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Original Article

Evaluating Illness Understanding and Preferences of End-of-Life Care Among Older Patients with Advanced Cancer in Vietnam

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ABSTRACT

Background/Purpose: Providing end-of-life (EOL) care inconsistent with patients' preferences increases the physical distress and decreases the quality of life of patients. This study aimed to evaluate illness understanding and preferences of EOL care among older patients with advanced cancer in Vietnam.

Methods: We performed a cross-sectional study at the Department of Geriatrics-Palliative Care at Ho Chi Minh City University Medical Center. Older people with stage IV cancer were enrolled in the study. Face-to-face interviews were conducted by palliative care specialists to explore patients' illness understanding and EOL care preferences.

Results: The study included 109 participants with a mean age of 70.9±3.5 years (44.1% female). Approximately 72% of the participants acknowledged their terminal illness, but 61.5% did not know their estimated life expectancy, and 89.9% were not aware of advanced care planning (ACP). Most participants wished to die at home (76.1%) and not receive mechanical ventilation (62.4%) or resuscitation (64.2%). More than half of the participants preferred being around their family members during the last hours of life (51.4%).

Conclusion: Most older patients with advanced cancer did not know their estimated life expectancy, and were relatively unfamiliar with advanced care planning. Hence, healthcare teams should identify patients' values and preferences and facilitate ACP discussions to ensure that EOL care is consistent with their wishes. This will reduce physical distress and healthcare costs for older patients with advanced cancer.

1. INTRODUCTION

Similar to many countries worldwide,[1-3] cancer became the fifth leading cause of mortality in Vietnam[4] in 2019. Approximately 60% of cancer cases occur in people aged ≥65 years.[5,6] Therefore, there is an increasing number of older patients with advanced cancer requiring palliative care and end-of-life (EOL)

care.[7] Previous studies have revealed that providing care inconsistent with patients' preferences increased the physical distress and healthcare cost,[8-10] and decreased the quality of life of patients.[8,10]

In a study on 221 patients with advanced cancer in South Africa, Megan et al. found that only 5.9% of patients acknowledged that their terminal illness and 97.7% did not have EOL care discussions.[11] In general, in low-and middle-income countries, EOL care receives little attention.[12] Similarly, in Asian countries, advanced care planning (ACP) or EOL care discussion remains challenging because of many difficulties, such as lack of education of health care professionals, fear of conflict with patient's family, or lack of a standardized system.[13-15] Vietnam, a fast-ageing Southeast Asian country,[16] also lacks palliative care services.[17]

Recently, some major and general hospitals have started palliative care services.[18] However, a study in a geriatric hospital in Vietnam reported that 40.5% of the physicians and 74.2% of the nurses showed insufficient knowledge on geriatric palliative care.[19] Moreover, to the best of our knowledge, studies on the preferences of older patients with advanced cancer are unavailable in Vietnam. Understanding their EOL care preferences will help ensure that the healthcare team provides EOL care that is consistent with the patient's wishes,[20] thus improving their quality of life. Therefore, this study aimed to evaluate illness understanding and EOL care preferences among older patients with advanced cancer in Vietnam.

2. METHODS

2.1. Study Design

We performed a cross-sectional study at the Department of Geriatrics-Palliative Care of the University Medical Center, a teaching hospital located in District 5 in Ho Chi Minh City with the largest palliative care department in southern Vietnam. The study was approved by the Institutional Review Board of the University of Medicine and Pharmacy at Ho Chi Minh City (approval number: 505/ĐHYD-HĐĐĐ). Data were collected by palliative care specialists from December 2019 to June 2020.

2.2. Participants

All patients with stage IV cancer with metastasis, diagnosed by oncologists or based on medical records, and treated in the Department of Geriatrics-Palliative Care during the study period were invited to participate in the study, regardless of whether they were receiving active cancer treatment or not. The inclusion criteria were as follows: age ≥60 years (most patients admitted to the department are older people); ability to communicate, understand, and use the Vietnamese language; and consent to participate in the study. The exclusion criteria were as follows: advanced stage of non-cancer diseases such as heart failure or chronic obstructive disease, acute conditions such as infection or delirium, uncompleted interview because of pain or nausea, and lacking the capacity to complete the interview because of dementia. Eligible participants were interviewed the day before hospital discharge. Written consent was obtained from all participants.

2.3. Procedures

The participants were interviewed face-to-face by the palliative care specialists in a private counseling room in the Geriatrics-Palliative Care Department using a structured questionnaire, reviewed by two senior specialists. The average interview time was 35 minutes per participant. The questionnaire included the following three parts:

(1) Demographic and personal information including age, gender, marital status, body mass index (BMI), living place, education, household family members, primary caregiver, comorbid diseases, activities of daily living (ADL), and medications. Multimorbidity was defined as the coexistence of ≥2 chronic diseases[21] and polypharmacy was defined as the concurrent use of ≥5 types of drugs.[22] The participants were also assessed using the Eastern Cooperative Oncology Group (ECOG) performance status,[23] which was graded from 0 to 5. A higher score indicates a lower level of functionality. The most common complaints of the participants were also collected.

(2) Illness understanding included acknowledgment of terminal illness and prognosis. To evaluate the participant's comfort in talking about death, the investigator used two questions: "Have you ever thought of advanced care planning?" and "Do you feel comfortable in a discussion about dying?". These could be answered as yes or no.

(3) Preferences for end-of-life care consisted of parenteral nutrition, mechanical ventilation, cardiopulmonary resuscitation (CPR), and the desire for death. Moreover, the participants were asked about their most concerning problems at the end of life such as pain, dyspnea, loneliness, economic burden, and being apart from their family. We chose these items because these were the most common concerns of cancer patients based on the clinical practice experience of palliative care doctors in our setting. We also asked this open-ended question "If you were close to dying, what would be the most important thing to you?".

2.4. Data Analysis

Data were processed using Epidata 3.1, and statistical

analyses were performed using Stata version 14 (Stata Corp, USA). Statistical significance was set at p <0.05. Discrete variables are expressed as counts and percentages, whereas age is presented as mean±*standard* deviation.

3. RESULTS

A total of 109 older patients participated in this study, and their mean age was 70.9±3.5 years (range: 60_88 years). Most participants resided in urban areas (67%), and 81 patients (74.3%) had more than two children. Hypertension, diabetes, and ischemic heart disease were the three most prevalent comorbid diseases (45%, 25.7%, and 15.6%, respectively). Fatigue (59.6%) and pain (55%) were the two most common complaints among the participants. Furthermore, we found that the most prevalent primary cancer sites were lung, colorectum, and liver (20.2%, 19.2%, and 18.3%, respectively). Most of the participants (85%) were admitted to the Geriatrics-Palliative Care Department for palliative care treatment such as controlling pain or dyspnea, and the remaining participants were admitted for other reasons such as infection or electrolyte disturbance. The demographic and medical characteristics of the patients are presented in Table 1.

3.1. Illness Understanding

Nearly three-fourths of the patients (71.6%) acknowledged that they had a terminal illness (Table 2). Moreover, 83 patients (76.1%) reported that they would like to share their disease information with family members, whereas only one patient (0.9%) preferred to keep it a secret.

3.2. End-of-life Care Preferences

We found that 64.2% of older patients with advanced cancer reported that they would not like to receive CPR at the end of life (Table 3).

4. DISCUSSION

4.1. Illness Understanding

This study addressed terminal illness understanding and end-of-life care preferences among older patients with advanced cancer in Ho Chi Minh City, the largest and most populous city in Vietnam. The results showed that more than 70% of participants acknowledged their terminal illness. This proportion is significantly higher than that reported by a study in South Africa, where only 5.9% acknowledged their terminal illness.[11] A study of Chinese patients with advanced cancer found that 82.3% of patients in palliative care had unmet information needs.[24] The relatively high percentage in our study may be due to the palliative care medicine implementation in some

Table 1. General characteristics of the study participants (n=109)

	N	%
Age (years)		
60_69	49	45.0
70_79	39	35.8
≥80	21	19.2
Gender		
Female	48	44.1
Male	61	55.9
BMI (kg/m^2)		
Underweight (< 18.5)	33	30.3
Normal weight (18.5_22.9)	53	48.6
Overweight (23_24.9)	23	21.1
Education		
Primary school	33	30.3
Secondary school	28	25.7
High school	33	30.3
College/University	15	13.7
Living place		
Rural area	36	33.0
Urban area	73	67.0
Religion		
Buddism	53	48.6
Christianity/Islam	16	14.7
No religion	40	36.7
Marital status		
Married	76	69.7
Single/divorced/widowed	33	30.3
Living status		
With family	108	99.1
Alone	1	0.9
Number of household members		
<4	80	73.4
≥4	29	26.6
Primary caregiver		
Child	66	60.6
Spouse	33	30.3
Relative	7	6.4
Other	3	2.7
Multimorbidity (yes)	37	33.9
Polypharmacy (yes)	81	74.3
Activities of daily living impairment (yes)	59	54.1
ECOG performance status (points)		
2	13	12.0
3	77	70.6
4	19	17.4
Primary cancer site		
Lung	22	20.2
Colorectum	21	19.2
Liver	20	18.3
Gastric/Esophagus	13	11.9
Pancreatic	12	11
Prostate	4	3.7
Other (Breast/Cervix/Bladder/Kidney)	17	15.7

Abbreviations: BMI, Body mass index; ECOG, Eastern Cooperative Oncology Group.

Table 2. Illness understanding of the study participants (n=109)

Characteristics	N	%
Terminal illness acknowledgment		
Yes	78	71.6
No	31	28.4
Estimated life expectancy acknowledgment		
Yes	42	38.5
No	67	61.5
Ever thought about advanced care planning		
Yes	11	10.1
No	98	89.9
Feeling comfortable in discussing dying		
Yes	87	79.8
No	22	20.2

Table 3. End-of-life care preferences of the study participants (n=109)

End-of-life care preferences	N	%
Would you like to have parenteral nutrition in case you cannot eat or drink?		
No	61	56.0
Yes	35	32.1
Not sure	13	11.9
Would you like to receive mechanical ventilation in case you cannot breathe?		
No	68	62.4
Yes	28	25.7
Not sure	13	11.9
Would you like to receive resuscitation?		
No	70	64.2
Yes	26	23.9
Not sure	13	11.9
Where would you want to be if you were dying at the end of your life?		
Home	83	76.2
Hospital	6	5.5
Refused to say	20	18.3
What is your most concerning issue at the end of life?		
Pain	51	46.8
Being apart from family	36	33.0
Dyspnea	15	13.8
Being a burden to the family	11	10.1
Loneliness	8	7.3
If you were close to dying, what is the most important thing to you?		
Being with family members	56	51.4
No pain	45	41.3
Not being a burden to my family	33	30.6
Being peaceful	28	25.7

major hospitals in Vietnam. Thus, physicians tended to discuss more with patients about their health status and applied the shared decision-making model.[18,25] In addition, our study population comprised older people; thus, they may be inclined to accept their terminal illness more easily than younger ones;[26-28] in a study investigating the influence of age on the preferences of EOL care, John et al.[26] found that older people were less likely to receive life-prolonging care than younger individuals.

In this study, 28.4% of the participants were unaware that they had advanced cancer, 61.5% did not know their estimated life expectancy, and nearly 90% were not familiar with ACP. These findings were similar to those of a study in South Africa, which reported that 84.6% of patients with advanced cancer did not know their estimated life expectancy.[11] In other Asian countries such as China, Japan, and Singapore, health care professionals were less likely to engage patients in discussion on ACP.[15] In Vietnam, although palliative care has been initiated in some hospitals,[18] ACP remains unfamiliar to most cancer patients. Moreover, because Vietnam is a country that has an Eastern cultural view, similar to China, discussion on ACP remains challenging because many people assume that it is a sensitive issue and may bring a bad prognosis.[29] Similarly, a study in China showed that 95.3% of older residents in nursing homes had never heard of advance directives.[30] Therefore, discussions on ACP should be facilitated for older patients with cancer to ensure that the EOL care suits their values and preferences. An interesting finding in our study is that nearly 80% of the participants felt comfortable in discussing dying. This may be because the participants were older people who were less likely to fear talking about death.[31,32]

4.2. EOL Care References

This study revealed that more than half of the participants (56.9%) refused parenteral nutrition if they could not eat or drink, 62.4% did not want to receive mechanical ventilation, and 64.2% did not want to receive CPR. These findings differed from those of a study in Thailand,[33] in which only 21.2% of the participants reported that passing away without CPR was good. This may be due to the age difference in the study populations; older adults may prefer a peaceful death compared to younger ones.[33,34] In a study on death perspectives in middle-aged and older Singaporeans, the dominant concern was having physical comfort at the end of life.[34]

Furthermore, we found that 76.1% of the participants preferred to die at home. This proportion was slightly higher than previously reported findings in Thailand (47%)[33] and Japan (43.7%)[35]. In Vietnam, most older people live at home and are cared for by their relatives;[36] thus, their home is the most familiar place. Moreover, they wished to be with their loved ones when they passed away (51.4%). Although we found high proportions of patients who preferred home death and to not receive CPR, we could not find any study on ACP engagement or do not resuscitate (DNR) decision-making in older cancer patients in Vietnam.

In a systematic review of ACP, Dian et al. reported that Asian health care professionals rarely facilitate ACP in their patients, although they acknowledged its importance.[15] We also found that the most concerning issue to the participants at the end of life was suffering from pain (46.8%); this is in line with the result of a study in the Czech Republic which reported that 67% of older patients preferred controlling their pain.[37] Moreover, this agreed with our clinical practice experience, pain was the leading cause of admission in older people with advanced cancer, and more than half of the participants (55%) in our study suffered from pain.

4.3. Strengths and Limitations

To the best of our knowledge, this is the first study that explores the illness understanding and preferences of end-of-life care among older people with advanced cancer in Vietnam. Face-to-face interviews were held by trained physicians so that the patients could self-report their understanding and preferences. Moreover, the study was conducted in the largest department of Geriatrics-Palliative Care in southern Vietnam. However, our study also had several limitations. First, we only recruited older patients in this study; thus, we could not compare the differences in understanding or preferences between younger and older people with advanced cancer. Second, this was a single-center study. Hence, our findings may not be nationally representative.

5. CONCLUSION

In summary, this study found that 71.6% of older patients with advanced cancer acknowledged that they were terminally ill; however, 61.5% of them did not know their estimated life expectancy, and nearly 90% had not thought about ACP. Home is the most common place where older patients wished to pass away. More than 60% of older patients with advanced cancer did not prefer to receive CPR. Therefore, palliative care should be broadly implemented in hospitals in Vietnam. The healthcare team should discuss the estimated life expectancy and ACP with older cancer patients to ensure that the care provided is relevant to their values and preferences, thus relieving patients from physical distress.

CONFLICTS OF INTEREST

All of the contributing authors declare that they have no conflict of interest.

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