Symptom Distress, Need for Care, and Nursing Care Received in Hospitalized Palliative Care Patients

นิพนธ์ต้นฉบับ

Original Article

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บทคัดย่อ

วัตถุประสงค์: 1) เพื่อศึกษาอาการทุกข์ทรมาน ความต้องการการดูแล และการพยาบาลที่ได้รับในช่วงแรกรับเข้าพักรักษา และช่วงก่อนกลับบ้านของผู้ป่วยระยะประคับประคองที่เข้าพักรักษาตัวในโรงพยาบาล 2) เพื่อเปรียบเทียบอาการทุกข์ทรมานในช่วงแรกรับเข้าพักรักษาตัวกับช่วงก่อนกลับบ้าน 3) เพื่อเปรียบเทียบความต้องการการดูแลกับการพยาบาลที่ได้รับ ทั้งช่วง ก) แรกรับเข้าพักรักษาตัว และ ข) ช่วงก่อนกลับบ้าน **วิธีการศึกษา:** การวิจัยเชิงพรรณนาแบบเปรียบเทียบมีกลุ่มตัวอย่างเป็นผู้ป่วยระยะประคับประคองที่พักรักษาตัวในโรงพยาบาลชุมชนแห่งหนึ่ง ในจังหวัดลพบุรีที่มีคุณลักษณะตามกำหนดจำนวน 90 คน คัดเลือกโดยใช้กรอบเวลาเป็นหน่วยการสุ่ม เครื่องมือที่ใช้ในการวิจัยเป็นแบบสัมภาษณ์อาการทุกข์ทรมาน ความต้องการการดูแล และการพยาบาล ที่ได้รับของผู้ป่วยระยะประคับประคองที่พักรักษาตัวในโรงพยาบาลที่ใช้มิติข้อคำถามตรงกัน (commensurate dimension) โดยอิงแนวคิดความสอดคล้องระหว่างความต้องการกับบริการการจัดหาเพื่อให้การสนับสนุน (need-supplies fit) และแนวคิดการรับรู้อาการ (perception of symptom) พบว่ามีค่าดัชนีความตรงตามเนื้อหาแต่ละส่วนได้เท่ากัน คือ 0.83 และค่าความเชื่อมั่นสัมประสิทธิ์แอลฟาครอนบาคเท่ากับ 0.76, 0.77 และ 0.75 ตามลำดับ วิเคราะห์ข้อมูลด้วยสถิติพรรณนาและเปรียบเทียบความแตกต่างโดยใช้สถิติทดสอบค่าที (paired t-test) **ผลการศึกษา:** 1) ในช่วงแรกรับเข้าพักรักษาตัว คะแนนเฉลี่ยโดยรวมของอาการทุกข์ทรมาน ความต้องการการดูแล และการพยาบาลที่ได้รับเท่ากับ 3.40, 3.63 และ 3.74 คะแนน ตามลำดับ ส่วนในช่วงก่อนกลับบ้านพบว่าคะแนนเฉลี่ยโดยรวมเป็น 0.39, 0.42 และ 0.44 คะแนน ตามลำดับ 2) พบว่าคะแนนเฉลี่ยอาการทุกข์ทรมานโดยรวมในช่วงแรกรับสูงกว่าช่วงก่อนกลับบ้านแตกต่างกันอย่างมีนัยสำคัญทางสถิติ (*P*–value < 0.001) 3) คะแนนเฉลี่ยความต้องการการดูแลต่ำกว่าคะแนนเฉลี่ยการพยาบาลที่ได้รับอย่างมีนัยสำคัญทางสถิติทั้งช่วงแรกรับ (*P*–value = 0.011) 4) และที่ตอนก่อนกลับบ้าน (*P*–value = 0.005) **สรุป:** อาการทุกข์ทรมาน ความต้องการการดูแล และการพยาบาลที่ได้รับ ที่ก่อนกลับบ้านต่างก็ลดลงจากเมื่อแรกรับเข้ารักษาในโรงพยาบาล และการพยาบาลที่ได้รับมีคะแนนสูงกว่าความทุกข์ทรมานทั้งที่แรกรับและก่อนกลับบ้าน พยาบาลอาจนำการประเมินอาการทุกข์ทรมาน ความต้องการการดูแล และการพยาบาลที่ได้รับในการดูแลคนไข้ได้

คำสำคัญ : อาการทุกข์ทรมาน, ความต้องการการดูแล, การพยาบาลที่ได้รับ, ผู้ป่วยระยะประคับประคองที่พักรักษาตัวในโรงพยาบาล

Editorial note
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Abstract

Objective: To determine levels of symptom distress, need for care, and perceived nursing care received among hospitalized palliative care patients, both at admission and discharge. We also aimed to compare symptom distress at admission with that at discharge, and compare the need for care and the perceived care received both at admission and at discharge. **Methods:** A sample of 90 palliative care patients at a community hospital in Lopburi province was recruited using the time frame sampling. The interview questionnaires on symptom distress, needs for care, and perceived care received with the commensurate dimensions suggested by the concepts of Need-supplies Fit and the Perception of Symptom were created. The Content Validity Index for each of all parts was 0.83 and Cronbach's alpha coefficients were 0.76 0.77 and 0.75, respectively. Data were analyzed using descriptive statistics and paired t-test. **Results:** At admission, the mean scores symptom distress, the needs for care, and the perceived care received were 3.40, 3.63 and 3.74 points, respectively; while those at discharge were 0.39, 0.42 and 0.44 points, respectively. The overall mean scores of symptom distress at admission was significantly higher than that at discharge (*P*–value < 0.001). The scores of the need for care were higher than those of the perceived care received both at admission (*P*–value = 0.011) 4) and at discharge (*P*–value = 0.005). **Conclusion:** Symptom distress, the need for care, and the perceived nursing care received among hospitalized palliative care patients were decreased from admission to discharge. The scores of the need for care were lower than those of the perceived care received both at admission and at discharge. Nurse could evaluate the symptom distress, the need for care, and the perceived nursing care received among hospitalized palliative care patients in their regular practice.

Keywords: symptom distress, needs of care, received nursing care, hospitalized palliative care patients

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Introduction

Palliative care patients are those suffering from incurable life-threatening illnesses. Their sufferings are multi-facet in nature including physical, mental, social and spiritual. These sufferings affect quality of life and impair a peaceful death.

Palliative care aims at taking care of the patients with their dignity maintained and quality of life preserved before their death. Palliative care also takes care of caregivers and family members of the terminally ill patients by identifying, evaluating and resolving the sufferings associated with the patients' illnesses. The care for caregivers and family members is also multi-facet, where physical, mental, social and spiritual aspects of the care are included starting from the diagnosis of the life-threatening illness to the end of life.

Symptom distress is inevitable among terminally ill and near-dead patients. Palliative care patients' health status is higher threatened by symptom distress caused collectively by various symptoms.[1] The symptom distress is intensified once the illness progresses which could lead to higher level of stress, anxiety, weariness, and desperation. These negative affects could cause treatment denial and discontinuation which in turn could make the alleviation of symptom distress even less effective and more complicate, and the symptom distress even more excruciating.

An early diagnosis of signs and symptoms of symptom distress is critical for the early and effective relief for palliative care patients. This diagnosis information could be useful in early planning for symptom distress alleviation to help the patients live with less evitable distress. In a relatively short end-of-life period, these patients should be able to complete their important deeds, restore their dignity and value, and achieve goals in their lives.[2]

Studies on symptom distress in palliative care patients had determined frequency and severity of the distress in specific time durations especially in those hospitalized[3] and those with localized cancers such as head and neck cancers undergoing chemotherapy.[4] For patients with metastatic cancer at the hospital discharge, the care to reduce symptom distress was highly needed.[5] These findings suggest that there has been a discrepancy about the need of care to reduce symptom distress in palliative patients at different points of care, specifically during and after hospitalization. In other words, whether palliative care patients at different stages of care suffer from different kinds and/or severity of symptom distress. In addition, whether the nursing care to relieve symptom distress meets these patients' needs has not been thoroughly understood. Since quality assurance has been implemented widely in almost all healthcare services including nursing care, healthcare providers are forced to achieve a high level of cost-containment while quality care is reserved. As a result, the patients are discharged as early as possible to reduce length of stay.[6] This widespread practice allows palliative care patients to receive only critical care provided in a brief period of time. Once out of critical stage, they are discharged for home self-care. This circumstance indicates a need for a patient evaluation before discharge. Such thorough patient evaluation would allow healthcare provider, as well as given patients and their caregivers to have a wide and deep understanding on the symptom distress unavoidable at home. The self-care strategies to help alleviate such distress and the referred service to the healthcare network in the patient's residence community could be planned by all parties.

Palliative care in Thailand has been developed for 10 years by hospitals under the provision of the Department of Medical Services, Ministry of Public Health, i.e., large hospitals specialized in specific groups of patients, not those at community level. Palliative care in the in-patient department at community hospitals has been at its early development stage with unclear protocol, no specific designed care area, and no specialists. Since palliative care patients needed to share in-patient space with other patients at community hospitals, the care quality could be lower than those provided by specialized hospitals.[7] To improve palliative care at the community hospital, the understandings on symptom distress, the need for care and nursing care provided are in need. This study aimed to determine symptom distress, the need for care and the perceive nursing care provided to the hospitalized palliative care patients at the community hospital both at 1) hospitalization admission and 2) discharge. For **specific objectives**, this study aimed to 2) determine the distress levels both at admission and discharge, 2) compare the distress levels at admission with those at discharge, 3) compare the distress level with the perceived care received level at admission, and 4) compare the distress level with the perceived care received level at discharge.

This study was based on various concepts including the Edmonton Symptom Assessment Scale (ESAS)[8], the Perception of Symptom[1], and the Need-supplies Fit.[9] The ESAS allowed the investigators to use nine significant symptoms that palliative care patients suffered; while the Perception of Symptom concept guided the investigators how to assess the perception on the care the palliative care patients received in this study. The Perception of Symptom concept states that individuals rate how much each symptom causes distress and strive for the distress relief.[1] In this study, palliative care patients were asked to rate the intensity or severity of the distress associated with each of the nine symptoms. Finally, the concept of Need-supplies Fit reflects the agreement between the need and the attempt/effort to serve the need.[9] In our study, the need was modified to the need for care and the attempt/effort to serve the need as the perceived care received. Based on the Need-supplies Fit concept, once the need for care was met by the care provided, satisfaction could be achieved in these palliative care patients; if not, dissatisfaction, strain and worse illness could be the result.[9]

Methods

This comparative descriptive study aimed to determine symptom distress in palliative care patients in a community hospital setting both at hospitalization admission and discharge for home self-care. The patients studied were those with stable disease and ability to communicate. The study was conducted in a 120-bed community hospital in Lopburi province, Thailand. Patients in male and female medicine-surgery wards, gynecological ward, and ICU ward were recruited for the study. Study population was patients diagnosed with terminal illness and in need of palliative care in a community hospital in Lopburi, Thailand. Study sample was those who met the following inclusion criteria. To be eligible, they had to 1) be 20 years or older, 2) be hospitalized for 4 days or longer, 3) have a good consciousness i.e., being well oriented to time and place, 4) have no difficulty communicating in Thai language, and 5) have stable vital signs. The sample was selected using a sampling frame to accommodate the uncertainty of admission date for given prospective participants. Based on the random sampling concept, taking all prospective participants during the study data collection period into account could offer a sound representativeness for the future patients.[10] The study was conducted from August, 2016 to January, 2017.

Sample size was based on an effect size of 0.30, a type I error of 5% (i.e., significance level of 0.05), and a power of test of 0.80, as widely used in nursing research. As a result, a sample of 90 participants was needed.[11] Sample size calculation was performed using the G* Power 3.1.2® software.[12]

Data collection instruments

Data were obtained by means of interview questionnaires. The first part of the interview questionnaires collected demographic information of the participants including age, gender, religion, educational level, marital status, income sufficiency, major diagnosis, co-morbidity, additional care needed, number of hours from hospitalization to admission interview, and number of hospitalization days until discharge for home self-care.

In the second part of the interview questionnaires, questions pertaining to need-supplies fit concept, the perception of symptom[1] and the Edmonton Symptom Assessment Scale (ESAS)[8] were used. To address the opposite but parallel nature of the need for care and the care received while hospitalized, questions regarding symptom distress with comparable severity as suggested by the commensurate dimension were aligned.[9] In this second section, the three sets of interview questions were as follows.

The first set consisted of questions assessing symptom distress modified from the Edmonton Symptom Assessment Scale (ESAS). This scale was approved by the Palliative Care Program (Alberta, Canada) and has been used worldwide in palliative care patients.[13] The ESAS contained nine symptoms including 1) pain, 2) shortness of breath/difficulty breathing, 3) loss of appetite, 4) nausea/vomiting, 5) constipation, 6) fatigue/weakness/asthenia, 7) anxiety, 8) depression, and 9) agitation. Since flatulence/bloat, fear, and desperation have been shown in various literature to cause symptom distress, these three symptoms were included in our study resulting in a total of 12 symptoms. The severity of the symptom distress was measured using a 10-point rating scale of 0 point (no distress) to 10 points (worst distress). For example, 0 point for "no pain" to 10 points for "worst possible pain." The total score of this modified ESAS was a sum of 12 distresses to achieve a possible score of 0 to 120 points where higher scores indicated higher levels of symptom distress severity.

The second set of the second section was modified from the need-supplies fit.[9] The investigators modified the "need" from the original concept to the "need for care." The questions assessed the perception of the patients toward their own needs for palliative care for each of the 12 symptom distresses parallel with those 12 distresses of the modified ESAS mentioned above. The measure for the need for care of each of the 12 symptoms was in a 10-point rating scale similar to that mentioned previously from 0 "no need for care" to 10 "highest need for care." The possible total score of the scale was 0 to 120 points where higher scores indicated higher level of the need for care.

The last set of the second interview question section contained a 12 symptom distresses as mentioned above with a comprehensive commensurate assessment of level of the nursing care the patients received. The measurement was based on the need-supplies fit concept.[9] As a result, the scale ranged from 0 "care needed for the distress not received" to 10 "care received as much as needed for the distress." The possible total score was from 0 to 120 points where higher scores indicated the patient's higher perception of the nursing care received.

To help the patients answer the interview questions previously mentioned, the investigators used display boards of 1) symptom distress level, 2) the need for care and 3) perceived care received using gradient color consistent with the scale numbers 0 to 10. The scale pads were 9-inch wide and 12-inch length, made of plastic board and labeled with numbers 0 (light color) to 10 (dark color). Boards of symptom distress level were in red; while those measuring the need for care in green and the perceived nursing care received in blue.

Quality assurance of the data collection instruments

Content validity of the interview questionnaires of the three sections namely symptom distress level, the need for care and the perceived nursing care received among palliative care patients was examined by five experts specialized in palliative care including three nursing faculty members and two practicing nurses. These five experts were asked to rate for content congruence and the content validity index (CVI) was calculated. All three sections of the interview questionnaires had comparable CVIs of 0.83 which was higher than the acceptable level of 0.80.[12]

After content validity testing, the interview questionnaires were tested for internal consistency reliability in 20 patients comparable to the actual participants during July 1 – 31, 2016. Each of the three sections (namely symptom distress level, the need for care and the perceived nursing care received among palliative care patients) had an acceptable internal consistency reliability with Cronbach's alpha coefficients of 0.76, 0.77 and 0.75 which were higher than the acceptable level of 0.70.[12]

Participants right protection

This study was approved by the Ethic Committee on Human Study, Faculty of Nursing, Burapha University (Approval number: 06-05-2559; approval date: May 6, 2016). Before the interview, the investigators provided the prospective participants the information pertaining to study objectives, benefits from participation, and study protocol, and requested for participation. The collected data were secured and destroyed after the study completion. The participants were told that they could discontinue or withdraw from the study anytime with no justification needed and no effect on the care given.

Data collection procedure

The investigators obtained the permission to collect data from the community hospital director in Lopburi province, Thailand. Once permission was granted, the investigators contacted heads of male and female medicine-surgery wards, gynecological ward, and ICU ward for data collection. Objectives and details of data collection procedure were provided to the ward heads. In addition to the investigators, an experienced IPD nurse was trained to be a research assistant for data collection via the interview as follows. The research assistant was trained on the importance and objectives of the study, benefits from participation, participant right protection, data collection procedure, participant selection, introduction to the participant, participation request, inspection for questionnaire completion, the use of questionnaire and interview aids, and the interview termination. The research assistant was then practicing to the perfection under the investigator supervision before the actual data collection was allowed.

Data collection was conducted at two care steps, specifically the hospitalization admission and discharge for home self-care. At hospitalization admission, the investigation team was notified via telephone by the IPD nurse on-duty for the incoming palliative care patients likely meeting the study inclusion criteria. The investigation team met the patient and provided the information previously mentioned and asked for participation. Once written informed consent was obtained, the interview was conducted. At the discharge for home self-care, once the participant who was interviewed the admission was allowed to leave the hospital, the nurse on-duty was asked to notify the investigation team. To be eligible at this step, he participant needed to stay in the ward for at least 4 days.

Written informed consent was also obtained at this step before the interview.

Data analysis

Demographic and clinical status data were presented as descriptive statistics such as mean with standard deviation and frequency with percentage. Scores of 1) symptom distress level, 2) the need for care and 3) the perceived nursing care received among palliative care patients as the total sum score and individual symptom scores both at the hospitalization admission and at discharge for home self-care were presented as mean with standard deviation.

The comparisons of mean scores at different care steps were made using paired t-test including 1) the mean scores of symptom distress at admission and discharge, 2) the mean score of the need for care and the mean score of the perceived care received at admission, and 3) the mean score of the need for care and the mean score of the perceived care received at discharge. All comparisons were conducted using paired t-test with a significance level of 5% error. All statistical tests were carried out using the PSPP software program (available at https://www.gnu.org/software/pspp/).

Results

The majority of the participants were in their 70 – 79 years of age (Table 1). Male and female participants were in comparable proportion. All of them were Buddhist. Most of them had a primary education (61.1%) followed by those with no education (36.7%). Most of them were married; while as high as 22.2% were divorced, separated or widowed. Only 5.6% had a sufficient income. The majority had cancer as the main diagnosis (53.5%) while 63.2% had co-morbidities. Half of the participants (50.0%) had been hospitalized for 17 – 24 hours, followed by 32.2% hospitalized for 9 – 16 hours and the rest (17.8%) hospitalized for 1 – 8 hours. In terms of length of stay till the discharge to home self-care, 74.4% of them stayed for 4 – 6 days, while 21.2% for 7 – 9 days, while the rest (4.4%) stayed for at least 10 days (Table 1). It was found that three patients (3.3%) reported the need for additional home care because they had colostomy bag (2 patients) and tracheostomy (1 patient).

Table 1 Demographic and health status characteristics of the participants (N = 90).

Characteristics	Number	%
Age (yrs) (mean = 64.12 ± 14.17; Min = 30, Max = 93)		
30 - 39	4	4.4
40 - 49	10	11.2
50 - 59	20	22.2
60 – 69	21	23.3
70 - 79	24	26.7
80 - 89	7	7.8
≥ 90	4	4.4
Gender		
Male	47	52.2
Female	43	47.8
Religion		
Buddhism	90	100
Education		
Non/Informal education	33	36.7
Primary	55	61.1
Secondary	1	1.1
Bachelor's	1	1.1
Marital status		
Married	68	75.6
Widowed/divorced/separated	20	22.2
Single	2	2.2
Income sufficiency		
Sufficient	83	92.2
Insufficient	5	5.6
Having saving	2	2.2
Major diagnosis		
Cancer	48	53.5
Lung cancer	11	12.4
Liver cancer	13	14.6
Gastrointestinal tract cancer	6	6.6
Urinary tract cancer	16	17.7
Gynecological cancer	2	2.2
Heart failure	27	29.9
Chronic obstructive pulmonary disease	13	14.4
Hematologic disorder	2	2.2
Co-morbidities		
No	33	36.8
Yes	57	63.2
Need for additional home care	3	3.3
Having colostomy bag	2	2.2
Having tracheostomy	1	1.1
Number of hours from admission to interview (mean = 15.12 ± 6.22; Min = 2, Max = 24)		
1 - 8	16	17.8
9 - 16	29	32.2
17 - 24	45	50.0
Number of hospitalization days till the discharge interview (mean = 5.66 ± 1.86; Min = 4, Max = 13)		
4 - 6	67	74.4
7 – 9	19	21.2
≥ 10	4	4.4

Symptom distress at hospitalization admission and discharge for home self-care

At hospitalization admission, the scores of each of symptom distress were in a range of 0.16 - 7.80 points, with an average of 3.40 ± 2.90 points (Table 2). At discharge, the scores of all individual symptoms decreased to a range of 0.01 – 1.19 points (mean = 0.39 ± 0.60 points). The three distresses with the highest scores (5 or more out of 10 points) were fatigue/weakness/asthenia, shortness of breath/difficulty breathing, and pain (7.80, 6.76, and 5.49, respectively. At discharge, the distress from the two symptoms (depression and desperation) was gone with score of zero points. In addition to the 12 symptoms planned for the study, watery or loose stool was found at the admission with a mean score of 0.43 ± 1.90 points and cured at the discharge score of zero points (Table 2).

The mean score of overall symptom distress at admission was 40.82 ± 15.77 points (out of 120 points) and it significantly decreased to 4.78 ± 3.00 points at discharge (*P*-value < 0.001). This means that symptom distress decreased significantly at discharge to home self-care.

Table 2 Symptom distress at hospitalization admission and discharge for home self-care of palliative care patients (N = 90).

Symptom distress	Severity level of symptom distress					
	At hospitalization admission			At discharge for home self-care		
	Possible range	Actual range	$\overline{X}$ (*SD*)	Possible range	Actual Range	$\overline{X}$ (*SD*)
1. fatigue/weakness/asthenia	0 - 10	0 - 10	7.80 (2.39)	0 - 10	0 - 5	1.19 (1.06)
2. shortness of breath/ difficulty breathing	0 - 10	0 - 10	6.76 (3.87)	0 - 10	0 - 6	1.01 (1.25)
3. pain	0 - 10	0 - 10	5.49 (4.07)	0 - 10	0 - 4	0.78 (1.01)
4. agitation	0 - 10	0 - 10	4.58 (2.96)	0 - 10	0 - 4	0.53 (.82)
5. loss of appetite	0 - 10	0 - 10	4.41 (3.72)	0 - 10	0 - 3	0.43 (.75)
6. flatulence/bloating	0 - 10	0 - 10	3.47 (3.83)	0 - 10	0 - 3	0.41 (.68)
7. nausea/vomiting	0 - 10	0 - 10	3.40 (3.89)	0 - 10	0 - 3	0.21 (.66)
8. constipation	0 - 10	0 - 10	2.49 (3.30)	0 - 10	0 - 3	0.17 (.58)
9. anxiety	0 - 10	0 - 10	1.06 (2.33)	0 - 10	0 - 2	0.04 (.29)
10. fear	0 - 10	0 - 10	.73 (2.08)	0 - 10	0 - 1	0.01 (.10)
11. depression	0 - 10	0 - 8	.47 (1.55)	0 - 10	0 - 0	0
12. desperation	0 - 10	0 - 6	.16 (.91)	0 – 10	0 - 0	0
Other						
13. ถ่ายเหลว	0 - 10	0 - 10	0.43 (1.90)	0 – 10	0 - 0	0
Average of each distress			**3.40 (2.90)**			**0.39 (0.60)**
Average total score	**0 - 120**	**10 - 85**	**40.82 (34.9)***	**0 - 120**	**0 - 14**	**4.78 (7.2)***

*** paired t-test to compare 40.82 ± 34.9 and 4.78 ± 7.2, t_{89} = 23.22, *P*-value < 0.001**

The need for care and the perceived care received at hospitalization admission

At the admission, the scores of each of the nursing care needed questions were in a range of 0.14 - 7.98 points, with an average of 3.63 ± 2.82 points (Table 3). On the other hand, scores of the perceived care received of most symptom distress were higher than the scores of the care needed (1.21 – 8.15 points), except those of fear, depression and desperation, with an average of 3.74 ± 3.07 points. At admission, the score of the perceived care received for watery or loose stool (0.47 points) was slightly higher than that of the care needed (0.46 points).

At the admission, the mean score of overall need of care was 43.60 ± 16.53 points (out of 120 points); while the mean score of overall perceived care received was slightly higher (44.90 ± 16.71 points) with statistical significance (*P*-value = 0.011).

Table 3 The need for care and the perceived care received **at hospitalization admission** of palliative care patients (N = 90).

Symptom distress	The need for care			The perceived care received		
	Possible range	Actual range	$\overline{X}$ (*SD*)	Possible range	Actual Range	$\overline{X}$ (*SD*)
1. fatigue/weakness/asthenia	0 - 10	0 - 10	7.98 (2.71)	0 - 10	0 - 5	8.15 (2.57)
2. shortness of breath/ difficulty breathing	0 - 10	0 - 10	7.00 (3.94)	0 - 10	0 - 6	7.27 (3.83)
3. pain	0 - 10	0 - 10	5.82 (4.18)	0 - 10	0 - 4	5.91 (4.22)
4. agitation	0 - 10	0 - 10	5.09 (3.23)	0 - 10	0 - 4	5.33 (3.37)
5. loss of appetite	0 - 10	0 - 10	5.07 (4.17)	0 - 10	0 - 3	5.23 (4.15)
6. flatulence/bloating	0 - 10	0 - 10	3.87 (4.15)	0 - 10	0 - 3	3.97 (4.23)
7. nausea/vomiting	0 - 10	0 - 10	3.68 (4.19)	0 - 10	0 - 3	3.89 (4.30)
8. constipation	0 - 10	0 - 10	2.74 (3.55)	0 - 10	0 - 3	2.87 (3.68)
9. anxiety	0 - 10	0 - 10	1.14 (2.58)	0 - 10	0 - 10	1.21 (2.71)
10. fear	0 - 10	0 - 10	0.68 (1.93)	0 - 10	0 - 10	0.64 (1.97)
11. depression	0 - 10	0 - 8	0.39 (1.29)	0 - 10	0 - 7	0.29 (1.07)
12. desperation	0 - 10	0 - 7	0.14 (0.85)	0 - 10	0 - 7	0.14 (0.85)
Other						
13. ถ่ายเหลว	0 - 10	0 - 10	0.46 (1.94)	0 - 10	0 - 10	0.47 (1.97)
Average of each distress			**3.63 (2.82)**			**3.74 (3.07)**
Average total score	**0 - 120**	**10 - 85**	**43.60 (33.91)***	**0 - 120**	**10 - 83**	**44.90 (36.95)***

*** paired t-test to compare 43.60 ± 16.53 and 44.90 ± 16.71, t_{89} = -2.58, *P*-value = 0.011**

The need for care and the perceived care received at discharge for home self-care

At the discharge for home self-care, the scores of each of the nursing care needed questions were in a range of 0.01 – 1.21 points, with an average of 0.42 ± 0.68 points (Table 4). On the other hand, scores of the perceived care received of all symptom distress were similar or higher than the scores of the care needed (0.01 – 1.30 points), with an average of 0.44 ± 0.71 points.

Table 4 The need for care and the perceived care received **at discharge for home self-care** of palliative care patients (N = 90).

Symptom distress	The need for care			The perceived care received		
	Possible range	Actual range	$\overline{X}$ (*SD*)	Possible range	Actual Range	$\overline{X}$ (*SD*)
1. fatigue/weakness/asthenia	0 - 10	0 - 5	1.21 (1.18)	0 - 10	0 - 5	1.30 (1.28)
2. shortness of breath/ difficulty breathing	0 - 10	0 - 6	1.04 (1.34)	0 - 10	0 - 6	1.09 (1.37)
3. pain	0 - 10	0 - 5	0.90 (1.27)	0 - 10	0 - 5	1.01 (1.41)
4. agitation	0 - 10	0 - 4	0.56 (1.03)	0 - 10	0 - 4	0.56 (1.03)
5. loss of appetite	0 - 10	0 - 5	0.53 (0.97)	0 - 10	0 - 5	0.54 (0.99)
6. flatulence/bloating	0 - 10	0 - 3	0.43 (.82)	0 - 10	0 - 3	0.44 (0.83)
7. nausea/vomiting	0 - 10	0 - 3	0.21 (0.66)	0 - 10	0 - 3	0.21 (0.66)
8. constipation	0 - 10	0 - 3	0.18 (0.61)	0 - 10	0 - 3	0.18 (0.61)
9. anxiety	0 - 10	0 - 2	0.03 (0.23)	0 - 10	0 - 2	0.04 (0.29)
10. fear	0 - 10	0 - 1	0.01 (0.10)	0 - 10	0 - 1	0.01 (0.10)
11. depression	0 - 10	0 - 0	0	0 - 10	0 – 0	0
12. desperation	0 - 10	0 – 0	0	0 - 10	0 – 0	0
Other						
13. ถ่ายเหลว	0 - 10	0 - 0	0	0 - 10	0 - 0	0
Average of each distress			**0.42 (0.68)**			**0.44 (0.71)**
Average total score	**0 - 120**	**0 - 14**	**5.10 (8.21)***	**0 - 120**	**0 - 14**	**5.38 (8.57)***

*** paired t-test to compare 5.10 ± 8.21 and 5.38 ± 8.578, t_{89} = -2.88, *P*-value = 0.005**

At the discharge, the mean score of overall need of care was 5.10 ± 3.11 points (out of 120 points); while the mean score of overall perceived care received was slightly higher (5.38 ± 3.06 points) with statistical significance (*P*-value = 0.005).

Discussions and Conclusion

In this study, the majority of palliative care patients were in their 70 – 79 years of age. This is only natural since physiologically the elderly are more likely to have chronic and terminal illnesses. A relatively high proportion of palliative patients (36.7%) did not have any formal education. Since education has been a personal factor that could affect the perception and response to the symptom distress[1] which could also affect the findings in our study. Even though the majority of the patients were married, as high as 22.2% of them were divorced/separated/windowed and 2.2% were single. This discrepancy could also affect the perception on symptom distress, the need for care the perceived care received. As expected, about half (53.5%) of the patients had cancer and 63.2% had co-morbidities. These findings were consistent with the increasing organ deterioration and failure. This accumulated symptom distress could further trigger new or worsen existing distresses. This led to symptom distresses even more complicate and difficult to manage.[14]

Only 3.3% of the patients stated they needed the additional nursing care for their symptom distress. This could be attributable to the stable patients we recruited. The ability to communicate well with slight difficulty was the indicator of a relatively low need for palliative care. Therefore, the need for semi-intensive care with sophisticate devices at home was low. The investigators could reach the participants within a day (17 – 24 hours) for most cases (50.0%); followed by 9 – 16 hours (32.2%), and a fast access (1 – 8 hours) in 17.8%. The more time the patients stayed in the hospital, the more care they received. As a result, the perception of the need for nursing care could be less from the one at the admission time. In the future, the investigators could reach the participants faster to gain a less biased perception of the patients. The other findings indicating that most patients were not in a severe stage of palliative care was that most of them (74.4%) were discharge for home self-care within 4 – 6 days and only 3.3% reported the need for additional nursing care at home.

In terms of the symptom distress, the need for nursing care, and the perceived care received both at hospitalization admission and at discharge for home self-care are as follows. At admission, the three distresses with the highest scores (5 or more out of 10 points) were fatigue/weakness/asthenia, shortness of breath/difficulty breathing, and pain (7.80, 6.76, and 5.49, respectively. This finding was consistent with a study showing that cancer patients faced fatigue/weakness/asthenia the most.[15] About 48 – 75% of cancer patients encountered fatigue/weakness/asthenia and as high as 85% at the end-of-life stage did so.[16] Fatigue, weakness or asthenia was therefore common in palliative care patients with cancer and other co-morbidities.[16] In our study, patients with lung cancer, liver cancer, gastrointestinal tract cancer, urinary tract cancer, heart failure, chronic obstructive pulmonary disease, and hematological disorders combined were about 98% of all patients. Diseases in these stages could put a tremendous, detrimental effect on the patient body.

At admission, pain was the third most severe symptom distress. This finding was not entirely consistent with another study where pain was found the most common and severe distress among patients with metastasis cancers.[17] Based on previous studies, pain distress was found in 52 – 77% of cancer patients and 62 – 86% in cancer patients with metastasis. The pain originated from the metastasized organs could lead to the higher perception of distress and fear of pain.[18]

At discharge for home self-care, the 8 most severe symptom distresses had been alleviated from admission (from fatigue/weakness/asthenia (1.19 ± 1.06 points) as number 1 to constipation as number 8 (0.17 ± 0.58 points). The relief of these physical distresses could further benefit the psychological symptom distresses including anxiety (0.04 ± 0.29 points), fear (0.01 ± 0.10 points), depression (0.0 ± 0.00 points), and desperation (0.0 ± 0.00 points), ranked as the number 9, 10, 11 and 12, respectively. This could be attributable to the fact that symptom distress in the early stage of palliative care patients could be susceptibly and readily treated with advanced drug regimens and administrations. In addition, more skilled healthcare providers such as nurses, physicians, pharmacists, nutritionists and psychologists specialized palliative care have been involved in the comprehensive multidisciplinary care process as suggested in the palliative care manual.[19] This could lead to the better holistic care for palliative care patients since body and mind are connected and together affect the illness and well-being both at physiological and biochemical levels. Alleviated physical suffering could further help relieve psychological suffering.[20]

In short, our study found that the symptom distress decreased from admission to discharge. The total score of all distresses (40.82 ± 15.77 of 120 points) at admission was reduced to only 4.78 ± 3.00 points) at discharge with a statistical significance (P-value < 0.05). This was consistent with the study of Samuksamam that once taken care of, patient's distress was alleviated and the stress was further relieved.[21] Ultimately, physical and psychological well-being was restored and the suffering was diminished or even vanished.[21]

In this study, the perceived care received was higher than the need for care both at admission and discharge. At admission, fatigue/weakness/asthenia (7.98 ± 2.71 points), shortness of breath/difficulty breathing (7.00 ± 3.94 points), pain (5.82 ± 4.18 points), agitation (5.09 ± 3.23 points), and loss of appetite (5.07 ± 4.17 points) were the five most severe symptom distressed as indicated by the scores of the need for care. These five symptom distresses were also ranked the five most perceived care received with scores of 8.15 ± 2.57, 7.27 ± 3.83, 5.91 ± 4.22, 5.33 ± 3.37 and 5.23 ± 4.15 points, for fatigue/ weakness/ asthenia, shortness of breath/ difficulty breathing, pain, agitation and loss of appetite, respectively. For each of the five symptom distresses, the scores of the perceived care given was higher than that of the care needed. In addition, the average score of all individual distresses on the perceived care received (3.74 ± 3.07 points) was also higher than that of the need for care (3.63 ± 2.82 points). Once the mean score of the need for care and the mean score of the perceived care received (120 points for both) at admission were compared, the score of the perceived care received (44.90 ± 36.95 points) was slightly higher than that of the need for care (43.60 ± 33.91 points) with a statistical significance (*P*-value = 0.011). This was consistent with the need-supplies fit concept that if the need for care is met with the care provided, satisfaction could be reached.[9] If not, dissatisfaction could arise and lead to further more distress and severe stage of the illness. This suggested that even at the admission step with little hospitalized time, the care rendered to the patients met their expectation. This reflects the effectiveness of the care to alleviate the symptom distress among palliative care patients. Since the scores of the perceived care received for each of the individual distresses and the total scores were slightly higher than those of the need for care, the patients did not think that the care they received were excessive or unnecessary. This near optimal need and supply balance would not lead to the dependence on unnecessary care by healthcare providers. On the other hand, this also indicated that healthcare providers had provided an adequate level of care, not too much or too little.

At discharge to home self-care, scores of the need for care for each of all symptom distresses decreased to lower than 1 (0.01 – 0.90 of 10 points) in 8 distresses and to zero in anxiety and depression. Fatigue/weakness/asthenia and shortness of breath/difficulty breathing were the two symptom distresses that the scores remained higher than one (1.21 ± 1.18 and 1.04 ± 1.34 points, respectively). This suggested that once the patients had received care while hospitalized, the distress was reduced both physical and psychological ones. In terms of the perceived care received, all scores of each of all symptom distresses were higher than those of the care needed. In addition, most distresses had scores less than 1, except fatigue/ weakness/ asthenia and shortness of breath/difficulty breathing, and pain (1.30 ± 1.28, 1.09 ± 1.37, and 1.01 ± 1.41 points, respectively). This again indicated that healthcare providers had provided an adequate level of care, not too much or too little. Overall score of the care needed was 0.42 points while that of the perceived care received was 0.44. Again, the care received was perceived as higher than what the patients expected. Once the mean score of the need for care and the mean score of the perceived care received (120 points for both) at admission were compared, the score of the perceived care received (5.38 ± 8.57 points) was slightly higher than that of the need for care (5.10 ± 8.21 points) with a statistical significance (*P*-value = 0.005). This indicated that once care had been received for a certain period, the distress at discharge was reduced and even gone for depression and desperation. This was consistent with the need-supplies fit concept that if the need for care is met with the care provided, satisfaction could be reached.[9] If not, dissatisfaction could arise and lead to further more distress and severe stage of the illness. In addition, the provision of continuous care and monitoring, discharge plan, and information specific to individual patients was over expectation of the patients and caregivers. This also in part resulted in a score of the perceived care received that was higher than that of the need for care. In addition to the need-supplies fit concept, the person-environment fit concept was also of interest. The person-environment fit concept could help explain the patient's satisfaction that we observed in this study, even though we did not officially interview the patient on the satisfaction. Based on the person-environment fit concept, the environment, namely the management for the provision of continuous care and monitoring, discharge plan, and information specific to individual patients, could affect the satisfaction among the patients. In the future research, the satisfaction of the palliative care patients and their caregivers as affected by the care management could be determined.

This study had certain limitations. Since all palliative care patients were stable and able to communicate, the generalizability to a wider range of palliative care patients is limited. The results could not be applicable to those with unstable, life-threatening or end-of-life illness. Therefore, effective ways to study the concepts in those with end-of-life illness, unstable illness and inability to communicate should be explored and tested for the future research. Palliative care patients in other healthcare settings or levels should also be studied.

In terms of applicability, the interview forms of symptom distress, the need for care and the perceived care received should be included in the usual care practice for continuous evaluation when necessary. This could help nurses plan the care consistent with the specific patient's need from admission till discharge for periodical care plan such as daily, weekly, and monthly plan. The interview results could also be used for discharge plans for transferred community care and home self-care. For nursing education, understandings on symptom distress, the need for care and the perceived care received among palliative care patients should be included in the curriculum and training.

In conclusion, symptom distress at discharge for home self-care decreased from hospitalization admission among palliative care patients admitted to a community hospital. The perceived care received was higher than the need for care both at admission and discharge.

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References

1. Dodd M, Janson S, Facione N, et al. Advancing the science of symptom management. *J Adv Nurs* 2001;33(5):668-676.
2. World Health Organization. World Health Organization definition of palliative Care. 2012. (Accessed on May 12, 2018, at http://www.who.int/cancer/palliative/definition/en/)
3. Sigurdurdottir KR, Haugen DF. Prevalence of distressing symptoms in hospitalized patients on medical wards: A cross-sectional study. *BMC Palliat Care* 2008;23(7):16. (doi: 10.1186/1472-684X-7-16).
4. Soowit B. The assessment of the suffering symptoms in palliative care patients. *Songklanagarind J Nurs* 2015;35(1):153-164. (in Thai)
5. Makmai K, Sirichayanugul Cม Sirichayanugul T. Common symtoms and needs of discharge advance-stage cancer patients: A case-study at Phrae Hospital, Thailand. *Thai Cancer J* 2013;33(4):133-145. (in Thai)
6. Petchsri K, Boonyoung N, Geurgoolgitjagan N. Quality management for discharge planning of head nurses in the university hospital and regional hospitals in southern Thailand. *Songklanagarind* Med J 2006;24(1):19-26. (in Thai)
7. Bureau of Information, Ministry of Public Health. Public health pilot care for chronic end-stage patients in 16 Hospitals. 2014. (Accessed on May 12, 2018, at www.pr.moph.go.th) (in Thai)
8. Bruera E, Kuehn N, Miller M, Selmser P, Macmillan K. Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients. *J Palliat Care* 1991;7(2):6-9.
9. Caplan RD. Person-environment fit in organizations: Theories, factors, and values. In: Riley AW, Zaccaro SJ. Occupational stress and organizational effectiveness. New York. Praeger, 1987: pp.248-267.
10. Chirawatkul A. Statistics in research: appropriate Selection. Bangkok. Witthayaphat Co., Ltd., 2016: pp.19-20. (in Thai)
11. Srisatidnarakul B. The methodology in nursing research, 5th ed. Bangkok. U & I Inter Media Co., Ltd., 2010. (in Thai)
12. Faul F, Erdfelder E, Buchner A, Lang A-G. Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. *Beh Res Method* 2009;41:1149-1160.
13. Nekolaichuk C, Watanabe S, Beaumont C. The Edmonton Symptom Assessment System: a 15-year retrospective review of Validation studies (1991-2006). *Palliat Med* 2008; 22:111-122.
14. Lenz E, Pugh L, Milligan R, Gift A, Suppe F. The middle-range theory of unpleasant symptoms: An update. *Adv Nurs Sci* 1997;19(3):14-27.
15. Stark L, Tofthagen C, Visovsky C, McMillan SC. The symptom experience of patients with cancer. *J Hosp Palliat Nurs* 2012;14(1):61-70.
16. Bruera E, Yennurajalingam S. Palliative care: Overview of fatigue, weakness, and asthenia. 2013. (Accessed on May 1, 2018, at https://www.uptodate.com/contents/palliative-care-overview-of-fatigue-weakness-and-asthenia).
17. Get-Kong S, Hanucharurnkul S, McCorkle R, Viwatwongkasem C, Junda T, Ittichaikulthol W. Symptom experience, palliative care and spiritual well-being among Thais with advanced cancer. *Pacific Rim Inter J Nurs Res* 2010;14(3):219-234. (in Thai)
18. van den Beuken-van Everdingen MH, de Rijke JM, Kessels AG, Schouten HC, van Kleef M, Patijn J. Prevalence of pain in patients with cancer: a systematic review of the past 40 years. *Ann Oncol* 2007;18(9):1437-1449.

19. Khok Samrong Hospital. Quality of patient care process in Khok Samrong hospital. Care guidelines Palliative care (WI-PCT-02.03/01). Lopburi. Khok Samrong Hospital, 2558. (in Thai)
20. The Chopra Center. Mind-body connection: Understanding the psycho-emotional roots of disease. 2018. (Accessed on May 5, 2018, at https://chopra.com/articles/mind-body-connection-understanding-the-psycho-emotional-roots-of-disease)
21. Samuksamam S. Spiritual needs of the terminal ill patients. Master thesis. Master of Nursing Science in Adult Nursing program. Khon Kaen. Graduate School, Khon Kaen University, 2007. (in Thai)