

# Comparison of the factors associated with preference of life-sustaining treatment by caregivers' and health facility tenants' families: a cross-sectional study

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## Research article

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2 **caregivers' and health facility tenants' families: a cross-sectional study**

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## 25 **Abstract**

26 **Background:** Recently, advance care planning (ACP) in palliative care has been attracting  
27 attention in Japan. The Japanese counterpart was established by the Ministry of Health, Labor  
28 and Welfare in November 2018. Moreover, discussions on end-of-life treatment are  
29 important part of ACP It is suggested that individual feelings at the end-of-life are different;  
30 ACP depends on various situations. Decision making by patients themselves is  
31 recommended; however, there are cases where patients with dementia or other disorders  
32 cannot make decisions by themselves. Health providers may contact surrogates and consider  
33 their background for better ACP. We focused on patents' families and examined factors  
34 related to the preferences of home caregivers' and old-age health facility tenants' families on  
35 patient ACP, including life-sustaining treatment (LST) at end-of-life.

36 **Methods:** This cross-sectional study involved home caregivers' and old-age health facility  
37 tenants' families in Japan. We distributed 925 self-reported questionnaires comprising items  
38 such as number of people living together, comprehension of doctor's explanations, nursing  
39 care level and duration, the Patient Health Questionnaire (PHQ)-9 and Short Form (SF)-8,  
40 and caregivers' LST preference.

41 **Results:** A valid response was obtained from 619 respondents [242 men and 377 women (309  
42 in the home-care group, response rate = 61.1%; 310 in the facility-care group, response rate =  
43 74.0%)]. The mean age of the respondents was  $65.29 \pm 12.09$  years in the home-care group  
44 and  $63.24 \pm 10.39$  years in the facility-care group. LST preference was significantly

45 associated with sex, number of people living together, care duration, and comprehension of  
46 doctors' explanations in the home-care group but was not significantly associated in the  
47 facility-care group. Furthermore, PHQ-9/SF-8 scores were not significantly associated with  
48 LST preference of the groups.

49 **Conclusions:** Factors associated with decision on ACP differed between home caregivers'  
50 families and health facility tenants' families. In ACP, healthcare providers should be aware of  
51 the nature of each patient's caregiving situation and living environment when discussing LST  
52 preference.

53

54 **Keywords:** advance care planning, life-sustaining treatment, home caregiving, old-age health  
55 facility

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58

## 59 **Background**

60 Advance care planning (ACP) interventions help elicit a person's wishes for and maintain  
61 control over their end-of-life (EOL) care to ensure that those wishes are respected [1]. ACP  
62 has been attracting attention in Japan in recent years, and the Japanese counter-part was  
63 established by the Ministry of Health, Labor and Welfare in November 2018. Moreover,  
64 discussions on EOL treatment are also an important part of ACP. Despite widespread  
65 endorsement of ACP, few people discuss future treatment wishes with loved ones and  
66 healthcare professionals or record them in an advance directive [2–4]. Previous studies have  
67 found a mismatch between patient preferences and the care provided at the EOL when  
68 healthcare professionals make the decision about care [5, 6]. A systematic review of ACP  
69 highlighted that people with dementia are far less likely to have any form of ACP [7].  
70 Therefore, surrogates are frequently called upon to make healthcare decisions on behalf of the  
71 patient.

72 It has been revealed that there is considerable complexity in undertaking ACP in the context  
73 of dementia [8]. When a person has moderate-to-severe dementia, it is difficult to assess  
74 whether they have decision-making capacity for advance directives and other EOL care.

75 For several surrogates, this experience has a negative emotional effect [9]. Surrogates are  
76 expected to use their judgment concerning the type of decisions that the patient would prefer  
77 on the basis of their knowledge of the patients' values and preferences [9, 10]. In addition,  
78 numerous studies have shown substantial inaccuracy in the proxy predictions of patient  
79 preferences for healthcare [11]. Surrogate decision-makers are often unprepared to apply  
80 substituted judgment or the best-interest standard to decision making on behalf of the patient.  
81 The surrogate may pursue nonbeneficial treatment because they are unaware of the patient's  
82 preferences or grappling with their own complex emotions [12]. In response to situations like

83 this, ACP has been promoted as a mechanism to guide families and care providers in making  
84 decisions that an incapacitated patient would have made when he or she was still able to [13].  
85 Under such circumstances, there are cases in which elderly patients are cared for at homes  
86 and facilities. For families, taking care of a frail older adult may present challenges for both  
87 their next of kin and health services [14].

88 In Japan, several aged patients are in old-age health facilities, such as nursing homes, and it is  
89 expected that the number of elderly people in these facilities will increase. As the number of  
90 older adults in assisted living facilities (ALFs) increases, the number of people who die in  
91 these facilities is also expected to increase. Limited data exist on the number of older adults  
92 with advance directives living in ALFs. The findings from one survey of ALFs reported that  
93 48%–69% of deceased ALF residents had an advance directive; however, family members  
94 reported much higher estimates (91%–97%) [15]. There are now some data suggesting that  
95 ACP interventions in nursing homes and long-term care settings can reduce unnecessary, and  
96 sometimes traumatic, hospitalizations of frail older adults [16, 17].

97 Many families are expected to be surrogates for decision making when the intention of  
98 patients cannot be adequately expressed due to brain disorders, including dementia. In  
99 addition, it is expected that the number of elderly people staying in healthcare facilities will  
100 increase, and decision making in various scenarios can be considered. Previous studies [18–  
101 21] have reported the relationship between ACP and mental health, such as anxiety and  
102 depression. We hypothesized that the differences in environmental conditions, relationship  
103 with the physician, quality of life (QOL), and mental health among home caregivers' and old-  
104 age health facility tenants' families would affect decision making. Therefore, the purpose of  
105 this study was to examine factors influencing the preferences of home caregivers' and old-  
106 age health facility tenants' families on a patient's ACP.

107

108 **Methods**

109 This study was approved by the Human Subjects Institutional Review Board of Nihon  
110 University Itabashi Hospital Clinical Research Judging Committee (Approval No. RK-  
111 151213-3). The study was conducted in accordance with the principles embodied in the  
112 Declaration of Helsinki.

113 The purpose and contents of the questionnaires were explained to potential participants.  
114 Informed consent was obtained from all participants. Participants were asked to anonymously  
115 complete the questionnaire and return it in a sealed envelope to our research partners. If there  
116 were one or more questionnaire items that participants did not wish to answer, they were  
117 asked to return the questionnaire partly or completely unanswered.

118

119 ***Participants***

120 We sent questionnaires via mail to the co-operating staff members of two home-visit  
121 clinics and four geriatric health service facilities located in six different prefectures. The co-  
122 operating staff members distributed the questionnaires to 506 caregivers' and 419 old-age  
123 health facility tenants' families.

124

125 ***Instruments***

126 Each anonymous questionnaire contained an explanation of its purpose and content. The  
127 questionnaire [Additional file 1] included items on family demographics, care duration  
128 (month), case assessed code, comprehension level of doctor's explanations regarding the  
129 patients' conditions and diseases, whether the family had or had not told the patient what

130 disease he or she had, degree of nursing care, and life-sustaining treatment (LST) preference.

131 The questionnaire package also included the Short Form (SF)-8 [22–24] and Patient Health

132 Questionnaire (PHQ)-9 [25].

133 The following case assessed codes based on the Japanese long-term care insurance system were

134 employed:

135 Necessary support 1: require social support

136 Necessary support 2: require support for life

137 Nursing care 1: require partial care

138 Nursing care 2: require mild care

139 Nursing care 3: require moderate care

140 Nursing care 4: require severe care

141 Nursing care 5: require the most severe care (almost bedridden condition)

142

143 PHQ is a self-administered version of the PRIME-MD diagnostic instrument for common

144 mental disorders [25]. PHQ-9 is the depression module that scores the 9 DSM-IV criteria

145 from “0” (not at all) to “3” (nearly every day).

146 SF-8™, an eight-item survey that assesses health-related quality of life (HRQOL), is widely

147 used to evaluate allopathic treatment modalities and has been used in Japanese studies [24].

148 This instrument calculated eight health concepts: physical functioning (PF), role physical

149 (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning, role emotional

150 (RE), and mental health (MH). PF, RP, BP, and GH assess the physical aspects of HRQOL

151 and provide a physical component summary, whereas VT (social functioning), RE, and MH

152 assess the mental or psychosocial aspects of HRQOL and provide a mental component  
153 summary. The scoring was based on Japanese standards, and the scores ranged from 0 to 100;  
154 higher scores indicated better QOL. This scoring system is available in the SF-8™ manual  
155 [24] and was provided by the Institute for Health Outcome and Process Evaluation Research.

156

### 157 *Data collection*

158 We asked 925 participants (home-care group, 506; facility-care group, 419) to anonymously  
159 complete the questionnaire and return it in a sealed envelope to the co-operating staff  
160 members. Our acceptance criteria were as follows: participants should be  $\geq 20$  years old, be an  
161 integral part of a caregiving family, be able to answer the questions by themselves, and  
162 understand the purpose of this study. If there were one or more questionnaire items that  
163 participants did not wish to answer, they were asked to return the questionnaire partly or  
164 completely unanswered. Our inclusion criterion was that the questionnaire should be  
165 attempted by recipients (incomplete entries were accepted). Unresponsive participants and  
166 completely unlisted questionnaires were excluded.

167 A total of 619 returned questionnaires were judged as valid and included in the analyses.

168

### 169 *Data analysis*

170 All analyses were performed by a statistician at the Japan Institute of Statistical  
171 Technology using SPSS (ver. 20; IBM, Tokyo, Japan). We divided the participants into four  
172 groups: home caregivers (disease name-notified), home caregivers (disease name-NOT-  
173 notified), health facility tenants (disease name-notified), and health facility tenants (disease  
174 name-NOT-notified); disease name-notified means that the patient was notified their disease

175 name, and disease name-NOT-notified means that the patient was not notified their disease  
176 name. Further, chi-squared test and t-test were performed to determine significant  
177 differences. The data were summarized and analyzed via binominal logistic regression  
178 analysis with the home caregivers' and health facility tenants' families' answers of "not  
179 prefer" or "prefer" LST as the objective variable, and the regression coefficient of each item  
180 and its test result was obtained. The significance level was set at  $P < 0.05$ . The SF-8 scoring  
181 was based on the Manual of the SF-8 Japanese Version [24].

182

## 183 **Results**

### 184 *Demographic characteristics*

185 A valid response was obtained from 619 respondents (response rate = 66.7%; 242 men and  
186 377 women [309 in the home-care group, response rate = 61.1%; 310 in the facility-care  
187 group, response rate = 74.0%]). The mean age of the respondents was  $65.29 \pm 12.09$  years in  
188 the home-care group and  $63.24 \pm 10.39$  years in the facility-care group. The age among the  
189 home-care group was significantly higher ( $P = 0.026$ ) than that among the facility-care group.

190 The proportion of individuals living alone was significantly higher in the facility-care  
191 group (17.0%) than in the home-care group (5.5%;  $P < 0.0001$ ).

192 The mean care duration was  $73.63 \pm 95.32$  months in the home-care group and  
193  $58.40 \pm 84.78$  months in the facility-care group. The level of comprehension of the  
194 explanation by the physician of the patient's condition was "sufficient" in 63.6% (home-care  
195 group) and 66.9% (facility-care group), "sure" in 27.7% (home-care group) and 25.9%  
196 (facility-care group), and "not very well" in 5.3% (home-care group) and 2.6% (facility-care  
197 group), but the difference was not significant.

198           There were no significant differences in the age and sex of the patients between the  
199 groups, as answered by the participants who had only one patient (this condition applies to a  
200 question of dementia symptom). The level of care among the patients was significantly higher  
201 in the facility-care group than in the home-care group ( $P < 0.0001$ ). The rate of cancer as a  
202 main disease among the patients was significantly higher in the home-care group (5.9%) than  
203 in the facility-care group (1.7%;  $P = 0.018$ ). The rate of dementia symptom among patients  
204 was significantly higher in the facility-care group (73.2%) than in the home-care group  
205 (62.3%;  $P = 0.007$ ).

206

#### 207 ***Disease notification***

208           The rate of disease notification for patients was not significantly different between the  
209 groups (home-care group, 67.2%; facility-care group, 59.7%).

210

#### 211 ***Preference for decision making***

212           Table 1 shows the preferences of participants for decision making. The preference for  
213 decision making by the patients themselves was significantly higher than that by a family  
214 member in the home-care group ( $P < 0.0001$ ).

215

216

217

218

219

220 Table 1. How would you like to decide on life-sustaining treatment?

221 Facility-care group ( $P = 0.000$ )

Preference	Care location		
	Home	Facility	Total
<b>Patient</b>	89	38	127
	30.9%	13.1%	22.0%
<b>Family</b>	110	171	281
	38.2%	59.2%	48.7%
<b>Physician</b>	30	28	58
	10.4%	9.7%	10.1%
<b>Not sure</b>	51	43	94
	17.7%	14.9%	16.3%
<b>Other</b>	8	9	17
	2.8%	3.1%	2.9%
	288	289	577
	100.0%	100.0%	100.0%

222

223

224

225

226 ***PHQ-9 score***

227 The mean PHQ-9 score of the participants was significantly higher (more depressive) in  
228 the home-care group (mean =  $13.57 \pm 5.34$ ) than in the facility-care group (mean =  $12.48 \pm$   
229  $4.57$ ;  $P = 0.012$  by t-test).

230

231 ***SF-8 score***

232 Health-related QOL determined by the SF-8 total score of participants was significantly  
233 lower in the home-care group than in the facility-care group ( $P < 0.0001$  by t-test). The scores  
234 for the SF-8 subscales (GH, PF, RP, BP, social functioning, MH, and RE) were significantly  
235 lower in the home-care group ( $P = 0.028$ ,  $P = 0.033$ ,  $P < 0.0001$ ,  $P = 0.048$ ,  $P < 0.0001$ ,  $P =$   
236  $0.001$ , and  $P < 0.0001$ , respectively). Only one subscale, vitality, was not significant ( $P =$   
237  $0.051$ ).

238

239 ***Factor associated with LST preference in disease-notified group***

240 We used binomial logistic regression analysis to analyze the factors associated with the  
241 preference for the patient's LST among participants in disease-notified group. There was no  
242 significant difference in preference for PHQ-9 and SF-8 among the participants.

243 The preference for the patient's LST among participants was significantly associated  
244 with sex, number of people living together, and comprehension of the doctors' explanations  
245 of the patients' conditions in the home-care group (Table 2). The degree of preference for the  
246 patient's LST among women participants was significantly smaller than that among men. The  
247 degree of preference for the patient's LST among participants significantly reduced with the  
248 increase in the number of people living together. The comprehension of the doctor's

249 explanation significantly increased the degree of choosing “preference for LST” among  
 250 participants who selected “not very well” than among those who selected “sufficiently.”  
 251 However, there were no significant associations with any items in the facility-care group  
 252 (Table 3).

253 Table 2. Relevance of LST preference in the **home-care** (disease name-notified) group

	<i>P</i> value	Odds ratio (95% CI)
<b>Sex</b>	0.018*	0.240 (0.074–0.786)
<b>Age</b>	0.080	1.047 (0.994–1.103)
<b>Marital status:</b>	0.283	
<b>-Unmarried vs. married</b>	0.899	1.132 (0.165–7.779)
<b>-Unmarried vs. divorced</b>	0.165	5.054 (0.515–7.779)
<b>-Unmarried vs. widowed</b>	0.622	2.230 (0.092–54.012)
<b>Number of people living together</b>	0.034*	0.444 (0.209–0.942)
<b>Care duration</b>	0.403	0.997 (0.991–1.004)
<b>Comprehension degree of doctor’s explanations:</b>	0.180	
<b>-Sufficiently vs. some</b>	0.559	1.455 (0.414–5.113)
<b>-Sufficiently vs. not very well</b>	0.027*	11.937 (1.320–107.925)

254 \**P* < 0.05

255 Table 3. Relevance of LST preference in the **facility-care** (disease name-notified) group

	<b>P value</b>	<b>Odds ratio (95% CI)</b>
<b>Sex</b>	0.329	0.525 (0.143–1.918)
<b>Age</b>	0.220	1.054 (0.969–1.147)
<b>Marital status:</b>	0.715	
<b>-Unmarried vs. married</b>	0.259	0.378 (0.070–2.047)
<b>-Unmarried vs. divorced</b>	0.837	0.725 (0.034–15.51)
<b>-Unmarried vs. widowed</b>	0.999	
<b>Number of people living together</b>	0.874	1.043 (0.617–1.764)
<b>Care duration</b>	0.677	1.003 (0.990–1.016)
<b>Comprehension degree of doctor's explanations:</b>	0.956	
<b>-Sufficiently vs. some</b>	0.769	1.224 (0.319–4.699)
<b>-Sufficiently vs. not very well</b>	0.997	0.995 (0.081–12.265)

256

257 ***Factor associated with LST preference in disease-NOT-notified group***

258 We used binomial logistic regression analysis to analyze the factors related to preference  
259 for the patient's LST among participants in disease-NOT-notified group. There was no  
260 significant difference in preference for the PHQ-9 and SF-8 among the participants. The  
261 preference for the patient's LST among participants was significantly associated with the  
262 number of people living together and care duration in the home-care group (Table 4). The  
263 degree of preference for the patient's LST among participants significantly reduced with the

264 increase in the number of people living together. As long as the nursing care duration was  
 265 longer, “preference for LST” among participants became smaller. However, there were no  
 266 significant associations with any items in the facility-care group (Table 5).

267

268 Table 4. Relevance of LST preference in the **home-care** (disease name-**NOT**-notified) group

	<i>P</i> value	Odds ratio (95% CI)
<b>Sex</b>	0.431	0.493 (0.085–2.858)
<b>Age</b>	0.198	0.945 (0.867–1.030)
<b>Marital status: unmarried</b>	0.820	
-Unmarried vs. married	0.600	2.106 (0.130–34.192)
-Unmarried vs. divorced	0.351	5.920 (0.142–247.604)
-Unmarried vs. widowed	0.871	1.412 (0.022–90.761)
<b>Number of people living together</b>	0.034*	0.331 (0.119–0.922)
<b>Care duration</b>	0.046*	0.975 (0.950–1.000)
<b>Comprehension degree of doctor’s explanations:</b>	0.658	
-Sufficiently vs. some	0.654	1.463 (0.276–7.747)
-Sufficiently vs. not very well	0.245	7.117 (0.260–195.135)
-Sufficiently vs. never	0.644	2.494 (0.052–120.192)

269 \**P* < 0.05

270

271 Table 5. Relevance of LST preference in the **facility-care** (disease name-**NOT**-notified) group

	<i>P</i> value	Odds ratio (95% CI)
<b>Sex</b>	0.758	0.806 (0.204–3.181)
<b>Age</b>	0.247	0.957 (0.889–1.031)
<b>Marital status:</b>	0.819	
<b>-Unmarried vs. married</b>	0.417	3.329 (0.182–60.886)
<b>-Unmarried vs. divorced</b>	0.346	4.666 (0.190– 114.614)
<b>-Unmarried vs. widowed</b>	0.426	4.279 (0.119– 153.431)
<b>Number of people living together</b>	0.069	0.478 (0.216–1.059)
<b>Care duration</b>	0.975	1.000 (0.991–1.009)
<b>Comprehension degree of doctor's explanations:</b>	0.363	
<b>-Sufficiently vs. some</b>	0.074	3.555 (0.884–14.302)

272

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

274 The tendencies of the odds ratios for PHQ-9/SF-8 scores of participants (home-care  
275 group, PHQ-9/SF-8 =.916/1.034; facility-care group, PHQ-9/SF-8 = 1.029/.937), indicating a  
276 preference for LST, were not significantly different between the groups.

277

278 **Discussion**

279 We hypothesized that the differences in environmental conditions, relationship with the  
280 physician, QOL, and MH among home caregivers' and old-age health facility tenants'  
281 families would affect decision making. We classified the patients into home-care and facility-  
282 care groups. A home-care group may show greater respect for the patient's autonomy in  
283 activities of routine life. The percentage of patients with dementia was higher in the facility-  
284 care group (possibly because families place more severely affected patients in a facility) than  
285 in the home-care group, which indicates that there are difficulties in discussing ACP in  
286 advance because of dementia. In addition, respondent's age was higher in the home-care  
287 group than in the facility-care group, and aging makes care a greater burden. The home-care  
288 group had more number of patients with depression and lower QOL, which may be because  
289 of the daily care burden. To reduce the burden on caregivers themselves, it may be useful to  
290 encourage greater patient autonomy.

291 With regard to the preference for the patient's LST among participants, the number of  
292 people living together, sex, comprehension level of the doctors' explanations of the patients'  
293 conditions, and care duration were factors that were significantly associated with LST  
294 preference in the home-care group, but there were no significant associations with any factors  
295 in the facility-care group. These findings suggest that the home caregiver's preferences are  
296 influenced by giving 24-h care, which may increase the caregiver's distress. Longer care  
297 duration may reflect increased burden. In addition, the difficulty of care may be higher for  
298 home caregivers than for facility caregivers.

299 We found a significant difference in the relationships between LST preference and the  
300 PHQ-9/SF-8 scores between the home-care and facility-care groups. In the home-care group,

301 higher (more depressive) PHQ-9 scores were associated with lower LST preference, whereas  
302 in the facility-care group, higher PHQ-9 scores were associated with higher LST preference.  
303 The relationships between the SF-8 score and LST preference were also different between the  
304 home-care and facility-care groups. In the home-care group, higher SF-8 scores were  
305 associated with higher LST preference, whereas in the facility-care group, higher SF-8 scores  
306 were associated with lower LST preference. These results indicate that the factors influencing  
307 ACP differ depending on the patient's living environment and extent of care needed. The  
308 concept of ACP refers to a wide range of discussions that may include conversations about  
309 hopes and fears, identification of surrogate medical decision-makers, clarification of specific  
310 interventions a patient may wish to receive or forego, and completion of orders for life-  
311 sustaining therapy [26].

312 A substantial majority of patients at EOL cannot make treatment decisions for  
313 themselves owing to their physical deterioration or mental incapacity [9, 27–31]. In addition,  
314 caregivers worldwide prefer LSTs more than terminally ill cancer patients [27, 32–36]. A  
315 patient's healthcare experience, including the use of intensive life-sustaining procedures, may  
316 affect the health and well-being of family members [37, 38]. Surrogate decision making for  
317 seriously/terminally ill patients has been shown to be a challenging and emotionally  
318 tumultuous task [9]. Accurately understanding patients' preferences for EOL care can buffer  
319 the psychological burden of surrogate decision making [9, 39]; however, surrogates  
320 frequently do not accurately know their loved ones' treatment preferences [11]. With regard  
321 to the types of surrogates, Ouslander, et al. [40] reported that compared with healthcare  
322 providers, family members make more accurate decisions, and Parks, et al. [41] reported that  
323 compared with other relations, spouses make more accurate decisions. Furthermore, Schmid,  
324 et al. [42] suggested that compared with White surrogates, African–American surrogates may  
325 make more accurate decisions. Without accurately understanding patients' EOL care

326 preferences, family members and other surrogates often project their own preferences to  
327 shape the EOL care actually received by terminally ill patients [43–46]. Family caregivers of  
328 individuals with serious illness who undergo intensive life-sustaining medical procedures at  
329 EOL may be at risk of negative consequences, including depression [47]. Compared with the  
330 spouses of patients not undergoing intensive life-sustaining procedures, surviving spouses of  
331 those undergoing such procedures at EOL experience a greater increase in depressive  
332 symptoms [10]. Boerner, et al. [48] reported that the families that are best equipped to make  
333 collaborative decisions about EOL care and the distress associated with bereavement are  
334 precisely individuals who engage in ACP in the first place and have a high level of family  
335 functioning. Conversely, people who exhibit low levels of family functioning, including  
336 problematic decision making and communication styles, are the least likely to engage in  
337 ACP. There are families with patients, such as those with dementia, who cannot make  
338 decisions on their own, and ACPs are often required for unavoidable reasons. In a study on a  
339 similar theme as ours, Poppe, et al. [49] reported the importance of ACP for people with  
340 dementia and their family caregivers and noted that especially for patients in a facility  
341 suffering from dementia, discussions with the patient’s family about future ACP is required.  
342 In addition, we actually investigated the difference in LST preference between the facility-  
343 care patients’ and home caregivers’ families.

344         Difficult decisions about accepting or rejecting treatments are often left to family  
345 members who may not know the patient’s preferences or who may disagree with one another  
346 or with healthcare providers about an appropriate course of care [48]. In a study on surrogate  
347 decision-makers’ understanding of dementia patients using semistructured interviews with  
348 family members, many participants did not prefer the patients being kept alive by “machines”  
349 or “extraordinary measures” for EOL care [50]. Winter and Parks [51] reported that LST  
350 preference depends on patients’ condition; surrogates of healthy elders preferred more LST

351 compared with the surrogates of poor health elders. Moreover, stronger preferences for LST  
352 were expressed by non-Whites [51]. This study included 202 surrogates and non-Whites  
353 including 63 African–Americans and three individuals who indicated no primary racial  
354 group. In our study, 619 participants were analyzed and all participants were Asian  
355 (Japanese). In addition, our study included not only home caregivers but also families with  
356 patients in facilities and compared the LST preferences of both of them. This revealed  
357 differences in the factors associated with LST preferences, depending on where patients were  
358 cared for, among those in need.

359       Considering various social and psychological aspects when healthcare providers talk  
360 about ACP, patients and their families may appreciate a provider’s recommendations for care  
361 that are based on family and patient input, when possible. Healthcare providers need to make  
362 efforts to make better ACP possible considering various circumstances of patients and their  
363 families.

364       This study had certain limitations. Our study areas were broadly distributed throughout  
365 Japan (northern, eastern, and western), but the attitudes of the participants in these areas  
366 (called wards or municipalities) may differ from those of participants in rural areas.  
367 Levinson, et al. [52] found that elderly patients poorly understood the concept of resuscitation  
368 and predominantly relied on television and print media to define their understanding; further,  
369 this understanding may be inconsistent with their actual values and preferences. In addition,  
370 many people may not directly face LST situations, and individual understandings of LST may  
371 differ. This study was based on a self-reported questionnaire; therefore, further validation of  
372 the items, such as by conducting a quantitative study, is required to obtain more detailed  
373 information.

374 ACP is progressing in Japan and other countries. However, as aging in the society  
375 progresses, mental problems, such as dementia and physical troubles, increase, and the  
376 patient's understanding ability may be an issue. Owing to the results of our study on ACP  
377 among patients' families, factors influencing ACP among the families were clarified among  
378 them; furthermore, a considerable difference was observed depending on the environment in  
379 which the patient lived.

380 There is a financial burden in placing patients in geriatric healthcare facility, and under  
381 home-care, physical and mental burden is high. Moreover, a significant difference in  
382 consciousness toward ACP was observed. Compared with the facility-care group, the home-  
383 care group is considered affected by ACP owing to various factors, and we believe that it is  
384 necessary for medical providers to recognize this situation. Thus, the findings of this study  
385 suggest that healthcare providers need to discuss ACP with the patient's family to provide  
386 better support for ACP.

387

### 388 **Conclusions**

389 There are different opinions about ACP between home caregivers' and old-age health facility  
390 tenants' families. Healthcare providers need to consider the type and extent of a patient's care  
391 and their living environment when discussing ACP with a patient's family.

392

### 393 **List of abbreviations**

394 ACP: Advance care planning

395 ALF: Assisted living facilities

396 BP: Bodily pain

397 EOL: End-of-life  
398 GH: General health  
399 HRQOL: Health-related quality of life  
400 LST: Life-sustaining treatment  
401 MH: Mental health  
402 PF: Physical functioning  
403 QOL: Quality of life  
404 RE: Role emotional  
405 RP: Role physical

406  
407

408 **Declarations**

- 409 • **Ethics approval and consent to participate:** This study was approved by the Human  
410 Subjects Institutional Review Board of Nihon University Itabashi Hospital Clinical  
411 Research Judging Committee (Approval No. RK-151213-3). The study was conducted  
412 in accordance with the principles embodied in the Declaration of Helsinki. Informed  
413 consent was obtained from all participants.
- 414 • **Consent for publication:** Informed consent was obtained from all participants.
- 415 • **Availability of data and materials:** All data generated or analyzed during this study  
416 are included in this published article [and its supplementary information files].
- 417 • **Competing interests:** The authors declare that they have no competing interests.

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