Associations with the Japanese Population's Preferences for the Place of End-of-Life Care and Their Need for Receiving Health Care Services

Sakiko Fukui, R.N., Ph.D.¹ and Kazuhiro Yoshiuchi, M.D., Ph.D.²

Abstract

Purpose: The aims of this study were to identify the associations with the Japanese population's preferences for the place of end-of-life care and their need for receiving health care services.

Methods: A secondary analysis of a cross-sectional nationwide survey was conducted for 2000 randomly selected Japanese people aged 40–79 years.

Results: A total of 1042 people (55%) responded. Regarding preferred place of care, we set the place within the choices of "Home" (preferred by 44% of respondents), "Acute Hospital" (15%), "Palliative Care Unit" (19%), "Public Nursing Home" (10%), and "Private Nursing Home" (2%). Multinomial logistic regression analysis revealed that the people who preferred "Acute Hospital" tended to have the following need compared to those who preferred "Home," "Palliative Care Unit," or "Nursing Home": higher need for receiving end-of-life care not from its experienced professionals but from the same staff; higher need for using health care services in highly supported environment such as the need for being near health care staff whenever and for receiving treatment possibly until the end; and higher need for consulting nurses whenever. They had lower need for using home care services and daycare services and also lower need for instructing families about how to use insurance/public health services.

Conclusions: The present findings may help to develop an effective end-of-life care system in Japan considering Japanese people's need for health care services. Also, the results of this study may underscore the importance of education on receiving home care services especially for the people who presently prefer the hospital for end-of-life care.

Introduction

JAPAN DEMOGRAPHICALLY became the oldest country in the world as of 2004 (19.5% at age 65+ in 2004), and this fast-aging trend is estimated to continue in the future (39.6% at age 65+ by 2050).¹ Based on this population shift, Japan has a growing need for end-of-life care, as well as other aging nations.²

For its end-of-life care system in Japan, the Japanese Ministry of Health, Labor and Welfare has supported institutional palliative care services called palliative care units (PCU) initially, which have been covered by National Medical Insurance since 1991. However, the trends in the aging of the Japanese population dictate that more end-of-life care must be provided at home. Therefore, the government recently started to provide assistance for specialized home palliative care

teams, which have been covered by National Medical Insurance since 2006. These teams are expected to offer home palliative care for terminally ill patients provided by community physicians and nurses on a 24-hour basis. The physicians can obtain additional remuneration when patients die at home.³ The Japanese government also established the Cancer Control Act in 2007, which states the necessity of promoting qualified home palliative care and increasing the home death rate among terminally ill patients (by 40% in 2025). However, the home death rate has remained around 15%, and almost 80% of terminal patients die in general hospital wards.⁴

The Japanese government has surveyed preferences for end-of-life care and death among the general public every 5 years since 1998. The latest survey in 2008 revealed that 63% of Japanese would prefer to live at home when they are terminally ill. In contrast, 90% of the public assumes that home

¹Department of Community Health Nursing, Graduate School of Nursing, The Japanese Red Cross University, Tokyo, Japan.

²Department of Stress Sciences and Psychosomatic Medicine, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan.
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death is not possible, because they believe that it is difficult to be cared for at home at the end of life. The two most frequent reasons given were the uncertainty of receiving health care services when their physical condition worsens and the caregiver burden for family members.⁵ However, there is a lack of detailed findings about Japanese people's need for health care services during the end-of-life stage. Clarifying their need for health care services would hopefully bridge the gap between the Japanese general public's preference and the actual place of end-of-life care.

The aim of this study was thus to identify the Japanese people's need for health care services and the associations with their preference for place of end-of-life care.

Methods

Participants and procedures

This study was a part of a nationwide survey of the Japanese population, and the protocol has been described previously.⁶ We initially identified 2000 subjects in the general population by a stratified two-stage random sampling method of residents throughout Japan. To obtain a wide geographic distribution for the nationwide sample in this study, we randomly selected 80 census tracts according to the number of residents per tract. These 80 census tracts included an urban area (>1,000,000 residents per tract), mixed urban-rural areas (150,000–1,000,000 residents), and rural area (<150,000 residents). We then sampled 25 individuals in each census tract according to the national census method in Japan. We targeted the population of the study at 40–79 years, because we have experience with nationwide surveys indicating that the response rate of people more than 80 years of age was considerably lower than those under 80. We mailed self-administered questionnaires to potential participants in March 2010, and sent a reminder postcard 2 weeks later.

The study protocol was reviewed and approved by the Institutional Review Board and the Ethics Committee of The Japanese Red Cross University, Japan.

Questionnaire

We asked participants their place of end-of-life care preferences, assuming that they had a 1- to 2-month life expectancy, no physical distress, and needed care assistance in their daily activities. We offered five choices for preferred place of end-of-life care: home, acute hospital, PCU, public nursing home, and private nursing home, based on the international recommendations recently developed by the World Health Organization: it should be responsive to patient choice for place of end-of-life care and death.^{7–9}

Our questionnaire also inquired about their need for receiving health care services when they decide a preferred place of end-of-life care. It was developed by the authors based on a systematic literature review,^{10–14} including the literature related to health care service need.^{15–17} We assumed three hypothetical domains: (1) the need for receiving health care services in a highly supported environment; (2) the need for using health care services in home care settings; and (3) the need for consulting health care professionals and instructing how to care, when the participants decide their preferred place of care during the end-of-life stage. The first domain consisted of five components: to receive health care services

promptly wherever; to be near health care professionals whenever; to receive end-of-life care from the same hospital staff; to receive end-of-life care from its experienced professionals; to receive treatment possibly until the end. The second domain consisted of three components: to use sufficient health care services in home care settings; to use sufficient health care services in daycare centers; to receive sufficient health care services at home on a 24-hour basis when near death. The third domain consisted of four components: to contact/consult with physicians whenever; to contact/consult with nurses whenever; to instruct families about how to use insurance/public services; to instruct families about how to support/care patients until the end.

We asked participants to rate the relative importance of each component on a seven-point Likert scale (1, absolutely not important; 2, not important; 3, somewhat unimportant; 4, unsure; 5, somewhat important; 6, important; and 7, absolutely important). The content validity was assessed by full agreement of the authors and 5 expert panels. The feasibility and face validity of the questionnaire were confirmed by a pilot test of a convenient sample of 25 members of the general population.

We also inquired as to their demographic variables: age, gender, whether they had a spouse and children, the number of families living together, and the experience of caregiving for family members.

Analysis

First, we identified the associations between the participants' preferred place of care and their demographic variables, using χ^2 tests (Table 1).

Second, we confirmed the 3 conceptualized domains from a total 12 components on the need for receiving health care services from our questionnaire, using an explanatory factor analysis (principal method with promax rotation) and calculating Cronbach α coefficients as a measure of the internal consistency.

Third, to examine the determinants of place of care preference among the three domains, each of which were summed up from the related 3–5 components, we performed a multinomial logistic regression analysis, which was adjusted by gender, age, and caregiving experiences of families, because these were significantly associated with their preferences in the univariate analyses ($p < 0.05$; Table 2). In addition, to examine the determinants of place of care preference among each component regarding each of the three domains, we also performed three multinomial logistic regression analyses, with throwing these 3 variables (gender, age, and caregiving experiences of families) as covariates (Tables 3–5).

We created a multinomial-dependent variable including four possible categories of preference (home, acute hospital, PCU, and public nursing home), excluding the category of private nursing home because so few subjects chose it. All p values were two-tailed, and all data analyses were conducted using SAS 9.1 (SAS Institute Inc., Cary, NC).

Results

Study sample

Of the 2000 questionnaires sent to the general population, 90 were undeliverable and 1050 were filled out and returned. Of

TABLE 1. PREFERRED PLACE OF CARE^a AND THE ASSOCIATION WITH PARTICIPANT DEMOGRAPHIC VARIABLES

	Total n=912 n (%) or mean (standard deviation)	Home n=455	Acute hospital n=154	Palliative care unit n=200	Nursing home n=103	p value ^b
Gender						<0.001
Male	409 (100)	244 (59.7)	63 (15.4)	53 (13.0)	49 (12.0)	
Female	503 (100)	211 (41.9)	91 (18.1)	147 (29.2)	54 (10.7)	
Age (years) ^c						<0.001
<65	543 (100)	284 (52.3)	70 (12.9)	140 (25.8)	49 (9.0)	
65–74	295 (100)	143 (48.5)	62 (21.0)	52 (17.6)	38 (12.9)	
≥75	74 (100)	28 (37.8)	22 (29.7)	8 (10.8)	16 (21.6)	
Have spouse (married)	714 (100)	360 (50.4)	123 (17.2)	158 (22.1)	73 (10.2)	NS
Have children (son and/or daughter)	469 (100)	254 (54.2)	69 (14.7)	99 (21.1)	47 (10.0)	NS
Number of families living together (including respondent)						NS
Living alone	67 (100)	29 (43.3)	12 (17.9)	12 (17.9)	14 (20.9)	
≥Two	845 (100)	426 (50.4)	142 (16.8)	188 (22.2)	89 (10.5)	
Caregiving experiences of family members Experienced	269 (100)	127 (47.2)	61 (22.7)	54 (20.1)	27 (10.0)	0.04

NS, nonsignificant ($p \geq 0.05$)

^aParticipants were asked to choose their desired setting if they had a life expectancy of 1–2 months and no physical distress, but needed assistance in their daily activities.

^bDetermined using χ^2 test among the four groups.

^cDivided into three, based on Japanese medical insurance cutoff categories (<65, 65–74, and ≥75 years old).

these, eight subjects were excluded due to missing data. Thus, 1042 responses were analyzed (effective response rate, 55%).

There were no differences in gender and age between the respondents and the non-respondents, as well as the general population according to the vital statistics data for 2008.¹⁸

Preferred place of end-of-life care and association with demographic variables

Regarding the preference for place of end-of-life care, among 1042 respondents, 455 (43.7%) preferred home, 154 (14.8%) an acute hospital, 200 (19.2%) a PCU, 103 (9.9%) a public nursing home, 17 (1.6%) a private nursing home, and

the remaining 113 (10.8%) were unsure (Table 1). Table 1 indicated the statistical associations between the four categorized preferences and the respondent's demographic variables.

Factor analysis and internal consistency

An explanatory factor analysis showed that 3 conceptualized domains from a total 12 components were divided into 3 factors (factor 1, 2, 3) as we hypothesized. Cronbach α coefficients of these 3 domains were 0.73, 0.78, and 0.87, respectively, which means that each domain had sufficient internal consistency.

TABLE 2. DETERMINANTS OF PREFERRED PLACE OF CARE WITHIN THREE FACTORS (THE NEED FOR RECEIVING HEALTH CARE SERVICES IN HIGHLY SUPPORTED ENVIRONMENT, THE NEED FOR USING HEALTH CARE SERVICES IN HOME CARE SETTINGS, AND THE NEED FOR CONSULTING HEALTH CARE PROFESSIONALS AND INSTRUCTING HOW TO CARE): MULTINOMIAL LOGISTIC REGRESSION ANALYSIS

Variables ^a	Home OR (95% CI)	Palliative care unit	Nursing home
Factor 1 (Sum of 5 items on the need for receiving health care services in highly supported environment) ^b	0.93 (0.88–0.97)**	0.92 (0.87–0.98)**	0.97 (0.91–1.04)
Factor 2 (Sum of 3 items on the need for using health care services in home care settings) ^b	1.07 (1.01–1.14)*	1.15 (1.07–1.24)***	1.13 (1.04–1.24)**
Factor 3 (Sum of 4 items on the need for consulting health care professionals and instructing how to care) ^b	1.04 (0.98–1.10)	1.07 (1.00–1.15)*	0.92 (0.85–0.99)*

CI, confidence interval; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

^aDependent variable had four categories: "Acute Hospital," "Home," "Palliative Care Unit," or "Nursing Home." The last three were compared with the first category (Acute Hospital)

Independent variables summed up of items that had 7-response category (1: not at all important, 7: very important)

As covariates, gender, age, and caregiving experiences of families were thrown.

^bIndependent variables shown in this table (3 factors) were confirmed to divide these 3, using explanatory factor analysis (principal method with promax rotation) by throwing all 12 variables.

TABLE 3. DETERMINANTS OF PREFERRED PLACE OF CARE WITHIN THE NEED FOR RECEIVING HEALTH CARE SERVICES IN HIGHLY SUPPORTED ENVIRONMENT: MULTINOMINAL LOGISTIC REGRESSION ANALYSIS

Variables ^a	Home OR (95% CI)	Palliative Care Unit	Nursing Home
To receive health care services promptly wherever	1.01 (0.85–1.21)	1.20 (0.98–1.49)	0.92 (0.73–1.17)
To be near health care professionals whenever	0.84 (0.72–0.98)*	0.87 (0.73–1.04)	1.20 (0.97–1.48)
To receive end-of-life care from the same hospital staff	0.98 (0.84–1.14)	0.95 (0.79–1.13)	0.87 (0.71–1.07)
To receive end-of-life care from its experienced professionals	1.25 (1.06–1.47)**	1.64 (1.35–2.01)***	1.30 (1.04–1.63)*
To receive treatment possibly till the end	0.89 (0.78–1.02)	0.72 (0.61–0.84)***	0.72 (0.60–0.86)***

CI, confidence interval; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

^aDependent variable had four categories: "Acute Hospital," "Home," "Palliative Care Unit," or "Nursing Home." The last three were compared with the first category (Acute Hospital)

Independent variables had seven-response category (1: not at all important, 7: very important)

As covariates, gender, age, and caregiving experiences of families were thrown.

Determinants of preferred place of care within the need for receiving health care services

Table 2 presents the result of a multinomial logistic regression analysis to decide the determinants of place of care preference within the three domains, which are the sum scores of each three domains of the need for receiving health care services. Respondents who preferred "Acute Hospital" gave more importance to receiving health care services in a highly supported environment, than those who preferred "Home" or "PCU." However, they were less likely to give importance to using health care services in home care settings than those who preferred the other three places. Respondents who preferred "Acute Hospital" tended to have less need for consulting health care professionals and instructing how to provide care than those who preferred "PCU," whereas they tended to have a greater need for such support than those who preferred "Nursing Home."

Regarding the first domain, the need for receiving health care services in a highly supported environment, respondents who preferred "Acute Hospital" were more likely to have greater need to be near health care professionals whenever than those who preferred "Home," and they also were more likely to have greater need for treatment possibly till the end than those who preferred "PCU" and "Nursing Home." On the other hand, they were more likely to have less need for end-of-life care from experienced professionals; they tended to prefer to receive end-of-life care from the same hospital staff, than those who preferred the other three places (Table 3). As for the second domain, the need for using health care

services in home care settings, respondents who preferred "Acute Hospital" were more likely to have less need for sufficient health care services in home care settings than those who preferred "Home." They also were more likely to have less need for sufficient health care services at a daycare center than those who preferred "PCU" (Table 4).

Regarding the third domain, the need for consulting health care professionals and instructing how to care, respondents who preferred "Acute Hospital" were more likely to have a greater need to consult nurses whenever, and more likely to have less need for family instruction about how to use insurance/public health care services, than those who preferred "Home" (Table 5).

Discussion

The present study identified the rates of preferred place of care (hospital, 15%; home, 44%; PCU, 19%; public nursing home, 10%; private nursing home, 2%; unsure, 11%), while the actual rates of place of death in 2010 in Japan were: hospital, 78%; home, 12%; public nursing home, 1%; other, 9%.¹⁹ These data demonstrated discrepancies between the rates of actual and preferred place of care and death, which were similar to those in developed countries as summarized by recent reviews.^{20–23}

Almost 80% of Japanese people actually spent time and died in a hospital, instead of their different preferred place of care in their end-of-life stage. Studies revealed that the preferences for end-of-life care and death change with one's personal life experience.^{24,25} The hospital-preference group must

TABLE 4. DETERMINANTS OF PREFERRED PLACE OF CARE WITHIN THE NEED FOR USING HEALTH CARE SERVICES IN HOME CARE SETTINGS: MULTINOMINAL LOGISTIC REGRESSION ANALYSIS

Variables ^a	Home OR (95% CI)	Palliative Care Unit	Nursing Home
To use sufficient health care services in home care settings	1.34 (1.12–1.60)**	0.86 (0.70–1.06)	1.00 (0.79–1.27)
To use sufficient health care services in day care center	0.93 (0.77–1.11)	1.91 (1.52–2.40)***	1.00 (0.78–1.28)
To receive sufficient health care services at home on a 24-hour basis when near death	0.93 (0.79–1.08)	0.94 (0.78–1.12)	1.14 (0.92–1.40)

CI, confidence interval; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

^aDependent variable had four categories: "Acute Hospital," "Home," "Palliative Care Unit," or "Nursing Home." The last three were compared with the first category (Acute Hospital)

Independent variables had seven-response category (1: not at all important, 7: very important)

As covariates, gender, age, and caregiving experiences of families were thrown.

TABLE 5. DETERMINANTS OF PREFERRED PLACE OF CARE WITHIN THE NEED FOR CONSULTING HEALTH CARE PROFESSIONALS AND INSTRUCTING HOW TO CARE: MULTINOMINAL LOGISTIC REGRESSION ANALYSIS

Variables ^a	Home OR (95% CI)	Palliative Care Unit	Nursing Home
To contact/consult with physicians whenever	1.19 (0.84–1.69)	1.10 (0.72–1.69)	0.92 (0.59–1.44)
To contact/consult with nurses whenever	0.67 (0.47–0.97)*	0.96 (0.62–1.49)	0.94 (0.59–1.51)
To instruct families about how to use insurance/ public health care services	1.21 (1.00–1.46)*	1.21 (0.96–1.52)	0.93(0.73–1.20)
To instruct families about how to support/ care for patients till the end	1.11 (0.92–1.33)	1.05 (0.85–1.30)	1.02 (0.81–1.29)

CI, confidence interval; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

^aDependent variable had four categories: "Acute Hospital," "Home," "Palliative Care Unit," or "Nursing Home." The last three were compared with the first category (Acute Hospital).

Independent variables had seven-response category (1: not at all important, 7: very important)

As covariates, gender, age, and caregiving experiences of families were thrown.

have included the people who decided their place of end-of-life care preference as hospital from their own personal experience so far, such as their actual experience of a family member's hospital admission. Therefore, although the present study showed the hospital-preference group was a minority (15%), the present study focused on and clarified the differences in the place of care preference between people who prefer a hospital and those who prefer other places. The place where someone wishes to spend his/her remaining days may be different from the place where they are actually living. However, the attempt to clarify the difference between those who prefer a hospital and those who prefer somewhere else may actually serve to reduce the many people using hospitals and increase the number of people seeking end-of-life care at somewhere other than a hospital.

This study clarified some of the factors involved in the preference for place of end-of-life care within 3 domains among 12 components contributing to Japanese people's need for receiving health care services, when comparing people who prefer a hospital with those who prefer home, a nursing home, or PCU. From overall consideration of the results of the three domains, our study revealed that people who prefer to stay in the hospital during the end-of-life stage tended to be different from those who prefer the other three places. The people who prefer the hospital tended to have passive attitudes toward receiving health care services, such as staying in a 24-hour support environment and receiving 24-hour consulting support. People who prefer the other 3 places, however, tended to have an independent and positive attitude; they showed a greater need to learn about care and hoped to stay in a home care setting, not a hospital.

Regarding the first domain, "the need for health care services in a highly-supported environment," this study clarified that Japanese people who prefer an acute hospital tended to have a greater need to be near health professionals whenever, as well as a greater need for treatment possibly till the end, compared to those who prefer home, PCU, or nursing home for end-of-life care. However, the proportion of people who preferred to receive care at an acute hospital was only 15%, while about half of people (44%) preferred to be cared for at home. This minority of 15% preferred the highly-supported health care environment. These proportions were consistent with previous Japanese studies,^{5,26,27} and Asian studies suggested that it may be the reason that home palliative care

services in Asian countries are somewhat behind those of Western countries.^{28–30} In addition, some studies pointed out that many Asian people have believed the quality of hospital care is better than the care at home or nursing home^{31,32} and preferred to stay in the hospital than to be discharged to home palliative care.³³ However, in Japan, the government has strongly backed dissemination of home palliative care services, with insurance coverage of 24-hour home care support systems since 2006. Consequently, the Japanese home palliative care system is actually moving ahead and the philosophic underpinnings of home palliative care may also be spreading more among the Japanese population. Regarding the second domain, "the need for using health care services in home care settings," the present study clarified that people who preferred home had a higher need for home care services than those who prefer hospital. This result is opposite of the need of the first domain, which requires health care services in a highly supported environment such as in a hospital. Our research group previously clarified the positive correlation between the experience of a relative's dying at home and their own end-of-life care preference for a home care setting.⁶ Preferences for place of care are reportedly influenced by having experienced the home palliative care and death of a loved one.³⁴ This result might show a possible way to increase the number of people who die at home by reaching out to the people who have experienced bereavement care at home. Therefore, it is important to improve health care services and to provide the public with more information about them.

Moreover, the study clarified that the people who prefer PCU had a greater need for daycare services than those who prefer the hospital. Previous studies focused on clarifying the differences between the preferences for home care and institutional care.^{20–28} The present results are novel in that they serve to clarify the difference in Japanese people's perception between hospital and PCU preference. This may suggest that people who prefer PCU may feel more willing to receive home care services at the end of life than those who prefer a hospital. Therefore, to promote the use of home palliative care in Japan, the effective target may not be the people who prefer hospital but rather those who prefer PCU.

As for the third domain, "the need for consulting health care professionals and instructing how to care," two factors were clarified: the people who prefer the hospital had a greater need to contact/consult with nurses whenever than

those who prefer care at home; conversely, the people who prefer the hospital had less need for family instruction about how to use public health care services. These results may help to clarify the Japanese people's health-seeking behavior during the end-of-life stage in terms of a passive or positive attitude, as implied by recent studies.^{35–37}

In light of all of the present study findings, we should try to promote home palliative care in Japan according to the Japanese government policy. Besides, we must also prepare options from other choices of end-of-life care, such as a PCU and nursing home, as suggested by recent studies.^{25,38}

Our study has several limitations. First, as the response rate of this study was low (55%), a response bias might exist and the findings of our study might not be generalizable to the greater Japanese population. Second, respondents were not terminally ill during the study period. Thus, their preferences may well change if they were to experience a terminally ill situation. Also, their need for health care services, when they decided on a preferred place of end-of-life care, might reflect their expectation for care at the selected place. Next, we should focus longitudinally on evaluating the preferences and the need for health care services. Third, this study focused on comparing care preferences among hospital and three other places (home, PCU, and nursing home). The way to promote an end-of-life care system in Japan is also discussed in light of the present results. It is also necessary to further compare and discuss the differences among the preferences for the other three places as well as actual places of death in the future.

In conclusion, the present study revealed that the people who preferred an acute hospital setting tended to have a greater need for end-of-life care not from its experienced professionals but from the same staff. They also had a greater need for health care services in a highly-supported environment, including the availability of nearby health care staff whenever and treatment possibly till the very end. They also evidenced a greater need for consulting nurses whenever, compared to those who preferred home. Those with the hospital preference, of course, had less need for home care or daycare services and less need for family instruction on the use of insurance/public health services. The perceptions and attitudes of such Japanese people may provide the basis for useful consideration to take action for further promotion of end-of-life care in Japan.

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Address correspondence to:

Sakiko Fukui, R.N., Ph.D.

Graduate School of Nursing

The Japanese Red Cross University

4-1-3 Hiroo, Shibuya-ku

Tokyo 150-0012

Japan

E-mail: sfukui@redcross.ac.jp