



Patients' preferences and factors influencing initial advance care planning discussions' timing: A cross-cultural mixed-methods study

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Abstract

Background: Although advance care planning discussions are increasingly accepted worldwide, their ideal timing is uncertain and cultural factors may pertain.

Aim: To evaluate timing and factors affecting initiation of advance care planning discussions for adult patients in Japan and Taiwan.

Design: Mixed-methods questionnaire survey to quantitatively determine percentages of patients willing to initiate advance care planning discussions at four stages of illness trajectory ranging from healthy to undeniably ill, and to identify qualitative perceptions underlying preferred timing.

Setting/participants: Patients aged 40–75 years visiting outpatient departments at four Japanese and two Taiwanese hospitals were randomly recruited.

Results: Overall (of 700 respondents), 72% (of 365) in Japan and 84% (of 335) in Taiwan ($p < 0.001$) accepted discussion before illness. In Japan, factors associated with willingness before illness were younger age and rejection of life-sustaining treatments; in Taiwan, older age, stronger social support, and rejection of life-sustaining treatments. Four main categories of attitudes were extracted: the most common welcomed discussion as a wise precaution, responses in this first category outnumbered preference for postponement of discussion until imminent end of life, acceptance of the universal inevitability of death, and preference for discussion at healthcare providers' initiative.

Conclusion: The majority of patients are willing to begin discussion before their health is severely compromised; about one out of five patients are unwilling to begin until clearly facing death. To promote advance care planning, healthcare providers must be mindful of patients' preferences and factors associated with acceptance and reluctance to initiate advance care planning.

Keywords

Advance care planning, frailty, Far East, middle aged, aged, cross-cultural comparison

What is already known about the topic?

- Patients' initial negative reactions, anticipated or real, to discussion of advance care planning make healthcare providers hesitant to broach the subject, because patients may lose hope and ill-timed advance care planning may harm the doctor–patient relationship.
- Few studies are available to give guidance on when patients are psychologically prepared to begin advance care planning discussions.

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What this paper adds?

- In two Asian countries, Japan and Taiwan, 72% of Japanese and 84% of Taiwanese respondents are willing to begin advance care planning discussions before their health has deteriorated.
- An appreciable minority, 20%, however, wish to postpone these discussions until imminent end of life.
- “Asian attitudes” are not homogeneous: more Taiwanese than Japanese patients regard it as common sense to discuss advance care planning because death is inevitable. Japanese patients have more passive attitudes than Taiwanese toward advance care planning discussions and prefer advance care planning discussions held at healthcare providers’ initiative.

Implications for practice, theory, or policy

- Most Japanese and Taiwanese patients are willing to begin discussions before their health is severely compromised; a minority are unwilling until clearly facing end of life.
- Hence, to promote advance care planning, healthcare providers must be mindful of the diversity of patients’ preferences and cultural factors associated with acceptance of and reluctance to initiate advance care planning.

Introduction

Advance care planning enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate.¹ Discussions with family, or with physicians, or with both, about advance care planning are increasingly regarded as important for the management of end-of-life care.

Japan and Taiwan have traditionally had a family-centered decision-making culture.² In Japan, there has been a discordance between older adults and family caregivers (older adults tend to eschew prolonged survival to lessen burdens on their family, while caregivers’ responsibility does not permit giving up on a loved one).³ Thus, Japanese older adults feel a need to discuss advance care planning to address this discordance.⁴ In Japan, the prevalence of discussions approximately doubled from the second half of the 2000s (around 20% in both middle-aged and older adults)^{5,6} to the second half of the 2010s (35% in middle-aged adults; 47% in older adults).⁷ Although Japan still lacks legislation mandating advance care planning or advance directives, the doubled prevalence is perhaps attributable to rapid growth in the senior population and interest in patient autonomy at end of life.^{7,8}

In the Taiwanese family-centered, dominantly Confucian culture, communication at end of life, traditionally considered a psychological burden on older adults, has tended to be avoided;⁹ however, healthcare providers’ awareness in communication at end of life has changed since enactment of the Natural Death Act in 2000.¹⁰ In addition, a Patient Right to Autonomy Act was passed in 2015 and came into force on 6 January 2019; already annually over a thousand patients have participated in an advance care planning communication program undertaken since 2015 in Taipei.¹¹

Thus, although circumstances surrounding advance care planning legislation differ, interest in advance care planning has increased in both countries.

Particular triggers have been reported for initiating discussions: recurrence of cancer,¹² diagnosis with long-term or life-limiting conditions, or with conditions whose predictable trajectory results in a loss of capacity.^{13,14} However, finding triggers for patients with non-cancer chronic conditions is challenging. Chronic diseases are not perceived to be terminal even when diseases are progressive, and yet sudden changes in condition cause people to miss opportunities for discussions.¹³ Moreover, previous studies have reported barriers facing healthcare providers desiring to initiate advance care planning discussions in primary care settings.^{15,16} Patients’ negative reactions if planning is forced upon them too early worry healthcare providers; patients may lose hope¹⁷ and ill-timed advance care planning may harm healthcare provider–patient relationships.^{18,19} These fears and barriers may cause healthcare providers to miss opportunities for discussions. Few studies are available to give guidance on when patients are psychologically prepared (given their medical condition) to begin discussions. Knowing at what stage patients willingly accept discussions would facilitate healthcare providers’ attempts to surmount hurdles to timely discussions.

According to previous studies,^{20,21} in about 85% of terminally ill adults, physical function deteriorates, eventually reaching the frail stage, following one of three terminal illness trajectories: prolonged deterioration, gradual decline punctuated by acute episodes, and quick evident decline. Taking these illness trajectories into account, healthcare providers could pace discussions taking into account their patient’s expected disease course and deterioration from healthy to the frailest stage.

This study aimed, therefore, to evaluate patients’ willingness to initiate discussions at different stages of

physical decline and to identify patient-dependent factors related to the earliest propitious time for initiating discussions deemed acceptable by patients in Japan and Taiwan.

Methods

Study design and setting

This multi-centered cross-cultural survey seeking comprehensive understanding of preferred timings for initial advance care planning discussions in Japan and Taiwan adopted a convergent parallel mixed-methods design²² with three different scenarios in three questionnaires comprising multiple-choice questions and free descriptions (Supplementary Figure 1: study procedure diagram). It was conducted at six hospitals' outpatient departments, four in Japan (Shirakawa Kosei General Hospital in Shirakawa, Kanai Hospital in Kyoto, Kameda Medical Center in Kamogawa, and Medical Center Narita Hospital in Narita) and two in Taiwan (National Taiwan University Hospital and Taipei City Hospital, both in Taipei) from September 2017 to March 2018. All respondents were outpatients at departments of general internal medicine, family medicine, cardiology, respiratory medicine, hematology, endocrinology, or rheumatology. The study period was 1 week at each Japanese site, and 2 weeks at each Taiwanese site. The Ethics Committee of the Kyoto University Graduate School and Faculty of Medicine (R1029-1) and the National Taiwan University Hospital Research Ethics Committee (20170504RINC) approved this study.

Participants

On each day during the survey period, 20–30 patients aged 40–75 years were randomly sampled for participation from among all patients with appointments at participating outpatient departments. Participants were sampled in advance prior to their appointment day; each received one of the questionnaire's three versions (Scenarios 1–3) in the order of patients' arrival so that equal numbers of the three versions would be distributed. Patients incompetent to answer the questionnaire due to moderate or advanced dementia, a neurodegenerative disorder, or cerebrovascular disease and terminally ill cancer patients who might soon actually need to discuss advance care planning were excluded. After completing the questionnaire, patients received an honorarium worth approximately US\$5.

Questionnaire development

We created drafts (in Japanese) of three scenarios (cerebral infarction, heart failure, and incurable lung cancer) representing, respectively, three different illness trajectories:

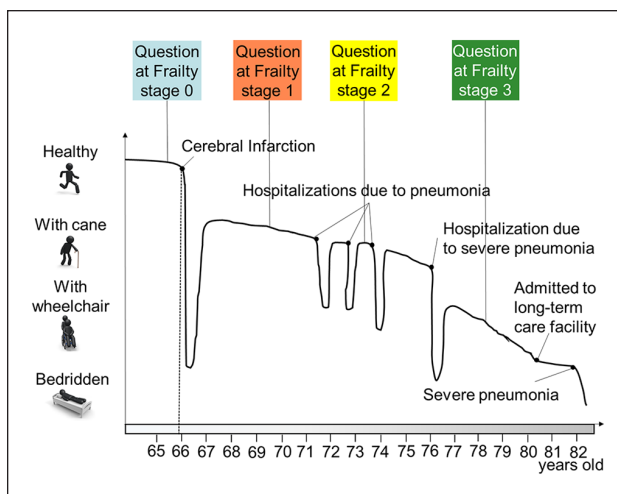


Figure 1. Illness trajectory of Scenario 1 (cerebral infarction).

prolonged deterioration, gradual decline punctuated by acute episodes, and quick evident decline. Two specialists with expertise regarding each scenario (total six) were consulted to ensure adequacy and accuracy of descriptions. The three questionnaires were pretested by conducting interviews with seven patients and seven healthcare providers to ensure that the questions would be understood and would adequately identify when patients would willingly initiate discussions. Pilot testing on 23 patients established a final version in Japanese, whereupon the Taiwanese version was developed. A Taiwanese co-author (W.-S.H), bilingual in Taiwanese and Japanese, did the Japanese-to-Taiwanese translation. A professional translator fluent in Japanese and Taiwanese created a back-translated Japanese version without seeing the original. We compared the original with the back-translated version (for Japanese-to-English translations of the scenarios, see Supplementary Text 1–3) and revised and finalized the Taiwanese-language version. Figure 1 shows, by way of example, the prolonged dwindling illness trajectory (see Supplementary Figures 2 and 3 for the two other illness trajectories).

Outcome variables

Based on previous studies,^{23–25} we defined advance care planning discussions as “making the wishes of individual patients known to persons close to them regarding the healthcare interventions, including life-sustaining treatments, they wish to receive or not to receive if they should become very ill or injured.” We defined four potentially acceptable stages for initiating discussions using the five components of “frailty” or deterioration of health (unintentional weight loss, self-reported exhaustion, slow walking speed, weakness, and low physical activity) described in the study of Fried et al.²⁶ We defined Frailty Stage 0 as having no component of frailty (i.e. healthy),

Frailty Stage 1 as having only one component, Frailty Stage 2 as having two components, and Frailty Stage 3 as having three or more of the above five components (Supplementary Table 1). Advance care planning was explained at the top of every questionnaire, which respondents were told to read before they read the scenario description. After reading each stage of the scenario, respondents were asked to choose one answer to the question: "If you were the patient described here, what would you say about starting to discuss advance care planning at this time?" The answers on a five-step Likert-type scale were "It's too early," "It's slightly early," "It's an appropriate time," "It's a little late," and "It's too late." Those choosing the "too early" and "slightly early" answers were instructed to proceed to the next step of the scenario. Those selecting one of the three "appropriate" or "late" answers were instructed to skip to the summary and outcome page.

The step at which, for the first time, respondents selected either "appropriate" or "late" answers was the time at which they were deemed willing to initiate discussions. We dichotomized the outcome variables into "Healthy" versus "Frail" to identify factors related to the earliest time at which patients were willing to begin discussions.

In addition, we elicited free descriptions of attitudes underlying respondents' choices by asking the following open-ended question: "Describe how you would feel if you had been asked to begin discussing advance care planning *before* you indicated (by choosing 'appropriate', 'a little late', or 'too late') that you are willing to begin advance care planning."

Exposure variables

Based on clinically relevant factors discussed by the authors as well as factors related to advance care planning discussions reported in previous studies (e.g. age,^{27,28} sex,^{27,28} marital status,²³ social support,²³ health literacy,²⁹ education,³⁰ income,³⁰ comorbidities, family caregiver experience,³¹ and end-of-life care preferences),⁶ the authors measured variables likely to be related to the stage at which respondents were willing to initiate discussions.

Data analysis

Quantitative analyses. We compared country-wise all-scenario data on how early respondents were willing to initiate discussions. We explored factors associated with respondents' selection of Frailty Stage 0 for initiating discussions using Poisson regression models with robust variance³² to estimate prevalence ratios (PRs). In these models (for Japan and Taiwan), the outcome variable is willingness at Frailty Stage 0 versus the reference category "Frail," and the exposure variables are age, sex,

marital status, social support, comorbidities, education, health literacy, annual income, family caregiver experience, and end-of-life care preferences. We performed a multiple imputation procedure (see Supplementary Text 4) and used STATA/IC 15 (StataCorp, College Station, TX, USA) for statistical analyses.

Qualitative analyses. Free descriptions were analyzed using qualitative content analysis.^{33,34} Using the conventional approach, we classified the transcribed answers, putting them into a manageable number of categories representing similar meanings to clarify patients' perceptions underlying their selection of the Frailty Stage at which they were willing to initiate discussions. A professional translator translated the Taiwanese answers into Japanese. Author J.M. and bilingual co-author W.-S.H checked and validated the translations. Three authors (J.M., A.K., and M.K.) then repeatedly read all 501 descriptions to ensure they were clearly understood. The first 151 descriptions (Japan: 78; Taiwan: 73) were then coded independently by the three authors to identify key perceptions. The same three authors discussed among themselves the coding label rationale and established a preliminary code list. The remaining 350 answers were equally divided among the three authors, who discussed whether additional codes were needed, and coded separately. The adopted codes were clustered into meaningful categories based on differences and similarities. Finally, the categories and quotations in Japanese were translated into English by authors J.M. and A.K., then proofread by an English-native speaker familiar with Japanese culture and fluent in Japanese. Descriptions, codes, and categories were managed using NVivo 11 (QSR International).

Integration of quantitative and qualitative analyses. We integrated quantitative and qualitative results using a joint display²² (Figure 3) comparing respondents' stated motives for selecting Frailty Stage 0 initiation.

Results

In total, responses from 700 respondents (Japan: 365; Taiwan: 335) were obtained. Japanese respondents' mean age was 63 (standard deviation (SD)=8.7) years and Taiwanese' was 56 (SD=8.9) years. In Japan, the response rate was 72.7% (of 502 patients); neither age nor sex differed between non-responders and responders. In Taiwan, the response rate was very similar, 73.1% (of 458 patients); however, non-responders were older than responders (64 vs 56 years old, $p < 0.001$) and disproportionately male (41% vs 19%, $p < 0.001$). Thus, compared with the Japanese, the Taiwanese respondents were younger, included more women, were more often single, more highly educated, more health-literate, and had less social support, lower

Table 1. Patient demographics in Japan and Taiwan.

Patient demographics	Japan		Taiwan		p value ^a
	N = 365	Missing data	N = 335	Missing data	
Age, mean (SD)	63 (8.7)	0	56 (8.9)	0	<0.001
Male, n (%)	175 (48)	0	63 (19)	0	<0.001
Marital status, n (%)		2		0	0.001
Single	32 (8.8)		64 (19)		
Married	284 (78)		223 (67)		
Divorced	26 (7.2)		30 (9.0)		
Bereaved	21 (5.8)		18 (5.4)		
Social support, ^b mean (SD)	67 (26)	1	63 (27)	0	0.04
Comorbidities ^c		0		0	<0.001
Without disease	38 (10)		109 (33)		
With one disease	108 (30)		120 (36)		
With two or more diseases	219 (60)		106 (32)		
Education duration, >12 years, n (%)	58 (16)	3	165 (49)	0	<0.001
Health literacy, ^d mean (SD)	33 (9.1)	2	42 (7.5)	1	<0.001
Annual income, n (%)		8		5	<0.001
<US\$20,000	60 (17)		118 (36)		
≥US\$20,000, <US\$50,000	163 (46)		158 (48)		
≥US\$50,000	134 (38)		54 (16)		
Family caregiver experience, ^e n (%)	165 (46)	4	182 (54)	0	0.02
Preference for end-of-life care, ^f n (%)		9		0	0.23
Do not want LSTs	278 (78)		260 (78)		
Want LSTs	10 (2.8)		19 (5.7)		
Entrust decision-making to family	40 (11)		30 (9.0)		
Do not know own preference	28 (7.9)		26 (7.8)		

LSTs: life-sustaining treatments; SD: standard deviation.

^ap values were obtained by Student's *t* test for differences in mean values and by the chi-square test for differences in percentages between Japan and Taiwan.

^bScore (range: 0–100) on the modified version of Medical Outcome Survey Social Support Scale (mMOS-SS).^{35,36} A higher score represents more adequate social support.

^cComorbidities defined as summing the total number³⁷ of the following diseases or medical conditions: hypertension, hypercholesterolemia, diabetes mellitus, gastrointestinal disease, cardiac disease, renal disease, respiratory disease, cerebrovascular disease, orthopedic disease, rheumatologic disease, psychiatric disease, and neoplasm.

^dScore (range: 0–50) on the short version of European Health Literacy Survey Questionnaire (HLS-EU-Q).^{38–40} A higher score represents more adequate health literacy.

^eThe question to patients: "Do you have experience as a family member's caregiver?"

^fThe question to patients: "Please think about situations in which you might become seriously ill or injured, or severely demented, and unable to express your own wishes when the possibility of recovering is very low. In that sort of situation, would you want to receive life-sustaining treatment(s)?" Patients selected an answer from the following alternatives: "I do not want LSTs," "I would want LSTs," "I would entrust these decisions to my family," or "I do not know my own preference(s)."

income, fewer comorbidities, and more family caregiver experience (Table 1 and Supplementary Table 2).

Quantitative results

A higher percentage of Taiwanese than of Japanese respondents selected Frailty Stage 0 (84% vs 72%, $p < 0.001$) in all scenarios. Either Frailty Stage 0 or Frailty Stage 1 was selected by 93% in Taiwan and 91% in Japan ($p = 0.26$) (Figure 2). Results scarcely differed among scenarios (Supplementary Figure 4).

Table 2 shows factors related to Frailty Stage 0 selection. Older Japanese patients had a lower tendency than

younger Japanese to select Frailty Stage 0 (age: 56–65 vs 40–55 years, PR: 0.81, 95% confidence interval (CI): 0.69–0.95; age: 66–75 vs 40–55 years, PR: 0.76, 95% CI: 0.64–0.90); older Taiwanese had a higher tendency than younger Taiwanese to select Frailty Stage 0 (age: 56–65 vs 40–55 years, PR: 1.08, 95% CI: 0.97–1.20; age: 66–75 vs 40–55 years, PR: 1.15, 95% CI: 1.00–1.32). Higher percentages of Taiwanese patients aged 56–65 and 66–75 years selected Frailty Stage 0 than did their same-age-group Japanese counterparts (Supplementary Figure 5). In both countries, more of those intending to reject life-sustaining end-of-life treatments tended to select Frailty Stage 0 than those who do not know their preferences. More

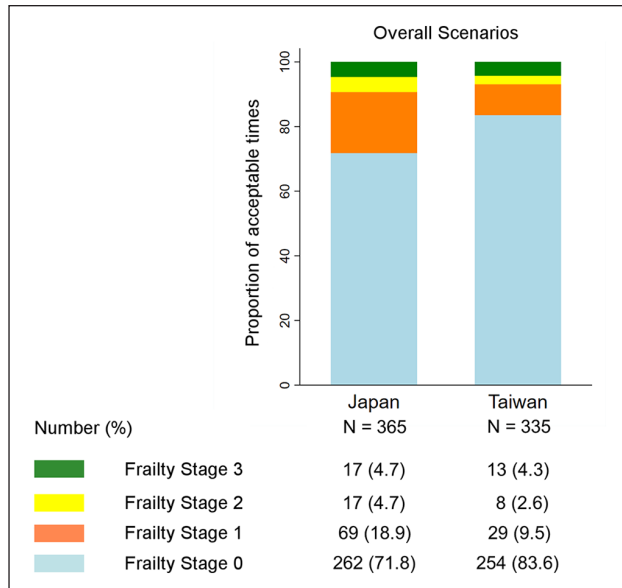


Figure 2. Percentages of acceptable times for initiating advance care planning discussions by country.

Taiwanese with higher levels of social support selected Frailty Stage 0 than did Taiwanese with lower levels.

Qualitative results

In total, 244 Japanese and 257 Taiwanese respondents provided actionable free descriptions. Table 3 shows categories of perceptions underlying the stage at which respondents were willing to initiate discussions. Four main categories were extracted.

Wise precaution. The first category is those descriptions expressing the belief that patients ought to convey their wishes in preparation for possible incapacitation in the future; in both countries, over 60% of responses were in this category. This category includes three sub-categories (whose meaning is clarified below by a representative patient's free description):

Forewarned is forearmed:

It is not too early to discuss advance care planning. It's always good to prepare for the worst. (70-year-old Japanese man)

Desire for autonomy:

When I discuss my own future decisions in healthcare with my doctor at an earlier stage, my judgement will be better because my mind will be clearer. (59-year-old Taiwanese woman)

Desire to avoid troubling others:

Before losing the ability to think, I'd like to decide my own end-of-life care by myself because I don't want to trouble people around me. (66-year-old Japanese man)

Postponement of advance care planning. The second category was coded "Postponement of advance care planning" (until imminent end-of-life), meaning contrastingly that discussions should not begin until patients accept that their end-of-life is approaching; in both countries, fewer than 20% of responses were in this category. The second category has two sub-categories (whose meaning is clarified below by a representative patient's free description):

Impossibility while healthy of knowing needs at end-of-life:

If I discussed advance care planning with my doctor while I am in good health, I might have to make decisions without understanding what I will really want at end-of-life, because the discussion will be based not on facts but on guesses, and I can't know what's good for me. (67-year-old Japanese man)

Uneasiness at too-early talk of advance care planning:

When I am not seriously ill, I would feel uncomfortable if a doctor talked to me about advance care planning. (56-year-old Taiwanese woman)

Universal inevitability of end-of-life. The third category is those descriptions expressing the belief that respondents accept the need to discuss future healthcare decisions because all men are mortal; this characterized more Taiwanese than Japanese replies:

Everyone will experience death. It always happens. (52-year-old Taiwanese man)

Advance care planning discussions at healthcare providers' initiative. The fourth category is descriptions signifying that patients unhesitatingly accept discussions when healthcare providers take the initiative; this characterized more Japanese than Taiwanese replies:

It's difficult for me to judge by myself when it is best to start advance care planning. I want opinions of healthcare providers when they consider it necessary. (59-year-old Japanese woman)

In other, low-frequency categories, 11 Taiwanese (but no Japanese) stated that advance care planning was necessary to conserve medical resources.

Integration of quantitative and qualitative results

Figure 3 shows the integrated results. The right side of Figure 3 represents percentages of those selecting Frailty Stage 0 in each category. Responses in the second category, "Postponement of advance care planning," were much lower (38% in Japan and 48% in Taiwan) than responses in the other categories.

Table 2. Factors related to selection of Frailty Stage 0 for initiation of advance care planning discussions in Japan and Taiwan.

Factors	Adjusted prevalence ratio (95% CI)	
	Japan, <i>n</i> = 365	Taiwan, <i>n</i> = 335
Age (years)		
56–65 (vs 40–55)	0.81 (0.69–0.95)*	1.08 (0.97–1.20)
66–75 (vs 40–55)	0.76 (0.64–0.90)**	1.15 (1.00–1.32)*
Sex male	1.03 (0.89–1.18)	0.99 (0.85–1.15)
Marital status		
Married (vs single)	1.33 (0.99–1.79)	0.92 (0.81–1.04)
Divorced (vs single)	1.27 (0.87–1.85)	0.96 (0.78–1.17)
Bereaved (vs single)	1.08 (0.69–1.67)	1.12 (0.99–1.28)
Social support ^a		
Second quartile (vs lowest quartile)	0.98 (0.82–1.18)	1.13 (0.98–1.30)
Third quartile (vs lowest quartile)	0.98 (0.81–1.18)	1.05 (0.91–1.21)
Highest quartile (vs lowest quartile)	0.98 (0.80–1.20)	1.16 (1.01–1.33)*
Comorbidities ^b		
With one disease (vs without disease)	0.92 (0.75–1.14)	0.96 (0.85–1.08)
With two or more diseases (vs without disease)	0.99 (0.82–1.20)	0.96 (0.85–1.08)
Education duration, >12 years (vs ≤12 years)	1.08 (0.92–1.27)	0.97 (0.87–1.08)
Health literacy, ^c adequate (vs poor)	0.98 (0.86–1.11)	1.01 (0.86–1.19)
Annual income		
≥US\$20,000, <US\$50,000 (vs <US\$20,000)	1.01 (0.82–1.24)	1.09 (0.97–1.23)
≥US\$50,000 (vs <US\$20,000)	0.93 (0.75–1.16)	0.95 (0.78–1.17)
Family caregiver experience ^d (vs no experience)	1.08 (0.95–1.23)	1.08 (0.97–1.20)
Preferences for end-of-life care ^e		
Do not want LSTs (vs do not know own preference)	1.64 (1.09–2.45)*	1.40 (1.01–1.93)*
Want LSTs (vs do not know own preference)	0.65 (0.25–1.72)	1.16 (0.75–1.78)
Entrust decision-making to family (vs do not know own preference)	1.53 (0.98–2.37)	1.32 (0.91–1.93)

CI: confidence interval; LSTs: life-sustaining treatments.

^aScore (range: 0–100) categorized into four categories (lowest, second, third, highest quartiles) on the modified version of Medical Outcome Survey Social Support Scale (mMOS-SS).^{35,36}

^bComorbidities defined by summing the total number³⁷ of the following diseases or medical conditions: hypertension, hypercholesterolemia, diabetes mellitus, gastrointestinal disease, cardiac disease, renal disease, respiratory disease, cerebrovascular disease, orthopedic disease, rheumatologic disease, psychiatric disease, and neoplasm.

^cScore of 33 or higher on the short version of European Health Literacy Survey Questionnaire (HLS-EU-Q)^{38–40} was defined as adequate health literacy.

^dThe question to patients: “Do you have experience as a family member’s caregiver?”

^eThe question to patients: “Please think about situations in which you might become seriously ill or injured, or severely demented, and unable to express your own wishes when the possibility of recovering is very low. In that sort of situation, would you want to receive life-sustaining treatment(s)?” Patients selected an answer from the following alternatives: “I do not want LSTs,” “I would want LSTs,” “I would entrust these decisions to my family,” or “I do not know my own preference(s).”

p* < 0.05, *p* < 0.001.

Table 3. Categories of patients’ free descriptions of their motives for choosing the most acceptable time for initiating advance care planning discussions.

Four main categories and other minor categories	<i>N</i> (%) ^a		<i>p</i> value ^b
	Japan, <i>n</i> = 244	Taiwan, <i>n</i> = 257	
1. Wise precaution	161 (66)	160 (62)	0.39
2. Postponement of advance care planning	45 (18)	50 (19)	0.77
3. Universal inevitability of end-of-life	12 (5)	52 (20)	<0.001
4. Advance care planning discussions at healthcare providers’ initiative	52 (21)	26 (10)	0.001
Other minor categories			
Entrust decision-making to family or doctors	3 (1)	0	
Advance care planning should be initiated from the age of 70	3 (1)	0	
Advance care planning is necessary to conserve medical resources	0	11 (4)	

^aThe category percentages add up to more than 100% because some patients’ descriptions fall into multiple categories.

^bThe *p* values in each main category for differences in percentages between Japan and Taiwan were obtained using the chi-square test.

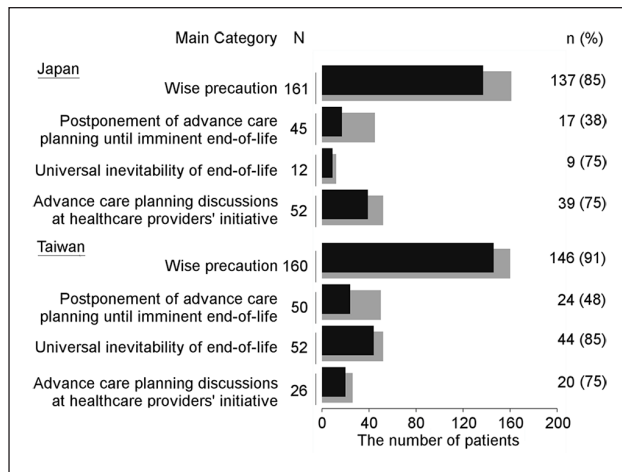


Figure 3. Percentages of patients preferring Frailty Stage 0 (i.e. while healthy) for initiation of advance care planning discussions by main category of motive for selection. *N* (the height of gray bar) represents the total number of patients in each main category; *n* (the height of black bar) represents the number of patients preferring Frailty Stage 0 in each main category; the number in parentheses represents the percentage of patients preferring Frailty Stage 0 in each main category.

Discussion

Main findings/results of the study

More than 70% of patients in both Taiwan and Japan were willing to begin discussions while they were still well; 90% in both countries were willing to begin talking about advance care planning at Frailty Stage 0 or Frailty Stage 1, that is, before suffering any serious incapacitation. In other words, both Japanese and Taiwanese are willing to begin preparing for their end of life even when they are not yet frail. In country-to-country comparison terms, more Taiwanese than Japanese patients preferred to initiate advance care planning while healthy (Frailty Stage 0).

These quantitative results were complemented by the following qualitative and integrated results that shed light on the motives for their decisions: in both countries more than 60% stated that advance care planning is a “wise precaution,” and yet a significant minority (almost 20%) do not want to initiate discussions until they actually face their end of life.

Strengths and weaknesses/limitations of the study

Healthcare providers will be helped in their work by having clues to the relative frequency and motives for choices by patients from a variety of cultural backgrounds. Healthcare providers unfamiliar with Asian values might expect Japanese and Taiwanese patients to think and act identically, which of course they do not.

Any of several characteristic differences between patient groups in Japan and Taiwan might explain the finding that more Taiwanese than Japanese patients are ready to discuss advance care planning while healthy. In this study, it might be because proportionally more older Taiwanese patients than their Japanese counterparts in equivalent age cohorts (56–65 years and 66–75 years) preferred Frailty Stage 0 (Supplementary Figure 4) for initiating discussions. This finding is also supported by multivariable analyses showing older Taiwanese patients to be more likely and older Japanese patients less likely to accept Frailty Stage 0 as the starting point for discussions (Table 3). This easier acquiescence in older Taiwanese patients surprised us because Taiwanese elders are known for being reticent about end-of-life issues.⁹ Taiwanese patients' preference for natural death is difficult to assess, because end-of-life communication is quasi-taboo.⁹ Compared to Japan, Taiwan is a more Confucian society where telling elders that their illness is fatal is avoided because this places a psychological burden on them.^{41,42} However, the enactment of the Natural Death Act in 2000 to facilitate older Taiwanese adults' wishes for a natural death has established several guidelines that facilitate truth-telling and support patients' autonomy.⁴³ According to a 2018 study,⁴⁴ Taiwanese healthcare providers now find truth-telling issues to be less problematic than before. In this changing social context and thanks to preparations for new advance care planning regulations under the Patient Right to Autonomy Act, Taiwanese older adults' attitudes toward discussions may already have softened as awareness grows that advance care planning does not conflict with patients' wishes. This attitudinal change may also provide a plausible explanation for our finding that, compared with Japanese patients, more Taiwanese regard it as common sense to discuss advance care planning because death is inevitable.

Contrastingly, Japanese patients, who prefer discussions at healthcare providers' initiative, had more passive attitudes than Taiwanese. This was unsurprising and consistent with a 2015 report that Japanese prefer having paternalistic, empathic, and compassionate healthcare providers play an active role in decision-making about end-of-life care.⁴⁵ This passivity may also be due to the traditional value of “enryo” in Japanese society (i.e. adopting a reserved and modest attitude showing consideration for others, putting others' interests above one's own).^{3,46} Japanese respondents clearly expressed concerns that stating their end-of-life wishes would burden their children: for this reason they avoid expressing their wishes on their own initiative, but they will accept advance care planning if healthcare providers initiate the discussions.

This study has several limitations. First, because it is scenario-based, it is uncertain—despite scenario validation during questionnaire development through interviews with clinical experts and patients—whether attitudinal findings accurately reflect patients' actual behavior. Second, despite multivariable analysis adjustment for sociodemographic

and health-related factors, other unknown or unmeasured confounding factors might be involved. Third, although response rates in both countries were relatively high, there might be some non-responder bias in Taiwan due to the differences in age and sex between responders and non-responders. In addition, sex bias between the two countries' samples is conceivable because of the lower proportion of Taiwanese than Japanese male responders, although in both Taiwanese and Japanese models, sex was not found to be associated with the preference for initiating discussions. Fourth, although we measured the number of comorbidities, we did not measure the frequency of participants' actual engagement in discussions, nor did we measure the severity of participants' diseases that might affect the possibility of actual discussions; however, because participants were patients with an outpatient appointment who visited a clinic by themselves, they were not terminally ill patients urgently actually requiring discussions. Fifth, the qualitative analysis itself might constitute a limitation, because it relied entirely on questionnaire respondents' free descriptions.

What this study adds

This is the first cross-cultural multi-centered Japan–Taiwan collaborative study identifying when patients are willing to initiate advance care planning discussions and what factors are associated with willingness to begin discussions before major debilitating health problems occur. Most patients with at least one component of frailty would be ready to accept advance care planning discussions, in both Taiwan and Japan. However, healthcare providers should bear in mind that 20% of patients are willing to begin discussions only in imminent end-of-life situations. Finding the best time to begin discussions is known to be challenging; our results may suggest ways to optimize timing. The authors intend next to design advance care planning promotion interventions taking into consideration cultural and normative aspects of patients' preferences for advance care planning communication in both countries. Moreover, this study highlights the need in Japan to launch public hearings leading to legislation comparable to Taiwan's Patient Right to Autonomy Act. It may prompt progress toward heightened advance care planning awareness among older Japanese, following Taiwan's lead.

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Author contributions

J.M., A.K., S.-Y.C., S.-H.H., W.-S.H., and S.F. contributed to study concept and design. J.M., J.-S.T., S.-H.H., N.K., K.O., and M.F. contributed to acquisition of data. J.M., A.K., S.-Y.C., S.-H.H., W.-S.H., M.K., Y.Y., S.S., and S.F. contributed to analysis and interpretation of data. J.M., A.K., Y.Y., and S.S. drafted the manuscript, and other authors revised it critically for important intellectual content. All authors read and approved the final manuscript.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethics approval and consent to participate

The Ethics Committee of the Kyoto University Graduate School and Faculty of Medicine (R1029-1) and the National Taiwan University Hospital Research Ethics Committee (20170504RINC) approved this study. Participants were informed in the explanation form before participating in this survey that they were under no obligation to answer any questions and they were able to rescind their consent to participate at any time. They were also informed that completing the questionnaire was regarded as consent to participate.

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Availability of data and materials

All data sets on which the conclusions of the paper rely are available on request to the corresponding author.

Supplemental Material

Supplemental material for this article is available online.

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