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

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 understand the experience of patients with cancer of palliative care and to 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 end-of-life care that is accordant with their wishes.

INTRODUCTION

Cancer is the leading cause of death in China, with an increasing incidence every year. According to statistics, there are approximately 4.3 million new cancer cases and 2.9 million cancer deaths every year in China, accounting for 24% of the new cases and 30% of cancer deaths worldwide. China has a lower cancer mortality rate than the UK and the USA, 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. According to the 2015 Quality of Death Index, China ranked 71st out of 80 countries and regions in terms of quality of palliative care. In order to promote the development of palliative care, the government began issuing a series of policies and guidance documents in 2016. 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. Moreover,
their knowledge and attitudes may also affect their decisions in EOL. 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. 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. Understanding the preferences of patients with cancer of EOL care could help healthcare providers know more about their concerns, which is a prerequisite for EOL care complying with patients’ preferences. Further research is needed to explore patients’ preferences of EOL care, which should also not be restricted to patients who will be dying. 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. 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. Some patients with cancer expressed their preference to die in a state of unconsciousness induced by drugs. Most patients with cancer would like to be informed of their diagnosis and prognosis, but more patients with cancer in South Africa did not want to know their prognosis. Regarding the preferred place of care and death, a larger proportion of patients with cancer chose to be at home, but patients with cancer in Pakistan preferred hospital-based care and death.

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. 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 ≥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) non-responsive (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. 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 co-authors 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.

### 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.

| Variables                      | N     | %  |
|--------------------------------|-------|----|
| Age                            | 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           | 6.61±6.11 (mean±SD) |
| Whether or not have discussed EOL treatment |       |    |
| No                             | 194   | 81.2 |
| Yes                            | 45    | 18.8 |

EOL, end-of-life.
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.

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. This could be explained by the initial stage of palliative
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. 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.

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

| Preferences to EOL care | N (%) |
|-------------------------|-------|
| 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) |
| 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) |

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
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.16 19 20 24 However, patients with cancer in Pakistan preferred a hospital-based death.15 Regarding the reasons why they preferred home, ‘home is the most familiar place’ and ‘hoping to 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.23

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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.27 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.24

Similar to previous findings,27 28 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.29 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.30 Families in mainland China tend to hide conditions from patients with cancer out of protectiveness.31 However, the accurate understanding of patients with cancer of their

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### 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* | N (%) |
|--------------------------------|-------|
| 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.
illness could allow them to choose care that is congruent with their wishes.\textsuperscript{32} Also, patients who are aware of the incurability of their disease are more likely to prefer hospice care,\textsuperscript{33} which is associated with better EOL care and higher probabilities to die in their preferred place.\textsuperscript{34} 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.\textsuperscript{35}

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\textsuperscript{27} 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,\textsuperscript{19,36} but was different from other studies,\textsuperscript{15,37} 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.\textsuperscript{38} 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.\textsuperscript{39,40} 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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**Ethics approval** The study had been approved by the institutional review board of behavioural and nursing research in School of Nursing of Central South University (12019014).

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**Data availability statement** Data are available upon reasonable request.

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