ประสบการณ์อาการ การจัดการอาการ และคุณภาพชีวิตในผู้ป่วยมะเร็งระยะลุกลามที่ได้รับการดูแลแบบประคับประคอง

Symptom experiences, symptom managements, and quality of life among advanced cancer patients receiving palliative care

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บทคัดย่อ

การศึกษานี้มีวัตถุประสงค์เพื่อ ศึกษาประสบการณ์อาการ การจัดการอาการและคุณภาพชีวิตในผู้ป่วยมะเร็งระยะลุกลามที่ได้รับการดูแลแบบประคับประคองโดยใช้กรอบแนวคิดการจัดการอาการ กลุ่มตัวอย่างเป็นผู้ป่วยมะเร็งระยะลุกลามจำนวน 120 คน ที่ได้รับการดูแลแบบประคับประคองจากโรงพยาบาลโรคมะเร็งแห่งหนึ่งในประเทศเวียดนาม เลือกกลุ่มตัวอย่างแบบเฉพาะเจาะจง ผลการศึกษาพบว่าอาการปวดเป็นอาการที่พบบ่อยที่สุด ร้อยละ 83.3% และทำให้เกิดความทุกข์มากที่สุด การจัดการอาการที่กลุ่มตัวอย่างใช้มากที่สุดได้แก่ การใช้ยาบรรเทาอาการปวด ร้อยละ 100 การจัดการอาการโดยไม่ใช้ยาที่พบมากที่สุดได้แก่การดูแลทางจิตวิญญาณ ร้อยละ 40 คุณภาพชีวิตของกลุ่มตัวอย่างอยู่ในระดับปานกลาง ผลการศึกษานี้สามารถใช้เป็นข้อมูลพื้นฐานในการควบคุมอาการและเพิ่มคุณภาพชีวิตสำหรับผู้ป่วยมะเร็งระยะลุกลามที่ได้รับการดูแลแบบประคับประคอง

คำสำคัญ: ประสบการณ์อาการ การจัดการอาการ คุณภาพชีวิต ผู้ป่วยมะเร็งระยะลุกลาม การดูแลแบบประคับประคอง

Abstract

This study aimed to investigate symptom experiences, symptom management strategies, and quality of life among advanced cancer patients receiving palliative care using symptom management model. A total of 120 advance stage cancer participants receiving palliative care at an oncological hospital located in Vietnam were recruited based on purposive sample method. The results revealed that pain was the most common (83.3%) and distressing symptom (Mean = 3.17, SD = 1.58). Most patients used pain killer medication for pain management (100%) and used spiritual therapy for non-pharmacological strategy (40%). Moreover, quality of life among patients was in moderate level. These findings would be used for baseline information in order to control symptoms and improve quality of life among Vietnamese advanced cancer patients receiving palliative care.

keywords: symptom experiences, symptom management strategies, quality of life, advanced cancer, palliative care.

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Introduction

Cancer, a chronic illness is the leading cause of death in the world; as such a recent global data on cancer shows a total of 18.1 million incidence and 9.6 million mortality cases.[1] In Vietnam, according to International Association of Cancer Registries there were about 0.16 million new incidence cases, about 0.3 million 5-year prevalence cases, and 0.11 million death cases in 2018.[2] It is unfortunate that up to 70% of Vietnamese cancer patients are reported to be in advanced stage.[3]

An advanced stage cancer patients experience symptoms such as pain, depression, fatigue, dyspnea, nausea, constipation, sleep disturbance, weakness, anorexia, dry mouth, confusion and others.[4] Generally, symptoms in advance cancer interact with each other leading to symptom cluster. These symptoms are related to physical as well as psychological characteristics, make patients uncomfortable and ultimately creating impact on quality of life.[5,6] Therefore, an accurate identification and management of symptom severity precisely has influence on symptom treatments as well as on overall outcomes. A holistic approach of palliative care plays an important role in controlling symptoms and improving quality of life.[7] The symptom management strategies based on palliative care are related to pharmacological strategies and non-pharmacological strategies. Although there were plenty of strategies for symptom management, the effectiveness management strategies were applied in reliability still limited understanding. Thus during palliative care, sometime symptoms are poorly reported or undergo control by patients and, thus restraining effective management strategies.[8]

In Vietnam, limited researches have focused on symptom experiences, symptom managements and quality outcomes among individuals with advanced stage cancer. Although there have been few studies to assess quality of life among specific cancers, research that have used symptom assessment tool in different advanced cancers could not be found.[9,10] Therefore, the current study is designed on Symptom Management Model, which has three interconnected concepts, namely symptom experience, symptom management strategies, and outcome.[11] A symptom experience is measure of symptom prevalence and distress. Pharmacological medication and non-pharmacological strategy are assessed in symptom management strategies and the effectiveness of approach is calculated in terms of quality of life (QoL).

Therefore this study aimed to determine the symptom experiences in advanced cancer patients hospitalized at palliative care clinic in Vietnam. This study was assessed the symptom experiences by measuring symptom prevalence and distress. Better understanding of symptoms results in enhanced symptom control strategy and improvement in the quality of life and treating symptoms individually. The exploration of the symptom experience, in our study subjects, may explicate current challenges regarding symptom management and help to design effective palliative care strategies in Vietnam.

Materials and Methods

Design and Sample: A cross-sectional descriptive study was designed and the sample size was calculated using the formula for cross-sectional study within proportion and infinite population.[12]

The confidence interval used was 95%, standard normal distribution = 1.96, the proportion = 0.77 and the error of sample proportion = 0.08 (10% of the proportion). Also, the sample size was surplus by 10% considering possible data missing during the study. The total sample size was calculated to be 120 patients. The purposive sampling method was chosen and the participants were selected based on following criteria's: (i) more than 18 years, (ii) being diagnosed with advanced cancer, (iii) receiving palliative care service, (iv) being able to read and communicate in the Vietnamese language, (v) had palliative performance scale more than 40%,[6] had Mini-Mental Status Examination more than 24 points.

Setting: The study was conducted in the Palliative Care Unit of Ho Chi Minh Oncology Hospital, Vietnam during May to June 2019.

Instruments: The research instrument was divided into four parts, including demographic and characteristic questionnaire, Memorial Symptom Assessment Scale-Short Form (MSAS-SF), Symptom Management Strategies among Advanced Cancer Patients Questionnaire, and Missoula Vitas Quality of Life Index-Revised (MVQoLI-R). Participants' report and medical records were used for data collection. A pilot study with 20 patients was conducted to test the feasibility of the study and reliability of the instruments. The findings were, MSAS-SF with Cronbach alpha of .85, Symptom Management Strategies among Advanced Cancer Patients Kuder-Richardson-20 (KR-20) = .76, MVQoLI-R with Cronbach alpha of .81. The item content validity index (I-CVI) was .97, as determined by three experts in cancer and palliative care area.

Demographic and characteristic questionnaire were included to get personal and clinical information's. They were designed to get data such as age, gender, marital status, religion, educational level, years of education, occupation, living location, family income, sufficiency of financial resources, type of living accommodations, method of payment for medical expenses and presence of a family caregiver. The type of cancer, length of time since diagnosis, co-morbid diseases and use of medical devices were obtained from the medical records.

Symptom experiences were assessed by Memorial Symptom Assessment Scale-Short Form (MSAS-SF).[13] This instrument consists of 32 symptoms, further distinguished into the physical and psychological symptoms. This study was evaluated prevalence and distress of symptoms with 28 specific symptoms. Patients were asked to respond "yes" or "no" regarding whether they experienced each respective symptom during the past week. Symptom distress was assessed on a 5-point Likert-Type scale where "0 = not at all" to "4 = very much". Characteristic of prevalent identifiable psychological symptoms, were scored as rarely (1), occasionally (2), frequently (3), and almost constantly (4). The higher the score, the greater the symptom experience.

The Symptom Management Strategies among Advanced Cancer Patients Questionnaire was developed by author. There were two main parts consisting of pharmacological and non-pharmacological strategies. Pharmacological strategies consisted of listing the palliative care medications, dose, and rout from medical records. Medications were divided into 14 groups, namely (1) analgesics and adjuvants, (2) sedatives, (3) sleeping pill, (4) laxative, (5) diuretic, (6) anti-inflammatory, (7) anti-diarrhea, (8) anti-cough, (9) anti-vomiting/anti-nausea,

(10) antiemetics, (11) anti-flatulent/relief of abdominal discomfort, (12) supplement diet, (13) antibiotic, and (14) progestin medication. For each received and not received medication the value 1 and 0 was applied respectively. To obtain a total score, the values were summed. The higher the total score, the more medications used. Similarly, non-pharmacological strategies included the assessment of 12 items. Each item was responded to as "yes" (currently using), or "no" (currently not using). Each "yes" response received a score of 1, while each "no" response received a score of 0. To obtain a total score for this section; the scores obtained for each of the four groups were summed. The higher the total score, the more strategies used. Finally, a total score of Symptom Management Strategies was obtained from the sum of pharmacological and non-pharmacological faction.

Missoula Vitas Quality of Life Index-Revised is a self-report of patients to help clinician and researcher to identify their quality of life from 25 items. Furthermore, 25 items were divided into five dimension groups, including symptoms, function, interpersonal, well-being, and transcendence. There were three scales for each dimension group: assessment, satisfaction, and importance. The scoring follows assessment from-2 to +2, satisfaction from-4 to +4, and importance from 1 to 5. The final score of each dimension is calculated as [(assessment + satisfaction)] x importance]. A negative dimension means reduced quality of life and vice versa. The size of each dimension reflects the amount of impact. Higher the score better is the quality of life.

It is important to mention that the questionnaire of this study was applied forward-back translation. A bilingual expert in English and Vietnamese language translated questionnaire from English version to the Vietnamese. Next, the information from patients was translated back to English. This translation was cross-checked by two other experts. Each questionnaire and information was considered valid only after verification by author and two independent translators.[14]

Data collection: The study received approval from the Center for Ethics in Human Research, Khon Kaen University (No. HE22016) and the Ho Chi Minh Oncology Hospital, Vietnam. The nurses on care unit supported to find patients based on purposive sampling method. Some participants in condition to interview were questioned by author for data collection. However, in inpatient setting, the inpatient clinical nurse had consent from patients and family, and filled up the questionnaire. The taken time to collect data was about 20-40 minutes in each subject. During the data collection, some participants were tired but no any emergency condition was aroused. In case of patients' tiredness, the researcher stopped to interview and asked physician for checking patients' issue. The interview continued after patients ready for interview again.

Data analysis: Descriptive statistics was used to analyze the data for demographics, symptom experience, symptom management strategies, and Missoula-VITAS QOL index-revised. Frequencies, percentages, means, and standard deviation were used for describing the data. The SPSS version 20.0 and Microsoft Excel was used for sorting and analyzing data.

Results

Demographic data: Demographic data shows that the mean age of participants was 60 years (20-92 years, SD=14), and the number of the male was more than the female (56.7% and 43.3% respectively). Over half of the participants reported their educational levels less than high school. A two third of the participants had family income more than 3,750.00 Vietnamese Dong per month. Furthermore, majority of the participant belonged to Vietnamese folk religion and Buddhism (51.7% and 34.2% respectively). Over 90% of participants were married and family members were the main caregiver. The study found that head and neck cancer was the most popular primary cancer site (20%). Majority of participants reported on stage II followed by IV (62.5% and 32.5% respectively), and hypertension was the most common specific co-morbidities (21.7%).

Table 1 Prevalence and distress of symptoms among advanced cancer patients (n=120)

	Prevalence		Distress	
Symptom	**N**	**Percentage**	**Mean**	**SD**
Concentrating difficulty	51	42.5	1.08	1.76
Pain	100	83.3	3.17	1.58
Lack of energy	97	80.8	2.98	1.38
Cough	38	31.7	1.89	2.04
Changes in skin	28	23.3	0.82	1.43
Dry mouth	38	31.7	1.26	1.35
Nausea	24	20.0	2.38	1.65
Feeling drowsy	14	11.7	1.50	2.25
Numbness/tingling in hands/feet	57	47.5	2.04	1.72
Sleeping difficulty	73	60.8	2.78	1.38
Feeling bloated	13	10.8	1.15	1.51
Problems with urination	28	23.3	1.89	1.67
Vomiting	18	15.0	2.33	2.11
Shortness of breath	42	35.0	2.38	1.66
Diarrhea	9	7.5	1.56	2.47
Sweats	8	6.7	2.13	1.61
Mouth sores	19	15.8	2.32	1.48
Problems with sexual interest or activity	55	45.8	0.00	0.00
Itching	11	9.2	1.64	1.87
Lack of appetite	59	49.2	2.85	1.28
Dizziness	32	26.7	2.19	1.40
Swallowing difficulty	32	26.7	2.97	1.59
Change in the way food tastes	42	35.0	2.40	1.86
Weight loss	74	61.7	1.55	2.08
Hair loss	11	9.2	1.73	2.93
Constipation	41	34.2	2.56	1.32
Swelling of arms or legs	19	15.8	2.42	2.03
"I don't look like myself"	76	63.3	1.93	2.11
Feeling sad	63	52.5	2.49	0.54
Worrying	62	51.7	2.45	0.60
Feeling irritable	56	46.7	1.96	0.43
Feeling nervous	33	27.5	2.15	0.43

Symptom experiences: Average score of symptom experiences by patient was 11.3 (SD = 4.11) with a range from 2-20 symptoms. Top five symptoms were pain (83.3%), lack of energy (80.8%), "I don't look like myself" (63.3%), weight loss (61.7%), and sleeping difficulty (60.8%). On the other hand, five most distressing symptoms were pain (mean=3.17, SD=1.58), lack of energy (mean=2.98, SD=1.38), swallowing difficulty (mean=2.97, SD=1.59), lack of appetite (mean=2.85, SD=1.59), and sleeping difficulty (mean=2.78, SD=1.28). Likewise, feeling sad (mean=2.49, SD=0.54) was the most prevalent psychological symptom (Table 1).

Table 2 Number and percentages of advanced cancer patients categorized by pharmacological strategies

Strategies	Number	Percent
1. Analgesics and adjuvants		
Strong opioids		
Fentanyl patches	3	2.6
Morphine injection	4	3.4
Morphine tablet	21	18.1
Oxycodone hydrochloride	1	0.9
Weak opioids		
Terpin Codein	2	1.7
Tramadol	68	58.6
Corticosteroid		
Dexamethasone	17	14.7
Methylprednisolone	22	19.0
Non-Opioids		
Diclofenac sodium	1	0.9
Paracetamol	68	58.6
Adjuvant		
Gabapentin	71	61.2
2. Sedatives	17	14.7
3. Sleeping pill	2	1.7
4. Laxative	75	64.7
5. Diuretic	16	13.8
6. Anti-inflammatory	1	0.9
7. Anti-diarrhea	5	4.3
8. Anti-cough	14	12.1
9. Anti-vomiting/Anti-nausea	16	13.8
10. Antiemetics	1	0.9
11. Antiflatulants/relief of abdominal discomfort	79	68.1
12. Supplement diet	23	19.8
13. Antibiotic	21	18.1
14. Progestin medication	1	0.9

Symptom management strategies: As shown in Table 2, various types of pharmacological palliative care strategies were applied on 116 patients to manage their illnesses. In term of palliative care, analgesics and adjuvants group was the most significant group used for symptom relieve among advanced cancer patients. Top five of the commonly applied drugs were gabapentin (61%), tramadol (59%), paracetamol (58%), omeprazole (51%), and lactulose (35%).

Table 3 Number and percentages of advanced cancer patients categorized by non pharmacological strategies (n=85)

Strategy Name	Symptom	Number	Percentage
Exercise	Pain, Lack of energy, Difficulty sleeping, Constipation	30	25.0
Yoga	Pain, Shortness of breath, Lack of energy	1	0.8
Tai Chi/Qigong	Pain, Shortness of breath	1	0.8
Acupuncture	Pain, Numbness/tingling in hands/feet	3	2.5
Acupressure	Pain, Numbness/tingling in hands/feet, Lack of energy	4	3.3
Diet/Nutrition supplement	Lack of appetite, Change in the way food tastes, Constipation, Lack of energy	10	8.3
Herbal	Lack of energy, Lack of appetite, Pain, Shortness of breath, Psychological symptom, Difficulty sleeping, Swelling of arms or legs, Cough	32	26.7
Relaxation technique (Watching TV, Reading)	Psychological symptom, Pain, Lack of energy	32	26.7
Massage	Pain, Lack of energy, Lack of appetite, Swelling of arms or legs, Numbness/tingling in hands/feet, Difficulty sleeping	20	16.7
Herbal	Lack of energy, Lack of appetite, Pain, Shortness of breath, Psychological symptom, Difficulty sleeping, Swelling of arms or legs, Cough	32	26.7
Psychological therapy	Psychological symptoms	5	4.2
Aromatherapy	Difficulty sleeping	1	0.8
Spiritual therapy (Prayer)	Psychological symptoms	48	40

On the other hands, a total of 85 patients were revealed to use therapies belonging to non-pharmacological strategy. Spiritual (40%) and herbal (26.7%) therapies were the two most frequent therapies advanced by patients. There were 40% of patients who reported that they prayed to keep calm and believed their value of life. This therapy supported to reduce their psychological symptoms. Meanwhile, herbal and relaxation therapies were the second most common symptom management strategies that patients used. According to patients' report, herb improved their energy, quality of sleeping, breathing, psychological symptom (feeling sad, worrying, feeling irritable, and feeling nervous) and reduces pain, lack of appetite, swelling of arms or legs, and cough. Also, 25 % of patients reported that exercise helped them to reduce pain, sleeping difficulty, constipation and improve their energy. Relaxation (watching TV, reading) was effective to reduce worrying and feeling sad in 26.7 % of patients, however, these activities were like their habit rather than therapy to manage symptoms (Table 3). It is vital to mention that the majority of information and performance of non-pharmacological therapies has come from patients.

Table 4 Range and mean of dimension of quality of life

Dimension	Possible range	Respondent range	Mean	Standard deviation	Median
Symptom Score	-30 to 30	-12 to 30	5.14	6.61	5.00
Function Score	-30 to 30	-18 to 30	5.03	8.61	6.00
Interpersonal Score	-30 to 30	-12 to 27.5	4.23	9.19	4.00
Well-being Score	-30 to 30	-20 to 25	2.68	8.64	4.00
Transcendent Score	-30 to 30	-27.5 to 30	5.01	8.73	6.00
Total score	0 to 30	10.2 to 26	17.21	3.04	17.28
Global score	1 to 5	1 to 4	2.88	1.03	3.00

Quality of life: The score for quality of life among study subjects was at moderate level with 17.21 (SD=3.04). The five dimensions' score sequence was symptom score 5.14 (SD=6.61), function score 5.03 (SD=8.61), interpersonal score 4.23 (SD=9.19), well-being score 2.68 (SD=8.64) and transcendent score 5.01 (SD=8.73). According to the global score, the mean was 2.88 (SD=1.03). No negative score was found in each dimension. (Table 4)

Discussion

The current study has investigated experiences among advanced cancer patients receiving palliative care based on Symptom Management Model. Patients with cancer rarely present with a single symptom, thus affecting the quality of life.[6,15] Among 28 symptoms considered, the study found that patients experienced an average of 11 symptoms. In general, the symptoms coexisting in advanced cancer patients produce symptom groups by interacting with each other. This led to symptom clustering. Supporting our findings, previous studies have reported that cancer patients experienced an average of 11-13 concurrent symptoms.[11,16] By understanding symptoms and their clusters, oncology nurses can develop more comprehensive assessments and set priorities in treatment planning, to reduce the total symptom burden.

Consistent with prior studies of symptom experience, the most prevalent and distressful symptom was found to be pain.[5,16] This is important finding because inadequate pain management can lead to sleep disturbances, decreased socialization, altered psychological status, increased physiological stress and decreased mobility.[17,18] Therefore, pain detraction is considered to be most important symptom impact on quality of life.[19] It is reported to be more severe during the terminal period with an incidence of 70%-90%, as in our study subjects. Beside pain the other distressing symptoms were lack of energy, swallowing difficulty, lack of appetite and sleeping difficulty.[20] A cluster analysis of these symptoms would result in better symptom control and improvement in the quality of life and treating symptoms individually.

The majority of patients with advanced cancer are also known to experience weight loss, reduced appetite, fatigue and weakness.[21,22] Our study subjects experienced lack of energy, weight loss, and sleeping difficulty as a second, fourth and fifth common symptoms respectively. The symptoms such as lack of energy, loss of appetite, swallowing difficulty, weight loss were reported to be coexisting symptoms associated with poor oral intake in previous studies.[5,23] More than half of the subjects in our study reported “I don’t look like myself”, making it the third most common symptom. This insight may be a result of body changes brought about by weight loss, swelling of legs/arms, skin changes, hair loss etc. which can be noticed well in our data.

The most frequently used pharmacological therapy was analgesic and adjutants for dealing with pain. It is not surprising as pain was the main symptoms in our subjects. Gabapentin, tramadol, paracetamol were most common among medications. This finding is different from a prior Thai study, wherein the most common medications for managing pain in cancer patients were various form of morphine.[16] However, it can be figured out that pain killer is the most significant to palliative care in symptom management strategies in both studies. Finding high use of laxative in our study may be due to use of opioids based medication because laxative serves as proactive treatments for opioids. This finding consistent to the mainly orientation of pharmacological strategies in Vietnam, that focus on pain killer, especially opioids.[3] When considering non-pharmacological management of symptoms, subjects themselves tended to use more than one type of non-pharmacological strategy at a time. Spiritual therapy and herbs were two mostly used and our findings were similar to the previous studies.[24,25]. Spirituality was one of significance needs among cancer patients in Vietnam.[3] Prayer was the most common spiritual therapy because of performing easily and non-cost. In general, most of the health services focuses on counseling, medicine, and psychological assistance and may combine it with non-pharmacological strategies to treat and manage the effects of cancer. It may help to reduce pain and other symptoms with lower dosages of medications.[26]

Moreover, our study revealed that the mean score for quality of life among advanced cancer patients receiving palliative care was 17.21. This value is lower than the similar study conducted in Thailand.[24] But the standard deviation of each dimension in our study was quite high compared to the mean value, indicating that the quality of life of each patient is uneven and poles apart. Author believes that quality of life is a broad concept to apply to terminally ill patients, since they are facing a life-threatening illness, as well as experiencing deterioration of their physical functioning. Earlier study has shown that a low quality of life score is significantly associated with depression, incapacity to pay, low response to treatment, and presence of side effects in Vietnamese cancer patients.[10] The finding recognized the strong relation between ages, occupation, income, education, disease stage and patient's quality of life. Most of the patients were aged from 40 to 60, which is a working age, but they were unable to work anymore. It not only decreased their family income but also increased the financial burden. This could be one of the explanations for the majority of patients not being satisfied with their health condition. In addition, plenty of participants had a lack of knowledge about their disease and were confused with their situation. They only wished to get their disease away, not only the symptom management. Therefore, knowledge on cancer and easy realization of cancer disease as a long term condition could make them mentally and physically strong, which is crucial for better quality of life among palliative care patients.

Conclusions

Pain was the most prevalence and distressing symptoms among advanced cancer patients receiving palliative care in Vietnam. That might identify why the symptom management strategies for these patients, which was focus on pain management. Following the several symptoms that patients suffered and symptom management strategies, the quality of life among these patients was moderate level. This current study provide the benefit database of symptoms patients experienced, pharmacological strategies, non-pharmacological strategies, and quality of life among advanced cancer patients receiving palliative care. Hence, the survey may help the palliative care health care provider to improve the quality of care and treatment to improve patients' quality of life.

Limitations

The authors acknowledge several limitations in this study. This is a cross-sectional descriptive study; therefore, the data were collected at one time, while symptoms among advanced cancer patients and quality of life usually changes anytime. Furthermore, the characteristic of participants in this study was not homoginity, such as general cancer site and setting (inpatients, outpatients, and homecare patients); therefore, the data is divergent. Generalizability of the finding is limited. Moreover, in this study, symptom perception did not explore respond of symptom. Symptom response may understand as symptom cluster, which represents to influence between symptoms with each other. Thus this may interfere results of this study.

Recommendations

This research work provides basic evidence for researcher and clinicians to improve the health care delivery. We recommend 1) creating an appropriate instrument to measure and control symptom experiences on patients, 2) applying non-pharmacological therapies to support symptom management, 3) focusing the symptom that patients' report with common characteristic and distressing, 4) symptom clustering analysis among advanced cancer patients receiving palliative care, 5) conducting the longitudinal study related to symptom experiences, symptom managements, and quality of life.

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