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ORIGINAL ARTICLE

Advance Care Planning in Japan;
Survey of the Primary Care Physicians' View

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ABSTRACT

Background: This study reports a critique of advance care planning (ACP) by primary care physicians (PCP) in the at-home medical-care field in Japan.

Methods: A cross-sectional survey was designed from previous research, piloted, revised, and sent out to all PCP during April and May 2019. The target participants were all the total 914 PCP registered online nationwide in Japan. After piloting, there were 28 question items with five Likert scale, plus some open-ended response items, treated by factor analysis to discover the leading essential characteristics of ACP.

Results: The mean scores for each of the 28 items ranged from 3.73 to 4.85, and the leading 18 items were analyzed to reveal there were five factors. These were;- 1. Trust in the Doctor-Patient Relationship, 2. Building-up Cooperation, 3. Enlightenment and Awareness of ACP, 4. Level up Views on Life and Death among Health Care Providers, and 5. Patient and Family Preparedness for Death. The inter-factor correlation ranged from 0.06 to 0.44, and Cronbach alpha coefficient ranged from 0.74 to 0.95. Findings showed that more PCP, than not, considered the important characteristics to be (a) Experience of bereavement with someone close, p <0.01, (b) Attached home visiting nurse office, p =0.04, and (c) Medical fee point as home care supporting clinic, p =0.02.

Conclusion: A total of five factors were statistically discovered to be necessary for ACP in Japan, and a total of three statistically confirmed basic characteristics.

I. Introduction

Japan has the highest proportion of old-aged people in the world, and there is consequently increasing interest in planning for and delivering medical and care support for these people.[1] Further it is becoming clear that old-aged patients and their families need guidance as to their various medical and care choices. Such medical and care support guidance should be from healthcare providers in a timely manner in advance of their making their decisions. The government Ministry of Health, Labour and Welfare has proposed Advance Care Planning (ACP) guidelines to be the most suitable and best decision support model and encourages the promotion of ACP throughout Japan.[2]

ACP guidelines improve the quality of end-of-life care, increase patient and family satisfaction, and reduce stress, anxiety, and depression in surviving relatives.[3,4] ACP increases the availability of in-hospital palliative care,[5] and increases end-of-life care at home.[6] Moreover, patients want to talk about their prognosis with both their primary care physician (PCP) and their specialist doctor,[7] but only 27.3% of physicians are aware and practice ACP.[1,8] One of the advantages of ACP is that the patient can convey their own wishes about end-of-life care, to their family and to their PCP and care providers.

For ACP to proceed seamlessly among various health-care providers, it is important to know the PCP view in charge of the patient's future medical needs and treatment. While some studies have explored the use of ACP through surveys on visiting-nurses and at-home care-providers, [9-12] there has been no research yet exploring what are the essential characteristics of ACP in Japan from the perspectives of the PCP in the at-home medical field. Therefore, this study set out to investigate what PCP consider to be the basic characteristics in practicing ACP, and to rate the various aspects of ACP.

II. Methods

1. Study design and Participants

This cross-sectional study was conducted during April and May 2019. The self-administered questionnaires involved all 914 PCP registered online nationwide in Japan with home-care support clinics (retrieved March 2019).[13] Of the total 914 registered, there were 45 registrations with insufficient postal-address data, and the survey was consequently sent out by letter-post to a total of 869 registered PCP.

Responses were received from 203 (giving a low response rate of 23.4%). Among these 203 returns, there were only 188 with complete data, with usable responses to all 28 items (giving a valid response rate 92.6%) to be included into this study using factor analysis.

2. Questionnaire

As no validated research tools existed for achieving the objectives of our study, the questionnaire was developed based on the previous study with key words end-of-life, decision-making and ACP.[14-28] The 21 of 28 questions are based on previous study and seven of 28 questions added after pilot test.

A pilot test found that PCP suggested to add additional more-detailed questions more-specifically relating to the current at-home health-care issues in Japan, and a further seven question items were added to make a usable survey instrument consisting of 28 questions with closed-responses on a five-point Likert scale (1 very-unnecessary, 2 unnecessary, 3 neither unnecessary nor necessary, 4 necessary, and 5 very necessary). The 28-item survey was then again piloted for final checking by three PCP and two university researchers in the at-home medical field.

3. Statistics analysis

The final questionnaire had 28 variables with high internal reliability at Cronbach alpha at 0.89. These 28 variables with an I-T correlation over 0.2 were then selected for factor analysis.

Factor analyses was to seeks the least number of factors which can account for the common variance (correlation) of a set of 28 variables, Student's t-test analyses was to seeks the difference between each variance and participants' basic characteristic. We were conducted with SPSS (version 23) and significance level was less than 0.05.

Primary analysis made 28 variables account for the common variance, which the number of principal components selected by Kaiser criterion and Scree Plot. The construct validity of factor analyzed with Kaiser-Meyer-Olkin (0.76) and Bartlett tests ($p < 0.01$).

Secondary analysis made the difference between the principle component and participants' basic characteristic, Gender, Age, Experience of doctor, Experience of PCP in home medical, Experience of bereavement with someone close, Number of doctor in clinic, Attached home visiting nurse office, Number of patients, Number of death certification in home, Medical fee point as home care supporting clinic.

4. Ethical considerations

This study protocol was approved by the institutional review boards of Kio university (No: H30-21), with participants' consent implied by the return of the questionnaires. This study was performed between April and May 2019; with a cover letter clearly stating the purpose of this study, the right to refuse to participate, strict safeguarding of the data except for the publication of anonymous statistically analyzed data, which does not specify individuals. According to the university ethics committee regulations, informed consent was not required in this study. It was assumed that each subject agreed to join the study of his/her own free will by returning the answered questionnaire.

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5. Definition of ACP in this study

This research defined ACP was a process whereby a patient, in consultation with health care providers, family and important others, makes decisions about his or her future medical and care. The role of PCP in ACP was almost being defined, as central within the context of the physician-patient relationship, providing information to makes decisions about patients' future medical and care.[29]

III. Results

1. Participant basic characteristic

Table 1 shows basic characteristics. Study participants had a mean age of 57.3 (SD = 9.7), experience of PCP in home medical 17.7 (SD = 9.3) years. As the situation of the clinic, number of patients had 320.1 (SD = 1,149.8), number of death certification in home had 36.4 (SD = 47.1) from January 2018 to December 2018. The percentage of participants' clinic with attached the home visiting nurse office was 35.1%, and the medical fee point as home care supporting clinic was 96.8%.

<Table 1> Participant Characteristic

Variable	N	Item	n	%	Mean ± SD	Median
Gender	188	Male	174	92.6		
		Female	14	7.4		
Age / yrs	187				57.3±9.7	59.0
Experience of doctor / yrs	187				30.9±9.2	32.0
Experience of primary care physician in home medical / yrs	187				17.7±9.3	17.0
Experience of bereavement with someone close	182	Yes	171	94.0		
		No	11	6.0		
Number of doctors in clinic (include part-time)	185				3.5±3.8	2.0
Attached home visiting nurse office	178	Yes	66	37.1		
		No	112	62.9		
Number of patients*	176				320.1±1,149.8	104.0
Number of death certification in home*	179				36.4±47.1	19.0
Medical fee point as home care supporting clinic	187	Yes	181	96.8		
		No	6	3.2		

*: The data period is from January 2018 to December 2018

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2. Necessary for ACP from primary care physicians' view

Table 2 shows necessary for ACP from PCP's view. The mean scores for each variable ranged from 3.73 to 4.85, and Item-Total correlations (I-T correlation) ranged from 0.21 to 0.63. The top five variables with the highest averages were patients 'preparedness for own death', 'improved care system', 'revision of medical fees (upgrade evaluation)', 'citizens awareness reform on life and death', 'level up views on life and death among doctors'.

In this study, factor analysis (principal factor method, pro-max rotation) was performed for all 28 variables because there were no variables under 0.2 with I-T correlation. The number of five factors was determined both Kaiser criterion (= eigenvalue) over 1.0 and reference of with good cohesion of meaning among variables in each factor. The requirement of deleting variables are 1) factor loading of each variable was less than 0.35, 2) variables showed similar factor loadings for multiple factors. The factor analysis was repeated under the same conditions (principal factor method, pro-max rotation) until there were no more variables to be deleted. As a result, 18 of 28 variables remained finally.

<Table 2> Necessary for ACP from Primary Care Physicians' View (N=188)

No	28 Variables	Mean*	SD	I-T correlation
1	patients' preparedness for own death	4.85	0.48	0.25
2	improved care system	4.81	0.43	0.63
3	revision of medical fees (upgrade evaluation)	4.81	0.45	0.50
4	citizens awareness reform on life and death	4.77	0.46	0.38
5	level up views on life and death among doctors	4.70	0.60	0.54
6	treatment decisions are made involving patient wishes	4.60	0.63	0.40
7	cooperation with home visiting nurse office	4.49	0.80	0.36
8	family preparedness for patient death	4.48	0.78	0.21
9	construction of information sharing system	4.48	0.72	0.48
10	cooperation between hospital and clinic in home medical field	4.46	0.79	0.40
11	cooperation between clinics	4.41	0.73	0.39
12	training in ACP	4.41	0.74	0.52
13	system for obtaining ACP specialized consultation and advice	4.41	0.70	0.42
14	hospitalized beds are available when the patient condition changes	4.41	0.77	0.57
15	explanation sufficiently to the family on clinical course	4.37	0.74	0.34
16	education on life and death in educational institutions	4.37	0.69	0.53
17	level up views on life and death among medical staff	4.36	0.80	0.56
18	cooperation with care managers on long-term care insurance law	4.34	0.70	0.40
19	appropriate transition from hospital to home medical field	4.27	0.78	0.53
20	family education on medical and care support for patients	4.22	0.90	0.59

No	28 Variables	Mean*	SD	I-T correlation
21	medical staff need adequate time to cope	4.21	0.78	0.31
22	treatment decisions are made involving family wishes	4.16	0.71	0.37
23	emergency hospital beds are secured	4.10	0.88	0.52
24	easy-to-use services in long-term insurance when needed	4.06	0.91	0.57
25	24-hour medical treatment in clinics	4.04	0.90	0.34
26	system to introduce smoothly patients who need home medical support	3.94	0.86	0.54
27	explanation sufficiently to the family about the condition and treatment of patient	3.91	1.02	0.36
28	family can provide medical and care support to patient	3.73	1.04	0.41

*: Five-point Likert scales about necessary for ACP 1('very-unnecessary') 2('unnecessary') 3('neither unnecessary nor necessary') 4('necessary') 5('very necessary')

3. Factor analysis on findings for ACP

Table 3 shows factor analysis on findings for ACP. Of the five extracted factors, the first factor consisted of four variables, we named "Trust in the Doctor-Patient Relationship". The second factor consisted of five variables, we named "Building-up Cooperation". The third factor consisted of five variables, we named "Enlightenment and Awareness of ACP". The fourth factor consisted of two variables, we named "Level up Views on Life and Death among Health Care Providers". The fifth factor consisted of two variables, we named "Patient and Family Preparedness for Death".

The inter factor correlation ranged from 0.06 to 0.44, the Cronbach alpha coefficient of each factor ranged from 0.74 to 0.95.

<Table 3> Factor Analysis on Findings for ACP

No	18 variables remained of necessary for ACP†	Factor loading*				
		1	2	3	4	5
Factor 1 "Trust in the Doctor-Patient Relationship" (α= 0.76)						
15	explanation sufficiently to the family on clinical course	0.93	-0.01	-0.10	-0.03	0.03
27	explanation sufficiently to the family about the condition and treatment of patient	0.90	0.06	-0.07	-0.07	0.05
6	treatment decisions are made involving patient wishes	0.61	-0.02	0.21	0.04	-0.06
22	treatment decisions are made involving family wishes	0.43	0.01	0.09	0.11	-0.09
Factor 2 "Building-up Cooperation" (α= 0.77)						
23	emergency hospital beds are secured	0.01	0.82	-0.08	0.05	0.16
14	hospitalized beds are available when the patient condition changes	0.04	0.80	0.01	0.03	0.14
10	cooperation between hospital and clinic in home medical field	-0.02	0.59	0.06	0.02	-0.11
7	cooperation with home visiting nurse office	0.05	0.45	0.05	0.00	-0.25
18	cooperation with care managers on long-term care insurance law	-0.03	0.40	0.19	0.05	-0.19
Factor 3 "Enlightenment and Awareness of ACP" (α= 0.74)						
12	training in ACP	-0.02	-0.04	0.76	-0.02	0.12
9	construction of information sharing system	0.03	0.18	0.60	-0.13	-0.01
13	system for obtaining ACP specialized consultation and advice	-0.04	0.19	0.57	-0.16	-0.01
16	education on life and death in educational institutions	-0.03	0.03	0.53	0.21	0.03
4	citizens awareness reform on life and death	0.16	-0.23	0.46	0.22	0.01
Factor 4 "Level up Views on Life and Death among Health Care Providers" (α= 0.95)						
17	level up views on life and death among medical staff	0.00	0.03	-0.01	0.96	-0.02
5	level up views on life and death among doctors	0.00	0.07	-0.05	0.92	0.02
Factor 5 "Patient and Family Preparedness for Death" (α= 0.81)						
1	patients' preparedness for own death	-0.04	-0.04	0.08	0.07	0.83
8	family preparedness for patient death	0.02	-0.04	0.04	-0.06	0.77
Inter-Factor Correlation						
Factor 1		1				
Factor 2		0.31	1			
Factor 3		0.26	0.44	1		
Factor 4		0.21	0.36	0.40	1	
Factor 5		0.10	0.06	0.10	0.20	1

* principal factor analysis, pro-max rotation

†: Excluded: Factor loading less than 0.35: No.19 (0.34), 20 (0.34), 24 (0.34), 28 (0.34), 21 (0.29), 3(0.27). Variables showing similar loadings on multiple factors: No.2, 11, 25, 26.

4. Factor scores and participant characteristics

Table 4-1 shows factor scores and participant characteristics (individual situation), table4-2 (clinic situation) and factor's mean score. As for individual situation, the mean score of "Trust in the Doctor-Patient Relationship" ($p <0.01$) was significantly higher PCP who had no experience of bereavement with someone close. As for clinic situation, the mean score of "Building up Cooperation" ($p =0.04$) was significantly higher clinic which attached home visiting nurse office, and "Trust in the Doctor-Patient Relationship" ($p =0.02$) was significantly higher clinic which medical fee point as home care supporting clinic.

<Table 4-1> Comparison of Basic Characteristics (Individual Situation) and Factor's Mean Score

	Gender			Age / yrs			Experience of doctor / yrs			Experience of primary care physician in home medical / yrs			Experience of bereavement with someone close		
	Male (n=174)	Female (n=14)	p	≧59 (n=99)	<59 (n=88)	p	≧32 (n=96)	<32 (n=91)	p	≧17 (n=94)	<17 (n=93)	p	Yes (n=171)	No (n=11)	p
Factor 1 (4 variables, 20 score)	18.79	19.00	0.65	18.68	19.00	0.17	18.69	18.95	0.28	18.66	18.95	0.23	18.78	19.55	< 0.01
Factor 2 (5 variables, 25 score)	22.81	23.65	0.19	23.16	22.55	0.07	23.11	22.62	0.14	22.96	22.80	0.63	22.90	22.18	0.32
Factor 3 (5 variables, 25 score)	21.56	21.50	0.93	21.65	21.47	0.65	21.43	21.71	0.47	21.40	21.72	0.42	21.57	21.09	0.57
Factor 4 (2 variables, 10 score)	8.09	8.21	0.80	7.94	8.27	0.20	8.04	8.16	0.64	7.99	8.23	0.36	8.08	7.91	0.76
Factor 5 (2 variables, 10 score)	8.48	8.86	0.37	8.52	8.50	0.91	8.50	8.51	0.98	8.62	8.40	0.33	8.66	7.73	0.08

Student t-test

<Table 4-2> Comparison of Basic Characteristics (Clinic Situation) and Factor's Mean Score

	Number of doctor in clinic (include part-time)			Attached home visiting nurse office			Number of patients*			Number of death certification in home*			Medical fee point as home care supporting clinic		
	≧2 (n=116)	<2 (n=69)	p	Yes (n=66)	No (n=112)	p	≧104 (n=88)	<104 (n=88)	p	≧19 (n=90)	<19 (n=89)	p	Yes (n=181)	No (n=6)	p
Factor 1 (4 variables, 20 score)	18.84	18.78	0.80	18.73	18.88	0.54	18.77	18.88	0.68	18.79	18.81	0.94	18.85	17.33	0.02
Factor 2 (5 variables, 25 score)	22.90	22.83	0.84	23.35	22.73	0.04	22.99	22.85	0.70	22.81	22.95	0.68	22.88	22.50	0.69
Factor 3 (5 variables, 25 score)	21.66	21.46	0.64	21.45	21.67	0.60	21.66	21.50	0.70	21.74	21.34	0.32	21.58	20.83	0.51
Factor 4 (2 variables, 10 score)	8.11	8.13	0.95	8.15	8.12	0.90	7.66	8.22	0.35	8.08	8.12	0.86	8.07	8.50	0.56
Factor 5 (2 variables, 10 score)	8.45	8.58	0.57	8.45	8.52	0.79	8.56	8.56	1.00	8.47	8.63	0.46	8.49	8.67	0.78

Student t-test, *: The data period is from January 2018 to December 2018

IV. Discussion

This study was the first nationwide in Japan to investigate the leading characteristics of ACP from the perspective of the PCP. PCP working in the at-home care field found 25 of 28 items with a mean rating of 4.0 or higher-indicating they are necessary. A statistical factor analysis on all 28 items found five factors: 1 Trust, 2 Cooperation, 3 Awareness of ACP, 4 Level up Views on Life and Death among Health Care Providers, and 5 Preparedness for Death.

Of interest, findings showed that 'explanation sufficiently to the family about the condition and treatment of patient' (No. 27) was rated as 3.91, not so high in this research. In Japan, there was a high prevalence of entrusting all decisions to the family (known as 'omakase').[30] Therefore, for 'Good Death' in Japan, it is important to have a good family relationship through spending enough time with one's family.[26] Another of our results also suggested that family structure differences can affect their end-of-life preferences.[31] Thus, the family has some influence on the end of life care in Japan. However, most PCP working in the at-home care field were ambivalent and reported that the family was not 'neither unnecessary nor necessary' for ACP. The cause for this matter requires further investigation.

Shared-decision-making (SDM) in practice between the doctor and patient is widely recognised in Western countries, but very much less so in Japan.[32,33] The notable absence of SDM in Japan may be the underlying reason for our PCPs to respond that more trust is needed: we found that the leading factor-1 was 'Trust in the Doctor-Patient Relationship'. Building and maintaining a good doctor-patient relationship should be perhaps introduced into medical education in Japan.

We identified the three differences of PCP characteristics and ACP. The previous research showed doctors' opinions and attitudes on obtaining the advance directives regarding the end of life treatment differed by their age.[34] However, in our study results, age differences were not found in all five ACP factors.

The overall findings from this study indicate that increased cooperation could benefit the current ACP field. The PCP working in the at-home care field throughout Japan report that more cooperation can help health care providers to work better seamlessly in teams. However, there were several limitations. First, the response rate was only 23.4%. Second, ACP has a wide meaning as a concept and there are multiple definitions, we selected one definition that clearly describes the role of the doctor in ACP, however this one might not be held universally. Third, this research is only a questionnaire survey, triangulation research is necessary to increase the confidence and reliability of this results.

Acknowledgment

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