Symptom Experience, Palliative Care and Spiritual Well-Being among Thais with Advanced Cancer

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Abstract: This descriptive cross-sectional study of Thais with advanced cancer aimed to: 1) describe symptom experiences, palliative care strategies and spiritual well-being; 2) examine the relationships among these three variables; and, 3) determine predictability of spiritual well-being by symptoms experienced and palliative care received. Two hundred and forty Thais with advanced cancer were purposively selected to respond to four questionnaires: Personal Information Questionnaire; Memorial Symptom Assessment Scale; Palliative Care Assessment Form; and, Spiritual Well-Being Scale.

The most common symptom reported by prevalence and distress was pain. Difficulty swallowing was reported as the most frequent symptom, while "I don't look like myself" was the most severe symptom. The palliative care methods used were a combination of pharmacological and non-pharmacological management strategies. Analgesics, specifically morphine, were the most common pharmacological agents used. The five non-pharmacological strategies most frequently used were: getting information/advice on self care; talking to someone who gave support/encouragement; changing food/eating behavior; reading Dhamma's book/bible of own religion and making merit; and, taking vitamins or dietary supplements. The two most effective non-pharmacological management strategies included: getting information/advice regarding self-care and talking to someone who gave support and encouragement. Nurses were the most often listed care providers involved in administering non-pharmacological strategies, especially regarding psychosocial care. Subjects reported moderate to high spiritual well-being. Positive relationships were found among the three dimensions of the symptom experience (frequency, severity & distress). Palliative care was found to have a positive relationship with spiritual well-being and a negative relationship with the three symptom dimensions, while spiritual well-being had a negative relationship with the three symptom dimensions. Symptom severity and palliative care, together, accounted for 48.9% of variance in spiritual well-being, while symptom distress and palliative care accounted for 48.8%, and symptom frequency and palliative care explained 48.3%.

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Introduction

According to the World Health Organization (WHO), cancer is a global health care problem. In 2002, 24.6 million people were living with cancer, with an additional 11 million being newly diagnosed and another 6.7 million dying.[1] In Thailand, cancer is the leading cause of death among adults.[2] As the number of people living with cancer continues to

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increase, more people are diagnosed with advanced stages of the disease. Those with an advanced stage of cancer suffer feelings of loss, fear, uncertainty and anxiety, as well as experience various symptoms (pain, depression, fatigue, dyspnea, nausea, constipation, sleep disturbance, weakness, anorexia, dry mouth and confusion).[3] All these symptoms have been reported to impact one's functional status and quality of life (QOL).[4]

A holistic approach of palliative care plays an important role in controlling symptoms and providing comfort.[5] Spiritual well-being is essential among those with advanced cancer because it is related to one's ability to search internally for strength and meaning, place the illness in a broader context and accept the condition.[6]

In Thailand, limited research has focused on symptoms and spiritual well-being among individuals with advanced cancer. Although there have been studies related to managing symptoms,[7] no research could be identified that describes, in detail, the use of palliative care that includes spiritual care, a broader concept than just symptom management. Spiritual well-being is an important dimension for those with advanced cancer, especially in the Thai culture, where spiritual beliefs most often are based on Buddhism. Such beliefs play a significant role in every step of daily life from birth through death.[8] Exploration of the symptom experience, palliative care and spiritual well-being, among this group, may explicate current challenges regarding symptom management and help identify effective palliative care strategies.

Conceptual Framework and Review of Literature

This study was guided by the Symptom Management Model (SMM)[9] within a palliative care context.[5] The SMM includes three interrelated concepts: symptom experience; symptom management strategies; and, outcomes. Symptom experience is the patient's perception of a symptom, including cognitive and emotional beliefs about the symptom, its causes and ways to cope.[9] Symptom experiences were assessed, in this study, by symptom prevalence, frequency, severity and distress.

Although SMM specifies symptom management strategies, they were expanded, in this study, to include palliative care, which aims to relieve suffering and improve quality of life by providing pain and symptom relief, and spiritual and psychological support.[5] Palliative care includes every aspect of a patient's needs and involves optimal care, which requires wide implementation with terminally ill patients.

The outcome, for this study, was spiritual well-being, a sense of connectedness or relationship with self, nature, mystery and God, or something greater than self that is defined by the individual in order to find meaning and purpose in life.[10-12] Paloutzian and Ellison[13] suggest spiritual well-being is comprised of two dimensions:1) religious well-being, a sense of well-being in relation to God; and, 2) existential well-being, a sense of life purpose and satisfaction.

The literature indicates individuals with advanced cancer experience numerous physical[14] and psychological symptoms.[15] Therefore, various palliative care strategies, including both pharmacological[16] and non-pharmacological strategies, may be needed to manage the illness. Non-pharmacological strategies include: cognitive behavior interventions;[17] complementary therapy (i.e. aroma therapy, reflexology, eating habits, exercise and Chinese medicine);[18] and, religious and spiritual coping.[19] All these strategies aim to relieve symptom distress and, thereby, enhance spiritual well-being of those with advanced cancer.[20] In the terminally ill, spiritual beliefs or well-being can be a source of strength and encouragement by helping one to understand his/her illness and suffering, and assist in coping with life's uncertainties.[21] Patients with an enhanced sense of psycho-spiritual well-being have been found to be able to cope more effectively with the terminal illness process.[22]

Research regarding symptom experiences, palliative care and spiritual well-being, among individuals with advanced cancer, rarely has been conducted in Thailand. In addition, findings from studies conducted in western cultures may not be applicable in the Thai cultural. Thus, the aims of this study were to: 1) describe Thais' symptom experiences, palliative care strategies and spiritual well-being; 2) examine the relationships among these three variables; and, 3) determine predictability of spiritual well-being by symptoms experienced and palliative care received.

Methods

Design and Sample: A cross-sectional quantitative descriptive design was used. Approval to conduct the study was obtained from the Institutional Review Board (IRB) of the primary investigator's (PI) university. The sample size was derived from an estimation of population proportion, plus an additional 25% was calculated for expected attrition,[23] resulting in an estimated 240 subjects.

Subjects were recruited, November 2008 to April 2009, from the in-patient departments (IPD) and/or out-patient departments (OPD) of two cancer centers and one university hospital. After reviewing medical records, all persons who met the inclusion criteria were approached by the PI. Using purposive sampling, 282 Thais were selected who were: (1) 18 years of age or older; (2) willing to participate; (3) able to speak, read and write Thai; (4) not receiving aggressive treatment for cancer; and, (5) diagnosed with an advanced stage of cancer. Each potential subject was informed regarding: the study's purpose; their right to refuse to participate without any reprecussions; the maintenance of confidentially and anonymity; and, what their involvement would entail.

Twenty-two (7.8%) potential subjects chose not to participate, due to feeling too ill or fatigued, and 20 (7.09%) could not be enrolled because relatives did not consent to their participation. Although each person had the independent legal right to decide whether to take part in the study, Thais often rely upon family members to assist in decision-making regarding health related issues. Finally, 240 individuals signed a consent form to participate.

Subjects ranged in age from 19 to 86 years (mean = 56.1 years). Although slightly more than half were female (n = 122; 50.8%), the majority were married (n = 184; 76.6%) and Buddhists (n = 232; 96.7%). They predominantly had a primary school education (n = 117; 48.8%) with a mean of 8.1 years of schooling; had no occupation outside of the home (n = 147; 61.25%%); lived in central Thailand (n = 114; 47.5%); had an average family income of 20,000 baht (30 baht = 1USD) per month; perceived themselves as having sufficient financial resources (n = 106; 44.2%); lived in their own home (n = 203; 84.6%); and, had their health care costs covered predominantly by the Thai universal health plan (n = 103; 42.9%) or government welfare program (n = 97; 40.4%). All reported having a family caregiver. Their average length of time since diagnosis was 24.16 months. The largest percentage had cancer of the gastro-intestinal tract (n = 59; 24.7%). On average, they had 0.4 co-morbid diseases (i.e. hypertension, diabetes mellitus, cardiovascular problems, chronic kidney disease and chronic obstructive pulmonary disease) and used 0.5 medical devices (i.e. a nasogastric tube, oxygen, and a central venous catheter for total parenteral nutrition).

Instruments: Four instruments were used to collect data. They were the: Personal Information Questionnaire (PIQ); Memorial Symptom Assessment Scale (MSAS); Palliative Care Assessment Form (PCAF); and, Spiritual Well-being Scale (SWBS). A pilot study with 30 patients was conducted to test the feasibility of the study and reliability of the instruments, which are reported below. None of those involved in the pilot study were included in the primary study.

The Personal Information Questionnaire (PIQ) contained 17 items and was developed by the PI. The PIQ sought to obtain demographic information, from each subject, about his/her: age, gender, marital status, religion, educational level (primary, secondary, college), 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, by the PI. The questionnaire took approximately 5 minutes to complete.

The Memorial Symptom Assessment Scale (MSAS), a reliable measurement tool developed by Portenoy and colleagues, was used to assess the prevalence, frequency, severity and distress of symptoms.[24] Dr. Portenoy granted permission for its use and translation into Thai for this study. The translation process recommended by Suwisith[25] was followed. The prevalence, severity and distress of symptoms were evaluated with 32 specific symptoms, while symptom frequency was evaluated in only 24 of these symptoms because frequency for 8 of the symptoms was not relevant (e.g. hair loss). Subjects were asked to respond "yes" or "no" regarding whether they experienced each respective symptom during the past week. Each "yes" response regarding symptom prevalence was scored as "1," while each "no" response was scored as "0." A negative response regarding whether a respective symptom was experienced led to a request to respond to the next symptom. A positive response to any given symptom led to a request to rate the frequency, severity and distress of the respective symptom. Rating of symptom frequency was done on a 4-point Likert-like scale where "1 = rarely" to "4 = almost constantly." Rating of symptom severity was done on a 4-point Likert-like scale where "1 = slight" to "4 = very severe." Symptom distress was assessed on a 5-point Likert-like scale where "0 = not at all" to "4 = very much." To obtain a total score, the values for the symptom dimensions (prevalence, frequency, severity, distress) were summed and an average was calculated. The higher the score, the greater the symptom experience.[24] The instrument took approximately ten minutes to complete. The internal consistency reliabilities of the MSAS, in the pilot study, were 0.73, 0.77, 0.78 and 0.82 for symptom prevalence, frequency, severity and distress, respectively. In this study, the internal consistencies of the MSAS were 0.85, 0.81, 0.84 and 0.88 for symptom prevalence, frequency, severity and distress, respectively.

The Palliative Care Assessment Form (PCAF) was developed by the PI based on a literature review and included reported pharmacological and non-pharmacological management strategies used in palliative care. Five oncology and palliative care experts (one oncology advanced practice nurse, three oncology and palliative care nursing instructors, and one palliative and end of life care physician) determined the content validity of the PCAF to be 0.95.

The pharmacological management strategies section of the PCAF consisted of a listing of the most commonly used palliative care medications. This included adjuvant medications (opioids, other analgesics, anti-depressants, anxioletics and anticonvulsants), laxatives, anti-flatulents and antiemetics, as well as a blank space for adding medications the subjects may have taken that were not on the list. Data were obtained, by the PI, from each person's medical record. For each listed medication either a "yes" or "no" response was assigned. For each "yes" response the value of 1 was applied, while each "no" response received the value of 0. To obtain a total score, the values were summed. The higher the total score, the more medications used.

In the non-pharmacological section of the PCAF, twenty-three management strategies were categorized into 4 major groups: psychosocial (n = 4); mine-body and spiritual intervention (n = 7);

physical (n = 8); and, traditional medicine, herbs and diet (n = 4). Each item was responded to as "yes" (currently using the management strategy), or "no" (currently not using the management strategy). 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.

To obtain a total score of palliative care, the total value from the pharmacological and non-pharmacological sections were summed. In addition, participants were asked to rate the overall effectiveness of both pharmacological and non-pharmacological management strategies using one of five choices: "got rid of symptoms"; "relieved symptoms"; "symptoms remained"; "symptoms worsened"; and, "uninterruptable effectiveness." If the management strategy was rated as either "got rid of symptoms" or "relieved symptoms" it was considered effective. An open-ended question ("From where or whom did you obtain this information or care?") was provided after each non-pharmacological management strategy to obtain information regarding the primary source of information or care. The sources then were grouped into categories (i.e. nurse, self, family member/relative, therapist) with the number of responses occurring within each category being summed. It took approximately ten minutes to complete the instrument.

The Spirituality Well-Being Scale (SWBS), purchased from Life Advance, Inc.,[27] is a reliable instrument developed by Paloutzian and Ellison[13] for the purpose of measuring spiritual well-being. Some items in the instrument required modification, due to cultural differences between the western world and Thailand (i.e. the word "God" needed to be replaced by the word "religion"). Therefore, Noipiang's[26] modified version of the SWBS was used in this study. Like the original version of the instrument, the modified SWBS consisted of 20 items that measured, through the use of two 10 item subscales, spiritual well-being [religious well-being (RWB) and existential well-being (EWB)]. Half of the items on each of the 10 item subscales were negatively worded. Subjects were asked to indicate, on a 6-point Likert-like scale (1 = strongly agree to 6 = strongly disagree), the degree to which they agreed or disagreed with each item. Items included statements such as: "I feel very fulfilled and satisfied with life" and "I feel unsettled about my future." Subjects' scores for negatively worded items were reversed prior to calculation of the total and subscale scores. Scores for the two subscales were obtained by summing the values of the individual items in each respective subscale. The total score was obtained by summing the item values for all 20 items. The two sub-scale scores could range from 10 to 60, while the SWBS total score could range from 20 to 120, and be interpreted to mean the higher the SWBS score the greater the amount of spiritual well-being one had. In the pilot study, reliabilities were found to be 0.93, 0.89 and 0.87 for the modified SWBS, RWB and EWB, respectively; while in this study they were 0.96, 0.93 and 0.94, respectively. The instrument took approximately five minutes to complete.

Data Collection: Those who consented to participate were approached, by the PI, either in a private part of the waiting room of the OPD or at their bedside on the IPD of each health care institution used for data gathering. Prior to distribution of the questionnaires, information regarding each subject's pharmacological management strategies, length of time since diagnosis, presence of co-morbid diseases and use of medical devices were obtained, by the PI, from the respective medical record and recorded on the appropriate questionnaire. Copies of each questionnaire then were distributed to each subject, and details regarding how to complete the questionnaires were explained to both the subject and his/her respective family members in attendance. Subjects were instructed to complete the questionnaires by themselves. If they needed assistance, due to illiteracy, illness or visual problems, the PI read the questionnaires aloud and asked the respective subject to verbally response. One-hundred and sixty-three required assistance (67.91%). The PI left the immediate area after distributing and explaining the questionnaires to those not requiring assistance. After 30 to 45 minutes the PI retrieved the completed questionnaires, and checked to verify the completeness of data. When missing data were noted, the PI verbally asked the respective subject to respond. Completed questionnaires then received a code number and were placed in a locked cabinet.

Data Analysis: Descriptive statistics were used to analyze the demographic, symptom experience, palliative care strategies and spiritual well-being data. Pearson's product-moment correlation was used to analyze the relationships among symptom experience (frequency, severity and distress), palliative care and spiritual well-being. Multiple regression was used to determine predictability of spiritual well-being by symptom experience (frequency, severity and distress) and palliative care.

Results

Symptom experience: Subjects reported experiencing between three and 32 symptoms (mean = 14.4), with pain being the most distressful. The most frequent symptom was "difficulty swallowing," while the most severe was "I don't look like myself." The rank order of the top ten symptoms, based upon frequency, severity and distress levels, are shown in **Table 1.**

Table 1 Means and standard deviations for symptom frequency, severity and distress (n=240)

Symptoms	Frequency	Severity	Distress
	Mean	Mean	Mean
Difficulty swallowing	**2.84 (SD = 1.13)^{1}**	2.45 (SD = 0.98)^{3}	2.28 (SD = 0.95)^{3}
Problem of urination	2.52 (SD = 1.16)^{2}	2.36 (SD = 0.94)^{7}	2.08 (SD = 0.77)^{6}
Pain	2.45 (SD = 0.74)^{3}	2.43 (SD = 0.73)^{6}	**2.36 (SD = 0.78)^{1}**
Sleeping difficulty	2.39 (SD = 0.60)^{4}	2.27 (SD = 0.61)^{10}	2.26 (SD = 0.64)^{4}
Feeling bloated	2.37 (SD = 0.71)^{5}		2.20 (SD = 0.69)^{5}
Lack of energy	2.36 (SD = 0.91)^{6}		1.90 (SD = 0.68)^{9}
Lack of appetite	2.31 (SD = 0.62)^{7}		
Shortness of breath	2.30 (SD = 0.71)^{8}	2.34 (SD = 0.68)^{8}	2.30 (SD = 0.66)^{2}
Feeling drowsy	2.27 (SD = 0.75)^{9}		
Numbness/tingling	2.19 (SD = 1.01)^{10}		
Swelling arms/legs		2.44 (SD = 0.66)^{5}	2.01 (SD = 0.61)^{7}
Itching			1.96 (SD = 0.69)^{8}
Mouth sore			1.87 (SD = 0.74)^{10}
"I don't look like myself"		**2.60 (SD = 0.66)^{1}**	
Weight loss		2.52 (SD = 0.62)^{2}	
Change in food taste		2.45 (SD = 0.76)^{4}	
Changes in skin		2.34 (SD = 0.73)^{9}	

$^{1-10}$ = ranking of symptom frequency, severity and distress.

Highest symptom experiences in each domain are **bolded**

Palliative Care: As shown in **Table 2**, subjects used various types of pharmacological palliative care strategies to manage their illnesses. Various forms of morphine were used most often, followed by other opioids, laxatives, anti-depressants, anxioletics, anti-flatulents, non-narcotic analgesics, anti-convulsants and antiemetics. As noted in **Table 3**, the non-pharmacological strategies used the most were: getting information/advice on self care and talking to someone who gave support/encouragement (psychosocial intervention); changing food/eating behaviors and taking vitamins or dietary supplements (traditional medicine, herbs and diet intervention); and, reading Dhamma's book/bible of own religion and making merit (mind-body and spiritual intervention). However, three of the non-pharmacological strategies were not used by any of the subjects. These included: using pet therapy (mind-body and spiritual intervention), and using ultrasound for pain relief and using transcutaneous electrical nerve stimulation (physical intervention).

Table 2 Pharmacological management by medication classification (n = 240)

	Pharmacological Management	n	Percent	Min dose (mg/day)	Max dose (mg/day)	Mean dose (mg/day)	SD
1.	**Adjuvants**						
	Opioid analgesics	**197**	**82.90**				
	Morphine injection	39	16.27	3	30	16.46	6.44
	Morphine solution	47	19.61	3	60	25.26	10.12
	Morphine tablet	36	15.02	10	160	51.39	36.97
	Morphine capsule	19	7.93	20	100	32.11	25.51
	Fentanyl	16	6.68	*12	*100	*39.81	22.96
	Tramadol	37	15.44	20	480	187.84	89.42
	Codeine	3	1.25	90	120	110.00	17.32
	Non-narcotic analgesics	**25**	**10.43**				
	Acetaminophen	25	10.43	1000	2000	1120.00	331.66
	Anti-convulsants	**23**	**9.58**				
	Gabapentin	18	7.5	100	1800	805.56	450.45
	Carbamazepine	5	2.08	200	800	520.00	268.33
	Anxioletics	**33**	**13.73**				
	Lorazepam	33	13.73				
	Anti-depressants	**35**	**14.57**				
	Amitriptyline	35	14.57				
2.	**Laxatives**	**61**	**25.40**				
	Senokort	47	19.65				
	Milk of Magnesia	14	5.75				
3.	**Anti-flatulents**	**28**	**10.40**				
	Mixture Carminative	9	3.74				
	Simethicone	19	6.66				
4.	**Antiemetics**	**14**	**5.80**				
	Metochlopramide	10	4.14				
	Ondesetron	4	1.66				

Note: One patient may have taken more than one type of medication listed.
* = microgram/day

Table 3 Non-pharmacological strategies by intervention group (n = 240)

Groups	n	Percent
Psychosocial intervention		
Getting information/advice on self-care	202	84.2
Talking to someone who gave support/encouragement	196	81.7
Enrolling in self-help group	6	2.5
Getting information/advice on coping skills	37	15.4
Mind-body and spiritual intervention		
Using progressive muscle relaxation technique	17	7.1
Meditating	99	41.3
Reading Dhamma's book/bible of own religion and making merit	166	69.2
Listening to music/music therapy	29	12.1
Practicing universal energy healing	6	2.5
Using art therapy	1	0.4
Physical (manipulation and body based methods) intervention		
Using exercise	70	29.2
Using massage or reflexology	35	14.6
Using acupuncture	2	0.8
Using hot or cold pack	14	5.8
Using hydrotherapy	3	1.3
Using aroma therapy	8	3.3
Traditional medicine, herbs and diet intervention		
Using herbs or traditional medicine	102	42.5
Using Ya-mhor (Thai folk medicine)	35	14.6
Changing food/eating behaviors	168	70.0
Taking vitamins or dietary supplements	134	55.8

Note: One patient might use more than one symptom management strategy

The largest proportion of subjects (n = 151; 62.92%) tended to use a combination of pharmacological and non-pharmacological strategies. Only 73 (30.42%) solely used non-pharmacological strategies and 16 (6.66%) solely used pharmacological strategies.

Care provider: The primary care provider (PCP) for activities listed under the four groups of non-pharmacological strategies varied. For activities within the psychosocial group, nurses (n = 199; 82.8%) were the PCPs, while participants (n = 165; 68.8%) served as PCPs for mind-body and spiritual interventions. Family members and relatives (n = 93; 38.8%) served as PCPs for activities within the traditional medicine, herbs and diet interventions, while therapists (n = 25; 10.4%) were the PCPs for activities within the physical interventions.

Effectiveness of palliative care used: Of the 240 subjects, 100 (41.7%) perceived, regardless of method used, both pharmacological and non-pharmacological strategies to be effective ("got rid of symptoms" or "relieved symptoms"). Sixty-six (66%) of these 100 used a combination of pharmacological and non-pharmacological strategies, while 34 (34%) solely used non-pharmacological strategies. Among the 100 subjects, the non-pharmacological strategies found to be the most effective included: getting information/advice about self-care (n = 100;100%); talking to someone who gave support/encouragement (n =100; 100%); reading Dhamma's book/bible of own religion and making merit (n = 96; 96%); changing food/eating behaviors (n = 89; 89%); taking vitamins or dietary supplements (n = 79; 79%); meditating (n = 61; 61%); and, using exercise (n = 61; 61%).

Spiritual well-being: Subjects reported their overall spiritual well-being to be high (n = 133; 55.4%) or moderate (n =107; 44.6%). None reported having low spiritual well-being. Overall, their religious well-being dimension was higher (mean = 51.75) than their existential well-being dimension (mean = 48.05).

Relationship among symptom experiences, palliative care, and spiritual well-being: As shown in **Table 4**, a positive relationship was found between palliative care and spiritual well-being. However, a negative relationship was found between symptom frequency, symptom severity and symptom distress with both palliative care and spiritual well-being. Not surprisingly, the three components of the symptom experience (frequency, severity and distress) were found to be positively related to each other.

Table 4 Relationships among symptom experiences, palliative care and spiritual well-being (n=240)

Variables	1	2	3	4	5
1. Palliative care	1.000				
2. Symptom frequency	-.203**	1.000			
3. Symptom severity	-.196**	.934**	1.000		
4. Symptom distress	-.170**	.919**	.953**	1.000	
5. Spiritual well-being	.479**	-.590**	-.594**	-.582**	1.000

**p < .01

Regarding predictability, as shown in **Table 5**, symptom severity and palliative care, together, accounted for 48.9% of the variance in spiritual well-being. However, symptom distress and palliative care accounted for 48.8%, while symptom frequency and palliative care explained 48.3% of the variance in spiritual well-being.

Table 5 Multiple regression analysis of spiritual well-being and predicting factors (symptom frequency, severity and distress, and palliative care)

Model	B	Std. Error	Beta	t	sig	R^2	Adjust R^2	Std. Error of the estimate	F change	P
						.483	.479	10.69	110.67	.000
Constant	120.55	3.60		33.48	.000					
Symptom frequency	-32.69	3.03	-.51	-10.78	.000					
Palliative care	2.02	.26	.375	7.81	.000					
						.489	.485	10.63	113.53	.000
Constant	112.01	3.66		33.31	.000					
Symptom severity	-35.22	3.20	-.52	-10.98	.000					
Palliative care	2.03	.26	.38	7.97	.000					
						.488	.483	10.64	68.81	.000
Constant	119.25	3.45		34.56	.000					
Symptom distress	-34.92	3.20	-.51	-10.93	.000					
Palliative care	2.11	.25	.39	8.30	.000					

Discussion

Consistent with prior studies of symptom experience, among women with breast and cervical cancer,[25, 27] findings in this study revealed subjects, with respect to each symptom dimension, rated their experience differently. However, the most prevalent and distressful symptom was found to be pain, while difficulty swallowing was the most frequent and "I don't look like myself" was the most severe. Finding pain to be the most distressful symptom is similar to findings of a previous study on Thais with advanced cancer,[7] as well as studies conducted in a Western culture where pain was found to be the most problematic symptom[28] and ranked as the second[29] or third[30] most distressing symptom. These findings are significant when one recognizes inadequate pain management might lead to sleep disturbances, decreased socialization,[31] altered psychological status, increased physiological stress, diminished immuno-competence, decreased mobility and deceased quality of life.[32]

Although inconsistent with prior findings,[7] the most frequently reported symptom, in this study, was difficulty swallowing, followed by urination difficulties and pain. One needs to recognize, however, 17 of the 43 subjects who reported difficulty swallowing had head-neck cancer, which may have led to their swallowing difficulties. However, as pointed out by Sumdangrit,[33] swallowing difficulties with advanced cancer might be associated with a psychological response to stress. A sore mouth also has been found to be a leading cause of swallowing difficulties, which often occurs concurrently with dehydration, anorexia, sleep disturbances and stress.[34]

With respect to symptom severity, "I don't look like myself" was the most severe symptom experienced. This perception may be a result of body image changes brought about by cachexia, weight loss, arm/leg swelling, skin changes and/or hair loss, especially in light of weight loss and arm/leg swelling being rated as severe and ranked second and fifth, respectively, in regards to severity. These changes affected their feelings and perceptions of themselves. Some stated: *"I think I don't look like myself because many things have changed. I have pain. I have no energy. I'm tired. My hair and skin are dry. I have lost weight and I easily feel irritable. I'm not the same as before."* Body image is a psychological construct that explains how one sees one's body, and can be affected by cancer and cancer treatments.[35] The majority of patients with advanced cancer are known to experience weight loss, reduced appetite, fatigue and weakness.[14, 17, 18] One's weight loss is readily noticeable and often generates negative comments from others. Such comments may lead to the individual feeling stigmatized, out of control with the situation, anxious and even fearful about what is happening.[35]

Various forms of morphine (injection, solution, tablet, capsule), followed by other opioids, were the most frequently used analgesics for dealing with pain. This is different from findings of a prior Thai study, wherein the most common medications for managing pain in cancer patients were found to be: acetaminophen (38.9%), tramadol (29%), morphine injection (6.9%), morphine tablet (6.9%) and fentanyl (1.5%).[36] The difference in findings may be related to the fact the previous study investigated individuals with all stages of cancer, while in this study only persons with an advanced stage of cancer were examined.

Sleeping difficulties and feeling bloated ranked fourth and fifth among distressful symptoms, and lead to use of anxioletics, anti-depressants and anti-flatulents. Even though constipation, nausea and vomiting were not reported as the most frequent experienced symptoms, laxatives and antiemetics were used because constipation, nausea and vomiting are common side effects of opioids. As suggested by WHO[16] and Herndon and colleagues,[37] drugs, such as laxatives and antiemetics, should be concomitantly prescribed, as proactive treatments, when using opioids.

With respect to non-pharmacological management of symptoms, the strategies differed among subjects based on their type of cancer, health care delivery system and regional/local culture. In addition, subjects tended to use more than one type of non-pharmacological strategy at a time. The first and second most frequently used strategies were within the psychosocial intervention group, and included: getting information/advice on self care; and, talking to someone who gave support and encouragement. These findings were similar to those found in a Japanese study, which explored the perceived effectiveness of psychosocial interventions with terminally ill cancer patients.[38] This study's findings of getting information/advice on self care and talking to someone who gave support and encouragement are compared, respectively, to the Japanese study's findings regarding the most effective psychosocial interventions (use of education and coping skills training; and, use of a supportive-expressive approach).

The third and fifth most frequently used strategies were within the traditional medicine, herbs and diet intervention group, and included: changing food/eating habits; and, taking vitamins or dietary supplements. Subjects reliance on traditional medicine, herbs and diet could be related to the fact that Thais, historically, have used traditional medicine and practitioners, and sought to prevent traditional practices from becoming extinct.[39] The Thai government also has tried to frame policies and introduce laws to promote and encourage use and continuation of local knowledge (i.e. traditional Thai diet and taking dietary supplements) related to traditional medicine. The Department for Development of the Thai Traditional and Alternative Medicine in the Ministry of Public Health provides information and services to those interested in traditional practices. Moreover, herbs, as well as traditional medicine and alternative therapies, are integrated into the health care system in Thailand and are reimbursable in the same manner as conventional medical care.

The fourth most used non-pharmacological strategy fell within the mind and spiritual intervention group, and included: reading Dhamma's book/bible of own religion and making merit. For Buddhists, afflictions, as well as death, are seen as common life events. In addition, the truth of life, for Buddhists, is that birth, aging, sickness and death are the four unavoidable events of humanity. Those who accept these principles believe all diseases are the result of karma and under the natural law.[40] Most subjects wore a necklace image of Buddha as a sacred object to protect them from wickedness. Additionally, many said the word, *"Thum-jai,"* (a combination of acceptance, patience, understanding, reason and obligation in a situation that cannot be changed) to show acceptance of their illness and hope that everything would get better. Thais use the word, *"Thum-jai"* whenever they need to make a life adjustment, especially when they are in a situation they do not want, but cannot avoid.[8]

The palliative care management strategies used included a combination of pharmacological and non-pharmacological strategies, as well as only non-pharmacological and only pharmacological strategies. A combination of pharmacological and non-pharmacological strategies was the predominant approach used to manage the effects of cancer and its treatment, and may have helped reduce pain and other symptoms with lower dosages of medications.[41]

Nurses were found to be the major source of information and provision of care for subjects, especially in regards to their psychosocial care. This may have been due to the fact subjects and their families had easy access to nurses at the two cancer centers and one university hospital used as data gathering sites. However, individuals with advanced cancer, who are facing a life threatening experience, are known to seek resources to help them mobilize and deal with their situation.[19] The nurse has been shown to be the one health care provider whom patients trust and believe is accessible.[42] However, nurses' relationships with patients and their families should be based on trust, personal attitudes and values.[43] Subjects, in this study, stated the nurses sat down, listened, talked and conveyed confidence to them and their families, as well as provided counseling and information as needed.

The findings revealed 100 subjects perceived, regardless of method used, both pharmacological and non-pharmacological management strategies to be effective ("got rid of symptoms" or "relieved symptoms"). The vast majority (66%) of the 100 subjects used a combination of pharmacological and non-pharmacological strategies. The fact the strategies were perceived to be effective most likely was due to the combined and/or complimentary effect they had in controlling symtoms.[31]

Positive relationships were found among the three dimensions of the symptom experience (frequency, severity & distress). Such findings are not surprising given the nature or interrelationship that exists among the three dimensions. As symptom frequency and/or severity increase, so will one's distress related to a symptom. As either frequency or severity of a symptom increases, one's perception that the other dimension is also increasing is likely.

A positive relationship was found between palliative care and spiritual well-being, while negative relationships were found between spiritual well-being and each dimension of the symptom experience (frequency, severity & distress), and between palliative care and each dimension of the symptom experience (frequency, severity & distress). Only one study could be located that noted findings similar to those found in this study. The study, conducted by Manning-Walsh,[44] found, among women with breast cancer, an inverse relationship existed between symptom distress and psycho-spiritual well-being. Symptom distress can hamper one's capability to function in his/her respective role, especially when illness management results in a low sense of spiritual well-being.[6] The fact that negative relationships existed between spiritual well-being and each dimension of the symptom experience (frequency, severity & distress), and between palliative care and each dimension of the symptom experience (frequency, severity & distress) was not surprising. As one encounters an increase in symptom frequency, severity and/or distress, it would only seem logical that one's spiritual well-being would suffer a negative impact. By the same token as one's palliative care strategies increase, each component of the symptom experience would likely decrease. The fact that a positive relationship was found between palliative care and spiritual well-being was not surprising. As one increases the use of palliative care, which subsequently leads to a decrease in symptom experience, one is likely to feel physically and mentally better. Feeling better both physically and mentally could enhance one's sense of spiritual well-being.

Consistent with prior findings of gynecological oncology patients,[43] subjects, in this study, were found to have high religious well-being, moderate existential well-being and moderate to high levels of total spiritual well-being. When faced with suffering and threats to their life, subjects frequently articulated spiritual concerns. In the Thai culture, one's family often is involved in providing care and making decisions for their ill family member. Due to their Buddhist's belief that one's actions should extend his/her own life, Thais try to assist ill family members in making merit and rituals, releasing fish or birds, and praying for spiritual support.

Although psychological distress, employment status and symptom experience have been found to be significant predictors of quality of life (QOL) and to explain 29.8% of its total variance, among Koreans with hepatocellular carcinoma,[45] in this study, symptom experience (frequency, severity, and distress) and palliative care, explained 48.35% to 48.8 % of the total variance of spiritual well-being. This increased variance might have resulted from the fact that spiritual well-being is different from QOL and spiritual well-being is important to Thai Buddhists. QOL may be too broad a concept to apply to terminally ill patients, since they are facing a life-threatening illness, as well as experiencing deterioration of their physical functioning. Spiritual well-being can help to enhance one's inner strength and courage; help with understanding one's illness; and, assist in grappling with the uncertainty of life.[21]

Limitations

As in all studies, limitations exist in this study. First, the cross-sectional design, by its nature, was limited and did not capture, over time, a change in behaviors or symptoms. In addition, a standardized instrument for measuring palliative care strategies was not used. Instead the questions asked were based on a literature review and cultural considerations. In light of the fact that subjects often were too ill to complete the questionnaires, a flexible data collection schedule was required. Also selection of a random sample could not be performed, due to limitations in patient access. Those with advanced cancer, in Thailand, are confined to their homes except when coming to a health care institution for a follow-up visit or hospital admission to manage an exacerbated symptom. Moreover, the study was conducted with subjects who were receiving care in only three specific hospitals. Thus, generalizability to other populations and settings is limited.

Conclusions and Recommendations

Secondary to the findings of this study, recommendations for future investigations include the: (a) examination of symptom clustering; (b) development of an intervention program based on basic knowledge of effective collaborative palliative care strategies carried out by health care providers, patients and family members; (c) assessment of the effectiveness of advanced practice nurses, as primary collaborators between palliative care team members, and patients and their families; and, (d) development of psychometrically sound and culturally sensitive instruments to measure spiritual well-being and palliative care strategies. Examination of symptom clustering may help in identifying co-existing symptoms, which, in turn, might assist in discerning what interventions may be clinically relevant in effectively managing multiple symptoms.

An effective collaborative intervention program, among health care providers, patients and family members, would need to include an initial and ongoing holistic assessment of physical, psychosocial and spiritual needs that addresses loss and fears experienced by patients and their families, as well as a range of both pharmacological and non-pharmacological management strategies. Such a program, potentially, could assist patients and family members in effectively dealing with the range of symptoms and problems they face, while coping with cancer. Assessment of the effectiveness of advanced practice nurses, as primary collaborators between palliative care team members, and patients and their families may assist in facilitating continuity of care. Finally, developing psychometrically sound and culturally sensitive instruments to measure spiritual well-being and palliative care, among Thais, may foster a more accurate assessment of these variables within the context of the culture.

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ประสบการณ์การเผชิญอาการ การดูแลแบบประคับประคอง และความผาสุกทางจิตวิญญาณในผู้ป่วยมะเร็งระยะลุกลาม

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บทคัดย่อ: การศึกษาภาคตัดขวางเชิงบรรยายในผู้ป่วยมะเร็งระยะลุกลามครั้งนี้มีวัตถุประสงค์เพื่อ 1) อธิบายประสบการณ์การเผชิญอาการ การดูแลแบบประคับประคอง และความผาสุกทางจิตวิญญาณ 2) ศึกษาความสัมพันธ์ของแปรดังกล่าวทั้งสามตัว และ 3) ทำนายผาสุกทางจิตวิญญาณของผู้ป่วยมะเร็งระยะลุกลามด้วยประสบการณ์การเผชิญอาการ การดูแลแบบประคับประคอง กลุ่มตัวอย่างเป็นผู้ป่วยมะเร็งระยะลุกลามจำนวน 240 คนที่มีคุณสมบัติตามเกณฑ์ที่กำหนด เครื่องมือที่ใช้ได้แก่ แบบบันทึกข้อมูลส่วนบุคคล แบบประเมินอาการ แบบประเมินการดูแลแบบประคับประคอง และแบบวัดความผาสุกทางจิตวิญญาณ

ผลการศึกษาพบว่าอาการที่มีความชุกและความทุกข์ทรมาณสูงสุดคืออาการปวด ส่วนอาการที่เป็นบ่อยครั้งคืออาการกลืนลำบากขณะที่ อาการที่ระดับความรุนแรงสูงสุดคือ มองดูตัวเองไม่เหมือนเดิม การดูแลแบบประคับประคองที่ผู้ป่วยได้รับมีหลากหลายวิธีการทั้งแบบใช้ยา และ ไม่ใช้ยา ยาที่ใช้มากที่สุดคือยาบรรเทาอาการปวดและยาเสริมฤทธิ์ สำหรับการดูแลจัดการแบบไม่ใช้ยา วิธีการที่ผู้ป่วยเลือกใช้ 5 วิธีแรกคือ การได้รับข้อมูล/ คำแนะนำในการดูแลตนเอง การได้รับการพูดคุยให้กำลังใจ การปรับเปลี่ยนอาหารและพฤติกรรมการรับประทานอาหาร ใช้การอ่านหนังสือธรรมะ/คัมภีร์ตามศาสนาที่นับถือและการปฏิบัติศาสนกิจ การรับประทานวิตามินและผลิตภัณฑ์เสริมอาหาร โดยวิธีที่ผู้ป่วยประเมินว่ามีประสิทธิภาพมากที่สุดคือการได้รับข้อมูล/ คำแนะนำในการดูแลตนเอง การได้รับการพูดคุยให้กำลังใจ ซึ่งพบว่าพยาบาลเป็นแหล่งประโยชน์สำคัญในการให้ความช่วยเหลือ ผู้ป่วยกลุ่มนี้มีความผาสุกทางจิตวิญญาณในระดับปานกลางถึงสูง สำหรับความสัมพันธ์ขององค์ประกอบของอาการทั้งสามด้านคือ ความถี่ ความรุนแรงและความทุกข์ทรมานมีความสัมพันธ์ทางบวกซึ่งกันและกัน การดูแลแบบประคับประคองมีความสัมพันธ์ทางบวกกับความผาสุกทางจิตวิญญาณ แต่มีความสัมพันธ์ทางลบกับประสบการณ์อาการทั้งสามด้าน ส่วนความผาสุกทางจิตวิญญาณมีความสัมพันธ์ทางลบกับประสบการณ์อาการทั้งสามด้าน ในการทำนายความผาสุกทางจิตวิญญาณด้วยการดูแลแบบประคับประคองและในประสบการณ์แต่ละด้านพบว่า ระดับความรุนแรงของอาการและการดูแลแบบประคับประคองสามารถอธิบายความแปรปรวนของความผาสุกทางจิตวิญญาณได้ถึงร้อยละ 48.9 ระดับความทุกข์ทรมาณของอาการและการดูแลแบบประคับประคองสามารถอธิบายได้ร้อยละ 48.8 และระดับความถี่ของอาการและการดูแลแบบประคับประคองสามารถอธิบายได้ร้อยละ 48.3

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คำสำคัญ: ผู้ป่วยมะเร็งระยะลุกลาม/ การดูแลแบบประคับประคอง/ ความผาสุกทางจิตวิญญาณ/ประสบการณ์การเผชิญอาการ

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