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# Associated factors for discussing advance directives with family physicians by noncancer outpatients in Japan

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## Abstract

**Background:** Advance directives (ADs) are seldom discussed between primary care physicians (PCPs) and their patients, especially those with noncancer diseases. The aim was to identify the factors associated with discussing AD by noncancer patients with their physicians.

**Methods:** This cross-sectional study was conducted in a hospital or clinic from October to December 2017. Physicians chose eligible noncancer patients aged 20 years or older to respond to an anonymous self-completed questionnaire inquiring about the objective variable "I want to discuss AD with my doctor," as well as basic characteristics, and facilitators and barriers to discussing AD identified in previous studies. The physicians responded to a survey comprising the Palliative Performance Scale (PPS) and inquiring about the disease category for each patient. Data were analyzed using binomial logistic regression analysis.

**Results:** A total of 270 patients (valid response rate, 79.6%) were included. Multivariate analysis identified a period of visit to the study site  $\geq 3$  years (odds ratio [OR], 2.07; 95% confidence interval [CI], 1.05-4.10), physicians who are very good at taking care of patients' disease (OR, 12.68; 95% CI, 1.12-143.22), and patients' worry about their quality of life (QOL) in the future (OR, 2.69; 95% CI, 1.30-5.57) as facilitators for discussing AD with physicians, and PPS  $\leq 90$  (OR, 0.51; 95% CI, 0.26-0.98) as a barrier.

**Conclusions:** Our study indicates that patients' future QOL concerns, a long period of visit to a hospital, and the presence of physical symptoms were associated with the willingness of noncancer patients to discuss AD with PCPs.

## KEYWORDS

family medicine, medical communication, medical ethics, shared decision making

## 1 | INTRODUCTION

The rapid aging of the Japanese population means that an increasing number of patients and their families are facing the end of life.<sup>1,2</sup>

However, reports indicate that approximately 70% of terminally ill patients who can never be cured experience difficulty making patient-oriented decisions.<sup>3</sup> It is particularly difficult to make a decision about medical procedures immediately before death.<sup>4</sup> One way to

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overcome this issue is to establish advance directives (ADs).<sup>5</sup> An AD is defined as an oral or written statement in which a person, prior to his or her possible state of incapacitation, gives instructions regarding medical treatment.<sup>5</sup> Japanese people are increasingly required to discuss ADs and to consider a patient-oriented end of life while they are still healthy enough to express their intentions.

Primary care physicians (PCPs) play an important role in discussing ADs with patients. Primary care physicians can consult with patients about ADs to direct them to appropriate end-of-life care<sup>6</sup> and encourage them to establish ADs.<sup>7</sup> However, patients tend to hesitate to discuss ADs with medical practitioners including their PCPs<sup>3,8</sup> despite hoping to do so.<sup>9</sup> As a result, ADs are not shared between PCPs and their patients. Some reasons for this are associated with difficulties discussing ADs between physicians and patients.<sup>10</sup> From the physicians' perspective, a lack of training in communication<sup>11</sup> and uncertainty about prognostic accuracy<sup>12</sup> are key barriers. From the patients' perspective, anxiety and denial of disease are key barriers.<sup>13,14</sup>

Most previous studies regarding discussions about ADs were conducted in cancer patients. Noncancer diseases, compared to cancer, have clinical courses that make it more difficult to predict the patients' prognoses.<sup>15,16</sup> Nevertheless, it is just as important to investigate discussions about ADs in noncancer patients as it is in cancer patients because the number of noncancer disease cases, like cancer cases, is increasing. However, few studies have been conducted on noncancer patients in primary care settings (PCSs), where patients may want to discuss ADs. Identification of facilitators and barriers to discussing AD for noncancer patients may increase their opportunities to discuss ADs with their PCPs.

Therefore, the present study was conducted to identify the factors associated with discussing AD by noncancer patients with their physicians.

## 2 | METHOD

### 2.1 | Study design

This was a cross-sectional study conducted using an anonymous self-completed questionnaire survey by patients and a background survey on patients by their physicians.

### 2.2 | Setting and participants

Surveys were conducted in the outpatient section of the General Internal Medicine/Family Medicine department at a small 30-bed hospital or clinic in a PCS. Both the hospital and clinic are public healthcare institutions in the same prefecture, located 30 minutes by car from the city center, which has a population of 200 000 people. Both medical institutions provide primary care. At both sites, one physician treated an average of 20 patients per half day, the consultation time per patient was around 10 minutes, and no other medical staff were present in the room during an examination.

Study participants included noncancer patients who visited the study site for at least 6 months and their physicians. All physician

participants were Japan Primary Care Association (JPCA)-certified family physicians or JPCA diplomates in primary care. There were four JPCA-certified family physicians in the hospital and one in the clinic. There was one JPCA diplomate in primary care in the hospital and one in the clinic. Patients who met the following criteria were eligible to participate in the study: age 20 years or older, and no history of malignancy or any previous malignancy for which the patient was no longer receiving treatment at the time of the study. The following patients were excluded from the study: those who did not consent to participate in the study; those who completed the questionnaire more than twice; and those who were unable to complete the questionnaire due to dementia or physical disability.

### 2.3 | Survey methods

Physicians who attended the outpatient section of the study sites for at least 6 months, including during the study period from October to December 2017, and agreed to participate in the survey were designated physician participants. At least two visits to the same physician were used to define continuous contact between a patient-physician pair. Given that prescription medications in Japan can be prescribed for up to 3 months in one visit, and most patients consulted the same physician, consecutive visits within 6 months was used as an index for continuous contact. Patients who visited the outpatient section attended by the physician participants during the 1-month survey were continuously sampled at the hospital/clinic. The receptionist confirmed that patients satisfied the criteria of "over 20 years old" and "consecutive visits within 6 months." Physician participants subsequently checked patients' eligibility by confirming that "the patient had no malignancy that needed treatment" based on the patients' medical chart and that "it was a regular visit" and "the patient had not participated in the study" before a medical examination. At the end of the medical examination, physician participants judged whether the patients were capable of completing a questionnaire by themselves. Among those judged capable, the physician participants asked eligible patients to participate in the questionnaire-based study and provided each patient with a patient questionnaire with written instructions. Those who were considered incapable were excluded. A nurse or the receptionist explained the questionnaire and responses to the patients. The physicians were not informed of whether the patients consented to the study or of their responses, and the patients were informed of this fact. Patients who consented to participate in the study completed the questionnaire and dropped it into a designated box outside the examination room. The physicians completed a physician questionnaire after the medical examination. The lead investigator matched serially numbered patient questionnaire forms with corresponding physician questionnaire forms.

### 2.4 | Survey items

In this study, AD was defined in the questionnaire as acceptable or unacceptable treatment when a patient is too critically ill or deteriorating to communicate their intentions.<sup>5</sup>

In Japan, there is currently no valid scale for assessing factors related to the willingness of patients to discuss AD with their physicians. Therefore, survey items were selected by referring to previous studies and by discussion among the authors. The survey items listed below were selected based on the facilitators and barriers to patients' discussion with physicians about AD reported in previous studies<sup>17-20</sup> in order of clinical significance.

## 2.5 | Patient questionnaire

The following patient characteristics were investigated: age, gender, education level, self-perceived health status (five levels: 1 = poor to 5 = good), and period of visit to the study site (<1 year, 1 year to <2 years, 2 years to <3 years, 3 years to <4 years, ≥4 years). Regarding AD-related experiences, participants were inquired about the presence or absence of experience with caring for the dying and experience with proxy decisions and asked to indicate the extent to which the following items applied to them using a 5-point Likert-type scale (1: not at all, 2: slightly, 3: moderately, 4: very, 5: extremely): "I have previously thought about AD," "I have discussed AD with my family or friends," and "I have discussed AD with my doctor." Patients were also asked to use the 5-point Likert-type scale to respond to the item "I want to discuss AD with my doctor," which was used as the objective variable in the survey. In addition, patients used the same scale to respond to the following six facilitators and three barriers to discussing AD reported in previous studies: facilitators: "It is important for me to think about AD," "My doctor cares about me as a person," "I trust my doctor," "My doctor is very good at taking care of my disease," "I worry about my quality of life in the future," "I worry that I could be a burden on my family and friends if I got very sick"; and barriers: "I would rather concentrate on staying alive than talk about death," "I feel that talking about death can bring death closer," and "I'm not sure which doctor will provide care if I get very sick."<sup>17-20</sup>

## 2.6 | Physician questionnaire

The general condition of each patient surveyed was assessed using the Palliative Performance Scale (PPS).<sup>21</sup> The PPS is an observer-rated tool used to assess five functional dimensions: ambulation, activity level and evidence of disease, self-care, oral intake, and level of consciousness. The PPS is divided into 11 levels from 0% (death) to 100% (healthy) in 10 percent increments.<sup>21</sup> The disease being treated or followed up was categorized by the physician participants according to the International Classification of Primary Care, Second Edition (ICPC-2).<sup>22</sup>

## 2.7 | Statistical analyses

Patients' education level was classified into two categories: high school diploma or lower and two-year college diploma or higher. Self-perceived health status, period of visit to the study site, and PPS score were analyzed as ordinal variables. Responses to all questions

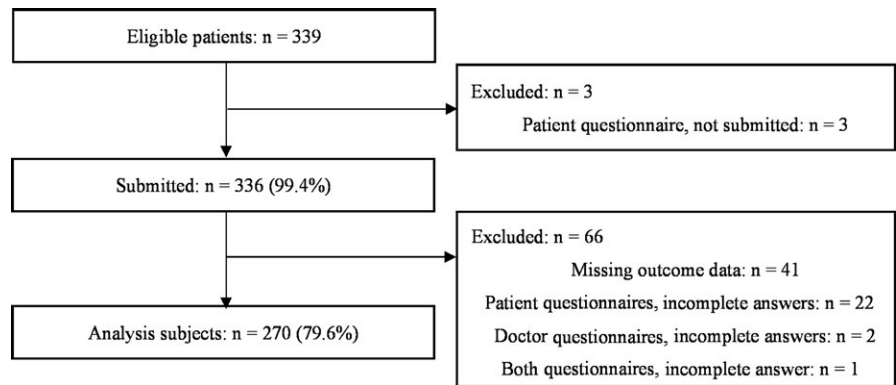
answered on the 5-point Likert-type scale were classified into two categories: not applicable, for responses of "1: not at all" and "2: slightly"; and applicable, for responses of "3: moderately," "4: very," and "5: extremely." The objective variable was "I want to discuss AD with my doctor," and the explanatory variables were age, gender, education level, self-perceived health status, period of visit to the study site, experience with caring for the dying, experience with proxy decisions, "I have previously thought about AD," "It is important for me to think about AD," facilitators and barriers to patients discussing AD with physicians, disease category, and PPS score. After descriptive statistics were determined for each variable, univariate analyses were performed for age using the Mann-Whitney U test and for nominal and ordinal variables using the chi-square test or Fisher's exact test at a significance level of <0.05.

In addition to significant variables identified by univariate analyses, and age and gender, which are potential confounders, patients' general condition in PCSs was considered relevant.<sup>23</sup> We employed the PPS as a validated tool for assessing patients' general condition in the palliative care field.<sup>24</sup> However, there were minimal differences in the general condition of patient participants receiving primary care, which is usually provided to relatively healthy individuals. Therefore, we concluded that it may be more clinically meaningful to use the PPS as a binomial qualitative tool based on the presence or absence of symptoms, rather than a quantitative tool. Accordingly, PPS scores were classified into two groups: scores of 100, indicating no symptoms, and scores of 90 or less, indicating the presence of symptoms. A binomial logistic regression analysis model was used to analyze differences between the symptom-free and symptomatic groups, with a significance level of <0.05. In view of potential multicollinearity, significant explanatory variables identified by univariate analysis were reviewed based on the correlation coefficients of similar variables to determine which variables to include in the binomial logistic regression analysis model. Statistical analysis was performed using SPSS ver.22 software (IBM Japan Co.,Ltd.,Tokyo, Japan).

This study was conducted with prior approval from the Ethics Committee of the Faculty of Medicine, University of Tsukuba (No. 1152-1).

## 3 | RESULTS

A survey flowchart is presented in Figure 1. Of the 339 patients surveyed, three did not submit a questionnaire form, while the remaining 336 responded to the questionnaire. A total of 295 patients (87.0%) who responded to the objective variable "I want to discuss AD with my doctor" were included in the univariate analyses, of which 270 (79.6%) were included in the multivariate analysis after excluding 25 patients who had missing data on any question in the patient and/or physician questionnaire. The characteristics of patients included in the univariate analyses are shown in Table 1. The mean ± SD age was 69.9 ± 11.3 years, 130 patients (44.1%) were male, 64 patients (21.7%) had an education level equivalent to a two-year college diploma or higher, 101



**FIGURE 1** Survey flow of patients

patients (34.4%) had a period of visit to the study site of  $\geq 3$  years, 222 patients (75.3%) had a PPS score of 100, and the most common self-perceived health status was 3 (147 patients, 49.8%). Major underlying diseases were cardiovascular diseases in 214 patients (72.5%) and endocrine/metabolic and nutritional diseases in 164 patients (55.6%).

Of the 295 patient participants, 74.2% replied positively to “I want to discuss AD with my doctor” (Figure 2). The distribution of other items such as experience with discussing AD, and facilitator and barrier factors are shown in Figure 2.

### 3.1 | Univariate analyses

The results of univariate analyses between the objective variable and the explanatory variables are presented in Table 1. No analysis was performed for the disease categories “pregnancy, childbearing, family planning” and “female genital system,” which were not relevant to this patient population. Explanatory variables with a significance level of  $<0.05$  were “I have previously thought about AD” ( $P < 0.01$ ), “It is important for me to think about AD” ( $P < 0.01$ ), “My doctor cares about me as a person” ( $P < 0.01$ ), “I trust my doctor” ( $P = 0.02$ ), “My doctor is very good at taking care of my disease” ( $P = 0.02$ ), “I worry about my quality of life in the future” ( $P < 0.01$ ), “I would rather concentrate on staying alive than talk about death” ( $P = 0.01$ ), and “I feel that talking about death can bring death closer” ( $P = 0.01$ ). The chi-square test also identified the period of visit to the study site as a significant factor ( $P = 0.03$ ). No significant correlation was observed between the objective variable and age, gender, education level, self-perceived health status, PPS score, experience with caring for the dying, experience with proxy decisions, or individual disease categories. After the univariate analyses, frequency distributions were determined using histograms to perform a multivariate analysis, with the period of visit to the study site being categorized into two groups ( $\geq 3$ ,  $<3$  years).

### 3.2 | Multivariate analysis

For the objective variable, binomial logistic regression analysis was performed using an analytical model that included the following explanatory variables: age and gender; basic characteristics that may

be confounders; significant variables identified by univariate analyses; and period of visit to the study site ( $\geq 3$ ,  $<3$  years). The analytical model did not include “I have previously thought about AD” and “It is important for me to think about AD” as explanatory variables because they were considered intermediate factors of the objective variable “I want to discuss AD with my doctor.” Additionally, the model included “My doctor is very good at taking care of my disease,” which was selected among three variables with a Pearson correlation coefficient of  $\geq 0.4$  and a two-sided  $P$ -value of  $<0.01$ , including “My doctor cares about me as a person” and “I trust my doctor.” The results are presented in Table 2. Period of visit to the study site (reference,  $<3$  years; odds ratio [OR], 2.07; 95% confidence interval [CI], 1.05-4.10;  $P = 0.04$ ), PPS score (reference, PPS 100; OR, 0.51; 95% CI, 0.26-0.98;  $P = 0.04$ ), “My doctor is very good at taking care of my disease” (reference, not applicable; OR, 12.68; 95% CI, 1.12-143.22;  $P = 0.04$ ), and “I worry about my quality of life in the future” (reference, not applicable; OR, 2.69; 95% CI, 1.30-5.57;  $P = 0.01$ ) were identified as significant variables.

## 4 | DISCUSSION

Among noncancer patients who visited an outpatient hospital or clinic in a PCS for at least 6 months in Japan, willingness to discuss ADs with their physicians was significantly positively correlated with a period of visit to the study site of  $\geq 3$  years, belief that “My doctor is very good at taking care of my disease,” and feelings of “I worry about my quality of life in the future” and was significantly negatively correlated with a PPS score of  $\leq 90$ .

The relationship between the period of visit to a study site and willingness of patients to discuss AD was not investigated in previous studies, including in a cross-sectional study in cancer and noncancer outpatients who visited a family physician or a specialist for at least 18 months<sup>17</sup> and a cross-sectional study in primary care outpatients aged 18 years or older.<sup>25</sup> It would have been difficult to follow up patients for over 3 years if the studies involved terminally ill cancer patients. The present study suggests that a certain period of time may be required to build a consultative relationship between physicians and patients to encourage patients to discuss AD with their physicians. A previous report suggested that patients want to

**TABLE 1** Patients' characteristics, predictors, and univariate analysis results

Variable	Total n = 295	I want to discuss AD with my doctor		P-value
		Yes, n = 219(%)	No, n = 76 (%)	
Age (mean ± SD)	69.9 ± 11.3	69.6 ± 10.8	67.0 ± 12.7	0.08 <sup>a</sup>
<65	72 (24.4)	47 (21.7)	25 (32.9)	0.05 <sup>b</sup>
≥65	221 (74.9)	170 (78.3)	51 (67.1)	
Data missing	2 (0.7)			
Gender (reference: male)				
Female	161 (54.6)	119 (55.3)	42 (55.3)	0.99 <sup>b</sup>
Male	130 (44.1)	96 (44.7)	34 (44.7)	
Data missing	4 (1.3)			
Educational level				
<Junior high school	70 (24.1)	55 (25.6)	15 (20.0)	0.65 <sup>b</sup>
High school diploma	156 (53.8)	111 (51.6)	45 (60.0)	
Two-year college or vocational school	30 (10.3)	23 (10.7)	7 (9.3)	
Four-year college degree	34 (11.7)	26 (12.1)	8 (10.7)	
Data missing	5 (1.7)			
(reference: ≤High school diploma)				
≥Two-year college	64 (21.7)	49 (22.8)	15 (20.0)	0.62 <sup>b</sup>
≤High school diploma	226 (76.6)	166 (77.2)	60 (80.0)	
Self-perceived health status				
1: poor	1 (0.3)	1 (0.5)	0 (0)	0.94 <sup>b</sup>
2	41 (13.9)	32 (14.8)	9 (11.8)	
3	147 (49.8)	108 (50.0)	39 (51.3)	
4	67 (22.7)	49 (22.7)	18 (23.7)	
5: good	36 (12.2)	26 (12.0)	10 (13.2)	
Data missing	3 (1.0)			
Palliative Performance Scale (PPS) score				
50	1 (0.3)	1 (0.5)	0 (0)	0.77 <sup>b</sup>
60	3 (1.0)	2 (0.9)	1 (1.3)	
70	4 (1.4)	3 (1.4)	1 (1.3)	
80	17 (5.8)	12 (5.5)	5 (6.8)	
90	45 (15.2)	30 (13.8)	15 (20.3)	
100	222 (75.3)	170 (78.0)	52 (70.3)	
Data missing	3 (1.0)			
(reference: 100)				
≤90	70 (23.7)	48 (22.0)	22 (29.7)	0.06 <sup>b</sup>
100	222 (75.3)	170 (78.0)	52 (70.3)	
Period of visit to the study site				
Over 6 mo to <1 y	32 (10.8)	22 (10.1)	10 (13.1)	0.03 <sup>b</sup>
Over 1 y to < 2 y	76 (25.8)	57 (26.1)	19 (25.0)	
Over 2 y to < 3 y	85 (28.8)	55 (25.2)	30 (39.5)	
Over 3 y to <4 y	28 (9.5)	26 (11.9)	2 (2.6)	
Over 4 y	73 (24.7)	58 (26.6)	15 (19.7)	
Data missing	1 (0.3)			
(reference: <3 y)				

(Continues)

**TABLE 1** (Continued)

Variable	Total n = 295	I want to discuss AD with my doctor		P-value
		Yes, n = 219(%)	No, n = 76 (%)	
Over 3 y	101 (34.4)	84 (38.5)	17 (22.4)	0.01 <sup>b</sup>
<3 y	193 (65.6)	134 (61.5)	59 (77.6)	
I have previously thought about AD				
Applicable	185 (62.7)	160 (74.8)	25 (34.7)	<0.01 <sup>b</sup>
Not applicable	101 (34.2)	54 (25.2)	47 (65.3)	
Data missing	9 (3.1)			
I have experience caring for the dying				
Yes	243 (82.4)	183 (84.7)	60 (78.9)	0.25 <sup>b</sup>
No	49 (16.6)	33 (15.3)	16 (21.1)	
Data missing	3 (1.0)			
I have experience with proxy decisions				
Yes	137 (46.4)	103 (48.6)	34 (45.9)	0.70 <sup>b</sup>
No	149 (50.5)	109 (51.4)	40 (54.1)	
Data missing	9 (3.1)			
Facilitators				
It is important for me to think about AD				
Applicable	253 (85.8)	208 (96.3)	45 (60.0)	<0.01 <sup>b</sup>
Not applicable	38 (12.9)	8 (3.7)	30 (40.0)	
Data missing	4 (1.4)			
My doctor cares about me as a person				
Applicable	277 (93.9)	205 (100)	72 (94.7)	<0.01 <sup>c</sup>
Not applicable	4 (1.4)	0 (0)	4 (5.3)	
Data missing	14 (4.7)			
I trust my doctor				
Applicable	291 (98.6)	218 (100)	73 (96.1)	0.02 <sup>c</sup>
Not applicable	3 (1.0)	0 (0)	3 (3.9)	
Data missing	1 (0.3)			
My doctor is very good at taking care of my disease				
Applicable	284 (96.3)	214 (75.4)	70 (24.6)	0.02 <sup>c</sup>
Not applicable	5 (1.7)	1 (20.0)	4 (80.0)	
Data missing	6 (2.0)			
I worry about my quality of life in the future				
Applicable	233 (79.0)	183 (86.7)	50 (67.6)	<0.01 <sup>b</sup>
Not applicable	52 (17.6)	28 (13.3)	24 (33.4)	
Data missing	10 (3.4)			
I worry that I could be a burden on my family and friends if I got very sick				
Applicable	273 (92.5)	206 (94.9)	67 (89.3)	0.08 <sup>c</sup>
Not applicable	19 (6.5)	11 (5.1)	8 (10.7)	
Data missing	3 (1.0)			
Barriers				
I would rather concentrate on staying alive than talk about death				
Applicable	265 (89.8)	203 (94.9)	62 (84.9)	0.01 <sup>b</sup>
Not applicable	23 (7.8)	12 (5.1)	11 (15.1)	
Data missing	7 (2.4)			

(Continues)

**TABLE 1** (Continued)

Variable	Total n = 295	I want to discuss AD with my doctor		
		Yes, n = 219(%)	No, n = 76 (%)	P-value
I feel that talking about death can bring death closer				
Applicable	178 (60.3)	142 (66.4)	36 (48.0)	0.01 <sup>b</sup>
Not applicable	111 (37.6)	72 (33.6)	39 (52.0)	
Data missing	6 (2.0)			
I'm not sure which doctor will provide care if I get very sick				
Applicable	212 (71.9)	164 (77.4)	48 (65.8)	0.05 <sup>b</sup>
Not applicable	73 (24.7)	48 (22.6)	25 (34.2)	
Data missing	10 (3.4)			
ICPC-2 category				
General and unspecified				
Applicable	2 (0.7)	2 (0.9)	0 (0)	0.55 <sup>c</sup>
Not applicable	293 (99.3)	217 (99.1)	76 (100)	
Blood, blood-forming organ and immune mechanism				
Applicable	2 (0.7)	2 (0.9)	0 (0)	0.55 <sup>c</sup>
Not applicable	293 (99.3)	217 (99.1)	76 (100)	
Digestive				
Applicable	74 (25.1)	49 (22.4)	25 (32.9)	0.07 <sup>b</sup>
Not applicable	221 (74.9)	170 (77.6)	51 (67.1)	
Eye				
Applicable	2 (0.7)	2 (0.9)	0 (0)	0.55 <sup>c</sup>
Not applicable	293 (99.3)	217 (99.1)	76 (100)	
Ear				
Applicable	2 (0.7)	2 (0.9)	0 (0)	0.55 <sup>c</sup>
Not applicable	293 (99.3)	217 (99.1)	76 (100)	
Cardiovascular				
Applicable	214 (72.5)	160 (73.1)	54 (71.1)	0.74 <sup>b</sup>
Not applicable	81 (27.5)	59 (26.9)	22 (28.9)	
Musculoskeletal				
Applicable	40 (13.6)	28 (12.8)	12 (15.8)	0.51 <sup>b</sup>
Not applicable	255 (86.4)	191 (87.2)	64 (84.2)	
Neurological				
Applicable	23 (7.8)	16 (7.3)	7 (9.2)	0.59 <sup>b</sup>
Not applicable	272 (92.2)	203 (92.7)	69 (90.8)	
Psychological				
Applicable	74 (25.1)	56 (25.6)	18 (23.7)	0.74 <sup>b</sup>
Not applicable	221 (74.9)	163 (74.4)	58 (76.3)	
Respiratory				
Applicable	14 (4.7)	10 (4.6)	4 (5.3)	0.51 <sup>c</sup>
Not applicable	281 (95.3)	209 (95.4)	72 (94.7)	
Skin				
Applicable	4 (1.4)	3 (1.4)	1 (1.3)	0.73 <sup>c</sup>
Not applicable	291 (98.6)	216 (98.6)	75 (98.7)	

(Continues)



**TABLE 1** (Continued)

Variable	Total n = 295	I want to discuss AD with my doctor		P-value
		Yes, n = 219(%)	No, n = 76 (%)	
Endocrine/metabolic and nutritional				
Applicable	164 (55.6)	126 (57.5)	38 (50.0)	0.26 <sup>b</sup>
Not applicable	131 (44.4)	93 (42.5)	38 (50.0)	
Urological				
Applicable	10 (3.4)	6 (2.7)	4 (5.3)	0.24 <sup>c</sup>
Not applicable	285 (96.6)	213 (97.3)	72 (94.7)	
Male genital				
Applicable	1 (0.3)	1 (0.5)	0 (0)	0.74 <sup>c</sup>
Not applicable	294 (99.7)	218 (99.5)	76 (100)	
Social problems				
Applicable	4 (1.4)	4 (1.8)	0 (0)	0.30 <sup>c</sup>
Not applicable	291 (98.6)	215 (98.2)	76 (100)	

<sup>a</sup>Unpaired t test.

<sup>b</sup>Chi-square test.

<sup>c</sup>Fisher's exact test.

discuss AD with physicians who understand them very well.<sup>26</sup> This is supported by our finding that the belief that "My doctor is very good at taking care of my disease" was a facilitator for discussing AD. Confidence established between physicians and patients may therefore contribute to willingness of patients to discuss AD with their physicians.

"I worry about my quality of life in the future" was also identified as a facilitator for discussing AD in a previous study.<sup>17</sup> However, in contrast to the previous finding that patients with anxiety or depression tended to want to discuss AD,<sup>17</sup> we found no association with such psychological diseases in this study. This may be due to differences in the proportion of patients with various psychological diseases between the studies. In the present study, the psychological disease category included not only depression and anxiety, but also insomnia, and many patients with psychological disease at outpatient primary care clinics, which are often visited by patients complaining of insomnia,<sup>27</sup> had insomnia without depression or anxiety. Therefore, the lack of an association between psychological diseases and willingness to discuss AD in this study may be due to a low rate of depression among participant patients in these PCSs.

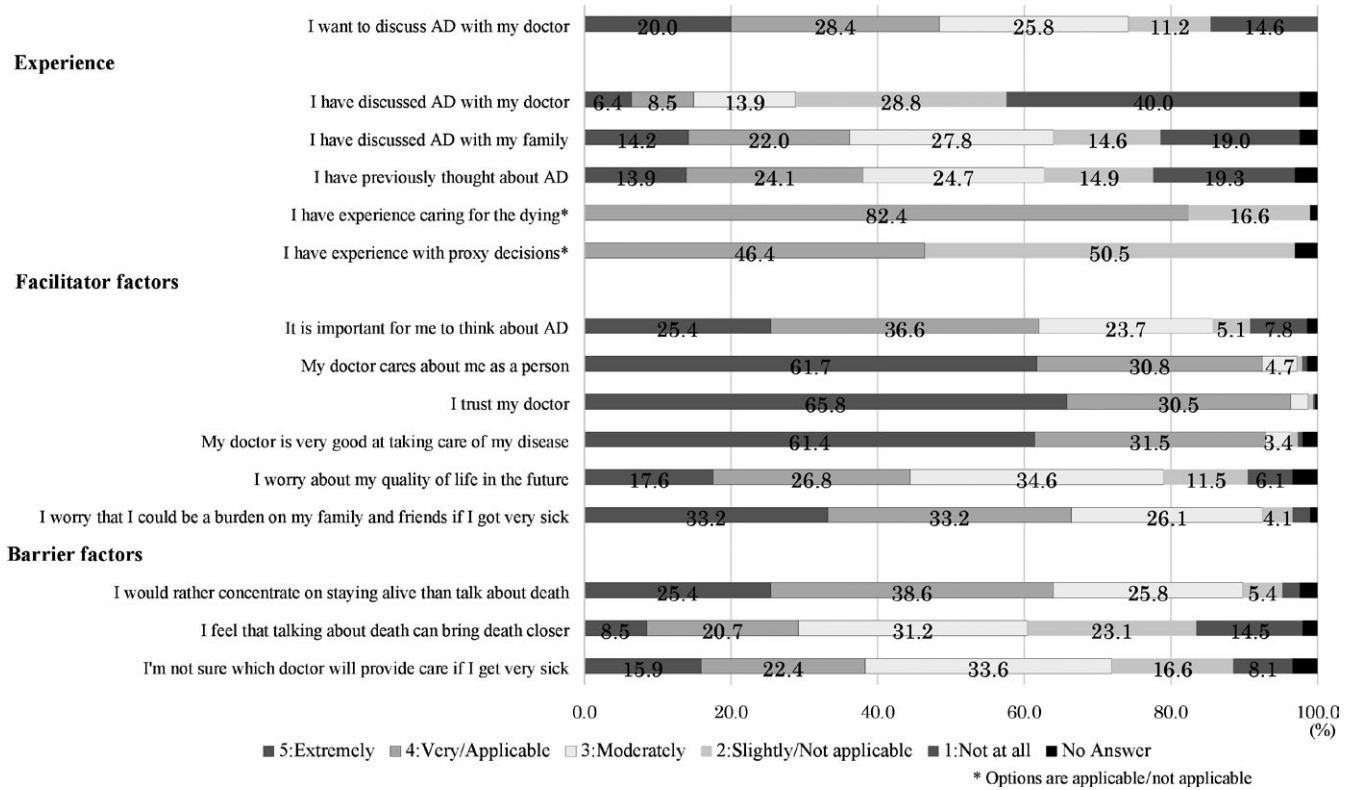
We also identified a PPS score  $\leq 90$  as a significant barrier to discussing AD. PPS score  $\leq 90$  indicates that physicians identified symptoms in patients. Therefore, our finding suggests that noncancer primary care patients with symptoms tended to be reluctant to discuss AD with their physicians. This may be partly explained by differences in the curability of diseases. Cancer patients coping with incurable disease after an informed diagnosis of cancer may have an opportunity to discuss AD as their symptoms or physical function deteriorate.<sup>28,29</sup> In contrast, noncancer patients with slow progressive diseases that follow a course of exacerbation and remission may feel that the disease has been cured when it is only transiently relieved. It is therefore conceivable that these patients are often

optimistic about transient symptom relief and avoid discussing AD when they experience symptoms. The present study suggests that noncancer patients who do not have symptoms associated with their chronic disease may be more inclined to discuss AD while noncancer patients with deteriorating physical function may be reluctant to talk about AD with their physicians.

To facilitate patient-oriented end of life, it is important to provide sufficient opportunities for patients to voice their intentions even while they are still healthy. However, establishing ADs too early leads to ambiguity and uncertainty, with ADs tending to be most uncertain in the general healthy population, followed by outpatients and then inpatients.<sup>30</sup> Therefore, physicians should be increasingly aware of chances to establish ADs to ensure that they are discussed in a timely manner.<sup>31</sup> To avoid missing out on such a chance, the present study suggests that physicians should discuss ADs with noncancer patients before the development of symptoms following a diagnosis.

The present study has several limitations. First, given that representative related factors were selected from those identified in previous studies, other potentially related factors may have been missed. Second, this was a cross-sectional study and was therefore not designed to demonstrate a causal relationship. Third, there may have been a degree of sampling bias because the study participants were only from two local areas. As we did not set any criteria for how physicians should determine patients' capability to complete the questionnaire, the physician participants may have assessed each patient's capability based on clinical observations. Further studies are needed to generalize the results to the entire Japanese population. Fourth, there may be a reporting bias associated with the frequency of visits. Patients with a higher frequency of visits may have increased desire to discuss AD. Further, we did not determine the number of visits by patients prior to the survey. Fifth, only five patients answered "No" to the item "My doctor is good at taking care of my disease," and the range of its CI was large, which may have

**Objective variables**



**FIGURE 2** Distribution of survey items: the objective variable, experience with discussing AD, and facilitator and barrier factors

reduced the stability of the multivariate model. However, we think that it was important to examine this factor because previous studies<sup>18-20</sup> have shown that patients' feelings toward their physician is a key factor in their willingness to conduct AD discussions with their

physician. Sixth, we analyzed data from the patient participants as a single group even though there were some differences in participant characteristics between the two study sites. Differences and similarities in participant characteristics between the two study sites are

**TABLE 2** Factors associated with "I want to discuss AD with my doctor" (binomial logistic regression analysis)

Variable	Reference	Univariate		Multivariate		P-value <sup>a</sup>
		Crude OR	95% CI	Adjusted OR	95% CI	
Age	<65 y	1.77	1.00-3.16	1.74	0.90-3.37	0.10
Gender	Male	1.00	0.59-1.70	0.98	0.53-1.80	0.98
Period of visit to the study site	<3 y	2.18	1.19-3.98	2.07	1.05-4.10	<b>0.04</b>
Palliative Performance Scale score	100	0.67	0.37-1.21	0.51	0.26-0.98	<b>0.04</b>
<b>Facilitators</b>						
My doctor is very good at taking care of my disease	Not applicable	12.23	1.34-111.23	12.68	1.12-143.22	<b>0.04</b>
I worry about my quality of life in the future	Not applicable	3.14	1.67-5.88	2.69	1.30-5.57	<b>0.01</b>
<b>Barriers</b>						
I would rather concentrate on staying alive than talk about death	Not applicable	3.00	1.26-7.14	1.38	0.41-4.65	0.60
I feel that talking about death can bring death closer	Not applicable	2.14	1.25-3.65	1.55	0.83-2.93	0.17

CI, confidence interval; OR, odds ratio.

<sup>a</sup>P-value was calculated for multivariate analysis.

The bold values indicate P-value is significant level of <0.05.

summarized in the Table S1. There were no differences in participant characteristics between the two locations except for mean age and period of visit to the study sites. In accordance with findings in the literature,<sup>17-20</sup> we hypothesized that the physician-patient relationship was a more significant factor for patients discussing AD with their physician than study location. Therefore, we analyzed the patient participants from the two sites as a single group. In the future, differences in patient characteristics among locations should be accounted for by increasing the sample size and comparison with findings from other studies. Finally, the PPS has been validated to assess the condition of patients receiving palliative care,<sup>24</sup> but not those receiving primary care. Nevertheless, the use of PPS in primary care was clinically meaningful because we compared the results of this study with those of studies in cancer patients. Further follow-up of noncancer patients in multiple PCSs over time may reveal changes in willingness toward discussing AD and the underlying reasons.

## 5 | CONCLUSIONS

Our study indicates that a patient's future QOL concerns, a long period of visit to a hospital, and the presence of physical symptoms are associated with the willingness of noncancer patients to discuss ADs with PCPs. These findings will be useful for developing strategies to encourage patients to discuss ADs with their physicians.

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## CONFLICT OF INTEREST

The authors have stated explicitly that there are no conflicts of interest in connection with this article.

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## REFERENCES

- Ministry of Health, Labor and Welfare Japan. Vital statistics, 2016 [Internet]. Tokyo: Ministry of Health, Labor and Welfare Japan [update Sep 2017; cited 2018 may 25]. Available from: <https://www.mhlw.go.jp/english/database/db-hw/vs01.html>
- National Institute of Population and Social Security Research. Population Projection for Japan, April 2017 [Internet]. Tokyo: National Institute of Population and Social Security Research. [update Jul 2017; cited 2018 may 25]. Available from: [http://www.ipss.go.jp/pp-zenkoku/e/zenkoku\\_e2017/pp\\_zenkoku2017e.asp](http://www.ipss.go.jp/pp-zenkoku/e/zenkoku_e2017/pp_zenkoku2017e.asp)
- Silveira MJ, Kim SYH, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med*. 2010;362(13):1211-8.
- Kinoshita Y, Aruga T, Yokota H, Koike K. End of life practices with critical care patients in Japan. *Nihon Kyukyū Igakukai Zasshi [Japanese]*. *J Japanese Assoc Acute Med*. 2016;27(11):716-21.
- Mahon MM. An advance directive in two questions. *J Pain Symptom Manage*. 2011;41(4):801-7.
- Spoelhof GD, Elliott B. Implementing advance directives in office practice. *Am Fam Physician*. 2012;85(5):461-6.
- Pungo PA. Advance directives in primary care setting. *Wien Klin Wochenschr*. 2004;116(13):417-9.
- Ministry of Health, Labor and Welfare Japan. Survey on medical consciousness at the final stage of life, 2018 [Japanese]. Tokyo: Study group on consciousness survey on terminal medical care. [update Mar 2018; cited 2018 may 27]. Available from: [https://www.mhlw.go.jp/toukei/list/dl/saisyuiryo\\_a\\_h29.pdf](https://www.mhlw.go.jp/toukei/list/dl/saisyuiryo_a_h29.pdf)
- Fischer S, Min SJ, Kutner J. Advance directive discussions do not lead to death. *J Am Geriatr Soc*. 2010;58:400-1.
- Bernacki RE, Block SD; American College of Physicians High Value Care Task F. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med*. 2014;174(12):1994-2003.
- Buss MK, Lessen DS, Sullivan AM, Von Roenn J, Arnold RM, Block SD. Hematology/oncology fellows' training in palliative care: results of a national survey. *Cancer*. 2011;117(18):4304-11.
- Clayton JM, Butow PN, Arnold RM, Tattersall MH. Discussing life expectancy with terminally ill cancer patients and their carers: a qualitative study. *Support Care Cancer*. 2005;13(9):733-42.
- Mack JW, Cronin A, Taback N, et al. End-of-life care discussions among patients with advanced cancer: a cohort study. *Ann Intern Med*. 2012;156:204-10.
- Michael M, Susan B. Psychiatric disorders in advanced cancer. *Cancer*. 2007;110(8):1665-76.
- Fox E, Landrum-McNiff K, Zhong Z, et al. Evaluation of prognostic criteria for determining hospice eligibility in patients with advanced lung, heart, or liver disease. *JAMA*. 1999;282(17):1638-45.
- Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at the end of life. *JAMA*. 2003;289(18):2387-92.
- Fakhri S, Engelberg RA, Downey L, et al. Factors affecting patients' preferences for and actual discussions about end-of-life care. *J Pain Symptom Manage*. 2016;52(3):386-94.
- Curtis JR, Patrick DL, Caldwell ES, Collier AC. Why don't patients and physicians talk about end-of-life care? Barriers to communication for patients with acquired immunodeficiency syndrome and their primary care clinicians. *Arch Intern Med*. 2000;160(11):1690-6.
- Knauff E, Nielsen EL, Engelberg RA, Patrick DL, Curtis JR. Barriers and facilitators to end-of-life care communication for patients with COPD. *Chest*. 2005;127(6):2188-96.
- Matthias G, Daniel TMCJ, Mehtap G-Y, Lawrence LSHKA. Facilitators of and barriers to advance care planning in adult congenital heart disease. *Congenit Heart Dis*. 2013;8(4):281-8.
- Anderson F, Downing GM, Hill J, Casorso L, Lerch N. Palliative performance scale (PPS): a new tool. *J Palliat Care*. 1996;12(1):5-11.
- World Health Organization, ed. *International Classification of Health Problems in Primary Care 2, ICPC-2*. Oxford, UK: Oxford University press; 1998.
- Leung JM, Udris EM, Uman J, Au DH. The effect of end-of-life discussions on perceived quality of care and health status among patients with COPD. *Chest*. 2012;142(1):128-33.
- Ho F, Lau F, Downing MG, Lesperance M. A reliability and validity study of the Palliative Performance Scale. *BMC Palliat Care*. 2008;7:10.

25. O'Sullivan R, Mailo K, Angeles R, Agarwal G. Advance directives Survey of primary care patients. *Can Fam Physician*. 2015;61:353-6.
26. Dow LA, Matsuyama RK, Ramakrishnan V, et al. Paradoxes in advance care planning: the complex relationship of oncology patients, their physicians, and advance medical directives. *J Clin Oncol*. 2010;28(2):299-304.
27. Yamada T, Yoshimura M, Nago N, et al. What is the common diseases and common health problems? -The use of ICPC in a community-based project on Health Care. Primary care. [Japanese]. 2000;23(1):80-9.
28. El-Sahwi KS, Illuzzi J, Varughese J, et al. A survey of gynecologic oncologists regarding the end-of-life discussion: a pilot study. *Gynecol Oncol*. 2012;124:471-3.
29. Keating NL, Landrum MB, Rogers S, et al. Physician factors associated with discussion about end of life care. *Cancer*. 2010;116(4):998-1006.
30. 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(7):1085-92.
31. Billings J, Bernacki R. Strategic targeting of advance care planning interventions: the goldilocks phenomenon. *JAMA Intern Med*. 2014;174(4):620-4.

#### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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