# **BMJ Open** Knowledge, attitudes and preferences of palliative and end-of-life care among patients with cancer in mainland China: a cross-sectional study

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#### ABSTRACT

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**Objectives** This study aimed to investigate the knowledge and attitudes of patients with cancer of palliative care and their preferences regarding end-of-life care in mainland China.

Design A cross-sectional study.

**Setting** This study was conducted in a tertiary cancer hospital.

**Participants** Two hundred forty-seven patients with cancer were recruited and consented to fill out the questionnaires.

**Outcome measures** The participants' knowledge and attitudes of palliative care and their preferences of end-of-life care involving place of care, place of death, truth disclosure and treatments during end-of-life were measured.

Results In total, 239 questionnaires were valid. The vast majority of patients with cancer (81.2%) had never heard about palliative care or related policies, and only a few of them (5.8%) had somewhat or totally understanding of palliative care. Most participants (75.3%) had supportive attitudes towards palliative care. In terms of preferences for end-of-life care, most patients with cancer preferred to be cared for at home at the end of their life and to die at home. The majority of patients with cancer (65.7%) wanted to know their diagnosis or prognosis of the disease, regardless of the type of disease. More than half of the participants (54%) wished to improve their quality of life rather than prolong their life expectancy. More than a third of the patients with cancer preferred to entrust a family member or agent to sign medical decision agreements for them.

**Conclusions** It is essential for healthcare providers to improve the understanding of patients with cancer of palliative care and be aware of the end-of-life care preferences of patients with cancer, in order to provide support that enables patients with cancer to receive endof-life care that is accordant with their wishes.

## INTRODUCTION

Cancer is the leading cause of death in China, with an increasing incidence every year.<sup>1</sup> According to statistics, there are approximately 4.3 million new cancer cases and 2.9 million cancer deaths every year in China,

# Strengths and limitations of this study

- This is a cross-sectional study on the knowledge, attitudes and preferences of palliative and end-of-life care issues, which have been scarcely investigated among mainland Chinese patients with cancer.
- We recruited patients with cancer by convenience sampling from a single hospital, which may limit the generalisability of the results.
- Some choices in the questionnaire involved hypothetical situations, so results can not necessarily present actual preferences when the patients with cancer come to the terminal stage.
- Only descriptive statistics were conducted, and the factors associated with the knowledge, attitudes and preferences of palliative and end-of-life care were not analysed.

accounting for 24% of the new cases and 30% of cancer deaths worldwide.<sup>1 2</sup> China has a lower cancer incidence but a 30% and 40% higher cancer mortality rate than the UK and the USA.<sup>1</sup> Therefore, patients with cancer compose the majority of subjects receiving palliative care and end-of-life (EOL) care in China.

Palliative care began in 1988 and has been developing for more than 30 years in mainland China.<sup>3</sup> According to the 2015 Quality of Death Index, China ranked 71st out of 80 countries and regions in terms of quality of palliative care.<sup>4</sup> In order to promote the development of palliative care, the government began issuing a series of policies and guidance documents in 2016.5-8 However, despite the policy, palliative care subjects are very critical in the development of palliative care as a whole. As the main subjects of palliative care in mainland China, the knowledge and attitudes of patients with cancer towards palliative care are critical factors that influence their willingness to accept it.<sup>9</sup> Moreover,

BMJ

their knowledge and attitudes may also affect their decisions in EOL.<sup>10</sup> Hence, an increased understanding of the knowledge and attitudes of patients with cancer towards palliative care is important, as it can provide references to further tailor intervention. In 2017, a survey was conducted to investigate outpatients' knowledge and attitudes regarding hospice care in two hospitals in Beijing, China. Results showed that patient awareness of hospice care was still low.<sup>11</sup> However, these results could not be generalised for other places in mainland China. Moreover, this also could not reflect the status of current knowledge and attitudes of patients with cancer towards palliative care, because a few years have passed. Thus, it is essential to conduct another study among patients with cancer.

EOL care is the support and care provided in the terminal phase of life.<sup>12</sup> Understanding the preferences of patients with cancer of EOL care could help health-care providers know more about their concerns, which is a prerequisite for EOL care complying with patients' preferences.<sup>13</sup> Further research is needed to explore patients' preferences of EOL care, which should also not be restricted to patients who will be dying.<sup>14</sup> Therefore, talking to patients with cancer about EOL care preferences in the early stages is also a requirement.

Up until now, EOL preferences among patients with cancer have been explored in some countries and regions.<sup>15-21</sup> These studies identified the preferences of patients with cancer for EOL treatment, communication, decision-making and place of care and death. Results showed that more patients with cancer preferred comfort care and maintaining their quality of life in EOL.<sup>19 20</sup> Some patients with cancer expressed their preference to die in a state of unconsciousness induced by drugs.<sup>18</sup> Most patients with cancer would like to be informed of their diagnosis and prognosis,<sup>15 17</sup> but more patients with cancer in South Africa did not want to know their prognosis.<sup>20</sup> Regarding the preferred place of care and death, a larger proportion of patients with cancer chose to be at home, 16-20 but patients with cancer in Pakistan preferred hospital-based care and death.<sup>15</sup> Therefore, we can conclude that different cancer populations have various preferences of EOL care under different cultural contexts.

EOL care practice in mainland China is different from western countries. The families are often involved in EOL decision-making in mainland China.<sup>22</sup> This may lead to situations where patients with cancer receive treatments that are inconsistent with their own wishes. Therefore, it is crucial to know the EOL care preferences of patients with cancer from their perspectives. There has been little research conducted on EOL care preferences among mainland Chinese patients with cancer. Given that patients with cancer in mainland China constitute a great portion of cancer populations worldwide, it is essential to investigate the knowledge, attitudes and preferences of palliative and EOL care among mainland Chinese patients with cancer. Therefore, the present study aimed to (1) investigate the knowledge and attitudes of patients with cancer of palliative care and (2) explore their preferences for EOL care, involving place of care and death, truth disclosure and treatment.

## **METHODS**

# **Research design**

This was a descriptive, cross-sectional study carried out among mainland Chinese patients with cancer.

## Setting and participants

This study was conducted in a tertiary cancer hospital in Hunan province, China. This hospital built the palliative care unit and has initiated palliative care service since 2013. In the palliative care unit, the patients are provided with symptom management, comfort care and psychological and spiritual support by the palliative care multidiscipline team. The patients with cancer in the other units of the hospital can also be referred to the palliative care multidiscipline team, if necessary. Potential participants in this hospital were invited to participate in the survey by convenience sampling from all patients with cancer who were hospitalised between December 2019 and January 2020. Inclusion criteria were (1) diagnosed with cancer, (2) aged  $\geq 18$  years with competent language communication abilities, (3) informed of his/her disease and (4) voluntarily participated in the study under the principle of informed consent. Exclusion criteria were (1) nonresponsive (did not complete the questionnaire) and (2) mentally unstable or having a major mental disorder.

#### **Data collection**

We used the questionnaire adapted from the one developed by Wen-Yu Hu.<sup>9</sup> One of our coauthors obtained permission to use and adapt the questionnaire. The original questionnaire was in traditional Chinese. There is little difference between the semantic expressions and formats of traditional Chinese and simplified Chinese, so we transformed the traditional Chinese into simplified and made some revisions to the expressions to make them semantically easier to be understood by mainland Chinese people. The structured questionnaire included three sections: general information, knowledge and attitudes towards palliative care and preferences of EOL care.

Section 1 included 14 items to collect participants' basic information, including gender, age, education, marital status and occupation, etc. In Section 2, there were 11 questions mainly focusing on patients' understandings and attitudes towards palliative care. Six questions were asked about understandings of palliative care, resuscitation, do not resuscitate (DNR), advance care planning and policies on palliative care. Five questions were used to assess the attitudes towards palliative care, DNR and signing on medical decision agreements. Section 3 aimed to collect patients' preferences of EOL care and involved four aspects: preferred place of care, preferred place of death, preferences of truth disclosure and preferred treatment. In the preferred place of care part, there were two items mainly assessing the preferred place of care and its relationship to medical insurance. In the preferred place of death part, there were four items asking participants about their choices and reasons for choosing their preferred place of death. As for truth disclosure, three items were used to evaluate the willingness to be informed of the diagnosis and terminal status of the disease. In the last part, two questions were used to assess participants' choices about the treatments and medical decisions in EOL.

# **Data collection procedures**

Before starting the investigation, we trained the data collectors in terms of what palliative care is and how to interpret the purpose, process and potential benefits/ harms to the participants to ensure the quality of data collection. Then, the data collectors introduced the definition of palliative care and the relevant research information to the potential participants and invited them to participate in the study. We obtained oral informed consent from all the participants who wanted to fill in the questionnaires. After that, the participants filled out the survey anonymously. In total, 247 participants were recruited in this study after we obtained informed consent. All questionnaires were completed by the participants themselves with no interference.

# **Research governance**

The study had been approved by the institutional review board of behavioural and nursing research in the School of Nursing of Central South University (12019014). The study strictly followed the principles of the Helsinki Declaration. All data in this study were kept secure and would not be accessible to any other people.

# **Data analysis**

After collection, all data were inputted by one of the coauthors and checked by another one. The data were analysed by IBM SPSS V.18.0. As there were no scores being summed up from these data, appropriate descriptive statistics were used to describe the participants' general information, knowledge and attitudes towards palliative care and preferences of EOL care. Means and SD were used to describe continuous variables (the participants' age and time since being diagnosed). Frequency (n) and percentages (%) were used to described the categorical variables (participants' other general information, each item of the knowledge and attitudes towards palliative care and preferences of EOL care). Regarding the missing data, we have removed the cases with missing data >20%. For cases with a few missing values, we kept these data for analysis, as these participants also provided important information about other items.

# Patient and public involvement

Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this research.

Table 1       Participants' basic information (n=239)				
Variables	N	%		
Age	49.63	49.63±11.65 (mean±SD)		
Gender				
Male	104	43.5		
Female	135	56.5		
Education level				
Primary school and below	75	31.4		
Middle school	78	32.6		
High school	41	17.2		
Above high school	45	18.8		
Marital status				
Married	215	90.0		
Divorced/widowed	12	5.0		
Unmarried/others	12	5.0		
Residence				
Rural area	154	64.44		
Urban area	85	35.56		
Religiosity				
None	215	90.0		
Yes	24	10.0		
Tumour site				
Head and neck	69	28.9		
Nervous	3	1.3		
Thorax	57	23.8		
Abdominal	18	7.5		
Digestive	30	12.6		
Genital	24	10.0		
Urinary	8	3.3		
Bone	3	1.3		
Lymphatic/haematological	9	3.8		
Others	18	7.5		
Time since diagnosed	Time since diagnosed6.61±6.11 (mean±SD)			
Whether or not have discussed EOL treatment				
No	194	81.2		
Yes	45	18.8		

EOL, end-of-life.

## RESULTS

## Participants' basic information

In this study, a total of 247 patients with cancer consented to participate in the survey and filled out the questionnaires. After removing the questionnaires with missing data >20%, 239 (96.8%) valid questionnaires still remained. Table 1 shows the basic information of the 239 participants. The mean age of the participants was 49.63 (SD=11.65) years old. The majority of patients with cancer (56.5%) were women, and the mean time since diagnosis was 6.61 (SD=6.11) months.

Table 2       Knowledge of palliative care (n=239)					
Items		N	%		
Knowled	dge				
Whether you have heard about palliative care or related policies					
No		194	81.2		
Yes		45	18.8		
Understa	anding palliative care				
Totally	do not understand	59	24.7		
Do no	t understand	118	49.4		
Neutra	al	48	20.1		
Some	what understand	13	5.4		
Totally	understand	1	0.4		
Understa	anding cardiopulmona	ary resuscit	ation*		
Totally	do not understand	25	10.5		
Do no	t understand	97	40.6		
Neutra	al	67	28.0		
Some	what understand	46	19.2		
Totally	understand	3	1.3		
Understa	anding DNR*				
Totally	do not understand	27	11.3		
Do no	t understand	108	45.2		
Neutra	al	65	27.2		
Some	what understand	37	15.5		
Totally	understand	1	0.4		
Understanding advance care planning*					
Totally	do not understand	40	16.7		
Do no	t understand	138	57.7		
Neutra	al	44	18.4		
Some	what understand	15	6.3		
Totally	understand	0	0		
Understanding policies on palliative care					
Totally	do not understand	50	20.9		
Do no	t understand	136	56.9		
Neutra	al	37	15.5		
Some	what understand	16	6.7		
Totally	understand	0	0		

\*The total number of participants was not 239, because there were missing data in this item.

DNR, do not resuscitate.

## Knowledge and attitudes towards palliative care

Table 2 shows the participants' knowledge of palliative care. Among the 239 patients with cancer, the majority of them (81.2%) had never heard of palliative care or the related policies. For those who had heard about palliative care or the related policies, they received information from newspapers, periodicals, social media, leaflets, health medical staff or hospital bulletin boards. Only 5.8%

of the participants had somewhat of an understanding of palliative care. Less than 10% of the participants had somewhat of an understanding of advance care planning and policies on palliative care. Regarding cardiopulmonary resuscitation and DNR, a limited number of participants had some understanding or total understanding.

Most participants (75.3%) held supportive attitudes towards palliative care. When asked about their preferences when signing EOL medical decision agreements, most of the participants (77.4%) claimed that they might sign any EOL medical decision agreements in advance when conscious and competent. One hundred fifty-eight (66.1%) participants agreed that they might sign agreements to not undergo intensive rescuing when at the terminally ill stage. However, if their relatives were ill and came to the terminally ill stage, more participants (59.4%) held a different attitude. Other detailed information is presented in table 3.

### **EOL care preferences**

Table 4 displays the results of participants' preferences of EOL care. Most (n=157, 65.7%) of the participants preferred to be cared for at home in the EOL, and 79.1% (n=189) preferred to die at home. Even when they were treated in the hospital, most of them (84.9%) indicated that they would like to come back home when dying. 'Home is the most familiar place' (n=145, 71.4%) and 'hoping to be accompanied by families' (n=157, 77.3%)were the most common reasons for choosing home as the place of death. When asked about why they would not choose to die at home, the majority of the respondents did not want to cause their families any distress (n=25, 75.8%). Regarding truth disclosure, 65.7% of patients with cancer wanted to know their diagnosis or prognosis of the disease regardless of the type of disease, and 74.1%of them wished to know the terminal stage of their disease when they came to EOL. As for preferred treatments in EOL, more than half of the participants (54%) wished to improve their quality of life rather than prolong their life expectancy in EOL care. A small portion (13.8%) of patients would not sign any medical decision agreements in written or in oral form. More than a third preferred to entrust a family member or agent to sign medical decision agreements for them.

## DISCUSSION

In this study, we explored the knowledge, attitudes and preferences of palliative and EOL care issues among patients with cancer in mainland China. The findings will not only provide deep insight into the thoughts of patients with cancer on EOL care but also have implications for caring for terminally ill patients with cancer.

In the current study, the majority of patients with cancer had a limited understanding of palliative care, advance care planning and cardiopulmonary resuscitation and DNR, which was similar to previous findings.<sup>11</sup> This could be explained by the initial stage of palliative

Table 3       Attitudes towards palliative care (n=239)				
Items	N	%		
Attitude towards palliative care*				
Completely agree	8	3.3		
Agree	172	72.0		
Disagree	44	18.4		
Completely disagree	2	0.8		
Whether DNR is ethically the already performed*	same as removing	g the CPR		
Yes	38	15.9		
No	64	26.8		
Not sure	136	56.98		
Whether or not you will sign any EOL medical decision agreements in advance when you are conscious and competent*				
Highly possible	17	7.1		
Possible	168	70.3		
Impossible	47	19.7		
Highly impossible	4	1.7		
Whether or not you agree to sign agreements to not receive intensive rescuing when at the terminally ill stage*				
Highly possible	20	8.4		
Possible	138	57.7		
Impossible	70	29.3		
Highly impossible	10	4.2		
Whether or not you agree to sign agreements to not receive intensive rescuing when your relative is sick and at the terminally ill stage*				
Highly possible	6	2.5		
Possible	89	37.2		
Impossible	124	51.9		
Highly impossible	18	7.5		

\*The total number of participants was not 239, because there were missing data in this item.

CPR, cardiopulmonary resuscitation; DNR, do not resuscitate; EOL, end-of-life.

care in mainland China. Broad propaganda and education are needed to promote the recognition of patients with cancer of palliative care, including expanding media coverage, organising various on-site promotion activities and healthcare providers' advocating.<sup>11</sup> However, most participants (75.3%) already have supportive attitudes towards palliative care after being introduced to it by data collectors. This indicates that palliative care would be accepted among patients with cancer, but does not mean that most patients with cancer would choose palliative care when they arrive at the terminal stage.<sup>11</sup>

When asked about their preferences when signing EOL medical decision agreements, most of the patients with cancer (77.4%) claimed that they might sign any EOL medical decision agreements in advance when conscious and competent. Most patients with cancer might agree to

Table 4Preferences of patients with cance(n=239)	er to EOL care
Preferences to EOL care	N (%)
Preferred place of care	
Preferred place of care in the EOL*	
Home	157 (65.7)
General hospital ward	24 (10.0)
Palliative care unit	26 (10.9)
Nursing home	9 (3.8)
Others	18 (7.5)
Whether or not related to medical insurance*	
Yes	71 (29.7)
No	72 (30.1)
Not sure	84 (35.2)
Preferred place of death	
Preferred place of death in the EOL*	
Home	189 (79.1)
Hospital	24 (10.0)
Community care facilities	7 (2.9)
Others	18 (7.5)
Whether or not you will come back home when dying in the hospital*	
Yes	203 (84.9)
No	33 (13.8)
The reasons why you are choosing to die at home (n=203, multichoice)†	
Home is the most familiar place	145 (71.4)
Hoping to be accompanied with families	157(77.3)
Wishing to die before the tablets of ancestors	29 (14.3)
Others	6 (3.0)
The reasons why you are not choosing to die at home (n=33, multichoice)‡	
Fear of not having access to adequate medical care	10 (30.3)
Hoping to not cause any distress to families	25 (75.8)
Fear of families' confusions when dying	13 (39.4)
Others	3 (9.1)
Preferences of truth disclosure	
Willingness to know the diagnosis and prognosis of the disease*	
No	22 (9.2)
Only want to know the curable disease	58 (24.3)
Yes, no matter what type of disease it is	157 (65.7)
Do you want your doctor to tell your family or friends about your illness?*	
No	32 (13.4)
	Continued

Continued

Table 4 Continued		
Preferences to EOL care	N (%)	
Only wishing the families to be informed	58 (24. 3)	
Only wishing myself to be informed	42 (17.6)	
Wishing myself and families to be informed	106 (44.4)	
Willingness to know the terminal stage of the disease when coming to the EOL		
No	26 (10.9)	
Only wishing the families to be informed	36 (15.1)	
Only wishing myself to be informed	71 (29.7)	
Wishing myself and families to be informed	106 (44.4)	
Preferred treatment		
Preferred treatment in the EOL*		
Strongly wishing to prolong life expectancy	37 (15.5)	
Wishing to prolong life expectancy	68 (28.5)	
Wishing to improve quality of life	54 (22.6)	
Strongly wishing to improve quality of life	75 (31.4)	
Willingness to sign medical decision agreements in the EOL*		
No, neither in written nor in oral form	33 (13.8)	
Yes, only in oral form	40 (16.7)	
Yes, entrusting a family member or agent to sign after dictation	95 (39.7)	
Yes, signing in written form	64 (26.8)	
*The total number of participants was not 239, because there were missing data in this item.		

†Among 203 participants who will come back to home when dying in the hospital.

‡Among 33 participants who will not come back to home when dying in the hospital.

EOL, end-of-life.

not receive intensive rescuing when arriving at the terminally ill stage. This may be because patients with cancer don't want to endure unnecessary suffering or cause any other financial burdens for their families. However, a larger proportion of the participants was unlikely to agree to not receive intensive rescuing when their relatives were in a terminally ill stage. This could be because they may have a stronger willingness to extend their relatives' lives with intensive rescuing in order to avoid regrets.<sup>23</sup>

The most important finding in the present study was that most patients with cancer would like to be cared for at home and die at home. Even when they were cared for at a hospital, the majority of them wished to come back home when dying. These results were consistent with findings from previous research studies.<sup>16 19 20 24</sup> However, patients with cancer in Pakistan preferred a hospital-based death.<sup>15</sup> Regarding the reasons why they preferred home, 'home is the most familiar place' and 'hoping to

be accompanied by families' were listed as the most two common reasons in this study. The EOL stage is the last opportunity for one to say goodbye to their families in the last period of life, which may not only provide one with a valuable opportunity to express emotions but also to alleviate loneliness.<sup>25</sup> Also, in mainland China, dying at home has a special cultural meaning for both the patients and their families, as the thought of 'Fallen leaves return to the roots-to revert to one's origin' has been embedded in traditional Chinese culture. Some patients in this study even claimed that they wished to die before the tablets of their ancestors. The results revealed that we need to make efforts to facilitate the home-based palliative care in mainland China, so that the patients with cancer can receive quality EOL care at home. At present, home care is usually provided by medical community hospitals and health clinics in mainland China.<sup>26</sup> To achieve a better EOL quality of life at home, it is necessary to enhance community's capabilities to provide home-based palliative care services in the next decade.

There was also a minor portion of patients with cancer not choosing home as the place of care and death. The most common reason for not choosing home as the place of care was the hope of not causing any burden to families. Additionally, the preferred place of care and death may be influenced by financial issues.<sup>27</sup> Since there is no specific public medical insurance for EOL care in mainland China, it costs much more to be cared for and die in hospitals or nursing homes. Therefore, some patients with cancer choose to be cared for and die at home partly because of financial burdens. This was consistent with another finding in this study that revealed that nearly a third of the participants' choices were related to medical insurance. Overall, when patients make the decisions regarding their preferred place of care and death, they may take various factors into consideration, such as personal values, family burden, healthcare needs and practical reasons. Individual patients with cancer make a specific decision on where to spend the rest of their life. To better understand the preferences of patients with cancer in terms of place of care and death, every effort should be made to allow their actual concerns to be heard and their unique needs met.<sup>24</sup>

Similar to previous findings,<sup>27 28</sup> most of the patients with cancer in this study wanted to know their diagnosis or prognosis of the disease regardless of the type of disease. Even when it came to the terminal stage, the majority of them wanted to know their condition. In western countries, it is the patients' right to get a full understanding of their disease, and the physicians have an obligation to inform them.<sup>29</sup> In mainland China, the patient is possibly the last one in the family to know the diagnosis or prognosis. The physicians tend to inform the families about the patients' condition and seek their advice about whether or not to tell patients with cancer the truth.<sup>30</sup> Families in mainland China tend to hide conditions from patients with cancer out of protectiveness.<sup>31</sup> However, the accurate understanding of patients with cancer of their

illness could allow them to choose care that is congruent with their wishes.<sup>32</sup> Also, patients who are aware of the incurability of their disease are more likely to prefer hospice care,<sup>33</sup> which is associated with better EOL care and higher probabilities to die in their preferred place.<sup>34</sup> The findings in this study provide real thoughts about truth disclosure from the perspectives of patients with cancer. Since discord exists among patient preferences, caregiver preferences and caregiver predictions of patient preferences, it is better for healthcare providers to emphasise the necessities and benefits of informing patients about their illness alongside their families and to include patients in decision-making discussions to avoid medical disputes.<sup>35</sup>

In this study, more than half of the patients with cancer wanted an improved quality of life rather than a longer life expectancy in the EOL. This finding was different from another previous study<sup>27</sup> conducted in mainland China. This may be caused by the different populations in these two studies. The previous study investigated the EOL care preferences among nursing home residents, while our study investigated the patients with cancer. The patients with cancer are more likely to have a better quality of life in EOL, because they may have experienced suffering and pain during treatments. This finding was consistent with some research<sup>19 36</sup> but was different from other studies<sup>15 37</sup> conducted in other countries. Prioritising a better quality of life or longer life expectancy is not an issue related to right or wrong. It is related to patients' individual views and choices towards EOL care. However, aggressive treatments and life-sustaining treatments that may prolong the life expectancy in the EOL will increase the patients' suffering. From the perspective of healthcare providers, we need to try our best to recommend a better way for patients with cancer to improve their EOL care.

A portion of patients with cancer in this study would not sign any medical agreements in a hypothetical EOL stage, and most of them preferred to entrust a family member or agent to sign medical decision agreements for them. This finding was similar to that which was observed in Macao, China.<sup>38</sup> In that qualitative study, most participants deferred the decision-making to their families. This may be explained by the diminished sense of autonomy in decision-making under the family-centred model.

#### Strengths and limitations

There were several strengths in our study. First, there were few reports on the knowledge, attitudes and preferences of palliative and EOL care issues for mainland Chinese patients with cancer. This study will contribute to an understanding of palliative and EOL care knowledge, attitudes and preferences among patients with cancer as a whole. Additionally, due to the important cultural differences in mainland China and the ever-increasing importance of palliative care and EOL care, a study in the Chinese cancer population was needed.

Limitations also need to be acknowledged. The sample source in this study was limited. The participants were all recruited in one tertiary patient with cancer hospital in one province. Therefore, the opinions of patients with cancer in other areas of mainland China remain to be discussed. In addition, the findings in this study were informed by patients with cancer rather than from the perspectives of terminally ill patients with cancer. The findings may not present the thoughts of terminally ill patients with cancer, as preferences of EOL care change over different stages of diseases.<sup>39 40</sup> We did not evaluate the stage of the patients with cancer, and this would be another limitation. When evaluating participants' preferences of medical decision agreements at the EOL, we did not specify the detailed medical decision agreements. This may lead to different recognitions for different patients. Additionally, some choices involved hypothetical situations, such as the hypothetical terminal stage. Therefore, the choices cannot necessarily present a real situation faced by a terminally ill patient in the future. More research is needed to explore the views and preferences of terminally ill patients with cancer towards EOL care.

#### **CONCLUSIONS**

Patients with cancer had a limited knowledge of palliative care but held supportive attitudes towards it. Most patients with cancer preferred home as the place of care and death in EOL care and also preferred being informed of their diagnosis and prognosis, receiving treatments improving their quality of life and entrusting a family member or agent to sign medical decision agreements. It is essential for healthcare providers to increase the understanding of patients with cancer of palliative care and be aware of the EOL care preferences of patients with cancer, in order to provide support that enables patients with cancer to receive EOL care that is accordant with their wishes, thus improving their EOL experience.

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- 1 Feng R-M, Zong Y-N, Cao S-M, *et al.* Current cancer situation in China: good or bad news from the 2018 Global Cancer Statistics? *Cancer Commun* 2019;39:22.
- 2 Chen W, Zheng R, Baade PD, et al. Cancer statistics in China, 2015. CA Cancer J Clin 2016;66:115–32.
- 3 Ning XH. Hospice and palliative care in mainland China: history, current status and challenges. *Chin Med Sci J* 2018;33:199–203.
- 4 The Economist intelligence unit. quality of death index, 2015. Available: https://perspectives.eiu.com/healthcare/2015-qualitydeath-index
- 5 National Health Commission. Notice on issuing practice guidelines of palliative care (trial), 2017. Available: http://www.nhc.gov.cn/yzygj/ s3593/201702/3ec857f8c4a244e69b233ce2f5f270b3.shtml
- 6 National Health Commission. Notice on issuing the basic standards and management norms of palliative care centers (trial), 2017. Available: http://www.nhc.gov.cn/yzygj/s3593/201702/2f50fdc62fa8 4cdd9d9a09d5162a661f.shtml
- 7 National Health Commission. Notice on the issueing guidelines for the reform and development of nursing services, 2018. Available: http://www.nhc.gov.cn/yzygj/s7659/201807/1a71c7bea4a04d5f82d1 aea262ab465e.shtml
- 8 State Council of the central Committee of the Communist Party of China. medium and long-term national plan for population aging, 2019. Available: http://www.gov.cn/xinwen/2019-11/21/content\_ 5454347.htm
- 9 Chen T-R, Hu W-Y, Two S-N, et al. What influences the willingness of cancer patients to receive hospice palliative care at end of life? Jpn J Clin Oncol 2019;49:361–6.
- 10 Cagle JG, Kovacs PJ. Informal caregivers of cancer patients: perceptions about preparedness and support during hospice care. *J Gerontol Soc Work* 2011;54:92–115.
- 11 Ni K, Gong Y, Li F, et al. Knowledge and attitudes regarding hospice care among outpatients and family members in two hospitals in China. *Medicine* 2019;98:e15230.
- 12 Li T, Pei X, Chen X, *et al.* Identifying end-of-life preferences among Chinese patients with cancer using the heart to heart card game. *Am J Hosp Palliat Care* 2021;38:1049909120917361.
- 13 Romo RD, Allison TA, Smith AK, et al. Sense of control in end-of-life decision-making. J Am Geriatr Soc 2017;65:e70–5.
- 14 Hunt KJ, Shlomo N, Addington-Hall J. End-of-life care and achieving preferences for place of death in England: results of a populationbased survey using the VOICES-SF questionnaire. *Palliat Med* 2014;28:412–21.
- 15 Zafar W, Hafeez H, Jamshed A, et al. Preferences regarding disclosure of prognosis and end-of-life care: a survey of cancer patients with advanced disease in a lower-middle-income country. *Palliat Med* 2016;30:661–73.
- 16 Loh AZH, Tan JSY, Jinxuan T, et al. Place of care at end of life: what factors are associated with patients' and their family members' preferences? Am J Hosp Palliat Care 2016;33:669–77.
- 17 Hirano H, Shimizu C, Kawachi A, et al. Preferences regarding end-oflife care among adolescents and young adults with cancer: results from a comprehensive multicenter survey in Japan. J Pain Symptom Manage 2019;58:235–43.
- 18 Miccinesi G, Bianchi E, Brunelli C, et al. End-of-life preferences in advanced cancer patients willing to discuss issues surrounding their terminal condition. Eur J Cancer Care 2012;21:623–33.
- 19 Waller A, Sanson-Fisher R, Nair BR, et al. Preferences for end-of-life care and decision making among older and seriously ill inpatients: a cross-sectional study. J Pain Symptom Manage 2020;59:187–96.

- 20 Shen MJ, Prigerson HG, Ratshikana-Moloko M, et al. Illness understanding and end-of-life care communication and preferences for patients with advanced cancer in South Africa. J Glob Oncol 2018;4:1–9.
- 21 Alyami HM, Chan RJ, New K. End-Of-Life care preferences for people with advanced cancer and their families in intensive care units: a systematic review. *Support Care Cancer* 2019;27:3233–44.
- 22 Huang Q-S. A review on problems of China's hospice care and analysis of possible solutions. *Chin Med J* 2015;128:279–81.
- 23 Malhotra C, Farooqui MA, Kanesvaran R, et al. Comparison of preferences for end-of-life care among patients with advanced cancer and their caregivers: a discrete choice experiment. *Palliat Med* 2015;29:842–50.
- 24 Tang ST. When death is imminent: where terminally ill patients with cancer prefer to die and why. *Cancer Nurs* 2003;26:245–51.
- 25 Yeh S-T, Ng Y-Y, Wu S-C. Hospital and patient characteristics regarding the place of death of hospitalized impending death patients: a multilevel analysis. *Int J Environ Res Public Health* 2019;16:4609.
- 26 Lu Y, Gu Y, Yu W. Hospice and palliative care in China: development and challenges. Asia Pac J Oncol Nurs 2018;5:26–32.
- 27 Ni P, Zhou J, Wang ZX, et al. Advance directive and end-of-life care preferences among nursing home residents in Wuhan, China: a cross-sectional study. J Am Med Dir Assoc 2014;15:751–6.
- 28 Jiang Y, Liu C, Li J-Y, et al. Different attitudes of Chinese patients and their families toward truth telling of different stages of cancer. *Psychooncology* 2007;16:928–36.
- 29 Fallowfield L, Jenkins V. Communicating sad, bad, and difficult news in medicine. *Lancet* 2004;363:312–9.
- 30 Hahne J, Liang T, Khoshnood K, et al. Breaking bad news about cancer in China: concerns and conflicts faced by doctors deciding whether to inform patients. *Patient Educ Couns* 2020;103:286–91.
- 31 Wang D-can, Guo C-bin, Peng X, et al. Is therapeutic non-disclosure still possible? A study on the awareness of cancer diagnosis in China. Support Care Cancer 2011;19:1191–5.
- 32 Yoo SH, Lee J, Kang JH, et al. Association of illness understanding with advance care planning and end-of-life care preferences for advanced cancer patients and their family members. Support Care Cancer 2020;28:2959–67.
- 33 Mack JW, Walling A, Dy S, et al. Patient beliefs that chemotherapy may be curative and care received at the end of life among patients with metastatic lung and colorectal cancer. Cancer 2015;121:1891–7.
- 34 Wright AA, Keating NL, Ayanian JZ, *et al*. Family perspectives on aggressive cancer care near the end of life. *JAMA* 2016;315:284–92.
- 35 Shin DW, Cho J, Kim SY, *et al.* Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end-of-life choices. *Psychooncology* 2015;24:212–9.
- 36 Chung RY-N, Wong EL-Y, Kiang N, et al. Knowledge, attitudes, and preferences of advance decisions, end-of-life care, and place of care and death in Hong Kong. a population-based telephone survey of 1067 adults. J Am Med Dir Assoc 2017;18:367.e19–367.e27.
- 37 Tan WS, Bajpai R, Ho AHY, *et al*. Retrospective cohort analysis of real-life decisions about end-of-life care preferences in a Southeast Asian country. *BMJ Open* 2019;9:e024662.
- 38 Ho S-W, Sanders GF. Preferences on end-of-life decisions among older Chinese in Macau. J Transcult Nurs 2015;26:741–3.
- 39 Agar M, Currow DC, Shelby-James TM, et al. Preference for place of care and place of death in palliative care: are these different questions? *Palliat Med* 2008;22:787–95.
- 40 Ali M, Capel M, Jones G, et al. The importance of identifying preferred place of death. BMJ Support Palliat Care 2019;9:84–91.