

# The Preference of Place of Death and its Predictors Among Terminally Ill Patients With Cancer and Their Caregivers in China

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## Abstract

**Purpose:** To describe the preference of place of death among Chinese patients with cancer and their caregivers and to identify factors associated with the preference. **Methods:** A prospective questionnaire research was conducted in terminally ill patients with cancer and their caregivers. Questions included sociodemographic characteristics and information about patients' diseases and patients' preference of place of death. **Results:** Home (53.64%) was the first choice for 522 patients, 51.34% of participated caregivers chose home as the preferred place of death, and patient-caregiver dyads achieved 84.10% agreement. Patients who lived in rural area, with lower education level and lived with relatives, expressed more preference to die at home. **Conclusion:** This study described information about the preference of place of death and its potential predictive factors in terminally ill patients with cancer in mainland of China.

## Keywords

palliative care, terminally ill cancer, place of death, patients' preference, decision making, home death

## Introduction

It is very important for terminally ill patients with cancer to die in their ideal dying place. For health care services, meeting the preferences of patients is an essential task and one of the ultimate measures to success in palliative care therapy.<sup>1</sup> Understanding the preference of place of death in patients and their caregivers is the first step to ensure them a good death. Previous studies found that most patients with terminally ill cancer preferred to receive home care and die at home.<sup>2-5</sup>

However, evidence on preferences of place of death and associated factors has been mainly from the research in Western countries.<sup>6</sup> There are little studies focused on the preference of place of death in Chinese people. One study, which covered the Chinese emigrants living in European countries indicated that these patients were more likely to die at hospital,<sup>7</sup> while the other study based on Taiwanese identified that the majority of terminally ill patients with cancer and their family caregivers preferred to die at home.<sup>8</sup> These 2 studies provide useful insights about the preferred place of death in Chinese patients with cancer; however, the living background, medical insurance system, and social support are quite different among patients in mainland, in Taiwan, and those emigrated to Western countries.

Thus, the purpose of this study is to describe the preference of place of death among patients with cancer and their caregivers and to identify the potential factors associated with preference of place of death in mainland of China. The findings

may be useful for the planning of palliative care strategies in mainland of China.

## Methods

### Samples and Methods

The study was carried out between December 2007 and December 2012 in the form of a face-to-face interview using questionnaires. The sample came from in- and out-patients and their family caregivers in Department of Integrated Therapy, Fudan University Shanghai Cancer Center, China. The inclusion criteria are as follows: (1) participants who were older than 18 years and had the full capacity for civil conducts; (2) patients who were diagnosed as having cancer and evaluated by their primary physician to be at a terminal stage, continuing to progress and unresponsive to curative cancer treatment; (3) patients who had a complete cognitive ability

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and could communicate coherently with interviewers; (4) each participant identified 1 primary caregiver as the person most involved in the patients' care; and (5) patient-caregiver dyads were excluded if either the patient or the caregiver refused to participate in the research. The protocol of the study was approved by the ethical review board of Fudan University Shanghai Cancer Center.

The interview was conducted in a separate ward room for privacy. Patients and their caregivers were interviewed separately to ensure independent responses. The project researchers include 4 interviewers who were attending physicians in Integrated Therapy Department. To standardize presentation of questions, interviewers were trained in conducting the interviews. They were asked to identify patients without judging their emotional readiness to talk about their preference for place of death. They explained the purpose and detailed information about this program to all patients who participated and their caregivers. Then they got the written informed consents from all participants including patients and their caregivers before they were involved in the study. They collected the answers of the questions and testified that the participants completed the questionnaire.

### Questionnaires

Questions on sociodemographic characteristics covered age, sex, marital status, religious belief, education, residential area, living arrangement, and medical resources. Information on the educational background was obtained by asking the highest level of education. Taoism, Buddhism, Christian, and Catholic were the most popular religious beliefs among Chinese. Medical insurance covered means patients have the basic social medical insurance. These patients can get reimbursement for most health care fees. Patients without medical insurance have to pay for the health care fees by themselves. Other situation included commercial medical insurance and rural cooperative medical insurance, which could provide partial reimbursement.

Questions on diseases information covered Karnofsky Performance Status (KPS), primary tumor site, survival time since first diagnosis, and satisfaction with the treatment or not. The KPS was used to quantify patients' general well-being and activities of daily life. The survival time since first diagnosis was recorded as months since patients were diagnosed as cancer.

The most important question was where do you prefer to die if circumstances allowed you to choose at your terminal stage of life. Home and hospital are the most important choices. There are 3 kinds of hospital in China. Tertiary hospital provides special medical services as the highest level hospital. Secondary hospital is a kind of regional hospital to offer comprehensive medical services, and community hospital is the place to provide basic medical services. Hospice and nursing home are not the choice in our questionnaire because they are not common for terminal patients with cancer in mainland China yet. Questions for family caregivers also included their gender, age, relationship with patients, living with patients or not, and their preference for the patients' place of death.

**Table 1.** Characteristic of the Participated Patients.

Variables	N	%
<b>Gender</b>		
Male	279	53.4
Female	243	46.6
<b>Age</b>		
≤60	211	40.4
>60	311	59.6
<b>Primary sites of tumor</b>		
Lung	108	20.7
Breast	49	9.4
liver	44	8.4
Colon	68	13.0
Other gastrointestinal	98	18.8
Head and neck	19	3.6
Female genital organs	56	10.7
Hematology	9	1.7
Urinary	33	6.3
Others	38	7.3
<b>Religious</b>		
Taosim or Buddhism	33	6.3
Christian or Catholic	12	2.3
Others	6	1.2
None	471	90.2

### Statistical Analyses

Frequencies and percentages were calculated to describe patients' characteristics. Pearson chi-square test was conducted to explore relationships between preference and variables. The  $\kappa$  statistic was used to compare the congruence between patients' and caregivers' preferences. Multivariable logistic regression was employed to determine how significant variables contributed to predict place of death. Significant level was set at  $P < .05$ . Data were analyzed using SPSS for Windows version 16.0 (SPSS 16.0).

## Results

### General Characteristics of Patients

A total of 805 in- and out-hospital patients with terminal cancer and their family caregivers were enrolled in our department between December 2007 and December 2012. Finally, 522 patients and their caregivers agreed to participate and their information were collected. Response rate was 64.84%. Of the participants, 53.45% were male. The median age of 522 patients who participated was 63 years (range: 21-95 years). Most of the patients were married ( $N = 422$ , 80.84%) and lived with their spouses or children ( $N = 326$ , 62.45%). Most patients in this study claimed no religious affiliation ( $N = 471$ , 90.23%). The most common site of cancer was lung cancer ( $N = 108$ , 20.69%). The median survival time since first diagnosis was 13 months (range: 2-52 months). Details are shown in Table 1.

**Table 2.** Preference of Place of Death of 522 Patients and Their Caregivers.

Preference	Patients		Caregivers	
	N	%	N	%
Home	280	53.6	268	51.3
Hospital	204	39.1	207	39.7
Community hospital	68	13.0	69	13.2
Regional hospital	33	6.3	28	5.4
Tertiary hospital	103	19.7	120	23.0
Decided by family	38	7.3	–	–
Decided by patients	–	–	47	9.0

### Preference of Place of Death in 522 Patients and Their Caregivers

In our research, 53.64% of the participants preferred to die at home. The second preference was hospital (39.08%). Among 3 kinds of hospital (tertiary hospital, secondary hospitals, and community hospitals), tertiary hospital was the first choice both for patients and caregivers. A small percentage of the patients cannot decide by themselves, they believed in their family. Of the caregivers who participated, 51.34% chose home as the preferred place of death for their patients. Details are shown in Table 2.

### Factors Associated With Preference of Patients

More married patients chose to die at home (home vs hospital 232 vs 154,  $P = .028$ ). Patients who lived with their spouse or family would like to choose home than hospital as their place of death (home vs hospital: 220 vs 89,  $P < .001$ ). Patients with low-level education more preferred to die at home (home vs hospital, 188 vs 76,  $P < .001$ ). An association was also observed between marital status and the preference of place of death. More than 60.4% (168 of 278) of the patients living in rural area preferred to die at home in contrast to 45.9% (112 of 244) of the patients living in urban area ( $P = .004$ ). Patients with bad status (KPS  $< 30$ ) and those who survived more than 6 months since diagnoses were more likely to prefer to die at home ( $P < .001$ ). Satisfaction for the treatment also do influence the choice ( $P = .017$ ). Details are shown in Table 3.

Our research showed that the age of patients was not associated with the choice of place. And other characteristics such as gender, religious belief, medical resource, and primary tumor site had no association with patients' choice either. Details are not shown in the article.

The multivariable logistic regression analysis was further used to investigate the predictors of preference for home ( $N = 484$ , patients and caregivers who choose home or hospital). Table 4 showed that preference for dying at home rather than in a hospital was more common in patients who lived in rural area, who lived with their spouse or family, or with lower education level.

**Table 3.** Demographic Data of the 522 Patients With Cancer and Associated Factors.

Variables	Home (N = 280), %	Hospital (N = 204), %	Decided by family (N = 38), %	$P^a$
	Marital status			
Marital status	82.9	75.5	94.7	
Widowed	11.4	21.1	2.6	
Divorced	3.2	1.0	2.6	
Single	2.5	2.4	–	
Education				<.001
Elementary school or lower	67.1	37.2	15.8	
Secondary school	19.3	32.4	31.6	
College or above	13.6	30.4	52.6	
Urbanization				.004
Yes	4.0	55.9	47.4	
No	6.0	44.1	52.6	
Living arrangements, %				<.001
Spouse/family	78.6	43.6	44.7	
Live along	19.3	51.5	44.7	
Others	2.1	4.9	10.6	
KPS				<.001
<30	74.3	36.8	52.6	
$\geq 30$	25.7	63.2	47.4	
Duration of diagnosis				<.001
Survival of 6 months or less	19.6	27.9	47.4	
Survival of more than 6 months	80.4	72.1	52.6	
Satisfaction or not				.017
Yes	75.4	90.7	78.9	
No	24.6	9.3	21.1	

Abbreviation: KPS, Karnofsky Performance Status.

<sup>a</sup> Pearson chi-square test was conducted to explore relationship between the preference and variables.  $P < .05$  was considered be significantly different.

### Factors for Caregivers' Choice and the Choice Congruence

Caregivers' general characteristics are shown in Table 5. Only the living situation did play a role in their choice of patients' place of death ( $P = .036$ ). Agreement on the preferred place of death among patients and their family caregivers was 84.10%. The  $\kappa$  coefficient of overall congruence on preferred place of death was .719, indicating substantial congruence between patients and family caregivers on preferences for the place of death.

### Discussion

In mainland of China, no official statistics existed concerning the preference of place of death among terminally ill patients with cancer. This study established reliable information about the preference for place of death and described the associated factors of preference for the first time in mainland of China.

**Table 4.** Logistic Regression Analysis for the Predictors of Preference of Dying at Home.<sup>a</sup>

Variables	Level	AOR	OR (95% CI)	P value
Education	Elementary school or lower			Ref
	Secondary school	0.409	0.247-0.679	.001
	College or above	0.384	0.220-0.670	.001
Urbanization	Yes			Ref
	No	1.969	1.290-3.007	.002
Living arrangements	Spouse/family			Ref
	Live along	0.429	0.126-1.461	.176
	Other	0.725	0.566-3.366	.041

Abbreviations: AOR, adjusted odds ratio; CI, confidence interval; OR, odds ratio; Ref, reference category.

<sup>a</sup> Only significant factors are shown in the table ( $P < .05$ ). The unshown variables included age, gender, religious belief, medical resource, primary tumor site, and satisfaction with the treatment was found not to be significant.

**Table 5.** Demographic Data of the 522 Family Caregivers of Patients With Cancer and Factors for Preference.

Variables	Home (N = 268), %	Hospital (N = 207), %	Decided by patients (N = 47), %	P <sup>a</sup>
Gender				
Male	51.9	58.0	57.4	.727
female	48.1	42.0	42.6	
Age				.378
21-35	60.8	53.6	48.9	
36-64	34.0	39.1	48.9	
≥65	5.2	7.3	2.2	
Relationship to patients				.180
Wife/husband	28.4	26.6	42.6	
Daughter/son	67.9	65.7	53.2	
Others	3.7	7.7	4.2	
Lived with patient or not				.036
Yes	51.1	44.9	68.1	
No	48.9	55.1	31.9	

<sup>a</sup> Pearson chi-square test was conducted to explore relationship between the preference and variables.  $P < .05$  was considered to be significantly different.

In 805 terminally ill patients with cancer, only 522 patients–caregiver dyads agreed to participate. The rate (64.84%) was much lower than previous research in Western countries while was similar with the study in Taiwan and Japan.<sup>9,10</sup> This phenomenon reflected the traditional view to death among Asian countries. In China, it is believed that the topic of death may influence the mood of patients and bring misfortune. Therefore, they avoid talking about the death openly. This is actually the most significant barrier to improve the quality of good death in Chinese patients.

For 522 patient–caregiver dyads who participated in this study, home was the first preferred place of death while the second choice was hospital. A study from the United States

showed that death in hospital was most common for Asian immigrants.<sup>7</sup> Similar results were achieved in a research about patients born in China who lived in British and Canada.<sup>11</sup> The discrepancy of our research with these studies is interesting. The possible reasons for the difference may be living background and difference in medical insurance for these patients in different countries. And the social support for these emigrants is different from patients in mainland, which also do affect their choice.<sup>12</sup> However, the gap between choosing home and hospital was not as obvious as previous research in other countries. The percentage of choosing home was lower than other studies in Western countries previously, in which there were more than two-thirds of patients choosing home as their place of death.<sup>4</sup> In other words, the percentage of choosing hospital was higher than previous research, in which 20% or less was reported for preference of place of death.<sup>5,13</sup> It is not hard to understand that there are lots of patients who still choose hospital as the ideal place of death in China. The application of home palliative care services for patients with cancer in China still lags behind those in Western countries. The most important reason is that home-based palliative care service was not available in many regions of China yet.<sup>14</sup> Therefore, hospital is still an important choice for patients who want to relieve disease suffering. Tertiary hospital was the first choice for patients and caregivers who chose hospital as the ideal place of death. Tertiary hospitals are considered to be more professional and comfortable for both patients and family. Community hospital only provides the basic medical care and nursing for patients; it is a kind of hospital similar to hospice and nursing homes in Western countries. Community hospital was identified as the preferred place of death for 13.3% of respondents in our study, while hospice was identified as the preferred place by 6% to 30% of patients in previous research in Western countries.<sup>15</sup> In China, community hospital provides medical services for all kinds of patients, not only for patients with cancer. Therefore, the medical source provided for patients with cancer in community hospital is severely limited. However, since 2012, the government realized the problem and began to provide more hospice service at community hospital which may increase the number of patients who choose community hospital as their place of death in the near future.

Some predictive factors for patients' preference in this study were similar to previous studies in other countries.<sup>11</sup> There exists a difference in place of preference between rural and urban areas like many other countries. In our research, patients in rural area were more likely to die at home (60.43%). In some regions, dying at home has special cultural meaning in terminally ill patients, which is similar to previous research.<sup>7</sup> They believed that home is one of the most important factors for good death. This difference occurs due to the culture discrepancy in different areas and medical resource distribution. And the difference in choice also affects the palliative care progress in different areas. Home care service needs to be more valued in these rural areas.

Previous research showed that people with lower education more often prefer to die in hospital.<sup>16</sup> Our research obtained the

opposite results. The possibility may be that lower educated persons in Western countries have less access to home-based care because of the financial resources. In China, patients with lower education were more likely to be affected by the traditional Chinese culture, in which home was considered as the best choice for place of death.

Social support was one of the most consistently influential determinants of home death in previous research.<sup>17,18</sup> In our study, patients who were married and/or lived with a relative had a higher chance to choose home as the preferred place of death than patients without these supporting factors. Caregivers who lived with patients also have more will to choose home as the place of death for patients. Those patients living with relatives may have more intimate relationship with their caregivers. The closer psychological bond between patients and their caregivers may be one of the possible reasons to choose home as their place of death.

The status of the patients also affected the preference. Patients with bad status (KPS < 30) and those who were diagnosed more than 6 months were more likely to prefer to die at home, which is opposite to the previous research.<sup>14</sup> One of the possible reasons is that patients with poorer health have less confidence to release suffering. Therefore, they would like to spend the end of their life with their family at home rather than hospital after a long time of suffering from the disease.

Patients and their caregivers had good congruence about the preference. End-of-life care decisions were not discrete and isolated events but family events. In our study, the patient–family congruence on preferred place of death is high. It not only influences the choice of dying at home but also significantly contributes to quality of life of terminally ill patients with cancer.<sup>19</sup> It is indicated that family caregivers had a clear recognition of patients' preferences.

Our study has several limitations. First, the samples were collected in 1 medical center. Although our medical center is one of the biggest cancer hospitals and patients enrolled in our center are from different parts of our country, it is an academic setting; a multi-center survey which includes patients who never reached the academic centers for their treatments need to be done considering the differences across the China mainland. Second, the response rate was lower (64.84%) because of the traditional culture of Chinese. The reason for refuse to participate may reflect some kind of attitudes toward death; we may conduct further study to explore it. Finally, the study about actual place of death of these participants need to be conducted in the near future. The discrepancies between the rates of actual and preferred place of death and its reasons deserve to be analyzed.

## Conclusion

This survey study for the first time shows that home is the first choice of place of death for terminally ill patients with cancer and their caregivers in spite of a less gap between the choice of home and hospital in mainland of China. Patients who are

living in rural areas, with lower educational level, and living with relatives have the more possibility to express their preference to die at home. The rate of choosing home as the preferred place of death will increase due to the development of home palliative care service and more attention paid by the whole society.

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