

Factors Influencing a Family's Decision Regarding the Withdrawal of Life Support in Palliative Care Patients

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Abstract

Objective: Thailand has just applied Withdrawal of life support (WDS) in palliative care patients. In Asian cultures, family members often conceal the diagnosis and prognosis from the patient; hence, the WDS decision mostly falls on the family members. This study's objective is to explore the factors that influence a family's decision regarding WDS in palliative care patients.

Method: A prospective, cross-sectional survey was conducted at Roi Et Hospital in northeast Thailand between 1 August 2019 and 31 July 2020. Data were collected via interviews with 282 surrogated family members of palliative care patients who had undergone intubation. The structured questionnaire comprised the following: 1) patient's demographic data, 2) family's demographic data, and 3) factors influencing the family's decision regarding the WDS. Descriptive, univariate, and multivariate analyses were performed using multiple logistic regressions.

Results: Of the 282 participants, 85.1% lacked palliative care knowledge and 86.9% had no experience of terminal illness care. Furthermore, 61.3% of the family members agreed to WDS. The factors influencing the family's decision were usage of inotropic drug (OR Adj. = 3.84; 95% CI: 2.05-7.17), family consensus (OR Adj. = 3.30; 95% CI: 1.42-7.71), experience of terminal illness care (OR Adj. = 3.20; 95% CI: 1.21-8.42), advance care plan (OR Adj. = 2.87; 95% CI: 1.17-6.23), place of death (OR Adj. = 3.59; 95% CI: 1.84-7.02), and personal aspects (OR Adj. = 1.18; 95% CI: 1.10-1.25).

Conclusion: The factors influencing the decision of WDS were recognition of disease severity by family members, family's experience, and patient's wish. This was related to the local culture. Hence, measures should be taken to develop palliative care in Thailand considering its unique culture. Programs to educate the citizens, promote living wills, provide advanced directive care to decrease caregiver burden, and prepare for the increasingly ageing society are necessary.

Keywords: Withdrawal of life support; Family decision; Palliative care; End of life care; Asian cultures; Factor; Thailand

Introduction

Palliative care focuses on managing patients with life-threatening illness, to prevent and relieve their suffering and improve their quality of life until the end of life. The process involves all-round treatment, including relieving their physical, psychological, psychosocial, and spiritual suffering [1]. Withdrawal of life support (WDS) is an alternative process used for palliative care patients who are terminally ill and is not intended to accelerate patient's death. The decision of WDS is based on medical principles, medical ethics, and law. The guidelines for helping physicians provide improved and quality end-of-life care for patients including preparation for the withdrawal of life-sustaining measures, assessment of distress, pharmaceutical management of distress, and discontinuation of life-sustaining measures and monitoring [2,3]. Each year, approximately 40 million people around the world require palliative care [4-6]. In Thailand, an upper-middle-income country, the leading causes of death are cancer, cardiovascular diseases, and pneumonia [7]. Recently, palliative care has been increasingly provided to terminally ill patients in limited hospitals and communities. Roi Et Hospital is one of the palliative care units to care for patients until the disease progresses to the end of life. The services include inpatient, ambulatory, and home visits, along with care from the primary doctor. Currently, the number of patients in Roi Et Hospital who require palliative care has increased, with 22.56% of palliative care patients requiring WDS in 2019 [8]. Although many patients have undergone WDS, no previous study has reported on the factors influencing a family's decision regarding the WDS in palliative care patients in Thailand. Therefore, this study

aimed to explore the factors that influence a family's decision regarding the WDS in palliative care patients. Our findings could contribute to an increasingly ageing society and decrease the psycho-socioeconomic burden on family members and the nation.

Material and methods

This was a prospective, cross-sectional survey study. All data were collected from Roi Et Hospital in the north-eastern region of Thailand from 1 August 2019 to 31 July 2020. Of the 1,792 palliative care patients, 398 had undergone intubation. We selected palliative care patients who had been diagnosed with terminal illnesses and who had undergone intubation and their primary doctors had suggested that the disease was severe (APACHE II score > 34), irrespective of whether the family member decided to perform WDS for the patient. We excluded palliative care patients who had an illness caused by an accident, were engaged in a lawsuit because of Thai law regulation, whose family members refused to participate, who passed away

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before the family meeting, or whose family members disagreed with the care plan and caused conflicts in the family. The Withdrawal of Mechanical Ventilation in Anticipation of Death in the Intensive Care Unit study [9] was used for sample size calculation using the mean of two independent proportions $p_1 = 0.873$, $p_2 = 0.964$, $\alpha = 0.05$, $\beta = 0.20$.

Data collection

Research tools

A three-part questionnaire was used to collect information regarding the patients, family members, and factors influencing WDLS. Part 1 comprised demographic data of the patients, such as gender and age, principal diagnosis, inotropic drug usage, ward of admission, central venous catheter usage, haemodialysis, consciousness, patient's awareness of the disease(s) and prognosis, and advance care plan. Part 2 included demographic data of family members who made the decision regarding WDLS, such as gender, age, relationship with patient, primary caregiver, education level, occupational status, palliative care knowledge, and experience in terminal illness care. Part 3 comprised factors influencing WDLS and included personal aspect, family and caregiver aspect, socioeconomic aspect, and spiritual aspect. Personal aspect included if the patient was older, had severe symptoms and poor prognosis, progressive disease, incurable disease, if symptoms worsened during treatment, and suffering during treatment. Family and caregiver aspect included the presence of a primary caregiver for the patient, additional caregivers who rotated, caregiver burden, and others who obliged to take care. Socioeconomic aspect included caregiver's problems during the care of the patient, primary caregiver's salary, work-related problems, financial problems or traffic problems. Spiritual aspect included if the families and communities had strict cultural or religious beliefs regarding death and their preferred place of death according to their local culture. The assessment of the research tools was conducted by palliative care doctors and three experts. They verified that the index of item-objective congruence was 0.75 and Cronbach's alpha coefficient was 0.87.

Data collection process

After assessment of the patients, the primary doctor suggested if the disease was severe and terminal. The primary doctor consulted with the palliative care team to determine the best supportive care and advance care plan for the patients who had undergone intubation; end-of-life decisions for the patients were usually made at the family meeting. Next, all family members decided on whether to perform WDLS for the patient. Only the surrogated family member was asked to provide informed consent and interviewed using the three-part structured questionnaire by the trained interviewer. Other data were collected from medical documents. The interview took approximately 30-45 min.

Statistical analysis

The data analyses used descriptive statistics and inferential statistics, which included univariate and multivariate analyses using multiple logistic regression. Statistical significance was set at $p < 0.05$.

Ethical considerations

This study was approved by the Ethical Committee of the Roi Et Hospital. The reference number is RE042/2562. This study was conducted in accordance with the principles set by the Declaration of Helsinki and its future amendments or comparable standards.

Results

Data were collected for 282 (70.9%) of the 398 patients in the sample group. A total of 116 (29.1%) patients were excluded; the APACE II score of 56 patients was < 34 points, 4 patients were suffering from accident-related illness, 8 patients' family members disagreed with the care plan resulting in family conflicts, and the family members of 48 patients refused to participate. For the analysis, we included 282 surrogated family members of palliative care patients as participants. The family members were at least 20 years old and could read, write, and communicate in the Thai language. The proportion of surrogated family members who decided to perform WDLS was 61.3% (95% CI: 55.39-67.06). A total of 82.6% participants relied on family consensus decisions, while the rest relied only on the surrogated family members' decisions.

The mean (\pm SD) age of the patients who received mechanical ventilation was 67.2 ± 13.1 years -62.1% were men, and 74.8% were general ward patients. The diagnostic categories on admission were as follows: sepsis in 65 patients (23.0%), end-stage renal disease in 49 patients (17.4%), hepatocellular carcinoma/ cholangiocarcinoma in 46 patients (16.3%), lung cancer in 45 patients (16.0%), and other categories in 27.3%. Of the patients, 40.1% received inotropic drugs, 13.8% used central venous catheters, 9.6% received haemodialysis, 36.5% were in coma, and 71.6% and 34.4% knew about the disease and prognosis, respectively. The data are shown in Table 1.

Of the 282 participants, 77.3% were women, 63.1% were a descendant, 42.9% had graduated primary school, 38.3% worked in agriculture, 33.7% earned < 150 US dollars per month, 95.4% were primary caregivers, 85.1% lacked basic knowledge of palliative care, 13.1% had experience of terminal illness care, and 19.1% patients had informed the caregiver about their final care wishes and the family regarding their preferred place of final care and place of death; the mean (\pm SD) age was 46.4 ± 10.9 years. The data are shown in Table 2.

Family's opinions on the factors

This study showed four aspects of care, which included individual, family and caregiver, socioeconomic, and cultural aspects. Regarding the individual aspect, the participants thought the 'disease was the most severe and progressive' (92.1%), followed by 'it was incurable' (88.9%), 'patient's symptoms worsened during treatment' (80.1%), and 'patient was older' (42.6%). Regarding family and caregiver aspects, 95.3% of the patients had primary caregivers, 51.3% had additional caregivers who rotated, and the primary caregiver had a caregiver burden of 8.2%. Regarding the socioeconomic aspects, 52.2% of the primary caregivers had salaries, 11% had trouble travelling between their house and the hospital, and 7.8% had financial problems. Regarding culture, 12.5% of the families and communities had strict cultural or religious beliefs regarding death and 19.2% followed strict local culture regarding the place of death (Most patients needed to die at home. If they died at the hospital, they may not bring the corpse back to the community). Furthermore, some villages believed that they could not have multiple corpses and more than one funeral at the same time.

When comparing the family member who decided to perform WDLS to the one who did not require WDLS, after adjusting for sex and age, we found that the factors that influenced family decision regarding the WDLS were inotropic drug usage ($OR_{Adj.} = 3.84$; 95% CI: 2.05-7.17), family consensus ($OR_{Adj.} = 3.30$; 95% CI: 1.42-7.71), experience of terminal illness care ($OR_{Adj.} = 3.20$; 95% CI: 1.21-8.42), patient informing the caregiver of their final care wishes in advance ($OR_{Adj.} =$

Table 1: General characteristics of patients in palliative care treatment (n = 282).

Characteristics and factor of patients	Total (n = 282)		WDLS Yes (n = 173)		WDLS No (n = 109)		p-value
	n	%	n	%	n	%	
Gender							0.272
Male	175	62.1	103	59.5	72	66.1	
Female	107	37.9	70	40.5	37	33.9	
Age (years)							0.16
<60	74	26.2	40	23.1	34	31.2	
60-69	73	25.9	42	24.3	31	28.4	
70-79	79	28	56	32.4	23	21.1	
≥80	56	19.9	35	20.2	21	19.3	
Mean (SD)	67.2	-13.1	68.5	-12.6	65.2	-13.6	
Principle diagnosis							0.077
Heart failure	16	5.7	13	7.5	3	2.8	
Lung cancer	45	16	29	16.8	16	14.7	
Hepatocellular carcinoma/cholangiocarcinoma	46	16.3	24	13.9	22	20.2	
End-stage renal disease	49	17.4	29	16.8	20	18.3	
Stroke	33	11.7	22	12.7	11	10.1	
CA prostate	10	3.5	5	2.9	5	4.6	
Sepsis	65	23	35	20.2	30	27.5	
Others	18	6.4	16	9.2	2	1.8	
Ward							0.901
General ward	211	74.8	129	74.6	82	75.2	
Intensive care unit	71	25.2	44	25.4	27	24.8	
Inotropic drug used							0.001*
No	169	59.9	91	52.6	78	71.6	
Yes	113	40.1	82	47.4	31	28.4	
Central venous catheter							0.69
No	243	86.2	148	85.5	95	87.2	
Yes	39	13.8	25	14.5	14	12.8	
Haemodialysis							0.863
No	255	90.4	156	90.2	99	90.8	
Yes	27	9.6	17	9.8	10	9.2	
Consciousness							0.253
Alert	66	23.4	36	20.8	30	27.5	
Drowsiness	45	16	30	17.3	15	13.8	
Stupor	68	24.1	47	27.2	21	19.3	
Coma	103	36.5	60	34.7	43	39.4	
Patient knew about the disease							0.269
No	80	28.4	45	26	35	32.1	
Yes	202	71.6	128	74	74	67.9	
Patient knew about the prognosis							0.095
No	185	65.6	107	61.8	78	71.6	
Yes	97	34.4	66	38.2	31	28.4	

2.87; 95% CI: 1.17-6.23), patient informing the family regarding a place of final care or place of death in advance (OR_{Adj.} = 3.59; 95% CI: 1.84-7.02), and personal aspect (severe and progressive disease, incurability of disease, and worsening of symptoms) (OR_{Adj.} = 1.18; 95% CI: 1.10-1.25). The data are shown in Table 3.

Discussion

In this study, palliative care patients who underwent mechanical ventilation and family decisions regarding the WDLS had the same baseline characteristics. The prevalence of WDLS was among 61.3% of all palliative care patients, which was higher than that in previous years [8] and consistent with the situation globally [9]. According to the demographic data of patients and family, the north eastern region of

Thailand is a low socioeconomic society and mainly agricultural. Most people live with their extended family; hence, most of the caregivers are descendants of the patient. Consequently, although the patient is conscious and alert, the doctors are responsible for informing the family members about the patient's diagnosis and prognosis, advance care plan, and WDLS decision. Nearly one-fourth of the patients were diagnosed with sepsis, which is generally found in developing countries. However, most of them were placed in the general ward instead the ICU because of a lack of hospital resources. In addition, Thailand has more palliative care knowledge, and patients can access palliative care treatment easily. Medical staff understand and accept the palliative care concept more than they did in the past, which could contribute in preparing the nation to deal with the increasingly ageing society in the near future.

Table 2: General characteristics of family members (n = 282).

Characteristics and factors of family members	Total (n = 282)		WDLS Yes (n = 173)		WDLS No (n = 109)		p-value
	n	%	n	%	n	%	
Gender							0.721
Male	64	22.7	40	23.1	24	22	
Female	218	77.3	133	76.9	85	78	
Age (years)							0.142
<40	67	23.8	48	27.7	19	17.4	
40-49	109	38.6	66	38.2	43	39.5	
50-59	75	26.6	44	25.4	31	28.4	
≥60	31	11	15	8.7	16	14.7	
Mean (SD)	46.4	-10.9	45.6	-10.5	48.4	-11.1	
Relationship with patients							0.134
Husband/Wife	66	23.4	33	19.1	33	30.3	
Descendant	178	63.1	118	68.2	60	55.1	
Parents	3	1.1	1	0.6	2	1.8	
Sibling	18	6.4	10	5.8	8	7.3	
Relative	17	6	11	6.3	6	5.5	
Primary caregiver							0.814
No	13	4.6	7	4	6	5.5	
Yes	269	95.4	166	96	103	94.5	
Family consensus							0.025*
No	49	17.4	37	31.4	12	11	
Yes	233	82.6	136	78.6	97	89	
Education							0.488
Primary school	121	42.9	68	39.3	53	48.6	
Secondary school	52	18.4	34	19.6	18	16.5	
High school	54	19.2	33	19.1	21	19.3	
Bachelor's Degree	49	17.4	33	19.1	16	14.7	
Master's Degree/Higher	6	2.1	5	2.9	1	0.9	
Occupation							0.644
Public servant	23	8.1	14	8.1	9	8.3	
Trade	38	13.5	24	13.9	14	12.8	
Agriculture	108	38.3	68	39.3	40	36.7	
Employment	51	18.1	35	20.2	16	14.7	
State enterprise	6	2.1	3	1.7	3	2.8	
Unemployed/others	56	19.9	29	16.8	27	24.7	
Monthly Income (US dollars)							0.146
≤150	95	33.7	57	32.9	38	34.9	
151-300	75	26.6	48	27.8	27	24.8	
301-450	39	13.8	18	10.4	21	19.2	
>451	73	25.9	50	28.9	23	21.1	
Basic knowledge of palliative care							0.074
No	240	85.1	142	82.1	98	89.9	
Yes	42	14.9	31	17.9	11	10.1	
Experience of terminal illness care							0.010*
No	245	86.9	143	82.7	102	93.6	
Yes	37	13.1	30	17.3	7	6.4	
Patient informed the caregiver of their final care wishes							<0.001*
No	228	80.9	128	74	100	91.7	
Yes	54	19.1	45	26	9	8.3	
Patient informed the family regarding the place of final care or place of death							<0.001*
No	184	65.2	91	52.6	93	85.3	
Yes	98	34.8	82	47.4	16	14.7	
Factors influencing the family's decision regarding WDLS for palliative care patients							
Personal aspect (Mean ± SD)	30.34	± 5.23	31.82	± 4.66	28	± 5.24	<0.001*
Family aspect (Mean ± SD)	15.2	± 3.51	15.32	± 3.49	15.01	± 3.54	0.464
Socioeconomic aspect (Mean ± SD)	6.41	± 0.23	6.71	± 0.29	5.93	± 0.36	0.094
Spiritual aspect (Mean ± SD)	0.83	± 0.12	1.01	± 0.16	0.55	± 0.15	0.083
Total (Mean ± SD)	52.78	± 8.49	54.86	± 7.97	48.49	± 8.28	<0.001*

Table 3: Multivariate factors influencing the family decision regarding WDLS for palliative care patients.

Factors	WDLS		Crude OR (95% CI)	Adjusted OR (95% CI)	p-value
	Yes n (%)	No n (%)			
Inotropic drug used					<0.001
No	91 (52.3)	78 (71.6)	1.00	1.00	
Yes	82 (47.7)	31 (28.4)	2.29 (1.37-3.83)	3.84 (1.37-3.83)	
Family consensus					0.006
No	37 (31.4)	12 (11.0)	2.20 (1.09-4.43)	3.30 (1.09-4.43)	
Yes	136 (78.6)	97 (89.0)	1.00	1.00	
Experience of terminal illness care					0.019
No	143 (82.7)	102 (93.6)	1.00	1.00	
Yes	30 (17.3)	7 (6.4)	6.5 (1.80-8.29)	3.20 (1.27-7.09)	
Patient informed the caregiver of their final care wishes					0.003
No	128 (74.0)	100 (91.7)	1.00	1.00	
Yes	45 (26.0)	9 (8.3)	3.87 (1.80-8.29)	2.87 (1.17-6.23)	
Patient informed the family regarding a place of final care or place of death					<0.001
No	91 (52.6)	93 (85.3)	1.00	1.00	
Yes	82 (47.4)	16 (14.7)	5.18 (2.82-9.53)	3.59 (2.89-9.53)	
Personal aspect	31.82 (4.7)	28.00 (5.2)	1.17 (1.11-1.24)	1.18 (1.10-1.25)	<0.001

Factors that influenced family decisions regarding the WDLS were related to six statistically significant factors: inotropic drug usage, family consensus, family members' experience in end-of-life care, final care wishes informed in advance, place of death, and personal aspects (severe and progressive disease, incurable, and worse symptoms). The inotropic drugs used were norepinephrine bitartrate and dopamine. The patients which shock stage were given inotropic drugs before palliative care team assessment. If the family members decided to opt for WDLS, palliative care team included inotropic drugs at home. If the family members decided to continue treatment, palliative care team managed the symptoms and continued using inotropic drugs. This was consistent with the results of previous studies. Each study reported an important factor that affected decision-making, which included poor prognosis related to severe disease, inotropic drug usage, poor cognitive function, poor quality of life, and living will. Cook et al. [10] reported that the factors related to a physician's decision regarding the WDLS in an ICU were inotropic drug usage, age, severity of disease, organ failure, poor prognosis [11-13,16], and cognitive function [10]. In an ICU at a cancer centre, the factors related to WDLS were living will [11,12,14], quality of life [12-14], prognosis, and medical resources [14]. In Thailand, the laws regarding palliative care (living will) are still unknown, misunderstood, and inaccessible to the public. People do not have a living will; however, they could inform their caregiver of their final care wishes. People believe that talking about death, severe disease, or the end of life is taboo and sensitive. Therefore, doctors often discuss bad news with the relatives and conceal it from the patients. Most patients do not know the true disease or prognosis; hence, they cannot prepare themselves or make an advance care plan. This study found that 27.7% of the patients had informed their caregiver of their final care wishes and 34.8% had informed the family about a place of final care or place of death, although they did not know about their disease and prognosis which was related to WDLS. Further, all patients who conveyed their wishes regarding their death plan chose to die at home. This study was conducted in the north-eastern region of Thailand and 100% of patients chose to die at home as they believed that if they died outside, their remains would not be brought back to their house for religious ceremonies. This was consistent with the results of previous studies. Scott et al. studied the palliative care concept in northern

Thailand and found that the doctors concealed the nature of the disease and prognosis from the patients. The family believed in repaying the gratitude of the parents and took care and protected them from both physical and mental harm. The family believed that giving bad news to a patient would discourage them and lead to death. They believed that the home held their mind and souls when the end of life came; hence, most patients needed to die at home [15]. Similar to Hung et al.'s [13] study in Taiwan, discussing death and a living will with patients directly is a sensitive subject and cannot be discussed openly in Asian cultures [16,17]. Close relatives are the main decision makers for treatment [13]. Phua et al. [16] studied the factors related to WDLS in Asian ICUs and found that many correlated with decision-making based on personal attitudes; country or locality; and cultural, religious, and legal fragments. Asian cultures focus on family consensus [11,13,14,16] while western cultures focus on the rights of patients [16]. The United States and Western Europe have laws to support patients' living will, and the treatment is provided based on the patients' needs. However, when patients cannot make decisions, the doctor asks the family or relatives to decide on a treatment plan [18,19].

In Thailand, most patients have WDLS performed at home, which differs from European countries where WDLS is performed in the ICU [2,3,9,10,12]. This study found that 17.3% of family members had experience in end-of-life care, which is an important factor when deciding on WDLS for patients. Family members' experience in end-of-life care allowed them to understand the patients' needs and increased confidence in their care. However, some patients who knew about their disease and prognosis were able to prepare an advance care plan. This prevented medical futility and reduced treatment costs. Finally, when the patient was unconscious, the primary decision maker or the family participated in planning the treatment to reduce conflicts with the healthcare team and family members.

This study has some limitations. First, some participants did not know about their disease and prognosis; hence, they did not know about the advance care plan for the patients, which made data collection complicated and incomplete. Second, the relatives who did not take care of patients often had opposing opinions with relatives who regularly took care of the patients. Hence, patient care plans

changed, which made data collection complex and incomplete. Third, the relatives were afraid of the patient's death in the hospital and took them home without waiting for the palliative care team. Hence, we could not collect data. Fourth, most relatives lacked knowledge regarding palliative care treatment. Therefore, they did not create an advance care plan as Thai traditions and culture emphasise on the patient's benefit more than autonomy.

Conclusion

The factors influencing WDLS were severity of the patient's disease, family opinion, and patient's wishes. This study revealed that most patients do not know about their disease and prognosis. Hence, they cannot plan about treatment care. As a result, treatment may not be beneficial. Modern medical facilities, area, religion, culture, and beliefs regarding end-of-life care in each country and culture are different. Asian cultures focus on family consensus and western cultures focus on the rights of patients (autonomy). However, in all cultures, when patients cannot make decisions, the doctor allows families to participate in the decision-making on their behalf for the benefits of the patients. This includes bad news and confrontations with death. It is also a challenge to have an open dialogue in Asian countries. Most of the families were from low socioeconomic backgrounds, and they had their own unique culture. Hence, efforts should be made to develop palliative care in Thailand considering its unique culture. Programs to educate the citizens, promote living wills, advanced directive care to decrease caregiver burden, national burden, and prepare for the increasingly ageing society are necessary.

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Conflict of Interest

The author declares that there are no conflicts of interest.

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