

# Preferences for End-of-life Care among Terminal Cancer Patients in China: A Discrete Choice Experiment

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## Research article

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# Preferences for End-of-life Care among Terminal Cancer Patients in China: A Discrete Choice Experiment

## Abstract

**Background:** Knowing terminal cancer patients' treatment preferences will improve patient-centered health care, better inform surrogates and medical staff of patient preferences and enhance the quality of end-of-life (EoL) care. In China, little is known about terminal cancer patients' preferences. We aimed to examine the preferences for EoL care of terminal cancer patients.

**Methods:** Data on 183 terminal cancer patients aged over 50 years old was collected by discrete choice experiment (DCE). Each DCE scenario described six attributes: hospitalization days, life extension, quality of life (QoL), adverse treatment reactions, place of death preference and out-of-pocket payments. Patient preferences were derived using a mixed logit model and the marginal willingness to pay (WTP) were estimated from the regression coefficients.

**Results:** Patients' preferences for moderate survival time, better quality of life, lower risk of adverse reaction, home death and lower payments were all statistically significant in driving choice between treatment models. Extending life and QoL were the most important attributes. Patients were willing to pay RMB256,895.45 to improve QoL from a bad level to a very good level, significantly higher than their willingness to pay for half additional life year (RMB233,446.16) and one additional life year (RMB182,298.76). This indicates that patients were not willing to blindly pursue life extension and neglect the QoL, but preferred to trade off life extension for QoL. The predicted uptake of optimal end-of-life care scenario was 91.04%.

**Conclusions:** Our study contributes to the development of patient-centered preferences for end-of-life care models that improve advanced terminal patient's care and provide empirical evidence for physicians and surrogates to operationalize end-of-life care trade-offs.

## Keywords

End-of-life care, preference, quality of life, discrete choice experiment, health policy, cancer patients

## **Background**

China's National Cancer Center estimated that there were 4.29 million new cancer cases in 2015, with the annual incidence increasing by about 3.9% over the past decade [1]. On average, more than 10 thousand people are diagnosed with cancer every day, or 7.5 people are diagnosed with cancer every minute [1]. More than 2.8 million China cancer deaths occurred in 2015, accounting for 31.82% of all global cancer deaths [2]. Over the past decade, China's cancer mortality rate has increased by 2.5% a year [1]. From cancer alone, the number of people in need of end-of-life care poses a significant challenge to China's public health system and to millions of Chinese families.

In China, the annual medical expenditure on malignant tumors exceeds RMB220 billion [3]. Accounting for about 40% of the total health care expenses, mainly driven by hospital costs, terminal cancer imposes a per capita expenditure of RMB83,035 on urban cancer patients and RMB39,827 on rural cancer patients in the last three months of life [4]. End of life health care costs imposed a significant economic burden on patients and their families, with more than 90% of end-of-life families experiencing catastrophic health expenditure [5], with 32.83% of patients borrowing from family and friends to cover their medical expenses [4]. Worries about money, physical pain, psychological pressure and fear of death affect terminal cancer patients' choice of treatment [6]. In China, most terminal cancer patients' end-of-life quality is poor, partly due to the overuse of aggressive hospital-based treatments and the low use of palliative care [4].

An important prerequisite for improving the quality of patient-oriented end-of-life care is to understand patient preferences, or patient care trade-offs, including life extension, quality of life, place of care and place of death. An Australian cross-sectional study found most older and seriously ill inpatients preferred end of life care that maintained their quality of life and relieved their symptoms compared with life extension [7]. Patients in two London hospitals with advanced prostate cancer were willing to pay to reduce the burden of adverse reactions [8] and a Singapore study found advanced cancer patients were willing to pay to avoid severe pain, to die at home and not to be a burden on their families [9]. In contrast, Voogt et al. found Dutch patients suffering cancer for less than 6 months were more inclined to prefer life extension treatments than those with a longer history of cancer [10]. The extant literature reflects no agreement on the place of care and place of death. In an Australian [7] and a multicountry study (England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain) most advanced cancer patients preferred home death [11]. In a lower

middle income country, Pakistan, Zafar et al. found a majority of adult cancer patients expressed a preference for end-of-life hospital-based care [12]. A Dutch study found that participants had fixed preferences for either home care or hospital treatment [13]. A meta-study found that most people prefer to die at home [14], but a Canadian study across five hospitals found only half preferred dying at home [15] and among South African advanced palliative care cancer patients, about 60% preferred to die at home [16].

While international end-of-life trade-off studies are inconsistent, there is lack of evidence on end-of-life cancer patient preferences in China. China is unique with a low shared decision-making between patients and physicians [17] and a strong surrogate-doctor relationship, where surrogates, mainly family members, make end-of-life cancer treatment decisions. Chinese traditional social customs partly explain why the majority of treatment decisions are made by surrogates rather than terminal cancer patients themselves [18]. As a result, physicians and surrogates operationalize care trade-offs without knowing cancer patients' preferences, especially how much life-time terminal cancer patients would be willing to sacrifice to attain their palliative care goals [19]. Surrogates frequently prefer more aggressive cancer treatments, and often have greater willingness to pay to extend life, than patients themselves [9]. We examine Chinese terminal cancer patients' end-of-life stated care preferences. Our study provides empirical evidence for clinicians and surrogates on how to operationlize patients' preferences for end-of-life care, to improve the quality of patient-centered care and to promote patient "good death".

## Methods

To reveal terminal cancer patients' preferences for the end-of-life care, we undertook a discrete choice experiment. DCE is a powerful method to examine preferences over hypothetical alterative scenarios in the health field [8,9,13,18-20], where each scenario comprises a number of attributes (days of hospital stay, days of extended life, quality of life improvement, adverse treatment reaction, place of death and out-of-pocket expenses) and each attribute has different levels, as shown in Table 1. Willingness to pay and probability analysis were undertaken based on the discrete choice model.

### Identification of Attributes and Levels

The identification of the attributes and their levels is key for ensuring the validity of DCE. We retrieved relevant end-of-life care attributes and their levels from the extant literature [4,5,8,9,20,23-24]. The levels

of hospitalization days and out-of-pocket costs attributes were based on previous retrospective studies of cancer patients [4,5]. The attributes were then ranked, categorized and reduced through interviews with ten cancer patients and two experts in the field of palliative care. The specific attribute levels in the DCE design were chosen to ensure trade-offs between tasks and refined through data from a 20 cancer patient pilot survey. The description of the attributes and levels are displayed in Table 1.

### **Experimental Design**

Using STATA 15, a D-efficient partial profile design was used to guarantee efficient estimates of the preference parameters. Sixteen hypothetical two-alternative choice tasks were created, but to reduce the cognitive burden on respondents, these 16 choice tasks were randomly divided into two questionnaire versions. As shown in the example in Figure 1, each questionnaire included 8 choice tasks, where respondents were asked to choose which treatment from two alternatives they would prefer. The two-part questionnaire sought information on respondents' background characteristics as well as DCE preferences. Background characteristics comprised sex, age, location, educational attainment, job status, income, cancer type and cancer stage.

### **Survey Design**

A pilot survey was conducted with 20 respondents in July 2018. Based on the pilot, our final questionnaires were revised, and the phraseology and question layout improved. To promote survey accuracy, our DCE started with a general description and an illustrative example of a simplified choice set to familiarize the respondents with the choice tasks ahead[21].

### **Sample**

Selected randomly from cancer hospital medical records in Shandong Province, 183 advanced cancer patients were surveyed face-to-face by trained interviewers between August and November 2018. Previous studies found that projection bias may influence patients' decision making [25], where patients with serious diseases may make decisions based on their current suffering[25] and serious health conditions are associated with high preference stability. Further, older people more accurately predicted their emotional responses and display more stable preferences than younger people[26]. Therefore, our sample inclusion

criteria were patients (1) aged over 50 years old; (2) diagnosis of a stage III or IV cancer; (3) hospitalized and receiving aggressive treatment, such as surgery, radiotherapy, chemotherapy, and targeted therapy; and (4) without cognitive impairments. Based on the Orme equation, the minimum sample size should be 62.5[27]. Our sample size was 183 patients, suggesting that the effect of all attribute levels can be accurately estimated. In total, 2928 observations comprised the database. All patients provided informed consent and the study was approved by Shandong University Ethics Committee (No.20180710).

### Mixed logit model and Willingness to Pay

Based on the Bayesian information criteria and Akaike information criteria[28], a mixed logit model was used to estimate patient preferences. Each attribute level, other than out-of-pocket costs, which was introduced as a continuous variable, was coded as a dummy variable. Mixed logit models that overcome the problem of preference heterogeneity and independence from irrelevant hypothesis were used to analyze preferences, with individual utility estimated by equation 1:

$$U_{ijs} = \beta_0 + \beta_1 cost_{ijs} + \beta_2 inpatient1_{ijs} + \beta_3 inpatient2_{ijs} + \beta_4 inpatient3_{ijs} + \beta_5 extendlife1_{ijs} + \beta_6 extendlife2_{ijs} + \beta_7 extendlife3_{ijs} + \beta_8 qol1_{ijs} + \beta_9 qol2_{ijs} + \beta_{10} qol3_{ijs} + \beta_{11} AR1_{ijs} + \beta_{12} AR2_{ijs} + \beta_{13} AR3_{ijs} + \beta_{14} home + \varepsilon_{ijs} \quad (1)$$

where  $U_{ijs}$  is the utility of respondent i for alternative scenario j in the choice tasks (here  $j = 1, 2; s = 1,..,8$ ),

$\beta$  is a parameter vector relating attribute values and utility levels and  $\varepsilon_{ijs}$  is error of utility.

The willingness to pay for a given change in an end-of-life care scenario is the amount of money (or money equivalent), that would represent individual's marginal payments for the changed attribute levels in a new alternative scenario [23]. WTP was estimated from the mixed logit model by comparing the coefficients of the attribute level with that of costs [29]. WTP estimates were undertaken using the nlcom procedure in STATA 15:

$$WTP_i = -\frac{\beta_i}{\beta_{cost}} \quad (2)$$

The probability of choosing a given scenario was predicted from the mixed logit model estimates.

$$P_i = \frac{e^{\beta' x_j}}{\sum e^{\beta' x_j}} \quad (3)$$

## **Results**

### **Respondent characteristics**

Table 2 presents the demographic characteristics of the terminal cancer patients: patients were on average 61.05 years old, mostly males (69.75%), who lived mainly in rural areas (71.09%), had over six years education (67.21%) and a monthly income below RMB3000 (72.68%). In terms of cancer types, 53.58% of patients were diagnosed with urological cancer (renal, bladder and prostatic), 19.67% with digestive system cancer (gastric, colorectal and liver cancer) and 16.39% with lung cancer. Roughly fifty percent (50.82%) had stage III cancer.

### **Estimation of preferences and their heterogeneity**

Table 3 presents the results of the mixed logit model. All attributes were significant ( $p<0.05$ ), except inpatient days. Life extension and quality of life were the most important attributes, followed by out-of-pocket costs, adverse reactions and place of death. Terminal cancer patients chose the end-of-life treatment that could appropriately prolong life, better improve the quality of life, had small risk of adverse reactions and cost less. Patients were more likely to choose to die at home than die in hospital.

### **Willingness-to-pay**

Table 4 shows the willingness to pay for specific attribute level changes. We defined a base end-of-life treatment choice set: less than one week of inpatient days, four months life extension, very bad quality of life, no adverse reactions and hospital death. Patients' WTP for quality of life 3 improvements was RMB256,895.45, significantly higher than RMB182,298.76 for one additional life year (quality of life 1). We also found that patients' WTP for 4-10 additional life months (RMB233,446.16) was significantly greater than 4-6 months of additional life (RMB212,362.87). But patients' WTP for 4-16 months (RMB182,298.76) was lower than that for 4-6 months (RMB212,362.87) and 4-10 months (RMB233,446.16). This suggests that patients were willing to extend their lives within certain limits, but were not willing to blindly pursue life extension and neglect the quality of life. Our data show the trade-off between life extension and quality of life. Patients were more willing to pay for treatment with low adverse reactions and to pay for home death. As shown in Table 4, the maximum willingness to pay for the optimal end-of-life care scenario (ten months life extension, very good quality of life, no adverse reactions, and

death at home) was RMB548,923.54.

### **Probability of take-up**

Figure 2 presents the end-of-life care uptake probabilities. We defined a base end-of-life care scenario: RMB10000 costs, less than one week of inpatient days, four months life extension, very bad quality of life, no adverse reactions and hospital death. The base end-of-life care scenario is indicated as zero change in the probability on the X-axis in Figure 2. When the quality of life improved from QoL0 to QoL3, the uptake increased 61.62%; and when life extension increased from four month to ten months, the uptake increased 57.15%. The uptake rate increased about 20% when the place of death changed from hospital to home. However, the uptake rate decreased about 40% when the costs increased up to RMB140000. The predicted uptake of the optimal end-of-life care scenario (ten months life extension, very good quality of life, no adverse reactions, RMB10000 costs and death at home) was 91.04%.

### **Discussion**

Our study quantified preferences for end-of-life care among terminal cancer patients. We showed that terminal cancer end-of-life patients preferred higher quality of life, moderate life extension, less out-of-pocket costs, lower adverse reactions and death at home. Patients had a greater WTP for a moderate life extension, but lower WTP for the longest life extension. Patients had a greater WTP for the highest quality of life than for life extension.

The trade-offs between life extension, relief of pain and psychological pressure exists among all patients with advanced cancer. Although patients were WTP for a moderate life extension, our study found that the highest quality of life was patients' highest priority. When life prolongation increased from 6 months to ten months, the WTP increased from RMB212,362.87 to RMB233,446.16, which was higher than the WTP for moderate quality of life improvements. Patients preferred to pay the highest (RMB256,895.45) to obtain enhanced quality of life rather than life extension. These results present a more detailed and complicated picture of trade-offs between life extension and quality of life among terminal cancer patients, which complements and extends previous research [7,10,19]. Waller et al. found Australian inpatients preferred end-of-life care reducing pain and discomfort as much as possible, even if it meant not living longer [7].

Rubin et al. found that 86.7% of U.S. hospitalized seriously ill patients would trade at least one year of a five-year lifespan to avoid a scenario where they died in the ICU with moderate pain and suffering [19]. Voogt et al. found Dutch patients suffering cancer for less than 6 months were more inclined to prefer life extension than those with a longer history of cancer [10].

Our results extend our knowledge of cancer treatment preferences for end-of-life care. Knowing Chinese cancer patients' terminal care preferences inform physicians and surrogates how to operationalize care trade-offs, especially comfort-oriented care. But, comfort-oriented care that improves the quality of life in China has a long way to go. As death approaches, especially in the last three months of life, the use of health resources by patients with advanced cancer increased dramatically. For Taiwanese end-of-life cancer patients, the use of chemotherapy, emergency care, hospitalization, and ICU increased [30]. A Chinese study found that more than 91% of urban patients with advanced cancer received hospitalization, with an average of 2.13 hospitalizations per capita and 41.13 hospital days per capita. For Chinese rural cancer patients, 72.19% received hospitalization, with 2.02 hospitalizations per capita and 27.22 hospital days per capita [4]. Another Chinese study found that the proportion of small cell cancer patients receiving chemotherapy in the last month of life was twice as high as in the last two months of life [31]. These data confirm that end-of-life cancer care and cancer deaths in China occurred overwhelmingly in hospital, with only 12% of mainland cancer patients receiving end-of-life palliative care[4]. The first reason is the lack of supply of hospice services. In China, there are few specialized agencies and a shortage of professional hospice care personnel[32]. Second, low awareness of hospice care leads to low acceptance, which is due to the lack of hospice education and publicity. Third, the fear of death by patients and their family caregivers reinforces the choice of hospital-based life extension treatment. Given inadequate patient-carer shared decision-making, family caregivers as surrogates often prefer more aggressive treatment because they see the social value of treatment, including the financial and emotional effect, for the family as greater than the private value for the patient [18].

Our results show that terminal cancer patients preferred home death to hospital death, and were willing to pay more to choose home death. These findings support previous studies [13,14]. Why patients wish to die at home is a complex mix: patients who die at home tend to have a higher quality of life and lower medical costs [33]; family members and carers of patients who die at home usually have a better quality of life, while

carers of patients who die in hospital have more severe depression symptoms [34]; and Chinese cultural values plays a vital role in the attitude towards death and death place. Influenced by the traditional Chinese culture of home burial, many people want to return to their hometown at the end of their lives. Contrary to patients' stated preferences, 62.43% of urban cancer patients die in hospital [35].

We found out-of-pocket costs was a significant attribute influencing preferences, which is consistent with some previous studies [8,9,11]. A respective study of 792 cancer patients found that patients faced with out-of-pocket expenditures of more than 50% of their medical expenses could cause catastrophic health expenditure, driving many patients into poverty [4,5]. Surprisingly, the length of hospitalization days was not a significant attribute. We inferred that there may be no directly positive correlation between medical costs and hospitalization days in patients' minds. While patients were only sensitive to the final medical cost, they did not relate actual number of hospital inpatient days to final medical costs. These relationships require further research.

Our study has several limitations. First, DCEs may not represent all complex real-life end-of-life care choices given the limited number of attributes and levels. Given we only explored patients aged over 50 years old, the results may be not representative of all cancer patients. For example, we do not know if end-of-life preferences differed between young cancer patients and old cancer patients. Since overall cancer incidence increased in all adolescents and young adults (aged 15-39 years) during the most recent decade, future studies should explore the care preferences of adolescents and young adults. The majority of patients were diagnosed with urological, digestive system and lung cancer, with other cancers under-represented. Further studies of other types of cancers should be undertaken. Preference heterogeneity may exist among different populations. The influence of demographic characteristics, such as gender and education on preferences needs to be further explored. Considering most surrogates prefer life-extension treatments, a preference examination for family caregivers should be undertaken.

## Conclusion

Our study contributes to the development of patient-centered preferences for end-of-life care models that improve advanced terminal cancer patient's quality of end-of-life care and provide empirical evidence for physicians and surrogates to operationalize cancer patient preferences. Besides, expanding the supply of

palliative care services, we recommend enhancing hospice education to improve the awareness and acceptance of hospice care, promoting death education to relieve fear of death in hospital and at home, and improving shared decision making between patients, surrogates and medical staff to improve the quality of end-of-life outcomes.

## Abbreviations

EoL: end of life;

DCE: discrete choice experiment;

WTP: willingness to pay;

QoL: quality of life

## Declarations

### Ethics approval and consent to participate

All patients provided informed consent and the study was approved by Shandong University Ethics Committee (No.20180710).

### Consent for publication

Informed consent for publication was obtained from all participants.

### Declaration of conflicts of interests

We declare no competing interests.

### Availability of data and material

The dataset supporting the conclusions of this article is available from the corresponding author on reasonable request.

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### Authors' contributions

AL and JW contributed towards the article by making substantial contributions to conception and design. AL contributed towards the article by collecting data and undertaking the statistical analysis, interpretation of the data, and writing the manuscript. SN, EM and LK engaged in interpreting the results and writing the paper. SW engaged in undertaking the statistical analysis and part of literature survey. All authors read and

approved the final version of the manuscript.

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## Figures

Treatment Characteristics	Treatment A	Treatment B
Number of days you have to stay in hospital	10 days	less than 7 days
Number of days to extend life	10 months	4 months
Quality of life improved by the treatment	Very good	Bad
Side effect of the treatment	Moderate	No
Your out-of-pocket costs in receiving the treatment	140,000RMB	80,000RMB
Place of deathplace	In hospital	At home
<b>Your choice</b>		

Figure 1

An example of a choice task

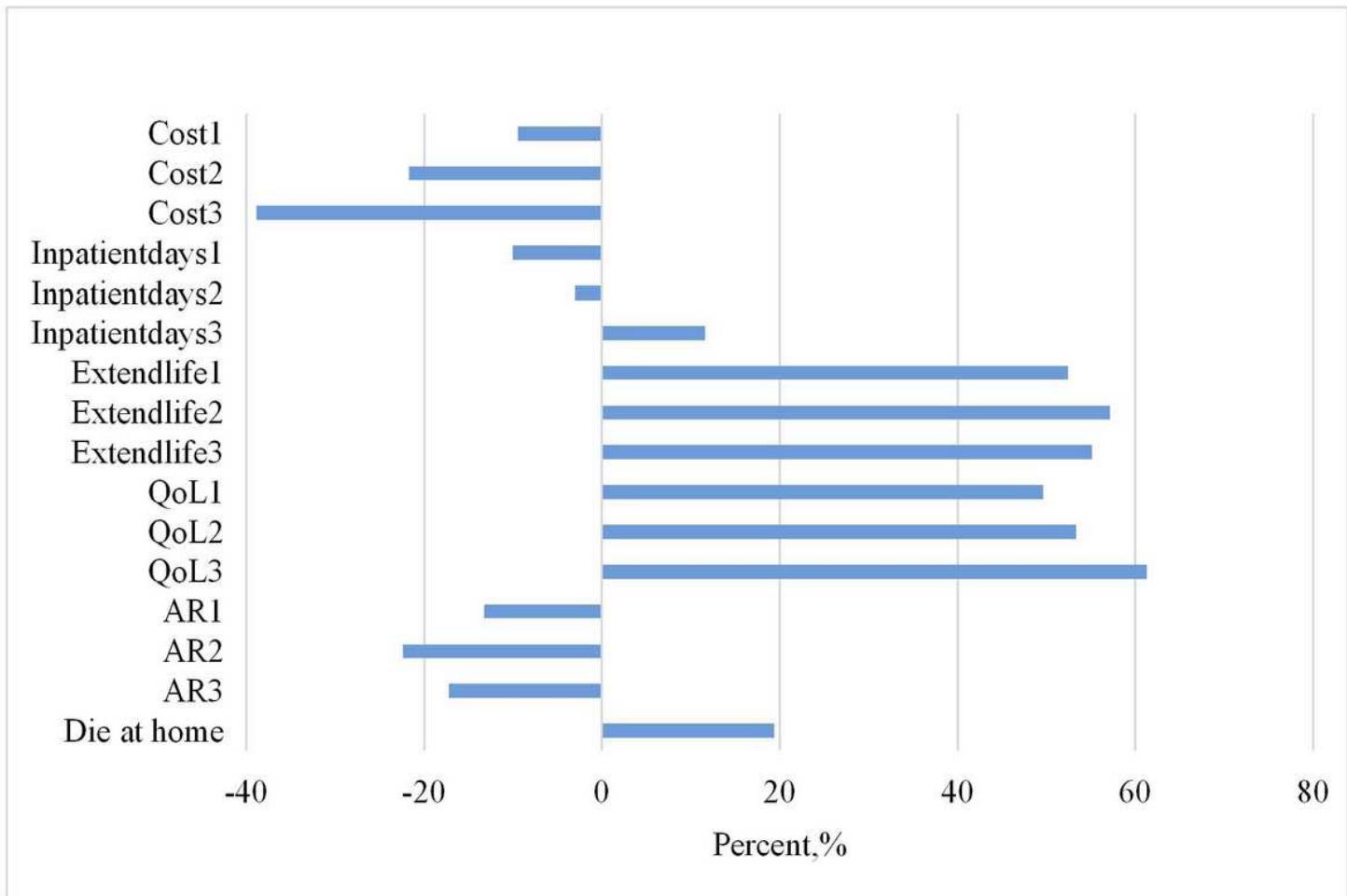


Figure 2

## Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Appendix1SupplementalMaterial.docx](#)