Public Awareness and Attitude toward Palliative Care in Thailand

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ABSTRACT

Objective: This study aims to examine the Thai public's awareness and attitude toward the end of life and palliative care.

Methods: We surveyed between February and April 2018. The sampling was framed by the Thailand National Statistical Office and used a stratified four-stage sampling. A total of 2,394 adults aged 20 to 80 years who had lived in one of nine provinces across all of Thailand for at least 3 months were interviewed with a questionnaire, which consisted of four parts.

Results: Thai culture and tradition were the main barriers to discuss the end of life preparation. Only 43% of the respondents, most of whom were elderly with chronic diseases, had concerned about the end of life. Most elderly respondents preferred to receive end-of-life care at home. Only 24% of respondents knew of palliative care. Most respondents believed that palliative care was provided in public hospitals. Most respondents (92%) were familiar with section 12 of the National Health Act., B.E. 2550, which states that a person has the right to refuse medical treatment; however, majority (79%) had never heard of a living will and only 14% had experience of advance care planning.

Conclusion: Public awareness on the end of life preparation of Thai people was challenged and limited. The main barriers to concerns about it are attitude and knowledge. Promoting and educating palliative care is necessary as well as improve the availability of palliative care, both institutional and home-based care.

Keywords: End of life; palliative care; advance care planning; living will (Siriraj Med J 2020; 72: 424-430)

INTRODUCTION

Many countries are experiencing rapid population ageing. Because of age-related increases in cancer and non-communicable diseases (NCDs), the need for palliative care is also increasing. According to the World Health Organization (WHO) Global Health Estimates, there were approximately 54.6 million deaths in 2011, the majority of which were caused by NCDs (66%). Moreover, over 29 million deaths were the result of diseases requiring palliative care, and approximately 20.4 million patients, most of whom were adults aged over 60 years (69%), were reportedly in need of palliative care at the end of life.[1]

As people age, they live and die with increasingly complex medical conditions, which in turn leads to an increasing demand for palliative care. The WHO has advocated that palliative care be made a public health service because it can substantially improve the quality of life of patients and families.[2] Moreover, the Worldwide Palliative Care Alliance (WPCA) recommends in 2014 that palliative care be integrated into health systems alongside curative care. In fact, palliative care should be provided even when curative care is unavailable.[1]

Unfortunately, the World Health Assembly has noted that the availability of palliative care services is limited worldwide-more than 40 million people globally

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Received 1 April 2020 Revised 8 June 2020 Accepted 17 July 2020
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http://dx.doi.org/10.33192/Smj.2020.57

were in need of palliative care in 2016, most of whom live in low and middle income countries; only 14% of these individuals, however, actually received palliative care.[1,3,4,5] Most of the developing countries are facing challenges of resourcing, availability of morphine, number of hospice-palliative care services.

Many countries are aware of the increasing need for palliative care and thus have begun concentrating on the development of palliative care services. The first step to this end is understanding public awareness of the end of life and palliative care. International studies on public awareness of palliative care have been used as evidence in support of the development of palliative care systems suitable to a given context. These studies revealed that the main barriers to use of palliative care were attitudes based in the culture and traditions of the country, along with knowledge of palliative care, especially among the developing countries.[6,7,8,9] Furthermore, most people were found to experience an end of life that fit with their way of life and culture and preferred home as the place of death.[10,11,12] Overall, palliative care services are facing many challenges, especially in developing countries, where there is need to change the traditionally negative attitudes toward the end of life and palliative care, as well as increase knowledge and health care system resources for the same.[13,14] Table 1 shows a summary of the literature review public awareness of palliative care and the end of life.

TABLE 1. Summary of literature review on public awareness of palliative care.

Author	Country	Sample	Methodology	Findings
Australian Department of Health and Ageing 2003[18]	Australia	• 750 members of the general population • 100 patients and family members	• Focus group	• 75% heard about PC • 41% able to explain PC • 37% had experience with PC • 51% were informed of PC by doctors
McIlfatrick et al. 2011[10]	Northern Ireland	• 600 members of the Patient and Client Council for Northern Ireland, all aged 18 years or older	• Postal and online survey	• 56% unaware of PC • Culture and traditions were the main barriers • Lack of resources for promoting PC
MacLeod et al 2012[11]	New Zealand	• 1,011 adults aged 18 years or older	• Online survey	• 65% aware of PC • 82% agree that PC is an important service •Aged was related to awareness of PC
Harris/Decima Inc. 2013[8]	Canada	• 2,976 adults aged 18 years or older	• Online survey	• > 50% aware of PC • Home was the preferred place of death of the majority • Culture and traditions were the main barrier
Hospis Malaysia 2016[9]	Malaysia	• 600 adults aged over 20 years	• Three levels of study (national level, provider level, and community level) • Interview survey	• National study: 56,384 patients needed palliative care (96.1% were adults and 3.9% were youth) in 2012 • Provider study: lack of health professionals on PC • Community study: >50% unaware of PC and 72.4% reported that PC services should be covered by public health

Abbreviation: PC = palliative care

According to a 2011 WPCA report on the level of palliative care development, Thailand is designated as level 3a, which means "isolated palliative care provision". More specifically, it means *"development of palliative care activism that is patchy in scope and not well-supported; source of funding that is often heavily donor dependent; limited availability of morphine; and a small number of hospice-palliative care services that are often home-based in nature and limited in relation to the size of the population"*.[15] Like other countries, Thailand is experiencing changing demographics due to an ageing society, which has led to an increasing demand for palliative care services. In 2015, more than 23% of deaths were due to cancer, of which 61% were elderly deaths which related to the number of palliative care needs.[16] However, health care costs are comparatively higher at the end of life than during other periods of life, and can lead to catastrophic health expenditure especially among poor households.[14]

The Thai government adopted the National Health Act, B.E. 2550 in 2007, Section 12 of the National Health Act endorsed the right of terminally ill patients to refuse futile medical interventions to prolong natural death or to end the severe suffering from that illness by writing a living will as a part of advance care planning of palliative care. The National Health Act provides a legal tool for society to respect patient's right to self-determination, and it is not to hasten death or active euthanasia or mercy killing.[17]

The research aims to explore public awareness, attitudes, and knowledge regarding palliative care in Thailand.

MATERIALS AND METHODS

We conducted a questionnaire survey using the Thailand NSO's sampling frame and a four-stage stratified sampling method. In the first stage, nine provinces were randomly selected to represent each part of the country. These provinces included Chiang-Rai and Sukhothai from the north, Khon-Kean and Buri-Rum from the northeast, Ayutthaya and Rayong from the center, Trang and Surat-Thani from the south, and Bangkok. In the second stage, 24 enumeration areas in each province were randomly selected. In the third stage, 20 households in each enumeration area were randomly selected. Finally, people aged 20–80 years who had lived in each of the households for a minimum of 3 months were randomly selected.

In total, 2,394 adults were interviewed face to face using a structured questionnaire during February and April 2018. This questionnaire was adopted from similar studies in other countries, translating into Thai language and develop some questions to be more suitable with Thai context.[6,7,18] The questionnaire was divided into four parts: 1) respondent demographic characteristics consisted of 12 questions; 2) information on the respondent's attitude toward end of life consisted of 6 questions; 3) information on the respondent's knowledge, attitudes and expectations toward palliative care and related legislation consisted of 9 questions; and 4) information on advance care planning consisted of 4 questions.

The interview took approximately 20 minutes. At the beginning of interview, each respondent was informed the objective and the steps of interview in the research, then was asked to sign on consent form to participate in the research. At the end of the interview, respondents received an umbrella costing about 100 THB as a gift of appreciation.

This research is approved by Khon-Kaen University Ethics Committee in Human Research (HE 603032). The institutional review board number was IRB00008614.

The project is approved by ethics committee and the preserve respondent' anonymity was concern by the researchers, the personal information of the respondents was recoded, and the results were shown as overall population. The data were analyzed by using Microsoft Excel 2016, Tableau Software version 10.5 and IBM SPSS Statistics 24.

RESULTS

Of the 2,394 respondents, 60% were female, 47% were aged 40–59 years, 74% were married or in a couple, 74% were covered under the universal health insurance scheme, 73% were employed, and half had education level at secondary school and below. The average family size was 4.2 persons and the average household annual income was 9,692.52 USD.[11] Nearly all respondents (95%) had a good health status and thought that their health would worsen as they aged.

Public Awareness of End of Life

Less than half (43%) of respondents were concerned about the end of life, and this proportion was higher among respondents older than 60 years of age (60%) and respondents with poor health (66%) as well as had education at secondary and below (53%).

Furthermore, only 37% of respondents had ever had a discussion about the end of life, with 33% holding discussions with family members and 2% with doctors. The main barriers to holding discussions about the end of life were culture and tradition, the perceived difficulty of beginning such a discussion, and the knowledge that talking about the end of life cause family members to become upset.

TABLE 2. Characteristics of respondents.

		Number	%
Gender	Male	954	39.85
	Female	1,440	60.15
Age (years)	20–29	228	9.52
	30–39	349	14.58
	40–49	550	22.97
	50–59	578	24.14
	60–69	483	20.18
	70–80	206	8.60
Marital status	Single	356	14.87
	Marriage	1,774	74.10
	Widow	205	8.56
	Divorce	59	2.46
Education	Secondary school and below	1,215	50.75
	High school	737	30.79
	University	442	18.46
Current health status	Good health	2,260	94.40
	Poor health	134	5.60
Employment	Civil servant	46	1.92
	Public employee	59	2.46
	Private employee	371	15.50
	Employer/owner	920	38.43
	Unemployed	658	27.49
	Other	340	14.20
Public health insurance	Civil Servant Medical Benefits	108	4.51
	Universal Health Coverage	1,770	73.93
	Social Security Scheme	472	19.72
	Other	44	1.84
Household annual income		**Average (USD)**	
	Total	9,692.52	
	Bangkok	11,552.66	
	Central	13,275.37	
	Northeast	4,159.94	
	Southern	1,4301.45	
	Northern	5,142.61	

Remark: 1 USD = 32.669 THB (Bank of Thailand 18.09.2018)

The majority of respondents preferred receiving palliative care at home (59%), with a minority opting to receive care at the hospital (40%). The preference was related to the age of respondents, with older respondents being more likely to prefer care at home. The chi-square test showed that the age of respondents who prefer care at home significantly differ from those prefer care at hospital. (Chi-square = 73.493, df = 4, P-value = 0.000).

Knowledge, Attitudes, and Expectations towards Palliative Care

Only about one fourth of the respondents knew of palliative care. However, 88% of respondents reported that palliative care is provided to all patients at the end of life, regardless of their illness; only about 5% of respondents reported that palliative care services were for only patients dying of life-threatening disease such as cancer or HIV/AIDS. Furthermore, most respondents (87%) believed that palliative care was mainly provided in public hospitals, while 33% believed that it was provided at home and 24% believed that it was provided at private hospital.

Most respondents expected that palliative care involved medical services, medical equipment, and psychological support (with 97%, 97% and 95% respectively), while fewer expected it to involve spiritual and social care or homemaking (41% and 37%, respectively). Nevertheless, 98% of respondents strongly agreed that palliative care should be integrated into care for anyone with chronic or life-limiting conditions that palliative care should be provided in a setting chosen by patients, that palliative care improves quality of life of patients, and that palliative care greatly reduces stress and burden placed on a patient's family.

Eighty percent of respondents indicated that palliative care should be a service provided by a public institution affiliated with a central or local government, and importantly palliative care services should be provided as one of benefit package under the public health insurance scheme. About 17% of respondents mentioned that family members had the responsibility of looking after patients receiving palliative care. Only a few respondents (4%) suggested including palliative care into private insurance schemes. The doctor was the main source of information for people seeking for information on palliative or end-of-life care (56%), followed by health center or community health volunteers (14%), and web pages or other media (8%).

Advance Care Planning

Advance care planning refers to the process of reflecting and communicating a written desire to let other know the needs of patients as well as pre-treatment planning. Advance care planning can include communication of patient preferences, advance decisions, and proxy nominations.

Thailand enacted National Health Act, B.E. 2550 on March 3, 2007. As noted earlier, section 12 of this act concerns end of life and advance care planning. About 92% of respondents seem to understand legally context as situations related to section 12. Despite this, only 21% of respondents had heard of advance care planning, with a greater proportion of female respondents than male respondents being aware of such care planning (23% and 17% respectively). The proportions of respondents who knew of advance care planning were higher among those aged 40–59 years (24%) and those living in Bangkok (44%).

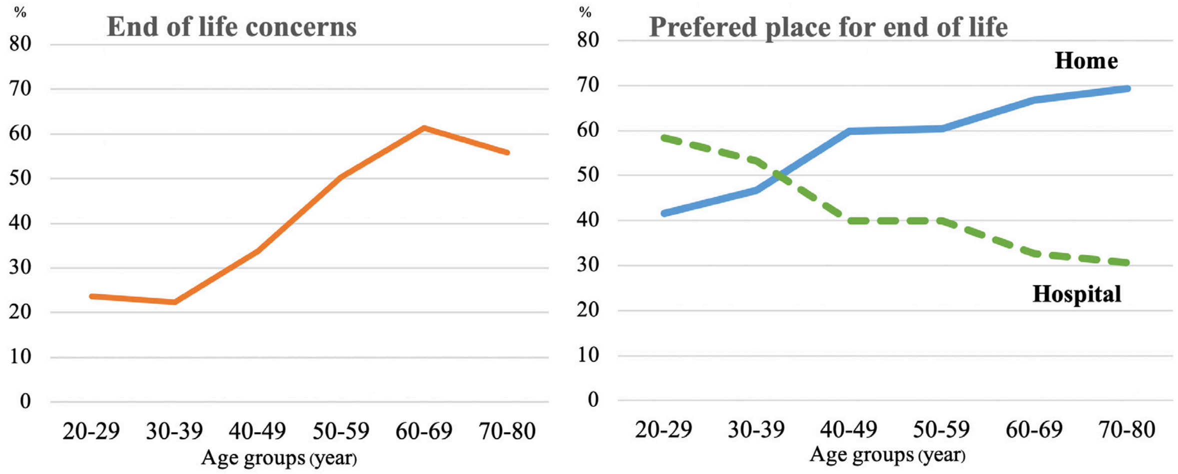

Fig 1: End of life concerns and preferred place of death by age group (shown as %).

[i] There are three main public health insurance schemes in Thailand: the Civil Servant Medical Benefit scheme (CSMBS), Social Security Scheme (SSS) and Universal Healthcare Coverage Scheme (UCS). The UCS covers the majority of Thais.

[ii] 1 USD = 32.669 THB (Bank of Thailand 18.09.2018)

Only 14% of respondents had experience of advance care planning or a living will. After respondents received information about advance care planning, 72% of respondents planned to perform advance care planning and living will. However, 13% insisted that they did not want such planning ahead of death.

Many patients desired to receive end-of-life care at home, but were admitted to the hospital anyways. The main reasons for the admissions were the recommendation of a physician or health care provider, agreement among family members, and the decision of a caregiver based on the belief that healthcare providers could manage the patient's pain and symptoms.

DISCUSSION

The main barrier was culturally determined negative attitudes and poor knowledge toward end-of-life care. The end of life remains an avoided topic of discussion among Thais, just as among citizens of developed countries such as Canada and Northern Ireland.[6,7,8] The second barrier was a lack of knowledge of palliative care. Most respondents reported that they were unaware of dying and palliative care. A higher proportion of older respondents had an awareness, likely because of their higher risk of health problems (especially chronic illness) and the fact that they are the population group with greatest need for palliative care.[1] However, the promoting and educating for all population is necessary to improve awareness and attitude toward palliative care such as adding palliative care in teaching program.

For the majority of Thais, the home was the preferred place of care and death, much the same the populations of other countries.[10,11,12] Some countries showed large variations in preferred place of death according to healthcare resources, availability of a hospital, availability of long-term care beds, and the number of health personals.[10,11] Obtaining sufficient healthcare resources is a challenge in the development of palliative care systems.[13] While home is the preferred place of care and death for the majority of individuals, the limited coverage of a health system can be a barrier to the provision of home-based palliative care. As a result, patients and families bear the brunt of home care costs. The cost of care has been found to differ according to place of care-at home, palliative care costs in the last month of life were 826.47 USD, while at the hospital, the costs were 1,377.45 USD.[19] Thus, home-based palliative care costs less than does hospital-based care for patients. Promoting home-based palliative care would be more cost-effective for patients, meaning that home care services should be improved to better serve patients' need for palliative care. Moreover, an effective referral system should be created to improve the linkage between institutional and home care.[20]

Palliative care has been promoted as an approach to improve the quality of life of patients and families, and covers prevention, treatment, and management of other problems, whether physical, mental, or spiritual.[20] We found that only one out of every five respondents knew of palliative care; however, most Thais knew that palliative care was meant for all end-stage patients, regardless of their illness, and perceived that it was primarily focused on medical care rather than social or spiritual care.

However, the concepts of advance care planning and euthanasia are much more widely debated. Thai law has granted people the right to choose to die in a passive manner.[17] Active euthanasia or mercy killing is not considered legally or ethically acceptable in Thailand, unlike in countries such as Switzerland, Belgium, the Netherlands, and the United States.[21,22] In addition, some developed countries have a longstanding practice of publicly discussing and empowering society to directly deliberate on euthanasia issues.[23]

As noted above, the World Health Assembly indicated that palliative care service has limited availability across the world, especially in low and middle income countries.[1,3,4,5] Palliative care can be further developed in these countries by managing its barriers and thereby raising public awareness, particularly by changing culture-bound attitudes and increasing available resources. Enhancing the knowledge and skills of health care providers involved in institutional and community-based palliative care is also necessary.[24] Increasing communication among health professionals or health care providers and the population may also be important, given that health care providers are the key information source of palliative care.

CONCLUSION

The ageing population is leading to an increasing need for palliative care. Despite this, the development of palliative care services continues to face challenges. In Thailand, end of life remains a topic of discussion to be avoided, and the main barriers to discussing the end of life are culture-bound attitudes and limited knowledge of palliative care. Promoting and educating palliative care for general population is necessary as well as improve availability of palliative care both institutional and home-based care as home was preferred place of death.

ACKNOWLEDGMENTS

The researchers wish to express their deepest thanks to all those who helped in completing the study: the National Statistical Office, Thai Health Promotion Foundation, and the Thailand Development Research Institute. The researchers want to specially thank Associate Professor Dr. Worawan Chandoevwit, who provided suggestions and encouragement.

Competing interest: No competing financial or non-financial conflicts of interest exist.

Funding: This research was supported by the Thai Health Promotion Foundation and Thailand Development Research Institute.

List of abbreviations

WHO = World Health Organization, NCD = non-communicable disease, WPCA = Worldwide Palliative Care Alliance

REFERENCES

1. World Health Organization. Global atlas of palliative care at the end of life. [Online]; 2014 [cited 2016 July 28]. Available from: www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf.
2. Davies E, Higginson I. The solid fact: Palliative care. [Online]; 2004 [cited 2016 July 28]. Available from: www.euro.who.int/_data/assets/pdf_file/0003/98418/E82931.pdf?ua=1.
3. World Health Organization. Palliative care for non-communicable diseases: a global snapshot in 2015. [Online]; 2018 [cited 2018 October 19]. Available from: http://apps.who.int/iris/bitstream/handle/10665/206513/WHO_NMH_NVI_16.4_eng.pdf?sequence=1.
4. World Health Organization. Palliative care. [Online]; 2018 [cited 2018 October 19]. Available from: http://www.who.int/en/news-room/fact-sheets/detail/palliative-care.
5. World Health Organization. 10 facts on palliative care. [Online]; 2017 [cited 2018 October 19]. Available from: http://www.who.int/features/factfiles/palliative-care/en/.
6. Anderson R, Grant L. What is the value of palliative care provision in low-resource settings? BMJ Global Health 2017;2: 1-3.
7. Groeneveld EI, Cassel JB, Bausewein C, Csikós A, Krajnik M, Ryan K, et al. Funding models in palliative care: lessons from international experience. Palliat Med 2017; 31:296-305.
8. Canadian Hospice Palliative Care Association, What Canadians say: The way forward survey report, for the way forward initiative. [Online]; 2013 [cited 2018 October 19]. Available from: http://www.hpcintegration.ca/resources/what-canadians-say.aspx
9. Malaysia H. Palliative care need assessment report. [Online]; 2016 [cited 2018 October 19]. Available from: https://www.hospismalaysia.org/wp-content/uploads/2016/10/Palliative-Care-Needs-Assessment-Malaysia-2016.pdf
10. McIlfatrick S, Hasson F, McLaughlin D, Johnston G, Roulston A, Rutherford L, et al. Public awareness and attitudes toward palliative care in Northern Ireland. BMC Palliative Care 2013;12:1-7.
11. MacLeod RD, Thompson R, Fisher JW, Mayo K, Newman NW, Wilson DM. New Zealanders' knowledge of palliative care and hospice services. N Z Med J 2012; 125:51-60.
12. Cohen J, Pivodic L, Miccinesi G, Onwuteaka-Philipsen BD, Naylor WA, Wilson DM, et al. International study of the place of death of people with cancer: a population-level comparison of 14 countries across 4 continents using death certificate data. Br J Cancer 2015;113:1397-404.
13. Neergaard MA, Jensen AB, Sondergaard J, Sokolowski I, Olesen F, Vedsted P. Preference for place-of-death among terminally ill cancer patients in Denmark. Scand J Caring Sci 2011;25:627-36.
14. Gauthier G, Bernard E, Darrieux JC. End of life at home and preference for a place of death: a literature review. Exercer 2015;118:52-60.
15. Lynch T, Connor S, Clark D. Mapping levels of palliative care development: a global update. J Pain Symptom Manage 2013; 45:1094-106.
16. Ministry of Public Health. Public Health Statistics 2015 Nonthaburi: Strategies and Planning Division; 2015.
17. The National Health Commission Office. National Health Act, B.E. 2550 (A.D. 2007). [Online]; 2017 [cited 2018 October 19]. Available from: https://en.nationalhealth.or.th/wp-content/uploads/2017/11/HealthAct07.pdf.
18. The Australian Institute of Health and Welfare. Palliative care services in Australia. Canberra: The Australian Institute of Health and Welfare; 2013.
19. Chandoevwit W, Vajragupta Y. Long term care insurance system: Long term care system for Thailand (in Thai). Bangkok: Thailand Development Research Institute (TDRI); 2017. Report No.978-616-92250-5-8.
20. World Health Organization. WHO definition of palliative care. [Online]; 2018 [cited 2018 October 17]. Available from: http://www.who.int/cancer/palliative/definition/en/.
21. The National Health Commission Office. Thai living will (in Thai). [Online]. [cited 2018 October 19]. Available from: http://www.thailivingwill.in.th/.
22. Bosshard G, Fischer S, Bar W. Open regulation and practice in assisted dying: How Switzerland compares with the Netherlands and Oregon. Swiss Medical Weekly 2002; 132:527-34.
23. Nunes R, Rego G. Euthanasia: A challenge to medical ethics. J Clin Res Bioeth 2016;7: 1000282.
24. Millintangkul U. National policy on palliative care in Thailand. [Online]; 2015 [cited 2019 June 2]. Available from: https://en.nationalhealth.or.th/wp-content/uploads/2017/11/NationalPolicyonPCare2015_09_17-1.pdf.