

# End-of-life Care Preferences among Cancer Patients in Southern Thailand: A University Hospital-based Cross-Sectional Survey

Jarurin Pitanupong (✉ [pjarurin@medicine.psu.ac.th](mailto:pjarurin@medicine.psu.ac.th))

Prince of Songkla University

Sahawit Janmanee

Prince of Songkla University

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## Research Article

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# Abstract

**Background:** End-of-life care preferences may be highly individual, heterogenic, and variable according to culture and belief. This study aimed to explore preferences and factors associated with end-of-life care among Thai cancer patients with the goal of helping optimize their quality of life.

**Methods:** A cross-sectional study surveyed cancer outpatients at Songklanagarind Hospital from August to November 2020. The questionnaires inquired about: 1) personal and demographic information, 2) experiences with end-of-life care received by relatives, and 3) end-of-life care preferences. To determine end-of life preferences, the data were analyzed using descriptive statistics. The data concerning patient demographics and end-of-life care preferences were compared using Fisher's exact test.

**Results:** The majority of the 96 cancer outpatients were female (65.6%), and the overall mean age was  $55.8 \pm 11.6$  years. More than half of them had an experience of observing someone die (68.8%), and they were predominantly satisfied with the care received by their relatives in passing away at home surrounded by family (47.0%) and being conscious until the time of death (68.2%). Most participants preferred receiving the full truth regarding their illness (99.0%), being free of uncomfortable symptoms (96.9%), having their loved ones around (93.8%), being mentally aware at the last hour (93.8%), and having the sense of being meaningful in life (92.7%). Their 3 most important end-of-life care wishes were receiving the full truth regarding their illness, disclosing the full truth regarding their illness to family members, and passing away at home.

**Conclusion:** In order to optimize the quality of life of terminal patients, end-of-life care should ensure they receive the full truth regarding their illness, experience no distress symptoms, remain mentally aware at the last hour of life, feel meaningful in life, and pass away comfortably with loved ones around.

## Background

According to WHO, cancer is one of the leading causes of death worldwide. In 2018, a study found that around 9.6 million people die from cancer every year, and the number of people dying from cancer is on the rise. Cancer patients suffer from both the disease and the related therapeutic processes, especially during the terminal stage [1]. Therefore, for patients who have a life-threatening disease and a life expectancy of 6 to 12 months, the care process should focus on improving the quality of life during the end-of-life (EoL) stage in order to assist patients to die in peace and comfort, and with dignity [2].

During the past decade, awareness on EoL care has increased, and the concepts related to it have changed over time [3-6]. Across cultures and ethnicities, being free from pain and shortness of breath, not being a burden to one's family, and feeling that one's life is completed have been rated as the core components of EoL care [7]. However, EoL care preferences are highly individual and heterogenic and vary widely according to one's culture and beliefs [4,6].

In the United States of America, a study found that the most important EoL care preferences among terminally ill patients were: being mentally aware until the last hour; having funeral arrangements planned; not being a burden to the family or society; being able to help others [8]; dying in one's sleep; and experiencing a quick, painless, and peaceful death, without suffering and while praying [8,9].

In the EU, a study in Sweden identified these EoL care preferences among adult palliative cancer patients: living with the prospect of imminent death, preparing for death, and dying comfortably [4]. Besides, various studies from Asia, South Korea, China, and Japan have reported these 4 most important components regarding EoL care preferences: not being a burden to others, having a good relationship with family members, having a good relationship with medical staff, and being free from physical and psychological discomfort [10-12].

However, the associated factors that lead to differences in EoL care preferences are age, religion, occupation, education, economic status, being married, having a family or caregiver, current serious illness, history of hospitalization, being a caregiver for a seriously ill patient, having the experience of a closed one dying, and self-satisfactory [11,13]. As reported previously, there are some different aspects regarding EoL care preferences between Asian and Western countries. The topics of death and dying could be discussed more freely in the West than in Asia. Moreover, in Asian societies, the family is more involved in decision-making related to EoL care, and Asians choose to die at home more frequently than Western people [1]. Hence, understanding the patients' EoL care preferences is key to succeeding in improving their quality of life. If health care providers do not have a firm grasp on these issues, the caring process that aims to promote a good quality of life for patients may be compromised [6,14].

In Thailand, a study conducted among Thai elderly patients from the central and northeast regions in 2017 revealed that their 3 most important EoL care preferences were receiving the full truth about their illness, passing away at home and having loved ones around at the time of death, and receiving relief from uncomfortable symptoms such as pain and shortness of breath [13]. However, to our knowledge, no study on EoL care preferences has been conducted in the Southern Region of Thailand over the past decade. Therefore, this study aimed to evaluate the EoL care preferences and associating factors among cancer patients from the South in order for its findings to provide basic knowledge that may be useful for the employment and/or establishment of a realistic and effective caring process through various psychosocial support frameworks before, during, and after the dying period.

## Methods

After being approved by the Ethics Committee of the Faculty of Medicine, Prince of Songkla University (REC: 63-099-03-4), this cross-sectional study was conducted at Songklanagarind Hospital, which is an 800-bed university hospital that serves as a tertiary referral center in Southern Thailand. All cancer patients who attended the radiotherapy clinic from August to November 2020 were invited to participate in this study. To be included, one had to meet the criteria of being a cancer outpatient aged more than 18 years old, being able to understand and use the Thai language, acknowledging his/her cancer diagnosis,

agreeing to participate in the study, and completing all of the questionnaires. Meanwhile, the cancer outpatients who were unaware of their cancer diagnosis, lacked the mental capacity to complete all of the questionnaires, did not wish to participate and/or wanted to stop completing the questionnaires were excluded.

In respect to the sample size calculation, the literature review suggested that the proportion of patients that agreed with each item of EoL care preference had to be at least 50.0%.<sup>1</sup> The following formula was used by the researcher to calculate the sample size:

$$n = \frac{z_{\alpha/2}^2 p(1-p)}{d^2}$$

where  $Z_{\alpha/2}$  represented the critical value of the normal distribution at  $\alpha/2$  (e.g., for a confidence level of 95%,  $\alpha$  was 0.05 and the critical value was 1.96);  $d$  indicated the margin of error, which was determined to have the value of 0.1; and  $p$  signified the proportion of preference toward EoL care. Therefore, we needed at least 96 subjects.

The researcher approached all of the potential cancer outpatients for recruitment and handed them an information sheet, which delineated the rationale for the study and the allotted time to complete the survey. They had at least 10-15 minutes to consider whether to collaborate in the study or not. If they wished to participate, they were asked to sign the informed consent form and were invited to a private location to complete the questionnaires. The researcher observed the participants' reactions and informed them that they could stop at any time if they felt uneasy, distressed, or were unwillingness to participate any further. Moreover, if the participants exhibited a high level of distress or worry, advice or further clinical management was provided to them.

## Measures

The questionnaires were reviewed by 5 psychiatrists, and a content validity was performed; the CVI was 0.8. A pilot study was done on 25 participants, and the Cronbach's alpha was 0.8. The questionnaire was composed of 3 parts:

1) Personal and demographic information inquiry consisting of questions related to age, gender, marital status, religion, income, education, hometown, number of household members, history of substance use, physical and psychiatric illness, history of hospital admission, and perception concerning their satisfaction with their health and life.

2) Inquiry regarding experiences with EoL care involving their relatives, which consisted of questions on experiences related to seeing someone die and being an EoL caregiver. Each item was rated as 'yes' or

'no'; the attitude toward experiences with the death of a relative was rated as 'satisfied', 'unsatisfied', or 'neither satisfied nor unsatisfied', meanwhile the attitude toward remembered death was rated as 'agree', 'disagree', or 'neither agree nor disagree' [1].

3) Inquiry on EoL care preferences, which consisted of 2 categories (total 15 items) [1,13].

3.1) Importance of EoL care comprised the 12 following items: receive the full truth about their illnesses, disclose the truth about their illnesses to family members, have loved ones around when needed, not be a burden to the family, complete unfinished business and be prepared to die, feel that life is meaningful, receive relief from uncomfortable symptoms, receive both physical and psychological treatment, participate in and perform religious rituals, be involved in treatment decisions, be mentally aware at the last hour, and pass away at home.

3.2) EoL care preferences consisted of the 3 following items: withholdment of futile life-sustaining treatment, administration of active pain control, and performance of active euthanasia.

The scores of all the 15 questions ranged from 1 to 5 (strongly agree, agree, disagree, strongly disagree, and neither agree nor disagree). The responses of 'strongly agree' and 'agree' were classified as indicating approval for the intervention [13]. Furthermore, the participants were asked to rate the 3 most important components among the 15 items.

## Statistical methods

Descriptive statistics such as proportion, mean, and standard deviation (SD) were calculated. The data related to patient demographics and end-of-life care preferences were compared using Fisher's exact test. The statistical significance was defined as a p-value of less than 0.05.

## Results

### Demographic characteristics

From August to November 2020, 96 cancer outpatients participated in the survey by completing the constructed questionnaires. The majority of them were female (65.6%), married (80.2%), and Buddhist (72.9%). The mean age was  $55.8 \pm 11.6$  years, and the median income (IQR) was 20,000 (10,000–37,500) baht per month. In additions, most participants were satisfied with their health (73.9%) and reported no history of substance use, physical illness, or psychiatric illness (89.6%, 63.5%, 97.9%, respectively). The most common physical diseases were hypertension (18.8%), diabetes mellitus (12.5%), and dyslipidemia (10.4%). Moreover, most participants were satisfied with their life (83.3%) (Table 1).

Table 1  
Demographic characteristics (n = 96)

<b>Demographic characteristics</b>	<b>Number (%)</b>
Gender	
Male	33 (34.4)
Female	63 (65.6)
Marital status	
Single / Divorced	19 (19.8)
Married	77 (80.2)
Religion	
Buddhism	70 (72.9)
Islam, Christianity	26 (27.1)
Education	
Primary school and below	39 (40.6)
Secondary school	28 (29.2)
Bachelor degree and above	29 (30.2)
Hometown	
Songkhla Province	25 (26.0)
3 Southern Border Provinces	21 (21.9)
Other	50 (52.1)
Physical illness	
No	61 (63.5)
Yes	35 (36.5)
Psychiatric illness	
No	94 (97.9)
Yes	2 (2.1)
History of substance use	
No	86 (89.6)
Yes	10 (10.4)
Number of household members	

<b>Demographic characteristics</b>	<b>Number (%)</b>
Alone	5 (5.2)
Less than 3	15 (15.6)
More than 3	76 (79.1)
History of admission	
Yes	46 (47.9)
No	50 (52.1)
Satisfaction with own health	
Excellent	3 (3.1)
Good	29 (30.2)
Fair	39 (40.6)
Poor	25 (26.0)
Satisfaction with life	
Satisfied	80 (83.3)
Unsatisfied	16 (16.7)

## **Experiences related to end-of-life care for relatives**

Sixty-six participants (68.8%) reported having had the experience of seeing a loved one die, and half of them had had the role of an EoL caregiver. The majority of them were satisfied with the end-of-life care their relatives had received in respect to passing away at home with family members around (47.0%) and being conscious until the time of death (68.2%). However, concerning the issues of dying in the hospital and resuscitation being administered or withheld, the majority of participants failed to give an opinion either way (66.7% and 69.7%, respectively) (Table 2).

Table 2  
Experience with and attitude towards the end-of-life care received by relatives (n = 66)

Type of EoL care	Number (%)
Passing away at hospital with CPR	
Good	8 (12.1)
Bad	14 (21.2)
No opinion	44 (66.7)
Passing away at hospital without CPR	
Good	14 (21.2)
Bad	6 (9.1)
No opinion	46 (69.7)
Passing away at home among family	
Good	31 (47.0)
Bad	15 (22.7)
No opinion	20 (30.3)
Attitude toward remembered death	
Good	45 (68.2)
Bad	14 (21.2)
No opinion	7 (10.6)

## End-of-life care preferences

In regard to the importance of EoL care, most participants identified five major caring components as the most important ones: receiving the full truth about their illnesses (99.0%), being relieved from uncomfortable symptoms such as pain and shortness of breath (96.9%), having loved ones around when needed (93.8%), being mentally aware until the time of death (93.8%), and having the feeling of being meaningful in life (92.7%). However, passing away at home was rated as the least important component among the five (61.5%), and one-third of them found it difficult to give an opinion about this component (31.2%) (Table 3).

Table 3  
End-of-life care preference (n = 96)

EoL care preference	Total (n = 96)	Age group (years)			P-value Fisher's exact test
		< 50 (n = 26)	50–60 (n = 44)	> 60 (n = 26)	
Importance of EoL care					1
Receiving the full truth regarding their illness					
Disagree	1 (1.0)	0 (0)	1 (100)	0 (0)	
Agree	95 (99.0)	26 (27.4)	43 (45.3)	26 (27.4)	
No opinion	-	-	-	-	
Disclosing the full truth regarding their illness to family members					0.61
Disagree	7 (7.3)	1 (14.3)	5 (71.4)	1 (14.3)	
Agree	88 (91.7)	25 (28.4)	38 (43.2)	25 (28.4)	
No opinion	1 (1.0)	0 (0)	1 (100)	0 (0)	
Having loved ones around when needed					0.501
Disagree	3 (3.1)	0 (0)	2 (66.7)	1 (33.3)	
Agree	90 (93.8)	26 (28.9)	41 (45.6)	23 (25.6)	
No opinion	3 (3.1)	0 (0)	1 (33.3)	2 (66.7)	
No physical or psychological burden to the family					0.089
Disagree	22 (22.9)	2 (9.1)	13 (59.1)	7 (31.8)	
Agree	69 (71.9)	21 (30.4)	29 (42)	19 (27.5)	
No opinion	5 (5.2)	3 (60)	2 (40)	0 (0)	
Complete unfinished business; prepare to die					0.289

EoL care preference	Total (n = 96)	Age group (years)			P-value  Fisher's exact test
		< 50 (n = 26)	50–60 (n = 44)	> 60 (n = 26)	
Disagree	12 (12.5)	1 (8.3)	8 (66.7)	3 (25)	
Agree	83 (86.5)	25 (30.1)	35 (42.2)	23 (27.7)	
No opinion	1 (1.0)	0 (0)	1 (100)	0 (0)	
Having the sense of being meaningful in life					0.528
Disagree	3 (3.1)	1 (33.3)	2 (66.7)	0 (0)	
Agree	89 (92.7)	23 (25.8)	40 (44.9)	26 (29.2)	
No opinion	4 (4.2)	2 (50)	2 (50)	0 (0)	
Being free of uncomfortable symptoms such as pain and shortness of breath					0.77
Disagree	2 (2.1)	0 (0)	2 (100)	0 (0)	
Agree	93 (96.9)	26 (28)	41 (44.1)	26 (28)	
No opinion	1 (1.0)	0 (0)	1 (100)	0 (0)	
Being treated both physically and psychologically					0.032
Disagree	6 (6.2)	0 (0)	6 (100)	0 (0)	
Agree	89 (92.7)	26 (29.2)	37 (41.6)	26 (29.2)	
No opinion	1 (1.0)	0 (0)	1 (100)	0 (0)	
Having religious rituals conducted the life					0.638
Disagree	16 (16.7)	6 (37.5)	7 (43.8)	3 (18.8)	
Agree	73 (76)	17 (23.3)	34 (46.6)	22 (30.1)	

EoL care preference	Total (n = 96)	Age group (years)			P-value Fisher's exact test
		< 50 (n = 26)	50–60 (n = 44)	> 60 (n = 26)	
No opinion	7 (7.3)	3 (42.9)	3 (42.9)	1 (14.3)	
Being involved in treatment decisions					0.168
Disagree	15 (15.6)	6 (40)	4 (26.7)	5 (33.3)	
Agree	77 (80.2)	20 (26)	36 (46.8)	21 (27.3)	
No opinion	4 (4.2)	0 (0)	4 (100)	0 (0)	
Being mentally aware at the last hour of life					0.619
Disagree	4 (4.2)	0 (0)	2 (50)	2 (50)	
Agree	90 (93.8)	25 (27.8)	41 (45.6)	24 (26.7)	
No opinion	2 (2.1)	1 (50)	1 (50)	0 (0)	
Passing away at home					0.381
Disagree	7 (7.3)	1 (14.3)	4 (57.1)	2 (28.6)	
Agree	59 (61.5)	13 (22)	30 (50.8)	16 (27.1)	
No opinion	30 (31.2)	12 (40)	10 (33.3)	8 (26.7)	
Preference of EoL care Withhold of futile life-sustaining treatment					0.415
Disagree	19 (19.8)	7 (36.8)	8 (42.1)	4 (21.1)	
Agree	74 (77.1)	17 (23)	35 (47.3)	22 (29.7)	
No opinion	3 (3.1)	2 (66.7)	1 (33.3)	0 (0)	
Active pain control					0.951

EoL care preference	Total (n = 96)	Age group (years)			P-value Fisher's exact test
		< 50 (n = 26)	50–60 (n = 44)	> 60 (n = 26)	
Disagree	8 (8.3)	3 (37.5)	3 (37.5)	2 (25)	
Agree	87 (90.6)	23 (26.4)	40 (46)	24 (27.6)	
No opinion	1 (1.0)	0 (0)	1 (100)	0 (0)	
Active euthanasia					1
Disagree	38 (39.6)	11 (28.9)	17 (44.7)	10 (26.3)	
Agree	57 (59.4)	15 (26.3)	26 (45.6)	16 (28.1)	
No opinion	1 (1.0)	0 (0)	1 (100)	0 (0)	

Regarding EoL care preferences, most participants reported a high level of preference for active pain control (90.6%) (Table 3). Moreover, the 3 most important reported components regarding EoL care wishes were: receiving the full truth about their illnesses, disclosing the full truth concerning their illnesses to the family, and passing away at home with loved ones around when needed and being mentally aware until the last hour. Moreover, receiving relief from uncomfortable symptoms such as pain and shortness of breath was also highly preferred.

## Association between demographic characteristics, experiences related to EoL care received by relatives, and EoL care preferences

We tried to discover the factors that associate with EoL care preferences. However, the majority of responses were agreement with one another, so no differences between the participants could be calculated. Therefore, according to this dataset, it might be concluded that no factors were associated with EoL care preferences.

## Discussion

This is the first study from Southern Thailand that surveyed the EoL care preferences of cancer patients. The five most important components of EoL care discovered were: receiving the full truth about their

illnesses, being relieved from uncomfortable symptoms such as pain and shortness of breath, having loved ones around when needed, being mentally aware until the time of death, and feeling meaningful in life. Furthermore, the participants placed a high level of preference on receiving the full truth about their illnesses, disclosing the full truth about their illnesses to the family, passing away at home with loved ones around when needed, and being mentally aware until the time of death. These findings support those of prior reports from the United States of America [8, 9] and the EU [4] as well as a study conducted among Thai elderly patients from the Central and Northeastern Regions of Thailand in 2017 [13]. A reason for this might be the fact that most participants in this study were older adults with a mean age of 55.8 years. Also, knowing the full truth about one's illnesses, being mentally aware until the time of death, preparing for death, and dying peacefully while feeling comfortable and without pain or suffering might be universal core EoL care preferences among terminally ill patients [4, 8, 9]. Although this study found a statistically different distribution among age groups regarding the end-of-life care preference of receiving both physical and psychological treatment, it was observed that the majority of respondents were in accord regarding this preference. Therefore, it could be said that there was insufficient evidence to conclude a difference between ages related to what type of treatment they preferred to receive.

Almost all participants identified 'receiving the full truth about their illnesses' as their number one need in regard to EoL care. Moreover, being mentally aware at the last hour of life was one of the five top EoL care preferences. This indicates that autonomy was of a critical importance to our cancer patients. However, since 'disclosing the full truth regarding their illnesses to family members' was a significant preference, it could be said that they were also likely to involve their family in the decision-making process related to EoL care. This finding is consistent with those of a prior study on Northern Thai patients with a terminal illness; they desired that both physicians and relatives be involved in deciding the EoL care they received [13]. Furthermore, this finding supports the report of a former study that Asian patients were more likely to have their family involved in medical decision-making rather than exercising full autonomy or decide only by themselves like most American and European patients do [1, 15, 16]. Concerning this matter and in light of this finding, Thai physicians should ask their patients whether they wish to receive information regarding their health conditions and treatment and to what extent, as well as whether they would like to be involved in making decisions related to their care or prefer that their families handle such matters [17].

In relation to being relieved from uncomfortable symptoms, the participants identified that 'being free from symptoms such as pain and shortness of breath', which cause suffering, was the second important component of EoL care. Once more, this finding is consistent with those of a prior study. They found that even before the EoL stage, nearly half of patients with cancer reported moderate to severe pain; up to 30.0% identified the pain as severe, and an estimated 25.0% died in pain [18]. Therefore, all physicians should make the exploration and relief of their patients' distress and suffering a priority of medical care. Moreover, knowledge of pain concepts, basic end-of-life pain management, and symptom control should be offered to patients and their families [19–21].

Regarding passing away, a good death is one that is free from avoidable suffering, for the patient, their relatives, and caregivers alike; in general accord with the patient's and family's wishes; and reasonably consistent with clinical, cultural, and ethical standards [10, 22]. Prior studies have identified some factors that influence the passing away process; they are: the location of patient domicile, previous occupation, educational level, family income, family size, and dissatisfaction with life [13, 23]. Moreover, it is known that most elderly Thai patients prefer dying at home [13]. However, this study revealed that only two-thirds of the participants agreed with passing away at home with loved ones around when needed and being mentally aware at the time of death, whereas one-third of them had no opinion on this matter. It seems that death with meaning and being remembered may be more significant than the place of death [24]. For cancer patients and their families, palliative home care might be difficult to manage due to factors such as the low level of home care support received by the public health system, and weakened family networks [25, 26]. Hence, the choice to die in a hospital might be less difficult for their families [23]. However, the preference for dying at home is greater when the patient lives with a caregiver, and the family physician makes home visits [27]. Therefore, both physicians and caregivers should pay attention to the patients' desires regarding the care they wish to receive as well as respect their characterization of a meaningful death. Moreover, patient care during the last hour in hospitals should be modified in order to make it as similar to passing away at home as possible.

Towards the good death, the concept, attitude, interconnectedness among family, caregiver, and health-care provider should be tuned in. These refer to the physical (symptom control), social (loved ones' presence), emotional (sharing emotions), and spiritual (inner peace) dimensions. Moreover, the patient's awareness, acceptance of death, ability to say goodbye to family and friends meaningfully, and the respect for the patient's wishes should be ensured [23]. For dying individuals to experience love and be understood as valuable even were both of healing. If health-care professionals can provide a compassionate and peaceful environment that facilitates acceptance and hope, the spiritual life of patients is enhanced [22, 28].

Finally, given the importance of family caregivers and health-care providers in providing care and their impact on the patients' dying process, it is necessary to reflect upon how their attitudes and prior experiences influence the care for the dying [23, 28]. Hence, a good relationship with family members and healthcare providers improves the patient's level of self-satisfaction, makes the avoidance of death less likely and the acceptance of death more possible, and enhances their feeling of interconnectedness [13, 28]. These would go a long way in optimizing the terminally ill patients' quality of life during their EoL period.

To our knowledge, this is the only study on this topic conducted in Southern Thailand during the past decade, which employed an adequate sample size. However, the study was quantitative, and the sample size was restricted to only cancer outpatients in the lower Southern Thailand. Hence, its findings may not represent the situation of cancer patients in the whole country fairly. Henceforward, future studies should include a larger number of cancer outpatients from other hospitals within Thailand; in other words, multi-

center research that aims to elucidate issues should be conducted. Moreover, such studies should employ a more qualitative approach or in-depth methodology that is adept to explore specific disorders.

## **Conclusion**

The care for terminally ill patients that is focused on optimizing their quality of life during the end-of-life period should ensure that the patients receive the full truth about their illnesses, be free of distress symptoms, remain mentally aware until the last hour of life, feel that they are meaningful in life, and pass away comfortably with loved ones around. Further studies encompassing other areas or settings and employing a more qualitative approach are recommended.

## **Abbreviations**

EoL: End-of-life

## **Declarations**

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## **Authors' contributions**

JP and SJ were involved in the conceptualization and design of the study, data collection and analysis, as well as the drafting of the manuscript and figures. All authors contributed to and approved the final manuscript.

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## **Availability of data and materials**

The dataset supporting the findings of this study can be made available upon request to the corresponding author via email at [pjarurin@medicine.psu.ac.th](mailto:pjarurin@medicine.psu.ac.th).

# Ethics approval and consent to participate

The Ethics Committee of the Faculty of Medicine, Prince of Songkla University approved this study (REC: 63-099-03-4). Adhering to the policy of strict confidentiality, the signatures of participants were required, but personal identifiers were removed before data analysis, and all of the participants retained the right to withdraw from the study at any time. We confirm that all methods were carried out in accordance with relevant guidelines and regulations in the Ethical Declaration. We also confirm that informed consent was obtained from all participants.

## Consent for publication

Not applicable.

## Competing interests

The authors declare that they have no conflicts of interest.

## Author details

<sup>1</sup>Department of Psychiatry, Faculty of Medicine, Prince of Songkla University, Hat Yai, Songkhla, 90110, Thailand

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