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Clinicians' practices and attitudes regarding advance care planning in mainland China: A multicenter cross-sectional survey

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Original Article

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Abstract

Objectives. This study aims to explore clinicians' practices and attitudes regarding advance care planning (ACP) in mainland China.

Methods. This study was a multicenter cross-sectional survey. Clinicians from tertiary hospitals in Beijing, Guangxi, and Inner Mongolia were invited to participate in the study. A questionnaire was formulated based on related literature to obtain information including demographic characteristics, and practices and attitudes toward ACP.

Results. The total number of participants included 285 clinicians. The data response rate was 84.57%. Most of the clinicians had an inadequate understanding of ACP. Only a few clinicians had experience in participating or witnessing an ACP or related end-of-life discussions. Among 285 clinicians, 69.82% of clinicians were willing to introduce ACP to patients. Two hundred and thirty-eight (83.51%) clinicians wanted more education on ACP. Almost all clinicians believed that patients had the right to know about their diagnosis, prognosis, and available care options. Most clinicians (82.11%) regarded that ACP was partially feasible in mainland China. If clinicians had a serious illness, almost everyone was willing to find out their true health status and decide for themselves, and 81.40% wanted to institute an ACP for themselves. The biggest barriers to the use of ACP in mainland China were cultural factors. Statistical analysis revealed that some or good understanding level ($P = 0.0052$) and practical experience ($P = 0.0127$) of ACP were associated with the positive willingness.

Significance of results. ACP is still in its infancy in mainland China. Clinicians had inadequate understanding and minimal exposure to ACP. Most clinicians recognized the value and significance of ACP and had a positive attitude toward ACP. Clinicians need to be provided with education and training to promote their ACP practices. Culturally appropriate ACP processes and documents need to be developed based on Chinese culture and Chinese needs.

Introduction

To help patients achieve high quality of life toward the end of life, it is important to honor patient's rights of autonomy and improve the extent to which patients receive health care that is consistent with their values and preferences in the event of incapacity (Heyland et al., 2010; Sinuff et al., 2015). Advance care planning (ACP) is defined as a process that supports patients in understanding and sharing their values, life goals, and preferences regarding future medical care (Sudore et al., 2017).

ACP has been embedded in healthcare systems in developed countries. However, it is still new to the clinicians and general public in mainland China. Beijing Civil Affairs Bureau approved the foundation of the Beijing Living Will Promotion Association in June 2013. The website of association "Choice and Dignity" (http://www.lwpa.org.cn/) could provide advice on instituting ACP and access to a Chinese-language version of ACP document called *Five Wishes*. However, the practices in the clinical setting are still rare.

A clinician plays a critical role in ACP communication, as well as ensuring the realization of patients' goals. A survey among doctors working in the largest teaching hospital at the University of Hong Kong found that 94% of participants indicated a willingness to discuss ACP with patients (Luk et al., 2015). Despite the clinicians' crucial role in the implementation of ACP, their practices and attitudes toward ACP are not well explored in mainland China.

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This study aims to explore clinicians' practices and attitudes regarding ACP in tertiary hospitals in mainland China. Furthermore, to fully understand their attitude toward ACP, we aim to explore clinicians' attitudes to their own healthcare autonomy and end-of-life care, as well as the willingness of instituting their own ACP.

Methods

This study used a cross-sectional survey design to examine the proposed aims.

Subjects

Chinese hospitals are organized according to a 3-tier system (Primary, Secondary, or Tertiary institutions) that recognizes a hospital's ability to provide medical care, medical education, and conduct medical research. Tertiary hospitals round up the list as comprehensive or general hospitals at the city, provincial or national level, which are responsible for providing specialist health services, perform a bigger role with regard to medical education and scientific research, and serve as medical hubs providing care to multiple regions.

We aim to explore the clinicians' practices and attitudes regarding ACP in tertiary hospitals. Clinicians from tertiary hospitals in Beijing, Guangxi, and Inner Mongolia were invited to participate in the study through a designing clinical research course. The clinicians voluntarily participated in this course.

Questionnaire

A questionnaire was formulated by members of the research team based on related literature to obtain information including demographic characteristics, practices, and attitudes toward ACP. The questionnaire referred to a survey exploring the general public's attitudes toward ACP in 15 different provinces throughout mainland China, and an ACP guide for adolescents and young adults called Voicing My CHOiCES™ (Zadeh et al., 2015; Kang et al., 2017). Before beginning the survey, participants were provided with a standard definition of ACP and advance directive (AD). The questionnaire was piloted and revised to ensure the validity of the results.

Data collection

Questionnaires were distributed and collected anonymously. A questionnaire survey platform called "Wenjuanxing" (www.wjx.cn) was used for data collection. To ensure that there was no missing value in the questionnaire, the questionnaire could not be submitted if the required contents were not completed. This survey was conducted from October to December 2019. Duplicate questionnaires were deleted based on IP address. Participants who were not clinicians were excluded. This study was approved by the Ethics Committee of Beijing Children's Hospital Affiliated to Capital Medical University.

Statistical analysis

Data were analyzed by using SAS 9.4. Descriptive statistics were used to summarize the data. Chi-square test or the Fisher exact test were used to measure differences, with P-values < 0.05 considered statistically significant.

Table 1. Socio-demographic characteristics of clinicians

Variable	*n* (%)
Gender	
Male	74 (25.96)
Female	211 (74.04)
Academic degree	
Doctor	50 (17.54)
Master	172 (60.35)
Bachelor	63 (22.11)
Title	
Professor	31 (10.88)
Assistant professor	43 (15.09)
Attending	79 (27.72)
Resident	132 (46.32)
Religion	
Without religious beliefs	275 (96.49)
With religious beliefs	10 (3.51)
Center	
Beijing	116 (40.70)
Nei Monggol	93 (32.63)
Guangxi	76 (26.67)

Results

The total number of participants included 285 clinicians. The data response rate was 84.57% (285/337). Clinicians' socio-demographic characteristics are shown in Table 1. The participants were predominately female (74.04%). The median age of participants was 32 (interquartile range: 29, 37) years. Participants were from Beijing (40.70%), Inner Mongolia (32.63%), and Guangxi (26.67%), respectively.

Clinicians' practices toward ACP

Clinicians' practices toward ACP are shown in Table 2. The results showed that most of the clinicians had an inadequate understanding of ACP. One hundred and eighty-eight (65.96%) had no understanding of ACP. Only a few clinicians had experience in participating or witnessing an ACP or related end-of-life discussions. Forty percent of clinicians only disclosed prognosis to family members.

Clinicians' attitudes toward ACP

Clinicians' attitudes toward ACP are shown in Table 3. Among 285 clinicians, 69.82% of clinicians were willing to introduce ACP to patients. Two hundred and thirty-eight (83.51%) clinicians wanted more education on ACP. Almost all clinicians believed that patients had the right to know about their diagnosis, prognosis, and available care options. Most clinicians (82.11%) regarded that ACP was partially feasible in mainland China.

Table 3 also shows clinicians' attitudes to their own health care autonomy and end-of-life care, as well as the willingness of

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Table 2. Clinicians' practices toward ACP

Questions	Answer	*n* (%)
What is your understanding level of ACP before you read this questionnaire?	No understanding	188 (65.96)
	Some understanding	82 (28.77)
	Good understanding	15 (5.26)
Have you ever discussed ACP or related end-of-life issues with patients before?	Yes	34 (11.93)
	No	251 (88.07)
Have you ever witnessed any ACP or related end-of-life discussions between doctors and patients?	Yes	38 (13.33)
	No	247 (86.67)
If a patient enters the end stage of life-threatening disease, who will you disclosed his/her prognosis with first?	Patients and their family members	155 (54.39)
	Only family members	114 (40.00)
	Only patients	16 (5.61)

instituting their own ACP. If they had a serious illness, almost everyone was willing to find out their true health status and decide for themselves, and 232 (81.40%) wanted to institute an ACP for themselves. The main concerns during end-of-life care were functional maintenance and quality of life in 144 (50.53%) participants.

Table 4 shows the perceived barriers to the use of ACP in mainland China. The biggest barriers were cultural factors. Under the background of Chinese culture, talking about death was often taboo, and withholding bad news could protect patients. Other barriers included the lack of knowledge in healthcare providers and the public, the lack of relevant legislation and protocol on ACP, and the possible disadvantages brought by ACP.

Participants who wanted to institute ACP were required to answer their preferred content in ACP (Table 5). The results showed that participants attached importance to expressing preferences for medical care, comfort, and support. Most participants did not want to make after-death arrangements for themselves and express their spiritual thoughts.

Table 3. Clinicians' attitudes toward ACP

Questions	Answer	*n* (%)
Are you willing to introduce ACP to patients?	Yes	199 (69.82)
	No	7 (2.46)
	I don't know	79 (27.72)
Are you willing to introduce ACP to your family members?	Yes	192 (68.07)
	No	9 (3.16)
	I don't know	82 (28.78)
Would you want more education regarding ACP issues?	Yes	238 (83.51)
	No	47 (16.49)
Do you think that patients have the right to know about their diagnosis, prognosis, and available care options?	Yes	278 (97.54)
	No	7 (2.46)
Do you think ACP is feasible in China?	Completely feasible	45 (15.79)
	Partially feasible	234 (82.11)
	Infeasible	6 (2.11)
If your expected survival time is less than 6 months, are you willing to institute an ACP?	Yes	232 (81.40)
	No	10 (3.51)
	I don't know	43 (15.09)
Do you want to know your real medical condition (including bad news) and make medical decisions for yourself? (For example, the true severity of the disease, the expected survival time, etc.)	Yes	273 (95.79)
	No	12 (4.21)
Do you want end-of-life invasive treatment measures (including electric defibrillation, extracorporeal compression, tracheal intubation, ventilator-assisted ventilation, tracheotomy) if such can only delay your death, with no chance of recovery?	No	218 (76.49)
	Yes	67 (23.51)
Do you want life-support treatment (including nutritional support such as tube feeding or percutaneous endoscopic gastrojejunostomy, broad-spectrum antibiotics, blood transfusion, hemodialysis) if you have late-stage Alzheimer or are in a persistent vegetative state?	No	240 (84.21)
	Yes	45 (15.79)
Which are your main concerns among the 5 universal health care priorities during end-of-life care	Maintain the functions of life, independence, and quality of life	144 (50.53)
	Reduce discomfort (such as pain and nausea)	104 (36.49)
	Someone will take care	26 (9.12)
	Extend lifetime	4 (1.40)
	Medical expenses	2 (0.70)
	Other	5 (1.75)

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Table 4. Barriers to use of ACP in mainland China

Barriers	*n* (%)
Talking about death is taboo in Chinese culture	241 (84.56)
Requests from the family to withhold bad news	219 (76.84)
Patients and family members lack awareness of ACP	168 (58.95)
China does not have legislation on ACP/AD	168 (58.95)
Talking with patients about ACP will upset or overwhelm them	158 (55.44)
ACP discussions may cause medical disputes	147 (51.58)
Unrealistic expectations from patients about their prognosis	146 (51.23)
Clinicians lack knowledge, competency, or skills of ACP discussions	143 (50.18)
Lack of a protocol or procedure	139 (48.77)

Table 5. Preferred content in ACP

Content	*n* (%)
My medical care decisions and life support preferences	209 (90.09)
How I want to be comforted	172 (74.14)
What I would like my family and friends to know	159 (68.53)
How I would like to be supported	148 (63.79)
How I would like to share my belongings	129 (55.60)
How I would like to plan my own funeral and memorial service	86 (37.07)
How would I like to be remembered for the years after I am gone	35 (15.09)
My spiritual thoughts	32 (13.79)

Two hundred and thirty-two participants who wanted to institute ACP were required to answer their preferred content in ACP.
The questionnaire offered explanations and examples for each content of ACP.

Influencing factors of clinicians' willingness to introduce ACP to patients

We assessed the associations between clinicians' practices toward ACP and willingness to introduce ACP to patients. For the purpose of analysis, willingness to introduce ACP to patients was dichotomized as positive (yes) or negative (no or I don't know). Statistical analysis revealed that some or good understanding level ($P = 0.0052$) and practical experience ($P = 0.0127$) of ACP were associated with the positive willingness (Table 6). We further analyzed the differences in perceived barriers between the two groups (Table 7). More clinicians with negative willingness regard "ACP discussions may cause medical disputes" and "clinicians lack knowledge, competency, or skills of ACP discussions" as barriers. More clinicians with positive willingness regard "unrealistic expectations from patients about their prognosis" and "lack of a protocol or procedure" as barriers.

Discussion

To our knowledge, this study is the first reported multicenter investigation of clinicians' practices and attitudes toward ACP/AD in mainland China. In addition, this study is the first reported clinicians' willingness of instituting their own ACP in mainland China.

ACP is an essential component of palliative care. However, the completion rate of ACP is very low in China, and most patients refuse to be involved in ACP (Gu et al., 2016; Kang et al., 2017). Exploring clinicians' practices and attitudes of ACP will be useful to help us find a way to better promote and implement ACP in mainland China.

This study showed that clinicians had inadequate understanding and minimal exposure to ACP, even if they were from tertiary hospitals. Similar conclusions were drawn in Tang et al.'s study, which reported that nurses in southwest China had limited knowledge and practices on ACP (Tang et al., 2020). Lack of ACP education for healthcare providers is regarded as largely responsible. Conversations concerning ACP are sensitive topics, and therefore a strong body of knowledge is the premise for clinicians to perform ACP practice professionally (Nakazawa et al., 2014; Lee et al., 2017; Juliá-Sanchis et al., 2019; Howard et al., 2020). However, ACP-related theoretical and practical education is very few, even palliative care education is very limited in mainland China (Ye et al., 2019). ACP should be included in all levels of education for clinicians. Furthermore, it is crucial to provide clinicians with specific training and resources needed to implement ACP.

Clinicians' attitude toward ACP is a critical factor in their willingness to initiate or participate in ACP discussions. Although the awareness of ACP was fairly low, once learn about the standard

Table 6. Influencing factors of clinicians' willingness to introduce ACP to patients

		Positive	Negative	Chi square	*P*
What is your understanding level of ACP before you read this questionnaire?	No understanding	121 (64.36)	67 (35.64)	7.824	0.0052
	Some or good understanding	78 (80.41)	19 (19.59)		
Have you ever discussed ACP or related end-of-life issues with patients before?	Yes	30 (88.24)	4 (11.76)	6.211	0.0127
	No	169 (67.33)	82 (32.67)		
Have you ever witnessed any ACP or related end-of-life discussions between doctors and patients?	Yes	30 (78.95)	8 (21.05)	1.732	0.1882
	No	169 (68.42)	78 (31.58)		
If a patient enters the end stage of life-threatening disease, who will you disclosed his/her prognosis with first?	Patients and their family members or only patients	124 (72.51)	47 (27.49)	1.468	0.2256
	Only family members	75 (65.79)	39 (34.21)		

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Table 7. Differences in perceived barriers among participants

Barriers	Positive	Negative	Chi square	*P*
ACP discussions may cause medical disputes	94 (47.24)	53 (61.63)	4.980	0.0256
Clinicians lack knowledge, competency, or skills of ACP discussions	92 (46.23)	51 (59.30)	4.104	0.0428
Unrealistic expectations from patients about their prognosis	111 (55.78)	35 (40.70)	5.466	0.0194
Lack of a protocol or procedure	105 (52.76)	34 (39.53)	4.206	0.0403

There was no significant difference among the other barriers.

definition of ACP, most clinicians had a positive attitude toward ACP. Most clinicians wanted more education on ACP and were willing to introduce ACP to patients and their own family members. This result is similar to that of Luk et al. in Hong Kong, which found that physicians working in Hong Kong were willing to initiate ACP discussions, although many had limited knowledge or experience relating to ACP (Luk et al., 2015). A literature review shows that physicians overall have a positive attitude toward ACP/AD, even across cultures. For the 12 quantitative studies, the quantified positive attitudes toward ACP/AD ranged from 93.4% to 44.9% (Coleman, 2013). These results suggest that clinicians are willing to participate in ACP and prior knowledge of ACP will increase the chance of their learning and practices, implying the importance of education and dissemination of ACP among clinicians.

Among 285 clinicians, almost everyone was willing to find out their true health status and decide for themselves, and about 80% wanted to institute an ACP for themselves. This result indicates that the concept of "good death" has gradually been influencing clinicians' awareness of end-of-life care and patient autonomy. Clinicians recognize the purpose and value of ACP, which is the basis for clinicians to use ACP. It can be inferred that, equipped with enough knowledge and training, clinicians would be even more willing and also more able to promote ACP.

Although clinicians realize the value and significance of ACP, there are still many barriers to ACP practice in mainland China. This study found that, different from western countries, the main barriers of ACP implementation in China were mostly related to cultural factors. In Chinese culture, death is a taboo topic that people feel uncomfortable discussing, which may hinder the chance in ACP discussion (Cheng et al., 2014, 2019). In addition, telling patients the truth about their disease is believed to be bad for the patients' health and recovery, and is considered dehumanizing and immoral by the Chinese. Many families decide not to disclose prognosis to the patients in China, which lead to inconsistencies between opinion and behavior in clinicians (Xu, 2007; Chaitin and Rosielle, 2013). As is shown in this study, although almost all clinicians believed that patients had the right to know about their diagnosis, prognosis, and available care options (Table 3), 40% of them only disclosed prognosis to family members (Table 2). As ACP is a culturally sensitive topic, future research should focus on the influences of cultural factors on ACP discussion, and develop culturally sensitive strategies to facilitate these discussions without disrupting harmony in Chinese families (Teno et al., 1997; Brown, 2003; Lee et al., 2017). In addition, legislation on ACP should be developed to decrease the potential risks of medical disputes and protect the patients' rights.

Exploring the preference of ACP among Chinese is the first step to develop culturally appropriate ACP procedures and documents. This study is the first reported Chinese preferred content in ACP. This research shows that the Chinese may not want to make after-death arrangements for themselves. Most after-death arrangements are made according to local customs. In addition, we found that clinicians considered spiritual thoughts to be an unnecessary part of ACP. The possible reason is that existing spiritual supports are mostly religious supports, and China has low proportions of religious populations. However, Cai et al. found that Chinese nonreligious parents have a strong need for spiritual support when faced with life-threatening conditions of their children (Cai et al., 2020). Spirituality is a fundamental element of the human experience, and spiritual support should be offered to all patients and their families regardless of their affiliated status with organized religion (Best et al., 2014). Future research needs to explore the unique spiritual needs of the Chinese and develop the corresponding ACP module.

Limitation

The recruitment of subjects was done by convenience sampling and limited to a subset of clinicians working in hospitals in three regions reduces sample representativeness and generalizability of results.

Conclusion

Although ACP has been launched in Asia for several decades, it is still in its infancy in mainland China. This study indicated that clinicians had inadequate understanding and minimal exposure to ACP. Most clinicians recognized the value and significance of ACP and had a positive attitude toward ACP. The main barriers of ACP implementation in China were mostly related to cultural factors. Clinicians need to be provided with education and training in order to promote their ACP practices. Culturally appropriate ACP processes and documents need to be developed based on Chinese culture and Chinese needs.

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