A Survey of Opinions Regarding wishes Toward the End-of-Life among Thai Elderly

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Background: *Knowledge of wishes toward the end-of-life is crucial for carrying out high quality palliative care. However, advance directive is not commonly available among Thais, particularly for non-cancerous older patients.*
Objective: *The present study aimed to explore Thai older person's wishes toward cares needed at the end-of-life.*
Material and Method: *A convenience sample of 100 older patients, who attended geriatric clinic at a university hospital in Thailand, was recruited. A 3-page questionnaire developed to suit Thai culture was utilized to elicit opinions concerning circumstances around end-of-life period.*
Results: *All participants were Buddhists with mean age of 75.9 (8.2). Toward the end-of-life, the majority wanted to know the truth about their illnesses and to be free from uncomfortable symptoms. Seventy-five percent did not want "prolong-life" treatments when chance of surviving is slim. Age less than 70 and having education of no more than 6 years were factors associated with being unwilling to prolong suffering with OR of 9.88 (1.20-81.57, p = 0.03) and 3.15 (1.11- 8.95, p = 0.03), respectively. Interestingly, fifty-six percent of elderly did not want to die at home. Age less than 70 was the only factor significantly associated with being unwilling to die at home with OR of 2.80 (95% CI = 1.05-7.47, p = 0.04).*
Conclusion: *The present study illustrated older persons' opinions in relation to cares at the end-of-life from a Thai perspective, which showed some similarities and differences when compared to western countries. These opinions should be crucial for carrying out optimal and qualitative end-of-life care for older people when advanced care planning is not in place for the individual.*

Keywords: *End-of-life care, Advance care planning, Elderly, Questionnaire, Thailand*

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With the recent growth of the aging population and advances in modern medicine, the leading causes of death nowadays are chronic illnesses in older persons. Older people, therefore, have been the majority of the population requiring palliative care for several terminal medical illnesses. In order to provide comprehensive continuing care for older people, quality end-of-life care should be one area of focus among several others. However, it has been demonstrated that clinical care of older adults with serious and advanced illnesses, particularly care toward the end-of-life, is in need of improvement[1].

Good death has been a central concept of palliative and end-of-life care since the beginning. The original model was to keep patients free from unpleasant symptoms without discomfort in areas of the psychological, emotional, social and spiritual[2]. The meaning of 'good death' and composition of it has however, been changing[2,3]. It is a subject which is difficult to quantify scientifically but is influenced by philosophical ideas, which are believed to be culture-based issues. This has been affirmed by the evidence that decision making with regard to good death and end-of-life issue were different among racially and ethnically diverse groups[4,5]. It is, therefore, essential to gather patients' opinions on what composes a

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peaceful death from their perspective in order to carry out compassionate end-of-life care.

Providing care that is in accordance with patients' wishes is an essential component of end-of-life care. This would be eased, at least to some extent, when advance directives are in place. However, expressing wishes in relation to death has not been a popular concept among people in Thailand and several Asian countries despite the growing awareness of this issue in Western countries. This culture has brought about difficulties for practicing physicians taking care of Thai patients at the end-of-life[6].

There have been some studies with respect to concepts around good death in Thais and Buddhists[7,8] and end-of-life decision[6] in Thailand. The results have emphasized some differences in culture compared to Western culture and stressed the need to explore several issues around end-of-life from local area. Those studies[6-8], however, were case series and a study conducted in a small group of selected individuals[7]. There is a need for exploring some general principles in relation to care toward the end-of-life, to provide empirical evidence of opinion from target population. The authors, therefore, conducted the present study and aimed to explore preferences toward end-of-life among Thai older persons with chronic illnesses.

Material and Method

The present study was conducted at Siriraj Hospital, a 2,300-bed university hospital in Thailand during May 2010 to February 2011. A convenience sample of 100 older patients who attended to geriatric clinic for regular follow-up of their chronic illnesses was approached and recruited in the study. Five-category Likert scale, thirteen-situation-based questionnaire developed to suit Thai cultural context was used to elicit older persons' opinions concerning cares needed toward the end-of-life. Participants were also enquired to rank the three most important circumstances from their view points. Information regarding demographic data, co-morbid illnesses and functional status were collected from older persons and their families. Informed consents were obtained from all participants. This study was approved by Siriraj Institutional Review Board.

Development of questionnaire

The questionnaire was developed based on literature review of studies in relation to patients' wishes toward the end of life. Items were chosen from previous studies[7,9-11] from Eastern and Western countries. A number of discussions were held among investigators in order to select and modify questions suitable to local culture. Three of the investigators (VS, RP and JA) are geriatricians who have had experience in taking care of older persons which ranged from 10-25 years and one (RP) has also been teaching in palliative care in the faculty. The questionnaire was designed to collect participants' demographic information, health status and previous experiences in end-of-life. A 13-item, 5-category Likert scale was used to elicit participants' opinions toward various activities in relation to events at the end-of-life. Participants were asked to imagine that if they were reaching the last 3 months of their life, how much they would agree with those statements. Items in the questionnaire covered physical needs and psychological needs, autonomy issues and closure of life affairs; which are domains in comprehensive palliative assessment.

Statistical analysis

Descriptive statistics were used for participants' characteristics. For continuous data, parametric and non-parametric tests were applied, as appropriate, after examining the distribution of variables. Categorical variables were presented as numbers and percentages. For the purpose of exploring factors associated with interested items, responses were collapsed into agreement for totally agree and agree, while the rest were classified as disagree. Place of death and decision not to prolong treatment were items considered to be of interest for further exploration for the associated factors. Simple binary logistic regression analysis was carried out to assess crude odds ratio (OR) with 95% confidence interval (95% CI) for association between participants' characteristics and interesting opinions. Factors analyzed in univariate analysis showing $p<0.20$ would be further examined in multiple binary logistic regression models. Statistical value of <0.05 was determined as significant in the final model. All statistical analyses were carried out using SPSS version 17.0 (SPSS, Chicago, IL, USA).

Results

Among enrolled participants, all were Buddhists with mean age of 75.9 (8.2). Approximately half of subjects had no more than 6 years of education, 75% were female and 65% rated themselves as not being in good health. Ninety-one percent of subjects were independent in daily life with an average of 2 co-morbid diseases. Ninety-five percent reported being

satisfied in life (Table 1).

Responses to the questionnaire regarding circumstances around end-of-life period were illustrated in Table 2. With respect to their wishes towards the end of life, more than 90% of participants reported wishing to be free from uncomfortable symptoms and to be informed of the truth of their illnesses, to both them and families. Psychological needs, such as wishing to be cared for not only physically but also mentally and spiritually, having loved ones around and being mentally aware toward the last hours of life, were attributes rated as important among approximately 80% of participants. Seventy-six percent did not want to receive treatments to prolong life when the chance of surviving is slim. Interestingly, 44% of older persons wish to die at home and 31% preferred not to have any religious ritual conducted near the time of death.

Logistic regression models were applied to investigate factors associated with unwilling to die at home. The only factor significantly associated with unwillingness to die at home was age less than 70 with OR of 2.80 (95% CI = 1.05-7.47, p = 0.04). Factors associated with unwillingness to receive prolonging treatments with limited chance of survive were further explored using logistic regression models. After adjusted in multivariate analysis, age less than 70 and having education no more than 6 years were associated with unwilling to prolong suffering with OR of 9.88 (1.20-81.57) and 3.15 (1.11- 8.95), respectively (Table 3). Participants were also asked to rank the three most important aspects in their mind, older persons rated presence of loved ones, not receiving prolonging treatment and knowing the truth as the highest priorities when they reached the end-of-life period.

Table 1. Baseline characteristics of participants

Characteristics	n = 100
Mean age, year (SD)	75.9 (8.2)
Female*, %	75.8
Buddhism, %	100.0
Marital status, %	
Married	82.0
Education, %	
Illiterate	8.0
Primary school (6 years)	40.0
Secondary school (12 years)	23.0
Bachelor's degree	29.0
Family monthly income[+,++], %	
≤10,000 Baht	31.6
10,001-20,000 Baht	22.4
20,001-30,000 Baht	13.3
>30,000 Baht	32.7
No. of underlying diseases, median (range)	2 (0-6)
Independent in activities of daily life, %	91.0
Family size (person), %	
Less than 3	38.0
Three or more	62.0
History of seriously ill, %	72.0
In good health, %	35.0
Satisfaction in life, %	95.0
Prior experience of watching someone dying, %	79.0
Prior experience of caring for someone at the end-of-life, %	60.0

*1 missing data; [+]2 missing data, [++]1 USD = 30 Baht

Discussion

Results from the present study demonstrate some interesting opinions from older people with respect to their wishes toward the end-of-life from Thai perspective that is a Buddhist society. Freedom from suffering which was attributed as important in the vast majority of participants in this study appears to be an intuitive empirical wish across the world[7,9,10]. This reiteration should be emphasized for practicing physicians to always look for and alleviate any uncomfortable symptoms, not only pains, for all patients reaching end of life.

With respect to autonomy, which is a priority in Western bioethics, this has been substantially different among Asians with a wide range of expression for their preferences[4,11-3]. In the present study, expressing wish of wanting to receive all information about their own illnesses could be viewed as a representative of autonomy. This idea was placed as a high priority among participants in the present study. This appears contradictory to prior beliefs among Chinese[12], Japanese[11] and Koreans[4,13] where the family-centered model of decision-making was predominate. Families in Asian countries often expect that information regarding a critical prognosis be disclosed to the family rather than to the patient in the first instance. The family often requests that grave prognoses or certain stigmatizing diagnoses be hidden from the patients[12]. However, there has been a move toward emphasizing an individual's right among newer Asian generations in recent studies[14] where patients were more likely to express wishes to have direct communication with physician for disclosing their own diagnosis and prognosis. This latter trend is in concordance with the present study.

Table 2. Questions from thirteen-situation-based questionnaire utilized in enquiring wishes toward the end-of-life

Statements	Rating: no of participants				
	5 Strongly agree	4 Agree	3 Neutral	2 Disagree	1 Strongly disagree
1. You wish to receive all the truth about your illnesses	70	21	4	2	3
2. You wish for your family to know all the truth about your illnesses	63	27	5	4	1
3. You wish to be involved in decisions about treatment received	45	28	11	7	9
4. You wish to name a surrogate decision maker for health care in advance in order to make decision when you are not capable of	46	33	14	2	5
5. You wish to have relief of uncomfortable symptoms such as pain, shortness of breath, to minimum level	65	28	5	1	1
6. You wish to be respected, not being treated only for diseases but have spiritual needs met	64	21	8	3	4
7. You wish to have your love ones around when needed	52	31	14	1	2
8. You wish not to be physical and psychological burden to family	49	31	11	6	3
9. You wish to complete unfinished business, be prepared to die and say goodbye to family and friends	48	29	10	8	5
10. You wish not to receive treatments to prolong life when chance of surviving is slim	54	22	7	8	9
11. You wish to have your religious ritual conducted at the end of life	38	31	17	8	6
12. You wish to be mentally aware toward the last hour of your life	52	30	7	6	5
13. You wish to pass away at home	29	15	29	11	16

Table 3. Factors associated with unwillingness to receive prolonging treatment when chance of survival is slim

Characteristics	Multivariate analysis odd ratio (95% CI)	p-value
Age <70 years old	9.88 (1.20-81.57)	0.03
Education 6 years or less	3.15 (1.11-8.95)	0.03
Good health	3.17 (0.96-10.46)	0.06
History of severely ill	1.72 (0.49-6.08)	0.40

Use of life support is another focus for advance care planning which could lead to a management dilemma. Buddhism emphasizes the transitory quality of life and the belief that life should not be unnecessarily prolonged and that nature should be allowed to take its own course. It could have been thought that Buddhists would be less likely to request intensive treatments when approaching death, particularly when chance of survival is limited. The present study affirms this belief showing that Thai older people are more ready to "let go", more likely to agree with not prolonging suffering when the chance to survive is slim. The proportion of this is higher than in the studies conducted in USA[10] and Japan[5]. Nevertheless, bringing this concept into practice in Thailand has not been simple, as pointed out in recent studies[6,15]. It seems to be a common phenomenon for Thai older patients to receive all available treatments with requests from families. This practice might stem from belief that family members have to pay their respect back to parents by providing 'the best care'. Unfortunately, in many occasions, particularly for older persons with complex chronic medical illnesses reaching their end-of-life, 'the best available care' might not be in the best interest of older patients, according to result from the present study.

Influence of age on decision of preferences for aggressive care and life sustaining treatments has

been studied[16-18] with inhomogeneous results. In studying critically ill patients, older persons appeared to prefer less aggressive care compared to younger patients after adjusted for other covariates[16], while some others showed contrary results[18]. The present study showed that the young-old group was more likely to refrain from prolonging treatments compared to old-old. One explanation suggested in previous studies, stressed out, that 'feeling of being a burden' might be one reason for the decision[18]. In order to test this hypothesis, further analysis was conducted to investigate the association in the present study and it was found that people who agree with the statement 'wish not to receive prolonging treatments' were more likely to agree with the statement 'wish not to be a burden' with OR of 4.7.

Last place of care for dying patients is another important issue in end-of-life care, particularly on carrying out "good death". There was some evidence showing that many people died in institutions with less peaceful death compared to ones who passed away at home[19]. Results from studies conducted among Westerners showed that 60-80% of participants expressed wishes to die at home[20]. This has also been a traditional belief among Thai practitioners that patients would have wished to pass away surrounded by family at home. Previous studies regarding good death in Thais did not specifically study on place of death[7]. The present study interestingly demonstrated that only 44% of older people would wish to die at home. Age less than 70 was the only factor associated with unwilling to die at home. The reason for this phenomenon could not be investigated in the present study. Some explanations could have been that they did not wish to be physical burden for family during the dying time, or that they placed trust on health care providers for relieving any suffering symptoms when the final time is approached. Moreover, there is no community hospice service in Thailand at present. It would be interesting to explore whether delivery of this type of care would have changed this attitude.

Bringing about 'end of life conversation' has not been easy, even in Western countries[21]. This would be a more challenging task for physicians to carry out this task in Asian culture where discussion about death could be seen as a taboo topic[14]. The present study was therefore carried out using a questionnaire in order to avoid many barriers. The finding that very few older persons declined to participate in the study might infer that open discussion of this issue is feasible in routine practice.

Conclusion

The present study illustrated older persons' opinions in relation to cares at the end-of-life from Thai perspective. In order to provide patient-centered care for the elderly, preferences for treatment should be directly sought for, from the patient, particularly when aim is to focus on palliative treatment. Thai older persons appear to be willing to receive relevant information and to make some important decisions. Results from the present study could be used as empirical evidence to refer to when discussing related issues with older patients and families.

Potential conflicts of interest

None.

References

1. Chun A, Morrison SR. Palliative care. In: Halter JB, Ouslander JG, Tinetti ME, Studenski S, High KP, Asthana S, editors. Hazzard's geriatric medicine and gerontology. 6th ed. New York: McGraw-Hill; 2009: 373-84.
2. Walters G. Is there such a thing as a good death? Palliat Med 2004; 18: 404-8.
3. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. Ann Intern Med 2000; 132: 825-32.
4. Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. Gerontologist 2005; 45: 634-41.
5. Hirai K, Miyashita M, Morita T, Sanjo M, Uchitomi Y. Good death in Japanese cancer care: a qualitative study. J Pain Symptom Manage 2006; 31: 140-7.
6. Stonington S, Ratanakul P. Is there a global bioethics? End-of-life in Thailand and the case for local difference. PLoS Med 2006; 3: e439.
7. Rodpal J, Kespichayawattana J, Wisesrith W. Good death : perspectives of Thai Buddhist elderly. J Health Sci 2007; 16: 924-933.
8. Kongsuwan W, Touhy T. Promoting peaceful death for Thai Buddhists: implications for holistic end-of-life care. Holist Nurs Pract 2009; 23: 289-96.
9. Heyland DK, Dodek P, Rocker G, Groll D, Gafni A, Pichora D, et al. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. CMAJ 2006; 174: 627-33.
10. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family,

physicians, and other care providers. JAMA 2000; 284: 2476-82.
11. Miyashita M, Sanjo M, Morita T, Hirai K, Uchitomi Y. Good death in cancer care: a nationwide quantitative study. Ann Oncol 2007; 18: 1090-7.
12. Ip M, Gilligan T, Koenig B, Raffin TA. Ethical decision-making in critical care in Hong Kong. Crit Care Med 1998; 26: 447-51.
13. Blackhall LJ, Murphy ST, Frank G, Michel V, Azen S. Ethnicity and attitudes toward patient autonomy. JAMA 1995; 274: 820-5.
14. Chan HY, Pang SM. Readiness of Chinese frail old age home residents towards end-of-life care decision making. J Clin Nurs 2011; 20: 1454-61.
15. Stonington S. Facing death, gazing inward: end-of-life and the transformation of clinical subjectivity in Thailand. Cult Med Psychiatry 2011; 35: 113-33.
16. Hamel MB, Lynn J, Teno JM, Covinsky KE, Wu AW, Galanos A, et al. Age-related differences in care preferences, treatment decisions, and clinical outcomes of seriously ill hospitalized adults: lessons from SUPPORT. J Am Geriatr Soc 2000; 48 (5 Suppl): S176-82.
17. Cherniack EP. Increasing use of DNR orders in the elderly worldwide: whose choice is it? J Med Ethics 2002; 28: 303-7.
18. McPherson CJ, Wilson KG, Murray MA. Feeling like a burden to others: a systematic review focusing on the end of life. Palliat Med 2007; 21: 115-28.
19. Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, et al. Family perspectives on end-of-life care at the last place of care. JAMA 2004; 291: 88-93.
20. Vassal P, Le Coz P, Herve C, Matillon Y, Chapuis F. Return home at the end of life: Patients' vulnerability and risk factors. Palliat Med 2011; 25: 139-47.
21. Larson DG, Tobin DR. End-of-life conversations: evolving practice and theory. JAMA 2000; 284: 1573-8.

การสำรวจความเห็นเกี่ยวกับความมุ่งหวังในช่วงสุดท้ายของชีวิตของผู้สูงอายุไทย

วราลักษณ์ ศรีนนท์ประเสริฐ, อักษรา ขจรกิจเจริญ, ปฐวี ณ บางช้าง, เจนนิส หวังตระกูลดี, เจนวิทย์ วงศ์บุญสิน, วรรณศิริ คุปต์นิรัติศัยกุล, สกาวรัตน์ กรบงกชมาศ, จินตนา อาศนะเสน, รุ่งนิรันดร์ ประดิษฐสุวรรณ

ภูมิหลัง: *การได้รับทราบถึงความมุ่งหวังเกี่ยวกับวาระสุดท้ายของชีวิตของผู้ป่วย เป็นสิ่งสำคัญที่ช่วยให้การดูแลแบบประคับประคองเป็นไปอย่างมีคุณภาพ อย่างไรก็ตามการแสดงความมุ่งหวังในวาระสุดท้าย เป็นสิ่งที่ไม่ค่อยได้กระทำกันในหมู่คนไทย โดยเฉพาะอย่างยิ่งผู้สูงอายุที่ไม่ได้เป็นมะเร็ง การศึกษานี้จึงมีวัตถุประสงค์ เพื่อศึกษาความมุ่งหวังของผู้สูงอายุไทยเกี่ยวกับการดูแลในระยะสุดท้ายของชีวิต*

วัสดุและวิธีการ: *การเก็บข้อมูลได้จากกลุ่มประชากรผู้สูงอายุจำนวน 100 ราย ที่มารับการตรวจติดตามที่คลินิคผู้สูงอายุของโรงพยาบาลศิริราช ซึ่งเป็นโรงพยาบาลมหาวิทยาลัย โดยการศึกษาได้ใช้แบบสอบถามจำนวน 3 หน้า ที่มีการพัฒนาปรับปรุงเพื่อให้เหมาะกับวัฒนธรรมไทย โดยจะเป็นแบบสอบถามที่มุ่งถามความคิดเห็นเกี่ยวกับสถานการณ์ต่างๆ ในช่วงเวลาสุดท้ายของชีวิต*

ผลการศึกษา: *ผู้เข้าร่วมศึกษาทั้งหมดเป็นชาวพุทธโดยมีอายุเฉลี่ย 75.9 (8.2) ความมุ่งหวังของผู้เข้าร่วมวิจัยส่วนใหญ่ ต้องการทราบความจริงเกี่ยวกับอาการป่วยของตัวเอง และไม่อยากให้มีอาการที่ทำให้เกิดความไม่สบายตัวในช่วงสุดท้ายของชีวิต ร้อยละ 75 ของผู้สูงอายุไม่อยากได้รับการรักษาเพื่อยืดเวลาหากความหวังในการรอดชีวิตมีน้อย อายุน้อยกว่า 70 ปี และผู้ที่มีการศึกษาน้อยกว่า 6 ปี เป็นปัจจัยที่สัมพันธ์กับการไม่อยากเหนี่ยวรั้งชีวิต โดยมี OR = 9.88 (1.20-81.57, p = 0.03) และ 3.15 (1.11-8.95, p = 0.03) ตามลำดับ เป็นที่น่าสังเกตว่า ร้อยละ 56 ของผู้สูงอายุไม่ได้ต้องการเสียชีวิตที่บ้านอายุน้อยกว่า 70 ปี เป็นปัจจัยเดียวที่สัมพันธ์กับการไม่อยากเสียชีวิตที่บ้านโดยมี OR = 2.80 (95% CI = 1.05-7.47, p = 0.04)*

สรุป: *การศึกษานี้แสดงความเห็นของผู้สูงอายุเกี่ยวกับการดูแลที่ผู้สูงอายุอยากให้เกิดขึ้นในช่วงวาระสุดท้ายของชีวิต จากมุมมองของคนไทย ซึ่งมีทั้งส่วนที่เหมือนและต่างกับประเทศตะวันตก ความเห็นเหล่านี้น่าจะเป็นสิ่งที่มีประโยชน์ในการดูแลผู้สูงอายุที่อยู่ในช่วงวาระสุดท้ายของชีวิต โดยเฉพาะอย่างยิ่งเมื่อผู้สูงอายุไม่ได้แสดงเจตจำนงเกี่ยวกับ การดูแลในวาระสุดท้ายไว้*