



**Development and Psychometric Evaluation of the End-of-Life Decision
Scale (EoLDS) for Thai Buddhist Adults with Chronic Illness**

Navarat Rukchart

**A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of
Doctor of Philosophy in Nursing (International Program)**

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Thesis Title Development and Psychometric Evaluation of the End-of-Life Decision Scale (EoLDS) for Thai Buddhist Adults with Chronic Illness

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ชื่อวิทยานิพนธ์	การพัฒนาและประเมินคุณภาพแบบประเมินการตัดสินใจในระยะสุดท้ายของชีวิตในผู้ป่วยโรคเรื้อรังที่นับถือศาสนาพุทธ
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บทคัดย่อ

การตัดสินใจในระยะสุดท้ายของชีวิตเป็นเรื่องที่มีความยุ่งยากและมีความซับซ้อน เพราะเป็นการตัดสินใจที่เกี่ยวกับชีวิตและความตายซึ่งตั้งอยู่บนพื้นฐานคุณค่าและความเชื่อของผู้ป่วย นอกจากนี้ยังมีผู้ที่มีส่วนเกี่ยวข้องซึ่งอาจนำไปสู่ความขัดแย้งทางความเชื่อและคุณค่าได้ การศึกษาวิจัยนี้มีวัตถุประสงค์เพื่อพัฒนาและประเมินคุณภาพแบบประเมินการตัดสินใจในระยะสุดท้ายของชีวิตในผู้ป่วยโรคเรื้อรังที่นับถือศาสนาพุทธ กระบวนการพัฒนาแบบประเมิน ประกอบด้วย (1) การพัฒนารอบแนวคิดโดยการบูรณาการ การทบทวนวรรณกรรมและการสัมภาษณ์ผู้ป่วยโรคเรื้อรังที่นับถือศาสนาพุทธจำนวน 12 คน เกี่ยวกับการตัดสินใจและเหตุผลประกอบการตัดสินใจ (2) สร้างแบบสอบถาม โดยแบบประเมินการตัดสินใจในระยะสุดท้ายของชีวิตในผู้ป่วยโรคเรื้อรังที่นับถือศาสนาพุทธแบ่งออกเป็นแบบสอบถามย่อย 4 ชุด ได้แก่ แบบสอบถามย่อยชุดที่ 1: การตัดสินใจรับการรักษาพยาบาลเพื่อยืดชีวิต แบบสอบถามย่อยชุดที่ 2: การตัดสินใจยุติ/ยับยั้งการรักษาพยาบาลเพื่อยืดชีวิต แบบสอบถามย่อยชุดที่ 3: การยินยอมให้แพทย์/พยาบาลตัดสินใจแทน และแบบสอบถามย่อยชุดที่ 4: การยินยอมให้ครอบครัวตัดสินใจแทน (3) กำหนดรูปแบบของแบบสอบถามย่อยทั้ง 4 ชุดเป็นแบบประมาณค่า 6 ระดับ สำหรับการประเมินคุณภาพแบบประเมินการตัดสินใจในระยะสุดท้ายของชีวิตในผู้ป่วยโรคเรื้อรังที่นับถือศาสนาพุทธประกอบด้วย (1) การตรวจสอบความตรงเชิงเนื้อหาได้ค่าดัชนีความตรงเชิงเนื้อหาของแบบสอบถามย่อยชุดที่ 1, 2, 3, และ 4 เท่ากับ .86, 1.00, 1.00, และ 1.00 ตามลำดับ (2) การตรวจสอบความเที่ยงของแบบสอบถามย่อยทั้ง 4 ชุด โดยใช้ค่าสัมประสิทธิ์แอลฟาของครอนบาค ได้ค่าความเที่ยงของแบบสอบถามย่อยชุดที่ 1, 2, 3, และ 4 เท่ากับ .90, .91, .97 และ .92 ตามลำดับ (3) การวิเคราะห์โครงสร้างของแบบประเมินการตัดสินใจในระยะสุดท้ายของชีวิตในผู้ป่วยโรคเรื้อรังที่นับถือศาสนาพุทธโดยการวิเคราะห์องค์ประกอบ กลุ่มตัวอย่าง ได้จากการคัดเลือกแบบเฉพาะเจาะจง ประกอบด้วยผู้ป่วยโรคเรื้อรังที่นับถือศาสนาพุทธที่ตัดสินใจรับการรักษาพยาบาลในระยะสุดท้ายของชีวิต 260 คน ยุติ/ยับยั้งการรักษาพยาบาลเพื่อยืดชีวิต 286 คน ยินยอมให้แพทย์/พยาบาลตัดสินใจแทน 199 คน และยินยอมให้ครอบครัวตัดสินใจแทน 250 คน

วิเคราะห์ข้อมูลโดยการวิเคราะห์องค์ประกอบเชิงสำรวจ (Exploratory Factor Analysis: EFA) ผลจากการศึกษาพบว่า (1) แบบสอบถามย่อยชุดที่ 1: กลุ่มที่ตัดสินใจรับการรักษาพยาบาลเพื่อยืดชีวิตมีเหตุผลประกอบการตัดสินใจ 4 องค์ประกอบ มีข้อคำถาม 39 ข้อ สามารถอธิบายความแปรปรวนของตัวแปรได้ร้อยละ 63.98 ค่าน้ำหนักขององค์ประกอบอยู่ระหว่าง .46-.82 และค่าความเที่ยงเท่ากับ .97 (2) แบบสอบถามย่อยชุดที่ 2: กลุ่มที่ตัดสินใจยุติ/ยับยั้งการรักษาพยาบาลเพื่อยืดชีวิตมีเหตุผลประกอบการตัดสินใจ 4 องค์ประกอบ มีข้อคำถาม 37 ข้อ สามารถอธิบายความแปรปรวนของตัวแปรได้ร้อยละ 64.71 ค่าน้ำหนักขององค์ประกอบอยู่ระหว่าง .44-.87 และค่าความเที่ยงเท่ากับ .96 (3) แบบสอบถามย่อยชุดที่ 3: กลุ่มที่ยินยอมให้แพทย์/พยาบาลตัดสินใจแทนมีเหตุผลประกอบการตัดสินใจ 3 องค์ประกอบ มีข้อคำถาม 32 ข้อ สามารถอธิบายความแปรปรวนของตัวแปรได้ร้อยละ 67.45 ค่าน้ำหนักขององค์ประกอบอยู่ระหว่าง .53-.82 และค่าความเที่ยงเท่ากับ .96 และ (4) แบบสอบถามย่อยชุดที่ 4: กลุ่มที่ยินยอมให้ญาติตัดสินใจแทนมีเหตุผลประกอบการตัดสินใจ 3 องค์ประกอบ มีข้อคำถาม 30 ข้อ สามารถอธิบายความแปรปรวนของตัวแปรได้ร้อยละ 63.41 ค่าน้ำหนักขององค์ประกอบอยู่ระหว่าง .50-.85 และค่าความเที่ยงเท่ากับ .95

ผลการวิจัยครั้งนี้แสดงให้เห็นว่าแบบประเมินการตัดสินใจในระยะสุดท้ายของชีวิตในผู้ป่วยโรคเรื้อรังที่นับถือศาสนาพุทธทั้ง 4 ชุดมีคุณภาพเพียงพอต่อการนำไปใช้ประเมินการตัดสินใจในระยะสุดท้ายของชีวิตในผู้ป่วยโรคเรื้อรังที่นับถือศาสนาพุทธ เพื่อที่พยาบาลและทีมสุขภาพสามารถส่งเสริมให้ผู้ป่วยที่อยู่ในระยะสุดท้ายของชีวิต ได้ตัดสินใจตามความเชื่อและคุณค่าของคน

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ABSTRACT

The decision at the end-of-life is difficult and complicated because it is a decision that related to the beliefs and values of the patients. Moreover, there are many people involved and it could lead to a conflict of beliefs and values. This research aimed to develop and evaluate psychometric properties of the End-of-Life Decision Scale (EoLDS) for Thai Buddhist adults with chronic illness. The development process of the EoLDS consisted of: (1) determination of the conceptual framework by integration of literature reviews and interviews of 12 Thai Buddhist adults with chronic illnesses regarding their decision and reasons of the decision, (2) generation of an item pool and the EoLDS was divided into four subscales including Subscale 1: Continuing LST, Subscale 2: Forgoing LST, Subscale 3: Allowing physicians/nurses to make decision, and Subscale 4: Allowing family to make decision, (3) determination of scale format using a six-point rating scale. Psychometric evaluation consisted of: (1) determination of content validity using content validity index (CVI), the CVIs of Subscale 1, 2, 3, and 4 were .86, 1.00, 1.00, and 1.00 respectively. (2) determining reliability with the Cronbach's alpha of Subscale 1, 2, 3, and 4 were .90, .91, .97, and .92 respectively. (3) determining construct validity using exploratory factor analysis. The samples were purposively selected: 260 patients who chose continuing LST, 286 for forgoing LST, 199 for allowing physicians/nurses to make decision, and 250 for allowing family to make decision. The results showed the components of reasons supporting each subscale of end-of-life decision. Subscale 1: Continuing LST consisted of four factors with 39 items and a total percent of variance was 63.98, factor loadings ranged from .46-.82 and Cronbach's alpha was .97. Subscale 2: Forgoing LST consisted of four factors

with 37 items and a total percent of variance was 64.71, factor loadings ranged from .44-.87 and Cronbach's alpha was .96. Subscale 3: Allowing physicians/nurses to make decision consisted of three factors with 32 items and a total percent variance was 67.45, factor loadings ranged from .53-.82 and Cronbach's alpha was .96. Subscale 4: Allowing family to make decision consisted of three factors with 30 items and a total percent of variance was 63.41, factor loadings ranged from .50-.85 and Cronbach's alpha was .95.

The End-of-Life Decision Scale showed quality of psychometric properties which can be used to measure decisions of Thai Buddhist patients with chronic illness at the end-of-life. Then, nurses and other health care providers can use to support patients to make end-of-life decision based on their values and beliefs.

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CONTENTS

		PAGE
Abstract.....		v
Acknowledgement.....		ix
Contents.....		x
List of Tables.....		xii
List of Figures.....		xiv
 Chapter		
1	Introduction.....	1
	Background and significance.....	1
	Objectives of the study.....	6
	Research questions.....	7
	Conceptual framework.....	7
	Definition of terms.....	19
	Significance of the study.....	19
	Summary.....	21
2.	Literature Review	22
	Chronic illness.....	23
	End-of-life care and treatment at the end of life	29
	End-of-life decision of patients with chronic illness.....	40
	Reasons related to end-of-life decision.....	49
	Scales related to end-of-life decision.....	62
	Summary.....	72

CONTENTS (Continue)

	PAGE
Chapter	73
3 Methodology.....	73
Introduction.....	73
Phase 1: Scale development.....	73
Phase 2: The psychometric evaluation.....	82
Protection of Human Subjects' Rights.....	89
Summary.....	89
4 Results and Discussions.....	92
Introduction	92
Results	92
Results from factor analysis.....	102
Discussions.....	108
Summary.....	144
5 Conclusions and Recommendations.....	145
Conclusions of the results	145
Implications and recommendations.....	148
Limitation.....	150
References.....	152

CONTENTS (Continued)

	PAGE
Appendices.....	170
A Interview guideline.....	171
B Protection of Human Subjects' Rights.....	176
C Generation of an item pool.....	179
D Content validity form.....	183
E List of Experts.....	185
F Research instrument.....	187
VITAE	214

LIST OF TABLES

TABLE		PAGE
1	Scales related to end-of-life decision.....	67
2	Types of end-of-life decision and reasons of end-of-life decision from a comprehensive literature review.....	75
3	Types of end-of-life decision and reasons of end-of-life decision from individual interviews.....	79
4	Integration of literature review and individual interviews.....	80
5	Demographic characteristics of subjects	94
6	Number and percentage of subjects who had disease, treatment, impact from the disease, and dependence on others.....	96
7	Number and percentage of subjects who had experience in using life sustaining treatment	97
8	Number and percentage of subjects participating in Buddhist rites.....	98
9	Number and percentage of subjects who using dharma principles in everyday life.....	100
10	Factor 1: Trust in Modern Treatment and Advance Medical Technology of Subscale 1: EoLDS-Cont.....	104
11	Factor 2: Living for Family and Love Ones of Subscale 1: EoLDS-Cont	105

LIST OF TABLES (Continued)

TABLE		PAGE
12	Factor 3: Need More Time to Do Good Karma for Better Life after Death of Subscale 1: EoLDS-Cont	106
13	Factor 4: Personal Beliefs Related to Death of Subscale 1: EoLDS-Cont	107
14	Cronbach's Alpha Coefficients of Total and Four Factors of the Subscale 1: EoLDS-Cont	107
15	Factor 1: Death is the Truth of Life to be Accepted of Subscale 2: EoLDS-Forgo.....	116
16	Factor 2: Prolong Death is Prolong Suffering of Subscale 2: EoLDS-Forgo.....	117
17	Factor 3: Fear to Burden Family and Separate from Family at the End-of-Life of Subscale 2: EoLDS-Forgo.....	118
18	Factor 4: Avoiding Death and Prolong Life are not Peaceful and not Ending of Karma of Subscale 2: EoLDS-Forgo.....	119
19	Cronbach's Alpha Coefficients of Total and Four Factors of the subscale 2: EoLDS-Forgo.....	119
20	Factor 1: Physicians/Nurses are Moral Competent of Subscale 3: EoLDS-MD/RN.....	128
21	Factor 2: Patients and Families Have Low Confidence in Decision Making of Subscale 3: EoLDS-MD/RN.....	123

LIST OF TABLES (Continued)

TABLE		PAGE
22	Factor 3: Avoiding Conflict with Family of Subscale 3: EoLDS-MD/RN.....	130
23	Cronbach's Alpha Coefficients of Total and Three Factors of Subscale 3: EoLDS-MD/RN.....	130
24	Factor 1: Believe in Family's Loving and Caring of Subscale 4: EoLDS-Fam	138
25	Factor 2: Family is Supporter and Avoid Conflict with Family of Subscale 4: EoLDS-Fam.....	139
26	Factor 3: Giving a Chance to Family for Repaying the Gratitude of Subscale 4: EoLDS-Fam.....	140
27	Cronbach's Alpha Coefficients of Total and Three Factors of Subscale 4: EoLDS-Fam.....	140

LIST OF FIGURES

FIGURE		PAGE
1	Process of scale development	91
2	Summarized results from factor analysis.....	102
3	Scree plot for factor analysis subscale 1: EoLDS-Cont.....	103
4	Scree plot for factor analysis subscale 2: EoLDS-Forgo.....	115
5	Scree plot for factor analysis subscale 3: EoLDS-MD/RN.....	127
6	Scree plot for factor analysis subscale 4: EoLDS-Fam.....	137

CHAPTER 1

INTRODUCTION

Background and significance

Chronic illness is one of the major challenges in health care systems around the world today. With improvement in access to medical services and standardization in diagnostic processes coupled with public health awareness and education campaigns, the incidence and prevalence of chronic disease seems to increase exponentially in many countries and is particularly noticeable in developing countries. Health statistics, for example reported twenty-two million recorded cases of chronic illness in a population of sixty-four million for the country of Thailand (Medical Statistics Center Online, 2009). The Thai Health Promotion Foundation (2009) reported the top five chronic diseases, in order of prevalence, as: diabetes mellitus (number of patients from 2008-2010 are 388,551, 558,156, and 607,828, respectively), hypertension (number of patients from 2008-2010 are 494,809, 780,629, and 859,582, respectively), ischemic heart disease (number of patients from 2008-2010 are 159,176, 228,032, and 253,016, respectively), cerebro-vascular disease (number of patients from 2008-2010 are 124,532, 176,202, and 196,159, respectively), and cancer (number of patients by the year 2010 is 241,051).

Chronic illness is caused by disease that produces symptoms and signs within a variable period of time, runs a long course, typically allows only partial recovery and is considered as a permanent health condition. It includes acute illnesses (diseases), such as acute renal failure and cancer that become chronic illness.

By its nature, chronic illness can never be completely cured and typically required long-term care. It affects not only the patient but also the family and local community involving in managing patient care. Unfortunately, within the confines of current available medical treatments, such patients slowly worsen over time and barring other causes, the disease process leads to death (Larsen, 2009).

Death and dying is the final phase of the chronic illness trajectory framework from the nine phases of: 1) the pre trajectory, 2) the trajectory, 3) stable, 4) unstable, 5) acute, 6) crisis, 7) comeback, 8) downward, and 9) dying (White & Lubkin, 1998). In the dying phase, the patient's organs will eventually begin to fail. Life sustaining treatment with advanced technology is commonly used to prolong life in the dying phase. Although advanced technology is aimed for prolong life, it can be said that it only prolongs dying phase, which prolongs mental and physical sufferings. The use of life sustaining therapies in patients with curable illness is rarely questioned, but it is not always clear how such therapies should be used in patients with progressive, late stage, and incurable diseases. Seriously ill patients who are at the end-of-life need to be able to make such decisions. They and their families will find it difficult to decide on whether to continue medical treatment or not and, if so, how much the treatment is warranted and for how long. In these instances, patients typically rely on their physicians or other trusted health professionals for guidance. However, end-of-life decisions are difficult for individuals who, due to lack of education and understanding, are unable to make appropriate and quality decisions about their treatment and thus are unable to prepare for the procedures that express their preferences and decisions before they are incapable of making such a decision (Ganz, et al., 2006).

End-of-life decision causes ethical issues within the health care setting since making end-of-life decision is sensitive and painful. Due to difficulties in making such decision, some patients prefer that end-of-life decisions be made by their family or their family in consultation with an attending physician who can present the patients prognosis and describe the likely course that the disease will run (Kim & Kjervik, 2005). It is imperative; therefore, that families and health care providers are absolutely involved in decision process. A recent study showed that 1.9-5.1% of subjects decided to terminate treatment based on their health care team's opinion, and 1.9-4.8% of subjects who were Thai Muslim patients with chronic illness decided whether to terminate or continue their treatment based on families' opinion (Nijinikaree, 2003). In addition, Neounoi (2005) studied decisions of patients and surrogates on treatment at the end-of-life and found that 27.50% and 12.50% of subjects allowed physicians and families, respectively, to make a decision for them. Moreover, Manasurakarn (2007) found that Thai Buddhist chronically ill patients allowed physicians (18.1%) and families (10.5%) to make the decisions for them. Furthermore, the study by Sittisombut and Intong (2009) found that 57.2% of northern Thai patients with terminal illness had a high regard for their physicians' authority in making decisions on end-of-life care, 28.3% of the patients transferred their decisions to relatives, physicians. All of these are the percentage of individual decision expressing their desire to accept or to refuse life sustaining treatment which is not made by them but made by physicians or their families. The important reasons that they transferred their decisions to others because they trust health care providers and families, and they lack knowledge of the treatment and physical and mental suffering from the illness and treatment.

Some patients understand that they have the freedom to act upon end-of-life choices. These are autonomous persons who make decision at the end-of-life by themselves. According to the Thai National Health Act, B. E. 2550, Section 12, it is stated in the following amendment that: “A person shall have the right to make an advance directives to refuse the health care services which is supplied merely to prolong death at his/her terminal stage of life or to cease the severe suffering from illness” (The National Health Commission Office, 2007). This provision promotes patient autonomy. As a result of the Thai National Health Act; an individual’s wish at the end-of-life will be respected. The review of related literatures revealed four types of end-of-life decisions (1) continuing life sustaining treatment, (2) forgoing life sustaining treatment, (3) allowing physicians/nurses to make decision, and (4) allowing family to make decisions (Manasurakarn, 2007; Neounoi, 2005; Nijinikaree, 2003).

The literature reviews also designated that patients made decisions at the end- -of-life based on values, beliefs, such as religious values, social values, and other factors such as family burden/concern, advanced medical technology/chronic illness. The studies showed the reasons for the patients and families’ decision to forgo life sustaining treatment such as feeling fear to face the long period of using life sustaining treatment (Manasurakarn, Chaowalit, Suttharangsee, Issaramalai, & Geden, 2008), fear of suffering from treatment (Manasurakarn, et al., 2008; Neounoi, 2005; Rothman, Van Ness, O’ Leary, & Fried, 2007), due to their religious beliefs (Ai, Park, & Shearer, 2008; Cohen, McCannon, Edgman-Levitan, & Kormos, 2010; Kongsuwan, Chaipetch, & Matchim, 2012; Manasurakarn, et al.; 2008, Neounoi, 2005), having no ideas or knowledge about the treatment and the diseases (Foo, Lee, & Soh, 2012; Foo, Zheng, Kwee, Yang., & Krishna, 2013; Ganz, et al., 2006) fear to burden family (Foo

et al., 2012; Kwon, et al., 2009; Manasurakarn, et al., 2008; Nijnikaree, 2003; Rietjens, Van der Heide, Onwuteaka-Philipsen, Van der Maas, & Van der Wal, 2006), due to their wishes and preferences (Kim & Kjervik, 2005; Romer & Hammes, 2004), due to cost of health care (Foo, et al., 2012; Kwon, et al., 2009; Yusuf & Nuhu, 2011), due to socioeconomic background (Yusuf & Nuhu, 2011), need to complete tasks (Foo et al., 2012; Manasurakarn, et al., 2008), no hopes of recovery (Foo, et al., 2012). In Thai context, religious belief is a major factor in shaping people's way of living and thinking in the society (Komin, 1991). Therefore, Thai Buddhists with chronic illnesses relied on the Buddhist concepts and teaching when they make decision at the end of life. The Study by Neiounoi (2005) on decision made on treatments at the end-of-life of 280 chronically ill patients and 280 surrogates of the patients found that the reasons why the patients and surrogates decided to forgo treatments was mostly because of their religious belief, such as death is inevitable, prolonging life is prolonging suffering to the body and the need for peaceful death.

As a part of patient assessment, nurses should consider asking about end-of-life choices to indicate their respect for patient autonomy and take role as nurse advocacy when patients become incapable. The nursing goal is to facilitate the patient's participation in decision making, which requires an accurate assessment of patient capacity (Bandman & Bandman, 2002). However, assessment scales regarding end-of-life decision are not readily available or not available, especially in Buddhist and Thai context. Some scales related to end-of-life decision were developed in the western context. For example, Gauthier and Froman (2001) developed the Preferences for Care Near the End of Life (PCEOL). Siminoff, Rose, Zhang, and Zyzanski (2006) developed the instrument to assess level of family discord concerning the treatment of

the last state cancer. Erci and Ozdemir (2008) developed the treatment decision evaluation scale and its psychometric properties for Turkish patients with cancer. Lee et al. (2010) developed a scale for the End-of-Life Caregiving Appraisal. However, how the patients make decision at the end-of life was not clearly explained. Moreover, these studies addressed only values common to Western beliefs. There are no suitable scales for assessing end-of-life-decision in the Thai context, with suitable components compatible to the cultural context in which the patients live. Furthermore, these scales were not cover four types of end-of-life decision.

This study developed a scale to measure end-of-life decision for Thai Buddhist adults with chronic illness. The scale could be useful for Thai nurses and healthcare providers in assessing end-of-life decisions among Thai Buddhist adults with chronic illnesses. Moreover, health care providers can use the results of the study to advocate patient's rights and promote self-determination for chronically ill patients in the Thai context.

Objectives of the study

1. To develop the End-of-Life Decision Scale (EoLDS) for Thai Buddhist adults with chronic illness.
2. To evaluate the validity and reliability of the End-of-Life Decision Scale (EoLDS) for Thai Buddhist adults with chronic illness.

Research questions

1. What are the components of the End-of-Life Decision Scale (EoLDS) for Thai Buddhist adults with chronic illness?
2. How valid and reliable is the End-of-life Decision Scale (EoLDS) for Thai Buddhist adults with chronic illness?

Conceptual framework

The conceptual framework of this study was developed by the integration of literature reviews (Burkhardt & Nathaniel, 2002) and individual interviews of 12 Thai Buddhist patients with chronic illness. The foundation for end-of-life decision is the principle of patient autonomy. Ethical principle has been the major theoretical framework of scale development to measure end-of-life decision that covers two basis elements of autonomous decision and surrogate decision (Burkhardt & Nathaniel, 2002). Autonomous decision consisted of continuing life sustaining treatment and forgoing life sustaining treatment. Whereas, surrogate decision consisted of allowing physicians/nurses to make decision and allowing family to make decision. In addition, reasons supporting each type of end-of-life decision were identified. The details of the conceptual framework are as follows:

1. Continuing life sustaining treatment

Continuing life sustaining treatment is an individual decision-making for the purpose of prolonging one's life by using life-sustaining treatment at the end of life, even if there is no chance for them to regain full viability (Flynn & Davis, 1990). Life sustaining treatments are medical intervention which helps preserve life such as ventilator, hemodialysis, and blood transfusion. Knox (1989) describes the ability of modern medical technology that can sustain vital bodily functions but cannot reverse the underlying disease process that may cause pain and suffering, or even death.

The reasons supporting end-of-life decision are Buddhist values, social values, family concern, and advanced medical technology/chronic illness.

1.1 Buddhist values

Buddhist values, Buddhist values related to decision to continue life sustaining treatment included the Four Noble Truths and the Law of Karma. The Four Noble Truths consist of suffering, the cause of suffering, the cessation or extinction of suffering, and the path to the cessation of suffering, are the Buddhist philosophy which help Buddhism to understand suffering (Payutto, 1995). Lord Buddha taught persons not to be careless in spending their lives, but to do useful things for their own lives and others' lives. The essence of Buddhism is to teach the people to understand the Four Noble Truths to realize suffering and impermanence of life in which death could happen at any time. So, Buddhism should study and learn

Buddhist principle to understand 1) the meaning and the value of life, 2) the process of dying, and 3) the preparation for death. Moreover, birth, old-age, pain of diseases, and death, all of which are sufferings which are part of human life. In addition, Paonil & Sringernyuang (2002) stated that human life is short and it is easy to get sick or die. People should practice hard and do everything to develop ourselves to live with wisdom. Some Buddhists decide to continue life sustaining treatment because they need to know the meaning of suffering and find ways to understand and reduce suffering before die. Some Buddhists believe life is valuable, people need to preserve life as long as possible. According to first precept of the five precepts state that hurt or short life or kill animal is sin.

In addition, the Law of Karma is one part of the natural law that refers to the result of action or cause and effect relationship in living (Payutto, 1995). Buddhist philosophy states that everything is subject to the Law of Karma (Payuttho, 1995). Doing good Karma is by living a morally sound life and trying to follow the Buddhist doctrines. Based on this belief, some people decided to prolong life because they need more time to do good Karma. Supporting by Manasurakarn (2007) study found that participants decided to continue life sustaining treatment based on the Law of Karma values: reciprocity of Karma.

1.2 Social values

Social values related to continuing life sustaining treatment are grateful value and personal believe. Gratefulness or reciprocity of goodness, expressed in Thai as “Bunkhun”, is a highly valued characteristic trait in Thai society

(Komin, 1991). Thus, people need to be grateful to their own body and parents. The results of negligence to the body are the source of diseases (Paonil & Sringernyuang, 2002).

Personal beliefs related to death are defined as social values such as Supernatural Miracle, Holy Thing, Fate, Virtue, and Will Power. Some examples of these beliefs in Thai context are beliefs in spirits, predestinated fortune (“duang” in Thai), wishes making and vows to the spirits (bon ban sarn klaw in Thai), and some supernatural rituals to stop bad fortune (by sprinkle holy water) (Komin, 1991).

Additionally, the concepts of hopes are also found in Thai context. Patients who believe life is value need to live as long as possible to do most benefits of good thing (Gauthier, 2005; Manasurakarn, 2007 Nijnikaree, 2003). Furthermore, hope has been described as being spiritual well-being in terms of providing a sense of meaning and purpose of life (Averilletal, 1990 as cited in Chaplin & McIntyre, 2001). Thus, hope to survive can lead the patients decided to continue the treatments as a study by Manasurakarn (2007).

1.3 Family concern

Family concern relate to continuing life sustaining treatment are concern about their descendants, passionate with family, and waiting for achievement of their descendants. Some people wish to live long enough to make or join important events such as birthday, holiday, or family events or to complete an unfinished task, such as reconciling with a relative, may choose aggressive therapy in order to achieve that goal (Arnold, 2001).

1.4 Advanced medical technology/chronic illness

Advanced medical technology/chronic illness relate to end-of-life decision are medical interventions, which are used to preserve life. Knox (1989) stated that the ability of modern medical science to prolong life often exceeds the ability to restore health. The potential of medical technology can sustain vital organ but it is unable to reserve the underlying disease process that may cause pain and suffering, or even death. However, advanced medical technologies have created hope for people in society to prolong life (White & Lubkin, 1998) such as dialysis, organ transplantation, surgery, chemotherapy, radiation.

2. Forgoing life sustaining treatment.

Forgoing life sustaining treatment refers to individual decision making to refuse life sustaining treatment at the end-of-life. Withholding and withdrawing life sustaining treatments are two types of forgoing life sustaining treatments. Withholding life sustaining treatment is defined as a decision not to start or not to sustain further use of life prolonging treatments. Withdrawing life sustaining treatment refers to stopping treatments once it has been started (Hall & Rocker, 2000; Hudak, Gallo, & Morton, 1998).

The reasons supporting forgoing life sustaining treatment are also categorized into four dimensions: Buddhist values, social values, family burden/concern, and chronic illness.

2.1 Buddhist values

Buddhist values related to forgo life sustaining treatment included the Four Noble Truths or Ariya-sacca, the Three Characteristics of Existence, and the Law of Karma.

The Four Noble Truths or Ariya-sacca are the truths of suffering, the cause of suffering, the existing of suffering, and the path to the cessation of suffering (Payutto, 1995). Based on this principle, death is the truth of life which all human beings must accept. In this view, prolong life is wrong. Death is inevitable, nobody can control death. Death is already set; people must go when death arrives. Moreover, death is the way to overcome suffering. Thus, useless to prolong life.

The Three Characteristics of Existence, the natural law of Buddhist doctrine, also mention that life exists and extinguishes under the true nature of world. According to this principle, all of life is not permanent and is made from five groups (Pancakkhanda): rupa or material form; vedana or feeling; sanna or perception; sankhara or impulse; and vinnana or consciousness. There is no owner, no real self (Chanchamnong, 2003). Based on this Buddhist principle, death is only leaving from compounded things or five groups (Pancakkhanda). According to Buddhist principle, Death is natural, prolonging life is against nature; everyone is born and finally dies.

The Law of Karma is Buddhist principle that relates to cause and effect and can be classified as both values of life and death (Chanchamnong, 2003). Some people believed that life is living for reciprocity to Karma while some

believed that death is the end of Karma. Thus, the view of death that is focused on Karma such as death is karma, nobody can refuse Karma, death is release Karma, The patients who believe these values thoroughly will realize that all diseases are the result of Karma and under the natural law that refers to the working of intention, or the process of mental proliferation and its consequences (Payutto, 1995). Moreover, quality of death such as need peaceful death is another reason related to forgo life sustaining treatment.

2.2 Social value

People who have chronic illnesses typically find it very difficult to return back to normal health and it often becomes a life long illness. In general, society views chronically ill negatively because of their on the national economy. Some views them as a nonproductive person (Curtin & Lubkin, 1998). Based on this view, some chronic illness patients fear to burden family and society because they cannot work or contribute for the benefit to family and society. Thus, they tend to forgo life sustaining treatment. The studies indicated that the participants felt that life was not invaluable if they could not take care of themselves (Manasurakarn, 2007; Meissner, et al., 2010; Nijinikaree, 2003; White & Fitzpatrick, 2006).

Additionally, the Thai National Health Act Section 12 provides that at any time, a person shall enjoy the right to stop medical service, which may merely be to prolong death or to suffering at the end-of-life by expression of the living will or advance directive to the medical personnel” (The National Health

Commission Office, 2007). Based on this law made the chronic illness patients decided to refuse treatment at the end-of-life as an autonomous person.

2.3 Family burden/concern

Living with chronic illness has caused physical, psychosocial, spiritual, and social problems for both the patient and family (Curtin & Lubkin, 1998). Some of the impacts including duration of hospitalizations, increased financial crisis, social burdens, emotional difficulties, feeling of anxiety and frustration, and changes in body appearance are problems causing burden to patients and their families and make patients think about death or decide to forgo life sustaining treatment (Larsen, 2009). Families are responsibility to chronic illness patients for longer care, thus it makes chronic illness patients concern about family.

2.4 Chronic illness

Chronic illness related to forgoing life sustaining treatment are prognosis of underlying chronic disease which put the patients in irreversible state or impairments where they need supportive care, maintenance of function and prevention of disability (Curtin & Lubkin, 2009). Moreover, the problem of symptoms distress from chronic illness affect not only the physical but the psychosocial and spiritual aspects of quality of life as well (Taylor, Jones, & Burn, 1998). These problems made them suffer from the chronic diseases and trend to decide to forgo life sustaining treatment. A study reported that chronic illness was one reason that made

the patients decided to forgo life sustaining treatment (Nijnikaree, 2003). Moreover, some studies indicated that the patients did not want to suffer any longer (Manasurakarn, 2007; Meissner, et al., 2010; Nijnikaree, 2003; White & Fitzpatrick, 2006).

3. Allowing physicians/nurses to make decision

Allowing physicians/nurses to make decision refers to the situation that patients allow health care providers such as physicians/nurses to make decisions at the end-of-life for them. The reasons supporting allowing physicians/nurses to make decision are also categorized into four dimensions: Buddhist values, social values, reduce conflict with family, and advanced medical technology/chronic illness.

3.1 Buddhist values

From Buddhist perspective, physician/nurses are expected as loving-kindness and compassion. This character reflects the concept of Metta-Karuna (mercy-kindness) in Buddhism. Compassion or karuna is at the transcendental and experiential heart of the Buddha's teachings. Compassion is one of the most important attributes for physicians practicing medical services. It has been suggested that felt compassion brings about the desire to do something to help the sufferer (Cassell, 2009).

3.2 Social values

Physician/nurses are expected by society to do good and not do harm to the patient, and to be honest. Thus, the reasons supporting this type of end-of-life decision included respect for physician, and lack of knowledge that lead to no confidence for self/family end-of-life decision. Respect for physicians/nurses can be demonstrated in trust in physicians/nurses' knowledge and competence, and trust in the physician experience. The study indicated that the patients lack of education and understanding the treatment (Ganz, et al., 2006). Moreover, in Thai society, education and competence orientation are Thai social values. From these values led people respect for person in high position such as physicians/nurses (Komin, 1991).

3.3 Reduce conflict with family

Since end-of-life decision is difficult and complex for patients (Manasurakarn, et al., 2008; Steinhauser, et al., 2000). The decision making at the end-of-life varies from one to another individual according to their beliefs and values of life. If the patients make their own end-of-life decision, it may be different from family and made mistake. To reduce conflict with family, Thais patients tend to delegate end-of-life decision to physicians/nurses.

3.4 Advanced medical technology/chronic illness

Advanced medical technology/chronic illness related to allowing physicians/nurses to make decision. Since being with the impaired role as chronic illness patients, most patients tend to delegate end-of-life decision making to health care professional (Lewis & Lubkin, 1998). Furthermore, advanced medical technology/chronic illness are not always easily quantified or understood by patients and their caregivers (Campbell, Williams, & Orr, 2010). Thus, patients tend to allow physicians/nurse to make decision at the end of life.

4. Allowing family to make decision

Allowing family to make decision can be called surrogate decision making which refers to decision made by significant persons for the patients. (Burkhardt & Nathaniel, 2002). The reasons supporting allowing family to make decision are also categorized in four dimensions: Buddhist value, social values, family love, and chronic illness.

4.1 Buddhist value

Buddhist value related to allowing family to make decision is family members are trues friends to make good wish. In addition family takes responsibility to patients with chronic illness (Pierce & Lutz, 2009). Thus, families are true friends at the end of-life by Buddhist perspective. Moreover, respect for family can be demonstrated in belief in family decision as (1) trust in the family

decision, (2) the family knows what the patient needs, and (3) the family loves and has a good wish for the patient (Manasurakarn, 2007).

4.2 Social values

Social values related to allowing family to make decision are grateful values and do not want to burden their family (kreanjai). Thai society people are taught to be grateful to a person who renders goodness (Katanyu) to them such as parents and teachers (Komin, 1991). Thus, elderly patients wanted their family, descendants, to be a quality person in taking care of their seniors at the end-of-life. It is considered a good deed of the descendants for this arrangement and therefore wanted them to take a responsibility to make the end-of-life decision for them. These reasons for delegating the end-of-life decision to the family members who were taking care of them were in corresponding to the findings in a study of Neunoi (2005) which found that patients and surrogates decided to prolong life because they needed to repay the kindness for parents

Furthermore, Thai society most parents do not want to burden their family that is called in Thai “kreanjai.” Thus, they tend to allow family to make decision at the end-of-life. In addition, financial burden is a problem that can occur in chronic illness patients. It is usually the family member who terminates employment in order to stay home and care for the patients. Moreover, other family members may need to work more hours to earn enough to support the family. Such problem leads the chronic illness patient delegates end-of-life decision to their family.

4.3 Family love

Family love is related to allowing family to make decision. Since family life in Thai culture is more closely united than that in western culture hierarchies, with the parents at the top (Knutson, 2004). Moreover, with a confidence of love and best wishes from the family, Thais tend to delegate the end-of-life decision to family. The love and good wishes from the family was found to influence the decision to delegate the end-of-life decision in a study by Manasurakarn (2007) which found that subjects allowed family to make decision based on the reasons: the family knows what the patients' need, the family loves and has a good wish for patients.

4.4 Chronic illness

Being with chronic illness, the patients struggle to undertake their body malfunction and maintain personal and social identities. Psychological well-being is an essential component of health related quality of life and it can influence the overall adjustment of patients with chronic illness. Without it, the patients may withdraw from their social network (Biordi, 1998). Some had experience of discomfort, pain or fear of pain, anxiety, loss of hope and other physical symptoms increasing dependence on family or decreasing their end-of-life decision ability.

Definition of terms

Thai Buddhist adults with chronic illnesses refer to patients got chronic illness who believe that the Buddhist principles can solve the problem in human life and society. They engage in some or several kinds of Buddhist activities such as

mindfulness meditation, making good merit (giving charity or offering food to monks), chanting, or listening to Dharma tapes (Buddhist discourse about the reality of life).

End-of-life decisions refer to how Thai Buddhist adults make decision when they face the terminal illness scenario. There are four types of end-of-life decision: (1) continuing life sustaining treatment, (2) forgoing life sustaining treatment, (3) allowing physicians/nurses to make decision, (4) allowing family to make decision.

Life sustaining treatment refers to a treatment that is used to prolong lives of terminally ill patients including cardiopulmonary resuscitation, mechanical ventilation therapy, artificial feeding nutrition and hydration, dialysis and antibiotic therapy.

Significance of the study

1. Nurses and other health care providers can use the four subscales: EoLDS to assess end-of-life decision for Thai Buddhist adults with chronic illness.
2. Educators can use the end-of-life decision components for curriculum development in nursing ethics.
3. Researchers can use the end-of-life decision scale to investigate end-of-life decision of other groups of patients.

Summary

Since there is no up to date scale suitable for assessing end-of-life decision among Thai Buddhists adults with chronic illness, therefore the End-of-Life Decision Scale developed in this study can be used as a very useful and essential measuring scale for nurses and health care providers in caring for patients at the end-of-life stage. Moreover, this scale will enable healthcare administrators to assess end-of-life decisions for chronically ill patients and use the results to advocate patient rights. Finally, it can be used to support end-of-life decision based on the National Health Act section 12.

CHAPTER 2

LITERATURE REVIEW

Introduction

The review of literature to support the development of the End-of-Life Decision Scale for Thai Buddhist Adults with Chronic Illness includes the following topics:

1. Chronic illness
 - 1.1 Definitions of chronic illness
 - 1.2 Chronically ill patients
 - 1.3 Chronic illness trajectory
 - 1.4 Problems of the chronically ill patients
2. End-of-life care and treatments at the end-of-life
 - 2.1 End-of-life
 - 2.2 End-of-life care
 - 2.3 End-of-life treatments
3. End-of-life decision of patients with chronic illness
 - 3.1 Definition of end-of-life decision
 - 3.2 Types of end-of-life decision
 - 3.3 Laws related to end-of life decision
4. Reasons related to end-of-life decision
5. Scales related to end-of-life decision

1. Chronic illness

1.1 Definitions of chronic illness

Chronic illness is defined as medical conditions or health problems associated with symptoms or disabilities that require long term (3 months or longer) management (Robert Wood Johnson Foundation, as cited in Smeltzer & Bare, 2000). Chronic illness can also be defined as the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of future disability (Curtin & Lubkin, 1998). Chronic illness is a group of health conditions that persists for a long time. It is caused by non-reversible pathologic alteration and required specific training of the patient for rehabilitation, and may be expected to require a long period of supervision or care. Chronic illnesses generally cannot be prevented by vaccines or cured by medication, nor do they just disappear (Commission on Chronic Disease, as cited in Larsen, 2009; Feldman, as cited in Larsen, 2009; Webster's New World Medical Dictionary, 2008).

1.2 Chronically ill patients

Chronically ill patient is a patient who has the irreversible presence, accumulation or latency of disease state or impermanent who involves the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability (Curtin & Lubkin 1998). Miller (2000) defined chronic

illness patient as a person who has an altered health state that will not be curable. There are many types of chronic illnesses but the top five chronic illnesses are diabetes mellitus, hypertension, ischemic heart disease, cerebrovascular disease, and chronic vascular disease (Thai Health Promotion Foundation online, 2009).

In short, a chronically ill patient refers to a person who has an illness that is permanent or the poor health condition that lasts for so long that it may get worse slowly over time and leads to death. It may cause permanent changes to the body. It will certainly affect the person's quality of life. People who have chronic illnesses typically find it very difficult to return back to normal health and it often becomes a life long illness.

1.3 Chronic illness trajectory

The trajectory framework developed by Corbin and Strauss (1988) provides a conceptual basis for developing a nursing model that gives direction for practice, teaching, and research in the area of chronic illness. Corbin and Strauss (as cited in White & Lubkin, 1998) divided chronic illness in nine phases as follows:

1.3.1 The pre trajectory phase is described as the stage at which the person is at risk for developing a chronic condition because of genetic factor or lifestyle behaviors that increase susceptibility to chronic illness.

1.3.2 The trajectory phase is characterized by the onset of symptoms or disability associated with a chronic condition.

1.3.3 The stable phase is when the illness course and symptoms are under control; biography and everyday life activities as being managed within limitations of illness.

1.3.4 The unstable phase is the period of inability to keep symptoms under control or reactivation of illness; biographic disruption and difficulty in carrying out everyday life activities; adjustments being made in regimen, with care usually taking place at home.

1.3.5 The acute phase is characterized by severe and unrelieved symptoms or the development of illness complications necessitating hospitalization or bed rest to bring illness course under control; biography and everyday life activities temporarily placed on hold or drastically cure back.

1.3.6 The crisis phase is the stage when critical or life-threatening situation requiring emergency treatment or care; biography and everyday life activities suspended until crisis passes.

1.3.7 The comeback phase is described as the gradual return to an acceptable way of life within limits imposed by disability or illness; involves physical healing, stretching limitations through rehabilitative procedure, psychosocial coming to terms and biographic reengagement with adjustments in everyday life activities.

1.3.8 The downward phase is the illness course characterized by rapid or gradual physical decline, accompanied by increasing disability or difficulty in controlling symptoms; requires biographic adjustment and alteration in everyday life activities with each major downward step.

1.3.9 The dying phase is described as the final days or weeks before death, characterized by gradual or rapid shutting down of body processes, biographic

disengagement and closure, and relinquishment of everyday life interests and activities. This phase is not linear; death is identified as outcome. People living with chronic illnesses have multiple complex goals and priorities that evolve over time. Repeated hospitalizations are not uncommon during the course of this phase of chronic illness. Often death comes while an individual is hospitalizing, but with the advent of home hospice care, more and more chronic illnesses reach termination in the home (White & Lubkin, 1998).

Dying trajectories can be divided into quick and lingering categories (Glaser & Strauss, as cited in White & Lubkin, 1998). Quick dying trajectories occur over relatively short periods of time and may be expected or unexpected. Sometimes it is apparent that death will occur quickly and expectedly within hours or at most a few days. Quick death can come when someone who was expected to die eventually, dies unexpectedly as a result of a sudden deterioration (the terminal cancer client who has a massive myocardial infarction). Lingering trajectory has two major features: long duration and slow but steady downward movement. It has greater potential for biological, human, or psychological unpredictability than does the quick trajectory. If lingering is relatively short (days to weeks), with little pain and a reasonably high level of family acceptance, it is not greatly upsetting (Glaser & Strauss, as cited in White & Lubkin, 1998).

1.4 Problems of the chronically ill patients

There are several aspects of problems that affect the chronically ill patients. The problems are always associated with quality of life within the context of physical, psychological, and economic difficulty.

1.4.1 Physical problems

Chronic illnesses are the leading cause of physical disability. Functional status is affected by the disability of chronically ill patients to continue functioning in daily activities, such as self-care, school, and work (Taylor, Jones, & Burns, 1998). Hand inflexibility, weakness, fatigue, chronic pain, and bladder continence are some of the examples of the disability. The result from dysfunction of body structure may lead to unemployment. The lack of employment has an effect on economic problems and social isolation (Biordi, 1998). Chronic illness was one factor that made the patients decide to forgo life sustaining treatment because they did not want to suffer from the illness and they felt that life was worthless if they could not take care of themselves (Manasurakarn, 2007; Meissner, et al., 2010; Nijnikaree, 2003; White & Fitzpatrick, 2006). Gauthier (2005) suggested that a physical crisis is a major precursor to the decision to stop aggressive and curative treatment. Some had experience of discomfort, pain or fear of pain, and other physical symptoms increasing dependence on others or decreasing their functioning ability.

1.4.2 Psychological problems

Chronic illness symptoms affect the patients both physically and psychologically. The patients may experience distress, fear, anxiety, loss of hope, and helplessness. Being with chronic illness, the patients struggle to undertake their body malfunction and maintain personal and social identities. Psychological well-being is an essential component of health related quality of life and it can influence the overall

adjustment of patients with chronic illness. Without it, the patients may withdraw from their social network (Biordi, 1998). Edward (2005) suggested that the common fears confronting people with life-sustaining illness are fear of separation, fear of being a burden to others, fear of losing control, fear of being unable to complete task and responsibilities, fear of debilitating symptoms, fear of being dependent on others, and fear of dying. Chronic illness frequently affects the quality of the patients' social relationships and roles, at the same time; social support also affects their quality of life. Social support is a significant contributor to health-related quality of life (Taylor, Jones, & Burns, 1998). Gauthier (2005) suggested that a sense of security and strength, an opportunity to communicate in a transcendent realm made patients accept the finality of life. In addition, Gauthier described that psychological problems such as the extreme feeling of anger and frustration changed patient's decision making authority at the end-of-life from self to family.

1.4.3 Economic problems

Chronically ill patients also face financial suffering because the additional expenses for some medical items are not covered by insurance (Larsen & Lubkin, 2009). However the economic impact of chronically ill patients on individuals and their family has received scant attention to nursing literature review. Taylor, et al. (1998) found that chronically ill patients often have significant burden in finances. Additional expense on items not covered by insurance, transportation to medical or treatment appointments, extra cost of special dietary feed and supplements can add up to a financial burden (Gautheir, 2005; Sprung et al, 2003; White &

Fitzpatrick, 2006). These studies indicated that the patients themselves are the most appropriate persons to make the end-of-life decision in the absence of socioeconomic burden.

2. End of life care and treatment at the end-of-life

Advances in medical and life-sustaining technologies have contributed to extending human life expectancy. Most chronically ill patients must; however, eventually face the process of planning for their future medical care which involves three issues of 1) end-of-life, 2) end-of-life care, and 3) end-of-life treatment. The contents are as followings:

2.1 End-of-life

End-of-life or death is inevitable for mankind, and it can occur at any age. Death is manifested as cessation of respiration and heart beat caused by physiologic dysfunction, generally related to an illness or trauma that overwhelms the compensatory mechanism of the body (Kazanowski, 2002). Poor (2001) stated that death or end-of-life has been considered as natural as birth and simply as the last stage of life. Death may be sudden and unexpected, caused by heart attack or accidents, for example. Death may be prolonged and coming after a distressing long term of illness. Death may come quietly during the sleeping period. Some deaths are planned by those who choose to die on their own terms by way of suicide. Due to advanced medical technologies, medical treatment can prolong life, but it cannot prevent death. Arnold

(2001) indicated that death is understood and confronted on two perspectives: in a traditional sense and in the logical sense. In the traditional sense, death is a life experience as in spiritual or religious events. In the logical or scientific sense, death is viewed as physical and psychological events. To the most common sense; however, death causes grief and bereavement (Wills, 2001).

2.1.1 Definitions of death

The definition of death and response are explained in this section for future informed references and understanding. Scholars define death in many views such as death is absent of life, an experience as a spiritual or religion event, and an abstract notion to concepts such as loss, grief, bereavement, mourning, and separation (Arnold, 2001). In scientific terms, Bandman and Bandman (2002) defined death in two definitions, (1) irreversible cessation of respiration and circulation, and (2) irreversible cessation of all function of the brain. Arnold (2001) stated the concept of death accepted by the general public and medical and legal professions is recognized by circulatory and respiratory functioning were the essential defining characteristic of life, the absence of which consequently defined death.

Today, death becomes an ethical issue because it intrigues important questions, such as “when does life end?” “how can we be sure that someone has died?” and “who can designate if someone is dead?” Apparently, death comes quietly in the presence of the blinking lights of the monitors, pumps, drips, and suction of critical care units (Bandman & Bandmand, 2002). Under such conditions, death is impersonal. Death appears to be a separation of body from tubes and

machines. In this manner, death is an unnatural and impersonal event related solely to the use of technology. Death may be due to someone's decision, rather than the natural failure of the heart which pumps blood. In some cases, when the fundamental nature of the patient has long been absent, family has exhausted its grief during the prolonged period when the patient was neither responsive nor dying, neither dead nor alive. The family aches for resolution of an ambiguous situation in which neither grief nor hope is appropriate. All people know death is inevitable and it is natural human experience. However, people fear death and respond to death in several different ways (Santrock, 1999).

2.1.2 Response stages of patients at the end-of-life

Patients at the end-of-life need to determine their own course of treatment based upon a prediction of patient prognosis, such as life-sustaining treatment. It is difficult to predict or know how long the patient is likely to live in such a critical situation. This makes patients, at the end-of-life feel loss and grief, and respond to it differently (Kinzbrunner, 2002). Kubler-Ross as cited in Taylor, Lillis, and LeMone (2001) described the response of patients at the end-of-life period in five stages as (1) denial and isolation, (2) anger, (3) bargaining, (4) depression, and (5) acceptance.

Details of each of these stages are described as follows:

2.1.2.1 Denial and isolation is the first stage of dying, in which the person denies that death is really going to take place. The person may say, "No, it can't be me. It's not possible" this is a common reaction of patients with terminal

illness. However, denial is usually only a temporary defense and is eventually replaced by increased awareness when the person is confronted with such matters as financial considerations, unfinished business, and worries about surviving family members (Santrock, 1999). In the denial and isolation stage, the person denies that he or she will die. The person may repress what is discussed, and may isolate self from reality. The patients may think, “they make a mistake in the diagnosis.”

2.1.2.2 Anger is the second stage of dying, in which the dying person recognizes that denial can no longer be maintained. Denial often gives way to anger, resentment, rage, and envy. The dying person’s common question is, “why me?” At this point, the person develops into the difficult state of caring. Anger may shift and project on to physicians, nurses, family members, and even God. The realization of loss is so enormous that those who symbolize life, energy, and component functioning are especially salient targets of the dying person’s resentment (Santrock, 1999).

2.1.2.3 Bargaining is the third stage of dying, in which the person develops the hope that death can somehow be postponed or delayed. Some persons are involved into a bargaining or negotiations -often with God- as they try to delay death. Psychologically, the person is saying, “yes, me but...” in exchange for a few more days, weeks, or months of life. The person promises to lead a reformed of life dedicated to God or to the service of others (Santrock, 1999).

2.1.2.4 Depression is the fourth stage of dying, in which the dying person comes to accept the certainty of death. At this point, a period of depression or preparatory grief may appear. The dying person may become silent, refuse visitors and spend much of time crying or grieving. This behavior should be

perceived as normal in this circumstance and is actually an effort to disconnect the self from all love objects. Attempts to cheer up the dying person at this stage should be discouraged, suggests by Kubler-Roses, because the dying person has a need to contemplate impending death (Santrock, 1999).

2.1.2.5 Acceptance is the fifth stage of dying, in which the person develops a sense of peace, an acceptance of one's fate and, in many cases, a desire to be left alone. At this stage, feelings and physical pains may be virtually absent. Kubler-Ross described this fifth stage as the end of dying struggle, the final resting stage before death (Santrock, 1999). When the step of acceptance comes, the patient feels tranquil. He or she has accepted death and is prepared to die. In this stage, the patient has found some peace and is withdrawing into the self (Wills, 2001).

2.2 End-of-life care

End-of-life care is the care provided to a person who is in final stages of life. It is also known as hospice care, comfort care, supportive care, palliative care or symptom management (Dyer, 2006). End-of-life care encompasses pain and symptom control, communication about diagnosis, prognosis and treatment options, advanced care planning and the emotional and psychological support of patient and families. The following topics will focus only hospice care, palliative care, and euthanasia.

2.2.1 Hospice Care

Hospice care is the service which is provided in private homes or independent and assisted-living facilities (Murphy, 2007). The service can also be provided in hospital and nursing homes when there is a signed contract between the hospice organization and the facility. Hospice care can assist a family to take care of patient at home, but hospice nurse do not routinely provide 24 hours in homecare. One of the virtues of hospice care is that the responsibility for making choices concerning care at the end of one's life rest with the patient. In order to qualify for hospice, a patient must have a prognosis of living for six months or less.

2.2.2 Palliative care

Palliative care is defined as the active care of patients whose disease is not responsive to curative treatment (Griffie, 2001). The care include the comprehensive management of the physical, psychological, social, spiritual, and existential needs of patients. The goal of palliative care is holistic to achieve the best possible quality of life for patients and families such as management of pains and psychological, social, and spiritual problems (Taylor, et al, 2001; Warring & Krieger-Blake, 2010). Singer, Martin, and Kelner (1999) defined five components of quality end-of-life care identified by patients as 1) adequate pain and symptom management, 2) avoiding inappropriate prolongation of dying, 3) achieving a sense of control, 4) relieving burden, 5) strengthening relationships with love ones. It is concluded that palliative care helps patients to live well in the final day of life.

2.2.3 Euthanasia

Euthanasia is the act of painlessly putting to death for persons who are suffering from an incurable disease or severe disability (Santrock, 1999). Euthanasia is also known as mercy killing. Distinctions are made between two types of euthanasia: active and passive. Active euthanasia occurs when death is induced deliberately, as by the injection of a lethal dose of a drug. Passive euthanasia occurs when a person is allowed to die by withholding an available treatment, as well as withdrawing life sustaining treatment, e.g. turning off a respirator or a heart lung machine.

2.3 End-of-life treatment

End of life treatments are medical interventions, which are used to preserve life. Knox (1989) stated that the ability of modern medical science to prolong life often exceeds the ability to restore health. The potential of medical technology can sustain vital organ but it is unable to reserve the underlying disease process that may cause pain and suffering, or even death. EOL treatment is conceptualized on a four level continuum: (1) palliative, (2) active, (3) aggressive, and (4) invasive. The first level of care provides comfort and alleviates pain and discomfort but it does not cure diseases or prolong life. Before the introduction of treatment such as intravenous (IV) medications and chemotherapy, EOL treatment was primarily palliative. Palliative care is often provided by love ones and by organizations such as Hospice. The second level involves noninvasive efforts to preserve or prolong life. Intervention

may involve measures such as oral antibiotic and assistance with eating and drinking. The third level involves treatments such as the administration of IV medications and artificial hydration and nutrition. The fourth level involves invasive treatments such as artificial ventilation and cardiopulmonary resuscitation (Mackelprang, & Mackelprang, 2005). There are several invasive end-of-life treatments as followings:

2.3.1 Cardiopulmonary resuscitation

Cardiopulmonary resuscitation (CPR) is first suggested as useful for witnessed arrests, sudden death in young people, drowning, and arrests of known etiology, like anesthesia (Hall, 1996). Instead, almost all hospitals and nursing homes in the United States have policies that CPR must be done in all patients who die -for any reasons, at any ages and within any conditions. Rosenfeld, Wenger, and Kagawa-Singer (2000) conducted in-depth interviews with 21 elderly to identify the desired features of the end-of-life medical decision-making from the perspective of elderly individuals. The results suggested that informants were concerned primarily with the outcomes of serious illness rather than the medical interventions that might be used.

2.3.2 Mechanical ventilations

Mechanical ventilators are medical technology for life support (Scott, 2010). When the dying patient is in respiratory distress or failure and the family has told the physician to continue life-sustaining treatment, intubation and mechanical ventilator will be operated. Nahm and Resnick (2001) studied the end-of-

life treatment preferences among older adults. The results indicated that 49% of participants (n = 191) did not want to be put on respirator.

2.3.3 Artificial feeding and hydration

Artificial feeding and hydration are types of medical life sustaining treatment (Scott, 2010). The problems about these live sustaining treatments are the disinclination of health care providers, patients, and families. Some believe that terminating this life sustaining treatment may cause a painful way to die. Some believe feeding is symbol of caring. Others believe that artificial feeding and hydration may cause suffering (Baergen, 2001).

2.3.4 Hemodialysis

Hemodialysis is a type of life sustaining treatment for the patient who has a kidney failure (Scott, 2010). The procedure may be performed three or more times weekly, usually involves transporting the patient to the dialysis setting which is an additional stressor. At the end of life, when body functions are shutting down, dialysis does not improve the quality of the patient's life neither it maintains normal kidney functions. Morton et al. (2012) studied factors influencing patients' choice of dialysis versus conservative care to treat end-stage kidney disease of 105 patients. Results show that the patients were more likely to choose dialysis than conservative care if dialysis involved an increased average life expectancy (odds ratio [OR] 1.84, 95% confidence interval [CI] 1.57-2.15), if they were able to dialyze

during the day or evening rather than during the day only (OR 8.95, 95% CI 4.46-17.97), and if subsidized transport was available (OR 1.55, 95% CI 1.24-1.95). Patients were less likely to choose dialysis over conservative care if an increase in the number of visits to hospital was required (OR 0.70, 95% CI 0.56-0.88) and if there were more restrictions on their ability to travel (OR=0.47, 95%CI 0.36-0.61). Patients were willing to forgo 7 months of life expectancy to reduce the number of required visits to hospital and 15 months of life expectancy to increase their ability to travel. In addition, Nahm and Resnick (2001) studied the end-of-life treatment preferences among older adults. The result indicated that 51% of participants (n = 191) did not want to receive dialysis but would prefer those treatments that will keep them comfortable.

2.3.5 Chemotherapy and radiation

Chemotherapy and radiation can be helpful in the earlier stages of cancer; but once organ failure begins, they add great stress to body functions (Scott, 2010). Chemotherapy has many adverse effects, such as severe gastrointestinal distress, diminution of blood cell counts, weakness, neurologic problems, and reduction of immune system function. Radiation requires the patient to be transported to the treatment facility and to lie on the hard surface in an uncomfortable position when she or he is already weak and wants to be left undisturbed.

2.3.6 Antibiotic

Antibiotic is drugs used to fight infection for terminally ill patients with diminished immune system. Patients can have drugs adverse effects, such as nausea, vomiting, diarrhea, and yeast infection, adding to the patient's normal discomfort (Scott, 2010).

2.3.7 Surgery

Surgery is sometimes carried out as a palliative measure to alleviate intractable pain caused by the pressure on nerves or when infection is spreading as in the end stage of diabetes (Scott, 2010). Patients with advanced disease often undergo surgery with the goal of palliation to achieve a longer survival, even when cure is not a realistic goal (Ferrell, Juarez, & Borneman, 2010).

2.3.8 Blood transfusions

Blood transfusions can sometimes prolong life for a few days, but there are always risks of hypervolemia or allergic reaction (Scott, 2010). Blood transfusion for patients at the end of life may help control the symptom and improve quality of life.

2.3.9 ICU admission

ICU admission is an aggressive treatment at the end of life. The goal of care in ICU is to sustain life through aggressive, curative therapy and the use of life-support interventions. ICU is the site of much end-of-life limitation of treatment (withholding/withdrawing) decision making (Baggs & Schmitt, 2000).

2.3.10 Do Not Resuscitate (DNR)

Do Not Resuscitate (DNR) does not mean do not treat. CPR will not be done in every condition. Do Not Resuscitate Order (DNR) is prescribed in hospital or nursing home settings in collaboration with the patient, family, and health-care provider, usually after the determination that the patient will not benefit from receiving cardiopulmonary resuscitation (CPR) (Murphy, 2007). Some patients fear that if they choose DNR status, they will suffer and be alone at the time of their death. Nahm and Resnick (2001) studied the end-of-life treatment preferences among older adults. The result indicated that half of participants (n = 191) did not want CPR.

3. End-of-life decision of patients with chronic illness

In this era in which the boundaries between life and death are being challenged and changed by medical and biotechnological advances, issues related to the end of life have gained the increased visibility among the public, health professionals, and policymakers (Manasurakarn, et al. 2008). End-of-life decision has

involved several people who have different values. Health care providers need a better understanding and experiences of the cultural beliefs that influence end-of-life perceptions before designing health information strategies. One possible ethical dilemma in this area relates to the use of medical technology which makes it possible for the patients to continue breathing as long as they are connected to the machine (Poor, 2001). Poor also defined that death is seen as failure by the health care professional view. Winter and Parks (2008) studied about family discord and proxy decision makers' end-of-life treatment decisions. The results indicated that family discord concerns the care of an elderly relative which was associated with preferences for both life-prolonging and palliative end of life care. Higher family discord was associated with weaker preferences for palliative care and stronger preferences for life prolonging care. These effects were independent of the end-of-life values associated with the treatment preferences, longevity/religion, and pain management/dignity.

3.1 Definition of end-of-life decision

End-of-life decision refers to the person's freedom to make decisions about end-of-life care or end of life treatment based on personal goals and an appreciation for self in relation to others (Burkhardt & Nathaniel, 2002). Moreover, Campbell, Gorman, and Kalowes (2010) describe end-of-life decision as a situation that patients make their decisions to stop life-sustaining therapy such as mechanical ventilator, dialysis, and cardiac device.

3.2 Types of end-of-life decision

There are four types of end-of-life decision, (1) continuing life sustaining treatment, (2) forgoing life sustaining treatment, (3) allowing physicians/nurses to make decision, and (4) allowing family to make decision. The details of each type are described as follows:

3.2.1 *Continuing life-sustaining treatment*

Continuing life-sustaining treatment is an individual decision-making for the purpose of prolonging one's life by using life-sustaining treatment at the end-stage of life, even if there is no chance for them to regain full viability (Flynn & Davis, 1990). Life sustaining treatments are medical intervention which helps preserve life such as ventilator, hemodialysis, and blood transfusion. Knox (1989) describes the ability of modern medical technology that can sustain vital bodily functions but cannot reverse the underlying disease process that may cause pain and suffering, or even death. Nijnikaree (2003) studied the perspective of Thai Muslim patients on end-of-life decision. The results showed that less than 10% of subjects decided to continue life-sustaining treatment. Manasurakarn (2007) studied values underlying end-of-life decision of Thai Buddhist patients and their families. The results indicated that 19.5% of participants decided to continue the treatment.

3.2.2 Forgoing life-sustaining treatment

Forgoing life-sustaining treatment refers to individual decision making to refuse life sustaining treatment at the end stage of life. Withholding and withdrawing life-sustaining treatments are two types of forgoing life-sustaining treatments. Withholding life-sustaining treatment is defined as a decision not to start or not to sustain further use of life prolonging treatments. Withdrawing life-sustaining treatment refers to stopping treatments once it has been started (Hudak, Gallo, & Morton, 1998, Hall & Rocker, 2000).

3.2.3 Allowing physicians/nurses to make decision

Allowing physician to make decision refers to the situation that patients allow health care providers to make decisions at the end of life for them. There are many reasons that patients allow physicians to make decision. Manasurakarn (2007) found that the reasons why patients allow physicians to make decision for them because they trust the physicians in their knowledge, competence, and experience to help them. Burkhardt and Nathaniel (2002) found that some clinicians believe that they know what the best is for the patient in the current circumstances.

3.2.4 Allowing family to make decision

Allowing family to make decision refers to delegation of decisions at the end of life to patient's family. Several reasons why patients allow their family

to make decision were discussed. The study indicated that there were two values related to delegation of decision: respect for family and family concerns. Three reasons for respect for family were 1) trust in the family decision, 2) the family knows what the patient needs, and 3) the family loves and has a good wish for the patient. Three reasons for family concerns include 1) close to the family more than others, 2) love and attached to the family, and 3) care for family's feeling (Manasurakarn, 2007). The Thai cultural issue in respect for hierarchical relationships was found to support this type of decision making. Family life in Thai culture is more closely united than that in western culture hierarchies, with the parents at the top. In Thailand, children are taught to respect their parents (Knutson, 2004).

Moreover, the love and well wishes from the family was found to influence the decision to delegate the end-of-life decision in a study by Manasurakarn (2007). The participants allowed family to make decision based on the reasons the family knows what the patients' need are, and the family loves and has a good wish for patients.

Allowing physicians and family to make a decision can be called surrogate decision making referring to decision made by significant persons for the patients when they lack decision-making capacity (Burkhardt & Nathaniel, 2002). Surrogates may be family members, friends, or other trusted individuals (Winzelberg, Hanson, & Tulskey, 2005). They become surrogates because they are the patient's legal health care proxy or because of their relationship with the patient. In situation in which a patient has no advanced directives, or has not named a surrogate to make a decision making in the event of incapacity, health care providers should do with family and others to identify a surrogate (Burkhardt & Nathaniel, 2002). A primary

surrogate's role is to support patient autonomy by expressing the "substituted judgment" of the patient they represent, there by ideally making the same decisions the patient would. If unable to communicate confidently the patient's preference, surrogates are asked to consider the patient's best interest.

The underlying and foundation for end-of-life decision have been the principles of patient autonomy. Ethical principle has been the major theoretical framework of instrument development to measure end-of-life decision that covers four basic elements as follows (Burkhardt & Nathaniel, 2002).

1) The autonomous person is respected. Respect for persons at the end-of- life requires that each individual be treated as unique and entitled to treatment that is respectful of his human dignity (Schwarz & Tarzian, 2010).

2) The autonomous person must be able to determine personal goals. These goals may be explicit and of a global nature, or may be less well defined.

3) The autonomous person has the capacity to decide on a plan of action. The person must be able to understand the meaning of the choice to be made and deliberate on the various options, while understanding the implications of possible outcomes.

4) The autonomous person has the freedom to act upon the choices. The person can formulate goals, understand various options and make decision, and they have a freedom to implement their plan.

Common choices of autonomous decision at the end of life are as follows:

Withdraw a treatment which leads to the patient's death. The problem with making a moral distinction between withholding and withdrawing

treatment is that this position may lead to reluctance on the part of health care providers to begin treatments of potential benefit to patients because they fear of being forced to continue these treatment, even if they prove such treatments are proved to be of no value (Knox, 1998). Withdrawal of mechanical ventilation should not be viewed more differently than withdrawal of other life sustaining therapies, such as dialysis (Scanlon, 2003). However, the withdrawal of ventilator usually results in death more quickly than the withdrawal of other therapies and the proximity of the two events can be deeply upset for all involved individuals. Nijnikaree (2003) studied the perspective of Thai Muslim patients about end-of-life decision. The result showed more than 80% of subjects decided to forgo life-sustaining treatment. Manasurakarn (2007) studied values underlying end-of-life decision of Thai Buddhist patients and their families. The result indicated that 51% of participants decided to forgo the treatment. Meissner, et al. (2010) studied epidemiology and factors associated with end-of-life decisions of patients in a surgical intensive care unit. The result revealed that 0.6% of the subjects decided to withhold therapy and 0.5% decided to withdraw therapy.

The problem about decisions made by surrogates or others is that they do not reflect the patient's values, including culture and spiritual perspective (Burkhardt & Nathaniel, 2002). A study showed that end-of-life decision between patients and surrogates are different. Neunoi (2005) compared end-of-life decisions between patients and their surrogates and identify reasons for the decision made. The results indicated that the surrogates chose forgoing life-sustaining treatment less than the patients did.

Although dying and death are a natural part of human life (Sahlberg-Blom, Ternstedt, & Johansson, 2000), end-of-life decision is a difficult and challenging situation for patients, families, and health care providers to decide whether to start, continue, or stop life sustaining treatment; and who is the best to make decision. Sittisombut and Inthong (2009) studied surrogates' decision making for end-of-life care in the terminally ill patients to identify persons to whom northern Thai patients with terminal illness wished to transfer their decisions on end-of-life care for cardiopulmonary resuscitation. From interviews with 152 eligible subjects, 57.2% had a high regard for their physicians authority in making decisions on end-of life care, 28.3% transferred their decisions to relatives, and only 14.5% opted for shared decision making among relatives and physicians. In the provision of cardiopulmonary resuscitation, 44.1 % of subjects expressed a desire for family to make decisions together with physicians, 33.6% gave directives to the family alone and only 22.4% transferred their decisions to physicians.

3.3 The laws related to end-of life decision

In the United States, The Patient Self-Determination Act is a federal law requiring institutions such as hospitals, nursing homes, health maintenance organizations, and home care agencies to provide written information for adult patients regarding their rights to make health care decisions. Such decisions include the right to refuse treatment, and to write advance directives for guiding decisions should they become incapacitated (Burkhardt & Nathaniel, 2002). The Federal Patients Self-Determination Act (1990) requires that every individual receiving health

care be informed in writing of his or her right under state law to make decision about that care, including the right to refuse it and to initiate written advance directives (Bandman & Bandman, 2002). In 2007, Thai government enforced the national Health Act which states “A person shall have the right to make an advance directives to refuse the health care services which is supplied merely to prolong death at his/her terminal stage of life or to cease the severe suffering from illness” (The National Health Commission Office, 2007).

Advance directive is an instruction that indicates health care interventions to initiate or withhold, or that designates someone who will act as a surrogate in making such decisions in the event that the person loses decision-making capacity. It supports people in making decision on their behalf, and ensures that patients receive end-of-life care they want (Burkhardt & Nathaniel, 2002). This allows patients to participate in making their own decisions regarding the care they would prefer to receive if they deal with terminal illness (Gomez, 2002). There are two types of advance directives: living wills and durable powers of attorney. Living wills are legal documents giving directions to health care providers related to withholding or withdrawing life support if certain condition exists. Durable power of attorney allows a competent person to designate another as a surrogate or proxy to act on the patient’s behalf in making health care decisions in the event of the loss of decision-making capacity.

Living will or advance directive is a new concept within the legal system of Thailand. The National Health Act Section 12 provides that at any time, a person shall enjoy the right to stop medical service, which may merely be to prolong death or to suffering at the end of life by expression of the living will or advance

directive to the medical personnel” (The National Health Commission Office, 2007, p. 10). In Thailand, the “right to die” law is not well known and not be responsibility to the health care team. Possible paternalistic attitudes of some clinicians may result in their disregarding advance directives. Because of their belief, they know what the best is for the patient in the current circumstances.

4. Reasons related to end-of-life decision

An end-of-life decision is one of important aspects of healthcare. Advanced medical technology has chapped the circumstances of death, giving people options that may impact when, where and how people die. Intervention at the end of life can now prolong lives even there is little or no hope of recovery or a meaningful existence. There are four types of end-of-life decision: (1) Continuing life sustaining treatment, (2) Forgoing life sustaining treatment, (3) Allowing physicians/nurses to make decision, (4) Allowing family to make decision. The reasons related to each type of end-of-life decision are as follows:

4.1 Reasons for continuing life sustaining treatment

Continuing life-sustaining treatment is an individual decision-making for the purpose of prolonging one’s life by using life-sustaining treatment at the end stage of life, even if there is no chance for them to regain full viability (Flynn & Davis, 1990). Life sustaining treatments are medical intervention which helps preserve life such as ventilator, hemodialysis, and blood transfusion. Knox (1989) describes the ability of modern medical technology that can sustain vital bodily

functions but cannot reverse the underlying disease process that may cause pain and suffering, or even death.

The reasons related continuing life sustaining treatment consist of Buddhist values, social values, family concern, and advance medical technology.

4.1.1 Buddhist values

Buddhist values related to decision to continue life sustaining treatment included the Four Noble Truths and the Law of Karma. The Four Noble Truths consists of suffering, the cause of suffering, the cessation or extinction of suffering, and the path to the cessation of suffering, are the Buddhist philosophy which help Buddhist to understand suffering (Payutto, 1995). In addition, Paonil & Sringernyuang (2002) stated that human life is short and it is easy to get sick or die. We should practice hard and do everything to develop ourselves to live with wisdom. Some Buddhists decide to continue life sustaining treatment because they need to know the meaning of suffering and find ways to understand and reduce suffering before they die. Some Buddhists believe life is valuable, people need to preserve life as long as possible. According to first precept of the five precepts state that hurt or short life or kill animal is sin. Manasurakarn (2007) studied about the values underlying end-of-life decision of Thai Buddhist patients and their families and found that participants decided to continue life sustaining treatment based on the Law of Karma values: reciprocity of Karma. Furthermore, Buddhists believe that doing bad things is sin. Sin in Buddhism is unacceptable actions, such as negligence to take care

the body. The results of negligence to the body are the source of diseases (Paonil & Sringernyuang, 2002).

The Law of Karma is one part of the natural law that refers to the result of action or cause and effect relationship in living (Payutto, 1995). Buddhists try to do good Karma and keep away from bad one. In this sense, (the preceding cause) transmits its potential force to, and is received by, the following effect. Life is made possible because each of these factors is both conditioning and conditioned, with no beginning and no end points: the process is an endless cycle. Death is considered an integral part of existence and is one phase of this endless cycle; death is seen as terminating the cycle. This conditioned existence is called in the Buddhist Texts samsara. It can be summarized in the words, “good deeds bring good results, and bad deeds bring bad result.” Buddhist philosophy states that everything is subject to the Law of Karma (Payuttho, 1995). Doing good Karma is by living a morally sound life and trying to follow the Buddhist doctrines. Based on this belief, some people decided to prolong life because they need more time to do good Karma.

According to the Law of karma, most people at the end of life aware that they need more time to do good Karma such as building temple, seeing descendant become a monk which are important good karma for Buddhism. Thus they decided to prolong life, although in a short time.

4.1.2 Social values

Social values related to continuing life sustaining treatment are grateful value and personal believe. Gratefulness or reciprocity of goodness, expressed

in Thai as *Bunghun* is a highly valued characteristic trait in Thai society (Komin, 1991). Thus, people need to be grateful to their own body and parents. The results of negligence to the body are the source of diseases (Paonil & Sringermyuang, 2002). Moreover, personal beliefs related to death are defined as social values such as Supernatural Miracle, Holy Thing, Fate, Virtue, and Will Power. Some examples of these beliefs in Thai context are beliefs in spirits, predestinated fortune, (*duang* in Thai), wishes making and vows to the spirits (*bon ban sarn klaw* in Thai), and some supernatural rituals to stop bad fortune (by sprinkle holy water) (Komin, 1991).

Additionally, the concept of hopes is also found in Thai context. Hope has been described as being spiritual wellbeing in terms of providing a sense of meaning and purpose of life (Averilletal, 1990 as cited in Chaplin & McIntyre, 2001). Hope is the reason underlying patient's decision to continue the treatments. They hope for a miracle, hope to survive, and still need to live (Manasurakarn, 2007). Moreover, some patients hope to recovery and survive again because they have the experience from others.

According to this Thai social value, Thai people decide to continuing life sustaining because they want to live for making merit. Merit will send them re-birth in the good place. Patients who believe life is value need to live as long as possible to do most benefits of good deeds (Gauthier, 2005; Manasurakarn, 2007 Nijinikaree, 2003).

4.1.3 Family concern

Since, death is viewed as loss, grief, bereavement, mourning, and separation (Arnold, 2001). Nobody wants to die. Everybody fears of death and does not want to talk about it. Thus, most people tend to prolong life because they do not want to separate from family. The study showed that Thai Buddhist patients decided to prolong life because of family concern such as worries about their descendant, passion with family to lose care taker, and wait for seeing a success of their descendant (Manasurakarn, 2008). Some people wish to live long enough to make or join important events such as birthday, holiday, or family events or to complete an unfinished task, such as reconciling with a relative, may choose aggressive therapy in order to achieve that goal (Arnold, 2001).

4.1.4 Advanced medical technology/chronic illness

Advanced medical technology/chronic illness relate to end-of-life decision are medical interventions, which are used to preserve life. Knox (1989) stated that the ability of modern medical science to prolong life often exceeds the ability to restore health. The potential of medical technology can sustain vital organ but it is unable to reserve the underlying disease process that may cause pain and suffering, or even death. However, advanced medical technologies have created hope for people in society to prolong life (White & Lubkin, 1998). End stage renal disease (ESRD) patients, who are on dialysis, is an example of advance technology to prolong life, mechanical ventilators are medical technology for life support; chemotherapy and

radiation are helpful for cancer patients (Scott, 2010). Moreover, pain control to reduce physical suffering is common used at the end-of-life (Paice & Fine, 2001)

4.2 Reasons for forgoing life sustaining treatment.

The reasons supporting forgoing life sustaining treatment are also categorized into four dimensions: Buddhist values, social values, family burden/concern, and chronic illness.

4.2.1 Buddhist values

Buddhist values related to forgo life sustaining treatment included the Four Noble Truths or Ariya-sacca, the Three Characteristics of Existence, and the Law of Karma.

The Four Noble Truths or Ariya-sacca are the truths of suffering, the cause of suffering, the existing of suffering, and the path to the cessation of suffering (Payutto, 1995). Based on this principle, death is the truth of life which all human beings must accept. In this view, prolong life is wrong. Death is inevitable, nobody can control death. Death is already set, people must go when death arrives. Moreover, death is the way to overcome suffering. Thus, useless to prolong life.

The Three Characteristics of Existence, the natural law of Buddhist doctrine, also mention that life exists and extinguishes under the true nature of world. According to this principle, all of life is not permanent and is made from five groups (Pancakkhanda): rupa or material form; vedana or feeling; sanna or

perception; sankhara or impulse; and vinnana or consciousness. There is no owner, no real self (Chanchamnong, 2003). Based on this Buddhist principle, death is only leaving from compounded things or five group (Pancakkhanda). According to Buddhist principle, Death is natural, prolonging life is against nature; everyone is born and finally dies.

The Law of Karma is Buddhist principle that relates to cause and effect and can be classified as both values of life and death (Chanchamnong, 2003). Some people believed that life is living for reciprocity to Karma while some believed that death is the end of Karma. Thus, the view of death that is focused on Karma such as death is karma, nobody can refuse karma, death is release Karma, The patients who believe these values thoroughly will realize that all diseases are the result of Karma and under the natural law that refers to the working of intention, or the process of mental proliferation and its consequences (Payutto, 1995).

4.2.2 Social values

People who have chronic illnesses typically find it very difficult to return back to normal health and it often becomes a life long illness. In general, society views chronically ill negatively because of their on the national economy. Some views them as a nonproductive person (Curtin& Lubkin, 1998). Based on this view, some chronic illness patients fear to burden society because they cannot work or contribute for the benefit to society. Thus, they tend to forgo life sustaining treatment. The studies indicated that the participants felt that life was not invaluable if they could

not take care of themselves (Manasurakarn, 2007; Meissner, et al., 2010; Nijnikaree, 2003; White & Fitzpatrick, 2006).

Additionally, the Thai National Health Act Section 12 provides that at any time, a person shall enjoy the right to stop medical service, which may merely be to prolong death or to suffering at the end-of-life by expression of the living will or advance directive to the medical personnel” (The National Health Commission Office, 2007). Based on this law, the chronic illness patients realized that they have the rights to refuse treatment at the end-of-life as an autonomous person.

4.2.3 Family burden/concern

Living with chronic illness has caused physical, psychosocial, spiritual, and social problems for both the patient and family. Some of the impacts including duration of hospitalizations, increased financial crisis, social burdens, emotional difficulties, feeling of anxiety and frustration, and changes in body appearance are problems causing burden to patients and their families and make patients think about death or decide to forgo life sustaining treatment (Larsen, 2009). In addition, Taylor, et al. (1998) found that chronically ill patients often have significant burden in finances. Supporting by the study of Manasurakarn (2007) found that the reason that patients with chronic illness (73%) decided to forgo life sustaining was family burden.

4.2.4 Chronic illness

Chronic illness related to forgoing life sustaining treatment are prognosis of underlying chronic disease which put the patients in irreversible state or impairments where they need supportive care, maintenance of function and prevention of disability (Curtin & Lubkin, 2009). Moreover, the problem of symptoms distress from chronic illness affect not only the physical but the psychosocial and spiritual aspects of quality of life as well (Taylor, Jones, & Burn, 1998). These problems made them suffer from the chronic diseases and trend to decide to forgo life sustaining treatment. A study reported that chronic illness was one reason that made the patients decided to forgo life sustaining treatment (Nijnikaree, 2003). In addition, poor prognosis is another that patients decided to forgo life sustaining treatment (Foo, et al., 2012). Moreover, some studies indicated that the patients did not want to suffer any longer (Manasurakarn, 2007; Meissner, et al., 2010; Nijnikaree, 2003; White & Fitzpatrick, 2006).

4.3 Reasons for allowing physicians/nurses to make decision

Allowing physicians/nurses to make decision refers to the situation that patients allow health care providers such as physicians/nurses to make decisions at the end-of-life for them. The reasons supporting allowing physicians/nurses to make decision are also categorized into four dimensions: Buddhist values, social values, reduce conflict with family, and advanced medical technology/chronic illness.

4.3.1 Buddhist values

From Buddhist perspective, physician/nurses are expected as loving-kindness and compassion. This character reflects the concept of Metta-Karuna (mercy-kindness) in Buddhism. Compassion or Karuna is at the transcendental and experiential heart of the Buddha's teachings. Compassion is one of the most important attributes for physicians practicing medical services. It has been suggested that felt compassion brings about the desire to do something to help the sufferer (Cassell, 2009). Patients who are at the end-of-life need to be able to make such decisions. They and their families will find it is difficult to decide on whether to continue medical treatment or not and, if so, how much the treatment is warranted and for how long. In these instances, patients typically rely on their physicians or other trusted health professionals for guidance or make decision.

4.3.2 Social values

Physician/nurses are expected by society to do good and not do harm to the patient, and to be honest. Thus, the reasons supporting this type of end-of-life decision included respect for physician, and lack of knowledge that lead to no confidence for self/family end-of-life decision. Respect for physician can be demonstrated in trust in physician knowledge and competence, and trust in the physician experience. The study indicated that the patients lack of education and understanding the treatment (Ganz, et al., 2006). Moreover, in Thai society, education

and competence orientation are Thai social values. From these values led people respect for person in high position such as physicians/nurses (Komin, 1991).

4.3.3 Reduce conflict with family

Since end-of-life decision is difficult and complex for patients (Manasurakarn, et al., 2008; Steinhauer, et al., 2000). The decision making at the end-of-life varies from one to another individual according to their beliefs and values of life. If the patients make their own end-of-life decision, it may be different and made mistake. To reduce conflict with family, Thais patients tend to delegate end-of-life decision to physicians/nurses.

4.3.4 Advanced medical technology/chronic illness

Advanced medical technology/chronic illness related to allowing physicians/nurses to make decision. Since being with the impaired role as chronic illness patients, most patients tend to delegate end-of-life decision making to health care professional (Lewis & Lubkin, 1998). Furthermore, advanced medical technology/chronic illness are not always easily quantified or understood by patients and their caregivers (Campbell, Williams, & Orr, 2010). Thus, patients tend to allow physicians/nurse to make decision at the end of life.

4.4 Reasons for allowing family to make decision

Allowing family to make decision can be called surrogate decision making which refers to decision made by significant persons for the patients. (Burkhardt & Nathaniel, 2002). The reasons supporting allowing family to make decision are also categorized in four dimensions: Buddhist values, social values, family love, and chronic illness.

4.4.1 Buddhist value

Buddhist value related to allowing family to make decision is family members are true friends to make good wish. In addition family takes responsibility to patients with chronic illness (Pierce & Lutz, 2009). Thus, families are true friends at the end of-life by Buddhist perspective. Moreover, respect for family can be demonstrated in belief in family decision as (1) trust in the family decision, (2) the family knows what the patient needs, and (3) the family loves and has a good wish for the patient (Manasurakarn, 2007).

4.4.2 Social values

Social values related to allowing family to make decision is grateful values. In the Thai society people are taught to be grateful to a person who renders goodness (Katanyu) to them such as parents and teachers (Komin, 1991). Thus, elderly patients wanted their family, descendants, to be a quality person in

taking care of their seniors at the end-of-life. It is considered a good deed of the descendants for this arrangement and therefore wanted them to take a responsibility to make the end-of-life decision for them. These reasons for delegating the end-of-life decision to the family members who were taking care of them were in corresponding to the findings in a study of Neunoi (2005) which found that patients and surrogates decided to prolong life because they needed to repay the kindness for parents

Furthermore, Thai society usually aware of this problem, most parents do not want to burden their family that is called in Thai “kranjai.” Thus, they tend to allow family to make decision at the end-of-life. In addition, financial burden is a problem that can occur in chronic illness patients. It is usually the family member who terminates employment in order to stay home and care for the patients. Moreover, other family members may need to work more hours to earn enough to support the family. Such problem leads the chronic illness patient delegates end-of-life decision to their family.

4.4.3 Family love

Family love is related to allowing family to make decision. Since family life in Thai culture is more closely united than that in western culture hierarchies, with the parents at the top (Knutson, 2004). Moreover, with a confidence of love and best wishes from the family, Thais tend to delegate the end-of-life decision to family. The love and good wishes from the family was found to influence the decision to delegate the end-of-life decision in a study by Manasurakarn (2007) which found that subjects allowed family to make decision based on the reasons: the

family knows what the patients' need, the family loves and has a good wish for patients.

4.4.4 Chronic illness

Being with chronic illness, the patients struggle to undertake their body malfunction and maintain personal and social identities. Psychological well-being is an essential component of health related quality of life and it can influence the overall adjustment of patients with chronic illness. Without it, the patients may withdraw from their social network (Biordi, 1998). Some had experience of discomfort, pain or fear of pain, anxiety, loss of hope and other physical symptoms increasing dependence on others or decreasing their functioning ability. These chronic illness problems lead the patients are unconfident to make decision by themselves. Furthermore, the person who is chronically ill may feel guilty about the demands his or her illness makes on the family. Thus, chronically ill patients tend to allowing end-of-life decision to make decision. In addition, Gauthier described that psychological problems such as the extreme feeling of anger and frustration changed patient's decision making authority at the end-of-life from self to family.

5. Scales related to end-of-life decision

In general there are no gold standards of end-of-life decision tools. It is not clear what end-of-life decision should contribute to the numerator and it is not easy to determine who is at the end of their lives to identify the denominator. Decision-

making about whether to prolong life or not to prolong life is often difficult. Moreover, there is no existing instrument related to end-of-life decision made for Buddhists. Although there are those in other religions such as for Christians in western cultures which is different from Buddhists. There are not many instruments focusing directly on end-of-life decision. Mostly, it is included in a part of the instruments which measure preference or desire of patients at the end of life. According to the literature review seven tools related to the end-of-life decision were found as described hereafter.

5.1 Preference Care Near the End of Life (PCEOL) Scale (Gauthier & Froman, 2001). The study aimed to develop and evaluate an instrument, the Preferences for Care near the End of Life (PCEOL) scale, and to generate initial estimates of the stability and internal consistency of responses when the scale was used with a sample of healthy individuals. The scale consisted of five dimensions: (1) autonomous physiological decision making, (2) decision by health care professional, (3) spirituality, (4) affective communication, and (5) family. One dimension was related to decision-making. The process of developing the scale consisted of the extensive review of related literature and in-depth interview. The scale obtained the recognized validity and reliability. Psychometric validation was carried out using response data from 198 subjects of university students and community-residing adults. Content validity index for the 77 items was .96 by expert clinicians. This convenient sampling had an age range of 17-76 years and a mean of 27 years. The result of exploratory principle components factors analysis for 43 items that met the established criteria showed the 5-factor structure which explained 68% of the variance. These factors, namely, autonomous decision making, health care

professional decision making, spirituality, affective communication, and family had Cronbach alphas ranging from .68 to .91. Retest stability correlations for a subset of 38 respondents who answered the PCEOL scale twice ranged from .80 to .94.

5.2 Attitudes of Older People to End-of-Life Issues (AEOLI). The study aimed to develop an end-of-life attitudes questionnaire for use in a large community-based sample of older people. The structure contents from literature review and focus group about issues related to cancer, death, dying and palliative care, and health care near the end-of- life. Participants were volunteers from two general practices local to the Royal Free Hospital in North London (one in an affluent area, the other in a socio-economically deprived area). Two nominal groups were conducted with a group of social science academics (n=10) and a group of specialist palliative care professionals (n=5). Reliability: The test-retest reliability was assessed using Cohen's Kappa statistic for categorical variables. Kappa values $>.40$ are considered to represent moderate concordance, values $>.6$ reflect substantial concordance. The questionnaire was opened to testing of internal consistency, as questions cover different aspects of a theme. However, there is evidence of internal consistency (an underlying true score) in 'living wills' (Cronbach alpha=.68), 'euthanasia and physician-assisted suicide' (Cronbach alpha=.77) and 'quality versus quantity of life' (Cronbach alpha=.52).

5.3 End-of-Life Caregiving Experience Appraisal Scale (EOLCAS) (Lee et al., 2010). The purposes of this study were to develop a scale that can evaluate the experiences of EOL caregivers, and to test the reliability and validity of this scale. The scale domains were derived from systematic review of 35 relevant studies. The content validity of the scale was measured with nurse scholars and clinicians using content validity index. To examine construct validity, a total of 175 caregivers from

tertiary hospital setting in Korea participated in this study. For the construct validity, factor analysis was utilized (suffering and burden), one positive appraisal (maturation), and one neutral appraisal (social support pursuit). The Cronbach's alpha for the entire scale was .84 indicating adequate reliability. However, Cronbach's alpha of subscales was varied.

5.4 Development and Initial Psychometric Evaluation of Nurses' Ethical Decision Making Around End-of-Life-Care Scale in Korea (NEDM-EOLCS) (Kim, 2011). The purposes of this methodological study were (1) to develop a scale with content domains and items capable of describing Korean nurses' ethical decision making at the end of life and (2) to evaluate the scale's psychometric properties using Korean nurses (N=230). A tool was developed to isolate appropriate content domains and items and validated for validity and reliability of the instrument using a psychometric test. The coefficient of the NEDM-EOLCS of 55 items was .95. Those of the three subscales were .95, .88, and .89, which are sufficient to establish the .33 reliability. The content validity was established through the I-CVI and achieved .83, which was an excellent criterion upon reviews by the six-expert panel.

5.5 The Family Decision-Making Self-Efficacy Scale (Noland et al., 2009). The purpose of this study was to develop a scale to measure family members' confidence in making decisions for their terminal ill love ones in two scenarios: with conscious patients scenario and for unconscious patients scenario. Interviewed guided by self-efficiency theory was developed into six themes within family decision making self-efficiency to generate items. Internal consistency was tested by 30 family members of patients with amyotrophic lateral sclerosis. Stability test after four weeks by 10 family members was conducted. On the basis of a survey of family members of

patients with amyotrophic lateral sclerosis (ALS) enriched by in-depth interviews guided by Self-Efficacy. The themes that were refined by a panel of end-of-life research experts. With 30 family members of patients in an outpatient ALS and a pancreatic cancer clinic, the internal consistency using Cronbach's alpha, the test-retest reliability assessment in a subset of 10 family members. Items with item to total scale score correlations of less than .40 were eliminated. Results: A 26-item scale with two 13-item scenarios resulted, measuring family self-efficacy in decision making for a conscious or unconscious patient with a Cronbach's alphas of .91 and .95, respectively. Test - retest reliability was $r = .96, p = .002$ in the conscious scenario and $r = .92, p = .009$ in the unconscious scenario.

There were several end-of-life decision scales developed in different contexts (patients, nurses, caregiver, family member, healthy people), for different purposes, and with different components, but no gold standard have been available. However, these scales were not included four types of end-of-life decision. In addition these scales were not specific in Thai context. Thus, the task of clearly defining the underlying structure of end-of-life decision for Thai Buddhists with chronic illness assumes great importance. Therefore, the development of end-of-life decision scale for this group of people is essential (Table 1).

Table 1

Scales related to end-of-life decision

Instrument/ Author/year	Purpose	Conceptual basis	Subject	Psychometric properties	Results
1. Preferences for Care Near the End of Life Scale (PCEOL) (Gauthier & Froman, 2001)	To construct the preferences for care near the end of life scale	Literature reviews, interview panel experts and nurses who work with patients near the end of life	A convenience sample of 198 adults	77 items Five point Likert scale is used for self-report Internal consistency Retest stability	Content validity IR, CVI = .96, .97 ranged from .68-.91 ranged from .80-.94 Factor loading ranged from .54-.85, 68 % of variance for five factors

Table 1 (continued)

Instrument/ Author/year	Purpose	Conceptual basis	Subject	Psychometric properties	Results
2. Attitudes of Older People to End-of-Life Issues (AEOLI) (Catt, et al., 2005)	To develop an end-of-life attitudes questionnaire for use in a large community- based sample of older people	End of life issues Living Will Death & dying Religion and faith Euthanasia	Older people	Internal consistency	A 27-item attitudes of older people to end-of-life issues (AEOLI) living wills $\alpha = .68$ Euthanasia $\alpha = .77$ quality versus quantity of life $\alpha = .52$ Kappa values $> .60$

Table 1 (continued)

Instrument/ Author/year	Purpose	Conceptual basis	Subject	Psychometric properties	Results
3. End-of-life Caregiving Experience Appraisal Scale (EOLCAS) (Lee et al., 2010)	To develop a scale that can evaluate the experiences of EOL caregivers, and to test the reliability and validity	Systematic review of 35 relevant studies. EOL caregiving experiences of people caring for older adults	Nurse scholars and clinicians	The content validity Internal consistency of the EOLCAS obtained for 4 factors. EFA	CVI value < .80 $\alpha = .86, .72, .79, .49$ respectively Total scale = .84 32 items of EOLCAS, five factors with 53.47% of the variance

Table 1 (continued)

Instrument/ Author/year	Purpose	Conceptual basis	Subject	Psychometric properties	Results
4. Nurses' Ethical Decision Making Around End-of-Life-Care Scale in Korea (NEDM-EOLCS) Kim (2011)	To develop and evaluate a tool to measure Korean nurses' ethical decision-making processes in EOL care situations	1. Perceived professional accountability 2. Moral reasoning and moral agency 3. Moral practice at the end of life	Six nursing ethics experts three Korean nurses with more than 2 years' experience	Content validity Initial internal consistency with 67 item	I-CVI = .83 $\alpha = .94$
				Item analysis	8 items were deleted
			230 Korean nurses with 2 years' experience and work at the general medical/surgical care unit, oncology unit, and critical care unit	Internal consistency reliability of the 55-item EFA	$\alpha = .95$ 66.3% of the variance 4 items were deleted because of poor factor loading The three subscales reported α .95, .88, and .89

Table 1 (*continued*)

Instrument/ Author/year	Purpose	Conceptual basis	Subject	Psychometric properties	Results
5. The Family	To develop and	In-depth interview of	30 family	Internal consistency (13	$\alpha = .91, .95.$
Decision-Making	validate a scale	family members with	members	items within the	
Self-Efficacy	to measure	amyotrophic lateral		conscious scenario of	
Scale (Nolan, et	family member	sclerosis was guided		the scale, 13 items	
al., 2009)	confidence in	by self-efficiency		within the unconscious	
	making	theory.		scenario of the scale)	
	decisions		10 family	Test-retest	$r = .96, p = .002$ in the conscious
			members		scenario
					$r = .92, p = .009$ in the unconscious
					scenario

Summary

End-of-life decision is the important issue in health care settings nowadays. Accepting or refusing treatment at the end-of-life is a patients' right. However, end-of-life decision varies based on the patients' values. Most of studies focus on end-of-life care and some part of end-of-life care related to end-of-life decision. This could be because: (1) end-of-life decision is a situation which is complex and challenges for the patients, (2) end-of-life decision varies among people with individual beliefs and values about religion, social values, personal values, and other factors, and (3) making end-of-life decision is a difficult and painful process because it is related to life and death.

Four types of end-of-life decisions and components commonly found from literature reviews of Western and Asian cultures are: (1) continuing life sustaining treatment, (2) forgoing life sustaining treatment, (3) allowing physicians/nurses to make decision, and (4) allowing family to make decision. In Asian culture contexts; however, four end-of-life components were Buddhist values, social values, family concern, and chronic advanced medical technology/chronic illness were established. This information from literature review was integrated with the interviewed data from Thai Buddhist adults with chronic illness in order to gain more understanding about end-of-life decision in the Thai context.

CHAPTER 3

METHODOLOGY

Introduction

The objectives of this study were to develop the End-of-Life Decision Scale (EoLDS) for Thai Buddhist adults with chronic illness and to evaluate its psychometric properties. Two research questions were: (1) what are the components of the EoLDS for Thai Buddhist adults with chronic illnesses? (2) how valid and reliable is the EoLDS for Thai Buddhist adults with chronic illnesses?

This chapter presents the research procedure in constructing EoLDS. The procedure included two phases with eight steps. Phase 1: the scale development included (1) determination of the conceptual framework, (2) generation of an item pool, and (3) determination of item format. Phase 2: the psychometric evaluation involved (4) determination of the content validity, (5) determination of reliability: pre-testing, (6) determination of construct validity: field testing, (7) item analysis, and (8) determination of reliability.

Phase 1: The scale development

To develop the End-of-Life Decision Scale for Thai Buddhist adults with chronic illness, three steps of determination of a conceptual framework, generation of an item pool, and determination of item format were performed successively. The details of each step are described as followings:

Step 1: Determination of the conceptual framework

The conceptual framework of the End-of-Life Decision Scale for Thai Buddhist adults was identified with three successive stages (1) a comprehensive literature review, (2) individual interviews, and (3) an integration of literature reviews and individual interviews.

1.1 A comprehensive literature review

The aim of this step was to explore types of end-of-life decision and reasons for the decision as well as to develop an interview guide for constructing the components of the EoLDS. This step began with a review of literature relevant to the construct of end-of-life decisions. The approach used for a literature review included a comprehensive electronic search of several databases, such as CINAHL, Science Direct, ProQuest, Medline, Pub-Med. Furthermore, books, journals, and unpublished studies such as master thesis and doctoral dissertations both in Thai and English were reviewed. The keywords: end-of-life care, end-of-life decision, chronic illness, Buddhist principles, and chronically ill patients at the end-of-life were used with studies cited from 1987-2013. Related literature in Asian countries was also included since their cultures were comparable to Thai culture and not all aspects of end-of-life decision were found in studies in the context of Thai culture.

The literature reviewed found four types of end-of-life decision as (1) continuing life sustaining treatment, (2) forgoing life sustaining treatment,

(3) allowing physicians/nurses to make decision, (4) allowing family to make decision. The reasons supporting end-of-life decision consisted of values, beliefs, and other factors such as religion, social values, family, and chronic illness (Table 2).

Table 2

Types of end-of-life decision and reasons of end-of-life decision from a comprehensive literature review

Types of end-of-life decision	Reasons	Theory
1. Continuing LST	1.1 Need to know the meaning of suffering and find the ways to understand and reduce suffering before die	The Four Noble Truths
	1.2 Need more time to do good Karma	The Law of Karma
	1.3 Reciprocity of goodness to own body/parents	Grateful values
	1.4 Give a chance for descendent to do good things	
	1.5 Believe in God, higher power, miracle, spirits, predestinated fortune (“duang” in Thai), wishes making and vows to the spirits (bon ban sarn klaw in Thai), and some supernatural rituals to stop bad fortune (by sprinkle holy water)	Personal believe
	1.6 Concern about descendants, passion with family, waiting to see a success of his or her descendant	Family concern

Table 2 (continued)

Types of end-of-life decision	Reasons	Theory
	1.7 Potential of advanced medical technology can preserve life, advanced medical technology have created hope for people in society to prolong life	Advanced medical technology/chronic illness
	1.8 Hope from advanced medical technology can prolong life	Hope
2. Forgoing LST	2.1 Death is inevitable, death is the truth of life, death is the way to overcome suffering, useless to prolong life	The four Noble Truths: suffering of birth, old age, sickness and death is unavoidable
	2.2 Life is not permanent' life is made from compounded thing,	The Three Characteristics of Existence
	2.3 Nature law/do not need to against the nature, death is the law of Karma	The Law of Karma
	2.4 Need nature death	Quality of death
	2.5 Need peaceful death	
	2.6 Life is invaluable if cannot self-care	Quality of life
	2.7 The Rights to die (Thai Health Act Section 12)	The Rights to Die Law
	2.8 Do not want to burden family	Family concern

Table 2 (continued)

Types of end-of- life decision	Reasons	Theory
3. Allowing physicians/nurses to make decision	3.1 Physicians/nurses are Loving-Kindness, compassion	Buddhist principle: Kindness value (Metta-Karuna)
	3.2 Respect for physicians' knowledge, competence, experience	Professional Code of ethics
	3.3 Trust in physicians/nurses decision	Physicians/ nurses-relationships
	3.4 Patient' s lack of education and understanding about new medical	Lack of knowledge, information
4. Allowing family to make decision	4.1 Respect for family	Respect for family
	4.2 Trust in family decision	Trust and relationships
	4.3 Believe in family's love	Believe in family
	4.4 Giving a chance to family for taking care before death	Grateful values

1.2 Individual interviews

The purpose of the interviews was to explore patients' decision at the end-of-life and reasons for their decision.

The participants for this interview were 12 persons, purposively selected from Thai Buddhist adults with chronic illness who met the following criteria: (1) having chronic illnesses, such as kidney disease, cancer, hypertension, and diabetes mellitus, for at least three months, and (2) being at least 40 years old.

The participants were interviewed individually using a case scenario of patient at the end-of-life. Open-ended questions were asked to explore participants' decisions and reasons for their decisions. Each interview was tape recorded for at least 60 minutes. Interview data were transcribed and content analysis was performed. The resulting data were used to develop themes of reasons supporting each type of end-of- life decision.

The decisions and reasons for end-of-life decision for Thai Buddhist adults with chronic illness were analyzed and then categorized into four types of end-of-life decision with reasons supporting each type of end-of-life decision (Table 3).

Table 3

Types of end-of-life decision and reasons of end-of-life decision from individual interviews

Types of end-of-life decision	Reasons	Theory
1. Continuing life sustaining treatment because of the duty to prolong life/concern for family/fear of death/hope/unfinished task	1.1 Duty to prolong life	Five precepts
	1.2 Life is very important and that everybody should maintain life	
	1.3 Concern for family, attachment to the family	Family concern
	1.4 Fear of death	Personal values
	1.5 Unfinished task	
	1.6 Believe that medical technology has the ability to change the nature/ hope	Advanced medical technology
2. Forgoing life sustaining treatment because death is the fact of life which is inevitable/ need peaceful death and not to burden family/society	2.1 Death is nature, Death is part of human life, Death is inevitable	Natural law, the Four Noble Truths
	2.2 Believe that death is the end of Karma	The Law of Karma
	2.3 Need peaceful death	Quality of death
	2.4 Do not want to burden family/society, Krenng- jai attitude	Family burden/ Family concern
3. Allowing physicians/nurses to make decisions because of trust in their competences	3. Trust in physician/ nurses' competences, knowledge, and experience	Trust and relationships
4. Allowing family to make decisions because families love me, they must know my needs	4.1 Respect and trust in family decisions making	Trust in family decision
	4.2 Families are responsible for all expenses and it is the chance for them to do good deeds, care for family's feeling	Family role

1.3 *An integration of literature review and individual interviews*

This step aimed to develop a conceptual framework by integration of literature review and individual interviews. The conceptual framework included types of end-of-life decision and reasons for each type of end-of-life decision (Table 4).

Table 4

Integration of literature review and individual interviews

Types of decisions	Reasons
1. Continuing life sustaining treatment	1.1 Buddhist values: Four Noble Truths, Law of Karma 1.2 Social values: grateful value, personal believe 1.3 Family concern 1.4 Advanced medical technology/chronic illness
2. Forgoing life sustaining treatment	2.1 Buddhist values: Four noble truths, Law of Karma, the Three Characteristics of Existence 2.2 Social values 2.3 Family burden/concern 2.4 Chronic illness
3. Allowing physicians/nurses to make decision	3.1 Buddhist values: Loving-Kindness, compassion (Meta-Karuna) 3.2 Social values: Respect for physicians/nurses, trust in physicians/nurses 3.3 Reduce conflict with family 3.4 Advance medical technology/chronic illness
4. Allowing family to make decision	4.1 Buddhist values: Family is true friends to make good wish 4.2 Social values: Render goodness (Katanyu) 4.3 Family love 4.4 Chronic illness

Step 2: Generation of an item pool

The purpose of this step was to generate an item pool for the EoLDS from the result of the literature reviews and individual interview. Four sets of questionnaires regarding four types of end-of-life decision and reasons for the decision were generated as a large item pool of items. The total numbers of the initial items pool were 79 items included four subscales: (1) Subscale 1: Continuing life sustaining treatment (EoLDS-Cont), 17 items, (2) Subscale 2: Forgoing life sustaining treatment (EoLDS-Forgo), 27 items, (3) Subscale 3: Allowing physicians/nurses to make decision (EoLDS-MD/RN), 27 items, and (4) Subscale 4: Allowing family to make decision (EoLDS-Fam), 8 items (Appendix C).

Step 3: Determination of the item format

The purpose of this step was to design the item format. All items were a six-point scale format ranging from 0 to 5, where 0 means “the statement is not the reason for decision,” and 5 means “the statement is extremely the reason for the decision.” A 6-point rating scale was used as the scale format in this study. The 6-point rating scale format can be used to avoid a neutral ambivalent midpoint (Devellis, 2012). Moreover the 6-point rating scale format had higher trend of discrimination and reliability than Likert’s scale 5 points (Chomeya, 2010,). The items were scored as follows:

0 = the statement is not the reason for decision

1 = the statement is hardly the reason for decision

2 = the statement is slightly the reason for decision

3 = the statement is moderately the reason for decision true

4 = the statement is considerably the reason for decision

5 = the statement is extremely the reason for decision

The EoLDS version 1 was constructed as the result of the Phase 1: the scale development with 79 items.

Phase 2: The Psychometric Evaluation

The objective of this phase was to determine the validity and reliability of the EoLDS. The psychometric evaluation comprised testing involved the rest five steps of (4) determination of the content validity, (5) determination of reliability: pre-testing, (6) determination of construct validation: field testing, (7) item analysis, and (8) determination of reliability.

Step 4: Determination of the content validity

The objective of this step was to determine a content validity index based on the experts' judgment. Two groups of experts were asked to evaluate all the questionnaire items in the EoLDS version 1. The EoLDS version 1 was sent to the first group of five experts, four of which were nurse educators: two in ethics and end-of-life care, one in development of instrument, one in development of instrument and ethics, and one physician who worked in end-of-life care setting. These five experts were asked to determine content validity of each set of questionnaire. In assessing the relevancy of the items to the content addressed by the objectives of the

assessing the relevancy of the items to the content addressed by the objectives of the study, the four point scale: 1 = not relevant, 2 = a little relevant, 3= quite relevant, 4= very relevant were used. The result showed that 4 experts rated each item at 3-4 point while one expert suggested that the reasons were not comprehensive, the researcher should revise the scale in order to cover important aspects related to Buddhist and Thai culture. Then, the researcher revised the EoLDS version 1 as recommended by adding reasons supporting end-of-life decision which resulted in EoLDS version 2. This EoLDS consisted of 4 subscales with a total of 146 items. Subscale 1: EoLDS-Cont (47 items) for the decision to continue life sustaining treatments, Subscale 2: EoLDS-Forgo (37 items) for the decision to forgo life sustaining treatment, Subscale 3: EoLDS-MD/RN (32 items) for the decision to allow physicians/nurses to make decision, and Subscale 4: EoLDS-Fam (30 items) for the decision to allow family to make decision.

The EoLDS version 2 was then sent to the second group of three experts including: a nurse educator in development of instrument and ethics, a nurse educator in end-of-life care, and a philosopher in Buddhism who worked as a professor at department of philosophy. The result of this step was EoLDS version 3 with 42 items for Subscale 1: EoLDS-Cont, 37 items for Subscale 2: EoLDS-Forgo, 32 items for Subscale 3: EoLDS-MD/RN, 30 items for Subscale 4: EoLDS-Fam with the total of 141 items. The CVIs of the EoLDS version 3 were .86, 1.00, 1.00, and 1.00 respectively.

Step 5: Determination of reliability: pre-testing

The purpose of this step was to determine the reliability of the EoLDS version 3, the researcher administered EoLDS version 3 to 120 subjects (30 for each of the four subscales of EoLDS) who were Thai Buddhist adults with chronic illness and met the following criteria: (1) having chronic illnesses, such as kidney disease, cancer, hypertension, and diabetes mellitus, for at least three months, (2) being at least 40 years old.

These subjects were also asked to comment on: readability, clarity of items, and length of time spent in answering the questionnaire. Finally Cronbach's alpha coefficient was used to determine internal consistency reliability of the EoLDS version 3. The Cronbach's alpha coefficients of the 1-4 subscales were .90, .91, .97 and .92 respectively. The results of this step were the EoLDS version 3.

Step 6: Determination of construct validity: field testing

The purpose of this step was to determine construct validity of the four subscales EoLDS.

Samples and setting. The subjects were purposively selected from the chronic outpatient clinics of four government hospitals in southern Thailand: Chumporn, Suratthani, Songkhla and Satun hospitals. Purposive sampling was used to choose Thai Buddhist adults with chronic illness from upper and lower part of southern Thailand. The subjects were Thai Buddhist adults with chronic illness who met the following criteria: (1) having chronic illnesses, such as kidney disease,

cancer, hypertension, and diabetes mellitus, for at least three months, (2) being at least 40 years old, and (3) willing to participate in this study.

The estimate sample size of this step was based on the statistical tool for factor analysis. Hair, Black, Babin, and Anderson (2010) stated that the ratio of about 5-10 subjects per item is accepted for psychometric evaluation of new tool. Since the EoLDS version 3 had 42 items for Subscale 1: EoLDS-Cont, 37 items for Subscale 2: EoLDS-Forgo, 32 items for Subscale 3: EoLDS-MD/RN, 30 items for Subscale 4: EoLDS-Fam, the minimum is to have at least 210, 185, 160, and 150 subjects for each subscale respectively. However, the large samples size for factor analysis method the more expectable than the small sample size. In this study 260, 286, 199, and 250 subjects were included in Subscale 1: EoLDS-Cont, Subscale 2: EoLDS-Forgo, Subscale 3: EoLDS-MD/RN, and Subscale 4: EoLDS-Fam respectively.

Instrument. The instrument for field test consisted of two parts of the EoLDS version 3 and the Demographic Data Form.

Data collection. The researcher sent a permission letter to the directors of target government hospitals asking for permission to conduct the study. Upon receiving the written permission from the hospitals, the researcher trained the research assistants who were staff nurses with master degree, of these target hospitals to collect the data. A package of questionnaire including the EoLDS version 3 and the Demographic Data Form with a cover letter was sent to the research assistants to interview with four groups of samples who made decision to continue, or forgo, or allow physicians/nurses to make decision, or allow family to make decision for them. A total number of 995 questionnaires were completed by the researcher/research

of each, was judged to be the best solution since it is the most parsimonious and theoretical interpretable with acceptable percentage of variance and adequate factor loadings (Dixon, 2005). Even though Waltz et al. (2010) stated that a priori set criterion of item loading at .30 is the minimum that was recommend. This study used the rotated factors by testing the items loaded at .40 to indicate that the factor strongly affects the variable. To assess whether the set of items in the correlation matrix is suitable for principal components analysis, the researcher used the Kaiser-Myer Olkin (KMO) and Bartlett's Test of Sphericity. KMO is a statistic which tells whether we have sufficient items for each factor. It should be over .7. (Fisher, King, & Tague, 2001). In this study KMO of four Subscale-EoLDS were .94, .93, .95, .92 respectively. Then the correlations among items was sufficiently to make the statistic factor analysis. The Bartlett Test of Sphericity was used to check if the original variables were sufficiently correlated. The test should come out significant ($p < .05$). In this study Bartlett test of Sphericity was significant ($p = .00$). Those results demonstrated that it would be appropriated to use factor analysis. Furthermore, the criteria in evaluating item were: (1) the eigenvalues greater than 1, (2) the scree plot, (3) the factor loading cutoff point at least .40, (4) percentage of variance of each subscale greater than 50, and (5) the parsimony and theoretical interpretability. As a result, two items were rejected because of poor factor loading (item 15 and 16 of Subscale 1: EoLDS-Cont had factor loading .29, and .30 respectively). Thus, the EFA of each subscale met the priori criteria. Subscale 1: EoLDS-Cont consisted of four factors with 39 items, Subscale 2: EoLDS-Forgo consisted of four factors with 37, Subscale 3: EoLDS-MD/RN consisted of three factors with 32 items, and Subscale 4:

EoLDS-Fam consisted of three factors with 30 items. The EoLDS version 5 with total was 138 items.

Step 7: Item analysis

This step aimed to evaluate the performance of the individual items by item analysis which was one of the statistical procedures permitting an examination of the response pattern to each item that provides a guideline for its reversion. Item to item correlation, item to subscale correlations, and subscale to subscale correlation are helpful in deciding which items needs to be retained, revised, or deleted after exploratory factor analysis. The items with a level of .3 were adequate. The results in this study indicated that all of items in four subscale EoLDS were retained. The EoLDS version 5 (five version) with total was 138 items.

Step 8: Determination of reliability

This step aimed to test the reliability of subscales. Internal consistency was tested with Cronbach' alpha coefficient. The resulting alpha values of .97 for Subscale 1: EoLDS-Cont, .96 for Subscale 2: EoLDS-Forgo, .96 for Subscale 3: EoLDS-MD/RN, and .95 for Subscale 4: EoLDS-Fam were revealed.

Protection of Human Subjects' Rights

Approval of the study was obtained from the Institutional Review Board (IRB) of the Faculty of Nursing, Prince of Songkla University. The protection of human subjects in this study was assured by the used of two consent forms.

The first form was used in the first phase of scale development to gain permission for the individual interview during the process of qualitative study. The second form was used in the process of psychometric evaluation. The written informed consent were included: (1) the purpose of the study, (2) assurance for the subject's anonymity and confidentiality, (3) voluntary consent to participate in the study, (4) the right to withdraw from the study without any consequences, (5) benefits of using results of this study in the education, research, and administration of nursing area, name, address, and phone number of researcher, and statement of an approval from IRB, Faculty of Nursing, Prince of Songkla University were given to all Thai Buddhist adults with chronic illness. In addition, the proposal was also submitted to the directors of the hospital in order to obtain their permission to take the subjects in this study. (Appendix 4).

Summary

This study aimed at exploring the components of end-of-life decisions made by Thai Buddhist adults with chronic illnesses, and to develop a reliable and valid instrument to help nurses assess end-of-life decisions. Two research questions were (1) what are the components of an end-of-life decision scale for Thai Buddhist

adults with chronic illness, and (2) how valid and reliable was the end-of-life decision scale?

The development and evaluation of the EoLDS was completed in eight steps: (1) determination of a conceptual framework, (2) generation of an item pool, (3) determination of the item format, (4) determination of the content validity, (5) determination of reliability: pre-testing, (6) determination of construct validity: field testing, (7) item analysis, and (8) determination of reliability, resulting in the EoLDS which consisted of 39 items for Subscale 1: EoLDS-Cont with four factors, 37 items for Subscale 2: EoLDS-Forgo with four factors, 32 items for Subscale 3: EoLDS-MD/RN with three factors, and 30 items for Subscale 4: EoLDS-Fam with three factors, and the total of 138 items (Figure 1).

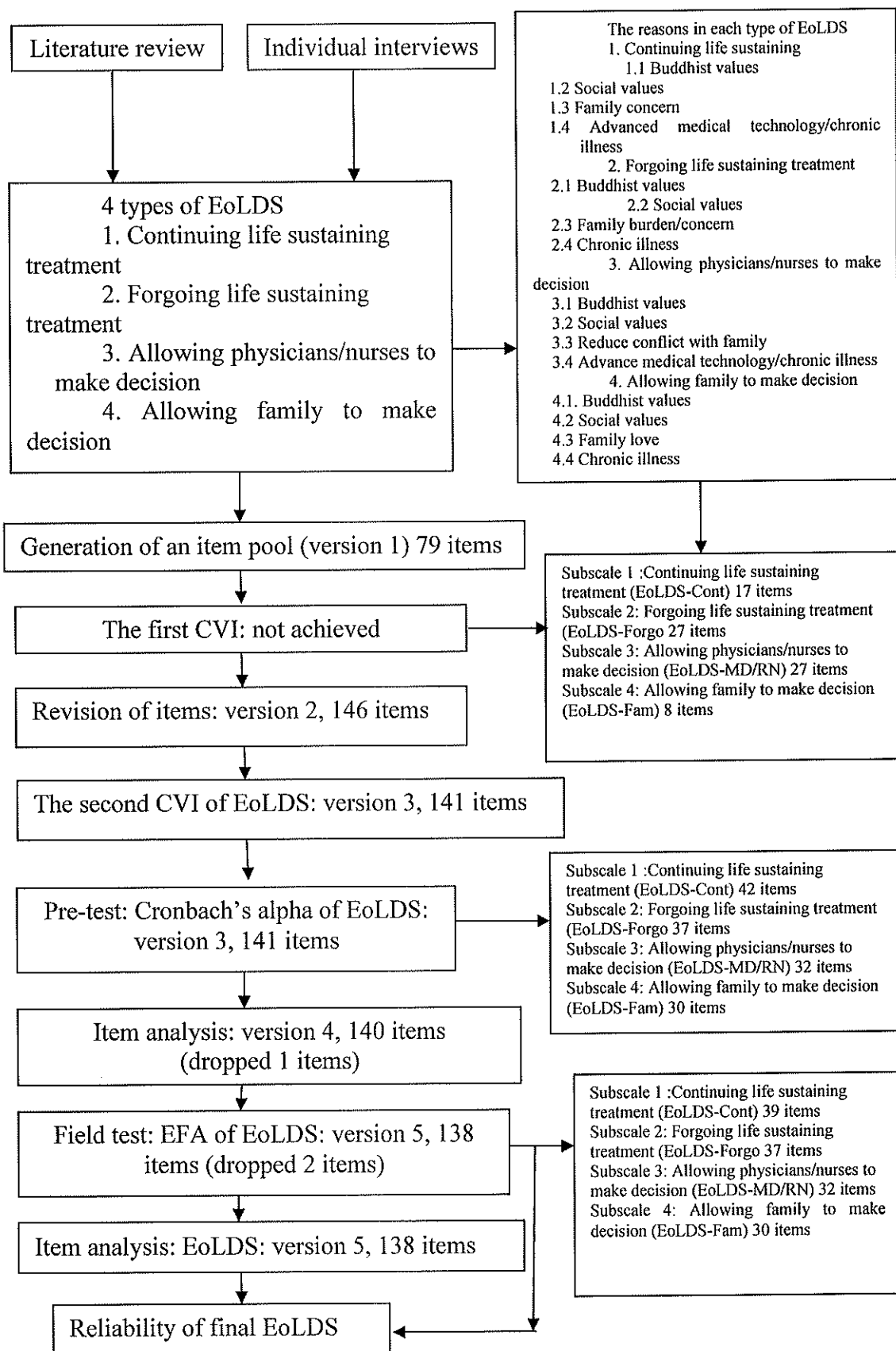


Figure 1 Process of scale development

CHAPTER 4

RESULTS AND DISCUSSION

Introduction

The main purposes of this study were to develop the End-of-Life Decision Scale (EoLDS) for Thai Buddhist adults with chronic illness and to determine its psychometric properties. This chapter presents the results of the study and discussion of the results. The results are presented in three parts: (1) demographic characteristics of the subjects, (2) the results from factor analysis, and (3) discussion.

Results

1. Demographic characteristics of the subjects

The demographic characteristics of the four groups of research subjects: those who decided to (1) continuing life sustaining treatment (EoLDS-Cont), (2) forgoing life sustaining treatment (EoLDS-Forgo), (3) allowing physicians/nurses to make decision (EoLDS-MD/RN), and (4) allowing family to make decision (EoLDS-Fam) are presented in Table 5.

Group 1: the EoLDS-Cont ($n_1=260$) were at the age ranged from 40 to 92 years old with an average of 59.13 years ($SD = 11.50$). Most of the subjects (56.20%) were in the middle age (40-60 years old). The majority of this group (72.30%) was female; most were married (68.80%) and completed the primary school

education (49.60%). They reported having unspecified occupations (27.30%), apart from the specified occupations of merchant, employee, farmer/agriculturist, government officer, and private business. Most of the subjects in this group were taking role as family's member (58.10%). They had a monthly income of 5,001-10,000 Baht (41.50%).

Group 2: the EoLDS-Forgo ($n_2=286$) were at the age ranged from 40 to 90 years old with an average of 60.81 years ($SD=11.81$). Most of the subjects (51.70%) were in the middle age (40-60 years old). The majority of this group (73.10%) was female; most were married (66.10%). They completed the primary school education (49.00%). They reported having unspecified occupation (37.10%), private business, government officer, merchant, farmer/agriculturist, and employee apart from the specified occupations. Most of the subjects in this group (57.70%) were taking role as family's member. They had a monthly income of more than 30,000 Baht (49.80%).

Group 3: the EoLDS-MD/RN ($n_3=199$) were at the age ranged of 40 to 90 years old with an average of 62.06 years ($SD=11.35$). Most of the subjects (54.80%) were the elderly (61-90 years old). The majority of this group (69.30%) was female; most were married (66.30%) and had the primary school education (56.80%). They reported having unspecified occupations, apart from the specified occupations of merchant, employee, farmer/agriculturist, government officer, and private business (36.20%). Most of the subjects in this group (56.80%) were taking role as family's member. They had a monthly income of 5,001-10,000 Baht (46.70%).

Group 4: the EoLDS-Fam were at the age ranged of 40 to 93 years old with an average of 62.95 years ($SD=12.19$). Most of the subjects (57.60%) were

the elderly (61-93 years old). The majority of this group (69.60%) was female; most were married (66.40%) and had the primary school education (60.40%). They reported having unspecified occupations apart from the specified occupations of merchant, employee, farmer/agriculturist, government officer, and private business (38.80%). Most of the subjects in this group (58.00%) were taking role as family's member. They had a monthly income of 5,001-10,000 Baht (50.00%).

Table 5

Demographic characteristics of subjects

Personal characteristics	Group 1 (n ₁ =260)		Group 2 (n ₂ =286)		Group 3 (n ₃ =199)		Group 4 (n ₄ =250)	
	N	%	N	%	N	%	N	%
Age	M=59.13	SD=11.50	M=60.81	SD=11.81	M=62.06	SD=11.35	M=62.95	SD=12.19
40-60	146	56.20	148	51.70	90	45.20	106	42.40
61-93	114	43.80	138	48.30	109	54.80	144	57.60
Gender								
Male	72	27.70	77	26.90	61	30.70	76	30.40
Female	188	72.30	209	73.10	138	69.30	174	69.60
Status								
Single	26	10.00	25	8.70	16	8.00	13	5.20
Marriage	179	68.80	189	66.10	132	66.30	166	66.40
Widow	55	21.20	72	25.20	51	25.60	71	28.40
Education level								
Non	8	3.10	3	1.00	10	5.00	11	4.40
Primary school	129	49.60	140	49.00	113	56.80	151	60.40
High school	49	18.80	61	21.33	31	15.60	35	14.00
Diploma	15	5.80	37	12.94	11	5.50	12	4.80
Bachelor degree	53	20.40	10	3.49	31	15.60	37	14.80
Master degree	4	1.50	9	3.14	3	1.50	4	1.60
Higher than Master degree	2	0.80	-	-	-	-	-	-

Group 1 = subjects who decided to continue life sustaining treatment (EoLDS-Cont)

Group 2 = subjects who decided to forgo life sustaining treatment (EoLDS-Forgo)

Group 3 = subjects who decided to allow physicians/nurses to make decision (EoLDS-MD/RN)

Group 4 = subjects who decided to allow family to make decision (EoLDS-Fam)

Table 5 (continued)

Personal characteristics	Group 1 (n ₁ =260)		Group 2 (n ₂ =286)		Group 3 (n ₃ =199)		Group 4 (n ₄ =250)	
	N	%	N	%	N	%	N	%
Occupations								
Unspecified	71	27.30	106	37.10	72	36.20	97	38.80
Farmer/Agriculturist	48	18.50	42	14.70	30	15.10	41	16.40
Employee	48	18.50	38	13.30	46	23.10	51	20.40
Merchant	43	16.50	28	9.80	12	6.00	23	9.20
Government officer	38	14.60	58	20.30	23	11.60	24	9.60
Private business	12	4.60	14	4.90	16	8.00	14	5.60
Family role								
Family member	151	58.10	165	57.70	113	56.80	145	58.00
Head of family	96	36.90	111	38.80	79	39.70	100	40.00
Alone	13	5.00	10	3.50	7	3.50	5	2.00
Income (Bath/month)								
<5,000	40	15.40	23	8.00	39	19.60	40	16.00
5,001-10,000	108	41.50	46	16.60	93	46.70	125	50.00
10,001-15,000	37	14.20	28	9.80	24	12.20	38	15.20
15,001-20,000	41	15.80	28	9.80	13	6.50	20	8.00
20,001-25,000	12	4.60	19	6.60	14	7.00	11	4.40
> 30,000	22	8.50	142	49.8	16	8.00	16	6.40

Table 6 showed that each group were diagnosed as hypertension (38.85%, 40.57%, 40.70, and 43.20%, respectively) and treated by oral medicine (95.38%, 93.00%, 97.48%, and 97.20%, respectively). The subjects in groups 1, 3, 4 had partial impacts from the disease (51.15%, 46.80%, and 50.00%, respectively) whereas most of group 2 reported non-impact from the disease (60.50%). However, the subjects in all groups could live independently from other people's assistance (57.31%, 63.29%, and 55.30%, respectively) whereas most of group 4 reported partial dependent (46.40%).

Table 6

Number and percentage of subjects who had disease, treatment, impact from the disease, and dependence on others

Personal characteristics	Group 1 (n ₁ =260)		Group 2 (n ₂ =286)		Group 3 (n ₃ =199)		Group 4 (n ₄ =250)	
	N	%	N	%	N	%	N	%
Disease								
Hypertension	101	38.85	116	40.57	81	40.70	108	43.20
Diabetes	55	21.15	42	14.70	37	18.59	75	30.00
Heart disease	9	3.50	9	3.11	5	2.50	8	3.20
Kidney disease	3	1.20	2	0.70	1	0.51	5	2.00
Cancer	9	3.50	8	2.80	9	4.52	1	0.40
Other diseases	83	31.90	109	38.12	66	33.18	53	21.20
Treatment								
Oral medication	248	95.38	266	93.00	194	97.48	243	97.20
Alternative treatment	12	4.62	20	7.00	5	2.52	7	2.80
Impact from the disease								
No impact	127	48.80	173	60.50	90	45.20	97	38.80
Partial impact	133	51.15	91	31.80	93	46.80	125	50.00
Severe impact	-	-	22	7.70	16	8.00	28	11.20
Dependence on others								
Independent	149	57.31	181	63.29	110	55.30	106	42.40
Partial dependent	82	31.54	91	31.80	73	36.60	116	46.40
Depended on others	29	11.15	14	4.91	16	8.00	28	11.20

Table 7 showed that the subjects in groups 1, 2 and 3 had indirect experience in using respirator (49.20%, 61.20%, and 48.20%, respectively), while 56.80% of group 4 had no experience in using respirator. Most of the subjects in group 1, 3, and 4 had no CPR experience (55.80%, 65.80%, and 63.20%, respectively), whereas 55.90% of group 2 had indirect CPR experience. Most of subjects in four groups had no dialysis experience (60.00%, 50.30%, 65.80%, and 70.80%, respectively). Most of them in group 1 and 2 had indirect ICU experience (52.30%

and 58.40%, respectively), whereas those in groups 3 and 4 had no ICU experience (48.70%, and 61.20%, respectively).

Table 7

Number and percentage of subjects who had experience in using life sustaining treatment

Experience in using life sustaining treatment	Group 1 (n ₁ =260)		Group 2 (n ₂ =286)		Group 3 (n ₃ =199)		Group 4 (n ₄ =250)	
	N	%	N	%	N	%	N	%
Respirator experience								
None	117	45.00	95	33.20	93	46.70	142	56.80
Direct experience	15	5.80	16	5.60	10	5.00	14	5.60
Indirect experience	128	49.20	175	61.20	96	48.20	94	37.60
CPR experience								
None	145	55.80	123	43.00	131	65.80	158	63.20
Direct experience	3	1.20	3	1.00	1	0.50	2	0.80
Indirect experience	112	43.00	160	55.90	67	33.70	90	36.00
Dialysis experience								
None	156	60.00	144	50.30	131	65.80	177	70.80
Direct experience	4	1.53	1	0.30	-	-	10	4.00
Indirect experience	100	34.60	141	49.40	68	34.10	63	25.20
ICU experience								
None	117	45.00	107	37.40	97	48.70	153	61.20
Direct experience	7	2.70	12	4.20	6	3.00	13	5.20
Indirect experience	136	52.30	167	58.40	95	47.70	84	33.60

Table 8 presents the Buddhist rite that Thai Buddhist adults with chronic illness participated in everyday life. The subjects in group 1 and 2 sometimes offered food to the monks (37.70%, and 36.40%, respectively), whereas those in groups 3 and 4 seldom offered food to the monks (37.20%, and 37.60%, respectively). The subjects in four groups often prayed (38.50%, 36.40%, 31.20%, and 28.00%,

respectively). The subjects in group 1 sometimes gave the offering dedicated to the monks (36.20%), whereas those in groups 2, 3, and 4 seldom gave the offering dedicated to the monks (42.30%, 43.20%, and 40.40%, respectively). The subjects in groups 1, 3, and 4 never practiced meditation (31.20%, 44.20%, and 44.00%, respectively), whereas 35.30% of those in group 2 seldom practiced meditation (35.30%). The subjects in groups 1 and 2 sometimes participated in Buddhist rite (39.20%, and 38.10%, respectively), whereas those in groups 3 and 4 seldom participated in Buddhist rite (38.00%, 37.20%, respectively). Other Buddhist rites such as walking with lighted candles in hand around a temple and offering robes to Buddhist priests at the monastery, the subjects in groups 1, 3, and 4 often participated in these rites (6.20%, 5.50%, and 2.40%, respectively), whereas 6.30% of subjects in group 2 never participated in this Buddhist rites. Finally, other Buddhist activity the subjects in groups 1, 2, 3, and 4 the data are not available (88.85%, 93.70%, 90.45%, 94.80% respectively).

Table 8

Number and percentage of subjects participating in Buddhist rites

Buddhist rites	Group 1 (n ₁ =260)		Group 2 (n ₂ =286)		Group 3 (n ₃ =199)		Group 4 (n ₄ =250)	
	N	%	N	%	N	%	N	%
Offer food to the monks								
Often	78	30.00	73	25.50	49	24.60	48	19.20
Sometimes	98	37.70	104	36.40	52	26.10	79	31.60
Seldom	73	28.10	95	33.20	74	37.20	94	37.60
Never	11	4.20	14	4.90	24	12.10	29	11.60
Pray								
Often	93	35.80	104	36.40	62	31.20	70	28.00
Sometimes	86	33.10	95	33.20	50	25.10	67	26.80
Seldom	60	23.10	77	26.90	54	27.10	66	26.40
Never	21	8.07	10	3.50	33	16.60	47	18.80

Table 8 (continued)

Buddhist rites	Group 1 (n ₁ =260)		Group 2 (n ₂ =286)		Group 3 (n ₃ =199)		Group 4 (n ₄ =250)	
	N	%	N	%	N	%	N	%
Give the offering dedicated to the monks								
Often	28	10.70	42	14.70	23	11.60	16	6.40
Sometimes	94	36.20	106	37.10	50	25.10	72	28.80
Seldom	111	42.70	121	42.30	86	43.20	101	40.40
Never	27	10.40	17	5.90	40	20.10	61	24.40
Practice meditation								
Often	40	15.34	47	16.40	26	13.10	22	8.80
Sometimes	61	23.46	78	27.30	36	18.10	37	14.80
Seldom	78	30.00	101	35.30	49	24.60	81	32.40
Never	81	31.20	60	20.90	88	44.20	110	44.00
N/A	-	-	-	-	-	-	8	3.2
Participate in Buddhist rites								
Often	76	29.20	71	24.80	49	24.00	61	24.40
Sometimes	102	39.20	109	38.10	60	30.00	78	31.20
Seldom	68	26.20	94	32.90	76	38.00	93	37.20
Never	14	5.38	12	4.20	14	7.03	18	7.20
Other Buddhist Activities								
Often	16	6.20	8	2.80	11	5.50	6	2.40
Sometimes	7	2.70	4	1.40	4	2.00	6	2.40
Seldom	6	2.30	6	2.10	4	2.00	1	0.40
N/A	230	88.85	268	93.70	188	90.45	237	94.8

Table 9 presents the Dharma Principle that Thai Buddhist adults with chronic illness used when they faced with the problems in everyday life. The subjects in groups 1, 2, and 3 sometimes used the Four Noble Truths (33.10%, 33.60%, and 29.65%, respectively), whereas 35.60% in group 4 seldom used the Four Noble Truths. The subjects in groups 1, 2, and 3 often used the Three Characteristics (35.00%, 34.60%, and 29.10%, respectively), whereas 31.20% of them in group 4 seldom used it. The subjects in groups 1, and 2 often used the Middle Way (38.50%,

and 35.00%), whereas 31.20% and 30.00% of subjects in groups 3 and 4 used it most of the time. The subjects in groups 1-4 often used the law of Karma (33.80%, 42.70%, 36.20%, and 30.80%, respectively). The subjects in every group often used the Five Precepts (37.70%, 44.80%, 39.70%, and 31.60%, respectively). The subjects in groups 1-3 often used the Four Sublime States of Mind (42.30%, 44.80%, and 35.70%, respectively), whereas 34.80% of them in group 4 used it most of the time. The subjects in groups 1-3 often used Sappurisa-dhamma or Qualities of a good man (44.20%, 40.90%, and 28.10%, respectively), whereas 34.00% of them in group 4 seldom used it. The subjects in groups 1-3 often used the Manual of Peace 38 steps (39.20%, 41.30, and 29.60%, respectively), whereas 36.00% of subjects in group 4 seldom used it.

Table 9

Number and percentage of subjects who using dharma principles in everyday life

Dharma Principle	Group 1 (n ₁ =260)		Group 2 (n ₂ =286)		Group 3 (n ₃ =199)		Group 4 (n ₄ =250)	
	N	%	N	%	N	%	N	%
<i>Four Noble Truths</i>								
Mostly	33	12.70	31	10.80	14	7.00	21	8.40
Often	82	31.50	84	29.40	56	28.10	66	26.40
Sometimes	86	33.10	96	33.60	59	29.60	61	24.40
Seldom	40	15.40	60	21.00	53	26.60	89	35.60
Never	19	7.30	15	5.20	17	8.50	13	5.20
<i>The Three Characteristics</i>								
Mostly	36	13.80	35	12.20	22	11.10	22	8.80
Often	91	35.00	99	34.60	58	29.10	72	28.80
Sometimes	75	28.80	88	30.80	51	25.60	68	27.20
Seldom	45	17.30	57	19.90	52	26.10	78	31.20
Never	13	5.00	7	2.40	16	8.00	10	4.00
<i>Middle Way</i>								
Mostly	26	10.00	36	12.60	22	11.10	24	9.60
Often	100	38.50	100	35.00	54	27.10	70	28.00

Table 9 (continued)

Dharma Principle	Group 1 (n ₁ =260)		Group 2 (n ₂ =286)		Group 3 (n ₃ =199)		Group 4 (n ₄ =250)	
	N	%	N	%	N	%	N	%
Sometimes	81	31.20	88	30.80	62	31.20	75	30.00
Seldom	38	14.60	55	19.20	48	24.10	74	29.60
Never	15	5.80	7	2.40	13	6.50	7	2.80
The Law of Karma								
Mostly	77	29.60	65	22.70	44	22.10	58	23.20
Often	88	33.80	122	42.70	72	36.20	77	30.80
Sometimes	63	24.20	56	19.60	34	17.10	36	14.40
Seldom	28	10.80	40	14.00	46	23.10	78	31.20
Never	4	1.60	3	1.00	3	1.50	1	0.40
Five Precepts								
Mostly	73	28.10	59	20.60	34	17.10	51	20.40
Often	98	37.70	128	44.80	79	39.70	79	31.60
Sometimes	54	20.80	60	21.00	35	17.60	41	16.40
Seldom	33	12.70	37	12.90	45	22.60	70	28.00
Never	2	0.80	2.00	0.70	5.00	2.50	9	3.60
Four Sublime States of Mind								
Mostly	51	19.60	47	16.40	22	11.10	18	15.60
Often	110	42.30	128	44.80	71	35.70	75	31.20
Sometimes	57	21.90	67	23.40	52	26.10	64	18.00
Seldom	35	13.50	39	13.60	47	23.60	85	34.80
Never	6	2.30	5	1.70	7	3.50	8	0.40
Sappurisa-dhamma or Qualities of a good man								
Mostly	33	12.70	43	15.00	23	11.60	29	7.20
Often	115	44.30	117	40.90	56	28.10	69	30.00
Sometimes	64	24.60	75	26.20	52	26.10	54	25.60
Seldom	36	13.80	44	15.40	56	28.10	90	34.00
Never	12	4.60	7	2.40	12	6.00	8	3.20
Manual of Peace 38 steps								
Mostly	46	17.70	45	15.70	24	12.10	29	11.60
Often	102	39.20	118	41.30	59	29.60	69	27.60
Sometimes	67	25.80	71	24.80	52	26.10	54	21.60
Seldom	35	13.50	44	15.40	55	27.60	90	36.00
Never	10	3.85	8	2.80	9	4.50	8	3.20

2. Results from Factor Analysis

After the four subscales of the End-of-Life Decision Scale (EoLDS) were developed, the exploratory factor analysis was performed to examine factor structure of each subscale. The five criteria for determining factor solution were set including: (1) the eigenvalue greater than 1, (2) the scree plot, (3) the factor loading cutoff of point at least .40, (4) percentage of variance of each subscale greater than 50, and (5) the parsimony and theoretical interpretability. The result of each subscale is presented and discussed as follows.

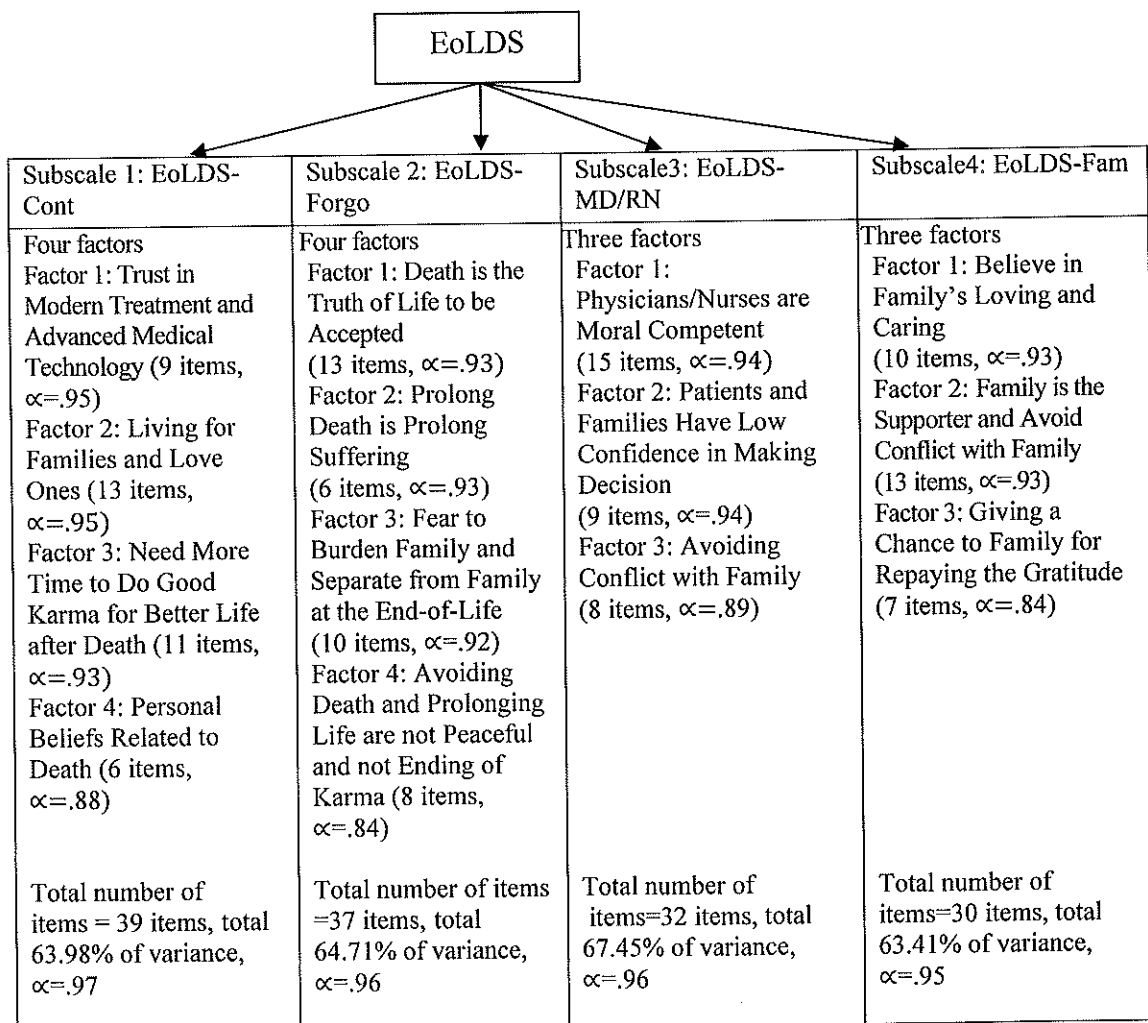


Figure 2 Summarized results from factor analysis

1. Subscale 1: Continuing Life Sustaining Treatment (EoLDS-Cont)

Varimax, quartimax, and equamax were performed to examine factor structures, basing on afore mentioned pre-set criteria. The scree plot (Figure 3) showed a break at the factors 3, 4 and 5. Therefore, factors 3, 4, and 5 were rotated. The four factor, equamax rotating, which combined characteristics of quartimax and varimax, balancing the advantages and disadvantages of each, was judged to be the best solution since it was the most parsimonious and theoretical interpretable with acceptable percentage of variance and adequate factor loadings.

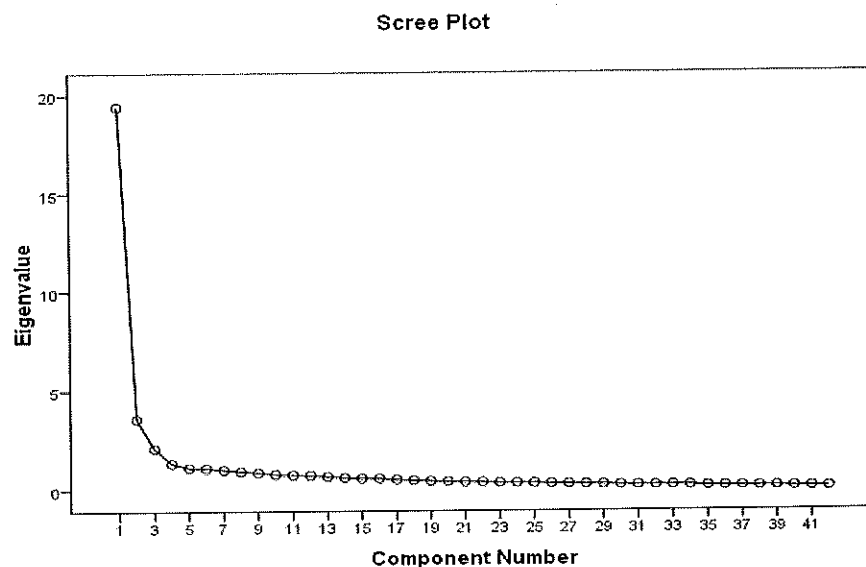


Figure 3: Scree plot for factor analysis of subscale 1: EoLDS-Cont

Note. Break in side of eigenvalue occurs at factor 3, 4, and 5

The factor analysis of subscale 1: EoLDS-Cont revealed four factors of a total number of 39 items and displayed a total variance of 63.98%. Details of each of the four factors are discussed as follows:

Factor 1: “*Trust in Modern Treatment and Advanced Medical Technology*” consisted of 9 items with factor loadings ranged from .46-.82, and accounted for 17.76% of variance with an eigenvalue of 19.38 (Table 10).

Table 10

Factor 1: Trust in Modern Treatment and Advanced Medical Technology of Subscale 1: EoLDS-Cont (n₁ =260)

Item no.	Item statements	Factor loadings
C37	Believe that hospital has advanced medical technology to prolong life	.82
C38	Trust in physicians/nurses' competence	.82
C36	Confidence in modern treatment	.76
C39	Currently, there are more modern and advanced medical technology	.76
C33	Treatment can reduce suffering from illness	.72
C35	Believe that illness could be cured	.69
C34	Have seen people with same illness survived by treatment	.67
C32	Treatment can relief pain from illness	.67
C19	It is common for Thai people to prolong life with modern medical equipment	.46

Eigenvalue =19.38

% of variance =17.76

Factor 2: “*Living for Families and Love Ones*” consisted of 13 items with a factor loading ranged from .56-.79, and accounted for 16.95% of variance with an eigenvalue of 3.57 (Table 11).

Table 11

Factor 2: Living for Families and Love Ones of Subscale 1: EoLDS-Cont (n₁=260)

Item no.	Item statements	Factor loadings
C27	Worries about family	.79
C21	Don't want family/love ones to lose care takers	.76
C22	Don't want family/love ones suffer from death	.75
C29	Feeling guilty to leave family without full treatment	.72
C26	Need time for family/love ones to prepare for separation	.72
C23	Hoping to see children/love ones success before death	.64
C28	Living for supporting family's emotion	.62
C24	Being alive makes a complete family	.59
C25	Need to complete some tasks	.59
C20	Being alive is will power of family/love ones	.59
C6	Leaving from love ones is suffering	.57
C30	Giving a chance for family to get involved in treatment	.56
C31	Giving a chance for family/love ones to take care in order to wipe out feeling guilty	.56

Eigenvalue =3.57

% of variance = 16.95

Factor 3: "*Need More Time to Do Good Karma for Better Life after Death*" consisted of 11 items with factor loadings ranged from .62-.74, and accounted for 16.78% of variance with an eigenvalue of 2.03 (Table 12).

Table 12

Factor 3: Need More Time to Do Good Karma for Better Life after Death of Subscale 1: EoLDS-Cont (n₁=260)

Item no.	Item statements	Factor loadings
C1	Because of life is suffering, person should prolong life in order to have clear understanding of suffering	.74
C4	Having more time to do good	.73
C11	Having more time to wipe out past wrong doings	.71
C12	Living to repay the kindness of the body	.70
C10	Having time to accumulate virtue for happiness after death	.70
C3	Living for redress karma	.68
C5	Living for increasing more good karma	.68
C8	Human does not own the body, it can't be neglected	.66
C9	Having a chance to repay the kindness of parents/families	.65
C7	Having more time to maintain the religion	.64
C2	Refusing treatment when sickness is sin	.62

Eigenvalue =2.03

% of variance = 16.78

Factor 4: “*Personal Beliefs Related to Death*” consisted of 6 items with factor loadings ranged from .53-.73, and accounted for 12.49% of variance with an eigenvalue of 1.25 (Table 13).

Table 13

Factor 4: Personal Beliefs Related to Death of Subscale 1: EoLDS-Cont (n₁=260)

Item no.	Item statements	Factor loadings
C14	Miracle of treatment is possible	.73
C16	Fate controls human's life, human stays alive if it's not the time to die	.67
C18	Sanctities can prolong human's life	.64
C15	Life needs to fight, even in terminal stage	.58
C13	Being virtuous will cause success of treatment	.55
C17	Illness is the test of life, person should not loss hope on treatment	.53

Eigenvalue =1.25

% of variance = 12.49

Cronbach's alpha coefficient was performed to examine internal consistency. The coefficient alpha of the total subscale was .97 and those of the four factors ranged from .88-.95 (Table 14).

Table 14

Cronbach's Alpha Coefficients of Total and Four Factors of the Subscale 1: EoLDS-Cont (n₁=260)

Factor	Number of item	Alphas
Factor 1 Trust in Modern Treatment and Advanced Medical Technology	9	.95
Factor 2 Living for Families and Love Ones	13	.95
Factor 3 Need More Time to Do Good Karma for Better Life after Death	11	.93
Factor 4 Personal Beliefs Related to Death	6	.88
Total	39	.97

Discussions

Discussion of Subscale 1: Continuing Life Sustaining Treatment (EoLDS-Cont)

The subscale 1: Continuing Life Sustaining Treatment Subscale (EoLDS-Cont) was for Thai Buddhist adults with chronic illness who made a decision to continue life sustaining treatment (LST) if they were at the end-of-life stage. It contained 39 items with a total variance of 63.98% which is sufficient as an effective scale as Hair, Black, Babin, and Anderson (2010) stated that each scale which accounts for at least 50% of variance can represent the concept. In addition, the total alpha of the subscale 1 was .97 and those of the four factors ranging from .88-.95 (Table 14) are acceptable as a high quality subscale as DeVellis (2012) stated that the alphas between .80 and .90 are very good scale. Details of each factor of the subscale 1: EoLDS-Cont is discussed as follows:

Factor 1: Trust in Modern Treatment and Advanced Medical Technology

This factor consisted of 9 items with factor loadings ranged from .46-.82, 17.76% of variance and eigenvalue of 19.38. This showed high loading scores and acceptable percentage of variance as Dixon (2005) suggested that factor loadings with at least 5% of variance and eigenvalues 1 or greater will be desirable as acceptable scales.

People in modern society believe that modern and advanced life sustaining treatment (LST) such as mechanical ventilation, renal dialysis, chemotherapy, antibiotics, artificial nutrition, and hydration can prolong life (Ellis & Hartley, 2004; Knox, 1989). LST is widely used in most hospitals in Thailand to prolong life of patients with critical or terminal illness. The subjects in this study tended to trust these LSTs, as reflected in the following items in this study: item C37 “believe that hospital has advanced medical technology to prolong life,” item C39 “currently, there are more modern and advanced medical technology,” item C36 “confidence in modern treatment”; and item C19 “It is common for Thai people to prolong life with modern medical equipment.” Belief in advanced medical technology made subjects believe that their diseases will be cured as reflected in item C35 “believe that illness could be cured” (Table 10). This finding was in accordance with the studies done by Manasurakarn (2007), and Neunoi (2005) which found that the chronically ill patients and surrogates decided to prolong life hoping for possibility to survive following modern and advanced treatment.

Moreover, experience of using LST was found in this study to support their decision to continue the LST, as reflected in item C34 “have seen people with same illness survived by treatment” (Table 10). Similar reasons were found in the studies of Manasurakarn (2007), and Neunoi (2005) which stated that chronically ill patients decided to prolong life using the LST because they had experience of seeing those LST when they went to the hospital as patients, spouse or relative of patients. In addition, most people at the end-of-life stage are suffering from pain caused by the disease (Burger, 2001) and these modern medical technologies for pharmacologic therapy, surgery, radiation therapy, chemotherapy, and hormone therapy are not only

for prolonging life but also for relieving pain and suffering (Fischer, et al., 2006). Thus, when patients at the end-of-life stage suffer severely from pain, they tend to accept the advanced LST for relieving their pain (Carmel, Werner, & Ziedenberg, 2007). This is precisely found in this study, as stated in item C32 “treatment can relieve pain from illness,” and item C33 “treatment can reduce suffering from illness” (Table 10).

Since modern and advanced medical technologies are new and complicated, physicians and nurses must be highly competent in using them to help patients effectively (Liver, 2009). For example, a physician may gradually increase the morphine dosage for a patient to relieve severe cancer pain, but high doses of morphine administration for relieving cancer pain may depress respiration and cause death (Burger, 2001). Therefore, health care providers’ knowledge and competence are essential in the subjects’ view as stated in item C38 “trust in physicians/nurses’ competence” (Table 10). This finding is similar to that found in Manaurakarn’ study (2007) showing that Thai Buddhist patients with chronic illness decided to continue life sustaining treatment because they trusted in health care providers’ competence.

Factor 2: Living for Families and Love Ones

The second factor encompassed 13 items with factor loadings ranged from .56-.79, 16.95% of variance and an eigenvalue of 3.57. This factor is acceptable for interpretation of the results (Dixon, 2005).

The subjects in this study took role as the chief and member of the family. They were responsible for their children and parents. Thus they felt they must

complete their jobs; and they needed more time to finish their work. Therefore, they decided to prolong life as reflected in item C27 “worries about family,” item C21 “don’t want family/love ones to lose care takers,” item C24 “being alive makes a complete family,” and item C28 “living for supporting family’s emotion” (Table 11). These findings are supported by the findings of Manasurakarn (2007) which revealed that Thai patients decided to continue life sustaining treatment because they were concerned about their descendents, passionate with family, and waiting for seeing achievement of their descendents.

Moreover, reasons for prolonging life by LST in the Thai society is based on relationship orientation such as gratefulness or reciprocity of goodness, expressed in Thai as Bunkhun. These reflects Thai cultural context through items such as item C30 “giving a chance for family to get involved in treatment,” and item C26 “need time for family/love ones to prepare for separation” (Table 11). These findings are in accordance with those found in a study by Manasurakarn (2007) showing that Thai patients decided to prolong life because they wanted to live for taking care of their parents or to “tob than bunkhun” as expressed in Thai.”

Factor 3: Need More Time to Do Good Karma for Better Life after Death

The third factor encompassed 11 items with factor loadings ranged from .62-.74, 16.78% of variance and an eigenvalue of 2.03. This factor is acceptable for interpretation of the results (Dixon, 2005).

Although death is accepted as natural human experience and it is inevitable, Thai Buddhists believe that if they accumulate good Karma when they are

alive, good Karma will pay back to them after they die. As Payutto (1995) stated that Karma is Buddhist precept and it is one part of the natural law referring to the result of action or cause and effect. People who always perform good Karma such as building image of Buddha, building temples and giving donation, will be happy and have less suffering after death.

In addition, Thai Buddhists believe that making merit makes them gain a better life now and in their next life. This belief is reflected in item C4 “having more time to do good”, item C5 “living for increasing more good karma,” item C3 “living for redress karma,” item C10 “having time to accumulate virtue for happiness after death,” and item C11 “having more time to wipe out past wrong doings” (Table 12). Thus, if the dying person had more previous good experience or positive karma they will die in peace. This was in accordance with the findings in a study by Nilmanat and Street (2007). They studied about the constructions of karma of four Thai family caregivers to the AIDS patients in Southern Thailand. Findings indicated that participants perceived that they had bad karma from their previous life and so it was inevitable that they would receive the fruit of their own karma in this life.

Additionally, the participants in this study believed life is suffering from birth, old age, sickness, and death. Thus, Buddhists need to know the meaning of suffering and find ways to understand and reduce suffering before they die. The Four Noble Truths, (1) suffering; (2) the cause of suffering; (3) the cessation or extinction of suffering; and (4) the path to the cessation of suffering, are the Buddhist philosophy which help Buddhist to understand suffering (Payutto, 1995). Therefore, subjects in this study decided to prolong life in order to have clear understanding of

sufferings, as reflected item C1 “because of life is suffering, person should prolong life in order to have clear understanding of suffering” (Table 12).

Moreover, Buddhists believe that doing bad things is sin. Sin in Buddhism is unacceptable actions, such as negligence to one’s own body. The results of negligence to the body are the source of diseases (Paonil & Sringernyuang, 2002). The result of negligence to parents is not being respected by others. Thus, people need to be grateful and value their own body and parents. Gratefulness is a highly valued characteristic trait in Thai society (Komin, 1991). Thus, subjects in this study decided to prolong life according to the value of Gratefulness as reflected in items C8 “human does not own the body, it can’t be neglected,” item C2 “refusing treatment when sickness is sin,” item C12 “living to repay the kindness of the body,” and item C9 “having a chance to repay the kindness of parents/families” (Table 12).

Factor 4: Personal Beliefs Related to Death

The fourth factor encompassed 7 items with factor loadings ranged from .53-.73, 12.49% of variance and an eigenvalue of 1.25. This factor is acceptable for interpretation of the results (Dixon, 2005).

Human are informed by the beliefs and values (Fry & Johnstone, 2008). Personal beliefs related to death are defined in terms such as Supernatural Miracle, Holy Thing, Fate, Virtue, and Will Power. Some examples of these beliefs in Thai context are beliefs in spirits, pre destined fortune, (Duang in Thai), wishes making and vows to the spirits (Bon ban sarnklaw in Thai), and some supernatural rituals to stop bad fortune (sprinkle holy water) (Komin, 1991). These supernatural or

miracle beliefs were reported by participants in this study as reflected in item C14 “miracle of treatment is possible,” item C16 “fate controls human’s life, human stays alive if it’s not the time to die,” and item C18 “sanctities can prolong human’s life.” Faith in God or religious preach gave hope and confidence for prolonging life as reflected in item C17 “illness is the test of life; person should not loss hope on treatment,” and item C15 “life needs to fight, even in terminal stage” (Table 13). The concept of hope for miracles and religious beliefs were also found in several studies in this area. A study on factors associated with decision making about end of life care among hemodialysis patients found that the participants believed that there was always hope in a miraculous cure from God and because of these beliefs, people feel there is hope to prolong life (Baharoon, et al., 2010). Several other studies in this area indicated that participants decided to continue life sustaining treatment because they hope to have a miracle (Gautheir, 2005; Manasurakarn, 2007; Nijinnikaree, 2003).

Subscale 2: Forgoing Life Sustaining Treatment (EoLDS-Forgo)

Again, the Varimax, Quartimax, and Equamax were performed to examine factor structure of Subscale 2, based on the pre-set criteria. The scree plot (Figure 4) showed the breaks at factors 3, 4, and 5. Therefore, factors 3, 4, and 5 were rotated. Factor 4 equamax rotation, which combines characteristics of quartimax and varimax, balancing the advantages and disadvantages, was judged to be the best solution since it was the most parsimonious and theoretically interpretable with acceptable of variance and adequate factor loadings.

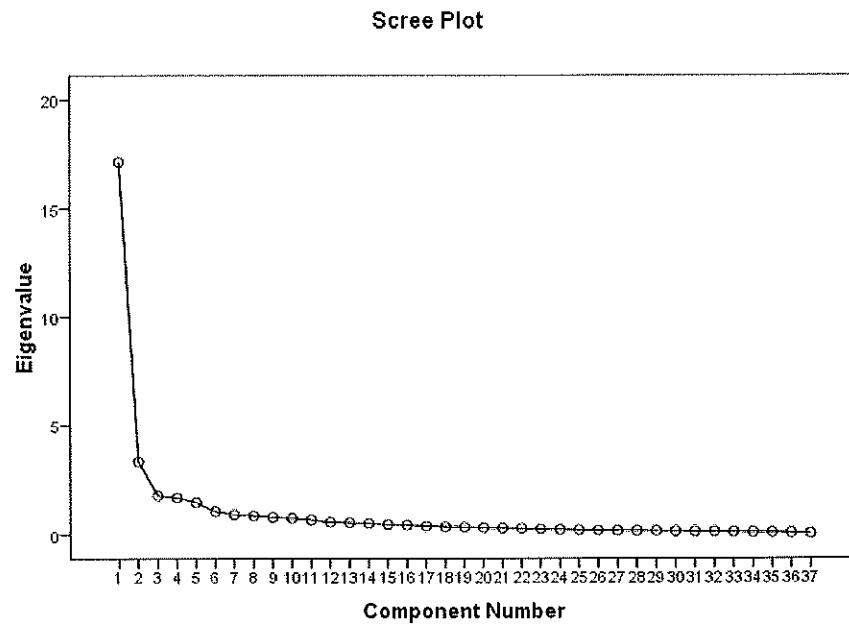


Figure 4: Scree plot for factor analysis of subscale 2: EoLDS-Forgo

Note: Break in side of eigenvalues occurs at factors 3, 4, 5

The factor analysis of subscale 2: EoLDS-Forgo revealed four factors of a total number of 37 items and displayed a total 64.71% of variance. Details of each of the four factors are discussed as follows:

Factor 1: *“Death is the Truth of Life to be Accepted”* consisted of 13 items with factor loadings ranged from .44-.72, and accounted for 18.53% of variance with an eigenvalue of 17.14 (Table 15).

Table 15

Factor 1: Death is the Truth of Life to be Accepted of Subscale 2: EoLDS-Forgo
($n_2 = 286$)

Item no	Item statements	Factor loadings
F11	Life is impermanent moment by moment, must be conscious and ready to die	.72
F2	Death is the truth that everyone must accept	.72
F12	Life is impermanent, birth, death	.71
F4	Death is inevitable	.69
F16	Buddhists don't attach compounded things, when death arrives we must accept it with peaceful mind	.67
F1	Death is leaving from compounded things	.66
F18	Need to die naturally without equipment	.63
F20	Don't want to against nature	.63
F10	Buddhists believe life is unpredictable, person must always be ready to die	.61
F19	Need to live life naturally before death	.60
F5	Death is already set, we must go when time arrives	.54
F15	When death arrives, no need to fight to prolong life	.49
F22	Thai citizens have rights to choose whether to prolong life	.44

Eigenvalue 17.14

% of variance 18.53

Factor 2: "*Prolong Death is Prolong Suffering*" consisted of 6 items with factor loadings ranged from .69-.87, and accounted for 16.25% of variance with an eigenvalue of 3.33 (Table 16).

Table 16

Factor 2: Prolong Death is Prolong Suffering of Subscale 2: EoLDS-Forgo (n₂=286)

Item no	Item statements	Factor loadings
F34	Treatment may cause more pain	.87
F33	Treatment may cause more suffering	.86
F36	Treatment may prolong life but it might be unconscious forever	.76
F32	Knowing that the disease is more severe than treat it	.73
F35	Treatment may interrupt peaceful death	.73
F37	Prolong life is useless	.69

Eigenvalue =3.33

% of variance = 16.25

Factor 3: *“Fear to Burden Family and Separate from Family at the End-of-Life”* consisted of 10 items with factor loadings ranged from .46-.83, and accounted for 15.99 % of variance with an eigenvalue of 1.78 (Table 17).

Table 17

Factor 3: Fear to Burden Family and Separate from Family at the End-of-Life of

Subscale 2: EoLDS-Forgo (n₂=286)

Item no	Item statements	Factor loadings
F29	Don't want family to lose income	.83
F30	Don't need family to waste money	.80
F25	Don't want family member exert for patients because there have other persons need to be taken care	.79
F31	Don't need family to waste time	.76
F28	Don't want to burden family	.67
F26	Don't want to live with suffering and make family gets stress	.67
F21	Don't want to burden family/society if cannot make contributions to benefit the family/society	.54
F23	Long life which depends on others is useless	.54
F24	Need peaceful death surrounded by family/love ones	.48
F27	Life support equipment separates from family	.46

Eigenvalue = 1.78

% of variance = 15.99

Factor 4: “*Avoiding Death and Prolonging Life are not Peaceful and not Ending of Karma*” consisted of 8 items with factor loadings ranged from .43-.78, and accounted for 13.93% of variance with an eigenvalue of 1.68 (Table 18).

Table 18

Factor 4: Avoiding Death and Prolonging Life are not Peaceful and not Ending of Karma of Subscale 2: EoLDS-Forgo (n₂=286)

Item no	Item statements	Factor loadings
F9	Death can release Karma	.78
F6	When death arrives, we redress Karma	.76
F3	Death is a way to overcome suffering	.71
F8	Death cannot be controlled by human	.60
F14	Prolong life is to refuse the fact of life	.49
F7	Death is karma, no one can refuse Karma	.46
F17	Prolonging life, mind is not peaceful before death	.43
F13	Prolonging life is wrong	.43

Eigenvalue 1.68

% of variance 13.93

Cronbach's alpha coefficient was performed to examine internal consistency. The coefficient alpha of the total subscale (37 items) was .96 and those of the four factors ranged from .84-.93 (Table 19).

Table 19

Cronbach's Alpha Coefficients of Total and Four Factors of the Subscale 2: EoLDS-Forgo (n₂=286)

Factors	Number of items	Alphas
Factor 1 Death is the Truth of Life to be Accepted	13	.93
Factor 2 Prolong Death is Prolong Suffering	6	.93
Factor 3 Fear to Burden Family and Separate from Family at the End-of-Life	10	.92
Factor 4 Avoiding Death and Prolonging Life are not Peaceful and not Ending of Karma	8	.84
Total	37	.96

Discussion of Subscale 2: Forgoing Life Sustaining Treatment Subscale (EoLDS-Forgo)

The subscale 2: Forgoing Life Sustaining Treatment Subscale (EoLDS-Forgo) was for those who made decision to forgo life sustaining treatment (LST) if they were at the end-of-life stage. It contained 37 items with a total variance of 64.71%. According to Hair, et al. (2010), each scale accounting for at least 50% of variance can represent the concept. In addition, the total alpha of the subscale 2 was .96 and those of the four factors ranging from .84 to .93 (Table 19) are acceptable as a high quality (DeVellis, 2012). Details of each factor of the subscale 2: EoLDS-Forgo are discussed as follows:

Factor 1: Death is the Truth of Life to be Accepted

This factor consisted of 13 items with factor loadings ranged from .44-.72, 18.53% of variance and an eigenvalue of 17.14. All people realize that death is natural human experience which is inevitable (Santrock, 1999). The finding indicated that the subjects in this study who were Buddhist decided to forgo LST because they believed that death is the truth of life which all human beings must accept. They made decision to forgo LST based on Buddhist values stating that death is the truth of life of all human beings, as reflected in the following items: item F2 “death is the truth that everyone must accept,” item F4 “death is inevitable,” item F1 “death is leaving from compounded things,” item F5 “death is already set, we must go when time arrives,” item F16 “Buddhists don’t attach for compounded things, when death arrives we must

accept it with peaceful mind,” and item F15 “when death arrives, no need to fight to prolong life” (Table 15).

According to Buddhist principle, the Three Characteristics of Existence or Tri-lakkana, states that all things are impermanent (Aniccata). Death is nature, prolonging life is against nature; everyone is born and finally dies. This belief is reflected in item F11 “life is impermanent moment by moment, must be conscious and ready to die,” item F12 “life is impermanent, birth, death,” item F18 “need to die naturally without equipment,” item F20 “don’t want to against nature,” item F10 “Buddhists believe life is unpredictable, person must always be ready to die,” item F19 “need to live life naturally before death” (Table 15). Similarly, the decision to forgo life-sustaining treatment was reported in a study by Manasurakarn et al. (2008) indicating that 70% of subjects decided to forgo life sustaining treatment based on Buddhist doctrine. Buddhists are taught to realize, understand, and accept death as laws of nature. The Thai Buddhists adults with chronic illness in this current study and those of Manasurakarn et al. (2008) decided to forgo life-sustaining treatment because they accepted the end stage of life according to this religious belief.

In addition, one item reflected the subjects knowledge of their rights as Thai citizens as stated in the Health Act Section 12 “*A person shall have the right to make a living will in writing to refuse the public health service which is supplied merely to prolong his/her terminal stage of life or to cease the severe suffering from illness.*” Item F22 “Thai citizens have the right to choose whether to prolong life.” Therefore, the right to refuse treatment at the end-of-life is one reason related to their decision to forgo life sustaining treatment.

Factor 2: Prolong Death is Prolong Suffering

This factor consisted of 6 items with factor loadings ranged from .69-.87, 16.25% of variance and an eigenvalue of 3.33. This factor is acceptable as a quality scale with a greater than 5 % of variance and the eigenvalue higher than 1 (Dixon, 2005). The alpha value in this factor is .93, which reflects high quality of the scale (DeVellis, 2012). Based on the belief that a medical treatment can prolong life, it prolongs suffering at the same time. Examples of sufferings from the end-of-life stage treatments include side effects from chemotherapy, headache, abdominal pain, chest pain, neuropathy, lack of energy, shortness of breath (Burger, 2001). The reasons for forgoing LST expressed by subjects in this study were pain and sufferings from treatments as reflected in item F34 “treatment may cause more pain,” item F33 “treatment may cause more suffering,” and item F36 “treatment may prolong life but it might be unconscious forever” (Table 16). These findings were supported by the study of Gauthier (2005) regarding decision making near the end-of-life stage of patients receiving hospital service. The finding suggested that the presence of pain and/or other physical symptoms can directly influence decision making to discontinue LST. Fear of pain has been reported as the main issues for terminally ill patients. Moreover, Mendelson, et al. (2003) stated that the reasons participants changed their mind and refused the treatment after one year were pain and discomfort. Findings in this study were also supported by Mansurakarn et al. (2008), and Neounoi (2005) which found that the patients decided to forgo life sustaining treatment because they fear of suffering from LST. Similarly, the Pew Research Center Survey (2013) which asked American adults about their personal preferences for medical treatment in

different scenarios, majority (57%) wanted to ask their doctors to stop medical treatment if they had a disease with no hope of improvement and they were suffering a great deal of pain. Supported by White and Fitzpatrick (2006) who stated that dialysis patients in Australia decided to discontinued dialysis treatment because they were painful and suffered.

Moreover, some subjects in this study described that LST may interfere peaceful death as reflected in item F35 “treatment may interrupt peaceful death.” Similarly, a study of Kongsuwong, Keller, Touhy, and Schoenhofer (2010) found that Thai Buddhist ICU nurses believed that receiving cardiac massage and similar procedures taken to prolong life caused suffering and prevented a peaceful death. Thai Buddhist patients in a study by Manasurakran (2007) stated they did not need technology before death because several kinds of medical equipments such as tubes into nose and mouth caused discomfort and distress.

Factor 3: Fear to Burden Family and Separate from Family at the End-of-Life

The third factor encompassed 10 items with factor loadings ranged from .46-.83, 15.99% of variance and an eigenvalue of 1.78. This factor is acceptable as a high quality scale with a greater than 5% of variance and the eigenvalue higher than 1 (Dixon, 2005). The alpha value in this factor is .92 reflecting high quality of the scale (DeVellis, 2012).

Being with chronic illness, patients are aware of financial burden on family and social resource (Taylor, Jones, & Burns, 1998). The reasons the subjects in

this study decided to forgo LST because they did not want to burden family. As shown in item F29 “don’t want family to lose income,” item F25 “don’t want family member exert for patients because they have other persons need to be taken care,” and item F28 “don’t want to burden family” (Table 17). Similarly, a study by Manasurakarn (2007) found that the participants decided to forgo LST because they did not want their families to lose income because they needed to be taken care. In addition, living with chronic illness has caused physical, psychosocial, spiritual, and social problems for both the patient and family. Some of the impacts including duration of hospitalizations, increased financial crisis, social burdens, emotional difficulties, feeling of anxiety and frustration, and changes in body appearance are problems causing burden to patients and their families and make participants think about death or decided to forgo LST (Larsen, 2009). As reflected in item F26 “don’t want to live with suffering and make family gets stress,” item F23 “long life which depends on others is useless,” item F31 “don’t need family to waste time,” and item F21 “don’t want to burden family/society if cannot make contributions to benefit the family/society” (Table 17). Several studies, Fried, & Bradley (2003), Gauthier (2005), Manasurakarn et al. (2008), Neounoi (2005), Rietjens et al. (2006), and Schaffer (2007) indicated that participants in their studies decided to forgo LST because they were concerned about being a burden to their family/society.

In addition, some participants did not want to rely on technology to prolong life. Patients who decided to prolong life usually needed LST and attempts to prevent premature death in ICUs (Kongsuwan & Locsin, 2009). LST may include ventilator to support aggressive treatment, such as cardiac massage that needs intensive care from nurses. Some LST activities made patients feel alone and

separated from family as reflected in item F27 “life support equipment separates from family.” Thus, they need peaceful death around their family as reflected in item F24 “need peaceful death surrounded by family/love ones.” Similarly, a study of Somanusorn (2010) found that participants described peaceful death as: dying naturally and having family with them side by side helped the dying person feel more comfortable, warm, secure, and less frightened of the arriving death.

Factor 4: Avoiding Death and Prolonging Life are not Peaceful and not Ending of Karma

The fourth factor encompassed 8 items with factor loadings ranged from .43-.78, 13.93% of variance and an eigenvalue of 1.68. This factor is acceptable as a quality scale with a greater than 5% of variance and the eigenvalue higher than 1 (Dixon, 2005). The alpha value in this factor was .84 reflecting high quality of the scale (DeVellis, 2012).

According to the Buddhists believe that death is the truth life, no one can control it, it is reflected in item F8 “death cannot be controlled by human” (Table 14). In addition, Buddhist precept explains that human life is Karma (Paonil, & Sringeriyuang, 2002). It is one part of the natural law that refers to the working of intension, or/and process of mental proliferation and its consequences. The Law of Karma that described death as reciprocity. Law of Karma is Buddhist value which can be classified as values of life and death. Some subjects believed that life is living for reciprocity to Karma while some believed that death is the end of Karma as reflected in item F9 “death can release Karma,” item F6 “when death arrives, we redress

Karma.” From this point of view, the subjects believed that prolonging life is against nature as reflected in item F13 “prolonging life is wrong,” and item F14 “prolong life is to refuse the fact of life,” and item F7 “death is Karma, no one can refuse Karma” This finding was supported by a study of Marnasurakarn (2007) finding that participants decided to discontinue LST based on the Buddhist doctrine including Law of Nature as prolonging life is going against nature.

Moreover, patients who decided to prolong life usually receive LST such as ventilator, cardiac massage, and/or life sustaining medications and therapy (Kongsuwan, & Locsin, 2009). These kinds of therapy may make the patients more painful and anxious, and interfere with peaceful death. Therefore, subject in this study decided to refuse treatment at the end-of-life stage as reflected in item F17 “prolonging life, mind is not peaceful before death” (Table 18). This concept of peaceful death was explained by family members of the patients and nurses in a study by Somanusorn (2010) as (1) die as sleep, (2) die without worry, (3) die as karma ending, lifetime finished, not postponing death, and die in sati, being conscious before passing away.

Subscale 3: Allowing Physicians/Nurses to Make Decision (EoLDS-MD/RN)

Again, the Varimax, Quartimax, and Equamax were performed to examine factor structure of Subscale 3, based on the pre-set criteria. The scree plot (see Figure 5) showed the breaks at factors 3, 4, and 5. Therefore, factors 3, 4, and 5 were rotated. Factor 3 equamax, which combines characteristics of quartimax and

varimax, balancing the advantages and disadvantages, was judged to be the best solution since it was the most parsimonious and theoretically interpretable with acceptable of variance and adequate factor loadings.

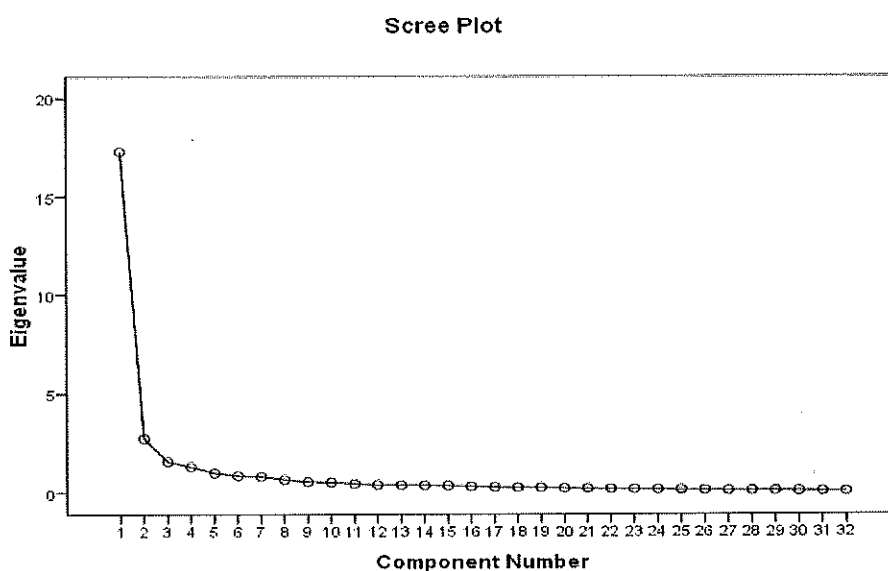


Figure 5: Scree plot for factor analysis of subscale 3: EoLDS-MD/RN

Note. Break in side of eigenvalues occurs at factor 3

The factor analysis of subscale 3 (EoLDS-MD/RN) revealed three factors of a total number of 32 items and displayed a total variance 67.45%. Details of each of the three factors are discussed as follows:

Factor 1: “*Physicians/Nurses are Moral Competent*” consisted of 15 items with factor loadings ranged from .53-.82, and accounted for 27.43% of variance with an eigenvalue of 17.29 (Table 20).

Table 20

Factor 1: Physicians/Nurses are Moral Competent of Subscale 3: EoLDS-MD/RN

(n₃ = 199)

Item No.	Item statements	Factor loadings
P4	Physicians/nurses are true friends in the time of sickness	.82
P2	Physicians/nurses have compassion	.79
P3	Physicians/nurses are willing to help patients	.76
P5	Physicians/nurses have more knowledge	.76
P6	Physicians/nurses have duty to help patients	.75
P1	Physicians/nurses are kind	.73
P7	Physicians/nurses know how to treat patients the best way	.73
P9	Believe in physicians/nurses' experiences	.71
P10	Be confident in physicians/nurses to make decision based on patient' benefits	.70
P12	Physicians/nurses are good person	.67
P14	Physicians/nurses have good wish to patients	.66
P13	Physicians/nurses are respectable	.66
P8	Confidence in physicians/nurses' capability	.66
P11	Put one's hopes into physicians/nurses' hand	.59
P15	After getting illness, must depend on physicians/nurses	.53

Eigenvalue 17.29

% of variance 27.43

Factor 2: "*Patients and Families Have Low Confidence in Decision Making*" consisted of 9 items with factor loadings ranged from .54-.80, and accounted for 22.11% of variance with an eigenvalue of 2.73 (Table 21).

Table 21

*Factor 2: Patients and Families Have Low Confidence in Decision Making of Subscale 3:
EoLDS-MD/RN (n₃=199)*

Item no	Item statements	Factor loadings
P29	Physicians/nurses clearly understand advanced medical technology more than others	.80
P32	Physicians/nurses know how to decrease suffering	.78
P31	Less understand treatment plan than physicians/nurses	.74
P30	Belief in physicians/nurses who give the good treatment	.77
P27	No knowledge of disease to make decision	.68
P16	Physicians/nurses make decision based on patients centered	.67
P28	Final stage of illness needs only physicians/nurses' help	.59
P22	Family believes in physicians/nurses competence	.54
P23	Family fully agrees, when physicians/nurses' make decision	.54
Eigenvalue 2.73		
% of variance 22.11		

Factor 3: “*Avoiding Conflict with Family*” consisted of 8 items with factor loadings ranged from .54-.86, and accounted for 17.91% of variance with an eigenvalue of 1.56 (Table 22).

Table 22

Factor 3: Avoiding Conflict with Family of Subscale 3: EoLDS-MD/RN (n₃=199)

Item no	Item statements	Factor loadings
P20	Own decision may not be accepted from family	.86
P18	Own decision may be different from family	.80
P17	Don't trust self/family' s decision	.79
P19	Own decision may be wrong, so physicians/nurses should make decision	.70
P26	Reduce the conflict with family from disagreement	.65
P21	Usually, family must approve for any decision	.58
P25	Reduce the family's anxiety	.57
P24	Family doesn't want to bother physicians/nurses	.54

Eigenvalue 1.56

% of variance 17.91

Cronbach's alpha coefficient was performed to examine internal consistency of all 32 items of Subscale 3: EoLDS-MD/RN. The coefficient alpha of the total subscale was .96 and those of the three factors ranged from .89-.96 (Table 23).

Table 23

Cronbach's Alpha Coefficients of Total and Three factors of Subscale 3: EoLDS-MD/RN (n₃=199)

Factors	Number of items	Alphas
Factor 1 Physicians/Nurses are Moral Competent	15	.96
Factor 2 Patient and Family Have Low Confidence in Decision Making	9	.94
Factor 3 Avoiding Conflict with Family	8	.89
Total	32	.96

Discussion of Subscale 3: Allowing Physicians/Nurses to Make Decision (EoLDS-MD/RN)

The subscale 3: Allowing Physicians/Nurses to Make Decision Subscale (EoLDS-MD/RN) is for those who delegated their end-of-life decision to physicians/nurses. It contained 32 items with a total variance of 67.45%. According to Hair, et al. (2010), each scale accounting for at least 50% of variance can represent the concept. In addition, the total alpha of the subscale 3 was .96 and those of the three factors ranging from .89-.99 (Table 23) are acceptable as adequate quality subscale as DeVellis (2012) stated that the alphas between .80 and .90 are very good scale. Details of each factor of the subscale 3: EoLDS-MD/RN is discussed as follows:

Factor 1: Physicians/Nurses are Moral Competent

The first factor encompassed 15 items with factor loadings ranging from .53-.82, and accounted for 27.43% of variances with an Eigenvalue of 17.29.

Moral competence refers to an individual's ability to live in a manner consistent with a personal moral code and role responsibilities such as knowledge, experience, and role (Zhang, Luk, Arther, & Wong, 2001). In this study the professional health care personnel such as physicians and nurses were regarded as moral and competent persons with good will, compassion, kindness, and willingness to care for the best of patients as reflected in item P2 "physician/nurses have compassion," item P3 "physicians/nurses are willing to help patients," item P1 "physicians/nurses are kind," and item P14 "physicians/nurses have good wish to

patients” (Table 20). These concepts of moral and competence of healthcare professionals in this study are similarly to the four attributes of moral competence found in a study of Jomsri, Kunavikitikul, Ketefian, and Chaowalit (2005). These four attributes of moral competence tend to follow the Buddhist principle called the ‘four sublime states of mind’ or Metta-Karuna which encompasses loving kindness, compassion, sympathetic joy and equanimity.

In addition, the patients’ perception of moral competence of professional healthcare personnel were reflected in item P6 “physicians/nurses’ have duty to help patients,” item P5 “physicians/nurses have more knowledge,” and item P9 “believe in physicians/nurses’ experiences” (Table 20). These perceptions are similar to those found in the studies of Manasurakarn (2007) and Browman and Singer (2001) which found that subjects allowed physicians to make decision for them at the end-of-life because they trusted the physician’s knowledge, competence, and experience.

These perceptions of moral competence of healthcare personnel made the subjects in the current study respect and trust professional health care personnel as reflected in item P4 “physicians/nurses are true friends in the time of sickness,” item P15 “after getting illness, must depend on physicians/nurses,” and item P11 “put one's hopes into physicians/nurses’ hand” (Table 20). The concept of moral competence the patients have towards the professional healthcare personnel was also found in a study by Manasurakarn (2007) which found that subjects allowed physician to make end-of-life decision because they trusted in physician’s knowledge and competence and they hoped they could survive in the care of moral and competent physicians and nurses.

Item P10 “be confident in physicians/nurses to make decision based on patients’ benefit,” and item P7 “physicians/nurses know how to treat patients the best way” reflected that the patients delegated their authority of end-of-life decision to the physicians/nurses because they trusted them. The items stated by subjects in this study are in accordance with professional healthcare concepts as mentioned in several studies in the area of EOL care decisions. Hebert, Moore, and Rooney, (2011) described that nursing professionals are essential to support EOL care decisions and advocate for patients and families across healthcare settings because they spend more time with patients who are facing death than any other members of the healthcare team and are the most trusted professionals. Moreover, nurses are a group of health care professionals who promote health, prevent diseases, and save lives (Liver, 2009). Supported by Kurz, and Hayes (2006), who stated that experts developed national recommendations for physician EOL education to improve medical students’, interns’, and residents’ knowledge, and to decrease anxiety related to care at the end of life, whereas nursing education program offered the modules of nursing care at the end of life such as pain management, symptom management, ethical/legal issues, cultural.

Factor 2: Patient and Family Have Low Confidence in Decision

Making

The second factor encompassed 9 items with factor loadings ranged from .54-.80. Use of advanced technology in LST for terminal stages of illness is complicated for general people to understand as professional health care personnel.

This is reflected in item P29 “physicians/nurses clearly understand advanced medical technology more than others,” item P31 “less understand treatment plan than physicians/nurses,” and item P28 “final stage of illness needs only physicians/nurses’ help” (Table 21). Moreover, Thai people believe in high educated people (those who have educational degrees) (Komin, 1991; Soupap, 1975). Thus, subjects in this study trusted and allowed physicians/nurses to make decision for their end-of-life decision as reflected in item P27 “no knowledge of disease to make decision.” Because of belief in physicians/nurses’ knowledge, participants delegated end-of-life decision to professional health care personnel as reflected in item P32 “physicians/nurses know how to decrease suffering.” These findings were supported by a study of Brown and Singer (2001). They conducted a qualitative survey with 40 Chinese seniors (65 year of age or older) and found that the reasons these participants allowed physicians to make decision at the end of life stage were their beliefs in physicians’ competence, professional knowledge and experience. Whereas the study by Nordgren and Fridlund (2001) about patients' perceptions of self-determination as expressed in the context of care found that the participant expressed a feeling of powerlessness because of not being part of decision-making, as well as lacking knowledge and information about treatment strategies. In addition, family of the patients in this study also believed in physicians/nurses’ competence as reflected in item P22 “family believes in physicians/nurses competence,” item P23 “family fully agrees when physicians/nurses’ make decision” (Table 21).

However, some items reflected that the subjects confided in physicians/nurses as found in Factor 1 because they were unconfident in themselves

and their families. Thus, they allowed physicians/nurses to make decision as reflected in item P16 “physicians/nurses make decision based on patients centered” (Table 21).

Factor 3: Avoiding Conflict with Family

The third factor encompassed 8 items with factor loadings ranging from .54-.86. Making decision at the end-of-life stage is very difficult and challenging for patients (Manasurakarn, et al., 2008; Steinhauer, et al., 2000). The decision making at the end-of-life stage varies from one to another individual according to their beliefs and values in life. If the patients make their own end-of-life decision, it may counter their family’s will (Goold, Williams, & Arnold, 2000) as reflected in item P20 “own decision may not be accepted from family” (Table 22). The sense of collectivism in Thai family is about the commitment to family (Komin, 1991). Important decisions must be agreed on among family members as reflect in item P21 “usually, family must approve for any decision.” Moreover, some subjects were not confident to make decision as reflected in item P18 “own decision may be different from family,” and item P17 “don’t trust self/family’s decision” (Table 22). Thus, to decrease family’s anxiety and conflict, subjects dedicated end-of-life decision to physicians/nurses as reflected in item P19 “own decision may be wrong, so physicians/nurses should make the decision,” item P25 “reduce the family’s anxiety, and item P26 “reduce the conflicts with family from disagreement” (Table 22). Thai people are concerned about the relationship among others. They avoid making others lose faces because they think it might affect in the long-term relationship (Komin, 1991). Furthermore, being considerate on other people’s feeling known as “kreangjai”

in Thai context is reflected in this factor. Healthcare providers such as physicians and nurses are seen as authority in Thai hierarchical and patriarchal society (Komin, 1991). Delegating decision to healthcare providers help the patient avoid conflict with his/her family. An example in item P24 “family doesn’t want to bother physicians/nurses” (Table 22). These findings were supported by Fleming’s study (2001) describing that end-of-life decision in Asian cultures is based on paternalistic model of trust and has been less focused on individual autonomy.

Subscale 4: Allowing Family to Make Decision (EoLDS-Fam)

Varimax, Quartimax, and Equamax were again performed to examine factor structure of Subscale 4, based on the pre-set criteria. The scree plot (Figure 6) showed the breaks at factors 3, 4, and 5. Therefore, factors 3, 4, and 5 were rotated. Factor 4 equamax, which combines characteristics of quartimax and varimax, balancing the advantages and disadvantages, was judged to be the best solution since it was the most parsimonious and theoretically interpretable with acceptable of variance and high factor loadings.

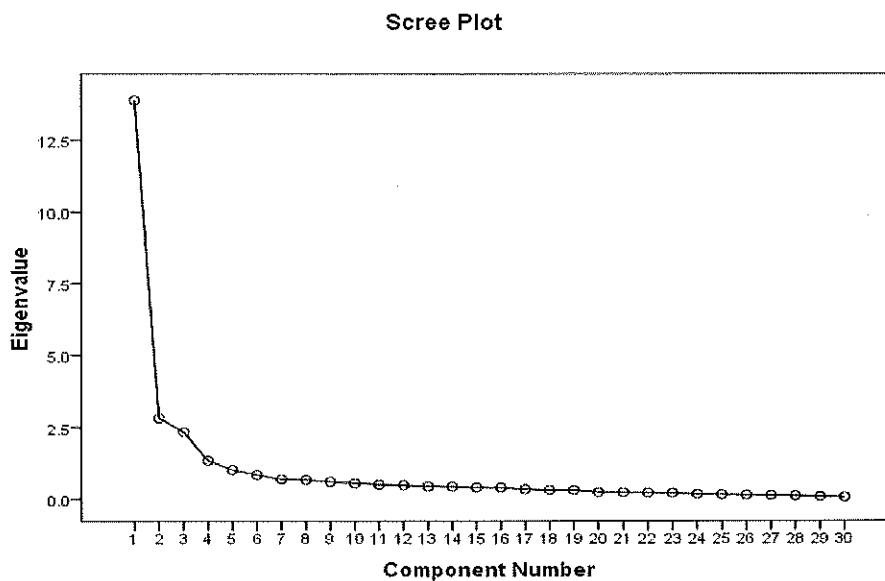


Figure 6: Scree plot for factor analysis of subscale 4: EoLDS-Fam

Note. Break in side of eigenvalues occurs at factor 3

The factor analysis of subscale 4 (EoLDS-Fam) revealed three factors of a total number of 30 items and displayed a total variance of 63.41%. Details of each of the three factors are discussed as follows:

Factor 1 “*Believe in Family’s Loving and Caring*” consisted of 10 items with factor loadings ranged from .50-.85, and accounted for 24.39% of variance with an eigenvalue of 13.86 (Table 24).

Table 24

Factor 1: Believe in Family's Loving and Caring of Subscale 4: EoLDS-Fam (n₄ = 250)

Item no	Item statements	Factor loadings
Fam19	Confidence in family's love	.85
Fam21	Trust the decision family makes because family is important	.83
Fam20	Confidence in family's wish	.83
Fam23	Believe family must make the best decision	.82
Fam18	Family knows the best for need	.79
Fam16	Love and related with family	.74
Fam17	Family has the rights to make decision	.73
Fam5	Trust family to make decision	.63
Fam13	Give priority to make decision to family because family take care	.63
Fam1	Family members are true friend to make good wish	.50

Eigenvalue 13.86

% of variance 24.39

Factor 2 "*Family is the Supporter and Avoid Conflict with Family*" consisted of 13 items with factor loadings ranged from .51-.81, and accounted for 23.96% of variance with an eigenvalue of 2.81 (Table 25).

Table 25

Factor 2: Family is the Supporter and Avoid Conflict with Family of Subscale 4:

EoLDS-Fam (n₄=250)

Item no	Item statements	Factor loadings
Fam26	Don't want to bother family because family pays for expenses	.81
Fam25	No income, no dare to make decision	.79
Fam24	Family pays expenses, the decision making must depend on family	.75
Fam14	Family pays expenses, family has right to make decision	.72
Fam11	Don't make conflict with family	.68
Fam22	Own decision may make family suffer	.63
Fam29	The impact from illness may make mistake in decision making	.63
Fam28	No way out, depend on family's decision	.61
Fam12	Give family with good feeling	.59
Fam9	Be afraid that the decision will differ from family's decision	.58
Fam30	The illness is too severe to own decision	.53
Fam15	Want family to know that family is important	.53
Fam10	Normally, family made decision important issues	.51
Eigenvalue 2.81		

% of Variance 23.96

Factor 3 "*Giving a Chance to Family for Repaying the Gratitude*" consisted of 7 items with factor loadings ranged from .52-.75, and accounted for 15.05% of variance with an eigenvalue of 2.33 (Table 26).

Table 26

Factor3: Giving a Chance to Family for Repaying the Gratitude of Subscale 4: EoLDS-Fam (n₄=250)

Item no	Item statements	Factor loadings
Fam4	Give a chance for family to repay the kindness	.75
Fam3	Give a chance for family to do good thing	.73
Fam8	Thai society gives priority to the family	.70
Fam6	Family members' role to manage when getting illness	.57
Fam7	When getting sick, family is the helper	.57
Fam27	Give a chance for family to participate in caring	.56
Fam2	Whoever make decision is not different because of predetermined life	.52

Eigenvalue 2.33

% of variance 15.05

Cronbach's alpha coefficient was performed to examine internal consistency of all 30 items of Subscale 4: EoLDS-Fam. The coefficient alpha of the total subscale was .95 and those of the three factors ranged from .84-.93 (Table 27).

Table 27

Cronbach's Alpha Coefficients of Total and Three Factors of Subscale 4: EoLDS-Fam (N=250)

Factors	Number of items	Alphas
Factor 1 Believe in Family's Loving and Caring	10	.93
Factor 2 Family is the supporter and Avoid Conflict with Family	13	.93
Factor 3 Giving a Chance to Family for Repaying the Gratitude	7	.84
Total	30	.95

Discussion of Subscale 4: Allowing Family to Make Decision (EoLDS-Fam)

The subscale 4: Allowing Family to Make Decision Subscale (EoLDS-Fam) is for those who delegated their end-of-life decision to family. It contained 30 items with a total variance of 63.41%. According to Hair, Black, Babin, and Anderson (2010), each scale accounting for at least 50% of variance can represent the concept. In addition, the total alpha of the subscale 4 was .95 (Table 27) and those of the three factors ranging from .84-.93 are acceptable as a high quality subscale as DeVellis (2012) stated that the alpha between .80 and .90 are very good scale. Details of each factor of the subscale 3: EoLDS-MD/RN are discussed as follows:

Factor 1: Believe in Family's Loving and Caring

The first factor encompassed 10 items with factor loadings ranging from .50-.85 and accounted for 24.39% of variances with an eigenvalue of 13.86. Subjects in this study described that they felt confident that their family love them as reflected in item Fam19 "confidence in family's love," and item Fam20 "confidence in family's wish." This confidence in love from the family was found in the study of Manasurakarn (2007) which found that Thai Buddhist patients with chronic illness had their family make the end-of-life decision based on the belief that family love and has good wish for them.

Moreover, with a confidence of love and best wishes from the family the subjects in this study delegated the end-of-life decision to family as reflected in item Fam23 "believe family must make the best decision," and item Fam18 "family

knows the best for need.” The love and good wishes from the family was found to influence the decision to delegate the end-of-life decision in a study by Manasurakarn (2007) which found that participants allowed family to make decision based on the same reasons as found in this current study: the family knows what the patients’ need are, and the family loves and has a good wish for patients.

Factor 2: Family is the Supporter and Avoid Conflict with Family

The second factor encompassed 13 items with factor loadings ranging from .51-.81, and accounted for 23.96% of variance with an eigenvalue of 2.81. Modern LST and other medical technology are expensive, making a high cost of health care. This expense may cause a financial burden and drain on the patients’ family and friend resource (Taylor, et al., 1998). Most of subjects had no income during their sickness, and all medical expenses depended on family so they were cautious of making decision on end-of-life stage. This caution was reflected in item Fam25 “no income, no dare to make decision,” item Fam24 “family pays expenses, the decision making must depend on family,” and item Fam14 “family pays expenses, family has right to make decision.” These reasons for delegating the end-of-life decision to the family were in accordance with those found in Nijnikama’s (2003) revealing that Thai Muslim patients allowed family to make end-of-life-decision because they had no income and unemployed. In addition, in Thai society, the term “kaeng jai” meaning worries about making others in difficulty is an important value (Komin, 1991). Thus, worries about the payment for high cost of LST were reflected in item Fam 26 “don’t want to bother family because family pays for expenses”

Moreover, the participants also expressed that they were concerned that the end-of-life decision that they made might cause a high burden or problems to the family when daughters, sons and descendents were taking care of them as reflected in item Fam11 “don’t make conflict with family,” item Fam22 “own decision may make family suffer” In addition, severe and chronic condition was another reason that influenced end-of-life decision as reflected in item Fam30 “the illness is too severe to own decision,” and item Fam29 “the impact from illness may make mistake in decision making” (Table 25). These worries were also found in a study of Neunoni (2005) which found that participants allowed family to make decision when the patients were in a severe chronic illness condition.

Factor 3: Giving a Chance to Family for Repaying the Gratitude

The third factor encompassed 7 items with factor loadings ranged from .52-.75 and accounted for 15.05% of variance with an eigenvalue of 2.33.

In the Thai society people are taught to be grateful to a person who renders goodness (Katanyu) to them such as parents and teachers (Komin, 1991). The items in this factor reflected this concept of being grateful. The subjects wanted their family, descendants, to be a quality person in taking care of their seniors at the end-of-life stage. It is considered a good deed of the descendents for this arrangement and therefore wanted them to take a responsibility to make the end-of-life decision for them. Thus, subjects in this study delegated end-of-life decision to family as reflected in item Fam3 “give a chance for family to do good thing,” item Fam4 “give a chance for family to repay the kindness,” and item Fam27 “give a chance for family to

participate in caring” (Table 26). These reasons for delegating the end-of-life decision to the family members who were taking care of them were in corresponding to the findings in a study of Neunoi (2005) which found that patients and surrogates decided to prolong life because they needed to repay the kindness for parents. Supported by the study of Kwak and Haley (2005) which reviewed the research literature on end-of-life decision making and found that Asian people preferred family center making decision more than other ethnic group.

Moreover, the finding indicated that the subjects in this study were elderly (60-70 years old) 29% and taking a role as family member. Thus, their daily livings were under family’s care as reflected in item Fam6 “family members’ role to manage when getting illness,” and item Fam7 “when getting sick, family is the helper” (Table 26). Similarly, a study of Manasurakarn et al. (2008) found that participants delegated end-of-life decision to family based on condition and roles of the patients in the family.

Summary

The four subscale EoLDS was found to be valid and reliable. The final version of four subscale of the End-of-Life Decision Scale for Thai Buddhist adults with chronic illness consisted of 39 items for subscale 1: EoLDS-Cont, 37 items for subscale 2: EoLDS-Forgo, 32 items for Subscale 3: EoLDS-MD/RN, and 30 items for subscale 4: EoLDS-Fam. Finally, the four subscale EoLDS was established to be a newly developed instrument that can be used in chronic illness care for Thai Buddhist adults in the Thai context.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

This chapter presents a conclusion of the research results and recommendations emerging from the study for nursing practice and administration and those for further research and theory development.

Conclusions of the Results

The End-of-Life Decision Scale (EoLDS) consists of four subscales: subscale 1: EoLDS-Cont, subscale2: EoLDS-Forgo, subscale3: EoLDS-MD/RN, and subscale4: EoLDS-Fam.

1. Subscale 1: EoLDS-Cont consists of four factors with a total number of 39 items, a total variance of 63.98 % and factor loadings ranging from .46 to .82. The total scale had Cronbach's alpha of .97.

Factor 1: *Trust in Modern Treatment and Advanced Medical Technology* (9 items) with factor loadings ranging from .46 to .82 and accounted for 17.76% of variance with an eigenvalue of 19.38. The factor had Cronbach's alpha of .95.

Factor 2: *Living for Family and Love Ones* (13 items) with factor loadings ranging from 0.56 to 0.79 and accounted for 16.95% of variance with an eigenvalue of 3.57. The factor had Cronbach's alpha of .95.

Factor 3: *Need More Time to Do Good Karma for Better Life after Death* (11 items) with factor loadings ranging from 0.56 to 0.79 and accounted for 16.78% of variance with an eigenvalue of 2.03. The factor had Cronbach's alpha of .93.

Factor 4: *Personal Beliefs Related to Death* (6 items) with factor loadings ranging from 0.53 to 0.73 and accounted for 12.49% of variance with an eigenvalue of 1.25. The factor had Cronbach's alpha of .88.

2. Subscale 2: EoLDS-Forgo consisted of four factors with a total number of 37 items, a total variance of 64.71 and factor loadings ranging from 0.43-0.87. The total scale had Cronbach's alpha of .96.

Factor 1: *Death is the Truth of Life to be Accepted* (13 items) with factor loadings ranging from 0.44 to 0.72 and accounted for 18.53% of variance with an eigenvalue of 17.14. The Cronbach's alpha was .93.

Factor 2: *Prolonging Death is Prolonging Suffering* (6 items) with factor loading ranging from 0.69 to 0.87 and accounted for 16.25% of variance with an eigenvalue of 3.33. The Cronbach's alpha was .93.

Factor 3: *Fear to Burden Family and Separate from Family at the End-of-Life* (10 items) with factor loadings ranging from 0.46 to 0.83 and accounted for 15.99% of variance with an eigenvalue of 1.78. The Cronbach's alpha was .92.

Factor 4: *Avoiding Death and Prolonging Life are not Peaceful and not Ending Karma* (8 items) with factor loadings ranging from 0.43 to 0.78 and accounted for 13.93% of variance with an eigenvalue of 1.68. The Cronbach's alpha was .84.

3. Subscale 3: EoLDS-MD/RN consists of three factors with a total number of 32 items, a total variance of 67.45%, factor loadings ranging from 0.53 to 0.86. The total scale had Cronbach's alpha of .96.

Factor 1: *Physicians/Nurses are Moral Competent* (15 items) with factor loadings ranging from 0.53 to 0.82 and accounted for 27.43% of variance with an eigenvalue of 17.29. The Cronbach's alpha was .96.

Factor 2: *Patients and Families Have Low Confidence in Decision Making* (9 items) with factor loadings ranging from 0.54 to 0.80, and accounted for 22.11% of variance with an eigenvalue of 2.73. The Cronbach's alpha was .94.

Factor 3: *Avoiding Conflict with Family* (8 items) with factor loadings ranging from 0.54 to 0.86 and accounted for 17.91% of variance with an eigenvalue of 1.56. The Cronbach's alpha was .89.

4. Subscale 4: EoLDS-Fam consisted of three factors with a total number of 30 items, a total variance of 63.41% and factor loadings ranging from 0.50 to 0.85. The total scale had Cronbach's alpha of .95.

Factor 1: *Believe in Family's Loving and Caring* (10 items) with factor loadings ranging from 0.50 to 0.85, and accounted for 24.39% of variance with an eigenvalue of 13.86. The Cronbach's alpha was .93.

Factor 2: *Family is the Supporter and Avoid Conflict with Family* (13 items) with factor loadings ranging from 0.51 to 0.81 and accounted for 23.96% of variance with an eigenvalue of 2.81. The Cronbach's alpha was .93.

Factor 3: *Giving a Chance to Family for Repaying the Gratitude* (7 items) with factor loadings ranging from 0.52 to 0.75 and accounted for 15.05% of variance with an eigenvalue of 2.33. The Cronbach's alpha was .84.

Implications and Recommendations

The EoLDS were developed to measure the end-of-life decision of Thai Buddhist adults with chronic illnesses. These measurements concentrated on the individual autonomy in making decision. The four subscales of EoLDS emerged from this study have strong psychometric properties that will be useful to assess the end-of-life decision for Thai Buddhist adults with chronic illnesses. These four Subscales of EoLDS are hoped to have a potential value for nursing professionals and nursing education, for further research and theory development of the area of end-of-life decision making.

However, other methods to examine the psychometric properties of the 4-Subscale-EoLDS such as test-retest reliability and known group validity are recommended for further development of the tool.

1. Nursing practice

The four subscales of EoLDS in this study can be used to effectively determine the of end-of-life decision of patients and those with different chronic illnesses, aging. For example, nurses working in taking care of patients with chronic illness, do not know the patient's wishes regarding life sustaining treatment, therefore they can use EoLDS to assess the end-of-life decision and reasons of patient before becoming to terminal illness to guide for care the patients at the end-of life. The results of which will provide healthcare providers in enhancing patients' autonomy in making end-of-life decision.

2. Nursing education

Thailand is a Buddhist society, but the End-of-life decision scale for Thai Buddhist adults with chronic illnesses had not been developed. The EoLDS emerged from this current study is hoped to be a valuable decision making scale for nursing education. It can be used to demonstrate to the nursing students how end-of-life decision can be made in the way that reflects the patient autonomy in end of life care setting. This study gives a good example on how to promote the patients' autonomy in other areas in nursing.

3. Nursing administration

At present, end-of-life decision is an important issue in healthcare areas including nursing professionals. Nursing administrator should educate staff nurse about using this tool when caring end-of-life patients and encourage staff nurse to use this tool to assess end-of-life patients 'need. In addition, nursing administrator can use the results of this study to enhance nurses' ability to advocate for patients at the end-of-life.

4. Research

The EoLDS can be used as a prototype decision making scale for researchers who are interested in researching or applying the components of end-of-life decision in similar or different settings and populations. Since end-of-life

decision is complex, difficult, painful, and psychologically hard to make for all patients, families, EoLDS can help this difficult communication easier. The EoLDS is an effective scale for beginning dialogue to assess end-of-life decision. Each subscale can be adapted for specific contexts and populations such as healthy people, acute illness care.

5. Theory development

End-of-life decision is a concept that differs across people, contexts, and times. Even though, several issues related to end-of-life decision scale have been discussed, the development of end-of-life decision scale may be feasible particularly for Thai Buddhist adults with chronic illness. The results of this study demonstrate that there are reliable and valid components of the EoLDS. If other researchers confirm this result in diverse cultural backgrounds or by using other methods to test this result in the same group of participants known as confirmatory factor analysis (CFA), then a theory of end-of-life decision can be developed. In brief, the EoLDS from this study can generate a body of knowledge of end-of-life decision concept at the individual level.

Limitation

In conducting a study on end-of-life decisions which is a sensitive issue, researcher had to take all effort to elicit accurate responses from patients with chronic illness. Data collection from patients with chronic illness caused fatigue and

stress to the patients. These were both physical and emotionally exhausts. It was also difficult to include the subject for the second time. Many of the prospect subjects did not want to take part in the interview. For example, from five subjects, just only one agreed to participate in this study. The limitation is number of subjects. Consequently, a test-retest procedure could not be used in this study.

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APPENDICES

APPENDIX A
INTERVIEW GUIDELINE

8. Family Role

- 1 Chief role 2 Family member

9. Health problems

- 1 Type of illness
- 2 Complication of illness
- 3 Length of illness
- 4 Type of treatment

11. Activities in everyday life

- Help yourself Dependence

12. Address: Province District

13. History of illness when admitted in hospital

- 1 Never 2 Ever (Please specify time and cause)
- 3 Specify of cause

14. Experience from of using respirator, cardiac massage, hemodialysis, ICU care

- 1 Never 2 Ever (Please specify type of experience)
- 3 Seen other used (Please specify type of material)

15. Buddhist activity in everyday life (Choose more than 1 item)

Buddhist activity	Always	Sometime	Seldom	Non practice
1. Offer food for monk				
2. Go to the temple				
3. Pray				
4. Give the offering dedicated to the monks Offering dedicated to Buddhist monks				

Buddhist activity	Always	Sometime	Seldom	Non practice
5. Participation in Buddhist activity				
6. Meditation Practice				
7. Other				

16. Buddhist Principle that always use in daily life

- 1 Four Noble Truth
- 2 The Three characteristic
- 3 Middle way
- 4 The law of karma
- 5 Five precepts
- 6 Four Sublime States of Mind
- 7 Sappurisa-dhamma
- 8 Qualities of a good man
- 9 Other

17. From No.16, what the most Buddhist Principle that you chose to practice in daily life?

Part 2: Interview guideline end-of-life decision

1. When talking about the death, what is your meaning?
2. Situation: Mrs. A had a chronic illness and got terminal illness that no chance of recovery at the end of life. She got suffering from pain and always received medicine to control pain. Sometime, she had dyspnea and condition become worse. She cannot help herself, her daily activity depended on other. Furthermore, she got renal failure and always admitted in hospital. The type of treatment had hemodialysis, giving food and fluid by tube feeding. Then, add more treatment such as intravenous fluid, blood transfusion, and antibiotics because she got septicemia. Finally, the doctor diagnosed Mrs. A as terminal illness that cannot be recovery. If you were Mrs. A, how would you make decision when you face this situation?

- 1. Continuing life substring treatment to prolong life
- 2. Forgoing life substring treatment
- 3. Allowing physician/nurses to make decision
- 4. Allowing family to make decision
- 5. Other (Please specify).....

1. Questions for you who decided to receive treatment to prolong life.

- 1.1 Why do you decided to prolong life?
- 1.2 The reasons supporting you decision are.....
.....

2. Questions for you who decide to refusing treatment to prolong life.

- 2.1 Why do you decided to refuse treatment to prolong life?
- 2.2 The reasons supporting you decision are
.....

3. Questions for patients who allow physicians/nurses to make decision to prolong life.

- 3.1 Why do you allow physicians/nurses to make decision?
- 3.2 The reason supporting you decision are
.....

4. Questions for patients who allow family to make decision

- 4.1 Why do you allow physicians/nurses to make decision
- 4.2 The reason supporting you decision are.....
.....

APPENDIX B
PROTECTION OF HUMAN SUBJECTS' RIGHTS

PROTECTION OF HUMAN SUBJECTS' RIGHTS

QUALITATIVE STUDY

Dear Participant,

My name is Navarat Rukchart. I am a doctoral student from the faculty of nursing, at Prince of Songkla University, Songkla province. I am interested in studying the development of the End-of-Life Decision Scale (EoLDS) for Thai Buddhist Adults with Chronic Illness. The purpose of the interview is to explore patients' decision at the end-of-life and reasons for decision. The result of this study will be used to develop the End-of-Life Decision Scale (EoLDS) for Thai Buddhist Adults with Chronic Illness in the future.

I would like to invite you to participate in this study. If you agree to participate in this study, you can give your oral consent or sign in this form. The interview will share about your experiences in providing decision at the end-of-life and reasons for decision for approximately thirty to sixty minutes. During interview, the researcher will take note/tape recorded in order to complete the data. Your answer and identity will be kept in the strictest of confidence, and will never be revealed.

There is no risk from subjects in this study. Your participation is voluntary; therefore you may withdraw from this study any time. There will be no penalty or any effect if you decide to refuse to participate. A form is attached below for you to sign your agreement. Your signature on this form will indicate that you consent to participate in this study.

.....
 (Mrs. Navarat Rukchart)
 Doctoral student
 Prince of Songkla University
 Date

This section for subject

I received all of the information about the study from both the above information and the researcher. I understand and agree with the researcher to participate in this study.

Signature of the participant.....
 Date

PROTECTION OF HUMAN SUBJECTS' RIGHTS

FIELD TEST

Dear Subject,

My name is Navarat Rukchart. I am a doctoral student from the faculty of nursing, at Prince of Songkla University, Songkla province. I am interested in studying the development of the End-of-Life Decision Scale (EoLDS) for Thai Buddhist Adults with Chronic Illness. The purpose of the interview is to explore patients' decision at the end-of-life and reasons for decision. The result of this study will be used to develop the End-of-Life Decision Scale (EoLDS) for Thai Buddhist Adults with Chronic Illness in the future.

I would like to invite to participate in this study. If you agree to participate in this study, you have the option of answering the questionnaire by yourself or to be interviewed about your experiences in providing decision at the end-of-life and reasons for decision for approximately thirty to sixty minutes. Your answer and identity will be kept in the strictest of confidence, and will never be revealed.

There is no risk from subjects in this study. Your participation is voluntary; therefore you may withdraw from this study any time. There will be no penalty or any effect if you decide to refuse to participate. A form is attached below for you to sign your agreement. Your signature on this form will indicate that you consent to participate in this study.

.....
 (Mrs. Navarat Rukchart)
 Doctoral student
 Prince of Songkla University
 Date

APPENDIX C
GENERATION OF AN ITEM POOL

Generation of an item pool

Type of EoLD	Reason
Continuing LST	1. Because of life is suffering, person should prolong life in order to have clear understanding of suffering
	2. Refusing treatment when sickness is sin
	3. Living for redress karma
	4. Having more time to do good
	5. Living for increasing more good karma
	6. Leaving from love one is suffering
	7. Having more time to maintain the religion
	8. Human does not own the body, it can't be neglected
	9. Having a chance to repay the kindness of parents/families
	10. Having time to accumulate virtue for happiness after death
	11. Having more time to wipe out past wrong doings
	12. Living to repay the kindness of the body
	13. Being virtuous will cause success of treatment
	14. Miracle of treatment is possible
	15. Life needs to flight, even in terminal stage
	16. Fate controls human's life, human stays alive if it's not the time to die
	17. Illness is the test of life, person should not loss hope on treatment
Forgoing LST	1. Death is leaving from compounded things
	2. Death is the truth that everyone must accept
	3. Death is the way to overcome suffering
	4. Death is inevitable
	5. Death is already set, we must go when time arrives
	6. When death arrives, we redress karma
	7. Death is karma, no one can refuse karma
	8. Death cannot be controlled by human
	9. Death can release karma
	10. Buddhists believe life is unpredictable, person must always be ready to die
	11. Life is impermanence moment by moment, must be conscious and ready to die
	12. Life is impermanence, birth, death
	13. Prolong life is wrong
	14. Prolong life is to refuse the fact of life
	15. When death arrives, no need to fight to prolong life
	16. Buddhists don't attach for compounded things , when death arrives we must except with peaceful mind
	17. Prolonging life, mind is not peaceful before death
	18. Need to die naturally without equipment

Generation of an item pool (continue)

	Reason
Type of EoLD Forgoing LST	19. Need to live life naturally before death
	20. Don't want to against nature
	21. Don't want to burden family/society if cannot make contributions to benefit the family/society
	22. Thai have right to choose whether to prolong life
	23. Long life which depends on others is useless
	24. Need peaceful death among family/love ones
	25. Don't want family member exert for patient because they have other persons need to take care
	26. Don't want to live with suffering and make family get stress
Allowing Physicians/Nurses to make decision	27. Life support equipment separates from family
	1. Physiciane/nurses are kind
	2. Physiciane/nurses have compassion
	3. Physicians/nurses are willing to help patients
	4. Physicians/nurses are true friend in the time of sickness
	5. Physicians/nurses have more knowledge
	6. Physicians/nurses have duty to help patients
	7. Physicians/nurses know how to treat patient the best way
	8. Confident in Physicians/nurses' capability
	9. Believe in Physicians/nurses' experiences
	10. Be confident in physicians/nurses to make decision based on patients' benefit
	11. Put one's hopes into physicians/nurses' hand
	12. Physicians/nurses are good person
	13. Physicians/nurses are respectable
	14. Physicians/nurses have good wishes to patients
	15. After getting illness, must depend on physicians/nurses
	16. Physicians/nurses make decision based on patients' centered
	17. Don't trust self/family's decision
	18. Own decision may be different from family
	19. Own decision may be made mistake, then physicians/nurses will make the decision
	20. Own decision may not be accepted from family
	21. Usually, family must approve for any decision
	22. Family believes in physicians/nurses capability
	23. Family fully agree, when physicians/nurses make decision
	24. Family doesn't want to bother physicians/nurses
25. Reduce the family's anxiety	

Generation of an item pool (continue)

Type of EoLD	Reason
Allowing Physicians/Nurses to make decision	26. Reduce the conflict with family from disagreement
Allowing Family to Make Decision	1. Family members are true friend to make good wish
	2. Whoever make decision is not different because of predetermined life
	3. Give a chance for family to do good thing
	4. Give a chance for family to repay the kindness
	5. Trust family to make decision
	6. Family members' role need to manage when getting illness
	7. When get sickness, family is helper
	8. Thai society gives priority to the family

APPENDIX D
CONTENT VALIDITY FORM

CONTENT VALIDITY FORM

Instruction: Please determine all items and check (✓) in the column related to your opinion and give suggestions or comment for improvement in the other comments column. The criterion of the opinion was described as follows:

Relevancy 1=not relevant 2=somewhat relevant 3=quite relevant 4=very relevant

Clarity yes=clear no=unclear

Conciseness yes=concise no=redundant

Item	Relevancy				Clarity		Conciseness		Other comments
	1	2	3	4	yes	no	yes	no	
1. Because of life is suffering, person should prolong life in order to have clear understanding of suffering									
2. Refusing treatment when sickness is sin									
3. Living for redress karma									
4. Having more time to do good									
5. Living for increasing more good karma									
.									
.									
.									

APPENDIX E
LIST OF EXPERTS

LIST OF EXPERTS

1. Professor Dr. Somparn Promta
Department of Philosophy, Faculty of Arts, Chulalongkorn University
2. Assoc. Prof. Dr. Temsak Phungrassami
Department of Radiation, Faculty of Medicine, Prince of Songkla University
3. Asst. Prof. Dr. Tasanee Nasae
Department of Administration Nursing, Faculty of Nursing
4. Asst. Prof. Dr. Wongchang Petpichetchian
Department of Surgical Nursing, Faculty of Nursing
5. Asst. Prof. Dr. Kittikorn Nilmanat,
Department of Medical Nursing, Faculty of Nursing, Prince of Songkla
University
6. Asst. Prof. Dr. Yaowarat Matchim,
Department of Medical Nursing, Faculty of Nursing, Prince of Songkla
University
7. Asst. Prof. Dr. Jaruwan Manasurakarn
Department of Medical Nursing, Faculty of Nursing, Prince of Songkla
University

APPENDIX F
RESEARCH INSTRUMENT

Research Instrument

No

EoLDS for Thai Buddhist adult with Chronic

Part 1 Demographic Data

Explanation Please remark \surd in front of item that you chose or fill in the blank on your opinion

1. Age Years

2. Sex

1 Male 2 Female

3. Status

1 Single 2 Marriage 3 Divorce

4. Education Level

1 No education 2 Primary education 3 Secondary education

4 Associate degree 5 Bachelor's degree 6 Master degree

7 Higher than master degree

5. Occupation

1 Student 2 Merchant 3 Employee

4 Agriculturist 5 government officer/State-enterprise employee

6 Private businesses 7 Private Practice 8 Other.....

6. Income/mount

6.1 If employed

1 <5,000 Baht 2 5,001-10,000 Baht

3 10,001-15,000 Baht 4 15,001-20,000 Baht

5 20,001-25,000 Baht 6 25,001-30,000 Baht

7 >30,000Baht

6.2 If unemployed, you receive financial support from whom (can chose more than one item)

1 Father 2 Mother 3 Husband

4 Wife 5 Children 6 Relative

7 Other

6.3 How much money you receive from funding support?

- 1 <5,000Baht 2 5,001-10,000 Baht
 3 10,001-15,000 Baht 4 15,001-20,000 Baht
 5 20,001-25,000 Baht 6 25,001-30,000 Baht

7. Family Role

- 1 Chief role 2 Family member 3 Alone

8. How many family member person

9. Health problems

- 1 No 2 Have (answer item no 9.1, 9.2, and 9.3)

9.1 Type of illness (can chose > 1 item)

- 1 Hypertension 2 Diabetes 3 Heart disease
 4 Renal failures 5 Cancer 6 Other

9.2 Length of illness (can chose > one item)

- 1 Hypertension Length of illnessYear
 2 Diabetes Length of illnessYear
 3 Heart disease Length of illness Year
 4 Renal failures Length of illness Year
 5 Cancer Length of illnessYear
 6 Other Length of illnessYear

9.3 Type of treatment (can chose > one item)

- 1 Oral medication 2 Injection 3 Physical therapy
 4 Hemodialysis 5 Other

10. How the level of the illness affects to your everyday life?

- 1 No 2 Little 3 Moderate 4 Severe

11. How the illness made you depended on other?

- 1 Nondependent 2 Partial dependent
 3 Moderate dependent 4 Too much dependent

12. To whom you are depended on (can chose > one item)

- 1 Father 2 Mother 3 Husband 4 Wife
 5 Children 6 Descendent 7 Neighbor 8 Close friends
 9 Caregiver

13. Direct/indirect experience from of using respirator

- 1 No 2 Have 3 Have seen from other
 4 Have heard from other 5 Have gotten from multimedia

14. Direct/indirect experience of cardiac massage

- 1 No 2 Have 3 Have seen from other
 4 Have heard from other 5 Have gotten from multimedia

15. Direct/indirect experience of hemodialysis

- 1 No 2 Have 3 Have seen from other
 4 Have heard from other 5 Have gotten from multimedia

16. Direct/indirect experience of ICU care

- 1 No 2 Have 3 Have seen from other
 4 Have heard from other 5 Have gotten from multimedia

17. Buddhist activity in everyday life

Buddhist activity	Always	Sometime	Seldom	Non practice
1. Give food for monk				
2. Pray				
3. Give the offering dedicated to the monks Offering dedicated to Buddhist monks				
4. Practice meditation				
5. Participation in Buddhist activity				
6. Other				

18. If always practice

- 1 before illness 2 after illness

19. Buddhist Principle that always use in everyday life

Dharma Principle	Frequency				
	Mostly	Often	Sometime	Seldom	Never
1. Four Noble Truths					
2. The Three characteristic					
3. Middle way					
4. The law of karma					
5. Five precepts					
6. Four Sublime States of Mind (Loving-kindness, Compassion, Sympathetic Joy, Equanimity)					
7. Sappurisa-dhamma: qualities of a good man; virtues of a gentleman					
8. Manual of peace 38 steps					
9. Other					

Part 2 End-of-Life Decision for Thai Buddhist adults with chronic illness

Explanation: Please consider situation in this part and make decision if you were the patient in this situation and chose the reason supporting you decision making

Situation

When the patient same as you got terminal illness, physician diagnosed as terminal stage and poor prognosis to cure with high medical technology. Prolonging death is prolonging death and suffering. If you were this patients, how do you make decision.

Please mark ✓ only one item in front of type of your EoLD that you chose

- (1) Continuing Life Sustaining Treatment (Answer only Subscae1)
- (2) Forgoing Life Sustaining Treatment (Answer only Subscale 2)
- (3) Allowing Physician/Nurse to Make Decision (Answer only Subscale 3)
- (4) Allowing Family to Make Decision (Answer only Subscale 4)

The statements of each Subscale are the reason supporting each type of EoLD that you have been chosen.

Please consider the statements that are the reason supporting your decision and mark✓ in the box of your answer

0 = the statement is not the reason for decision

1 = hardly agree on the statement as the reason for the decision

2 = slightly agree on the statement as the reason for the decision

3 = moderately agree on the statement as the reason for the decision

4 = considerably agree on the statement as the reason for the decision

5 = extremely agree on the statement as the reason for the decision

Subscale 1 For patients who chose continuing life sustaining treatment

Reasons related to make decision	Opinion Level					
	0	1	2	3	4	5
1. Because of life is suffering, person should prolong life in order to have clear understanding of suffering						
2. Refusing treatment when sickness is sin						
3. Living for redress karma						
4. Having more time to do good						
5. Living for increasing more good karma						
6. Leaving from love one is suffering						
7. Having more time to maintain the religion						
8. Human does not own the body, it can't be neglected						
9. Having a chance to repay the kindness of parents/families						
10. Having time to accumulate virtue for happiness after death						
11. Having more time to wipe out past wrong doings						
12. Living to repay the kindness of the body						
13. Being virtuous will cause success of treatment						
14. Miracle of treatment is possible						
15. Life needs to flight, even in terminal stage						
16. Fate controls human's life, human stays alive if it's not the time to die						
17. Illness is the test of life, person should not loss hope on treatment						
18. Sanctities can prolong human's life						
19. It is common for Thai people to prolong life with modern medical equipment						
20. Being alive is will power of family/love ones						
21. Don't want family/love ones lose care takers						

Reasons related to make decision	Opinion Level					
	0	1	2	3	4	5
22. Don't want family/love ones suffer from death						
23. Hoping to see children/love ones success before death						
24. Being alive makes a complete family						
25. Need to complete some tasks						
26. Need time for family/love ones to prepare for separation						
27. Worries about family						
28. Living for supporting family's emotion						
29. Feeling guilty to leave family without full treatment						
30. Giving a chance for family to get involved in treatment						
31. Giving a chance for family/love ones to take care in order to wipe out feeling guilty						
32. Treatment can relief pain from illness						
33. Treatment can reduce suffering from illness						
34. Have seen people with same illness survived by treatment						
35. Believe that illness could be cured						
36. Confidence in modern treatment						
37. Believe that hospital has advance technology to prolong life						
38. Trust in physicians/nurses' competence						
39. Currently, there are more modern and advance medical technology						

Subscale 2 For patients who chose forgoing life sustaining treatment

Reasons related to make decision	Opinion Level					
	0	1	2	3	4	5
1. Death is leaving from compounded things						
2. Death is the truth that everyone must accept						
3. Death is a way to overcome suffering						
4. Death is inevitable						
5. Death is already set, we must go when time arrives						
6. When death arrives, we redress karma						
7. Death is karma, no one can refuse karma						
8. Death cannot be controlled by human						
9. Death can release karma						
10. Buddhists believe life is unpredictable, person must always be ready to die						
11. Life is impermanence moment by moment, must be conscious and ready to die						
12. Life is impermanence, birth, death						
13. Prolong life is wrong						
14. Prolong life is to refuse the fact of life						
15. When death arrives, no need to fight to prolong life						
16. Buddhists don't attach for compounded things , when death arrives we must except with peaceful mind						
17. Prolonging life, mind is not peaceful before death						
18. Need to die naturally without equipment						
19. Need to live life naturally before death						
20. Don't want to against nature						
21. Don't want to burden family/society if cannot make contributions to benefit the family/society						
22. Thai have right to choose whether to prolong life						

Reasons related to make decision	Opinion Level					
	0	1	2	3	4	5
23. Long life which depends on others is useless						
24. Need peaceful death among family/love ones						
25. Don't want family member exert for patient because they have other persons need to take care						
26. Don't want to live with suffering and make family get stress						
27. Life support equipment separates from family						
28. Don't want to burden family						
29. Don't want family to lose income						
30. Don't need family to waste money						
31. Don't need family to waste time						
32. Knowing that the disease is more severe than treat it						
33. Treatment may cause more suffering						
34. Treatment may cause more pain						
35. Treatment may interrupt peaceful death						
36. Treatment may prolong life but it might be unconscious forever						
37. Prolong life is useless						

Subscale 3 for patients who allow physicians/nurses to make decision

Reasons related to make decision	Opinion Level					
	0	1	2	3	4	5
1. Physiciane/nurses are kind						
2. Physiciane/nurses have compassion						
3. Physicians/nurses are willing to help patients						
4. Physicians/nurses are true friend in the time of sickness						
5. Physicians/nurses have more knowledge						
6. Physicians/nurses have duty to help patients						
7. Physicians/nurses know how to treat patient the best way						
8. Confident in Physicians/nurses' capability						
9. Believe in Physicians/nurses' experiences						
10. Be confident in physicians/nurses to make decision based on patients' benefit						
11. Put one's hopes into physicians/nurses' hand						
12. Physicians/nurses are good person						
13. Physicians/nurses are respectable						
14. Physicians/nurses have good wishes to patients						
15. After getting illness, must depend on physicians/nurses						
16. Physicians/nurses make decision based on patient centered						
17. Don't trust self/family's decision						
18. Own decision may be different from family						
19. Own decision may be wrong, so physicians/nurses should make the decision						
20. Own decision may not be accepted from family						
21. Usually, family must approve for any decision						
22. Family believes in physicians/nurses competence						

Reasons related to make decision	Opinion Level					
	0	1	2	3	4	5
23. Family fully agree, when physicians/nurses make decision						
24. Family doesn't want to bother physicians/nurses						
25. Reduce the family's anxiety						
26. Reduce the conflict with family from disagreement						
27. No knowledge of disease to make decision						
28. Final stage of illness needs only physicians/nurses' help						
29. Physicians/nurses clearly understand advanced medical technology more than others						
30. Belief in physicians/nurses who give the good treatment						
31. Less understand treatment plan than physicians/nurses						
32. Physicians/nurses know how to decrease suffering						

Subscale 4 For patients who allow Family to make decision

Reasons related to make decision	Opinion Level					
	0	1	2	3	4	5
1. Family members are true friend to make good wish						
2. Whoever make decision is not different because of predetermined life						
3. Give a chance for family to do good thing						
4. Give a chance for family to repay the kindness						
5. Trust family to make decision						
6. Family members' role need to manage when getting illness						
7. When get sickness, family is helper						
8. Thai society gives priority to the family						
9. Be afraid that the decision will differ from family's decision						
10. Normally, family made decision important issues						
11. Don't make conflict with family						
12. Give family with good feeling						
13. Give priority to make decision to family because family takes care						
14. Family pays expense, family has authority to make decision						
15. Want family to know that family is important						
16. Love, and related with family						
17. Family has the right to make decision						
18. Family knows the best for need						
19. Confidence in family's love						
20. Confidence in family's wish						

Reasons related to make decision	Opinion Level					
	0	1	2	3	4	5
21. Trust the decision family makes because family is important						
22. Own decision may make family suffer						
23. Believe family must make the best decision						
24. Family pays expense, the decision making must depend on family						
25. No income, no dare to make decision						
26. Don't want to bother family because family pays for expense						
27. Give a chance for family to participate in caring						
28. No way out, depend on family's decision						
29. The impact from illness may make mistake in decision making						
30. The illness is too severe to own decision						

แบบสอบถาม

เลขที่

แบบสอบถาม การตัดสินใจในระยะสุดท้ายของชีวิตในผู้ป่วยโรคเรื้อรังที่นับถือศาสนาพุทธ

ส่วนที่ 1 ข้อมูลทั่วไป

คำชี้แจง กรุณาทำเครื่องหมาย ✓ หน้าข้อความที่ท่านเลือกหรือเติมคำลงในช่องว่างตามความเป็นจริงมากที่สุด

1. อายุ.....ปี
2. เพศ
 - 1 ชาย
 - 2 หญิง
3. สถานภาพสมรส
 - 1 โสด
 - 2 คู่
 - 3 หย่า/แยก/ม้าย
4. ระดับการศึกษา
 - 1 ไม่ได้รับการศึกษา
 - 2 ประถมศึกษา
 - 3 มัธยมศึกษา
 - 4 อนุปริญญา
 - 5 ปริญญาตรี
 - 6 ปริญญาโท
 - 7 สูงกว่าปริญญาโท (ระบุ).....
5. อาชีพ
 - 1 นักเรียน/นักศึกษา
 - 2 ค้าขาย
 - 3 รับจ้าง
 - 4 เกษตรกรรม
 - 5 รับราชการ/รัฐวิสาหกิจ
 - 6 ธุรกิจเอกชน
 - 7 กิจการส่วนตัว
 - 8 อื่นๆ (ระบุ).....
6. รายได้ต่อเดือน
 - 6.1 กรณีประกอบอาชีพ รายได้ต่อเดือน
 - 1 ต่ำกว่าหรือเท่ากับ 5,000 บาท
 - 2 5,001-10,000 บาท
 - 3 10,001-15,000 บาท
 - 4 15,001-20,000 บาท
 - 5 20,001-25,000 บาท
 - 6 25,001-30,000 บาท
 - 7 มากกว่า 30,000 บาท
 - 6.2 กรณีที่ไม่ได้ประกอบอาชีพ ท่านได้รับการสนับสนุนค่าใช้จ่ายจาก (เลือกตอบได้มากกว่า 1 ข้อ)
 - 1 บิดา
 - 2 มารดา
 - 3 สามี
 - 4 ภรรยา
 - 5 บุตร
 - 6 ญาติพี่น้อง
 - 7 อื่นๆ (ระบุ)

6.3 ท่านได้รับการสนับสนุนค่าใช้จ่ายต่อเดือน

- 1 ต่ำกว่าหรือเท่ากับ 5,000บาท 2 5,001-10,000 บาท 3 10,001-15,000 บาท
 4 15,001-20,000 บาท 5 20,001-25,000 บาท 6 25,001-30,000 บาท

7. บทบาทในครอบครัว

- 1 หัวหน้าครอบครัว 2 สมาชิกครอบครัว 3 อยู่คนเดียว

8. จำนวนสมาชิกในครอบครัว (ระบุจำนวน).....คน

9. ปัญหาสุขภาพในขณะนี้

- 1 ไม่มี 2 มี (หากมีตอบคำถามข้อ 9.1, 9.2, และ 9.3)

9.1 เจ็บป่วยด้วยโรค (เลือกตอบได้มากกว่า 1 ข้อ)

- 1 ความดันโลหิตสูง 2 เบาหวาน 3 โรคหัวใจ
 4 โรคไต 5 มะเร็ง 6 อื่นๆ (ระบุ).....

9.2 ระยะเวลาที่เจ็บป่วยด้วยโรค (เลือกตอบได้มากกว่า 1 ข้อ)

- 1 ความดันโลหิตสูง ระยะเวลาที่เจ็บป่วย.....ปี
 2 เบาหวาน ระยะเวลาที่เจ็บป่วย.....ปี
 3 โรคหัวใจ ระยะเวลาที่เจ็บป่วย.....ปี
 4 โรคไต ระยะเวลาที่เจ็บป่วย.....ปี
 5 โรคมะเร็ง ระยะเวลาที่เจ็บป่วย.....ปี
 6 อื่นๆ ระบุ ระยะเวลาที่เจ็บป่วย.....ปี

9.3 การรักษาที่ได้รับ (ตอบได้มากกว่า 1 ข้อ)

- 1 รับประทานยา 2 ฉีดยา 3 ทำกายภาพบำบัด
 4 ฟอกเลือด 5 อื่นๆ (ระบุ).....

10. ปัญหาสุขภาพ/ความเจ็บป่วยขณะนี้ มีผลกระทบในการดำรงชีวิตประจำวันเพียงใด

- 1 ไม่กระทบ 2 กระทบเล็กน้อย 3 กระทบปานกลาง 4 กระทบมาก

11. ปัญหาสุขภาพ/ความเจ็บป่วยขณะนี้ ทำให้ท่านต้องพึ่งพาผู้อื่นในการดำรงชีวิตประจำวันเพียงใด

- 1 ไม่ต้องพึ่งพา 2 พึ่งพาลเล็กน้อย 3 พึ่งพาปานกลาง 4 พึ่งพามาก

12. บุคคลที่ท่านพึ่งพาเป็นประจำ (เลือกตอบได้มากกว่า 1 ข้อ)

- 1 บิดา 2 มารดา 3 สามี 4 ภรรยา
 5 บุตร 6 หลาน 7 เพื่อนบ้าน 8 เพื่อนสนิท
 9 ผู้ดูแลที่จ้างมา

13. ประสบการณ์ทางตรงและ/หรือทางอ้อมเกี่ยวกับการได้รับการรักษาด้วยเครื่องช่วยหายใจ
- 1 ไม่เคย 2 เคยได้รับการรักษาด้วยเครื่องช่วยหายใจ
- 3 เคยเห็นผู้อื่นได้รับการรักษาด้วยเครื่องช่วยหายใจ 4 เคยได้รับการบอกเล่าจากผู้อื่น
- 5 เคยอ่านหนังสือหรือเห็นจากสื่อต่างๆ
14. ประสบการณ์ทางตรงและ/หรือทางอ้อมเกี่ยวกับการได้รับการรักษาด้วยการนวดหัวใจ
- 1 ไม่เคย 2 เคยได้รับการรักษาด้วยการนวดหัวใจ
- 3 เคยเห็นผู้อื่นได้รับการรักษาด้วยการนวดหัวใจ 4 เคยได้รับการบอกเล่าจากผู้อื่น
- 5 เคยอ่านหนังสือหรือเห็นจากสื่อต่างๆ
15. ประสบการณ์ทางตรงและ/หรือทางอ้อมเกี่ยวกับการได้รับการรักษาด้วยการฟอกเลือด
- 1 ไม่เคย 2 เคยได้รับการรักษาด้วยการฟอกเลือด
- 3 เคยเห็นผู้อื่นการได้รับการรักษาด้วยการฟอกเลือด 4 เคยได้รับการบอกเล่าจากผู้อื่น
- 5 เคยอ่านหนังสือหรือเห็นจากสื่อต่างๆ
16. ประสบการณ์ทางตรงและทางอ้อมเกี่ยวกับการเข้ารับการรักษาในไอซียู
- 1 ไม่เคย 2 เคยเข้ารับการรักษาในไอซียู
- 3 เคยเห็นผู้ป่วยในไอซียู 4 เคยได้รับการบอกเล่าจากผู้อื่น
- 5 เคยอ่านหนังสือหรือเห็นจากสื่อต่างๆ

17. กิจกรรมทางศาสนาที่ท่านปฏิบัติในชีวิตประจำวัน

กิจกรรมทางพุทธศาสนา	ปฏิบัติ สม่ำเสมอ	ปฏิบัติเป็น บางครั้ง	ปฏิบัติ นานๆครั้ง	ไม่ได้ ปฏิบัติ
1. ใส่บาตร				
2. สวดมนต์				
3. ถวายสังฆทาน				
4. นั่งสมาธิ				
5. ร่วมพิธีทางศาสนา เช่น เวียนเทียน งานบวช ฯลฯ				
6 อื่นๆ (ระบุ).....				

18. กรณีที่ปฏิบัติสม่ำเสมอ

- 1 ปฏิบัติก่อนเจ็บป่วย 2 ปฏิบัติหลังจากเจ็บป่วย

19. หลักคำสอนทางพุทธศาสนาที่ท่านนำมาใช้ในการดำเนินชีวิตประจำวัน หรือใช้เป็นเครื่องยึดเหนี่ยวจิตใจ

หลักธรรมคำสอนทางพุทธศาสนา	ความถี่ในการใช้				
	บ่อยมาก	บ่อย	บางครั้ง	นานๆ ครั้ง	ไม่เคยใช้
1. อริยสัจ 4 (ความจริง 4 ประการ คือ 1. ทุกข์ 2. สมุทัย การเกิดขึ้น หรือสาเหตุแห่งทุกข์ 3. นิโรธ ความดับทุกข์ 4. มรรค ทางที่นำไปสู่ความดับทุกข์)					
2. กฎไตรลักษณ์ คือ อนิจจัง ทุกขัง อนัตตา, ชีวิตไม่เที่ยง มีเกิดขึ้น ตั้งอยู่ ดับไป					
3. มรรค 8 (ทางสายกลาง) แนวปฏิบัติเพื่อการพ้นทุกข์ 8 ประการคือ 1) สัมมาทิฐิ คือความเข้าใจถูกต้อง 2) สัมมาสังกัปปะ คือความใส่ใจถูกต้อง 3) สัมมาวาจา คือการพูดจาถูกต้อง 4) สัมมากัมมันตะ คือการกระทำถูกต้อง 5) สัมมาอาชีวะ คือการดำรงชีพถูกต้อง 6) สัมมาวายามะ คือความพากเพียรถูกต้อง 7) สัมมาสติ คือการระลึกประจำใจถูกต้อง 8) สัมมาสมาธิ					
4. กฎแห่งกรรม (กฎแห่งการกระทำดีได้ดี ทำชั่วได้ชั่ว)					
5. ศีล 5					
6. พรหมวิหาร 4 (เมตตา กรุณา มุทิตา อุเบกขา)					
7. สัมปยุตธรรม 7 (คุณสมบัติของคนดี 7 ประการ) รู้จักเหตุ, รู้จักผล, รู้จักตน, รู้จักประมาณ, รู้จักกาล รู้จักชุมชน, รู้จักบุคคล					
8. มงคลชีวิต 38 ข้อ (คุณธรรม 38 ข้อที่ทำให้ชีวิตประสบความสำเร็จ เช่น การคบบัณฑิต, การบำรุงบิดามารดา, การสงเคราะห์บุตร, การสงเคราะห์ภรรยา, ทำงานไม่ให้ค้างค้ำ)					
9. อื่นๆ (ระบุ).....					

ส่วนที่ 2 การตัดสินใจในระยะสุดท้ายของชีวิตในผู้ป่วยโรคเรื้อรังที่นับถือศาสนาพุทธ
คำชี้แจง ขอให้ท่านพิจารณาสถานการณ์ที่กำหนดให้ และตัดสินใจว่าหากท่านอยู่ในสถานการณ์
 ดังกล่าว ท่านจะตัดสินใจอย่างไร ด้วยเหตุผลใด

สถานการณ์

เมื่อผู้ป่วยในวัยเดียวกันกับท่านมีอาการเจ็บป่วย แพทย์ลงความเห็นว่าเป็นการเจ็บป่วยในระยะสุดท้าย
 ของชีวิต และไม่มีหนทางใดที่จะรักษาให้หายได้ การรักษาด้วยอุปกรณ์ทางการแพทย์ที่ทันสมัยใน
 ปัจจุบัน ที่ต้องการช่วยยืดชีวิตของผู้ป่วย อาจจะเป็นเพียงการยืดความตายในระยะสุดท้ายของชีวิต
 ให้ยาวนานเท่านั้น ซึ่งไม่สามารถกำหนดได้นานเพียงใด อีกทั้งการรักษาด้วยอุปกรณ์ทางการแพทย์
 อาจทำให้ผู้ป่วยเจ็บปวดทุกข์ทรมานมากขึ้น

กรุณาทำเครื่องหมาย ✓ หน้าข้อที่ตรงกับการตัดสินใจเลือกของท่าน เพียง 1 ข้อ เท่านั้น

- (1) ตัดสินใจรับการรักษาพยาบาลด้วยอุปกรณ์ยืดชีวิต (ตอบคำถามเฉพาะชุดที่ 1)
 (2) ตัดสินใจไม่รับการรักษาด้วยอุปกรณ์ยืดชีวิต (ตอบคำถามเฉพาะชุดที่ 2)
 (3) ให้แพทย์/ พยาบาล ตัดสินใจแทน (ตอบคำถามเฉพาะชุดที่ 3)
 (4) ให้ครอบครัวตัดสินใจแทน (ตอบคำถามเฉพาะชุดที่ 4)

ข้อความของคำถามแต่ละชุดต่อไปนี้เป็นเหตุผลในการตัดสินใจที่ได้ท่านเลือกข้างต้น

ขอให้ท่านพิจารณาว่า ข้อความแต่ละข้อเป็นเหตุผลที่สำคัญเพียงใดในการตัดสินใจของท่าน

และทำเครื่องหมาย ✓ ในช่องที่ตรงกับคำตอบของท่าน

คะแนน 0	หมายถึง	ไม่ใช่เหตุผลที่ใช้ในการตัดสินใจ
คะแนน 1	หมายถึง	เป็นเหตุผลที่มีความสำคัญน้อยมาก
คะแนน 2	หมายถึง	เป็นเหตุผลที่มีความสำคัญน้อย
คะแนน 3	หมายถึง	เป็นเหตุผลที่มีความสำคัญปานกลาง
คะแนน 4	หมายถึง	เป็นเหตุผลที่มีความสำคัญมาก
คะแนน 5	หมายถึง	เป็นเหตุผลที่มีความสำคัญมากที่สุด

คำถามชุดที่ 1 สำหรับผู้ที่ตัดสินใจรับการรักษาด้วยอุปกรณ์ยึดชีวิต

เหตุผลที่ใช้ในการตัดสินใจ	ระดับความคิดเห็น					
	0	1	2	3	4	5
1. เพราะชีวิตเป็นสิ่งที่ทุกคนควรรักษาชีวิตไว้เพื่อให้รู้แจ้งในทุกข์นั้น						
2. การไม่รับการรักษาเมื่อเจ็บป่วยถือเป็นบาป						
3. อยู่เพื่อชดใช้กรรมให้หมดในชาตินี้						
4. ทำให้มีเวลาทำความดีได้มากขึ้น						
5. อยู่เพื่อสร้างกรรมดีเพิ่มเติมให้พอ						
6. การพลัดพรากจากคนที่รักเป็นทุกข์						
7. เป็นโอกาสในการบำรุงพระพุทธศาสนาได้นานขึ้น						
8. มนุษย์ไม่ได้เป็นเจ้าของร่างกาย จะปล่อยปละละเลยโดยไม่รักษาไม่ได้						
9. ทำให้มีโอกาสดทดแทนบุญคุณพ่อแม่/ผู้มีพระคุณมากขึ้น						
10. ทำให้มีเวลาสำหรับสะสมบุญกุศล เพื่อส่งผลให้มีความสุขหลังการตาย						
11. ทำให้มีโอกาสนำบุญลบล้างสิ่งที่เคยทำผิดในอดีต						
12. เป็นการทดแทนบุญคุณแก่ร่างกายที่ได้อาศัยอยู่						
13. คุณความดีที่สร้างมาจะช่วยให้การรักษาได้ผล						
14. ปาฏิหาริย์ในการรักษา เป็นสิ่งที่เกิดขึ้นได้						
15. ชีวิตต้องสู้แม้ในระยะสุดท้ายของชีวิต						
16. โชคชะตากำหนดชีวิตของมนุษย์ หากยังไม่ถึงเวลาก็ไม่ตาย						
17. การเจ็บป่วยเป็นบททดสอบของชีวิต ต้องไม่ท้อแท้ในการรักษา						
18. สิ่งศักดิ์สิทธิ์สามารถช่วยให้รอดชีวิตได้						
19. เป็นเรื่องปกติของสังคมไทยในปัจจุบันที่จะชะลอความตายด้วยอุปกรณ์สมัยใหม่ในการรักษา						

เหตุผลที่ใช้ในการตัดสินใจ	ระดับความคิดเห็น					
	0	1	2	3	4	5
20. การมีชีวิตอยู่ต่อไปจะได้เป็นกำลังใจให้ครอบครัว/คนที่รักต่อไป						
21. ไม่ต้องการให้ครอบครัว/คนที่รักลำบากที่ขาดคนดูแล						
22. ไม่ต้องการให้ครอบครัว/คนที่รักเป็นทุกข์จากการพลัดพราก						
23. หวังจะอยู่ดูความสำเร็จของลูกหลาน/คนที่รัก						
24. การมีชีวิตอยู่ต่อไปทำให้ครอบครัวสมบูรณ์						
25. ต้องการสะสมบางสิ่งบางอย่างให้เสร็จสิ้น						
26. ต้องการเวลาเพื่อให้คนในครอบครัว/คนที่รักเตรียมใจสำหรับการพลัดพราก						
27. เป็นห่วงคนในครอบครัว						
28. อยู่เพื่อเป็นที่พึ่งทางใจให้กับคนในครอบครัว						
29. รู้สึกผิดหากต้องจากครอบครัว/คนที่รักโดยไม่รักษาให้เต็มที่						
30. เปิดโอกาสให้คนในครอบครัวได้มีส่วนร่วมในการดูแลรักษา						
31. เปิดโอกาสให้คนในครอบครัว/คนที่รักมีเวลาในการดูแลเพื่อลดล้างความรู้สึกละอาย						
32. การรักษาจะช่วยลดความเจ็บปวดจากโรคที่เป็นอยู่						
33. การรักษาจะช่วยลดความทุกข์ทรมานจากการเจ็บป่วยได้						
34. เคยเห็นคนที่ป่วยเป็นโรคเดียวกัน รอดชีวิตจากการรักษา						
35. เชื่อว่าความเจ็บป่วยที่เกิดขึ้น ยังมีหนทางที่จะรักษา จึงยึดชีวิตไว้						
36. เชื่อมั่นในการรักษาแผนปัจจุบัน						
37. เชื่อว่าปัจจุบันโรงพยาบาลมีอุปกรณ์ที่ทันสมัยมากในการรักษาเพื่อยืดชีวิตของผู้ป่วย						
38. เชื่อในความสามารถของแพทย์/พยาบาล						
39. ปัจจุบันมีวิธีการรักษาใหม่ๆ ที่ทันสมัยและก้าวหน้ามากขึ้นเรื่อยๆ						

คำถามชุดที่ 2 สำหรับผู้ที่ตัดสินใจไม่รับการรักษาด้วยอุปกรณ์ยึดชีวิต

เหตุผลที่ใช้ในการตัดสินใจ	ระดับความคิดเห็น					
	0	1	2	3	4	5
1. ความตายเป็นการละสังขาร						
2. ความตายเป็นสังขารที่ทุกคนต้องยอมรับ						
3. ความตายเป็นหนทางการดับทุกข์						
4. ความตายเป็นสิ่งที่ไม่อาจหลีกเลี่ยงได้						
5. ความตายถูกกำหนดไว้แล้วเมื่อถึงเวลาก็ต้องไป						
6. เมื่อความตายมาถึงแสดงว่าได้ชดใช้กรรมหมดแล้ว						
7. ความตายเป็นเรื่องของกรรม ไม่มีใครปฏิเสธกรรมได้						
8. ความตายเป็นเรื่องที่เหนือการควบคุมของมนุษย์						
9. ความตายทำให้พ้นกรรม						
10. ชาวพุทธเชื่อว่าชีวิตเป็นของไม่แน่นอน ต้องพร้อมที่จะตายได้ตลอดเวลา						
11. ชีวิตมีเกิดดับตลอดเวลา ต้องมีสติเตรียมรับความตาย						
12. ชีวิตเป็นของไม่เที่ยง มีตายมีจาก						
13. การเอาชนะความตายด้วยการยึดชีวิตเป็นสิ่งที่ไม่ถูกต้อง						
14. การยึดความตายเป็นการปฏิเสธความจริงของชีวิต						
15. ถึงเวลาไปก็ต้องไป ไม่ต้องดิ้นรนต่อสู้เพื่อยึดชีวิต						
16. ชาวพุทธไม่ควรยึดติดในสังขาร เมื่อถึงเวลาก็ต้องยอมรับด้วยใจที่สงบ						
17. หากยึดชีวิต ทำให้จิตไม่สงบก่อนตาย						
18. ต้องการตายตามธรรมชาติโดยปราศจากเครื่องมือใดๆ ติดตัวก่อนตาย						
19. อยากมีชีวิตที่เหลืออย่างธรรมชาติ						
20. ไม่อยากฝืนธรรมชาติ						

เหตุผลที่ใช้ในการตัดสินใจ	ระดับความคิดเห็น					
	0	1	2	3	4	5
21. ไม่อยากเป็นภาระของสังคมหากมีชีวิตต่อ โดยไม่สามารถทำประโยชน์แก่สังคมได้						
22. คนไทยทุกคนมีสิทธิที่จะเลือกว่าจะยึดหรือไม่ยึดชีวิต						
23. ชีวิตที่ยืนยาวแต่ต้องพึ่งพาผู้อื่นเป็นชีวิตที่ไม่มีคุณค่า						
24. ต้องการตายอย่างสงบท่ามกลางครอบครัวและคนที่รัก						
25. ไม่อยากให้คนในครอบครัวทรมานเพื่อตนเพราะยังมีคนอื่น ๆ ในครอบครัวที่ต้องได้รับการดูแล						
26. ไม่อยากอยู่อย่างทรมานให้ครอบครัวต้องทุกข์ใจ						
27. อุปกรณ์ช่วยชีวิตทำให้ต้องห่างจากครอบครัว						
28. ไม่ต้องการเป็นภาระให้ครอบครัว						
29. ไม่ต้องการให้ครอบครัวขาดรายได้ที่ตรงมาคอยดูแล						
30. เกรงใจครอบครัวที่ต้องสิ้นเปลืองค่าใช้จ่ายในการดูแล						
31. เกรงใจครอบครัวที่ต้องเสียเวลามาดูแล						
32. อาการของโรครุนแรงเกินกว่าจะรักษาได้						
33. การรักษาอาจทำให้ทุกข์ทรมานมากขึ้น						
34. การรักษาอาจทำให้เจ็บปวดมากขึ้น						
35. การรักษาอาจขัดขวางการตายอย่างสงบ						
36. การรักษาอาจช่วยชีวิตได้ แต่อาจจะต้องนอนไร้สติตลอดไป						
37. กลัวว่าจะเป็นการยืดความตายโดยเปล่าประโยชน์						

คำถามชุดที่ 3 สำหรับผู้ที่ให้แพทย์/พยาบาล ตัดสินใจแทน

เหตุผลที่ใช้ในการตัดสินใจ	ระดับความคิดเห็น					
	0	1	2	3	4	5
1. แพทย์/พยาบาลมีใจเมตตา						
2. แพทย์/พยาบาลมีใจกรุณา						
3. แพทย์/พยาบาลมีความยินดีที่จะช่วยคนไข้						
4. แพทย์/พยาบาลเป็นกัลยาณมิตรที่ดียามเจ็บป่วย						
5. แพทย์/พยาบาลมีความรู้มากกว่า						
6. แพทย์/พยาบาลมีหน้าที่ช่วยคนไข้อย่างสุดความสามารถ						
7. แพทย์/พยาบาลรู้ดีว่าการรักษาแบบไหนเหมาะกับคนไข้						
8. เชื่อมั่นในความรู้ความสามารถของแพทย์/พยาบาล						
9. เชื่อในประสบการณ์ของแพทย์/พยาบาล						
10. เชื่อมั่นว่าแพทย์/พยาบาล ตัดสินใจเพื่อประโยชน์สูงสุดของคนไข้						
11. ผ่าทความหวังไว้กับแพทย์/พยาบาล						
12. แพทย์/พยาบาลเป็นคนดี						
13. แพทย์/พยาบาลเป็นคนที่น่าศรัทธา						
14. แพทย์/พยาบาลมีความหวังดีต่อคนไข้						
15. ยามเจ็บไข้ไม่สบายต้องพึ่งแพทย์/พยาบาล						
16. แพทย์/พยาบาลตัดสินใจโดยเน้นผู้ป่วยเป็นหลัก						
17. ไม่ไว้ใจการตัดสินใจของตัวเองและครอบครัว						
18. การตัดสินใจเองอาจไม่ตรงกับการตัดสินใจของครอบครัว						
19. การตัดสินใจด้วยตัวเองอาจผิดพลาดได้ จึงต้องให้แพทย์/พยาบาลช่วยตัดสินใจ						
20. การตัดสินใจเองอาจไม่ได้รับการยอมรับจากครอบครัว						
21. โดยปกติต้องให้ครอบครัวเห็นชอบในการตัดสินใจ						
22. ครอบครัวเชื่อความสามารถของแพทย์/พยาบาล						

เหตุผลที่ใช้ในการตัดสินใจ	ระดับความคิดเห็น					
	0	1	2	3	4	5
23. หากแพทย์/พยาบาลตัดสินใจ ครอบครัวจะยอมรับ						
24. ครอบครัวเกรงใจแพทย์/พยาบาล						
25. เพื่อให้ครอบครัวลดความกังวล						
26. เพื่อลดความขัดแย้งในครอบครัวจากความเห็นที่อาจไม่ตรงกัน						
27. ไม่มีความรู้เรื่องการเจ็บป่วยเพียงพอที่จะตัดสินใจเอง						
28. การเจ็บป่วยในระยะสุดท้ายแพทย์/พยาบาลเท่านั้นที่จะช่วยได้						
29. ปัจจุบันมีความก้าวหน้าด้านการรักษาที่ทำให้คนทั่วไปไม่สามารถเข้าใจได้ดีเท่าแพทย์/พยาบาล						
30. เชื่อว่าแพทย์/พยาบาลจะช่วยเหลือหาวิธีการที่ดีที่สุด						
31. ไม่เข้าใจแผนการรักษาพยาบาลได้ดีเท่าแพทย์/พยาบาล						
32. แพทย์/พยาบาลมีวิธีการที่จะช่วยลดความเจ็บปวดทุกข์ทรมาน						

คำถามชุดที่ 4 สำหรับผู้ที่ให้ครอบครัวตัดสินใจตัดสินใจแทน

เหตุผลที่ใช้ในการตัดสินใจ	ระดับความคิดเห็น					
	0	1	2	3	4	5
1. คนในครอบครัวถือเป็นกัลยาณมิตรที่มีแต่ความหวังดี						
2. ถึงใครตัดสินใจก็ไม่ต่างกันเพราะชีวิตถูกกำหนดไว้แล้ว						
3. เป็นการเปิดโอกาสให้ครอบครัวได้สร้างกรรมดี						
4. เป็นการเปิดโอกาสให้ครอบครัวได้ตอบแทนบุญคุณ						
5. ว่างใจการตัดสินใจของครอบครัว						
6. ยามเจ็บป่วยเป็นหน้าที่ของคนในครอบครัวต้องช่วยจัดการ						
7. ยามเจ็บป่วยต้องพึ่งพาอาศัยคนในครอบครัว						
8. สังคมไทยให้ความสำคัญกับครอบครัว						
9. กลัวว่าการตัดสินใจไม่ตรงกับความต้องการของครอบครัว						
10. โดยปกติครอบครัวเป็นผู้ที่ตัดสินใจแทนในเรื่องที่สำคัญๆ						
11. ไม่ต้องการขัดแย้งกับครอบครัว						
12. เพื่อความสบายใจของครอบครัว						
13. ครอบครัวดูแล จึงต้องให้ตัดสินใจ						
14. ครอบครัวรับภาระค่าใช้จ่าย จึงมีอำนาจในการตัดสินใจ						
15. ต้องการให้ครอบครัวรับรู้ว่าการครอบครัวมีความสำคัญ						
16. มีความรักความผูกพันกับครอบครัว						
17. ครอบครัวมีสิทธิในการตัดสินใจแทน						
18. ครอบครัวรู้ความต้องการดีที่สุด						
19. เชื่อมั่นในความรักของครอบครัว						
20. เชื่อมั่นในความหวังดีของครอบครัว						
21. ครอบครัวมีความสำคัญที่ต้องมอบความไว้วางใจให้ตัดสินใจแทน						
22. การตัดสินใจเองอาจทำให้ครอบครัวเป็นทุกข์						
23. เชื่อว่าครอบครัวต้องตัดสินใจในสิ่งที่ดีที่สุด						

เหตุผลที่ใช้ในการตัดสินใจ	ระดับความคิดเห็น					
	0	1	2	3	4	5
24. ครอบครัวรับภาระค่าใช้จ่าย จึงต้องให้ตัดสินใจแทน						
25. ไม่มีรายได้ของตัวเอง จึงไม่กล้าตัดสินใจ						
26. เกรงใจครอบครัวที่ต้องรับภาระค่าใช้จ่าย						
27. เปิดโอกาสให้ครอบครัวมีส่วนร่วมในการดูแล						
28. หมกหมุ่นทางรักษา แล้วแต่ครอบครัวจะตัดสินใจ						
29. ภาวะคุกคามของโรค อาจทำให้การตัดสินใจด้วยตนเอง ผิดพลาดได้						
30. อาการของโรครุนแรงเกินกว่าจะตัดสินใจเองได้						

VITAE

Name Mrs. Navarat Rukchart

Student ID 5210430003

Education Attainment

Degree	Name of Institutions	Year of Graduation
Diploma, N.S. (Nursing and Midwifery)	Songkhla Nursing College	1985
Master Degree (Adult Nursing)	Prince of Songkla University	2000
Bachelor of Arts (Mass communication)	Sukhothai Thammathirat	2009

Scholarships award during enrolment

Scholarship for student exchange program in University of Miyazaki, Japan for six weeks from University of Miyazaki, Japan.

Scholarship for studying overseas in School of Nursing, University of Kansas, Kansas City America for six month from Graduate School, Prince of Songkla University, Songkhla, Thailand.

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List of Publication

Rukchart, N., Chaowalit, A., Suttharangsee, W., Parker, M. E. (2014). End-of-Life Decisions among Thai Buddhist Adults with Chronic Illness. *Songklanagarind Journal of Nursing*, 34, 44-54.