doi:10.1111/imj.14958

ORIGINAL ARTICLE

Discussion of advance care planning on end-of-life decisions with lung cancer patients in Wuhan, China: attitude, timing and future directions

Liya Hu,1 Qian Chu,2 Zeng Fan2 and Yuan Chen 602

Departments of ¹Geriatrics and ²Oncology, Tongji Hospital, Tongji Medical College, Huazhong University of Science and Technology, Wuhan, China

Key words

end-of-life care, advance care planning, lung cancer, decision-making, palliative care.

Correspondence

Yuan Chen, Department of Oncology, Tongji Hospital, Tongji Medical College, Huazhong University of Science and Technology, Jiefang Avenue 1095, Wuhan 430030, China. Email: chenyuan008@163.com

Received 17 September 2019; accepted 17 June 2020.

Abstract

Background: Progress in advance care planning (ACP) in China has been hindered for decades compared with other countries.

Aims: To describe knowledge of ACP, end-of-life (EOL) care preferences and the predictors of patients' preference for ACP, as well as who should mention ACP among Chinese lung cancer patients.

Methods: Questionnaire-based interviews were carried out. Two hundred and fifty-eight lung cancer patients were recruited when first admitted to Tongji Hospital from October 2017 to November 2018. Social-demographic factors, which might influence patients' preference on ACP decisions and who should mention ACP, were evaluated using multivariate logistic regression analysis.

Results: A total of 91.1% (n = 235) of patients favoured ACP on EOL issues. One hundred and sixty (60%) patients wanted to make EOL decisions on their own. Only 10% of patients were familiar with advance directions. Eighty-two (31.8%) patients were familiar with do not resuscitate/do not intubate (DNR/DNI) directions. ACP was not mentioned in 92.2% of patients. Gender (male, OR = 4.87 (2.16–5.83)), tumour stage (Stage III, OR = 0.108 (0.06–0.51); Stage IV, OR = 1.780 (1.02–2.11)) and number of children (every increase in the number of children, OR = 0.267 (0.09–0.93)) were the significant predictors of preference for autonomous ACP. Female patients and patients currently receiving treatment are 2.743 and 1.8 times, respectively, more willing to need ACP initiated by doctors.

Conclusions: Chinese patients showed preferences towards ACP, but with inadequate knowledge. More assistance is needed with ACP for those patients, especially for females, patients with one child and those with early stage lung cancer. For female patients and patients receiving treatment, doctors may initiate ACP dialogue first.

Introduction

End-of-life (EOL) decisions, such as advance directives (AD), do not resuscitate/do not intubate (DNR/DNI) and last wishes, are unavoidable subjects that all palliative care physicians, patients and their caregivers must face. Advance care planning (ACP), which articulates the autonomy of patients' wishes, values and goals relevant to their current and future healthcare, is an effective process that implements EOL decisions and improves the quality of life (QOL) among EOL patients. Globally, ACP has become legislation, guidelines or practices

Funding: None. Conflict of interest: None. among western countries, such as America^{5,6} and Europe,^{7,8} and even among Asian countries like Japan,⁹ and Korea¹⁰ several decades ago. In the late 20th century in the United States, Oregon was the first state to pass the Patient Self-Determination Act, which guaranteed patients' involvement in decision-making regarding life-sustaining treatment.¹¹

In other parts of China, the Hong Kong Law Reform Commission announced the 'Substitute Decision-making and AD in Relation to Medical Treatment' consultation paper in 2004. Taiwan, in the late 20th century, legislated the Hospice-Palliative Care Act (HPCA) to assure full capacity to establish AD and make juridical EOL decisions for adults.¹² However, in mainland China so far, ACP still has not become legislated or documented

and it is developing slowly. Studies have shown that doctors in mainland China often avoid telling patients a 'bad' diagnosis or prognosis, which may hinder the ACP discussion.¹³ It is reported that nowadays in China nearly 90% of EOL decisions have been made by the spouse (45.6%), offspring (44.3%), parents (3.2%) and other relatives rather than patients themselves.¹⁴ Hence, how to implement ACP, in order to meet patients' needs on EOL decisions, is an urgent problem to be solved.

EOL decisions particularly vary depending on different laws, rules, traditions, religious beliefs and ethical views under different cultural backgrounds among different countries. 15,16 For instance, Chinese respondents seemed to favour more 'aggressive' treatment (55.7%) than Korean (10.1%) and Japanese (9.8%) patients, even in irreversible conditions, which may be due to the differences in healthcare systems, cultural differences and the longer lifespan in Korean Japan. 17 However, few studies have investigated the predictors influencing patients' preferences towards ACP or the best time to talk about EOL decisions and who should mention it against the background of Chinese hospices. Also, studies have shown that ACP on EOL decisions varies between cancer types. 18 Lung cancer ranks as the highest mortality rate among all cancer types in China. 19 Moreover, lung cancer patients often experience higher symptom burden than other cancer patients.²⁰ Given that, the present study aims to investigate the attitudes towards ACP among lung cancer patients, and to find out the predictors affecting patients' autonomous ACP choices and the best time to mention it.

Methods

Questionnaire modification and translation

No standardised instruments addressing these issues were available for use in this study. A self-administered questionnaire developed by the Johns Hopkins Medical Institution²¹ was used to obtain the expectations of ACP among cancer patients. Though Diaz-Montes's study, the questionnaire originated from literature reviews and clinical studies, and could be utilised among different types of tumours.21 We deleted two questions in the questionnaire. Question (item 2, Section A) of 'Ethnicity' was deleted because all patients were Han Chinese. The question of 'which type of cancer have you been diagnosed' was also deleted, because all of the included patients were lung cancer patients. At the same time, we added one question into the questionnaire, which was 'Do you think you need someone to make advance medical decisions for you', and the optional answers were: (i) I need someone to help me with the decisions; and (ii) I prefer to make it all by myself. Other parts of the questionnaire were not modified.

Translation of the questionnaire was carried out by four independent translators and two oncologists. Following a consensus meeting with oncologists who worked in Tongji Hospital, two independent translators, who spoke English as a native language and worked in Tongji Medical College, translated the questionnaire into Chinese. Two other independent translators, who had little knowledge about this questionnaire, translated this back into English. Three others whose major was English compared the two versions of the questionnaire. Lack of clarity or disagreement was resolved by discussions until a final consensus. Eventually, the questionnaire consisted of three sections containing 25 items (Supporting Information Appendix S1). The first section, which contained 10 items, covered the social-demography information. The second section, which contained nine items, covered patients' familiarity and attitudes towards ACP, such as the AD and DNR/DNI status. The last section, which included six items, aimed to understand patients' preference for the best discussion timing on ACP. This study was approved by the research ethics boards of Tongji Hospital.

Patient acquisition and data collection

All patients diagnosed with lung cancer were invited to participate in the present study at their first admission to Tongii Hospital for 13 months from October 2017 to November 2018. Patients were excluded if: (i) they were unconscious or too ill; or (ii) were conscious but their general physical condition could not meet the demand of an oral or written survey. To avoid implicit response bias, specially trained investigators first explained the purpose of our survey. All the surveys were carried out by the patients themselves. If needed, questions could be read aloud by the trained investigators to patients, mainly for the elderly and illiterate or semi-literate individuals. Their voluntary behaviour of submitting the questionnaire demonstrated their consent to participate in the study. All the questionnaires were carried out by patients themselves or aided by our trained investigators, thus to ensure that the answers were entirely from patients' perspectives. If the patients did not complete all the questions in the questionnaire, even with the help of our investigators, we considered this as an incomplete survey or that the patient refused to participate. Diseaseassociated information (e.g. age, gender, cancer aetiology, tumour stage and treatment status) was collected from electronic medical records. There were also patients who were told at an earlier stage of their disease. To protect their privacy and at the same time to avoid bias in our study, we excluded those patients' questionnaires after we double checked the disease-associated information with their electronic medical records.

Statistical analyses

Demographic distribution was analysed using descriptive statistics. Then, the Chi-squared test and t-test were used for categorical and continuous variables. Through the Chi-squared test associations between demographic variables and the ideal discussion timing of AD were further analysed. Binary logistic regression analysis was used to investigate the predictors of whether the autonomous choice of ACP on EOL decisions was influenced by age, number of children, tumour stage and other socialdemographic characteristics. Then we used binary logistic regression analysis to evaluate the associations between the initiation of ACP with social-demographic characteristics. The data were analysed using spss 17.0 for windows (IBM SPSS Statistics, IBM Corporation, Chicago, IL, USA). A P-value of less than 0.05 was defined as meaningful.

Results

From October 2017 to November 2018, 297 lung cancer patients were invited to take part in the survey, and 22 patients received assistance from our trained investigators. Among those (297 patients), 17 patients refused to participate, and eight patients took part in our survey but returned incomplete questionnaires, even with the help of our investigators. Two hundred and seventytwo (91.6%) lung cancer patients voluntarily returned the completed questionnaires. Fourteen of those patients, who did not know the truth of their tumour stage or tumour management stage (the answer in Section A7 and A8 inconsistent with corresponding electronic records), were excluded from the survey to avoid bias in our results. Finally, 258 patients' questionnaires were included for analysis. The sample size of 258 patients was sufficient to detect medium effect sizes (with a = 0.05 and $(1-\beta)$ or power = 0.8).

Demographic and clinical variables are presented in Table 1. The median age of the group was 54 years (range: 37–79 years). All patients reported having children and two-thirds had more than one child (median: 2, range: 1–7). A total of 71.7 percent of patients reported they were married, others were divorced or widowed, and none of the patients was single. Over 80% of the patients were at an advanced stage (27.9% of Stage III, 55% of Stage IV). Nearly half (40%) of the patients were diagnosed with adenocarcinoma or

Table 1 Demographic and clinical characteristics of patients

	· · · · · · · · · · · · · · · · · · ·
Baseline characteristics	All patients ($n = 258$)
Age (years)	
Minimum, maximum	37, 79
Mean (SD)	54 (9.3)
Gender, n (%)	
Male	133 (51.6)
Female	123 (48.4)
Cancer aetiology, n (%)	
Squamous cell carcinoma	99 (38.4)
Adenocarcinoma	102 (39.5)
Small-cell carcinoma	34 (13.2)
Other cancers	23 (8.9)
Tumour stage, n (%)	
Stage I	11 (4.3)
Stage II	33 (12.8)
Stage III	72 (27.9)
Stage IV	142 (55)
Marital status, n (%)	
Married	185 (71.7)
Divorced	41 (15.9)
Widow	32 (12.4)
Treatment status, n (%)	
Initial diagnosis	51 (19.8)
Recurrence	92 (35.7)
Remission	68 (26.4)
Unknown (patient unsure)	26 (10.1)
Missing (no answer)	21 (8.1)
Number of children, n (%)	
1 child	86 (33.3)
>1 children	172 (66.7)
Receiving treatment currently, n (%)	
Yes	176 (68.2)
No	61 (23.6)
Missing (no answer)	21 (8.1)
Economic burden, n (%)	
<4 scores	79 (30.6)
4–6 scores	92 (35.7)
>6 scores	87 (33.7)
Overall quality of life score, n (%)	
<4 scores	69 (26.7)
4–6 scores	92 (35.7)
>6 scores	97 (37.6)

squamous cell carcinoma, 13% diagnosed with small-cell carcinoma. Other cancers included sarcomatoid carcinoma, large-cell carcinoma and malignant teratoma (one patient). One hundred and seventy-six (68.2%) patients reported currently receiving treatment. Of those, 94 (53.4%) patients were receiving chemotherapy, targeted therapy or immunotherapy, 31 (17.6%) patients radiation therapy, 22 (12.5%) patients concurrent chemo-radiotherapy, and 29 (16.5%) patients hospice care. Patients' perceived quality of life was good (M = 6.7, SD = 2.88, range: 1–10; 0 = poor, 10 = good). Sixty to seventy percent of patients reported heavy

economic burden (≥4 scores), and half of the patients performed well physically.

There were 77.5% of patients who regarded hospice care important. One hundred and sixty (60%) patients wanted to make EOL decisions on their own (Table 2). However, only 10.1% of patients were familiar with AD. Eighty-two (31.8%) patients were familiar with DNR/DNI. ACP was not mentioned in 92.2% of patients. There were 61.2% of all patients who preferred advance decisions to be mentioned by doctors rather than by themselves. Pain control was the most vital problem among half (n = 127, 49.2%) of the patients, and EOL wishes (n = 69, 26.7%) ranked as the second. Only 11.6% (n = 30) of the patients ranked advance medical decisions the most important problem during EOL.

There were 32.6% (n = 84) of patients who thought the ideal discussion timing of AD was at diagnosis. Thirty-one percent (n = 80) of patients thought the ideal discussion timing of AD was when treatments were no longer an option. Most (n = 70, 27.1%) patients thought DNR/DNI should be mentioned when disease progressed. The majority (n = 141, 54.7%) of patients wished to emphasise the issue of pain and discuss their final wishes at diagnosis. These all suggested that

Table 2 Attitudes towards ACP on EOL decisions

	n (%)
Do you need EOL decisions made by others	
Need	98 (40.0)
No need	160 (60.0)
Who mention EOL decisions	
Doctors	158 (61.2)
Self	100 (38.8)
Importance of hospice care	
Very important	91 (35.3)
Important	109 (42.2)
Not so important	29 (11.2)
Not important at all	29 (11.2)
Familiar with advanced directives	
Yes	26 (10.1)
No	232 (89.9)
Familiar with DNR/DNI	
Yes	82 (31.8)
No	176 (68.2)
Mentioned ACP	
Yes	20 (7.8)
No	238 (92.2)
Most important during EOL	
Pain	127 (49.2)
EOL wishes	69 (26.7)
Advanced directives	30 (11.6)
Hospice care	32 (12.4)

ACP, advance care planning; DNI, do not intubate; DNR, do not resuscitate; EOL, end of life.

demographic variables have significant influence on patients' preferred timing of discussions on EOL decisions.

Binary logistic regression analysis was used to investigate the predictors influencing patients' autonomous choice of EOL decisions. Gender, tumour stage and number of children tended to become the significant factors to determine whether patients needed EOL decisions made by others (0 = no, 1 = yes). For gender, female was set as a reference category. For tumour stage, Stage I was set as the reference category. For the number of children, a single child was set as the reference category. Age, marital status, tumour type, treatment status, economic burden and QOL scores had no significant influence. Wald criterion indicated that gender (P = 0.005), tumour stage (Stage III, P = 0.001; Stage IV, P = 0.047) and number of children (P = 0.018) were significant predictors of favouring autonomous EOL decisions. It indicated that, compared with women, men were 4.87 times more willing to make EOL decisions on their own. Also, terminal cancer patients (Stage IV) were 1.78 times more willing to make autonomous EOL decisions than patients at a relatively early stage of cancer. Number of children was treated as a numerical variable. Namely, for every increase in the number of children, there were 2% more patients willing to arrange for others to help them make EOL decisions (Tables 3,4).

A total of 61.2% of patients expressed that ACP on EOL decisions should initially be mentioned by doctors. Binary logistic regression analysis was used to find out whether ACP on EOL decisions mentioned by doctors was influenced by demographic variables. Only 'gender' and 'receiving treatment currently' were found to be the predictors of whether patients needed EOL decisions mentioned by doctors (0 = doctors, 1 = patients themselves). For gender, female was set as reference category. It implied that females were 2.743 times more willing to need EOL decisions mentioned by doctors than men. Among patients who were now receiving treatment, EOL decisions were 1.8 times more preferred to be mentioned by doctors.

Discussion

The EOL care dialogue between cancer patients and doctors is an important part of the patient–doctor relationship. According to a report published by the Economist Intelligence Unit in 2015, mainland China ranked 71st on quality of death among 80 countries, with Taiwan at position 6 and Japan at position 14. ACP on EOL decisions is an important and meaningful approach to assist patients with decisions about living and dying. Our research aims to provide more clinical guidance for physicians on when and who should initiate EOL decisions

Table 3 Parameter estimates of binary logistic regression model predicting patients autonomous choices on EOL decisions†

Variable‡	β	Standard error	Chi- squared	P-value††	OR (95% CI)
Tumour stage§					
Stage II	0.611	0.774	0.623	0.43	0.543 (0.28-1.15)
Stage III	2.225	0.649	11.748	0.001**	0.108 (0.06-0.51)
Stage IV	-0.577	0.323	3.191	0.047*	1.780 (1.02-2.11)
No.	-1.319	0.559	5.571	0.018*	0.267 (0.09-0.93)
children¶					

†Please note that a logistic regression model was run, predicting whether patients need EOL decisions made by others on their behalf with the following variables as predictors: age, gender, marital status, tumour type, tumour stage, treatment status, number of children, economic burden, and QOL scores. No variables significantly predicted these outcomes except for gender, tumour stage and number of children. ‡Dependent variable, whether patients need EOL decisions made by others, was a dichotomous variable (0 = no, 1 = yes). §Tumour stage = coded as a categorical variable with Stage I as the reference category. ¶Number of children = coded as a categorical variable with single child as the reference category. ††P < 0.05, two-tailed. *Significant at P < 0.05, **Significant at P < 0.01. CI, confidence interval; EOL, end of life; OR, odds ratio.

under Chinese hospice settings. For this purpose, we planned to obtain a deeper understanding of patients' thoughts, to conduct more efficient EOLC dialogue and to promote the development of ACP in China.

Attitudes towards ACP

The present study showed a great disparity in the understanding of ACP on EOL decisions. Seventy percent of lung cancer patients considered ACP important. Another Chinese study also reported that more than 50% of patients with advanced cancers wanted to make advance decisions to reduce treatment, avoid pain and maintain dignity while they could still speak for themselves, ²⁴ which coincided with our results among lung cancer patients. But when it came to details of ACP, 50% of patients were not familiar with AD and DNR/DNI. It

implied that the majority of lung cancer patients in China wished to make autonomous EOL decisions but with inadequate knowledge. More than half of the patients wished to make EOL decisions on their own. Sixty percent of patients preferred their physicians initiated ACP conversations. From our results, 90% of patients had never heard of ACP from their physicians at all; this might be because this was their first admission to hospital. Also, some patients might have a life expectancy of more than 1 year, as some were Stage I–III, and thus it might be too early for them and their physicians to think about EOL discussions. In China, discussion of death is still taboo or not a commonly discussed topic.^{25,26} How to reach a consensus on EOL decisions for every single cancer patient is still a challenge for palliative care, but understanding the needs of patients might provide suitable breakthroughs on open discussion of ACP on life and death.

Factors predicting the preference of ACP and who to initiate it

In the present study, female patients prefer EOL decisions made with the aid of others and not by themselves alone. For female patients and patients receiving treatment, doctors may initiate ACP dialogue. Studies have shown that women with lung cancer often experienced much more symptom burden (distress, depression and anxiety) than men.²⁷ In another study among gynaecologic oncology patients, it showed that female patients were much more hesitant when making medical choices, which coincides with our results.²⁸ From the perspective of traditional culture, the primary decisionmakers in a Chinese family²⁹ are usually men, especially the husband or oldest son.³⁰ Therefore, we suggest more assistance of ACP on EOL decisions for female patients. Moreover, among females, it is 2.743 times more preferred than males to have ACP mentioned by their physicians. The early initiation of discussion about EOL among medical professionals would enable family

Table 4 Parameter estimates of binary logistic regression model predicting who to mention ACP on EOL decisions†

Variable‡	β	Standard error	Chi-squared	P-value††	OR (95% CI)
Gender§	2.009	0.37	7.425	0.006**	2.743 (2.273–3.285)
Currently receiving treatment¶	1.220	0.54	5.520	0.02*	1.800 (1.116-2.479)

†Please note that a logistic regression model was run, predicting whether patients need EOL decisions mentioned by doctors or by themselves with the following variables as predictors: age, gender, marital status, tumour type, tumour stage, treatment status, number of children, receiving treatment currently, economic burden and QOL scores. No variables significantly predicted these outcomes except for gender, receiving treatment currently. ‡Dependent variable, whether patients need EOL decisions mentioned by doctors or by themselves, was a dichotomous variable (0 = doctors, 1 = patients themselves). G (Gender = coded as a categorical variable with Female as the reference category. G (Receiving treatment currently = coded as a categorical variable with NO as the reference category. G (G), two-tailed. G), G0.5, **Significant at G0.01. ACP, advance care planning; CI, confidence interval; EOL, end of life; OR, odds ratio; QOL, quality of life.

members and treating physicians to make decisions based on what they think female patients would really want.

Patients with advanced lung cancer also preferred others to help make EOL decisions for them rather than early stage patients. Unlike other studies like Tajouri et al., 31 and Gordon and Shade 32, which found the severity of illness was positively associated with the preference of AD, our research found that patients at an early stage were more willing to favour autonomous decisions on ACP. This may reflect the Chinese culture, where Confucianism emphasising 'Da Tong (harmony)' plays an important role. Family harmony is usually considered more important than patients' autonomy. Therefore, they often preferred that their family make all care or treatment decisions. Moreover, studies have also shown that illness itself could become a factor undermining autonomy on medical decisions.³³ Schwartz et al.³⁴ proposed a concept of 'response shift', suggesting that once patients are confronted with a life-threatening disease they would vacillate or even abandon their true evaluation of a decision. A systematic process that aims to assist and coordinate ACP on the EOL decision-making process is urgently needed for patients confronting terminal illness.

According to our study, patients with only one child preferred making EOL decisions on their own. It is noteworthy that the average age of our patients was around 50 years, which means half have been part of the 'one-child policy' since the 1980s in China.³⁵ That means the majority of our patients were in a '4-2-1/4-2-2 family structure'.³⁶ They were likely to support four grandparents and with one or two children, which means immense economic burden and mental pressure. They have to make autonomous choices on their own, partly due to compulsion or necessity rather than free choice. They may need more help from outside resources to provide support on EOL decisions.

Best timing to discuss ACP

Our study suggests that the ideal time to address AD, pain problems and final wishes was when patients were diagnosed. The ideal timing to address DNR/DNI was when treatment is no longer an option. According to Chi-squared analyses, for patients with only one child they would prefer an early talk on AD and DNR/DNI. Perhaps patients were hoping to make their own choice earlier to avoid leaving too much pressure on their sole offspring. For patients in the early stage of lung cancer in our study, we suggested an early talk on DNR/DNI decisions. In Kang *et al.*'s study it was reported that 53% of Chinese cancer patients believed that discussions about AD such as living wills should take place soon after the

cancer diagnosis has been established,³⁷ which coincided with our results (Table 5).

Limitations of the study

Limitations exist in our study. Our data might be biased due to the wording of the questions or the invalidated questionnaire. Although the questionnaire was without tumour-type limitations, a more credible or validated

Table 5 Timing of ACP discussion

Most beneficial time to address ACP	n (%)
Time of AD	
No specific time	25 (9.7)
At diagnose	84 (32.6)
At treatment start	28 (10.9)
At treatment complete	5 (1.9)
At disease progression	36 (14)
At incurable stage	80 (31)
Time of DNR/DNI	
No specific time	68 (26.4)
At diagnose	15 (5.8)
At treatment start	13 (5.0)
At treatment complete	27 (10.5)
At disease progression	70 (27.1)
At incurable stage	65 (25.2)
Time of emphasis pain	
No specific time	26 (10.1)
At diagnose	141 (54.7)
At treatment start	34 (13.2)
At treatment complete	5 (1.9)
At disease progression	20 (7.8)
At incurable stage	32 (12.4)
Time of final wish	
No specific time	32 (12.4)
At diagnose	99 (38.4)
At treatment start	10 (3.9)
At treatment complete	59 (22.9)
At disease progression	20 (7.8)
At incurable stage	38 (14.7)
Time of spirituality	
No specific time	45 (17.4)
At diagnose	68 (26.4)
At treatment start	25 (9.7)
At treatment complete	16 (6.2)
At disease progression	69 (26.7)
At incurable stage	35 (13.6)
Time of palliative care	
No specific time	55 (21.3)
At diagnose	79 (30.6)
At treatment start	18 (7.0)
At treatment complete	21 (8.2)
At disease progression	40 (15.5)
At incurable stage	45 (17.4)

ACP, advance care planning; AD, advanced directives; DNI, do not intubate; DNR, do not resuscitate; EOL, end of life.

questionnaire needs to be developed for this kind of survey. Also, self-reported data reflected the views of respondents at the time of participation but it did not predict patients' preference as disease status progressed. Although the oncology department in our hospital is one of the biggest cancer centres in central China, more cross-sectional studies are needed to provide more data and guidance on ACP. More systematically personalised education and research on ACP discussion of EOL decisions are urgently needed among caregivers and palliative care centres in China.

Implications for psychosocial oncology

As an important part of human dignity, ³⁸ ACP guarantees patients' autonomous rights. It helps to improve patients' quality of life and even the tense doctor–patient relationships nowadays. ^{39,40} Through the results of our

References

- 1 Martin RS, Hayes B, Gregorevic K, Lim WK. The effects of advance care planning interventions on nursing home residents: a systematic review. *J Am Med Dir Assoc* 2016; **17**: 284–93.
- 2 Richards T, Coulter A, Wicks P. Time to deliver patient centred care. *Br Med J Publ Group* 2015; **350**: h530.
- 3 Coggon J, Law MC. Autonomy, and best interests: an argument for conceptual and practical clarity in the court of protection. *Med Law Rev* 2016; 24: 396–414
- 4 Kropf D, Fringer A, Loupatatzis B. P71: ACP can improve quality of LIFE in end-of-LIFE-care. *BMJ Support Palliat Care* 2015; **5**: 65.3–66.
- 5 Loggers ET, Starks H, Shannon-Dudley M, Back AL, Appelbaum FR, Stewart FM. Implementing a death with dignity program at a comprehensive cancer center. *N Engl J Med* 2013; **368**: 1417–24.
- 6 Tolle S, Back AL, Meier DE. End-of-life advance directive. N Engl J Med 2015; 372: 667–70.
- 7 Stallworthy EJ. Advance care planning. Nephrology (Carlton, Vic) 2013; 10: 1111.
- 8 Veshi D, Neitzke G. Council of Europe: guide on the decision-making process regarding medical treatment in end-of-life situations. *Med Law Int* 2016; 16: 94–102.
- 9 Ishikawa T, Fukui S, Sawai M. Age differences in decision-making factors on end-of-life care location for Musashino-city residents. *Jpn J Public Health* 2014; 61: 545–55.

- 10 Mo HN, Shin DW, Woo JH, Choi JY, Kang J, Baik YJ *et al.* Is patient autonomy a critical determinant of quality of life in Korea? End-of-life decision making from the perspective of the patient. *Palliat Med* 2012; **26**:
- 11 La Puma J, Orentlicher D, Moss RJ. Advance directives on admission clinical implications and analysis of the Patient Self-Determination Act of 1990. *JAMA* 1991; 266: 402–5.

222-31.

- 12 Yang C-L, Chiu T-Y, Hsiung Y-FY, Hu W-Y. Which factors have the greatest influence on bereaved families' willingness to execute advance directives in Taiwan? *Cancer nursing* 2011; **34**: 98–106.
- 13 Ni P, Zhou J, Wang ZX, Nie R, Phillips J, Mao J. Advance directive and end-oflife care preferences among nursing home residents in Wuhan, China: a cross-sectional study. *J Am Med Dir Assoc* 2014; **15**: 751–6.
- 14 Gu X, Chen M, Liu M, Zhang Z, Cheng W. End-of-life decision-making of terminally ill cancer patients in a tertiary cancer center in Shanghai, China. Support Care Cancer 2016; 24: 2209–15.
- 15 Ho ZJM, Krishna LKR, Yee CPA. Chinese familial tradition and Western influence: a case study in Singapore on decision making at the end of life. *J Pain Symptom Manage* 2010; **40**: 932–7.
- 16 Li LB. Clinical review: ethics and endof-life care for critically ill patients in China. Crit Care 2013; 17: 244.

study, we have more targeted populations and ideal timing to promote ACP in mainland China, although it also requires dissemination of positive information, doctor–patient transparency and enlightened government attitudes. Personalised practices and policies could be formed based on particular characteristics and cultural background in mainland China.

Conclusions

Our research provided insights into the attitudes towards ACP, and further provided more feasible clinical guidance on when and for whom to initiate this dialogue. Chinese patients still showed positive preferences towards AD, but with inadequate knowledge. More assistance will be needed on ACP among lung cancer patients, especially for females, patients with one child and those with early stage lung cancer.

- 17 Ivo K, Younsuck K, Ho YY, Sang-Yeon S, Seog HD, Hyunah B *et al.* A survey of the perspectives of patients who are seriously ill regarding end-oflife decisions in some medical institutions of Korea, China and Japan. *J Med Ethics* 2012; **38**: 310–6.
- 18 Johnson S, Butow P, Kerridge I, Tattersall M. Advance care planning for cancer patients: a systematic review of perceptions and experiences of patients, families, and healthcare providers. *Psychooncology* 2016; **25**: 362–86.
- 19 Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin 2018; 68: 394–424.
- 20 Grotmol KS, Lie HC, Loge JH, Aass N, Haugen DF, Stone PC *et al.* Patients with advanced cancer and depression report a significantly higher symptom burden than non-depressed patients. *Palliat Support Care* 2019; **17**: 143–9.
- 21 Díaz-Montes TP, Johnson MK, Giuntoli RL, Brown AJ. Importance and timing of end-of-life care discussions among gynecologic oncology patients. *Am J Hosp Palliat Med* 2013; **30**: 59–67.
- 22 Lovell A, Yates P. Advance care planning in palliative care: a systematic literature review of the contextual factors influencing its uptake 2008–2012. *Palliat Med* 2014; **28**: 1026–35.
- 23 Murray S. In: Line D, ed. *The 2015 Quality of Death Index: Ranking Palliative Care across*

- the World. A Report by the Economist Intelligence Unit. London, UK; 2015.
- 24 Cheng HWB. Advance care planning in Chinese seniors: cultural perspectives. *J Palliat Care* 2018; **33**: 242–6.
- 25 Ting FH, Mok E. Advance directives and life-sustaining treatment: attitudes of Hong Kong Chinese elders with chronic. *Hong Kong Med J* 2011; **17**: 105–11.
- 26 Huang C-H, Hu W-Y, Chiu T-Y, Chen C-Y. The practicalities of terminally ill patients signing their own DNR orders – a study in Taiwan. *J Med Ethics* 2008; **34**: 336–40.
- 27 Townsend EA, Miller VM, Prakash YS. Sex differences and sex steroids in lung health and disease. *Endocr Rev* 2012; 33: 1–47.
- 28 Hagedoorn M, Sanderman R, Bolks HN, Tuinstra J, Coyne JC. Distress in couples coping with cancer: a meta-analysis and critical review of role and gender effects. Psychol Bull 2008; 134: 1.
- 29 Wallace CL. Family communication and decision making at the end of life: a

- literature review. *Palliat Support Care* 2015; **13**: 815–25.
- 30 Ke L-S. Advance care planning in Taiwan. *Patient Educ Counsel* 2012; **89**: 213.
- 31 Tajouri TH, Ottenberg AL, Hayes DL, Mueller PS. The use of advance directives among patients with implantable cardioverter defibrillators. *Pacing Clin Electrophysiol* 2012; **35**: 567–73.
- 32 Gordon NP, Shade SB. Advance directives are more likely among seniors asked about end-of-life care preferences. *Arch Intern Med* 1999; **159**: 701–4.
- 33 Chan WCH. Being aware of the prognosis: how does it relate to palliative care patients' anxiety and communication difficulty with family members in the Hong Kong Chinese context? *J Palliat Med* 2011; **14**: 997–1003.
- 34 Schwartz CE, Ahmed S, Sawatzky R, Sajobi T, Mayo N, Finkelstein J et al. Guidelines for secondary analysis in search of response shift. Qual Life Res 2013; 22: 2663–73.

- 35 Jiang Q, Sánchez-Barricarte JJ. The 4-2-1 family structure in China: a survival analysis based on life tables. *Eur J Ageing* 2011; **8**: 119.
- 36 Hesketh T, Lu L, Xing ZW. The effect of China's one-child family policy after 25 years. *New Engl J Med* 2005; **353**: 1171–6.
- 37 Kang L, Liu X-H, Zhang J, Shan P-Y, Wang J-P, Zhong P et al. Attitudes toward advance directives among patients and their family members in China. J Am Med Dir Assoc 2017; 18: 808.
- 38 Mattson DJ, Clark SG. Human dignity in concept and practice. *Policy Sci* 2011; **44**: 303–19.
- 39 Jingang A. Which future for doctors in China? *Lancet* 2013; **382**: 936–7.
- 40 Taneja R, Faden LY, Schulz V, Rawal A, Miller K, Bishop KA *et al*. Advance care planning in community dwellers: a constructivist grounded theory study of values, preferences and conflicts. *Palliat Med* 2019; **33**: 66–73.

Supporting Information

Additional supporting information may be found in the online version of this article at the publisher's web-site:

Appendix S1 End-of-life choices questionnaire.