Impact of patients' expressed wishes on their surrogate decision makers' preferred decision-making roles in Japan

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Abstract:

Background: Home medical care (HMC) patients and their families are expected to prepare for end-of-life decision-making.

Objective: We investigated the decision readiness of HMC patients and their family surrogates.

Design: Cross-sectional survey.

Setting/Subjects: We collected data from dyads consisting of a HMC patient aged 65 years or older and a family member of the patient, recruited at four Japanese primary care clinics from January 2016 to November 2016.

Measurements: Surrogates completed a questionnaire on their sociodemographic and health status and their decision readiness. Primary HMC physicians provided information on their patients.

Results: A total of 337 dyads were screened, and 159 were included. The mean age of patients and surrogates was 86 and 64 years respectively, and 29% of patients were cognitively impaired. Only 1.9% of the patients left written advance directives, and 32% were entrusting all decision-making to the doctor or their family. Regarding the surrogate's preferred decision-making role, 21.9% of the surrogates preferred doctors to assume decision-making responsibility. A multivariate analysis revealed that no discussion of care goals (odds ratio [OR] 2.88, 95% confidence interval [CI] 1.02-8.17) and patients having expressed their wishes verbally, including entrusting decision-making to others (OR 2.51, 95% CI 1.07-5.89), were associated with surrogates' preference for doctors to have decision-making responsibility.

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Conclusions: Many patients preferred to entrust the end-of-life decisions to others rather than utilizing advance directives, which made surrogates more dependent on doctors for decision-making. Qualified advance care planning is required to promote familial discussion and surrogates' decision readiness.

Introduction

In home medical care (HMC) practice, physicians regularly provide in-home medical care for older patients who need maintenance of chronic conditions, assistance with activities of daily living (ADL), and end-of-life care. Because HMC patients are mostly frail and some of them are already unable to express their thoughts, many of them are surmised to need surrogate decision-making at the end of life. According to a recent survey in the United States, 70% of deceased patients lost their decision-making capacity at the end of life and 68% had advance directives.¹¹ However, completion rates for advance directives are much lower in some countries, including Japan, Korea, and China, where Confucianism influences the view of death and emphasizes the family over the individual.^{2,3,4} In East Asian culture, older adults believe end-of-life decision-making to be a family responsibility, because they wish to remove the burden of making decisions from patients.⁵ Thus, Japanese families play an important role in end-of-life decision-making making for older HMC patients.

A recent general population survey in Japan showed that two-thirds of older patients undertake advance directives only as a brief guide to their surrogate decision-maker, and these need to be supplemented by incorporating the family's thoughts and the doctor's view of the situation.^{*2} Patients frequently choose to entrust all decision-making to others (*omakase* in Japanese) as their end-of-life wishes, and expect family-centered decision making.^{*6} This is often expressed in the form of a brief, euphemistic remark that avoids further discussion of the subject. Japanese doctors and families also take the family to

be the decision-making authority regarding prognostic disclosure of a patient's incurable disease, and families often even decide whether or not to disclose the prognosis to the patient.^{*7,8,9} Family-centered decision-making is often applied even when the patient is competent to make decisions.^{*10}

On the other hand, surrogate decision-making can be a burden to family members, especially if they have had no prior discussions with the patient about treatment preferences.^{*11} This decisional conflict is eased when the patient has previously completed advance care planning, and family members are aware of the patient's preferences.^{*12,13}

Since the families provide a certain amount of daily decision-making and care for most patients under HMC, we surmise that family-centered decision-making at the end of life has broad acceptance. However, the actual practice of end-of-life decision-making among HMC patients and their families is not well understood. Data are especially lacking on family members' decision readiness and surrogate decision-makers' preferred roles in decision-making.

The aim of this study is to describe the decision readiness for end-of-life decisionmaking of HMC patients and their family surrogates, and to clarify surrogates' preferred roles in decision-making and associated factors such as patients' expressed wishes.

Methods

Study design

A cross-sectional survey was conducted after obtaining approval from the Ethics Committee of Hamamatsu University School of Medicine (Registration number: E15-209, Ethics Committee of Medicine) and the Institutional Review Board of Kikugawa General Hospital.

Participants, setting

Participants consisted of dyads of an older HMC patient and their surrogate decisionmaker. Dyads were included in the sample if the patient was 65 years or older, received HMC services from one of the selected clinics, and their surrogate could be contacted. Dyads were excluded from the survey when the surrogate had insufficient Japanese literacy to complete the survey; the patient was admitted to a hospital or a nursing home before the request for participation; or the patient was dying or dead, such that the primary HMC physician comprehended it inappropriate to ask for participation. Dyads were recruited from four primary care clinics that provided HMC and were registered as a home care support clinic, with acclaimed home care support functions available 24 hours a day, until the patient dies.*14 We selected two clinics from urban areas and two from rural areas, because the social and family life differs greatly between these two settings in general. Since one of our clinics catered to twice or three times larger numbers of study candidates as compared to the rest of the clinics, we adopted random sampling at this clinic. From the other three clinics, we sampled consecutive dyads. HMC patients were recruited without regard to diseases or decision-making capacity; therefore, informed consent wars obtained only from the patient's family member if the patient was demented and unable to understand the survey. Otherwise, both members of the dyad gave informed consent. Because there is no legal basis for designating a healthcare proxy in Japan, a patient's surrogate was defined in this survey as "a patient's family member or corresponding person who will make medical decisions on the patient's behalf when the patient lacks decision-making capacity due to illness." From January 2016 to October 2016, a total of 337 dyads in the four clinics were screened by the patients' primary HMC physicians, and 119 (35%) were excluded from the study for the following reasons: no informed consent obtained (n=21, 6%), problems with the surrogate's Japanese literacy (n=9, 3%), no surrogate available (n=29, 9%), patient admitted to a hospital during inclusion period (n=19, 6%), patient admitted to a nursing

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home during inclusion period (n=5, 1%), or patient deceased during inclusion period (n=29, 9%). Of 197 eligible dyads, 159 responded to the questionnaire (Fig. 1).

Variables, data sources

Surrogates responded to questionnaire measures on their sociodemographic status (age, gender, education, family composition), health status (history of hospitalization within five years, self-rated quality of life (QOL)), and readiness for surrogate decision-making (anticipatory guidance received at the beginning of HMC, care goals discussed with the doctor at the beginning of HMC, surrogate's preferred care goal for the patient, patient's expressed wishes, surrogate's preferred decision-making role). Primary HMC physicians provided information on the patients' health status (age, gender, disease, ADL according to the Katz index, estimated prognosis, cognitive skills for daily decision making (cognitive function to make decisions regarding daily life tasks), and ability to make oneself understood (ability to express ideas and needs), duration of HMC). These variables were collected simultaneously immediately following informed consent.

Self-rated QOL

Surrogates rated their own QOL on the Japanese version of the 8-item short form Medical Outcome Study (SF-8),^{*15} in which 5- or 6-point Likert scales are used. The SF-8 provides two summary scores: the Physical Component Scale and the Mental Component Scale. These two summary scores employ norm-based scoring, with a score of 50 corresponding to the national norm. We dichotomized the data by whether these scores fell above or below the national norm.

Patients' decision-making capacity

To clarify the decision-making capacity of the patient, we asked the primary HMC physician two questions: "cognitive skills for daily decision making" and "ability to make oneself understood." These questions are used in the Physician's Report for assessing a patient's care needs in the Long-term Care Insurance System in Japan, and are

originally extracted from the Long-term Care Facility Resident Assessment Instrument of the US Department of Health and Human Services.^{*16} Each question has four response options, and we dichotomized the variables by interpreting the top three as "competent" and the lowest as "impaired." Thus, for cognitive skills, "independent", "modified independent", and "cues or supervision required" were interpreted as "competent", while "severely impaired" was interpreted as "impaired", and for communication skills, "(makes oneself) understood", "usually understood", and "limited to making concrete requests" were interpreted as "competent", while "rarely or never understood" was interpreted as "impaired".

Status of patients' expressed wishes

Surrogates were asked whether the patient had expressed end-of-life wishes in case their condition should prevent them from describing their preferences. The following options were presented: 1) In writing (an advance directive), 2) Verbally, 3) A brief euphemistic remark of *omakase* entrusting all decision-making to the family, 4) A brief euphemistic remark of *omakase* entrusting all decision-making to the doctor, 5) None, 6) Don't know. Two response options relating to brief, euphemistic remarks were included because Japanese patients tend to prefer entrusting decision-making to others (*omakase*)^{*6} and avoiding awareness of death,^{*17} and these preferences imply that this type of brief remark may be a favored and realistic way for patients to communicate with their family. We present the full descriptive data on patients' expressed wishes, but trichotomized the responses for the purpose of analysis: 1 as "in writing," 2 to 4 as "verbal expression or *omakase*," and 5 and 6 as "not expressed."

Outcome variable: Surrogates' preferred decision-making roles

For the question relating to the surrogate's preferred decision-making role when the patient should lack decision-making capacity due to illness, response options were as follows: 1) You (the surrogate) prefer to make decisions by yourself, 2) You prefer to

make decisions after considering the doctor's opinion, 3) You prefer that the doctor make decisions after considering your opinion, 4) You prefer that the doctor make decisions. These options were composed with reference to the Control Preferences Scale, ^{*18} which is a widely-used instrument assessing patients' preferences regarding participation in health care decisions about life-threatening conditions. In this survey, we eliminated an option relating to shared decision-making from the original scale, because surrogate decision-making is essentially a shared process between the patient's family and their doctor, and additionally because we wished to obtain clear opinions from surrogates on decision-making responsibility. Response choices were dichotomized as "surrogate's responsibility" or "doctor's responsibility" for the analysis.

Statistical analysis

Frequencies, proportions, means, and standard deviations were used to characterize the study participants. Missing values were excluded from the analysis. To identify variables associated with the outcome variable (the surrogate's preferred decisionmaking role), we used a logistic regression analysis to calculate the odds ratio of a preference for doctor's responsibility with 95% confidence intervals and fit a multivariate model that adjusted patient's age and surrogate's age. All analyses were executed using IBM SPSS v. 23.

Results

Surrogates' and patients' characteristics for the 159 dyads are shown in Table 1 and Table 2. Surrogates' mean age was 64 (standard deviation [SD] 12) years, 50.9% were the patient's child, 88.7% lived with the patient, and 78.2% had lower mental health status than the national norm on the SF-8 Mental Component Scale. Patients' mean age was 86 (SD 8) years, 65.0% were partially or totally ADL dependent, and 28.7% were impaired in cognitive function.

Readiness for surrogate decision-making and surrogates' preferred decision-making role are presented in Table 3. At the beginning of HMC, 80.0% of the surrogates had been involved in a discussion of care goals with the doctor. Only 3 patients had completed written advance directives, and 44.8% of patients verbally told their surrogate something about their end-of-life care preferences. Among the patients who stated their wishes, *omakase* was the most frequent expression (32.1%). Regarding preferred decision-making roles at the time of surrogate decision-making, 21.9% of surrogates preferred doctor's responsibility. When patients expressed their wishes verbally or through *omakase*, surrogates leaned towards doctor's decision-making responsibility, while those with written advance directives or without any expressed wishes by the patient were less likely to indicate this preference (33.3%, 0%, 14.0%, respectively).

Table 4 summarizes the analyses of variables associated with surrogates' preference for doctor's responsibility. A univariate analysis revealed several variables associated with preference for doctor's responsibility, including surrogate's age of 65 years or older, surrogate's low score on the SF-8 physical component, patient's age of 85 years or older, and patient's wishes that were expressed verbally or through *omakase*. Since there was no correlation between surrogate's age and patient's age (Pearson's correlation coefficient r=0.11, p=0.16, not in table), we adjusted both of the ages for a multivariate analysis. The multivariate analysis revealed that no discussion on care goals at the beginning of HMC (odds ratio [OR] 2.88, 95% confidence interval [CI] 1.02-8.17) and patient's wishes expressed verbally or through *omakase* with reference to wishes not expressed (OR 2.51, 95% CI 1.07-5.89) were associated with surrogate's preference for doctor's responsibility.

Discussion

Our survey found that half of the surrogates of HMC patients had some kind of

knowledge about the patient's expressed wishes, and most of these expressions took the form of a brief, euphemistic remark about entrusting decision-making to others (*omakase*), rather than a more specific end-of-life care preference. One fourth of the surrogates reported that their preference with regard to decision-making role was for doctor's responsibility rather than their own responsibility. In addition, the patient having expressed their wishes verbally or through *omakase* made the surrogate more dependent on doctor's responsibility.

Frequency of patients' expressed wishes in HMC

The practical way for older HMC patients in Japan to express their wishes has been through *omakase*. In our survey, only 1.8% of patients had written advance directives, and this figure was in line with the general population according to the latest national survey.⁷² Another cross-sectional survey conducted between 1994 and 1996 found that entrusting decision-making to the family was unique to Japanese palliative care patients compared to those in the United States and Germany (29%, 0%, 0%, respectively).¹⁹ We demonstrated the prevalence of *omakase* (entrusting of decision-making) among Japanese older HMC patients for the first time, and the figure was similar to that of Japanese cancer patients receiving palliative care 20 years ago.¹⁹ In light of these comparisons, we conclude that written advance directives are under-utilized in current HMC practice, and the classic Japanese tendency to prefer *omakase* still exists in the context of advance care planning. In addition, this tendency may be equally strong in China and South Korea, as family-centered decision-making at the end of life has been favored in these two countries, although no comparable data is currently available.

Surrogates' preferred decision-making roles at the time of surrogate decisionmaking

A proportion of surrogates of HMC patients feel greatly under pressure and uncomfortable with the responsibility of surrogate decision-making, and depend on

doctors to make decisions. We found that a total of 21.9% of surrogates preferred doctors to assume decision-making responsibility. According to a national survey in the general population, 10% would refuse to accept the role of health care proxy for their relatives.^{*2} In the United States and Canada, 0-19% of family members of patients admitted to the intensive care unit (ICU) preferred doctors to assume decision-making responsibility.^{*20-}²³ We cannot compare the absolute numbers due to the differences in study settings and questionnaires, but we can note that some surrogates preferred doctors to have decision-making responsibility even in the HMC setting, where surrogates were more actively involved in daily decision-making and care for patients than in the ICU.

Some surrogates experienced interpersonal tension and could not make a decision when they had responsibility for their relative's life or death.^{*24} On the other hand, other surrogates reported that active involvement in decision-making allowed them to regain a sense of agency by actively making a decision consistent with the patient's wishes, and surrogates felt relieved by this experience.^{*22} Although emotions and preferred decision-making roles varied among surrogates, no clinician inquired about surrogates' preferred decision-making roles during family conferences in the ICU.^{*25} This implies an opportunity for clinicians to lessen surrogates' decisional conflict and support their decision-making by paying attention to surrogates' preferred roles during the shared process of end-of-life decision making.

Association between patients' verbally expressed wishes and surrogates' preferred decision-making roles

Our most important findings were that more surrogates preferred doctors to assume decision-making responsibility when they had not been involved in a discussion of care goals with the doctor at the beginning of HMC, and also when they had knowledge of the patient's verbally expressed wishes. These results can be interpreted as follows: while past experience of care goal discussion made the surrogates confident and ready for

surrogate decision-making, patients' verbally expressed wishes, including *omakase*, did not. The latter correlation was unexpected and inconsistent with previous findings. Advance care planning that allows the surrogate to understand the patient's wishes and values is proven to help surrogates to make decisions confidently and to ease their decisional burden.^{*11-13,21} One survey consisting of 16% Asian surrogates was an exception, showing no correlation between surrogates' preferred decision-making roles and their knowledge of patients' expressed wishes.^{*22}

One possible explanation for our unexpected result is the form of expression of patients' wishes: verbally or through *omakase*. These expressions may not arise from discussion between the patient and the surrogate, hence they did not contribute to the surrogate's decision readiness. A preference for *omakase* is usually conveyed in a brief sentence about decision-making roles, with no expression of the patient's preferences for specific treatment options or values regarding their own end of life.^{*10} This reflects traditional social values that respect interdependence and harmony.^{*26} However, surrogates commonly preferred to have more information on patients' individual preferences and values, in order to make decisions in accordance with patients' wishes.^{*27} Patients' expression of wishes without sufficient discussion of their preferences or values did not contribute to surrogates' decision readiness; thus, surrogates leaned toward preferring doctors to assume decision-making responsibility.

Limitation

Several limitations of this study should be acknowledged. First, since some of the study dyads living separately or with poor prognosis were hard to ask for their participation, the frequency of patients having expressed wishes might be misestimated. Second, only the surrogates reported on the status of patients' expressed wishes; there may be a perception gap between patients and surrogates on this question.^{*28} We tried to minimize this gap by defining the surrogate beforehand and collecting most of the data

from dyads living together. Third, as the number of dyads was small, the multivariate analysis might not produce the best possible explanatory model. Studies with larger sample sizes are needed to confirm our findings.

Conclusion

Our cross-sectional survey revealed the current status of preparation for end-of-life decision making among Japanese older HMC patients and their families. Written advance directives remained under-used, and many patients employed *omakase* as a means to express their end-of-life wishes to their family. From the standpoint of the HMC setting and family-centered decision making, surrogates were considered to take on decision-making responsibility, but some surrogates preferred doctors to make decisions on patients' end-of-life issues. Knowledge of patients' verbally expressed wishes, which probably arose without sufficient discussion of patients' preferences or values, made surrogates more dependent on the doctor. The implication for clinical HMC practice is that advance care planning is needed to promote familial discussion about end-of-life issues and to prepare for surrogate decision-making. Furthermore, clinicians should pay attention to surrogates' preferred decision-making role during family conferences. Further studies are needed to produce a clearer understanding of the association between patients' expressed wishes, including *omakase*, and surrogates' preferred decision-making roles and their singext.

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Author Disclosure Statement

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No informed consent obtained (n=21) Problem with surrogate's Japanese literacy (n=9) No surrogates available (n=29) Hospital admission during inclusion period (n=19) Nursing home admission during inclusion period (n=5) Deceased during inclusion period (n=29) Unknown (n=23)

Participated dyads consisting of a home medical care patient and patient's surrogate (n=197)



Dyads with complete questionnaire (n=159)



Characteristics	n	%
Age in years		
20-39	5	3.2
40-59	45	28.5
60-79	88	55.7
80-99	20	12.7
Gender		
Male	49	31.0
Female	109	69.0
Level of education in years		
-12	101	66.9
13-	50	33.1
Living with the patient		
Yes	141	88.7
No	18	11.3
Relationship to the patient		
Spouse	47	29.6
Child	81	50.9
Child in low	23	14.5
Others	8	5.0
History of hospitalization within 5 years		
Yes	37	23.4
No	121	76.6
SF-8 Physical component scale		
Higher than national norm	53	34.0
Lower than national norm	103	66.0
SF-8 Mental component scale		
Higher than national norm	34	21.8
Lower than national norm	122	78.2

Table 1. Characteristics of the surrogates (n=159)

Missing values are excluded from the table

SF-8, the Japanese version of the 8-item short form Medical Outcome Study

Characteristics	n	%
Age in years		
65-74	17	10.8
75-84	44	27.8
85-94	72	45.6
95-	25	15.8
Gender		
Male	68	42.8
Female	91	57.2
Diagnosis for HMC admission		
Malignancy	20	12.7
Stroke	27	17.1
Organ failure (any organ)	27	17.1
Dementia and/or frail	66	41.8
Others	18	11.4
Numbers of dependent ADL component by Katz index		
0-1 (independent)	55	35.0
2- (partially dependent-)	102	65.0
Prognostic estimation by the primary HMC physician		
6 months-	124	78.5
-5 months	34	21.5
Cognitive skills for daily decision making		
Competent	112	71.3
Impaired	45	28.7
Ability to make self understood		
Competent	123	78.3
Impaired		21.7
Duration of HMC		
-12 months	93	60.8
13 months-	60	39.2

Table 2. Characteristics of HMC patients (n=159)

Missing values are excluded from the table HMC, home medical care; ADL, activities of daily living

Variable	All ^a		Doctor's responsibility ^b (n=34, 21.9%)		Surrogate's responsibility ^b (n=121, 78.1%)	
Anticipatory guidance received at the beginning of HMC, n (%)						
Yes	70	(45.5)	13	(18.6)	57	(81.4)
No	84	(54.5)	20	(23.8)	63	(75.0)
Care goals discussed with the doctor at the beginning of HMC, n (%)				. ,		. ,
Yes	124	(80.0)	24	(19.4)	100	(80.6)
No	31	(20.0)	9	(29.0)	21	(67.7)
Surrogate's preferred care goals for the patient, n (%)				, ,		()
Palliative care goal	91	(57.2)	20	(22.0)	71	(78.0)
Life prolongation goal	36	(22.8)	9	(25.0)	27	(75.0)
Goals not established	31	(19.6)	5	(16.1)	26	(83.9)
Patient's expressed wishes, n (%)				, ,		,
In writing (an advance directive)	3	(1.9)	0	(0.0)	3	(100)
Verbally	16	(10.1)	5	(31.3)	11	(68.8)
Omakase, entrusting all decision-making to the family	37	(23.3)	12	(32.4)	25	(67.6)
Omakase, entrusting all decision-making to the doctor	14	(8.8)	5	(35.7)	8	(57.1)
None/Don't know	86	(54.1)	12	(14.0)	74	(86.0)

Table 3. Readiness for surrogate decision-making and surrogate's preferred decision-making role

Missing values are excluded from the table.

^aColumn percent

^bRow percent

HMC, home medical care

	Crude				Adjusted ^a		
Variables	OR	(95% CI)	р	OR	(95% CI)	р	
Surrogate characteristics							
Age of 65 years or older	3.60	(1.55; 8.35)	0.003	-			
Female	1.10	(0.48; 2.52)	0.820	1.67	(0.68; 4.10)	0.263	
No history of hospitalization within 5 years	0.99	(0.41; 2.43)	0.986	1.30	(0.49; 3.43)	0.602	
Level of education (13 years or more)	0.39	(0.15; 1.03)	0.057	0.67	(0.38; 1.17)	0.158	
Living separately with the patient	0.42	(0.09; 1.93)	0.266	0.36	(0.10; 1.34)	0.127	
Low SF-8 physical component scale	2.92	(1.13; 7.59)	0.028	2.59	(0.95; 7.06)	0.063	
Low SF-8 mental component scale	1.39	(0.52; 3.70)	0.509	1.61	(0.57; 4.54)	0.369	
Patient characteristics							
Age of 85 years or older	3.77	(1.46; 9.77)	0.006	-			
Female	1.29	(0.59; 2.80)	0.524	1.18	(0.50; 2.77)	0.705	
Partially or completely ADL dependent	1.07	(0.48; 2.42)	0.862	1.17	(0.49; 2.79)	0.726	
Impaired cognitive function for daily decision making	0.75	(0.31; 1.82)	0.528	0.75	(0.29; 1.93)	0.551	
Impaired communication skills to make oneself understood	0.59	(0.21; 1.65)	0.312	0.71	(0.24; 2.15)	0.543	
Less than 6 months of prognosis estimation	0.76	(0.29; 2.03)	0.586	0.76	(0.26; 2.17)	0.603	
Continuing HMC for 1 year or more	0.64	(0.28; 1.46)	0.289	0.68	(0.28; 1.65)	0.393	
Readiness for surrogate decision making							
No anticipatory guidance received at the beginning of HMC	1.39	(0.64; 3.05)	0.409	1.65	(0.70; 3.87)	0.252	
No discussion on care goals at the beginning of HMC	1.79	(0.73; 4.39)	0.206	2.88	(1.02; 8.17)	0.046	
Palliative care goal not established	0.94	(0.43; 2.03)	0.870	0.73	(0.32; 1.69)	0.468	
Patient's wishes expressed as "in writing" ^b	0.00	(0.00; -)	0.999	0.00	(0.00; -)	0.999	
Patient's wishes expressed as "verbally or through omakase"b	3.09	(1.39; 6.84)	0.006	2.51	(1.07; 5.89)	0.035	

Table 4. Variables associated with surrogates' preference for doctor's decision-making responsibility

Missing values are excluded from the table

^a Using multivariable logistic regression adjusted for patient's age and surrogate's age

^b Variables are compared with "None/Don't know" as the status of patient's expressed wishes

OR, odds ratio; CI, confidence interval; SF-8, medical outcome study 8-item short form; ADL, activities of daily living; HMC, home medical care