *Supportive Care in Cancer* 2010, 18(11): 1445-53.
- 9) Miyahara S, Hitomi H. A multilateral study of death at home in rural areas. *Nippon Nohson Igakukai Zasshi* 1999, 47(6): 879-893.
- 10) Hayakawa T, Tsuzuki T, Ikedo M, Hasegawa C, Sakata T, Tozawa H, Kanazawa T, Andoh T, Hayashi M, Kawai E, Miyaji M. Actual status of death at home in elderly patients who received home care service in rural area in Aichi prefecture. *Nippon Nohson Igakukai Zasshi* 2002, 50(5): 683-689.
- 11) Sugimoto H, Kondo K, Higuchi H, Kuze J, Makino T, Miyata K. Factors affecting the incidence of death at home; a national survey of home-visit nursing care station. *Rounen Syakai Kagaku* 2003, 25(1): 37-47.
- 12) Sanjo M, Miyashita M, Morita T, Hirai K, Kawa M, Akechi T, Uchitomi Y. Preferences regarding end-of-life cancer care and associations with good-death concepts: a population-based survey in Japan. *Ann Oncol* 2007, 18(9): 1539-1547.
- 13) Grande EG, Farquhar MC, Barclay ST. Caregiver bereavement outcome: relationship with hospice at home, satisfaction with care, and home death. *J Palliat Care* 2004, 20(2): 69-77.
- 14) Grande EG, Addington-Hall JM, Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? *Soc Sci Med* 1998, 47(5): 565-579.
- 15) Choi KS, Chae YM, Lee CG, Kim SY, Lee SW, Heo DS, Kim JS, Lee KS, Hong YS. Factors influencing preferences for place of terminal care and death among cancer patients and their families in Korea. *Support Care Cancer* 2005, 13(8): 565-572.