End-of-life decisions among Thai Buddhist adults with chronic illness

Navarat Rukchart *, Aranya Chaowalit**, Wandee Suttharangsee**, Marilyn, E. Parker***

Abstract

**Purpose:** This study aimed to explore the end-of-life decisions among Thai Buddhist adults with chronic illness.

**Methods:** Qualitative descriptive design was used. Twelve patients who met the inclusion criteria of participants were invited to participate in this study. Inclusion criteria were: 1) being Thai Buddhist, 2) having a chronic illness for at least three months, and 3) having age at least 40 years old. The participants were interviewed individually by using a case scenario. Open-ended questions were asked to explore participants’ decisions and reasons if they were faced with the proposed end-of-life scenario. Each interview was tape recorded. Interview data were analyzed by using content analysis approach. Ethical considerations were secured throughout the study.

**Results:** Four themes described patients’ decisions and their reasons according to end-of-life scenario were: 1) forgoing life sustaining treatment because death is the fact of life which is inevitable/need peaceful death and not to burden family/society, 2) continuing life sustaining treatment because of the duty to prolong life/concern for family/fear of death/hope/unfinished tasks, 3) allowing family to make decisions because families love me, they must know my needs, and 4) allowing physicians/nurses to make decisions because of trust in their competencies.

**Conclusion:** This study provided the knowledge about end-of-life decisions from the perspectives of Thai Buddhist patients living with chronic illness. Understanding the findings can assist healthcare providers to create appropriate interventions to support autonomous decisions of the patients regarding their life and death.

**Keywords:** end-of-life-decisions; death and dying; Thai Buddhist; chronic illness

* Ph.D. Candidate, Faculty of Nursing, Prince of Songkla University, Thailand
** Associate Professor, Faculty of Nursing, Prince of Songkla University, Thailand
*** Professor, University of Kansas Medical Center, School of Nursing, Kansas City, KS, USA
Introduction

Chronic illness is one of the major challenges facing healthcare system around the world today. With improvement in access to medical practitioners and standardization in diagnostic processes coupled with public health awareness and education campaigns, the incidence and prevalence of chronic disease seems to have increased exponentially in many countries. This is particularly noticeable in developing countries such as Thailand, Indonesia, and Philippines. The Thai Health Promotion Foundation (2010) reported the top five chronic diseases, in order of prevalence, as: diabetes mellitus, hypertension, ischemic heart disease, cerebro-vascular disease and cancer.

Chronic illness affects not only the patient but also the family and local community involved in managing patient care (Larsen, 2009). Its current treatment protocol causes physical, psychosocial, spiritual and social imbalances within the patient, the patient’s family, social and work communities. The impact on patients are frequency of hospitalizations, increasing financial costs, social burdens, emotional difficulties, feelings of anxiety, frustration, irritability and bitterness, change in body appearance, musculoskeletal, and/or neurologic changes in function. These stressors threaten both the patient’s and the family’s integrity (Larsen, 2009). Consequently, patients and their families usually consider health care management and issues concerning on dying and death.

End-of-life decision is a complex process requiring patients to identify and deliberate alternative actions and consequences in order to determine what they ought to do. There are many factors influencing end-of-life decisions. Many studies indicated that patients and families decided to forgo life sustaining treatment because of life experience (Manasurakarn, et al., 2008), fear of suffering from treatment (Manasurakarn, et al., 2008; Neounoi, 2005; Rothman et al., 2007), religious beliefs (Kongsuwan, Chaipetch & Matchim, 2012; Manasurakarn et al., 2008; Neounoi, 2005), and poor of prognosis (Foo et al., 2012; Ganz, Benbenishty, Herscher, Fischer, Gurman & Sprung, 2006). The other factors included fear of burden family (Foo et al., 2012; Manasurakarn, et al., 2008), the patients’ wish and preference (Kim & Kjervik, 2005; Romer & Hammes, 2004), cost of health care (Kwon et al., 2009; Yusuf & Nuhu, 2011), socioeconomic background (Yusuf & Nuhu, 2011), and need to complete task (Foo et al., 2012; Manasurakarn, et al., 2008).

Persons involving the end-of-life decision process include patients’ families and health care providers. Some patients prefer that end-of-life decisions be made by their family or physician due to the difficulty in making decision (Kim & Kjervik, 2005). Quinn, Schmitt, Baggs, Norton, Dombeck and Sellers (2012) stated that family was a primary decision maker. Similarly, Wagemans, Lantman-de-Valk,
Tuffrey-Wijne, Widdershoven and Gurfs (2010) indicated that the family involved in the end-of-life decisions in caring for persons with intellectual disabilities. Whereas, studies in the Thai context found that some patients with chronic illness (1.9-5.1%) decided to terminate treatment based on their health care team’s opinion, and some (1.9-4.8%) decided to terminate or continue treatment based on families’ opinion. Similarly, the study by Neounoi (2005) found that 27.50%, 12.50% of patients with chronic illness allowed physicians and families to make decision for them respectively. 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 and only 14.5% opted for sharing decision-making among relatives and physicians. In the provision of cardiopulmonary resuscitation, 44.1% of subjects expressed a desire for families to make decisions together with physicians, 33.6% gave directive to the families alone and only 22.4% transferred their decisions to physicians. The important reason that they transferred their decisions to others is because they trust health care providers and families.

In Thailand, The Thai National Health Act, B. E. 2550, Section 12, stated in the following amendment that: “A person shall have the rights 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; a persons’ wish at the end-of-life will be respected. Patients may refuse the treatment based upon the principle of autonomy to control treatment decision. However, the right to die is not commonly used in health care settings in Thailand.

As a part of patient assessment, nurses should consider asking about end-of-life choices to indicate their respect for patient autonomy and to act as a nurse advocate when patients become incapacitated. The nursing goal is to facilitate the patient’s participation in decision making, which requires an accurate assessment of patient capacity. However, studies about end-of-life decisions are limited in the Thai context. Most of the studies were developed in the western context which has different cultures and values. Exploring end-of life decisions among Thai Buddhist adults with chronic illness is essential. Understandings on this issue will be useful for healthcare providers to advocate patient rights and promote self-determination for chronically ill patients in the Thai context.

**Purpose**

The purpose of this study was to explore the end-of-life decisions among Thai Buddhist adults with chronic illness.
Methods

Design
A qualitative descriptive design was used to explore end-of-life decision from the perspective of Thai Buddhist adults with chronic illness. The settings for this study were the hospital and patient homes in the southern region of Thailand. Individual interview with a case scenario was used in data collection. Data were analyzed using content analysis.

Participants
Twelve patients with chronic illness were invited to participate in this study. Purposeful sampling was used to recruit the participants. Inclusion criteria of participant selection were: 1) being Thai Buddhist, 2) having a chronic illness for at least three months, and 3) age is at least 40 years old.

Data collection
The researcher interviewed twelve participants where it was convenient to them. The participants were interviewed individually by using a case scenario of a patient at the end-of-life. Open-end questions were asked to explore participants’ decisions and reasons supporting their decisions if they were faced with the proposed end-of-life scenario. The scenario that was used in this study was that of a patient presented with a terminal disease in a terminal stage with no likely chance of recovery. Each interview was tape recorded and lasted at least 60 minutes. Each participant was interviewed two times.

Data analysis
Interview data were transcribed. Qualitative content analysis approach was used to analyze the transcription data. Significant words, phrase, and sentences in the transcriptions that reflected the patients’ end-of-life decisions and their reasons were identified. Same meanings of these word, phrases, and statements were grouped and categorized. Ethical considerations were maintained throughout the study.

Results
Four themes of decisions and reasons for their decisions emerged: 1) forgoing life sustaining treatment because death is a fact of life which is inevitable/need peaceful death/not to burden family/society, 2) continuing life sustaining treatment because of the duty to prolong life/concern for family/fear of death/hope/unfinished task, 3) allowing family to make decisions because families love me, they must know my needs, and 4) allowing physicians/nurses to make decisions because of trust in their competencies.
Theme 1: Forgoing life sustaining treatment because death is the fact of life which is inevitable/ need peaceful death and not to burden family/society

The decision to forgo life sustaining treatments is an autonomous decision in which participants preferred to take an active role in determining the timing and circumstances of their dying. Most participants, nine of twelve, decided to forgo life sustaining treatments when their illness was diagnosed to be terminal. These participants described death and dying as part of human life; as natural birth, aging, illness, and death are part of life. The participants described end-of-life decisions as a difficult and complex situation. Most expressed a strong need to make decisions by themselves. Some did not fear death but they fear the suffering that they equated with prolonging death. Participants expressed a need for a peaceful death which was explained as: to die as in their sleep, to die without worry and with recognition that the time for life was finished. Moreover, they also did not want to burden their family/society. Most of participants expressed the fear that they would burden to their families. Excerpts, literally translated, from the interviews illustrate participants’ reasons and reflect beliefs and attitudes that influenced end-of-life decision:

“Talking about death and dying, it is difficult to imagine because it is far away from me, ...now I feel healthy, however, the story that you give to me and I try to imagine,...if I were the patients same as those, I would make decision by myself to stop life sustaining treatment, and if I were incapacitated, my family or physicians would make decisions....I know death is a truth of life, if it is time to go, we should go” C12

Other participants expressed the following feelings:

“...I believe in birth, aging, pain, and dying are a normal part of life...it is useless to prolong life...we can prolong life for a moment..., however, everybody dies” I believe in karma... karma leads us to be born, die,...death is based on karma... it’s time to go”

Some participants explained a desire to die naturally and to experience a “peaceful death”:

“...I want to die naturally... die asleep...nothing to do about my child, my work... ...to prolong life is to prolong suffering...I had seen some patients on respirators, on tubing... I think is the body suffers...I think ...like a person who is drowning. I know prolonging life is impossible...however...everybody dies...although we have advance technology, it is impermanent. ... I want to be allowed to die as naturally as possible”  ...” C7
Other participants expressed a belief that prolonging life is prolong suffering:

“...prolonging life is painful...I have seen patients who have a nasal tube or endotrachial,... on a respirator... I think...it was painful for them,[they were] breathless like they were downing... their body was suffering” C9

Some participants explained that:

“...I don’t want to burden my children. When I took care of my husband, I paid a lot of money for special nurses, caregivers although the government gave support for hospitalization.” C1, C7, C8

“...I don’t want to burden other people or society. Because of financial reasons even though you are using the country’s resource, it will be too much, it is unnecessary to prolong life...” C2

**Theme 2: Continuing life sustaining treatment because of the duty to prolong life/concern for family/fear of death/hope/unfinished task**

Continuing life sustaining treatments is another decision that involves life sustaining treatment intervention. Employing such life sustaining treatment may result in long term survival or delay death. Participants believed that technology could control the process of death and dying. Technological ability to alter the time of death by ventilator, cardiopulmonary resuscitation, artificial hydration and nutrition, antibiotic, dialysis, and alternative medicine was a few examples. Some participants, three of twelve, hoped to survive and live as long as possible and expressed as:

“I think life is important...the best thing is we should maintain life ... nowadays there are advanced technologies to preserve life ...to reduce suffering...to control pain... a lot of alternative medicine....I think I will do the best for my life without suffering...” C11

Some participants expressed that:

“Although death is a natural part of our life, I don’t want to die...., I hope to survive...I want to see the success of my children. My daughter is going to get married next year..., I want to take care them and want to live with them as long as possible...I believe medical technology could preserve my life” C8

Another participants said that:

“... first time ...after I know the bad news...I think... I will die...I feel afraid of death ...I don’t want to die now...I’m worried about my son...he is unemployed... ..I have debt to manage...” C12
Theme 3: Allowing family to make decisions because families love me, they must know my needs

Delegation of end-of-life decisions to a family member is another preference expressed by Thai Buddhists with chronic illness. These individuals expressed a desire to allow family to make decisions for them if they were unconscious or could not participate in the decision making process. Three of twelve participants gave reasons supporting this decision. Some participants explained this as:

“...If I am unconscious, it is up to my children, they know the best about my goals in life, especially my daughter...she will manage everything for me” C10

“... if I am unconscious, my family knows best what I will need, my family has the authority to make decisions...”

Theme 4: Allowing physicians/nurses to make decisions because of trust in their competencies

Delegation of end-of-life decisions to physicians/nurses illustrated patients’ belief that physicians/nurses would make the best decisions for them. The belief was based on trust in the competencies of the practitioners and knowledge of the disease and disease process. Some participants expressed this idea as:

“...Although physicians don’t know me better than my relatives ... physicians know best about my health and the progress of disease, ... to make decisions for me”

Discussion

Most participants in this study chose to forgo life sustaining treatments and expressed strong need to make such decisions by themselves. This finding supports previous studies reported by Neounoi (2005); Manasurakarn et al. (2008); and Sittisombut and Intong (2009). Participants also described reasons supporting their decisions as death is a fact of life which is inevitable/need peaceful death/and not to burden family/society. The reason that death is a fact of life which is inevitable, is related to religious belief and is recognized as a core of Buddhist values. In Buddhist view, death is natural, death is part of human life, and therefore prolonging death is impossible. Naturally, life trends to decay and breaks down over time. Lord Buddha said that birth, aging, sickness, and death are inevitable. This value is based on the three characteristics of Existence or tri-lakkhana which states that for all existing beings, there is no such thing as permanence. Similar to the study by Manasurakarn et al. (2008) the result indicated Thai Buddhists
selected to forgo life-sustaining treatment because they accepted the end stage of life and believe in the natural law that every human being will die. This time for death being described as natural and discouraging of death as being (Anattata) or death is inevitable (Aniccata/impermanence) in Buddhist teaching.

Peaceful death for Thai Buddhists is defined as a quality of death for human dignity. For Buddhists, a peaceful death leads to a better rebirth (Ratanakul, 2004). This is supported by studies by Neounoi (2005) and Manasurakarn et al. (2008) which indicated that Thai Buddhist patients decided to forgo life sustaining treatments because they desired a peaceful death. Other studies described peaceful death as: to die in one’s sleep, to die without worry, and to recognize this lifetime is finished (Somanusorn, 2010). Peaceful death is a core value for promoting a good death and successful rebirth in Thai Buddhist culture. Kongsuwan, Chaipetch, and Matchim (2012) found that Thai Buddhist participants who understood death was impending and preferred to prepare for a peaceful death with the right state of mind.

Most participants decided to forgo life sustaining treatments because they did not want to burden family/society. This was supported by the study of Manasurakarn et al. (2008) illustrating participant concern about being a burden to their family at the end-of-life. Having a chronic illness caused physical, psychosocial, spiritual, and social problems to the patient and their family. Examples include, duration of hospitalizations, increased financial costs, social burdens. These problems were described as burdens to patients and their families (Larsen, 2009). In addition, feelings of Kreng jai, being considerate of another person, and not wanting to impose or cause another person trouble, or hurt his/her feelings (Knutson, 2004) is found in Thai society. Neounoi (2005) and Manasurakarn et al. (2008) found that Thai patients decided to forgo life sustaining treatment because they were concerned about being burden family.

Decisions to continuing life sustaining treatments were based upon the participants’ perceived duty to prolong life, concern for family, fear of death, and desire to not leave an unfinished task. The result was supported by the studies of Neounoi (2005), Manasurakarn et al. (2008) and Sittisombut and Intong (2009).

The participants who expressed wanting to prolong life believed life is very important and that everybody should continue life. These participants desired to live as long as possible and they believed that technology has the ability to change the natural progression of illness. This perception increases rather than decreases the angst facing doctors, patients, and families. Previous studies supported this finding. Neounoi (2005) and Manasurakarn et al. (2008) found that Thai Buddhist patients with chronic illness and their families who decided to continue life sustaining treatment cited the value of preserving this life as the motivating factor.
Concerning on family was another reason that Thai Buddhists selected to continue life-sustaining treatment. The reasons illustrated worrying about family members, attachment to the family, and desiring to share the success or life experience with family members. This result was supported by the study of Neounoi (2005) and Manasurakarn et al. (2008) detailing that Thai Buddhists who decided to continue the treatment at the end-of-life because they attached to their family and concerned on.

Fear of death is a psychosocial response or problem of chronic illness patient (Larsen, 2009). This feeling often found when people grieve for the eventual loss of their lives. The result is supported by Mahrer-Imhof, Hoffmann and Froelicher (2006) who stated that being with chronic illness such as heart disease made patients fear of premature death.

Allowing family and physician/nurses to make decisions were found if participants would be incapacitated. These perceptions are in accordance with the study of Quinn et al. (2012) which stated that family played important role at the end-of life. Similarly, Wagemans et al. (2010) indicated that the family was involved in the end-of-life decision in the care for people with intellectual disabilities. Whereas, the study by Sittisombat and Intong (2009) found the patients in Northern Thailand had a high regard for their physicians’ authority to make decisions at the end-of life. Trust is an essential component to the patient and proxy relationship in making decision. Then, patients must believe that proxies are capable and willing to make decisions that are reflective of their treatment preferences (Romer & Hammes, 2004). Therefore, end-of-life discussion before incapacity with family and health care provider will protect the patients from unwanted treatments.

Conclusion and Recommendations

The findings of this study demonstrated the perspectives of Thai Buddhists with chronic illness in making end-of-life decisions influenced by values, beliefs and other factors. The findings could be used to improve end-of-life care for patients at the end stage. Nurse educators can integrate this issue into course content that is suitable for students’ learning needs. Researchers can utilize the findings in any study relating to end-of-life issues in the hospital setting and for other studies in the future. Finally, the findings can be used to support end-of-life decision based on the National Health Act section 12.
References


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