Current awareness of palliative care and attitudes toward death in China: a cross-sectional survey

Yan Yan $(MA)^{*1}$, Hongyan Zhang $(MD)^{*2}$, Weijian Gao $(BCh)^3$, Duanqi Liu $(MD)^2$, Motoki Endo $(PhD)^4$, Gautam A. Deshpande $(MD)^5$, Yuko Uehara $(MD)^{1,6}$, Daisuke Watanabe $(MD)^{1,7}$, Seiichiro Yoshikawa $(PhD)^8$, Akio Mizushima $(PhD)^1$

Corresponding Author:

Akio Mizushima (Prof.)

Department of Palliative Medicine, Juntendo University Graduate School of Medicine,

2-1-1 Hongo, Bunkyo-ku, Tokyo 113-8421, Japan

Tel: 81-3-3813-3111

Email: akiom@juntendo.ac.jp

^{*} Joint first authors

¹ Department of Palliative Medicine, Juntendo University Graduate School of Medicine, 2-1-1 Hongo, Bunkyo-ku, Tokyo 113-8421, Japan

² Department of Oncology, No.7 Medical Center of PLA General Hospital, No. 5, Nanmencang, Dongsi Shitiao, Beijing 100700, China

³ Medical School of Chinese PLA, 28 Fuxing road, Beijing 100853, China

⁴ Department of Public Health, Juntendo University Graduate School of Medicine, 2-1-1 Hongo, Bunkyo-ku, Tokyo 113-8421, Japan

⁵ Department of General Medicine, Juntendo University Graduate School of Medicine, 2-1-1 Hongo, Bunkyo-ku, Tokyo 113-8421, Japan

⁶ Department of Palliative Medicine, National Cancer Center Hospital East, 6-5-1 Kashiwanoha, Kashiwa-shi, Chiba 277-8577, Japan

⁷ Department of Urology, Koto Hospital, 6-8-5 Oojima, Koto-ku, Tokyo 136-0072, Japan

⁸ Cancer Therapeutic Center, Juntendo University Urayasu Hospital, 2-1-1 Tomioka, Urayasu City, Chiba 279-0021, Japan

Summary

Background An estimated 2,865,000 people died from cancer in China in 2018, many of whom would have benefitted from palliative care. However, as death remains a taboo subject in Chinese traditional culture, palliative care remains underdeveloped. Further studies on public awareness of palliative care and Chinese attitudes toward death are warranted.

Methods We conducted a cross-sectional online questionnaire survey study from December 2018 to January 2019, including breast cancer patients from 52 online support groups in China. The primary outcome was the degree of awareness of palliative care; additionally, we assessed attitudes towards death and end-of-life goals. Variables collected included socioeconomic parameters. Regression analyses were conducted to determine the association between these factors and awareness of palliative care.

Findings Among 549 breast cancer patients, 68 (12·4%) reported having heard about palliative care. Of the 481 participants who denied previous awareness, 326 patients (67·8%, out of 481) reported interest to learn more after reading a brief definition. Higher education level and household income showed a statistically significant relationship with awareness of palliative care. Regarding end-of-life goals, $64 \cdot 7\%$ of participating patients "preferred to spend the last period of life at home".

Interpretation This study revealed a markedly low public awareness of palliative care, demonstrating an urgent need for public education about palliative care in China. Educational programs targeting populations with lower education and income levels may be beneficial. Given strong family orientation in Chinese culture, caregiving roles for family members may facilitate successful palliative care implementation in China.

Funding None.

Research in context

Evidence before this study

China is seeing strong social demand to improve quality of life for end-of-life patients. Palliative care, however, has developed slowly due to the Chinese culture's adherence to traditional views of death as a taboo topic. Although several communities have been selected for national pilot programs establishing hospice wards in large hospitals and transforming community hospitals into hospices across China, this field remains significantly under-researched, with previous studies limited to specific areas including advance directives and psycho-oncological interventions. No in-depth study on public awareness of palliative care has been conducted, nor have there been any nationwide public surveys with a focus on cancer patients' opinions on death and dying.

Added value of this study

Our study is the first in-depth survey investigation on public awareness of palliative care and attitudes toward death in China. In this study, we attempted to clarify several fundamental questions, asking participating patients to help elucidate the current status of two conceptual components of end-of-life care [awareness of palliative care and attitudes toward death]. To better design future public health interventions, we also investigated demographic and socioeconomic variables that may be associated with low awareness, as well as social values in end-of-life care goals.

Implications of all the available evidence

Our findings provide strong evidence for the dire need for advocacy of palliative care, for increasing awareness and accessibility of this poorly understood care practice in China, especially among patients in lower socioeconomic strata. We propose several possible interventions that may increase awareness in China. In particular, patients' clear preference for spending their last period of time at home provides strong evidence to promote home nursing care services at the policy level, with close involvement of family members.

Introduction

With a massive population of more than 1·4 billion, China had more than 150 million people aged 65 or above in 2017, accounting for 10·7% of the total population.¹ Along with cardiovascular diseases, cancer is now a leading cause of death in the rapidly-aging country,² accounting for 26·06% of deaths in urban areas, and 22·92% of deaths in rural areas in 2016.³ There were an estimated 4,285,000 newly diagnosed cancer cases in China in 2018, with roughly 2,865,000 cancer deaths.⁴ Despite initiation of national cancer control programs, regular cancer screenings are not uniformly accessible across China. The majority of patients are diagnosed at late stages,⁵ with a cumulative 5-year prognosis of 40·5% in 2015.6

Palliative care, which aims to improve the quality of life of patients and families facing terminal illness,⁷ was introduced into China in the late 1980s. However, in a culture where discussing death remains taboo, families of terminal patients often feel pressure to opt for life-prolonging care. As such, palliative care has developed slowly in China over the last 30 years, with the Economist Intelligence Unit ranking China 71 out of 80 studied countries on palliative care in 2015.⁸ Though ancestor worship and reluctance to discuss the topic of death are shared cultural features in many East Asian countries, including Japan and Taiwan, palliative care has been more successfully promoted in these countries compared to China. A questionnaire survey conducted by Japan's Hospice Palliative Care Foundation in 2006 found that 90·7% of respondents had heard of palliative care, with 58·6% reporting a moderate to advanced awareness.⁹ Similarly, Taiwan passed the Natural Death Act in 2000, followed by the Patient Autonomy Act in 2015, where hospice and palliative care are currently covered by the National Health Insurance system.

Under strong pressure to switch the focus of the healthcare system from acute to chronic care, the Chinese government issued practice guidelines for hospice care in 2017, ¹⁰ and selected 3 cities and 2 districts in Beijing and Shanghai as pilot areas to promote palliative care services. Despite this, palliative care in China continues to face significant barriers including insufficient education and training resources, lack of legal and policy support, insufficient supplies of appropriate pharmaceuticals, a dearth of research, and unclear attitudes toward death in a rapidly changing society. ¹¹ Despite studies on public awareness of palliative care across the world over the past several decades, this field remains under-researched in China, with previous studies limited to specific areas including advance directives, advance care planning, and psycho-oncology. ^{12–14} As such, we aimed to design a questionnaire-based study of palliative care awareness and attitudes toward death in a rapidly modernizing China. Although palliative care is not only applicable to cancer, considering its massive incidence and mortality in China, we chose cancer patients as our study population. The objectives of the study are 1) to quantify current awareness of palliative care among target patients, as well as their attitudes toward death, and 2) to identify associated demographic factors which may facilitate future interventions. In addition, we investigated important culture-specific factors within the context of a Chinese cultural background, including family orientation, which may inform future palliative care programming.

Methods

Study design

The questionnaire was designed in collaboration with the Department of Oncology, No. 7 Medical Center of PLA General Hospital in Beijing, China, and the Department of Palliative Medicine, Juntendo University Graduate School of Medicine, Japan. Contents focused on "awareness and perception of palliative care" and "attitudes toward death". All participants self-reported whether they had heard of palliative care before, and if not, whether they would like to know more about palliative care after reading a written description of its' definition. Basic demographic and socioeconomic variables, including age, gender, education, household income, residence, religion, and occupation were also included. Factors such as the setting in which the diagnosis was made, the method of being informed of the diagnosis, subjective mental health status, previous personal experience with death, and preferred place of dying were also collected.

Exploratory pilot interviews (N=10) were conducted in December 2018 using face-to-face interviews at PLA General Hospital. All pilot participants were inpatients with a variety of cancer types and disease stages. Based on the pilot results, several adjustments were made to the questionnaire: 1) questions on cancer stage were removed since many patients were not informed clearly about disease details; and 2) questions about perceptions of death were re-designed as multiple-choice questions to better facilitate survey completion. Responses from the pilot survey were not included in the final study analyses.

The study was approved by Ethics Committee of No. 7 Medical Center of PLA General Hospital, China.

Study population

Because patients with breast cancer typically have better than 5-year survival rates and thus may be more resilient and positive toward treatment, we assumed a potentially higher engagement with sensitive topics of death and dying. To this end, we opted to limit our study to patients with breast cancer.

Breast cancer patients were recruited from 52 online patient association groups with a total of approximately 26,000 members across China. All participants were aware of their diagnoses, but not necessarily regarding stage or other clinical details. An electronic version of the questionnaire was sent to these groups along with a consent form in December 2018.

Statistical analyses

Surveyed participants were demographically categorized by gender, age, residence, education, religion, household income and occupation (medical professional or not). To determine statistical differences between groups, Chi-square test and t-test were performed for categorical variables, respectively. P < 0.05 was considered statistically significant. Subsequent logistic regression was performed for both univariable and multivariable analyses, with data reported as odds ratio with 95% confidence intervals. IBM SPSS Statistics V25® was used for logistic regression analyses.

Role of the funding source

There are no outside funding sources other than financial support from the authors' affiliated institutions. The first authors and the corresponding author had full access to all the data in the study and were responsible for the decision to submit for publication.

Results

Patient characteristics

Between December 27, 2018 and January 5, 2019, a total of 549 patients returned completed surveys (response rate, 2·1%). Surveys were represented from all provinces, provincial level municipalities, and autonomous areas except Tianjin, Hong Kong and Macau Special Administrative Regions, and Taiwan. Basic characteristics of the study population are described in Table 1. Since target subjects were exclusively breast cancer patients, 99·5% (N=549) of the respondents were women. 48·6% were between 40 to 49 years old; 71·4% reported living in an urban area; 45·7% reported college education or higher. 69·4% of respondents reported that they were non-religious. 73·5% of respondents' annual household income was less than CNY100,000 (approximately USD14,700). Regarding occupation, 5·3% (n=29) of respondents were medical professionals.

Only 20.9% of patients were diagnosed during a routine check-up; 61.4% were informed by doctors directly. 48.5% reported experiencing a mental health issue in the past three months. When asked about death and dying, 82.9% of respondents had previously experienced the death of a family member or friend. 64.7% reported that they would like to spend the last period of their life at home.

Awareness of palliative care

Of 549 respondents, 68 (12·4%) reported some previous knowledge or awareness of palliative care. Of the 481 participants who denied previous awareness, 326 patients (67·8%, out of 481) reported interest to learn more after reading a brief definition. Education level (p=0·0001), annual household income (p<0·0001), and being a medical professional (p=0·029) demonstrated

statistically significant associations with previous awareness of palliative care. (Table 1) On regression analyses, both univariable and multivariable analyses confirmed that higher education (univariable analysis: OR=0·476 (0·282-0·801), p=0·005), higher household income (univariable analysis: for sub-group of "more than CNY250K", OR=0·245 (0·097-0·617), p=0·003), and being a medical professional (univariable analysis: OR=0·342 (0·145-0·807), p=0·014) were associated with previous awareness of palliative care. (Table 2)

Attitudes toward death

355 (64·7%) of studied patients "preferred to spend the last period of life" at home, while 109 (19·9%) preferred a hospital. When asked about attitudes towards death, 270 (49·2%) reported that they were "afraid of losing family and friends"; 256 (46·6%) answered that they were "not afraid; a natural circumstance". "afraid of too much pain" was the 3^{rd} most frequently chosen answer, with 120 patients (21·9%) expressing this concern. (Figure 1a)

When asked "If you get the chance to fulfill wishes, what would they be?", 351 patients (63.9%) reported that they would "enjoy daily life with family". "seeing children get married" ranked second, followed by "seeing children go to college." (Figure 1b)

Discussion

Compared to studies of awareness of palliative care conducted in the US, Japan, Canada, New Zealand and United Kingdom, ^{16–20} this study revealed a much lower awareness of palliative care in China with only 12·4% of patients having heard this term.

After reading a brief written description about palliative care, however, 67.8% (326 out of 481) of participants without previous knowledge of the term showed interest in obtaining more information.

The very low awareness of palliative care in China suggests that public health education efforts are urgently needed. Notably, our findings showed that both education and household income are significantly correlated with awareness of palliative care in this population of breast cancer patients in China, a relationship similarly found in Taiwan.²¹ A questionnaire study in Saudi Arabia also revealed that employment and higher education were linked to better knowledge and awareness of palliative care.²² Considering China's massive population, public health education via mass media such as TV programs targeting people in lower socioeconomic strata may be impactful.

In China, the emphasis of medical education and clinical training has been on disease pathophysiology and treatment. This study received 29 responses from cancer patients who were medical professionals, of whom only 8 (27.6%) were previously aware of palliative care. Furthermore, we observed no significant difference regarding awareness of palliative care between patients whose diagnosis was informed to them by their doctors directly versus patients who were informed via other methods. These findings suggest that healthcare providers in China are ill-informed of palliative care options for their patients or are reluctant to introduce palliative care to patients who may benefit from this service. Our findings indicate that educational training programs for healthcare providers regarding the availability and appropriate use of palliative care is urgently required.

When asked about attitude towards death, "afraid of losing family and friends" was the most frequently chosen response. "Enjoying daily life with family" was unsurprisingly the most preferred response to future wishes. In addition, 64·7% of patients indicated that they would prefer spending their final days at home. These findings are consistent with the results of several previous surveys of Chinese diaspora communities: family as a major focus at the end of life was reported in a previous survey in Hong Kong;²³ similarly, unburdening of family was found to be an important motivation for care plans in a study of Chinese in the United States.²⁴ Regarding palliative care in China, family involvement may be as important as patient care; this cultural consideration will likely play a key role in the successful implementation of palliative care, as well as for its sustained adoption in China.

Limitations: This study has several limitations that warrant mention. First, our response rate was 2·1%, quite small considering the large number of cancer patients in China, and our sample may not be fully representative of all cancer patients. An age-selective bias is also possible, as younger patients may be more comfortable with internet-based tools than older patients. In addition, this online survey was self-administered via cancer associations. Those in lower socioeconomic strata and with other barriers to comprehensive care may have limited access to these resources. Since education level and household income show significant relationship with awareness of palliative care, we anticipate that actual awareness nationwide may be substantially lower. This differential bias further highlights the need for increased palliative care awareness interventions. Moreover, our questionnaire didn't ask further questions about the contents of palliative care to explore the extent to which respondents understood the concept clearly. We anticipate that raising awareness of palliative care, while conveying accurate ideas to the public, will remain a future challenge in China. Finally, 99·5% of the studied population was female. Considering extant societal norms for Chinese women regarding family expectations, the emphasis on the role of family at the end of life may be overemphasized. Future studies representative of gender, disease, and socioeconomic distribution are warranted.

Conclusion

Awareness of palliative care is considerably low $(12\cdot4\%)$ in China, but the majority of studied patients showed interest to know more about this concept. Education and household income level are found to have strong relationships with awareness of palliative care. The combination of public health programs targeting people with lower education and income level might effectively increase awareness. In order to improve availability of this important healthcare service, increased training for medical professionals is urgently needed. When implementing palliative care, emphasizing the role of family as a key cultural aspect warrants consideration for successful adoption.

Contributors' statement

DL and AM supervised the survey project. YY and HZ designed the questionnaire survey and prepared the questionnaire. WG and HZ prepared the consent form to participating patients and managed the pilot survey and online questionnaire in China. ME and YY conducted statistical analyses. YY wrote the first manuscript. YU, DW, SY and GD contributed in preparing the manuscript. All authors reviewed the manuscript.

Conflict of interest statement

The authors declare no conflicts of interest.

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Table 1 Basic characteristics of study population and awareness of palliative care (N=549)

				Awareness of Palliative Care						
		Study population (N=549)		Have heard before (N=68)		Never heard, but willing to learn more (N=326)		Never heard, and not interested (N=155)		Chi- Square (p-value)
Overall		549	100.0%	68	12.4%	326	59.4%	155	28.2%	
Gender										0.807
	Female	546	99.5%	68	12.5%	324	59.3%	154	28.2%	
	Male	3	0.5%	0	0.0%	2	66.7%	1	33.3%	
Age Group										0.235
	<40	94	17.1%	17	18.1%	47	50.0%	30	31.9%	
	40-49	267	48.6%	28	10.5%	164	61.4%	75	28.1%	
	>50	188	34.2%	23	12.2%	115	61.2%	50	26.6%	
Residence										0.124
	Rural	157	28.6%	17	10.8%	86	54.8%	54	34.4%	
	Urban	392	71.4%	51	13.0%	240	61.2%	101	25.8%	
Education										0.0001
	High school and less	298	54.3%	26	8.7%	168	56.4%	104	34.9%	
	College and higher	251	45.7%	42	16.7%	158	62.9%	51	20.3%	
Religion										0.207
	Non-Religious	381	69.4%	48	12.6%	234	61.4%	99	26.0%	
	Religious	168	30.6%	20	11.9%	92	54.8%	56	33.3%	
Household Income (annually)										< 0.0001
	<cny100k (~USD14,700)¹</cny100k 	404	73.6%	41	10.1%	233	57.7%	130	32.2%	
	CNY100K-250K (~USD14,700~USD36,	117	21.3%	16	13.7%	76	65.0%	25	21.4%	
	>CNY250K (~USD36,800)	28	5.1%	11	39.3%	17	60.7%	0	0.0%	
Medical Professional?									••	0.029
	No	520	94.7%	60	11.5%	310	59.6%	150	28.8%	
	Yes	29	5.3%	8	27.6%	16	55.2%	5	17.2%	
Method of informing diagnosis										0.534
	Informed by doctor directly	337	61.4%	42	12.5%	198	58.8%	97	28.8%	
	Informed by doctor through family	58	10.6%	10	17.2%	30	51.7%	18	31.0%	
	Found under other situations	154	28.1%	16	10.4%	98	63.6%	40	26.0%	
Preferred place of dying										0.207
	At home	355	64.7%	41	11.5%	214	60.3%	100	28.2%	
	In hospital	109	19.9%	10	9.2%	67	61.5%	32	29.4%	
	Not reported / Others	85	15.5%	17	20.0%	45	52.9%	23	27.1%	

Note:

¹ Currency rate: 100USD=679.12CNY (Bank of China, 2019/05/12/10:30:00, middle rate)

Table 2 Univariable and multivariable analyses of variables associated with awareness of palliative care (N=549)

		Univariable Analysis			Multivariable Analysis		
Variables ¹		OR (95% C.I.) p-val			OR (95% C.I.)	p-value	
Age Group							
	<40 (ref.)	1			1		
	40-49	0.584 (0.800-3.315)	0.187		0.503 (0.253-0.999)	0.050	
	>50	0.840 (0.468-1.510)	0.561		0.650 (0.314-1.345)	0.246	
Residence							
	Rural (ref.)	1			1		
	Urban	0.812 (0.453-1.455)	0.484		0.813 (0.414-1.598)	0.548	
Education							
	High school or less (ref.)	1			1		
	College and higher	0.476 (0.282-0.801)	0.005		1.966 (1.071-3.608)	0.029	
Religion							
	Non-Religion (ref.)	1			1		
	Religious	1.067 (0.611-1.861)	0.820		1.042 (0.585-1.857)	0.888	
Household income (annually)							
	<cny100k (~usd14,700)<sup="">2 (ref.)</cny100k>	1			1		
	CNY100K-250K (~USD14,700–USD36,800)	0.175 (0.077-0.398)	0.000		1.134 (0.582-2.211)	0.712	
	>CNY250K (~USD36,800)	0.245 (0.097-0.617)	0.003		4.617 (1.925-11.076)	0.001	
Medical Professional?							
	No (ref.)	1			1		
	Yes	0.342 (0.145-0.807)	0.014		2.820 (1.162-6.846)	0.022	

Note:

¹ Given the small number of men, gender was not analyzed in univariable and multivariable analysis.

² Currency rate: 100USD=679.12CNY (Bank of China, 2019/05/12/10:30:00, middle rate)

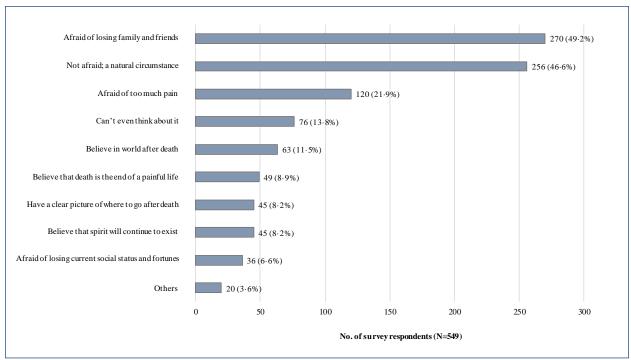


Figure 1a Perception of death ("How do you think about death?")

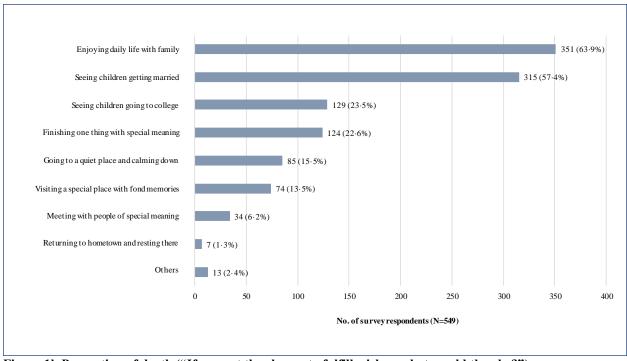


Figure 1b Perception of death ("If you get the chance to fulfill wishes, what would they be?")

Supplementary Materials

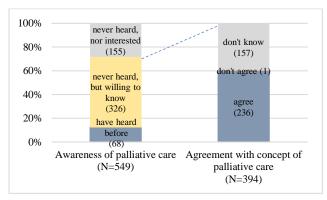
Regional distribution of survey respondents

This on-line questionnaire survey received responses from all provinces, provincial-level municipalities and autonomous regions in China, except Tianjin municipality, Hong Kong and Macau Special Administrative Regions, and Taiwan. All survey respondents were breast cancer patients.

Perception of palliative care

There were 68 studied patients who had previously heard about palliative care, and another 326 patients who reported to be interested in learning more after reading a written description of palliative care. (*Palliative Care*: an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering, by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual [WHO].)

Out of the above two subset groups of patients (N=394), a question of whether they would agree with the concept was then asked. 236 studied patients agreed with the concept of palliative care being effective (Fig. 1). When asked why they agree with the concept of palliative care (multiple choice), over 70% of those who agreed with the concept of palliative care chose "hope to mitigate pain", "hope to relieve financial burden to family"; more than 50% of them believed that "overtreatment is not desirable" (Fig. 2).



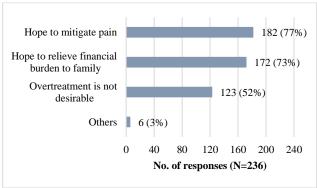


Fig. 1 Agreement with the concept of palliative care

Fig. 2 Reasons for agreeing with the concept of palliative care

Method of Informing Diagnosis

337 (61%) respondents received a cancer diagnosis directly from their doctor (Fig. 3). When asked if they prefer to be informed, 85% (465 out of 549) self-reported that they preferred to be informed, whereas the rest believed it would have been better without knowing the truth (Fig. 4).

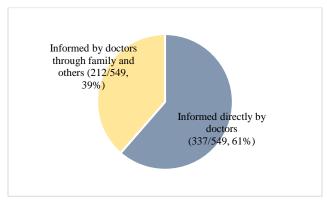


Fig. 3 Method of informing cancer diagnosis (N=549)

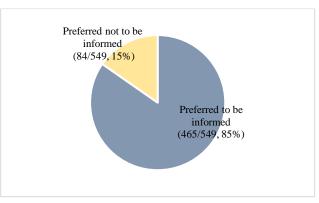


Fig. 4 Perception of being informed (N=549)

Access to professional mental and physical care

When being asked about professional instructions from nutritionists, psychologists and physical therapists, over 90% of the survey respondents (N=549) had never received treatment/care from professional psychologists, physical therapists, nor from professional nutritionists (Fig. 5).

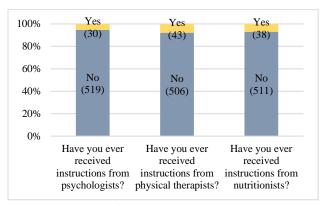


Fig. 5 Access to professional mental and physical care (N=549)

Patients' voices

At the conclusion of the questionnaire survey, some patients wrote concerns and comments regarding cancer treatment and the Chinese medical system in general. These quotations are categorized into "Physical concerns", "Concerns on communication with doctors and nurses", "Concerns on lack of other professional support rather than oncologists", "Concerns on lack of social support", "Spiritual concerns" and "Comments on healthcare insurance system". Selected quotations are listed in Table 1.

Table 1 Quotations from studied patients (N=549)

••	Patient	Age	Residence	Religion	Quotations			
Dharitaal	No.	57	C'.	N.	Cid-off-strange Control 1 11 11 division			
Physical concerns	#541	57	City	No religion	Side effects are too strong. Can't sleep well. Hope the situation will be improved.			
	#550	60	City	No religion	Oncological doctors can't only treat tumor. Side effects are more painful than the disease.			
••	#371	53	City	Christianity	Currently my most challenging issues are: fatigue and insomnia.			
Concerns on communication with doctors and nurses	#182	44	City	Buddhism	Hope medical staff pay more attention on explaining side effects of treatment plans. Hope to receive more encourage from doctors and nurses.			
	#186	51	City	Buddhism	Hope doctors will provide full information on treating plans, steps and scenarios, so patients will know what to expect.			
	#241	54	City	No religion	Hope to have a whole grasp on how treatments would affect work and life, including what medicine are used after surgery and what is the good way of rehabilitation.			
••	#394	57	City	No religion	Can't understand what were written on my pathological report.			
	#499	54	City	No religion	Hope doctors not only treat disease, but also pay attention to patients' feelings.			
Concerns on lack of other professional support rather than oncologists	#3	44	City	No religion	Hope there are a large number of psychologists to help cancer patients. Cancer patients need mental support and treatment. Being positive is crucial for patients on the way toward recovery. Hope more specialists realize the demand and work together to help cancer patients.			
••	#61	47	City	No religion	Hope to receive professional rehabilitation service after finishing treatment at hospital.			
•	#232	31	Rural	No religion	Don't have much knowledge about nutrition and physical therapy. Hope to receive systematical instruction on rehabilitation.			
•	#324	44	City	No religion	Hope there are independent institutions to provide professional psychological treatment and mental care to cancer patients, so patients and family would have less mental disorders.			
	#330	54	City	Christianity	Hope there is a rehabilitation center near home.			
••	#523	55	Rural	No religion	Physical therapy please. Psychological care please.			
Concerns on lack of social support	#111	52	City	No religion	Hope the whole society pay more attention on cancer and cancer patients. We need more educational programs on TV to provide prevention and early diagnosis information.			
	#142	42	Rural	Buddhism	Hope to have a national wide online network of cancer patients, so we could communicate and comfort each other. Hope hospitals open psychological clinics to help patients.			
	#509	46	City	No religion	Hope hospitals would keep tracking each cancer patient and organize patient groups for communication.			
Spiritual concerns	#208	38	Rural	No religion	Having felt lost after living as a cancer patient for such a long time			
Comments on health insurance system	#81	46	City	No religion	Hope everyone can afford medical service, and hope employers would have better understanding and support to cancer patients.			
	#488	45	City	Buddhism	Hope more anti-cancer drugs would be covered by insurance, and the percentage of covered fees would be increased, so cancer patients won't have much financial worries.			