

RESEARCH PAPER

Family social support and stability of preferences regarding place of death among older people: a 3-year longitudinal study from the Japan Gerontological Evaluation Study

KENJIRO KAWAGUCHI¹, KAZUSHIGE IDE¹, KATSUNORI KONDO^{1,2}

¹Department of Social Preventive Medical Sciences, Center for Preventive Medical Sciences, Chiba University, Chiba 260-8670, Japan

²Department of Geriatric Evaluation, Center for Gerontology and Social Science, National Center for Geriatrics and Gerontology, Obu 474-8511, Japan

Address correspondence to: Kenjiro Kawaguchi. Email: kkawaguchi0413@gmail.com

Abstract

Background: it remains unclear how family relationships could affect stability of end-of-life care preferences.

Objective: to describe change patterns of preferred place of death (POD) among older people and to examine associations between family social support and stability of preferences regarding POD.

Methods: this longitudinal study of 1,200 noninstitutionalized independent Japanese older people aged over 65 years used panel data between 2016 and 2019 from the Japan Gerontological Evaluation Study (JAGES). Preference stability was defined as the congruence of preferred POD based on questionnaires between baseline and follow-up. We performed multiple logistic regression analysis and gender-stratified analysis to examine associations between social support (spouse, children living together and children living apart) and preference stability.

Results: only 40.9% of participants had stable preferences. For a spouse, both receiving and providing social support was associated with less stable preferences (OR: 0.63, 95% CI: 0.43–0.93; OR: 0.55, 95% CI: 0.38–0.80, respectively), and providing social support to children living apart was associated with more stable preferences (OR: 1.35, 95% CI: 1.03–1.76). In gender-stratified analysis, significant associations between preference stability and providing social support to a spouse among women (OR: 0.53, 95% CI: 0.34–0.82) and providing social support to children living apart among men (OR: 1.72, 95% CI: 1.16–2.55) were observed.

Conclusions: family social support was associated with the stability of preferences, and the associations differed by support resources and gender. Incorporating family members in the process of end-of-life care discussion may be necessary for establishing stable preferences.

Keywords: social support, place of death, preferences, older people, end of life care

Key Points

- Only 40% of older people had stable preferences regarding place of death over three years.
 - For women, providing social support to a spouse was associated with less stable preferences.
 - For men, providing social support to children living apart was associated with more stable preferences.
 - Preference stability may require periodic reassurance and family involvement in end-of-life care discussions.
-

Introduction

The world population is rapidly aging. The proportion of the world population aged over 65 years has risen from 6% to 9% between 1990 and 2019, and is expected to double by 2050 [1]. The rapid growth of the older population has raised concerns about care for older people, especially end-of-life (EOL) care.

Providing high-quality EOL care compatible with people's preferences and values is vital. To respect an individual's autonomy, experts in EOL care recommend identifying and sharing the individual's goals and preferences for EOL care, such as treatments and place of death (POD), through discussions with health care professionals [2]. Although properly understanding their preferences is essential for fulfilling them, preferences regarding EOL care can vary over time. Therefore, preferences should be elicited through iterative discussions on the premise of such changeability [3]. Meanwhile, fulfilling preferences depends on the assumption that they are somewhat stable [4, 5]. If individuals' preferences are too fluid and unstable, it is impossible to provide EOL care in the manner they truly wish. Thus, knowledge of the factors that can change preference stability would enable timely discussions and reassurance of preferences [6].

POD is an essential component in EOL care. Achieving individuals' preferred POD is significant to them, their family members, and their caregivers and is considered as a quality indicator of palliative care [7]. A systematic review indicated that family is the most influential environmental factor on care preferences of older people with advanced illnesses, and family-related concerns and the degree of family support available significantly affect their care preferences [8]. Therefore, the quality of family relationships may affect the stability of preferences for POD.

Social support is a qualitative aspect of social relationships [9]. It has two primary dimensions: emotional support (e.g. valuing, loving and caring for someone) and instrumental support (e.g. financial aid); moreover, it is bidirectional, that is, it involves receiving and providing support [10]. Family social support motivates people to commit to healthier behaviours for family members [11]. Moreover, people with family social support are likely to consider and discuss EOL care in advance [12] and may have more stable preferences for their family members' benefit. However, the associations between family social support and preference stability have not been well studied [8].

The effect of family social support on stability of EOL care preferences may vary according to gender. A systematic review demonstrated that women tended to withhold medical treatments at the end of their lives compared to men [13]. According to previous research, women with advanced cancers were more likely than men to prefer palliative care and to have do-not-resuscitate orders [14]. These findings indicate that individuals' attitudes toward EOL care may differ by gender [15]. However, the influence of gender on these relationships remains unknown.

This study aimed to describe change patterns of preferred POD over time among Japanese older people, to examine the associations between family social support and preference stability, and to investigate gender differences in the associations. A clear understanding of preference stability and the link between family social support and stability may enable more older people to fulfil EOL care preferences.

Method

Data sources

We used data from the Japan Gerontological Evaluation Study (JAGES) [16]. The JAGES is an ongoing prospective cohort study of the social determinants of health among noninstitutionalized adults aged over 65 years who are independent in activities of daily living. Surveys have been conducted to inquire about health habits, psychological factors and a broad range of social determinants almost every three years since 2003. We used data from the 2016 and 2019 waves. The self-reported survey questionnaires in both waves comprised the core questions and one of the eight modules randomly distributed to the participants [16]. Each module had unique questions, and one module featured a question about the preferred POD.

Participants

The questionnaires were mailed to 34,566 individuals in 2016 (at baseline) and 45,971 individuals in 2019 (at follow-up). The response rates were 64.4% ($n = 22,258$) and 54.0% ($n = 24,806$), respectively. Participants were informed that selecting an acceptance checkbox on the questionnaire and returning it would signify consent to participate. This study included 1,268 participants who answered questionnaires in both waves. Sixty-eight participants were excluded because of missing information on family social support at baseline. The final sample included 1,200 participants.

Outcome variable

The preferred POD was assessed using the following question: 'Where would you like to spend the last days of your life?' Responses were 'home,' 'hospital,' 'hospice,' 'nursing home,' 'assisted living facility' and 'unknown.' 'Nursing home' and 'assisted living facility' were combined into 'institution' in our analysis. Missing values were classified into the 'unknown' category. Stability of POD preferences was defined as the congruence between responses (except for unknown) at baseline and follow-up. The other combinations were categorised as unstable.

Explanatory variables

Social support was assessed using four items [10]: 'Do you have someone who listens to your concerns and complaints?' (Receiving emotional support), 'Do you listen to someone's concerns or complaints?' (Providing emotional support), 'Do

you have someone who looks after you when you are sick and confined to a bed for a few days?’ (Receiving instrumental support), and ‘Do you look after someone when he/she is sick and confined to a bed for a few days?’ (Providing instrumental support). Each item had seven possible response categories: spouse, children living together, children living apart, relatives, neighbours, friends and others. Participants were allowed multiple selections. As per this study’s scope, we limited social support resources to three family relationships: spouse, children living together and children living apart. Participants who answered ‘yes’ to the items of receiving emotional and/or instrumental support were defined as those who received social support. Likewise, providing emotional and/or instrumental support was unified into providing social support. Not receiving social support or providing social support were treated as reference categories.

Covariates

We included sociodemographic and health-related factors as possible confounders based on previous research [17, 18]. We decreased the number of categories for some categorical variables to avoid few observations per category.

Sociodemographic factors

Sociodemographic factors included age, educational attainment, marital status, living arrangements, equivalized household income and population density. Age was classified into four groups: 65–69, 70–74, 75–79 and ≥ 80 years. Educational attainment (years of education) was categorised into three groups: ≤ 9 years, 10–12 years and ≥ 13 years. Marital status was divided into married and single. Living arrangements were classified as living alone and living with others. Equivalized household income was calculated by dividing the normalised household gross income by the square root of the number of household members and was categorised into three groups: $< \$20,000$, $\$20,000$ – $39,999$ and $\geq \$40,000$ per year (1 dollar = 100 yen) [19]. Population density per km^2 of the inhabitable area was categorised into three groups: $< 1,000$, $1,000$ – $4,000$ and $> 4,000$ persons per km^2 [20].

Health-related factors

Health-related factors included depressive symptoms, self-rated health, self-reported medical conditions and instrumental activities of daily living (IADL). Depressive symptoms were assessed using the Japanese short version of the Geriatric Depression Scale (GDS) (score range: 0–15; higher scores indicated worse depressive symptoms) [21]. Depressive symptoms were dichotomized into two groups: no depression (GDS < 5) and depression (GDS ≥ 5) [22].

Self-rated health was assessed with a standard one-item rating: ‘How would you rate your health at present?’ Response categories (excellent, good, fair and poor) were dichotomized into good (excellent/good) and poor (fair/poor) [23]. Self-reported medical conditions were categorised into two groups: presence or absence [23]. IADL was

measured using the five-item Tokyo Metropolitan Institute of Gerontology Index of Competence [24], which examines five activities that people may perform in daily life: (i) using public transportation, (ii) shopping for daily necessities, (iii) preparing meals, (iv) paying bills and (v) handling their own banking. Individuals with a total score of five were considered independent, and those with a total score of less than five were dependent [25].

Statistical analysis

We performed descriptive statistics for the changes in preferences regarding POD. We conducted multiple logistic regression analysis to estimate the odds ratios (ORs) of preference stability regarding POD for social support and the 95% confidence intervals (CIs). In Model 1, we estimated the ORs for each social support variable. In Model 2, all social support variables were considered simultaneously. Additionally, after testing for interactions between gender and each social support using Model 1, we performed a gender-stratified analysis to examine these associations using Models 1 and 2. Furthermore, in gender-stratified analysis, we examined the associations between emotional or instrumental support and preference stability using Model 1.

Missing values and multiple imputation

Missing values across all variables ranged from 0 to 12.4% (equivalized household income). A total of 21.0% (252 of 1,200 participants) were incomplete, which can lead to biased or inefficient estimates. To address this issue, we performed multiple imputation by chained equations to impute incomplete variables, including the outcome variable, and created 40 imputed datasets. The estimates and standard errors were obtained for each imputed dataset separately using logistic regression analysis and combined with Rubin’s rules [26]. In a sensitivity analysis, we examined whether similar results were obtained by categorising the missing values on the preferred POD as ‘unknown’ responses (Model 1).

All analyses were performed using Stata/SE 16.0 (Stata-Corp, College Station, TX, USA). All *P*-values were two-sided, and the statistical significance level was set at a *P*-value < 0.05 .

Results

Table 1 presents the participants’ characteristics. The mean (standard deviation) age was 72.9 (5.4) years, and 52.5% were women. Of the participants, 429 (40.9%) had stable preferences.

Table 2 shows a comparison of the preferences regarding POD between baseline and 3-year follow-up stratified by gender. Hospital for women and home for men were the most consistent choices (59.4% and 59.2%, respectively). The preference for institution was the least stable over the

Table 1. Baseline characteristics of study participants

Variables	Categories	n (%)
Age (years)	65–69	391 (32.6%)
	70–74	363 (30.2%)
	75–79	282 (23.5%)
	≥80	164 (13.7%)
Gender	Women	630 (52.5%)
Education (years)	≤9	324 (27.0%)
	10–12	500 (41.7%)
	≥13	375 (31.3%)
Marital status	Single	293 (24.7%)
	Married	893 (75.3%)
Living arrangements	Living alone	151 (13.3%)
	Living with others	988 (86.7%)
Household income (\$ per year)	<20,000	484 (46.1%)
	20,000–39,900	439 (41.8%)
	≥40,000	128 (12.2%)
Population density (persons per km ²)	<1,000	219 (18.2%)
	≥1,000–4,000	382 (31.8%)
	>4,000	599 (49.9%)
Geriatric Depression Scale	No depression	934 (80.2%)
	Depression	231 (19.8%)
Instrumental activities of daily living	Dependent	78 (6.7%)
	Independent	1,090 (93.3%)
Self-rated health	Poor	108 (9.2%)
	Good	1,061 (90.8%)
Self-reported medical conditions	Absent	248 (21.7%)
	Present	894 (78.3%)
Receiving social support		
Spouse	Yes	865 (72.1%)
Children living together	Yes	397 (33.1%)
Children living apart	Yes	543 (45.3%)
Providing social support		
Spouse	Yes	868 (72.3%)
Children living together	Yes	379 (31.6%)
Children living apart	Yes	511 (42.6%)
Preferred place of death	Home	390 (36.0%)
	Hospital	248 (22.9%)
	Hospice	128 (11.8%)
	Institution	72 (6.6%)
	Unknown	245 (22.6%)

3 years among women and men. Only 216 (39.8%) women and 213 (42.2%) men had stable preferences.

Table 3 provides the results of the multiple logistic regression analysis for the associations between social support and preference stability regarding POD. In Model 1, for a spouse, both receiving and providing social support was significantly associated with less stable preferences (OR: 0.67; 95% CI: 0.46–0.96; OR: 0.58; 95% CI: 0.41–0.84). Providing social support to children living apart was significantly associated with more stable preferences (OR: 1.33; 95% CI: 1.02–1.73). In Model 2, adjusted for social support variables simultaneously with all covariates except marital status, we obtained comparable results to those in Model 1 (OR: 0.63; 95% CI: 0.43–0.93 for receiving social support from a spouse, OR: 0.55; 95% CI: 0.38–0.80 for providing social support to a spouse, and OR: 1.35; 95% CI: 1.03–1.76 for providing social support to children living apart). We

observed no significant interactions of each social support variable by gender (Table 3).

Table 4 presents the results of the gender-stratified analysis of the associations between family social support and preference stability. Women who provided social support to a spouse were 47–50% less likely to have stable preferences (Model 1, OR: 0.53; 95% CI: 0.34–0.82; Model 2, OR: 0.50; 95% CI: 0.32–0.79), whereas men who provided social support to children living apart were 72–73% more likely to have stable preferences (Model 1, OR: 1.72; 95% CI: 1.16–2.55; Model 2, OR: 1.73; 95% CI: 1.17–2.58). Regarding the two types of social support, providing instrumental support to a spouse was significantly associated with less stable preferences among women (OR: 0.59; 95% CI: 0.39–0.89), while providing emotional and instrumental support was significantly associated with more stable preferences among men (OR: 1.57; 95% CI: 1.04–2.36; OR: 2.06; 95% CI: 1.30–3.28, Table 5).

In our sensitivity analysis, the overall results were similar to those of the initial analyses. Exceptionally, borderline significant associations between providing social support to children living apart and preference stability were observed. Additionally, women receiving social support from a spouse were less likely to have stable preferences (Appendix Table 1 available in *Age and Ageing* online).

Discussion

This study showed that approximately 40% of the participants maintained their preferences during the 3-year follow-up period. Women with stable preferences tended to favour hospital as a POD, whereas men tended to favour home. After adjusting for confounders, for women, providing social support (emotional support) to a spouse was related to less stable preferences, whereas for men, providing social support (emotional and instrumental support) to children living apart was related to more stable preferences.

Inconsistent with our findings, a previous systematic review [27] reported that ~80% of study participants did not change their home death preferences. This may be because, first, our study participants were healthier—90% of them reported good self-rated health—than the participants in the systematic review. Meanwhile, the systematic review included relatively vulnerable patients, such as terminally ill patients. Another systematic review [5] suggested that seriously ill patients had more stable EOL care preferences than older people without serious illnesses. They may consider and answer questions about preferred POD more carefully because the questions may be more relevant to them. Second, this study's follow-up period was longer than that of previous studies. Generally, preferences are more likely to change during a longer follow-up period. Only few studies [28] had a follow-up period of more than 2 years because of participants' poor health status. Third, preference instability may stem from the unique characteristics of older Japanese people. A study [29] involving this population

Table 2. A comparison of preferences regarding POD between baseline and 3-year follow-up by gender

Women		Follow-up					
Baseline	Home	Hospital	Institution	Hospice	Unknown	Row total	
Home	78 (53.1%)	19 (12.9%)	4 (2.7%)	11 (7.5%)	35 (23.8%)	147 (100.0%)	
Hospital	8 (6.1%)	82 (62.1%)	7 (5.3%)	11 (8.3%)	24 (18.2%)	132 (100.0%)	
Institution	5 (6.4%)	20 (25.6%)	25 (32.1%)	9 (11.5%)	19 (24.4%)	78 (100.0%)	
Hospice	3 (5.5%)	11 (20.0%)	1 (1.8%)	31 (56.4%)	9 (16.4%)	55 (100.0%)	
Unknown	20 (15.3%)	24 (18.3%)	6 (4.6%)	15 (11.5%)	66 (50.4%)	131 (100.0%)	
Column total	114	156	43	77	153	543	
Men		Follow-up					
Baseline	Home	Hospital	Institution	Hospice	Unknown	Row total	
Home	141 (61.6%)	37 (16.2%)	1 (0.4%)	6 (2.6%)	44 (19.2%)	229 (100.0%)	
Hospital	23 (21.3%)	58 (53.7%)	2 (1.9%)	2 (1.9%)	23 (21.3%)	108 (100.0%)	
Institution	4 (8.5%)	23 (48.9%)	6 (12.8%)	4 (8.5%)	10 (21.3%)	47 (100.0%)	
Hospice	1 (5.9%)	3 (17.6%)	0 (0.0%)	8 (47.1%)	5 (29.4%)	17 (100.0%)	
Unknown	16 (15.4%)	22 (21.2%)	5 (4.8%)	6 (5.8%)	55 (52.9%)	104 (100.0%)	
Column total	185	143	14	26	137	505	

Table 3. Results for multiple logistic regression models of the association between social support and stability of preferences regarding POD

Social support	Model 1 ^a Odds ratio (95% CI)	Model 2 ^b Odds ratio (95% CI)	Gender * Social support ^c Odds ratio (95% CI)
Receiving social support			
No social support	Reference	Reference	Reference
Spouse ^d	0.67* (0.46–0.96)	0.63* (0.43–0.93)	1.37 (0.71–2.65)
Children living together	0.85 (0.63–1.15)	0.87 (0.64–1.17)	1.08 (0.61–1.92)
Children living apart	1.05 (0.81–1.37)	1.03 (0.79–1.34)	1.15 (0.69–1.90)
Providing social support			
No social support	Reference	Reference	Reference
Spouse ^d	0.58** (0.41–0.84)	0.55** (0.38–0.80)	1.65 (0.87–3.14)
Children living together	0.92 (0.68–1.25)	0.92 (0.68–1.25)	1.43 (0.81–2.53)
Children living apart	1.33* (1.02–1.73)	1.35* (1.03–1.76)	1.44 (0.87–2.38)

95% CI: 95% confidence interval. * $P < 0.05$. ** $P < 0.01$. ^aWe examined associations between each social support variable and stability of preferences regarding POD after adjusting for covariates (age, gender, education, marital status, living arrangements, household income, population density, GDS, IADL, medical conditions and self-rated health). ^bSocial support variables (spouse, children living together and children living apart) were simultaneously entered into the models with all covariates except marital status (age, gender, education, living arrangements, household income, population density, GDS, IADL, medical conditions and self-rated health). ^cGender * Social support represents an interaction term between gender and social support. The statistical significance of the interaction term was examined using Model 1. ^dThe marital status variable was not included in the models due to multicollinearity.

demonstrated that their wishes for EOL care frequently varied during short periods of interviews. They tend to entrust EOL decision-making to others, such as medical care providers [30], which may deprive them of opportunities to consider EOL issues earnestly and destabilise their preferences.

We found gender differences in the associations between social support and preference stability. Several previous studies [6, 17] reported that social support helped to stabilise EOL care preferences; however, gender was not considered.

In this study, women preferred hospital as POD, and when they provided social support to a spouse, their preferences were more likely to change. This may arise from concerns about being a burden on the family [31]. A national survey [32] reported that more than 70% of the general public recognised not being a burden on the family—a wish

that might arise from their caregiving experience—as the most important factor in choosing their POD. According to a national survey [33], women accounted for 65% of adults aged over 65 years who had cared for family members. Additionally, women caregivers reported greater caregiver burden [34], higher depressive symptoms [35] and poorer physical health [36–38] compared with men. Their unstable preferences might imply that they are conflicted between their true desires for EOL care and concerns about being a burden on their family [39].

Consistent with previous research, men were more likely than women to prefer home as POD [40, 41]. Men also had more stable preferences when providing social support to children living apart. This could be because men expect their children to provide EOL care as a reward for their social support [8]. Furthermore, providing social support

Table 4. Results for gender-stratified multiple logistic regression models of the association between social support and stability of preferences regarding POD

	Women		Men	
	Model 1 ^a Odds ratio (95% CI)	Model 2 ^b Odds ratio (95% CI)	Model 1 ^a Odds ratio (95% CI)	Model 2 ^b Odds ratio (95% CI)
Social support				
Receiving social support				
No social support	Reference	Reference	Reference	Reference
Spouse ^c	0.69 (0.45–1.07)	0.68 (0.43–1.09)	0.53 (0.25–1.12)	0.49 (0.23–1.05)
Children living together	0.95 (0.61–1.48)	0.96 (0.63–1.49)	0.78 (0.50–1.22)	0.78 (0.50–1.22)
Children living apart	0.98 (0.68–1.40)	0.96 (0.67–1.38)	1.21 (0.83–1.77)	1.20 (0.82–1.76)
Providing social support				
No social support	Reference	Reference	Reference	Reference
Spouse ^c	0.53** (0.34–0.82)	0.50** (0.32–0.79)	0.65 (0.33–1.32)	0.57 (0.28–1.16)
Children living together	0.88 (0.57–1.35)	0.84 (0.55–1.29)	1.02 (0.66–1.58)	1.00 (0.64–1.56)
Children living apart	1.10 (0.77–1.58)	1.10 (0.77–1.59)	1.72** (1.16–2.55)	1.73** (1.17–2.58)

95% CI: 95% confidence interval. ** $P < 0.01$. ^aWe examined associations between each social support variable and stability of preferences regarding POD after adjusting for covariates (age, education, marital status, living arrangements, household income, population density, GDS, IADL, medical conditions and self-rated health). ^bSocial support variables (spouse, children living together and children living apart) were simultaneously entered into the models with all covariates except marital status (age, education, living arrangements, household income, population density, GDS, IADL, medical conditions and self-rated health). ^cThe marital status variable was not included in the models due to multicollinearity.

Table 5. Results for gender-stratified multiple logistic regression models of the association between emotional or instrumental social support and stability of preferences regarding POD

	Receiving emotional social support	Providing emotional social support	Receiving instrumental social support	Providing instrumental social support
	Odds ratio (95% CI)	Odds ratio (95% CI)	Odds ratio (95% CI)	Odds ratio (95% CI)
Women				
No social support	Reference	Reference	Reference	Reference
Spouse ^a	0.75 (0.50–1.13)	0.74 (0.50–1.09)	0.71 (0.47–1.09)	0.59** (0.39–0.89)
Children living together	0.93 (0.61–1.44)	0.81 (0.52–1.25)	0.95 (0.61–1.47)	0.94 (0.61–1.45)
Children living apart	0.91 (0.63–1.30)	1.19 (0.82–1.72)	1.05 (0.73–1.51)	1.02 (0.70–1.49)
Men				
No social support	Reference	Reference	Reference	Reference
Spouse ^a	1.11 (0.65–1.88)	1.17 (0.71–1.92)	0.72 (0.36–1.43)	0.77 (0.46–1.29)
Children living together	0.83 (0.48–1.45)	0.92 (0.56–1.52)	0.84 (0.53–1.32)	1.25 (0.78–2.00)
Children living apart	0.98 (0.63–1.53)	1.57* (1.04–2.36)	1.35 (0.91–2.02)	2.06** (1.30–3.28)

95% CI: 95% confidence interval. We examined associations between each social support variable and stability of preferences regarding POD after adjusting for covariates (age, gender, education, marital status, living arrangements, household income, population density, GDS, IADL, medical conditions and self-rated health). * $P < 0.05$. ** $P < 0.01$. ^aThe marital status variable was not included in the models due to multicollinearity.

may make them feel valued and enhance their willingness to live [42, 43], which can lead to their preference for living at home until death. Additionally, a close parent–children relationship may motivate discussions about EOL care preferences [12] and solidify their preferences. We did not obtain significant results for children living together due to the lack of male participants who lived with their sons or daughters (22.2% and 16.7%, respectively, data not shown). Further research is required on this topic.

Our study suggests important implications for healthcare practices. Our findings support that healthy older people require periodic re-evaluation of their preferences for EOL care due to their fluctuating preferences [4, 44]. Our study also demonstrates how family social support is associated with preference stability. Healthcare professionals often regard family members as a threat to patient autonomy

and discuss preferences with patients in isolation [45]. However, it may be preferable to consider the family context and facilitate family members’ participation in EOL care discussions regardless of the individual’s decision-making capacity. Healthcare professionals are likely to play an essential role in addressing family concerns or resolving conflicts between an individual’s and family’s preferences in the triadic relationship of an individual, family and healthcare professionals [46, 47]. This may allow individuals to have more stable preferences and realise them.

The strengths of our study include the relatively large sample size and longer follow-up period compared with prior studies. Additionally, gender differences in the associations between social support and preference stability were investigated. Nonetheless, our study has certain limitations. First, we included physically independent older people. We

could have obtained different results from near-death participants. However, identification of an individual's preference through repeated discussions is recommended for people of any age or stage of health [48]. Understanding how preferences in healthier people fluctuate over time is beneficial. Second, we targeted only Japanese people, which may limit the generalizability of our findings [49]. Third, we examined the link between social support and preference stability by limiting the social support resources to family. As community engagement in EOL care is gaining interest [50], future studies should investigate how other social support resources influence preference stability. Lastly, we selected preferred POD as an EOL care preference because the 2019 wave did not contain other questionnaire items regarding EOL care preferences. Further research on other EOL preferences is required.

Conclusion

Only 40% of noninstitutionalized independent older people had stable preferences regarding POD over 3 years. Women providing social support to their spouses were less likely to have stable preferences, while men providing social support to children living apart were more likely to have stable preferences. To our knowledge, this is the first study to focus on the associations between family social support and preference stability and gender differences in their associations. Incorporating family members in discussions regarding individual's preferences about EOL care, including POD, may contribute to more stable preferences and their realisation.

Supplementary Data: Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

Acknowledgements: This study received ethics approval from the Ethics Committee of Chiba University Faculty of Medicine (No. 2493), the National Center for Geriatrics and Gerontology (No. 992) and Nihon Fukushi University (No. 10-05).

We are grateful to Dr Masashi Tanaka for useful discussions. We would also like to thank Editage (www.editage.com) for English language editing.

Declaration of Conflicts of Interest: None.

Declaration of Sources of Funding: This work was supported by Grant-in-Aid for Scientific Research (15H01972, 15H04781, 15H05059, 15K03417, 15K03982, 15K16181, 15K17232, 15K18174, 15K19241, 15K21266, 15KT0007, 15KT0097, 16H05556, 16K09122, 16K00913, 16K02025, 16K12964, 16K13443, 16K16295, 16K16595, 16K16633, 16K17256, 16K17281, 16K19247, 16K19267, 16K21461, 16K21465, 16KT0014, 17K04305, 17K04306, 25253052, 25713027, 26285138, 26460828, 26780328, 18H03018, 18H04071, 18H03047, 18H00953, 18H00955, 18KK0057, 19H03901, 19H03915, 19H03860, 19K04785, 19K10641,

19K11657, 19K19818, 19K19455, 19K24060, 19K20909, 20H00557) from JSPS (Japan Society for the Promotion of Science); Health Labour Sciences Research Grants (H26-Choju-Ippan-006, H27-Ninchisyu-Ippan-001, H28-Choju-Ippan-002, H28-Ninchisyu-Ippan-002, H30-Kenki-Ippan-006, H29-Chikyukibo-Ippan-001, H30-Jyunkankinado-Ippan-004, 19FA1012, 19FA2001, 21FA1012, 21K19635), Research project on health and welfare promotion for the elderly from the Ministry of Health, Labour and Welfare, Japan; the Research and Development Grants for Longevity Science from Japan Agency for Medical Research and development (AMED) (JP18dk0110027, JP18ls0110002, JP18le0110009, JP20dk0110034, JP21lk0310073, JP21dk0110037), the Research Funding for Longevity Sciences from National Center for Geriatrics and Gerontology (24-17, 24-23, 29-42, 30-30, 30-22, 20-19, 21-20); Open Innovation Platform with Enterprises, Research Institute and Academia (OPERA, JPMJOP1831) from the Japan Science and Technology (JST); a grant from the Japan Foundation For Aging And Health (J09KF00804), a grant from Innovative Research Program on Suicide Countermeasures (1-4), a grant from Sasakawa Sports Foundation, a grant from Japan Health Promotion & Fitness Foundation, a grant from Chiba Foundation for Health Promotion & Disease Prevention, the 8020 Research Grant for fiscal 2019 from the 8020 Promotion Foundation (adopted number: 19-2-06), grants from Meiji Yasuda Life Foundation of Health and Welfare.

References

1. United Nations, Department of Economic and Social Affairs, Population Division. World Population Prospects 2019. New York, NY: United Nations, 2019.
2. Cheng SY, Lin CP, Chan HYL *et al.* Advance care planning in Asian culture. *Jpn J Clin Oncol* 2020; 50: 976–89.
3. Rietjens JAC, Sudore RL, Connolly M *et al.* Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol* 2017; 18: e543–51.
4. Ditto PH, Smucker WD, Danks JH *et al.* Stability of older adults' preferences for life-sustaining medical treatment. *Health Psychol* 2003; 22: 605–15.
5. Auriemma CL, Nguyen CA, Bronheim R *et al.* Stability of end-of-life preferences: a systematic review of the evidence. *JAMA Intern Med* 2014; 174: 1085–92.
6. Etkind SN, Lovell N, Bone AE *et al.* The stability of care preferences following acute illness: a mixed methods prospective cohort study of frail older people. *BMC Geriatr* 2020; 20: 1–13. <https://doi.org/10.1186/s12877-020-01725-2>.
7. Ali M, Capel M, Jones G, Gazi T. The importance of identifying preferred place of death. *BMJ Support Palliat Care* 2019; 9: 84–91.
8. Etkind SN, Bone AE, Lovell N, Higginson IJ, Murtagh FEM. Influences on care preferences of older people with advanced illness: a systematic review and thematic synthesis. *J Am Geriatr Soc* 2018; 66: 1031–9.

9. Huler G. Structural and functional aspects of social relationships and episodic memory: between-person and within-person associations in middle-aged and older adults. *Gerontology* 2022; 68: 86–97.
10. Shakespeare-Finch J, Obst PL. The development of the 2-way social support scale: a measure of giving and receiving emotional and instrumental support. *J Pers Assess* 2011; 93: 483–90.
11. Thoits PA. Mechanisms linking social ties and support to physical and mental health. *J Health Soc Behav* 2011; 52: 145–61.
12. Carr D, Moonman SM, Boerner K. End-of-life planning in a family context: does relationship quality affect whether (and with whom) older adults plan? *J Gerontol B Psychol Sci Soc Sci* 2013; 68: 586–92.
13. Rietjens JA, Deschepper R, Pasman R, Deliens L. Medical end-of-life decisions: does its use differ in vulnerable patient groups? A systematic review and meta-analysis. *Soc Sci Med* 2012; 74: 1282–7.
14. Sharma RK, Prigerson HG, Penedo FJ, Maciejewski PK. Male-female patient differences in the association between end-of-life discussions and receipt of intensive care near death. *Cancer* 2015; 121: 2814–20.
15. Perkins HS, Cortez JD, Hazuda HP. Advance care planning: does patient gender make a difference? *Am J Med Sci* 2004; 327: 25–32.
16. Kondo K, Rosenberg M, eds. *Advancing Universal Health Coverage through Knowledge Translation for Healthy Ageing: Lessons Learnt from the Japan Gerontological Evaluation Study*. Geneva: World Health Organization, 2018.
17. Danis M, Garrett J, Harris R, Patrick DL. Stability of choices about life-sustaining treatments. *Ann Intern Med* 1994; 120: 567–73.
18. Moriki Y, Haseda M, Kondo N, Ojima T, Kondo K, Fukui S. Factors associated with discussions regarding place of death preferences among older Japanese: a JAGES cross-sectional study. *Am J Hosp Palliat Care* 2021; 38: 54–61.
19. Mochida Y, Yamamoto T, Fuchida S, Aida J, Kondo K. Does poor oral health status increase the risk of falls?: The JAGES project longitudinal study. *PLoS One* 2018; 13: e0192251. <https://doi.org/10.1371/journal.pone.0192251>.
20. Iwai-Saito K, Shobugawa Y, Aida J, Kondo K. Frailty is associated with susceptibility and severity of pneumonia in older adults (a JAGES multilevel cross-sectional study). *Sci Rep* 2021; 11: 7966. <https://doi.org/10.1038/s41598-021-86854-3>.
21. Nyunt MSZ, Fones C, Niti M, Ng TP. Criterion-based validity and reliability of the geriatric depression screening scale (GDS-15) in a large validation sample of community-living Asian older adults. *Aging Ment Health* 2009; 13: 376–82. <https://doi.org/10.1080/13607860902861027>.
22. Tani Y, Sasaki Y, Haseda M, Kondo K, Kondo N. Eating alone and depression in older men and women by cohabitation status: the JAGES longitudinal survey. *Age Ageing* 2015; 44: 1019–26. <https://doi.org/10.1093/ageing/afv145>.
23. Ishikawa T, Haseda M, Kondo N, Kondo K, Fukui S. Predictors of home being the preferred place of death among Japanese older people: JAGES cross-sectional study. *Geriatr Gerontol Int* 2021; 21: 345–52. <https://doi.org/10.1111/ggi.14135>.
24. Koyano W, Shibata H, Nakazato K, Haga H, Suyama Y. Measurement of competence: reliability and validity of the TMIG index of competence. *Arch Gerontol Geriatr* 1991; 13: 103–16.
25. Tanimoto Y, Watanabe M, Sun W *et al*. Association between sarcopenia and higher-level functional capacity in daily living in community-dwelling elderly subjects in Japan. *Arch Gerontol Geriatr* 2012; 55: e9–13. <https://doi.org/10.1016/j.archger.2012.06.015>.
26. Rubin DB. Multiple imputation after 18+ years. *J Am Stat Assoc* 1996; 91: 473–89.
27. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care* 2013; 12: 1–13. <https://doi.org/10.1186/1472-684X-12-7>.
28. Wittink MN, Morales KH, Meoni LA *et al*. Stability of preferences for end-of-life treatment after 3 years of follow-up: the Johns Hopkins precursors study. *Arch Intern Med* 2008; 168: 2125–30.
29. Hattori A, Masuda Y, Fetters MD *et al*. A qualitative exploration of elderly patients' preferences for end-of-life care. *Jpn Med Assoc J* 2005; 48: 388.
30. Akechi T, Miyashita M, Morita T *et al*. Good death in elderly adults with cancer in Japan based on perspectives of the general population. *J Am Geriatr Soc* 2012; 60: 271–6.
31. Gardner DS, Kramer BJ. End-of-life concerns and care preferences: congruence among terminally ill elders and their family caregivers. *Omega: J Death Dying* 2010; 60: 273–97.
32. Ministry of Health, Labour and Welfare. Report of a Survey of Perceptions Regarding End of Life Care. Japan, 2018. Available from: <https://www.mhlw.go.jp/toukei/list/sai syuiryo.html> (29 May 2022, date last accessed).
33. Ministry of Health, Labour and Welfare. Kokumin Seikatsu Kiso Chosa, 2019 Nen [The comprehensive survey on living conditions]. Japan, 2019. Available from: <https://www.e-stat.go.jp/stat-search/files?page=1&layout=datalist&toukei=00450061&tstat=000001141126&cycle=7&tclass1=000001141143&tclass2val=0> (29 May 2022, date last accessed).
34. Xiong C, Biscardi M, Astell A *et al*. Sex and gender differences in caregiving burden experienced by family caregivers of persons with dementia: a systematic review. *PLoS One* 2020; 15: e0231848. <https://doi.org/10.1371/journal.pone.0231848>.
35. Yee JL, Schulz R. Gender differences in psychiatric morbidity among family caregivers: a review and analysis. *Gerontologist* 2000; 40: 147–64.
36. Schölzel-Dorenbos CJ, Draskovic I, Vernooij-Dassen MJ, Rikkert MGO. Quality of life and burden of spouses of Alzheimer disease patients. *Alzheimer Dis Assoc Disord* 2009; 23: 171–7.
37. Beeson R, Horton-Deutsch S, Farran C, Neundorfer M. Loneliness and depression in caregivers of persons with Alzheimer's disease or related disorders. *Issues Ment Health Nurs* 2000; 21: 779–806.
38. Thompson RTL, Lewis SL, Murphy MR *et al*. Are there sex differences in emotional and biological responses in spousal caregivers of patients with Alzheimer's disease? *Biol Res Nurs* 2004; 5: 319–30.
39. McCall K, Rice AM. What influences decisions around the place of care for terminally ill cancer patients? *Int J Palliat Nurs* 2005; 11: 541–7.
40. Foreman LM, Hunt RW, Luke CG, Roder DM. Factors predictive of preferred place of death in the general population of South Australia. *Palliat Med* 2006; 20: 447–53.

41. Fukui S, Yoshiuchi K, Fujita J, Sawai M, Watanabe M. Japanese people's preference for place of end-of-life care and death: a population-based nationwide survey. *J Pain Symptom Manage* 2011; 42: 882–92.
42. Lyyra TM, Heikkinen RL. Perceived social support and mortality in older people. *J Gerontol B Psychol Sci Soc Sci* 2006; 61: S147–52.
43. Ishikawa T, Fukui S, Fujita J, Fujikawa A, Iwahara Y, Takahashi K. Factors related to end-of-life care discussions among community-dwelling people in Japan. *J Pain Symptom Manage* 2022; 63: 539–47.
44. Ministry of Health, Labour and Welfare. Revised Guidelines of the Decision Making Process at the End of Life. Japan, 2018. Available from: <http://www.mhlw.go.jp/stf/houdou/0000197665.html> (29 May 2022, date last accessed).
45. Gomez-Virseda C, de Maeseneer Y, Gastmans C. Relational autonomy in end-of-life care ethics: a contextualized approach to real-life complexities. *BMC Med Ethics* 2020; 21: 50–14.
46. Tulskey JA, Steinhauer KE, LeBlanc TW *et al.* Triadic agreement about advanced cancer treatment decisions: perceptions among patients, families, and oncologists. *Patient Educ Couns* 2022; 105: 982–6. <https://doi.org/10.1016/j.pec.2021.08.001>.
47. Dove ES, Kelly SE, Lucivero F, Machirori M, Dheensa S, Prainsack B. Beyond individualism: is there a place for relational autonomy in clinical practice and research? *Clin Ethics* 2017; 12: 150–65.
48. Sudore RL, Lum HD, You JJ *et al.* Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. *J Pain Symptom Manage* 2017; 53: 821–832.e1.
49. Matsui M, Braun KL, Karel H. Comparison of end-of-life preferences between Japanese elders in the United States and Japan. *J Transcult Nurs* 2008; 19: 167–74.
50. Sallnow L, Paul S. Understanding community engagement in end-of-life care: developing conceptual clarity. *Crit Public Health* 2015; 25: 231–8.

Received 4 March 2022; editorial decision 15 July 2022