

Original Article

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Factors associated with surrogate families' life-sustaining treatment preferences for patients at home or in a geriatric health service facility: A cross-sectional study

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Abstract

Objective. Recently, end-of-life preference in palliative care has been gaining attention in Japan. The Ministry of Health, Labor, and Welfare established the Japanese basic policy in November 2018. Patients' decision-making is recommended; however, patients with dementia or other disorders cannot make such decisions by themselves. Thus, healthcare providers may contact surrogates and consider their backgrounds for better decision-making. Hence, the preferences of home caregivers' and geriatric health service facility (GHSF) residents' families on patient life-sustaining treatment (LST) were investigated.

Method. This cross-sectional study involved home caregivers' and GHSF residents' families in Japan. We distributed 925 self-reported questionnaires comprising items, such as the number of people living together, care duration, comprehension of doctor's explanations, the Patient Health Questionnaire (PHQ)-9 and Short Form (SF)-8, and families' LST preference for patients.

Results. In all, 619 valid responses were obtained [242 men and 377 women (309 in the HOME Caregivers Group, response rate = 61.1%; 310 in the GHSF Group, response rate = 74.0%)]. LST preference was significantly associated with sex, the number of people living together, care duration, and comprehension of doctors' explanations in the HOME Caregivers Group but was not significantly associated with the GHSF Group. Furthermore, PHQ-9/SF-8 scores were not significantly associated with LST preference.

Significance of results. There were many differences in opinions about LST preference between home caregivers' and GHSF residents' families. The results suggested that the burden of nursing care was greater and harder in home caregiver families, and these factors may be related to the LST preference for a patient.

Introduction

End-of-life (EOL) preference in palliative care has been attracting attention in Japan in recent years. Moreover, discussions on EOL treatment are also an important part of advance care planning (ACP). However, in Japan, some patients do not wish to know about the seriousness of their conditions and want to live as they usually did without the feeling of impending death (Shaku et al., 2015). A study by Mori et al. (2019) reported that physicians tend to either provide overoptimistic prognosis or never talk about prognosis with patients with advanced cancer. However, there are some cases in which even if people want to make their own decisions, they cannot. For example, in the case of a disease such as dementia, a substantial majority of patients at EOL cannot make treatment decisions for themselves because of their physical deterioration or mental incapacity (Sviri et al., 2009; Wendler and Rid, 2011; Heyland et al., 2013; Lee et al., 2013; Zaros et al., 2013; Torke et al., 2014). Surrogate decision-making for seriously/terminally ill patients has been demonstrated to be a challenging and emotionally tumultuous task (Wendler and Rid, 2011).

A systematic review reported that patients with dementia are less capable of making EOL choices (Lovell and Yates, 2014); therefore, surrogates are frequently asked to make healthcare decisions on such patients' behalf. A previous study reported that 70.3% of elderly end-stage patients who were required to make decisions were unable to make EOL care decisions (Silveira et al., 2010). In addition, significant complexity prevails in undertaking ACP in the context of dementia (Ryan et al., 2017).

Furthermore, surrogates experience negative emotional effects (Wendler and Rid, 2011). They are expected to use their judgment concerning the type of decisions that the patient would prefer (Abbott et al., 2001; Wendler and Rid, 2011), and they are often unprepared

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to apply substituted judgment or the best interest standards to decision-making on behalf of patients. They may pursue nonbeneficial treatment as they would be unaware of the patient's preferences or have grappled with their own complex emotions (Berlin et al., 2017). Under such circumstances, the elderly patients are cared for at homes and facilities for a longer time. For families taking care of an older patient may present challenges, such as the patient's dementia, a sense of hesitation regarding the use of public services, and seeking professional supporters for both their next kin and health services (Shiba et al., 2016).

In Japan, many aged patients are in geriatric health service facilities (GHSFs), such as nursing homes, and it is expected that the number of elderly people in these facilities will be increasing. One of the GHSFs' surveys reported that 48–69% of deceased GHSF residents had an advance directive; however, family members reported much higher estimates (91–97%; Daaleman et al., 2009). Moreover, families are expected to be surrogates for decision-making when the intentions cannot be adequately expressed by patients because of brain disorders.

Previous studies Garrido and Prigerson (2014), Chiarichiaro et al. (2015), Schulz et al. (2015), and Song et al. (2015) have examined the relationship between decision-making and mental health, such as depression and anxiety. Nakamura et al. (2018) studied surrogates of heart disease patients regarding life-sustaining treatment (LST) preference and revealed that sex difference was related to decision-making. Thus, there are various factors related to a family's decision-making concerning the EOL and LST of a family member.

LST is paramount to seriously ill patients, such as those who experienced cardiac arrest (Van Norman, 2017). LST includes intubation and mechanical ventilation, tracheostomy, gastrostomy tube insertion, enteral or parenteral nutrition, and cardiopulmonary resuscitation (Ornstein et al., 2017). Moreover, LST, a component of ACP, is a critical element of high-quality care, and decision-making regarding incorporating its use in the treatment of patients is important in facing EOL situations (Dingfield and Kayser, 2017).

This study's aim was to identify the factors associated with the preferences of home caregivers and GHSF residents' families on a patient's LST preference. Additionally, depending on the environmental difference between a home and a GHSF, the secondary aim was to identify the primary choices concerning who should make decisions about the patient's EOL and LST choices.

Material and methods

This study was approved by the Human Subjects Institutional Review Board of Nihon University Itabashi Hospital Clinical Research Judging Committee (Approval No. RK-151213-3). The study was conducted in accordance with the principles embodied in the Declaration of Helsinki.

The purpose and contents of the questionnaires were explained to potential participants. Informed consent was procured from all participants, and they were asked to anonymously complete the questionnaire and return it in a sealed envelope to our research partners.

Participants

We sent questionnaires through mail to the cooperating staff members of two home visit clinics and GHSFs located in six different prefectures (Hokkaido, Ibaraki, Saitama, Chiba, Kanagawa, and

Miyazaki). The cooperating staff members distributed the questionnaires to 506 home caregivers' (HOME Group) and 419 GHSF residents' (GHSF Group) families between February and May 2017.

Instruments

Each anonymous questionnaire contained an explanation of its purpose and content. The questionnaire (Additional file 1 in Supplementary material) included items on family demographics, care duration (in months), comprehension level of doctor's explanations regarding the patient's conditions and diseases, whether the family had informed the patient about the disease they had (disease notified or not), and LST preference (preference for ventilation and/or cardiac massage at the patient's EOL). The questionnaire package also included the Patient Health Questionnaire (PHQ)-9 (Kroenke et al., 2001) and Short Form (SF)-8 (Fukuhara et al., 1998a, 1998b; Fukuhara and Suzukamo, 2004). The PHQ is a self-administered version of the Primary Care Evaluation of Mental Disorders diagnostic instrument for common mental disorders (Kroenke et al., 2001). It is the depression module that attributes scores to the nine DSM-IV criteria, from "0" (not at all) to "3" (nearly every day). The SF-8™, an eight-item survey that assesses health-related quality of life (HRQOL), is widely employed to evaluate allopathic treatment modalities and has been used in Japanese studies (Fukuhara and Suzukamo, 2004). This instrument measures eight health concepts: Physical Functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional, and Mental Health. Physical functioning, Role Physical, Bodily Pain, and General Health assesses the physical aspects of HRQOL and provide a physical component summary, whereas Vitality, Social Functioning, Role Emotional, and Mental Health assesses the mental or psychosocial aspects of HRQOL and provide a mental component summary. The scores were determined based on the Japanese standards, ranging from 0 to 100; higher scores indicated better Quality of Life (QOL). This scoring system is available in the SF-8™ manual (Fukuhara and Suzukamo, 2004) and was provided by the Institute for Health Outcome and Process Evaluation Research.

Data collection

We requested 925 participants (HOME Group = 506; GHSF Group = 419) for their participation. Our acceptance criteria included the following: participants should be ≥20 years old; be an integral part of a home caregiving family and/or a GHSF resident's family; be able to answer the questions by themselves; and be able to understand the purpose of this study. If there were one or more questionnaire items that a participant did not wish to answer, they were asked to return the questionnaire partially or completely unanswered. Our inclusion criterion was that the questionnaire should be attempted by the participants. Unresponsive participants and completely unanswered questionnaires were excluded from the analysis. In all, 619 returned questionnaires were determined to be valid and included in the study analyses.

Data analysis

All analyses were performed by a statistician at the Japan Institute of Statistical Technology (Tokyo, Japan) using SPSS (ver. 20; IBM Corporation, Armonk, NY, USA). We divided the participants into four groups: home caregivers (disease name notified), home caregivers (disease name not notified), GHSF residents'

families (disease name notified), and GHSF residents' families (disease name not notified). "Disease name notified" and "Disease name not notified" mean that the patient (person being cared for) either was or was not notified, respectively, about their diseases. The division was made in accordance with Japanese-favored information, i.e., only for the family of a patient with a fatal diagnosis, wherein further decisions regarding the patient's treatment relied on the family members (Voltz *et al.*, 1998). The chi-squared test for categorical variables and student's *t*-test for continuous variables were performed to determine significant differences regarding the comparison of groups. Furthermore, data were summarized and analyzed through binomial logistic regression analysis with the home caregivers' and GHSF residents' families' answers for "prefer" or "not prefer" LST as the objective variable, and the scores of PHQ-9, SF-8, or question items were used as explanatory variables, obtaining the odds ratio by exponentiation of the regression coefficient of each item and its test results. The significance level was set at $P < 0.05$ (two-tailed). The SF-8™ scoring was based on the Manual of the SF-8™ Japanese Version (Fukuhara and Suzukamo, 2004).

Results

Demographic characteristics

Valid responses were obtained from 619 participants (response rate = 66.7%; 242 men and 377 women [309 in the HOME Group, response rate = 61.1%; 310 in the GHSF Group, response rate = 74.0%]). The mean age of the participants was 65.29 ± 12.09 and 63.24 ± 10.39 (years \pm SD) in the HOME and GHSF Groups, respectively (Table 1). It was observed using the *t*-test that the age among the HOME Group was significantly higher ($P = 0.026$) than that among the GHSF Group. Furthermore, using the chi-squared test, the proportion of individuals living alone was observed to be significantly higher in the GHSF Group (17.0%) than that in the HOME Group (5.5%; $P < 0.001$).

The mean care duration was 6.14 ± 7.94 and 4.87 ± 7.07 (years \pm SD) in the HOME and GHSF Groups, respectively. The level of comprehension of the explanation by the physician of the patient's condition was "sufficient" in 63.6% of the HOME Group participants and 66.9% of the GHSF Group participants; "sure" in 27.7% HOME Group participants and 25.9% GHSF Group participants; and "not very well" in 5.3% HOME Group participants and 2.6% GHSF Group participants. However, the differences in these rates using the chi-squared test were not significant between the two groups.

There were no significant differences in the distribution of age and sex according to the answers provided by the participants who had only one patient between the patient groups. Using the chi-squared test, we found that the rate of cancer as a main disease among the patients was significantly higher in the HOME Group (5.9%) than in the GHSF Group (1.7%; $P = 0.018$), and the rate of dementia symptoms among patients was significantly higher in the GHSF Group (73.2%) than in the HOME Group (62.3%; $P = 0.007$). The rate of disease notification for patients was not significantly different between the groups (HOME Group = 67.2%; GHSF Group = 59.7%). The mean PHQ-9 score of the participants was significantly higher (more depressive) in the HOME Group (mean = 13.57 ± 5.43) than in the GHSF Group (mean = 12.48 ± 4.57) ($P = 0.012$ by *t*-test).

HRQOL determined by the SF-8 total score of the participants was significantly lower in the HOME Group than that in the

GHSF Group ($P < 0.001$ by *t*-test). The scores for the SF-8 subscales (General Health, Physical Functioning, Role Physical, Bodily Pain, Social Functioning, Mental Health, and Role Emotional) were significantly lower in the HOME Group than that in the GHSF Group ($P = 0.028$, $P = 0.033$, $P < 0.001$, $P = 0.048$, $P < 0.001$, $P = 0.001$, and $P < 0.001$, respectively, using the chi-squared tests), and only one subscale, Vitality, was not significant ($P = 0.051$ using the chi-squared test).

Factors associated with LST preference in the disease notified group

We used binomial logistic regression analysis to analyze the factors associated with the preference for the patient's LST among participants in the disease notified group. The preference for the patient's LST among participants was significantly associated with sex ($P = 0.018$), the number of people living together ($P = 0.034$), and comprehension of the doctors' explanations of the patient's conditions ($P = 0.027$) in the HOME Group. The degree of preference for the patient's LST was significantly less ($P = 0.018$) among women ($n = 15$, 15.0%) than among men ($n = 17$, 31.5%). The degree of preference for the patient's LST among participants significantly decreased with an increase in the number of people living together. Comprehension of the doctor's explanation significantly increased the frequency of participants selecting "preference for LST" among those who selected "not very well" ($n = 14$, 5.3%) than among those who selected "sufficient" ($n = 168$, 63.6%). However, there were no significant associations among any items in the GHSF Group (Table 2). We also obtained the results of adding "long-term care level" as a factor related to ADL, "disease name (whether cancer or not)" as a factor related to the primary disease, and "presence or absence of dementia symptoms," but none of these three factors were significant.

There were no significant differences in preference for PHQ-9 and SF-8™ between the two groups as shown in Table 3.

Factors associated with LST preference in the disease not notified group

We used binomial logistic regression analysis to analyze the factors related to preference for the patient's LST among participants in the disease not notified group. The preference for the patient's LST among participants was significantly associated with the number of people living together ($P = 0.034$) and care duration ($P = 0.046$) in the HOME Group. The frequency of preference for the patient's LST among participants significantly decreased with an increase in the number of people living together. Moreover, the longer the nursing care duration, the less frequent was the participants' "preference for LST." However, there were no significant associations among any items in the GHSF Group (Table 4). We also obtained the results of adding "long-term care level" as a factor related to ADL, "disease name (whether cancer or not)" as a factor related to the primary disease, and "presence or absence of dementia symptoms," but none of these three factors were significant (Table 3). There was no significant difference in preference for the PHQ-9 and SF-8 between the two groups as described above.

Tendencies of the odds ratios for PHQ-9/SF-8 scores

The tendencies of the odds ratios for PHQ-9/SF-8 scores of the participants (HOME Group, PHQ-9/SF-8™ = 0.933/1.033;

Table 1. Demographic characteristics

		HOME	GHSF	
Participant	Sex	Male	110 (35.6%)	132 (42.6%)
		Female	199 (64.4%)	178 (57.4%)
	Mean age \pm SD	65.29 \pm 12.09	63.24 \pm 10.39	
	Number of people living together	0	16 (5.5%)	50 (17.0%)
		1	125 (42.8%)	129 (43.9%)
		≥ 2	151 (51.7%)	115 (39.1%)
	Comprehension of the explanation	Sufficient	168 (63.6%)	178 (66.9%)
		Some	73 (27.7%)	69 (25.9%)
		Not very well	14 (5.3%)	7 (2.6%)
Patient	Care duration (year)	6.14 \pm 7.94	4.87 \pm 7.07	
	Sex	Male	79 (28.2%)	74 (23.9%)
		Female	201 (71.8%)	236 (76.1%)
	Mean age \pm SD	85.25 \pm 9.43	86.44 \pm 8.912	
	Disease	Cancer	14 (5.9%)	4 (1.7%)
		Noncancer	207 (87.7%)	205 (87.6%)
		Unknown	15 (6.4%)	25 (10.7%)
	Dementia symptoms	No	104 (37.7%)	79 (26.8%)
		Yes	172 (62.3%)	216 (73.2%)
	Disease notification	Yes	92 (67.2%)	80 (59.7%)
No		45 (32.8%)	54 (40.3%)	

Table 2. Relevance of life-sustaining treatment (LST) preference in the HOME vs. geriatric health service facility (GHSF) Groups (disease name notified)

	HOME Group (N = 104) P-value Odds ratio (95% CI)	GHSF Group (N = 63) P-value Odds ratio (95% CI)
Sex	0.018* 0.240 (0.074–0.786)	0.329 0.525 (0.143–1.918)
Age	0.080 1.047 (0.994–1.103)	0.220 1.054 (0.969–1.147)
Marital status	0.283	0.715
Unmarried vs. Married	0.899 1.132 (0.165–7.779)	0.259 0.378 (0.070–2.047)
Unmarried vs. Divorced	0.165 5.054 (0.515–49.623)	0.837 0.725 (0.034–15.51)
Unmarried vs. Widowed	0.622 2.230 (0.092–54.012)	0.999
Number of people living together	0.034* 0.444 (0.209–0.942)	0.874 1.043 (0.617–1.764)
Care duration	0.403 0.997 (0.991–1.004)	0.677 1.003 (0.990–1.016)
Comprehension degree of doctor's explanations:	0.180	0.956
Sufficient vs. Some	0.559 1.455 (0.414–5.113)	0.769 1.224 (0.319–4.699)
Sufficient vs. Not very well	0.027* 11.937 (1.320–107.925)	0.997 0.995 (0.081–12.265)

CI, Confidence Interval.
* $P < 0.05$.

Table 3. Life-sustaining treatment (LST) preference for the PHQ-9 and SF-8™ among the HOME Group and geriatric health service facility (GHSF) Group

	HOME Group <i>P</i> -value Odds ratio (95% CI)	GHSF Group <i>P</i> -value Odds ratio (95% CI)
Notified group		
PHQ-9	0.262 0.933 (0.826–1.054)	0.635 1.029 (0.915–1.157)
SF-8	0.950 1.003 (0.907–1.110)	0.144 0.937 (0.859–1.022)
Not notified group		
PHQ-9	0.213 0.898 (0.759–1.063)	0.493 0.956 (0.840–1.088)
SF-8	0.342 1.063 (0.937–1.205)	0.377 1.040 (0.954–1.133)

CI, Confidence Interval, Notified Group: disease name notified group, Not Notified Group: disease name not notified group.

GHSF Group, PHQ-9/SF-8™ = 1.029/0.937) indicating a preference for LST were not significantly different between the groups.

Who should make decisions about the patient's EOL and LST choices?

Table 5 presents the preferences of the participants in decision-making for patients. The preference for decision-making by the patients themselves was significantly higher than that by a family member in the HOME Group ($P < 0.001$ using the chi-squared test).

Discussion

We hypothesized that the differences in environmental conditions among home caregivers and GHSF residents' families would be associated with the LST preference for patients. Although there are studies on surrogate decision-making in other countries, in this study, 619 participants were analyzed and all of the participants were Japanese who traditionally have unique feelings about EOL care. In addition, our study included not only home caregivers' but also GHSF residents' families and compared their LST preferences for patients.

With respect to the difficulty for a patient to decide the LST preference in advance, which was regarded as a real problem, the percentage of patients with dementia was higher in the GHSF Group (possibly because families kept more severely affected patients in a GHSF) than in the HOME Group. In addition, the participants' age was higher in the HOME Group than in the GHSF Group, and aging increased the burden of care on caregivers. The HOME Group had a greater number of participants with depression and lower QOL, which may be due to the daily care burden.

In primary outcomes, the number of people living together, sex, comprehension level of the doctors' explanations of the patient's conditions, and care duration were factors significantly associated with LST preference in the HOME Group; however, there were no significant associations in the GHSF Group with respect to any of those factors. These findings suggest that the home caregivers' preferences are influenced by the provision of 24-h care, which may increase the caregivers' distress because longer care duration may be an increased physical and mental

burden. In addition, the difficulty in providing care may be higher for home caregivers' than for GHSF residents' families. Thus, these results indicate that the factors associated with LST preference differed depending on the patient's living environment and extent of care. Boerner *et al.* (2013) reported that individuals who engage in the first place and have a high level of family functioning are precisely the ones best equipped to make collaborative decisions about EOL care and the distress associated with bereavement in families. However, it is not easy to maintain a high level of family function because of exhaustion and discussion caused by long-term care. Family caregivers of individuals who have a serious illness and who undergo intensive LST at EOL may be at risk of experiencing negative emotions, including depression (Ornstein *et al.*, 2017).

In secondary outcomes, the HOME Group may exhibit greater respect for the patient's autonomy for their EOL care in routine life activities. Without accurately understanding patient EOL care preferences, family members and other surrogates often project their own preferences to shape the EOL care actually received by terminally ill patients (Marks and Arkes, 2008; Moorman and Carr, 2008; Fritsch *et al.*, 2013; Ishikawa *et al.*, 2013). It is thought that closer families have lived with patients for many years and understand their feelings better through daily communication with them. In the case of elderly people, if physical activity is limited, muscle weakness and joint contracture are likely to occur, so it is important to maintain physical function by their own wishes even in home care. As an extension of the expectations of this family, it can be considered that the HOME Group expects patient independence regarding LST.

In a study on a similar theme of housing or facility care, Poppe *et al.* (2013) reported the importance of decision-making for people with dementia in a facility by their family caregivers, and discussions with their family about future decisions is required. In our study, from the aspect of PHQ-9 and SF-8, the causal relationship between mental health and LST was not statistically significant. However, HOME Group participants had a high degree of depression and low QOL. If the number of people living together is less, the burden of nursing care will increase in terms of time and physical condition, it will be less likely to sympathize with the burden of nursing care, and longer care period will affect mental health and lead to physical fatigue. It is suggested that mental health indirectly affects LST preference.

When compared with the GHSF Group's LST, the HOME Group's LST preference was associated with several factors, such as sex, the number of people living together, comprehension of the doctors' explanation, and care duration, and we believe that it is necessary for healthcare providers to recognize this situation. The concept of LST preference refers to various discussions that may include conversations about hopes and fears, identification of surrogate medical decision-makers, clarification of specific interventions that a patient may wish to receive or forego, and completion of orders for LST (Dingfield and Kayser, 2017). Difficult decisions on receiving or avoiding treatments are often left to family members who may not know the patient's preferences or who may disagree with one another or with healthcare providers about an appropriate course of care (Boerner *et al.*, 2013). The findings of this study support the idea that healthcare providers need to discuss LST preferences with patients' family members to provide better support for decision-making.

This study had certain limitations. Our study areas were broadly distributed throughout Japan (northern, eastern, and western), but the attitudes of the participants in these areas (called

Table 4. Relevance of life-sustaining treatment (LST) preference in the HOME vs. geriatric health service facility (GHSF) groups (disease name not notified)

	HOME Group (N = 54) P-value Odds ratio (95% CI)	GHSF Group (N = 71) P-value Odds ratio (95% CI)
Sex	0.431 0.493 (0.085–2.858)	0.758 0.806 (0.204–3.181)
Age	0.198 0.945 (0.867–1.030)	0.247 0.957 (0.889–1.031)
Marital status	0.820	0.819
Unmarried vs. Married	0.600 2.106 (0.130–34.192)	0.417 3.329 (0.182–60.886)
Unmarried vs. Divorced	0.351 5.920 (0.142–247.604)	0.346 4.666 (0.190–114.614)
Unmarried vs. Widowed	0.871 1.412 (0.022–90.761)	0.426 4.279 (0.119–153.431)
Number of people living together	0.034* 0.331 (0.119–0.922)	0.069 0.478 (0.216–1.059)
Care duration	0.046* 0.975 (0.950–1.000)	0.975 1.000 (0.991–1.009)
Comprehension degree of doctor's explanations:	0.658	0.363
Sufficient vs. Some	0.654 1.463 (0.276–7.747)	0.074 3.555 (0.884–14.302)
Sufficient vs. Not very well	0.245 7.117 (0.260–195.135)	–
Sufficient vs. Never	0.644 2.494 (0.052–120.192)	–

CI, Confidence Interval.

*P < 0.05.

Table 5. Who should make decisions for the patient's EOL and LST choices?

Preference	HOME Group	GHSF Group	Total
Patient	89	38	127
	30.9%	13.1%	22.0%
Family	110	171	281
	38.2%	59.2%	48.7%
Physician	30	28	58
	10.4%	9.7%	10.1%
Not sure	51	43	94
	17.7%	14.9%	16.3%
Other	8	9	17
	2.8%	3.1%	2.9%

EOL, end of life; GHSF, geriatric health service facility; LST, life-sustaining treatment.

wards or municipalities) may differ from those of participants in the rural areas. In addition, many people may not directly face LST situations, and individuals' understanding of LST may differ. Levinson et al. (2017) found that elderly patients poorly understood the concept of resuscitation and predominantly relied on television and print media to shape their understanding; furthermore, this understanding may be inconsistent with their actual values and preferences.

The difference in background between the families who chose home care and those who chose GHSF residence may

be related to our results. In addition, the contents of explanation provided by medical professionals about LST and timing of talk may affect the patient's family's preference. Although PHQ-9 and SF-8™ were used in this study, it is possible that their mental statuses were different when they decided on LST. People with mental illness were excluded as participants, but it is possible that other family members may have mental illness or other serious illness and may have chosen GHFS. Furthermore, this study was based on a self-reported questionnaire. Therefore, further validation of the items through a quantitative study is required to obtain information that is more detailed.

Conclusion

This study showed that there were different opinions regarding LST preference between home caregivers' and GHSF residents' families. We asked family members about their LST preferences when their patients were being cared for at home or in a GHSF. Our results suggest that factors such as "the number of people living together," "nursing care duration," and "the degree of understanding of doctor's explanation" were related to LST preference of patients. When compared with GHSF residents' families, home caregivers' families may face a greater burden of nursing care that may also be harder to provide. Thus, healthcare providers need to discuss patients' LST preferences considering this study's findings.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951521001401>.

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Conflict of interest. The authors declare that there is no conflict of interest.

Ethics approval and consent to participate. This study was approved by the Human Subjects Institutional Review Board of Nihon University Itabashi Hospital Clinical Research Judging Committee (Approval No. RK-151213-3). The study was conducted in accordance with the principles embodied in the Declaration of Helsinki. Informed consent was obtained from all participants.

Consent for publication. Informed consent was obtained from all participants.

Availability of data and materials. All data generated or analyzed during this study are included in this published article (and its supplementary information files).

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