

Advance Directives and End-of-Life Care: Knowledge and Preferences of Patients with Brain Tumours from Anhui, China

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Abstract

Background: In Mainland China, the advance directives (ADs) and end-of-life care of patients with tumours, especially patients with brain tumours who may have lost consciousness or the ability to speak at the early stage of their illness, have been poorly acknowledged. Thus, this study aims to clarify the knowledge and preferences of the ADs and end-of-life care of patients with brain tumours and to investigate the predictors of patients' preferences.

Methods: This was a population-based cross-sectional survey that was conducted via face-to-face interviews. Information on the sociodemographic factors, brain tumour illness, knowledge and preferences of the advance decisions and end-of-life care of the patients were collected.

Results: A total of 88.61% of the participants had never heard of ADs, but 65.18% would like to make ADs. Knowledge of ADs, receiving surgical treatment or radiotherapy, less than 70 years old, male, educational qualifications of college or beyond, childless, had medical insurance for nonworking or working urban residents and self-payment of medical expenses were predictors of preference for making ADs. A total of 79.43% participants would like to discuss end-of-life arrangements with medical staff, and 63.29% of participants were willing to receive end-of-life care although it could not delay death. A total of 65.82% patients with brain tumours wanted resuscitation, and as high as 45.45% of the patients thought that they did not need life support if they were in a persistent vegetative state. Brain primary tumours, ages of less than 70 years old, male, educational qualification of junior middle school or below, had children, had new rural cooperative medical insurance and had medical expenses paid by children or spouses were predictors of choosing appropriate palliative care.

Conclusions: ADs and end-of-life care have been poorly acknowledged amongst patients with brain tumours in mainland China. Additional efforts should be encouraged amongst patients with primary brain tumours, those are undergoing surgery and radiotherapy and those who have low socioeconomic status. Appropriate decision-making timing is encouraged to promote AD amongst Chinese patients with brain tumours.

Background

'Advance directives (ADs)' is the legal term for the documentation of the end-of-life care decisions that honour an individual's values and preferences[1-2]. In mainland China, advance directive discussions are challenging and complicated, and no relevant legal document exists; such a situation has an inevitable and important effect on patients with tumours because patients with tumours who convey their individual values and end-of-life decisions are more likely to receive the care that they want than those who do not[3]. ADs help patients understand end-of-life decision-making fully to generate an appropriate therapeutic schedule that may reduce chemotherapy and targeted medicine use and decrease hospitalisations[4]. Moreover, ADs allow patients with tumours to spend meaningful time with their families and die with dignity. Therefore, oncology medical staff should investigate the ADs of tumour

patients. In particular, in contrast to patients with other kinds of tumours (e.g. lung cancer) who may be consistently conscious, patients with brain tumours may lose consciousness or their ability to speak at the early stage of their illness. Thus, implementing the ADs of patients with brain tumours is important. However, few studies have concentrated on the knowledge and preferences of the ADs of Chinese patients with tumours, especially patients with brain tumours. In this work, we explored the challenges remaining in understanding the knowledge and preferences of ADs and end-of-life care decisions of patients with brain tumours and investigated the roles played by brain tumour illness, sociological status and economic condition in predicting the preferences of the participants.

Methods

Participants

Patients from Cancer hospital, Chinese academy of science, Hefei and The First Affiliated Hospital of Anhui Medical University were eligible if they had ages of more than 18 years old, confirmed brain tumour diagnosis, no disturbance of consciousness, the capacity to understand and talk to clinical staff and been assessed by clinical staff to be physically and mentally able to complete the questionnaire.

Study design

Follow-up was difficult given that patients with brain tumours have poor prognosis and may reside in rural areas. Thus, a cross-sectional study was conducted from January 1 to February 20, 2020. All patients with brain tumours who met the inclusion criteria were interviewed, amongst whom 44 were unwilling to be interviewed. Ethical approval of the research protocol (SL-KY2020-002) was granted by the Ethics Committee of the Cancer Hospital of the Chinese Academy of Science, Hefei.

Data collection procedure

Briefly, potentially eligible patients were identified by clinical staff from the clinician workstation. Considering some patients' family members usually asked the doctor to keep the patients' conditions confidential, we introduced our study to the patient's family members before we interviewed the patients. We provided the following information: *Our study is a face-to-face interview. Patients will be asked some questions about ADs (a written statement of a person's wishes regarding medical treatment that often includes a living will and is made to ensure that these wishes are carried out should the person be unable to communicate them to a doctor), which is not legal at present, and end-of-life care (support and medical care given during the time surrounding death).* Then, we asked family members two questions: (1) *'Does the patient know the real condition of their illness?'*(2) *'Do you allow the patient to participate in this interview?'*

If we had the permission of family members and the patients know the real condition of their illness, we then conducted our interview. The questionnaire was formulated in accordance with literature on ADs and end-of-life care. All data were collected by our research team through face-to-face interviews in the

patients' ward. Considering that not all patients with brain tumours could read, we read the question aloud and recorded the patients' answers.

Questions about AD

Patients were asked to respond to the following statement: (1) *'Have you heard of AD (a written statement of a person's wishes regarding medical treatment, often including a living will, made to ensure that these wishes are carried out should the patient be unable to communicate them to a doctor)?'* (2) *'In the future, if AD become legal in China and you are in a condition wherein you cannot make your own medical decisions (e.g. comatose or cannot speak), would you like to make an AD?'* (3) *'If you prefer to make an AD, your reasons will be to a) ensure that the end of my life is comfortable and avoid pain; b) avoid imposing economic burden on my family; c) hope my own wishes will be respected; d) avoid imposing burdens on society; e) consider that the quality of my life is more important than the length of my life; f) religious beliefs and g) I have witnessed the rescue of other people.'* (4) *'Your reasons for not preferring to make an AD are a) my family members will decide for me; b) I will let it be; c) I have no need to think about it now and my doctor will decide for me; d) my decision may change; e) I am not familiar with the concept of advance directives and f) religious beliefs.'*

Questions about end-of-life care

Firstly, patients were introduced the concept of end-of-life care as follows: *End-of-life care cannot cure your illness. It is care given to people who are near the end of their life and have stopped treatment to cure or control their disease. End-of-life care includes physical, emotional, social and spiritual support for patients and their families. The goal of end-of-life care is to control pain and other symptoms such that the patient can be as comfortable as possible. End-of-life care may include palliative care, supportive care and hospice care.* They were then asked to respond to the following statements: (1) *'Would you like the medical staff to discuss your illness and end-of-life arrangements directly with you?'* (2) *'If you were terminally ill (a few weeks before death), would you prefer to receive appropriate palliative care that cannot delay death but gives comfort?'* (3) *'If you were terminally ill (a few weeks before death) and in a critical moment (e.g. cardiac arrest), would you prefer receiving resuscitation (cardiopulmonary resuscitation, electrical defibrillation, endotracheal intubation or tracheotomy)?'* (4) *'If you were terminally ill (a few weeks before death) and in a persistent vegetative state (such as brain tumour progression), would you prefer life support (including nutritional support, such as tube feeding or percutaneous endoscopic gastrojejunostomy, broad-spectrum antibiotics, blood transfusions or ventilator-assisted ventilation)?'*

Sociodemographic and disease variables

Information about the patients, including sociodemographic factors, type of brain tumour, history of brain tumours and general condition, was recorded.

Data analysis

Data were analysed by using SPSS 22.0 (IBM Corp, Armonk, NY). The relationship amongst the participants' sociodemographic factors, history of brain tumours, preference for making ADs and preference for receiving appropriate palliative care were analysed via binary logistic regression. All p values less than 0.05 were considered to be statistically significant. Group comparisons were determined by two questions about ADs and end-of-life care.

Results

Characteristics of study participants

The sociodemographic characteristics of the 316 participants with brain tumours who were aged over 18 years old are reported in Table 1. Amongst the patients, 65.19% were female and 34.81% were male. In terms of marital status, approximately two-thirds of the participants were married, 15.83% were divorced, 11.39% were unmarried and 8.86% had lost their spouses. Over 70% of the participants had completed junior high school education or below, and only 24 had a bachelor/postgraduate/PhD degree. Although only 17.21% of the participants were urban residents, 76.9% of the participants had their own private housing. Moreover, the type of the medical insurance of the participants was related to their residence: 82.28% of the patients had new rural cooperative medical insurance, 22.71% had medical insurance for nonworking urban residents and only 6.01% had medical insurance for working urban residents.

Table 1

Characteristics of Brain Tumour Patients(n=316)

| Social and Demographic Characteristics | n(%) |
|---|-----------|
| Age,years | |
| 30-39 | 1805.69% |
| 40-49 | 2006.32% |
| 50-59 | 8827.84% |
| 60-69 | 9730.69% |
| 70-79 | 7222.78% |
| 80-89 | 216.64% |
| Sex | |
| Male | 11034.81% |
| Female | 20665.19% |
| Marital status | |
| Married | 20263.92% |
| Divorced | 5015.83% |
| Unmarried | 3611.39% |
| Widowed | 288.86% |
| Educational Qualifications | |
| Junior middle school or less | 22972.47% |
| Senior high school | 6319.94% |
| College or more | 247.59% |
| Residence | |
| Rural | 26082.29% |
| City | 5617.21% |
| Type of housing | |
| Private housing | 24376.9% |
| Retal housing | 226.96% |
| Children's housing | 5116.14% |
| Religious belief | |
| None | 23474.05% |
| Have | 8225.95% |
| Children | |
| None | 6119.3% |
| Have | 25580.7% |
| Type of medical insuranse | |
| New rural cooperative medical insurance | 26082.28% |
| Medical insurance for non-working urban residents | 3711.71% |
| Medical insurance for working urban residents | 196.01% |

Who will cover your medical expenses?

| | | |
|--------------------|-----|--------|
| Own | 110 | 34.81% |
| Children or spouse | 206 | 65.19% |

The tumour-related characteristics of the 316 participants are reported in Table 2. Over two-thirds of the participants had brain metastases, amongst which primary tumours were located in the lung (32.27%) and breast (35.75%). Nearly a quarter of the primary brain tumours were classified as gliomas. Only three patients had meningioma, and one patient had brain lymphoma. At the time of the interview, 73.74% of the participants were receiving radiotherapy, 8.22% were receiving surgery and 14.55% were receiving medicine. Only 11 participants were undergoing support treatment. Slightly more than one-half of the participants had been ill for less than 12 months, and 18.68% of the participants had lived for over 25 months. Only 26.27% of the patients with brain tumours were in good general condition with KPS scores of over 80. Over 70% of the patients with brain tumours had poor KPS scores of less than 80 and or even less than 50.

Table 2

General Condition of Brain Tumour Patients(n=316)

| Morbid Characteristics | n(%) |
|--------------------------------------|-------------|
| Type of brain tumour | |
| Glioma | 78(24.68%) |
| WHO I-II | 14(4.43%) |
| WHO III-IV | 64(20.25%) |
| Meningioma | 3(9.49%) |
| Lymphoma | 5(1.58%) |
| Brain Metastases | |
| From lung cancer | 102(32.27%) |
| From breast cancer | 113(35.75%) |
| From other cancer | 15(4.73%) |
| Treatment currently receiving | |
| Surgery | 26(8.22%) |
| Radiotherapy | 233(73.74%) |
| Medicine | 46(14.55%) |
| Support treatment | 11(3.49%) |
| Duration of illness | |
| 1month or less | 81(25.63%) |
| 2months to 6months | 32(10.13%) |
| 7months to 12months | 54(17.08%) |
| 12months to 24months | 90(28.48%) |
| 25 months or more | 59(18.68%) |
| Symptoms | |
| Headache | 181(57.27%) |
| epilepsy | 21(6.65%) |
| Movement disorders | 78(24.69%) |
| Language disorders | 36(11.39%) |
| KPS scores | |
| ≤50 | 37(11.71%) |
| 60-79 | 196(62.02%) |
| ≥80 | 83(26.27%) |

KPS scores=Karnofsky scores.

ADs

The knowledge and preferences of the patients for ADs are summarised in Table 3. A very low proportion of patients with brain tumours had ever heard of ADs, and 88.61% had never heard of ADs. After

introducing the concept of ADs to the patients, almost two-thirds of the participants stated that they would like to make ADs. As shown in Table 3, the main reason for wanting ADs was to ensure comfort at the end of their lives and reduce financial burdens on their family. For those who would not like to make ADs, the key reason was their lack of familiarity with the concept of ADs or they thought doctors (30.91%) or family member would make decisions for them.

Table 3

Knowledge and preferences of the study participants regarding ADs (n = 316)

| Questions | Answers | n% |
|---|-------------|-----------------|
| Have you heard of ADs (a written statement of a person's wishes regarding medical treatment, often including a living will, made to ensure these wishes are carried out should you be unable to communicate them to a doctor)[] | Yes | 36 (11.39%) |
| | No | 280 (88.61%) |
| In the future, if ADs were legal in China and you were in a condition wherein you cannot make your own medical decisions (e.g. in coma or cannot speak), would you like to make an ADs? | I would | 206 (65.18%) |
| | I would not | 110 (34.82%) |
| Reasons for preferring to make an ADs | | |
| Ensure that the end of my life is comfortable and avoid pain | | 93 (45.15%) |
| Avoid burdening my family's economic condition | | 66 (32.03%) |
| Hope my wishes could be respected | | 23 (11.17%) |
| Avoid imposing burdens on society | | 3 (1.45%) |
| Consider the quality of my life is more important than the length of my life | | 19 (9.23%) |
| Religious beliefs | | 0 |
| Witnessed the rescue of other people | | 2 (0.97%) |
| Reasons for preferring not to make an ADs | | |
| Family members will decide for me | | 15 (13.64%) |
| Let it be | | 5 (4.55%) |
| No need to think about it now and my doctor will decide for me | | 34 (30.91%) |
| Decision may change | | 6 (5.45%) |
| Not familiar with the concept of ADs | | 47 (42.73%) |
| Religious beliefs | | 3 (2.72%) |

ADs, advance directives

Predictors of preferring to make ADs

Bivariate analyses identified knowledge of ADs, receiving surgery or radiotherapy, age of less than 70 years old, male, educational qualification of college or beyond, without children, had medical insurance for nonworking or working urban residents and self-payment of medical expenses as significant predictors of preferring to make ADs. Table 4 shows the results of the binary logistic regression model.

Table 4

Binary logistic regression model prediction of preference for making ADs (n = 316)

| | OR | 95%CI | p value |
|---|--------|---------------|---------|
| Independent Predictors | | | |
| Heard of ADs | | | |
| Yes | 4.727 | 1.626-13.745 | 0.04* |
| No (reference group) | 1 | | |
| Current treatment | | | |
| Surgery | 34.5 | 4.918-242.028 | <0.001* |
| Radiotherapy | 14.223 | 2.985-67.778 | 0.001* |
| Medicine | 1.25 | 0.232-6.739 | 0.795 |
| Support treatment (reference group) | 1 | | |
| KPS scores | | | |
| <50 | 2.426 | 0.951-6.190 | 0.064 |
| 60-79 | 0.954 | 0.560-1.626 | 0.862 |
| >80 (reference group) | 1 | | |
| Age in years | | | |
| 30-49 | 4.756 | 1.971-11.476 | 0.001* |
| 50-69 | 3.424 | 2.031-5.773 | <0.001* |
| 70-89 (reference group) | 1 | | |
| Sex | | | |
| Male | 3.224 | 1.861-5.586 | <0.001* |
| Female (reference group) | 1 | | |
| Educational qualifications | | | |
| Junior middle school or less (reference group) | 1 | | |
| Senior high school | 0.848 | 0.428-1.503 | 0.572 |
| College or beyond | 3.905 | 1.131-13.487 | 0.031* |
| Residence | | | |
| Rural | 0.281 | 0.375-1.330 | 0.281 |
| Urban (reference group) | 1 | | |
| Children | | | |
| No children | 3.789 | 1.789-8.028 | 0.001* |
| Have children (reference group) | 1 | | |
| Type of medical insurance | | | |
| New rural cooperative medical insurance (reference group) | 1 | | |
| Medical insurance for nonworking urban residents | 2.767 | 1.171-6.535 | 0.02* |
| Medical insurance for working urban residents | 11.62 | 1.528-88.389 | 0.018* |
| Who will cover your medical expenses? | | | |
| Own | 2.568 | 1.511-4.365 | <0.001* |

ADs, advance directives; OR, odds ratio; CI, confidence interval.*p < 0.05

End-of-life care

Table 5 shows the attitudes and preferences of the patients for end-of-life care. A total of 79.43% of the participants would like the medical staff to discuss end-of-life arrangements with them. A total of 63.29% of the patients were willing to receive end-of-life care although it could not delay death. Over one-half the patients with brain tumours wanted resuscitation, 27.21% did not and 6.97% participants of the participants were unsure. As high as 45.45% of the participants thought that they do not need life support in a persistent vegetative state, whereas 50.63% wanted life support. Furthermore, 7.92% of the participants could not decide.

Table 5

Knowledge and preferences of end-of-life care of the study participants (n = 316)

| Questions | Answers | n% |
|---|-------------|--------------|
| | I would | 251 (79.43%) |
| Would you like the medical staff to discuss your illness and end-of-life arrangements directly with you? | I would not | 65 (20.57%) |
| | I would | 200 (63.29%) |
| If you were terminally ill (a few weeks before death), would you prefer receiving appropriate palliative care that cannot delay death but gives comfort? | I would not | 116 (36.71%) |
| | I would | 208 (65.82%) |
| | I would not | 86 (27.21%) |
| If you were terminally ill (a few weeks before death) and in a critical moment (e.g. cardiac arrest), would you prefer receiving resuscitation (cardiopulmonary resuscitation, electrical defibrillation, endotracheal intubation or tracheotomy)? | Not sure | 22 (6.97%) |
| | I would | 131 (41.45%) |
| | I would not | 160 (50.63%) |
| If you were terminally ill (a few weeks before death) and in a persistent vegetative state (such as brain tumour progression), would you prefer life support (including nutritional support, such as tube feeding or percutaneous endoscopic gastrojejunostomy, broad-spectrum antibiotics, blood transfusions or ventilator-assisted ventilation?) | Not sure | 25 (7.92%) |

Predictors of preferring appropriate palliative care

Bivariate analyses identified brain primary tumours, less than 70 years old, male, educational qualification of junior middle school or below, have children, new rural cooperative medical insurance or medical expenses paid by their children or spouse as significant predictors of preferring appropriate palliative care. Table 6 shows the results of the binary logistic regression model.

Table 6

Binary logistic regression model predicting preference for receiving appropriate palliative care (n = 316)

| Independent Predictors | OR | 95%CI | p Value |
|---|-------|--------------|---------|
| Type of brain tumour | | | |
| Brain primary tumour | 4.242 | 2.220-8.108 | 0.000* |
| Brain metastases (reference group) | 1 | | |
| Age in years | | | |
| 30-49 | 0.119 | 0.051-0.277 | 0.000* |
| 50-69 | 0.412 | 0.230-0.740 | 0.003* |
| 70-89 (reference group) | 1 | | |
| Sex | | | |
| Male | 1.911 | 1.156-3.160 | 0.012* |
| Female (reference group) | 1 | | |
| Educational qualifications | | | |
| Junior middle school or less (reference group) | 1 | | |
| Senior high school | 0.376 | 0.213-0.665 | 0.001* |
| College or more | 0.207 | 0.084-0.506 | 0.001* |
| Residence | | | |
| Rural | 1.054 | 0.577-1.923 | 0.865 |
| Urban (reference group) | 1 | | |
| Children | | | |
| None (reference group) | 1 | | |
| Have | 1.955 | 1.056--3.611 | 0.033* |
| Type of medical insurance | | | |
| New rural cooperative medical insurance | 6.435 | 2.065-20.050 | 0.001* |
| Medical insurance for nonworking urban residents | 3.187 | 0.888-11.447 | 0.076 |
| Medical insurance for working urban residents (reference group) | 1 | | |
| Who will cover your medical expenses? | | | |
| Self (reference group) | 1 | | |
| Children or spouse | 4.131 | 2.531-6.744 | 0.000* |

OR, odds ratio; CI, confidence interval.*p < 0.05

Discussion

Knowledge and preference of ADs and end-of-life care

In contrast to a previous study, which reported that 23.6% of cancer patients who receive radiotherapy have already signed ADs, our study found that only 11.39% participants had heard of ADs[5]. The

previous study was performed in Germany, which is a developed country wherein ADs have been legal for a few years[6]. By contrast, our patients with brain tumours originated from Anhui Province, China, a region with an underdeveloped economy. In addition, ADs are far from common in China. Thus, the knowledge of ADs is rather low. However, after introducing the concept of ADs to the patients, 65.18% preferred to make ADs; this result is inconsistent with a previous study showing that 22.4% of patients with cancer approved of ADs[7]. This discrepancy may be attributed to the fact that in the previous study, the participants originated from different regions of China with different cultures and had different types of cancer. By contrast, our study included only patients with brain tumours from the Anhui Region. Patients with brain tumours gave avoiding pain and burdening their family's economic condition as the two main reasons for approving ADs. The two main reasons of patients with brain tumours who did not prefer to make ADs were their lack of familiarity with ADs and their perception that their doctor would make decisions for them. We found that after introducing the concept of ADs to the patients, more than half of the patients with brain tumours preferred to make ADs. ADs can prevent the inappropriate treatment of patients with brain tumours when they are unconscious or cannot speak. Thus, patients with brain tumours must understand the concept of advance directives. This understanding can promote the acceptance of ADs amongst patients with brain tumours and encourage the subsequent formation of related policies and regulations related to ADs in mainland China.

A total of 79.43% of the participants would like to discuss their illness and end-of-life arrangements directly with medical staff, and 63.29% of the participants were willing to receive appropriate palliative care though it could not delay death. These results were roughly similar to the results of a survey of 1067 adults in Hong Kong regarding their preferences for end-of-life care; this previous survey reported that 92.2% of the participants thought that medical staff should speak to patients directly about their situation and end-of-life arrangements as good practice, and 87.6% of the participants would prefer to receive appropriate palliative care that may not prolong their life[8]. Thus, conversations about end-of-life arrangements with patients with brain tumours is important, and effective conversation helps ensure that the patients have accurate opinions about end-of-life arrangements, such as treatment plan or prognosis[9]. Our study also found that 65.82% of the participants wanted resuscitation when they were in a persistent vegetable state (such as brain tumour progression) and 41.45% of the participants wanted life support. In the future, our medical staff should intensify propagandising end-of-life care effectively to allow patients with brain tumours to make appropriate decisions.

Predictors of preferring to make ADs

Inconsistent with a previous study that found that knowledge of ADs is the primary predictor, in this study, the strongest predictors of ADs were receiving surgery and radiotherapy[10]. Patients with brain tumours who were receiving surgery or radiotherapy in our study would like to make ADs likely because surgical treatment or radiotherapy treatment is usually performed during the early stages of the disease, during which the patients are in a good condition, have a positive perspective of their disease and cannot fully understand their own illness. Thus, making ADs may reflect their expectations of their illnesses. A previous study suggested that ADs made by patients with cancer in the early stages cannot predict

consistently what the patients want at the end of their life because they may doubt the reality of their cancer diagnosis[11]. Another study suggested that patients who completely understand the role of radiotherapy and medicine are highly likely to utilise unaggressive treatments[12]. Thus, identifying an optimal time for patients with brain tumours to make ADs is a challenge, and AD interviews cannot be performed at a single time point. Instead, in the future, a longitudinal study should be encouraged to ensure the authenticity and consistency of ADs.

Next, we found that educational qualifications of college or more, having medical insurance for nonworking or working urban residents and self-payment of medical expenses are predictors of AD. These independent predictors were related to education and costs. Similarly, another study found that the rate at which Chinese patients with cancer will choose artificial ventilation will increase by almost 20% if the treatment is free[13]. Another study also reported that a high proportion of Chinese patients with high educational level have heard of ADs and wanted to make ADs[14]. In our study, patients with brain tumours who had medical insurance for nonworking or working urban residents usually live in modern cities and had jobs. These characteristics indicated that these patients had their own income and medical insurance that could cover 95% of the medical costs of treatment. Thus, these participants preferred to make ADs because their high educational level and economic independence provided them with their own decision-making power. The advancement of ADs amongst patients with brain tumours in poor economic groups and groups with low educational levels should be strengthened to ensure the popularity of ADs amongst various economic groups. We also confirmed that with the economic development of Anhui, the overall economic situation of the patient groups will improve. Thus, the application of advanced development is well guaranteed.

We also found that participants who were younger, male and without children were willing to make ADs. We found that older participants were not likely to make ADs. This result is consistent with the result of a study in Switzerland that identified the preferences and values of 50 elderly patients with cancer towards ADs; this study found that only a minority of elderly patients with cancer are prepared to put their personal wishes into writing[15]. This discrepancy might be attributed to the following: Elderly participants are highly sensitive to the Confucian values of traditional Chinese culture. However, compared with elderly patients, young patients are less influenced by Confucian values and more likely to express their individual value. In Chinese culture, women are likely to defer to their husbands. Thus, being male was one predictor of making ADs in this study. Participants without children wanted to make ADs because they did not have immediate relatives to discuss their disease condition. Given that women and the elderly are reluctant to provide ADs because of Chinese Confucian culture, ADs must be popularised amongst women and the elderly to maintain everyone's dignity.

Predictors of preferring receiving appropriate palliative care

Our logistic model showed that compared with participants with brain metastases, participants with brain primary tumours were more likely to prefer appropriate palliative care. This finding is one of the most important results of this study. Our patients with brain primary tumours mainly had gliomas (90.69%); the

main postsurgical treatments recommended for gliomas are surgery and radiotherapy[16-17]. Patients with primary brain tumours usually have rapid progress and poor prognosis. Importantly, primary brain tumours are severe upon diagnosis, and thus patients lack a remission period wherein they can stabilise their panic. Appropriate palliative care can provide comfortable treatment that may help patients release their fear of the unknown. By contrast, participants with brain metastases from lung cancer (44.34%) and breast cancer (49.13%) might have already received surgery, radiotherapy, chemotherapy, targeted therapy or immunotherapy before the emergence of brain metastases. Therefore, patients with brain metastases already understand these treatment goals and potential outcomes and were not likely to prefer appropriate palliative care that could prolong their life.

We found that patients with an educational qualification of junior middle school or below, new rural cooperative medical insurance (which can cover 50% of total medical expenses) and medical expenses paid by their children or spouse preferred receiving appropriate palliative care that could not delay death but only gave comfort. This result was dissimilar to the result of a study in Taiwan. The previous study found that patients with low socioeconomic status, have metastatic malignant disease, residing in urban areas or are in hospitals with more abundant health care resources are likely to receive aggressive end-of-life care to delay death[18]. However, one American study reported that patients living in low-income zip codes are less likely to receive aggressive end-of-life cancer treatment than patients living in other zip codes[19]. Aggressive end-of-life care may mean that the patient will spend high amounts of money on aggressive treatments. Patients with brain tumours with educational qualifications of junior middle school or below; new rural cooperative medical insurance, which can cover 50% total medical expenses and medical expenses paid by their children or spouse usually cannot afford such treatments by themselves.

In our study, we found that participants who were older, male and had children were more likely to receive appropriate palliative care; this result might imply that Confucian values still play an important role in our traditional culture[20]. In Chinese traditional culture, having the young die before the elderly is unacceptable, and many young patients with brain tumours and their family members would insist on receiving aggressive treatments till the last moment of life.

Promoting the model and content of end-of-life care amongst patients with brain tumours and familiarising them with the results of end-of-life care could bring to themselves are crucial. These approaches could help patients with brain tumours further understand end-of-life care and make reasonable choices. Only in this way could patients with brain tumours avoid the side effects of excessive medical treatment and prevent family members from making wrong decisions for patients with brain tumours after they lose consciousness.

Limitations

Our study has several limitations. Firstly, our study was executed in two hospitals and thus may feature sample bias. Secondly, our study participants were patients with brain tumours only. In the future,

patients with other types of tumours should be included. Furthermore, a longitudinal study should be performed to identify the optimal time for patients to state their true preferences.

Conclusion

This study illustrated the attitudes and preferences of patients with brain tumor regarding ADs and end-of-life care. Although AD and end-of-life care have not been systematically applied in Chinese patients with brain tumours and knowledge of AD is limited, most participants still prefer to demonstrate their individual value. Additional efforts should be made for patients with primary brain tumours undergoing surgery and radiotherapy and low socioeconomic status, and appropriate decision-making timing is encouraged in promoting ADs amongst Chinese patients with brain tumours.

Abbreviations

AD: Advance directives; KPS scores: Karnofsky scores; OR: odds ratio; CI: confidence interval.

Declarations

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Authors' contributions

YW ,YZ and HW contributed to the conception and design of the study. YH ,PZ ,ZH ,XX assisted for the acquisition and organisation of data and YW and YZ in the organisation of the database and data analysis. YW ,YZ ,HW contributed in the analysis and interpretation of data and revising the manuscript . All authors read and approved the final manuscript. The first two authors contributed equally to this paper.

Compliance with Ethical Standards

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Competing interests

The authors declare that they have no competing interests.

Ethics approval and consent to participate

The research protocol (SL-KY2020-002) was granted by Cancer hospital, Chinese academy of science, Hefei Ethics Committee. All subjects were informed about the aims of the study and gave written informed consent prior to their participation and the records did not contain information that could identify the participants. This study complied with all ethical guidelines for human experimentation stated in the Helsinki Declaration.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Consent for publication

Not applicable.

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References

1. Stewart K , Bowker L . Advance directives and living wills.[J]. Postgraduate Medical Journal, 1998, 74(869):151-156.
2. Silveira MJ, Kim SY, Langa KM .Advance directives and outcomes of surrogate decision making before death.N Engl J Med—2010—362:1211–
3. Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. J Clin Oncol. 2010; 28:1203–1208.
4. Doll KM, Stine JE, Van Le L, et al. Outpatient end of life discussions shorten hospital admissions in gynecologic oncology patients. Gynecol Oncol. 2013; 130:152–155.
5. van Oorschot B, Schuler M, Simon A, Flentje M. Advance directives: prevalence and attitudes of cancer patients receiving radiotherapy. Support Care Cancer. 2012;20(11):2729-2736.
6. EvansN,BauseweinC,MenacaA,etal.(2012)Acriticalreviewof advance directives in Germany: attitudes, use and healthcare professionals' compliance. Patient Educ Couns 87:277–288
7. Ni P, Zhou J, Wang ZX, Nie R, Phillips J, Mao J. 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(10):751-756.
8. Chung Y N , Wong L 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. Journal of the American Medical Directors Association, 2017, 18(4):367.e19-367.e27.
9. Weeks JC, Catalano PJ, Cronin A, Finkelman MD, Mack JW, Keating NL, Schrag D. Patients' expectations about effects of chemotherapy for advanced cancer. N Engl J Med. 2012;367(17):1616–25.
10. Zheng R J , Fu Y , Xiang Q F , et al. Knowledge, attitudes, and influencing factors of cancer patients toward approving advance directives in China. Supportive Care Cancer, 2016, 24(10):4097-4103.
11. Sanders, Justin. Finding the Right Words at the Right Time — High-Value Advance Care Planning. N Engl J Med, 372(7):598-599.

12. Mack J W , 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(11):1891-1897.
13. Ivo K, Younsuck K, Ho YY, et al. A survey of the perspectives of patients who are seriously ill regarding end-of-life decisions in some medical institutions of Korea, China and Japan. *J Med Ethics* 2012;38:310e316.
14. Kang L , Liu X H , Zhang J , et al. Attitudes Toward Advance Directives Among Patients and Their Family Members in China. *Journal of the American Medical Directors Association*, 2017:S1525861017302931.
15. Pautex S , Notaridis G , Laurence Déramé, et al. Preferences of elderly cancer patients in their advance directives. *Critical Reviews in Oncology/hematology*, 2010, 74(1):61-65.
16. SANAI N, BERGER M S. Surgical oncology for gliomas:the state ofthe art . *Nat Rev Clin Oncol*, 2018, 15(2): 112-125.
17. Valduvico I, Verger E, Bruna J, et al. Impact of radiotherapy delay on survival in glioblastoma. *Clin Transl Oncol*. 2013;15(4):278-282.
18. Chang C M , Wu C C , Yin W Y , et al. Low Socioeconomic Status Is Associated With More Aggressive End-of-Life Care for Working-Age Terminal Cancer Patients. *The Oncologist*, 2014, 19(12):1241-1248.
19. Mack JW, Chen LH, Cannavale K, Sattayapiwat O, Cooper RM, Chao CR. End-of-Life Care Intensity Among Adolescent and Young Adult Patients With Cancer in Kaiser Permanente Southern California. *JAMA Oncol*. 2015;1(5):592-600.
20. Epley, Kelly M. Care Ethics and Confucianism: Caring through *Li*. *Hypatia*.2015,30(4):881-896.

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