

RESEARCH ARTICLE

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Psychometric Properties of the Thai Version of Supportive Care Needs Survey-Partners and Caregivers (T- SCNS-P&C) for Cholangiocarcinoma Caregivers

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Abstract

Background: Unmet needs of cancer patients and caregivers are also closely linked with patients and their family well-being. Identifying and focusing on caregivers' unmet need have been recommended to reduce their burden and improve their quality of life (QOL). This study aimed to evaluate the psychometric properties of the Thai version of Supportive Care Needs Survey for Partners and Caregivers (T-SCNS-P&C) among Cholangiocarcinoma (CCA) caregivers. **Methods:** The T-SCNS-P&C was developed using standardized translation methodology. A total of 231 CCA caregivers completed the T- SCNS-P&C. The internal consistency of the scale was examined with Cronbach's alpha. Construct validity was analyzed using Pearson correlations coefficient with the physical effects, stage, anxiety and depression, age, and education level. To assess the factorial validity of the T-SCNS-P&C, confirmatory factor analysis (CFA) was performed. **Results:** The T- SCNS-P&C indicated good readability and high content validity for use as an assessment tool among Thai CCA caregivers. All Cronbach's α coefficients were above the minimum acceptable criterion of ≥ 0.70 . For construct validity, higher physical effect scores and higher anxiety and depression scores, as well as poorer QOL scores and younger caregivers, were significantly positively associated with higher levels of unmet needs. CFA indicated that the four factor structure of the T-SCNS-P&C was a good fit to the data. **Conclusion:** The T-SCNS-P&C demonstrated acceptable reliability and validity for assessing unmet needs among CCA caregivers in Thailand. Using this simple assessment to target the individual needs of these caregivers can help healthcare professionals providing effective personalized care.

Keywords: Caregivers- Thai- psychometric validation- supportive care- unmet needs

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Introduction

In Thailand, Cholangiocarcinoma (CCA), is the second-most common cancer occurred in male and the fifth cancer occurred in female (Medical Record and Databased Cancer Unit, 2021). The majority of CCA patients are often diagnosed when the disease is already progressed into advanced stages, which highly compromises therapeutic options, resulting in a dismal prognosis (Banales et al., 2016). However, due to the ongoing advances in medical technology for cancer screening and treatment modalities, including palliative care, have resulted in greater number of CCA survivors (Verkissen et al., 2019) and an expansive loading in contributing CCA survival cares.

Generally, the CCA survivors were often suffering from various symptom-related disease and treatment (Cai et al., 2016) with at least one or more combined

symptoms including pain (Ryu et al., 2010; Shun et al., 2008), psychological distress, and uncertainty. These may negatively influence their overall quality of life (QOL) and the QOL of their familial members (Jang and Jeong, 2021; Wen et al., 2018). As giving care to the love one with life-threatening illnesses, such as cancer especially with advanced cancers, these are affected caregiver burden (Sharpe et al., 2005). In addition, both cancer patients and their families always have needs since they encounter with hesitancy and unusual emotion about undesirable situation, such as cancer diagnosis (Printz, 2011).

Unmet needs, the indeterminable demands, help to determine the precedence of nursing intervention by indicating the most urgent necessity of cancer patients and their families (Sanson-Fisher et al., 2000). Unmet needs of patients can increase the level of caregiver burden (Sharpe et al., 2005; Kong and Guan, 2019), and

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caregivers' problems are also closely linked with patients' well-being (Milbury et al., 2013). Therefore, both unmet needs should be comprehensively assessed prior to designing and providing tailored palliative care services. Previous studies found caregivers reporting at least one need related patient cares that were unmet (Koohkan et al., 2019; Lambert et al., 2012), and a majority of their unmet needs was the information about cancer (Koohkan et al., 2019). Moreover, Sklenarova et al. (Sklenarova et al., 2015) found these unmet were regarding need of health care service, information, emotional and psychological needs, respectively.

There are two commonly measurement tools using to determine the unmet needs of the cancer (Girgis et al., 2011; Hodgkinson et al., 2007). One of them is the Cancer Survivors' Partners Unmet Needs (CaSPUN), a 36-item multi-dimensional tool, developed by Hodgkinson et al. in 2007 (Hodgkinson et al., 2007). However, this tool is definitely purpose for the caregivers caring for cancer patients at least one-year post-diagnosis. Another tool is the Supportive Care Needs Survey-Partners and Caregivers (SCNS-P&C) developed by Girgis et al. (Girgis et al., 2011). It is a multi-dimensional measurement tool consisting of 46 items; likewise, SCNS-P&C has been applied in many research areas (Best et al., 2014; Chen et al., 2016; Ownsworth et al., 2010) comparing with CaSPUN.

In Thailand, only a few studies were conducted for concerning family caregivers of cancer patients (Meecharoen et al., 2013), and no previous studies have been used this instrument for evaluating their unmet need. However, the utilization of the original version of the SCNS-P&C instrument has varied across studies as evidenced by the different numbers and natures of factors generated. There are also some methodological limitations in many of the previous validation studies of SCNS-P&C (Atli Özbaş et al., 2019; Baudry et al., 2019; Garvey et al., 2015; Liu et al., 2020; Rietveld et al., 2019), and lacking of psychometric measures limit the similarity of the findings, especially for those of difference in sociocultural background, it is vital to analyze the applicability of this scale for Thai society. Therefore, this study aims to carry out the Thai validity and reliability of the SCNS-P&C of CCA caregiver, which was originally developed to determine the supportive care needs of the relatives of patients diagnosed with CCA.

Materials and Methods

Study design and population

This two-phase cross-sectional study was designed to evaluate the psychometric properties of Thai supportive care needs survey—partners and caregivers (T- SCNS-P&C). First, involving the translation of the existing English version of SCNS-P&C (Girgis et al., 2011) into Thai, thereby establishing translational validity. Second, evaluating the psychometric properties of the T- SCNS-P&C.

Phase 1: Translation and content validity; Supportive care needs survey

The SCNS-P&C was originally developed to assess the multi-dimensional supportive care needs of cancer caregivers across the illness trajectory by Girgis et al. in 2011 (Girgis et al., 2011). This instrument consists of 45 items using a five-point rating scale (1-no need: not applicable; 2-no need: satisfied; 3- low need; 4-moderate need; 5-high need). It consists of four domains including, Health Care Service Needs, Psychological and Emotional Needs, Work and Social Needs, and Information Needs. The total score ranges from 45 to 225, a higher score indicating more supportive care needs. This English version has good internal consistency with Cronbach's alpha ranging from 0.88 to 0.94 for the four domains.

In our study, the SCNS-P&C items were translated from English into Thai using the forward and backward translation technique by four Thai English bilingual translators that was outlined by Brislin in 1970 (Brislin, 1970; Webber and Davies, 2011). Furthermore, we conducted a pilot test with 20 Thai CCA caregivers to evaluate the translational quality and the practical aspects of test administration. Each participant was asked to read and listen to each item in order to ensure their understanding.

Phase 2: Evaluating the Psychometric Properties of the T-SCNS-P&C

A total of 231CCA caregivers were drawn from Srinagarind Hospital, a public tertiary care university teaching facility. Only one family member was recruited for each CCA patient. Questionnaires were administered in December 2019 to February 2020. The inclusion criteria were: a family member of a patient diagnosed with CCA, 18 years of age or older, were capable of communication in Thai, and attending the hospital either inpatients or outpatients. Based on the minimum sample size recommendation for conducting confirmatory factor analysis (CFA).

Study instruments

The T-SCNS-P&C consists of 45 items that are distributed across 4 factors as follows: Communication and relationship (10 items), Health care and information (16 items), Social and work (11 items), and Psychological (8 items). All items are using a five-point rating scale. The total score was the sum of all need items, with higher scores indicating greater unmet needs.

The Thai version of Cancer Survivor's Unmet Needs (T-CaSUN) for CCA survivors were translated version of the CaSUN (Hodgkinson et al., 2007). This instrument is consisted of 20 items and distributed across 4 factors as follows: Intensive care (9 items), information (4 items), relationship (3 items), and medical care (4 items). All items are rated on participants answer whether the needs described by the items are not applicable, met, or unmet. If an unmet need is reported, the intensity of the need is then rated as weak (score 1), moderate (score 2), or strong (score 3), the total score was the sum of all need items, with higher scores indicating greater unmet needs.

The Thai version of the Memorial Symptom Assessment

Scale-Short Form (MSAS-SF) is a 32-item inventory rated on a 5-point Likert-type scale. Its purpose is to measure the frequency, severity, and distress associated with 32 separate, multidimensional symptoms experienced by patients (Chang et al., 2000). The MSAS-SF has been used with a wide range of illnesses and it's suitable for either clinical or research settings (Menezes et al, 2017; Webber and Davies, 2011; Wookey and McKean, 2016).

The Hospital Anxiety and Depression Scale (HADS) was used to assess a self-reported symptoms of anxiety and depression (Zigmond and Snaith, 1983). The HADS consists of 14 items including 7 items for anxiety and 7 items for depression. It evaluated the severity of symptoms throughout the previous week. The questions were rated on a 4-point Likert scale, with total scores ranging from 0 to 21 for both anxiety and sadness. A score of more than eight indicates that anxiety and sadness are being considered.

In addition, the questionnaire included questions relating to socio-demographics including gender, marital status, age, education level, religion and household income.

Sample size

The sample size was calculated using the formula "sample size = number of items X number of participants," which is a regularly used formula in survey development research. The sample size for each survey item should be between 5 and 10 participants, according to this calculation (Suresh et al., 2012). As a result, 231 CCA caregivers were included in this cross-sectional study.

Statistical analysis

Demographic data of the participants were summarized using descriptive statistics with means and standard deviation for continuous variables and counts and percentages, for categorical data.

For the T-SCNS-P&C measurement model, we specified the model as identified by several previous studies (Baudry et al., 2019; Liu et al., 2020; Rietveld et al., 2019). In particular, we followed the structure identified in the Taiwan study (Liu et al., 2020). Based on the results of the principal axis factoring, a CFA was performed using AMOS 26.0 software to precisely test the configuration of the factor structures of T-SCNS-P&C and determine whether the proposed factor structures adequately fit the data using maximum likelihood estimation. Model fit was assessed using the cumulative fit index (CFI), adjusted goodness of fit index (AGFI), root-mean-square error of approximation (RMSEA), and the Tucker-Lewis index. A model with TLI, CFI, GFI, and AGFI > 0.9, and RMSEA < 0.08 (Tabachnik and Fidell, 2012) was deemed to represent adequate model fit. We also reported the χ^2 statistics, typically a poor indicator of measurement model fit but included here for reasons of convention. Bartlett's test of sphericity and the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy were generated along with the CFA to provide further evidence of construct validity (Kaiser, 1974).

Internal consistency reliability was evaluated using Cronbach's alpha, and an acceptable reliability

was considered to be $\alpha > 0.7$ for all the subscales (Kline, 2000). The construct validity of T-SCNS-P&C was assessed using Pearson correlations with other variables such as MSAS-SF-T, T-CaSUN, HADS, sex, and educational level.

Ethical considerations

This research was approved by the research ethics committee of Khon Kaen University, Thailand (HE631628). Eligible participants were approached by nurses at their regular medical appointments or the study researcher at patient advocacy group meetings. After brief explaining the overview of the study protocol, we obtained the written informed consent from all participants.

Results

Two hundred and thirty-five CCA caregivers were included in this study with a mean age 46.11 (SD=11.46) years. The majority of participants were female (69.70%), married (95.24%), had a secondary school level of education (41.56%) (Table 1).

Construct validity

The T-SCNS-P&C measurement model was represented by 45 items distributed across four factors

Table 1. Baseline Characteristics of the Participants

Characteristics	Number	%
Gender n (%)		
Male	70	30.3
Female	161	69.7
Age (years) n (%)		
Mean \pm SD	46.11(\pm 11.46)	
Range	(19-74)	
Education n (%)		
Primary	73	31.6
Secondary	96	41.6
Bachelor	60	25.9
Master or Higher	2	0.9
Household income n (%)		
<5,000	53	22.9
5,000-9,999	53	22.9
10,000-14,999	66	28.5
15,000-19,999	33	14.2
20,000-24,999	7	3.3
\geq 25,000	19	8.2
Marital status n (%)		
Single	45	19.4
Married	175	75.6
Divorce	11	5.0
Caregiver type		
Partner	95	41.1
Child	131	56.7
Sister/Brother	5	2.2

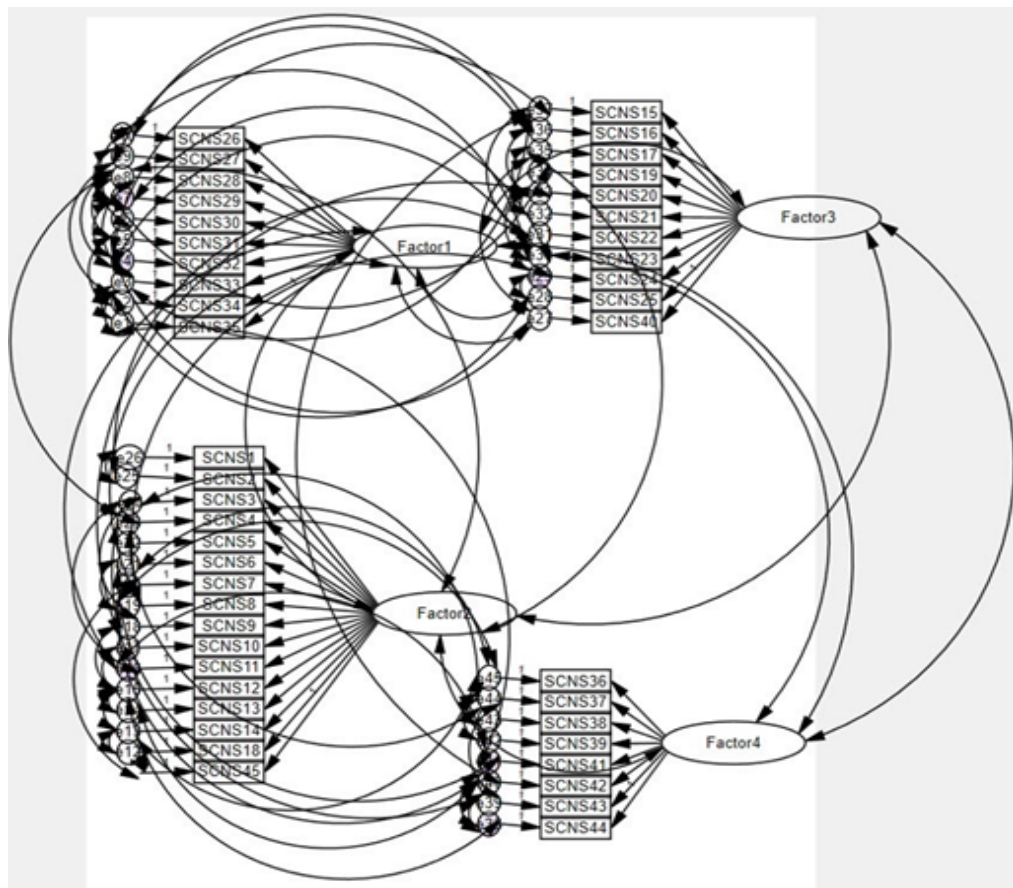


Figure 1. The Measurement Model for the CFA of T-SCNS-P&C based on a Four-Factor Structures Including: Communication and Relationship, Health care and information, Social and work, and Psychological.

and was fit using an unweighted least square CFA. Based on the five preestablished fit criteria, the model showed adequate fit to the data ($\chi^2 / df = 1.831$, GFI= 0.78, CFI = 0.94, and RMSEA = 0.06 (95%CI: 0.05–0.07). Standardized factor loadings ranged from 0.45 0.98 and all items in the model loaded significantly on their respective factors (all p-value < 0.05) except each factor-constraint item for which no significance test could be conducted (Table 2).

The KMO was 0.87, and Bartlett’s sphericity test was significant ($\chi^2 = 1591.416$, $df = 869$, and p-value < 0.001) indicating reasonable adequacy of the data for factor analysis.

Convergent validity

The correlations between the total scores of T-SCNS-P&C and anxiety and depression, physical symptoms and supportive care need of CCA patients also investigated with caregiver characteristics. Anxiety and depression from HADS subscales, sex, education level was found to be associated with various T-SCNS-P&C subscales (Table 3).

Internal consistency

The internal consistency of the T-SCNS-P&C was satisfactory with Cronbach’s alpha of 0.82 for the total scale, and 0.75 to 0.89 for each of the four domains. The corrected item-to-total correlations showed significantly low to moderate correlations ($r=0.27–0.64$) (Table 4).

Inter factor correlations

The inter factor correlations of the T-SCNS-P&C subscales are presented and illustrated that Communication and Relationship domain were strongly positively associated with Health care and information domain and moderately positively associated with Social and work domain and weakly positively associated with psychological domain. Health care and information domain was weakly positively associated with Social and work and psychological domain. Social and work domain was weakly positively associated with psychological domain (Table 5).

Discussion

To our knowledge, our study is the first of its kind in Thailand to carry out the Thai validity and reliability of the SCNS-P&C of CCA caregiver. The needs of family caregivers often go unmet in efforts focused on the health crisis of the patients. The SCNS-P&C (Girgis et al., 2011) is one of the most widely used instruments to measure supportive care need among cancer caregivers. However, several studies have adapted and translated the SCNS-P&C to be used across several healthcare setting and populations (Best et al., 2014; Chen et al., 2016; Ownsworth et al., 2010), so to use in these settings has generally not been supported by a prior appropriate validation. Indeed, to the best of our knowledge, only one previous study has conducted a CFA on the SCNS-P&C

Table 2. Standardized Factor Loading of the T-SCNS-P&C

SCNS-P&C items	Factor 1 Communication and relationship	Factor 2 Health care and information	Factor 3 Social and work	Factor 4 Psycho logical
26.Communicate with patient	0.96			
27.Communicate with family	0.97			
28.Support from family	0.88			
29.Talk to other cancer patients	0.94			
30.Discuss cancer at work/socially	0.95			
31.Concerns about recurrence	0.94			
32.Impact on relationship with patient	0.94			
33.Understand patient experience	0.97			
34. Balancing own and patient's needs	0.96			
35. Changes in patient's body	0.95			
1.Information care needs		0.68		
2. Information prognosis		0.7		
3. Information support services		0.84		
4. Information alternative therapies		0.72		
5. Information patient physical needs		0.73		
6. Information for decision making		0.79		
7. Best medical care patient		0.89		
8. Access local health services		0.74		
9. Involved in patient care		0.94		
10. Discuss concern with doctor		0.93		
11. Doctor coordinated care		0.71		
12. Case manager coordinated services		0.78		
13. Complaints regarding care addressed		0.77		
14. Reduce stress for patient		0.69		
18. Fertility problems in patient		0.68		
45. Opportunities to participate in decision making		0.92		
15. Look after own health			0.71	
16. Pain control for patient			0.75	
17. Fears about patient deterioration			0.73	
19. Practical caring tasks			0.73	
20. Accessible hospital parking			0.69	
21. Changes to patient's life/work			0.82	
22. Life/work changes for care			0.81	
23. Financial/government support			0.74	
24. Insurance for patient			0.6	
25. Access legal services			0.71	
40. Not acknowledging impact of caring			0.59	
36. Problems with sex life				0.96
37. Emotional support for self				0.66
38. Emotional support for loved ones				0.94
39. Feelings about death				0.74
41. Recovery not as expected				0.67
42. Decision making in uncertainty				0.66
43. Own spiritual beliefs				0.86
44. Meaning in patient's illness				0.74

Table 3. The Construct Validity for the Subscale of T-SCNS-P&C

Variable	Total score of T-SCNS-P&C	P-value
MSAS-SF-T	0.18	0.006
Sex	-0.147	0.026
Education level	0.16	0.015
T-CaSUN	0.148	0.011
HADS	0.22	0.001

Table 4. Cronbach's Alpha of Each Subscale of T-SCNS-P&C

Factor	Cronbach's alpha	95% CI
Communication and relationship	0.88	0.74- 0.96
Health care and information	0.89	0.65- 0.91
Social and work	0.85	0.74-0.91
Psychological	0.75	0.65- 0.81
Total scale	0.82	0.75- 0.86

(Chen et al., 2016), in this respect, the construct validity of SCNS-P&C has not been adequately established in a large majority of the studies having employed it.

The construct validation in this present study, we tested the structure of the SCNS-P&C identified in the Taiwan study (Chen et al., 2016), and established that the measurement model of the T-SCNS-P&C fits the data well. The findings of our study provide empirical evidence that the psychometric properties of the T-SCNS-P&C are satisfactory. The response rate was high with nearly 98%, and CCA caregivers answering all 45 items are distributed across 4 factors as follows: Communication and relationship (10 items), Health care and information (16 items), Social and work (11 items), and Psychological (8 items) on the T-SCNS-P&C scale for this population. On the basis of the analysis with a sufficient sample size, we found that the T-SCNS-P&C is a reliable and valid scale for routine using to assess the supportive care needs of Thai CCA caregiver in clinical practice. The T-SCNS-P&C presented good internal consistency ($\alpha = 0.82$, range of factor score = 0.75-0.89). In the original survey, a high internal consistency was found as well. Actually, coefficients above 0.95 indicating several items measure the same construct may be redundant. This suggests that future research could look into a shorter version of the survey.

Furthermore, the construct validity tends to supported that support care need was significantly correlated with physical effects, psychological, supportive care need of CCA patients, sex, and education level. These correlations may be explained that patients reported more unmet needs

when their caregivers were male, or those who suffered from psychological distress and having low education level are associated with need of caregivers (Morasso et al., 1999). In addition, variation of individual backgrounds (gender, and education level) may result in different ways of coping or responding to symptoms and help-seeking behavior (Sanson-Fisher et al., 2000). Likewise, caregivers with many physical problems probably experienced with many unmet needs (Chen et al., 2016). The unmet need of caregivers was also definitely increased when patients whom they were caring suffered from anxiety, depression, or low physical performance (Chen et al., 2016). Most common physical problems of the caregivers, the sole full-time caregiving, was sleepiness, and some of them had moderate to severe depression and anxiety. A lower functional status of the patients was associated with higher caregiver burden. Poorer physical status compared with before caregiving began, lower life satisfaction, and higher degrees of depression and anxiety were associated with higher caregiver burden (Liu et al., 2017).

In addition, in this study, a total score of the T-SCNS-P&C were significantly correlated with physical symptoms since these caregivers are expected to experience symptoms because of their prolong caregiving. This burden may cause psychological and physiological changes in the caregivers that may negatively influence their QOL as well as their mental and physical health (Lee et al., 2021). Informal caregivers commonly take care of their loved ones in period of their long-term survivorship (Chen et al., 2015); hence, the long-term caregiving process is physically and psychologically challenging, particularly when taking care of patients with advanced cancer (Cui et al., 2014).

Good relationship or communication between the healthcare team, cancer patients, and family can improve the patients' QOL. Our result revealed that communication and relationship subscale associated with both health care and information and social and work psychological subscale. As already noted, the need for both the information of cancer and the cancer care process was the first and most-prioritized unmet need of the family caregivers. Other studies have also confirmed that the need for information was the most important need of the informal caregivers of cancer patients. In a study conducted by Sajadian et al., (2015), getting information about breast cancer, self-care, and patient care, was the main need of the caregivers. In a study by Cui et al., (2014) of 649 family caregivers in Shanghai hospitals in China, the most prominent unmet needs included the need for knowledge about the disease, its treatment, and support from the healthcare staff.

There are several methodological limitations of this study. First, because this was a cross sectional designed

Table 5. Inter-Factor Correlation of T-SCNS-P&C

Domain	Health care and information	Social and work	Psychological
Communication and relationship	0.952	0.525	0.17
Health care and information	-	0.204	0.184
Social and work	-	-	0.113

All inter-factors correlation were statistically significant ($p < 0.001$).

study, test-retest reliability and criteria validity were not examined. Second, although the CFA supported the original model of the scale, we should be cautious of the fact that their certain items had low factor loadings and large residual errors.

To conclude, this study confirmed that the T-SCNS-P&C can serve as a valid and reliable tool to evaluate unmet needs among CCA caregivers. T-SCNS-P&C has the potential to identify the most beneficial interventions for individual CCA caregiver. A care needs assessment is one of the key principles for ensuring adequate care for CCA caregivers. Based on unmet needs identification, nurses may provide targeted interventions and individualized care aimed to positively influence the QOL of patients and their family members.

Author Contribution Statement

MS., PR., NM. envisioned the research idea. US. and MT. analyzed, interpreted the data, and helped to draft the manuscript. That was also discussed with MS. who supervised the research project. All authors revised the manuscript critically and approved the final version to be published.

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Ethical Approval

This research was approved by the research ethics committee of Khon Kaen University, Thailand (HE631628). The informed written consent was obtained from each of the study participants of this study. Besides, every participant was assured about the confidentiality of his personal information.

Availability of the data

Data can be provided on a duly justified request to the corresponding author.

Conflicts of Interest

The authors declare that there is no conflict of interests regarding the publication of this paper.

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