Values underlying end-of-life decisions of Thai Buddhist patients and their families

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Abstract:

The purposes of this descriptive research were to explore end–of–life decisions of Thai Buddhist patients and their families and reveal values underlying their end–of–life decisions. The 210–Thai Buddhists aged 40 years or above were recruited systematic randomly. The sample comprised three groups: 70 chronically–ill patients, 70 patients’ families who had and who had no experience in end–of–life decisions. The research instrument was the Demographic Data Form and the Values Underlying End–of–Life Decisions Interview Form with a short vignette of each end–stage patient. The instrument was tested for face validity and employed test–retest reliability: the Content Validity Index and the percentage of agreement index were 0.88 and 0.90, respectively. Data were collected using face–to–face interviews and analyzed using descriptive statistics and content analysis. The results showed that: More than half of the Thai Buddhist patients and their families (51.9%) decided to forgo life–sustaining treatment. Almost one–third of them allowed the physician (18.1%) or family (10.5%) to make the decisions for them. Only 19.5% decided to continue the treatment. The most important values for continuing and forgoing the treatment were hope (92.7%) and becoming free from suffering (47.7%), respectively. Respect was the most important value for Thai Buddhists who allowed their physician or family to make the decision for them (84.2% and 59.1%, respectively). The findings indicated that it is important for health care team to recognize patient’s preferences and values, patient autonomy and self–determination, and support the patients’ end–of–life decisions.

Key words: value, end–of–life decision, Thai Buddhist, chronically–ill patients and their families

Introduction

Making–decision at the end–of–life is very difficult and challenging for patients, their families, and health care providers for four reasons. Firstly, death is inevitable and an undesirable event for many. Secondly, end–of–life decisions are complex and unique. They challenge physical, spiritual, and especially emotional integrity. Thirdly, end–of–life decisions involve ethical dilemmas and conflicts for health
care providers, patients, and families. Lastly, these decisions vary from one individual to another according to their unique personal value systems.

Ethical dilemmas arising at the end-of-life are typically related to choosing between intervening to maintain life or foregoing life-sustaining treatments. Advances in modern medicine can extend life and as well as extend the dying process. Most patients not only want a “good life”, but are also concerned about a “good death”. Dilemmas usually arise when there are different values and wishes among the people involved in this decision making process.

Although decision to live or die is a patient’s right and his or her family’s right in the cases where the patient lacks decision-making capacity, often an end-of-life decision is made by a physician and often against the patient’s preference. As an example of this latter situation, we could consider the well-known case in Thailand of a famous monk named Buddhadasa Bhikkhu, where physicians continued life-sustaining treatment while Buddhadasa Bhikkhu expressed his wish to die peacefully without life-sustaining treatment. Based on a review of research articles published from 1990 to 2000, Baggs and Schmitt also found incongruence between care delivered and patient/family decisions/patients’ values because the end-of-life decision was very often made with little input from patient and family. They described three discrepancies: 1) nearly half of all patients who preferred not to have cardiopulmonary resuscitation (CPR) were still resuscitated, 2) family members believed that patients preferred comfort, but life-sustaining treatments were often used, and 3) family members indicated a sense of fear that health care providers may decide unilaterally to withdraw life-support equipment before the patient agreed to their withdrawal.

Patient advocacy is a very important role for nurses in end-of-life decisions. Nurses today do more than just give comfort care to the dying. They also assist patients with decision-making regarding future available care and help patients make choices regarding death by advocating and facilitating patients to clarify their understanding on end-of-life care, available technology and their wishes regarding death. In this role of advocate, nurses can assist, facilitate, and help patients to exert their autonomy in health care decisions based on their particular values and preferences.

Values vary among people, and the values an individual holds reflect cultural and societal influences. In Thai society, in which most people are Buddhist, there is no doubt that Buddhism plays a conscious and significant role in everyday life, and also influences patients’ end-of-life decisions. In Thailand the empirical understanding of end-of-life decisions is limited, particularly among Thai Buddhists. Exploring the values underlying end-of-life decisions of Thai Buddhists is important for health care providers and could assist the providers better understand of the values that affects patients’ and families’ decision-making. In turn, this information may offer the opportunity for nurses to provide better support and harmonious care, and protect the patients’ rights.

Materials and methods

The proposal of this study was approved by the Institutional Review Board (IRB) of the Faculty of Nursing, Prince of Songkla University, and the Research Ethics Committees of the involved hospitals. All human rights of the research subjects were recognized and protected in the study including: the right to protection from risk and harm, the right to self-determination, and the right to have autonomy and confidentiality.

To explore the values underlying end-of-life decisions in this study, descriptive method was employed. The sample size was estimated based on power analysis with a power of 0.80, and a population value of Cramer’s Statistic of 0.20, for which at least 149 participants should be sampled for an alpha level of 0.05. In the study, 210 participants from the Chronic Out-patient Clinics of Hadyai and Nakhon Sri Thammarat Regional Hospitals were recruited using a systematic random sampling method. The inclusion criteria were age 40 years or above Thai Buddhists, chronically-ill patients (n=70), patients’ families who had experience (n=70) and those who did not have experience in making the decisions (n=70). The Demographic Data Form and the Values Underlying End-of-Life Decisions Interview Form were two parts
of the research instrument. The interview form consisted of a vignette of the end-stage patient, a series of open-ended and close-ended questions, and five pictures of patients using various life-sustaining treatments. The instrument was tested for validity with face validity and the Content Validity Index (CVI). A panel of five expert judges was selected to provide content validity ratings of the items for clarity and relevance, and the result was a CVI of 0.88. The reliability of the instrument was determined with test-retest method. The percentage of agreement index was 0.90. Data were collected using face-to-face interviews and analyzed using descriptive statistics and content analysis.

Results

The majority of the participants were female (61.9%). The ages ranged from 40 to 79 with an average age of 56.38 years (SD=11.33). Most of them were middle aged (40–60 years, 61.0%). The most frequently reported illness in the chronically-ill patients in this study was organ failure due to illness (41.4%) followed by AIDS (22.9%). Almost all the participants had experience and/or had seen life-sustaining treatment of other persons (96.7%). The findings also revealed that Buddhism was an important for the majority of the participants to make decisions in daily life (87.6%). Merit and sin or boon–kam (39%) was the most important Buddhist doctrine for them, and followed by The Middle Path (17%). Most Buddhist activities of the samples were going to a temple (90%), and followed by offering Sanghadana or dedication to all monks (not one specific monk) (63.3%), offering food to a monk (62.9%), and praying (55.2%), respectively. Only 26.2% of them followed Sila or moral practice and only 17.1% of them practiced meditation. Overall, the personal demographic characteristics of the chronically-ill patients, and the patients’ families were similar.

Concerning overall the end-of-life decisions, 51.9% of them decided to forgo life-sustaining treatment (LST) on the vignette of an end-stage patient; 28.6% chose to make decisions regarding life-sustaining treatment by physician or family; only 19.5% of Thai Buddhists decided to continue the treatment, as shown in Table 1. The three studied groups comprising chronically-ill patients, patients’ families who had and those who had no experience in end-of-life decisions responded on the vignette similarly, as shown in Table 2.

<table>
<thead>
<tr>
<th>End-of-life decision</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Forgoing life-sustaining treatment</td>
<td>109</td>
<td>51.9</td>
</tr>
<tr>
<td>Continuing life-sustaining treatment</td>
<td>41</td>
<td>19.5</td>
</tr>
<tr>
<td>Allowing decision by others</td>
<td>60</td>
<td>28.6</td>
</tr>
<tr>
<td>Physician</td>
<td>38</td>
<td>18.1</td>
</tr>
<tr>
<td>Family</td>
<td>22</td>
<td>10.5</td>
</tr>
</tbody>
</table>

Table 1 End-of-life decisions of Thai Buddhist patients and patients’ families (N=210)
For values underlying the end-of-life decisions, the top three values for forgoing the treatment were prolongation of death is a sin (Sila, 100%), quality of death (95.4%), and prolongation of death is impossible (Anattata, 92.7%) but the most important value was freedom from suffering (47.7%). The top three values for continuing the treatment were hope (100%), life is valuable (92.7%), and family concern (75.6%). The most important value of continuing the treatment was hope (92.7%). For Thai Buddhists who allowed a physician to make the decision for them, their significant values were 1) respect for physician (100%) and hope (89.5%). In addition, for Thai Buddhists who allowed their family to make the decisions, their values were respect for family (100%) and family concern (95.5%). Respect was the most important value for Thai Buddhists who allowed physician and family to make the decisions for them (84.2% and 59.1%, respectively).

All end-of-life decisions of Thai Buddhists, the top three values underlying the decisions, and the most important value of each decision are shown in Figure 1.

**Discussions**

The discussion of the findings is presented in two parts: the end-of-life decisions of Thai Buddhists and values behind each decision.

For the end-of-life decisions, the majority of the chronically-ill patients and their families decided to forgo life-sustaining treatment. The results were supported by the studies of Diringer and colleagues, Ferrand and colleagues, Keenan and colleagues, and The Society of Critical Medicine Ethics Committee. It might be explained by three reasons: Firstly, the vignette which was used in this study was a case of severe, hopeless and end-of-life patient; secondly, all partici-

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**Figure 1** End–of–life decisions of Thai Buddhists, top three values underlying the decisions, and the most important value of the decision
pants were middle aged or elderly; and lastly, most of them had had direct or/and indirect experience of using life-sustaining treatment.

From the first and second reasons, several existing studies stated that irreversible stage and older age influenced forgo life-sustaining treatment decision as follows: 1) Diringer and colleagues\(^\text{17}\) studied 2,109 patients who were admitted to the ICU of a large academic tertiary care hospital, and found that the severity of illness and older age were factors that were independently associated with forgoing life-sustaining treatment, 2) a similar result was found in the study of The Society of Critical Medicine Ethics Committee,\(^\text{20}\) with the majority of patients deciding to forgo the treatment in irreversible and terminal stage, 3) Keenan et al.\(^\text{19}\) also found from their study that poor prognosis was the most common reason given for forgoing life-sustaining treatment. Based on the finding, it is possible that a low likelihood of recovery reflected poor expected quality of life and futility to continue life-sustaining treatment.\(^\text{21}\) Ferrand, et al.\(^\text{18}\) found that futility and poor expected quality of life were the most frequently cited reasons in 53% of 1,175 deaths in ICU who made decisions to limit life-supporting therapies.

For the last reason, previous experience with life-sustaining treatment, and having seen such treatment lead to increased/or prolonged suffering, and fearing the same for themselves. In this study, all of the participants who decided to forgo the treatments had experience of using life-sustaining treatment and/or know of life-sustaining treatment experiences of other persons (100%). This reason for forgoing treatment was also found in the studies of Keenan and colleague\(^\text{19}\) and Libbus and Russell.\(^\text{21}\) Both of these studied found that most of patients and their surrogates (86% and 70%, respectively) reported that the earlier experience affected to their choices.\(^\text{21}\) They concluded that patient experience and suffering strongly influenced their choices.\(^\text{19,21}\) Keenan, et al.\(^\text{19}\) and Nijinkaree\(^\text{22}\) also found that patient suffering was the most common reason for forgoing life-sustaining treatment.

Our study also found that 19.5% of the Thai Buddhists decided to continue the treatments. This may be because they thought they needed to survive, or did not wish to die for various reasons. Most of this group (92.7%) thought that life was very significant for them. Hall\(^\text{23}\) stated that people act to preserve life if life is valuable for them. From interview with five families’ member who had recently lost a terminally ill spouse or parent, Konishi, Davis and Aiba\(^\text{24}\) found that a major theme for the families who agreed to continue life-sustaining treatment was “the patient is alive”. They mentioned that forgoing the treatment would be cruel and the same as killing the patients, the patients are alive and have a right to receive a necessary treatment. Moreover, some of the participants who decided to continue the treatment thought that they feared to die, were concerned about family responsibilities or did not want to be separated from their loved one. Two participants stated that:

“I could not die at this time because I look after my grandchild whose parent had divorced and had a new family...living for my grandchild...I am concerned about him.”

( Participant no. 35)

“I need all treatment to prolong my life. Life is valuable. Although I clearly know that long term survival is impossible, I need to try for rescue...I fear regarding life after death...I don’t know where we go when we die.”

( Participant no. 180)

Interestingly, most of all participants preferred to make the decisions by themselves (71.4%: forgoing and continuing the treatments 51.9% and 19.5%, respectively). This was almost the same as the study of Heyland, Trammer, O’Callaghan and Gafni\(^\text{25}\) of 135 seriously ill hospitalized patients, which found that 71% of the patients preferred to participate in the decision-making. Another study by Chantagul\(^\text{26}\) found that more than 60% of patients requested their nurse to ask them for patient’s participation but only 30% of them were asked to participate in nursing care. The majority of all participants in this study chose to make the decision by themselves, and this could be explained that the “right to live or right to die” is a natural right of mankind.\(^\text{27}\) Therefore it is their righteous power to make decision by themselves with their life and their body because it is a self determination or human autonomy. These results indicate that, when possible, more Thai Buddhists preferred to make their own decisions regarding life-sustaining treatment rather than allowing other persons to make the decision for them.
However, 28.6% of all participants preferred to allow their physician (18.1%) or family (10.5%) to make the decision for them. These findings indicated a deep respect for their physician’s and/or family’s authority. Some, of course, may have felt uncertain about making such an important decision by themselves or they had not enough confidence for making the decision. Boyd and colleagues stated that confidence associated with the decisions and was increased with authority. The findings in this study were congruent with this idea. The majority of the participants who allowed a physician or their family to make the decision for them (63.16% and 72.7%, respectively) expressed the belief that they could not make the decision by themselves. They dare not to make the decision. Their family including their children looked after them and their life was under their family’s care. As reported by two participants:

“I dare not to make choice. I can’t choose by myself. My son gives me money for daily expenses and I fear that he should blame me, if I don’t ask him or don’t let him to make the choice.”

(Participant no. 22)

“I’m not sure that my decision is right or wrong. For me, thinking about death is an unwanted thought and unwanted to meet. The choice about death should be based on talking and discussing among several persons.”

(Participant no. 41)

In conclusion for the end-of-life decisions, 71.4% of our participants made decisions by themselves, which comprised forgoing and continuing 51.9% and 19.5%, respectively, with the remaining 28.6% of them allowing the decision to be made by the physician or their family. These results indicate that, when possible, most Thai Buddhists preferred to have their own decisions regarding life-sustaining treatment.

For values underlying end-of-life decisions of Thai Buddhists, personal values guide and inform their responses and decisions in all areas of our life. Therefore, the discussion of the findings regarding values underlying of each decision are discussed as follows: for forgoing the treatment at the end-of-life, although the majority of the participants stated that several Buddhist doctrine expression values underlined their decisions as shown above, the most important value of their decisions was the social expression values: freedom from suffering. This result might be explained in two ways: 1) enlightenment and acceptance of death should occur through practicing meditation, with which people can purify and calm their minds. With a peaceful and purified mind people can see and understand the real nature of existence and universal laws. But in this study, only 17.1% of the participants had practiced meditation; and 2) patient experience and suffering were strongly influenced the decision to forgo life-sustaining treatment. From the study, almost all the participants (96.7%) had had direct or/and indirect experience of using life-sustaining treatment. Below are two expressions from 95-Thai Buddhists who stated that “freedom from suffering” was their values; as they clearly expressed:

“I had experience about treatment for prolonging life. I saw a nurse and doctor compressing on a patient’s chest. I pitied the patient so much. It made me feel bad and afraid. I walked away from that place. From this experience, I told my family that at the death time let me die, don’t compress my chest in order to sustain my life.”

(Participant no. 21)

“I don’t need chest compression. I think it will make me suffer. A comfortable death is better than living with suffering. I am not afraid to die but afraid to suffer.”

(Participant no. 191)

For continuing the end-of-life treatment, the findings revealed that the significant values were “hope”, “life is valuable”, and “family concern”. Hope was the most important value underlying continuing the treatment in the study. It is possible that although all Thai Buddhists in the study were elderly and the majority had a hospital admittance history (65.7%), 78.6% of them perceived their health status to be healthy. So, they hoped to survive and have a miracle. The finding supported the idea that although the decision based on the vignette of an end-stage-patient, the hopeful participants still chose to continue the treatment. As five participants expressed:

“Uncertainty, I hope that I may survive (her Thai words: mai-tueng-tee-tai-mai-wai-che-wa-wad).”

(Participant no. 33)
"I hope to recover and survive because I have the experience in the cases of my wife, my father, and others. I found that although they were very sick patients, they escaped from death so I hope to have a miracle."

( Participant no. 30, 57, 151, and 185 )

For the value “family concern”, the participants reported that they were concerned about their family because they and their family lived together made them feel very close, loved each other, and were afraid of family separation. Chuaprapaisilp and Sirikarn stated that in Thai society when a death is coming, everything in the person’s life is being lost; they especially dislike being separates from their family or significant others. As reported by some participants:

“I love, am concerned about, and care for my father and my family members. I prefer to stay with them and am afraid of being separated from them.”

( Participant no. 99 )

“I don’t desire to separate or leave my children and my grandchild. I am concerned about their daily living and need to live with them as long as possible.”

( Participant no. 181 )

For allowing a physician to make the end-of-life decision, the most important value was “respect for physician”. This was also noted by Bowman and Singer who conducted a qualitative survey with 40 Chinese seniors 65 years of age or older and found that their respondents respected to physicians’ decisions because they believed in the competency of physicians, and trust their professional knowledge and their experience. They also stated that a medical paternalism influences to Chinese beliefs, so the relationship between physicians and patients is the trustworthiness of the physician. Fleming confirmed the finding that end-of-life decision in Asian cultures is usually based on a paternalistic model of trust and is less focused on individual autonomy. A prevailing paternalistic attitude that promotes a dependent role for a patient manifests in the decision being made on behalf of a patient because of the decision maker’s confidence that they know what is best for the patient.  

We might also consider the current “biomedical model” one of three paradigm models of the concept of death, which is a strong influence on health care personnel and society at present. According to this paradigm and concept of death, a doctor takes the role of repairing the impaired part of a patient and becomes involved in decision about the patient death. This paradigm also suggests that death should be prolonged through the use of advanced technology. It is possible that this model also influences the participants who said their decision was based on “respect”. For the value “respect”, the participants confide to their physician’s competency, professional knowledge and experience. As some of these participants stated:

“I confide in my doctor. I believe in his ability, because he has special knowledge in this area and also has lots of experience.”

( Participant no. 3 )

“I leave my life in the hands of my doctor. I think he can help me with his ability.”

( Participant no. 14 )

“If I did not respect a physician, I would not come to visit him.”

( Participant no. 59 )

“A doctor is like a god: he gives me a life or lets me survive.”

( Participant no. 114 )

In terms of allowing the decision to be made by the family at the end-of-life, the most important value was “respect for family”. It might be because they believe that their families love them, best understand their wishes, and should make the best decision for them. Furthermore, in Asian culture, the individual is considered an integral part of the family, thus the accomplishments and choices of the individual are not theirs alone, but belong to the family. As three participants stated:

“I confide in my family because I believe that they would select the best thing for me.”

( Participant no. 44 and 201 )

“I love my family. My family also loves me. We live together and clearly understand each other. They want only the best things for me.”

( Participant no. 115 )

For the value “family concern”, their reasons indicated that their family was their significant person or the most important person for them. Two participants expressed this as:
“For me, my life belongs to my daughter and my son. At the end-of-life, the decision depends on my daughter and my son. I care for their feelings.”

(Participant no. 23)

“I love, am concerned with, and feel very close with my family. If I make the decision by myself, it should be made my family sorrow.”

(Participant no. 179)

Conclusions and suggestions

More than half participants in the study (51.9%) decided to forgo life-sustaining treatment with 28.6% of them choosing to allow their physician or family to make the decision for them. Only 19.5% decided to continue the treatment. Although the study was restricted to end stage patient, some still decided to continue the treatments. Almost all (71.4%) made the decision to discontinue or continue treatment by themselves rather than having a physician or their family makes the decision for them. The findings also indicated that the end-of-life decisions are based on various values. Therefore, the health care team should be trained to recognize and assess patient preferences; help the patient with value clarification and promote a patient’s autonomy and self-determination.

The findings revealed that “respect for physician and family” was the values underlying end-of-life decisions of all participants who allowed a physician or family to make the decision for them. Therefore, assisting patients and families on making decisions at the end-of-life and solving their ethical conflicts and dilemmas related to the decisions, including an improving a quality of care regarding end-of-life decisions need an involvement of multidisciplinary health care team, especially a physician. Ethics rounds about end-of-life decision should be established as a method to encourage not only nurses but also the other health care team to be aware and enhance skills of the ethical decision making and ethical sensitivity and should be pushed to state in health care policy and should be included in physician and other health care team training. Moreover, the health care team should encourage or give an opportunity for patient and family to be involved participates in the decision. Finally, patient advocacy to refuse life-sustaining treatment in the terminal stage, following Section 12 of Thai National Health Act, B. E. 2550, should be the responsibility of the health care team.

The findings provide information for health care providers by assisting them in understanding the end-of-life decisions of Thai Buddhists. The findings may be used as a guideline for health care providers to assist patients and families make decisions at the end-of-life and solve ethical conflicts and dilemmas related to the decisions. Moreover, the results of this study may be used to improve quality of care regarding end-of-life decisions of Thai Buddhists by helping them to provide care based on patient’s best interests. In addition, these findings will provide baseline data for further research.

In brief, the descriptive knowledge that emerged from the study can be used to guide and understand values underlying end-of-life decisions in Thai Buddhists. However, research about end-of-life decisions should be continued.

References


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Appendix

Vignette

Mr. A (for a participant who is a male) or Ms. B (for a participant who is a female) is a terminally-ill patient whose illness cannot be cured. Mr. A or Ms. B has suffered pain over the past year and high doses of painkiller have been administered to the patient regularly. Sometimes it is difficult for him/her to breathe gasping for breath. The patient’s condition becomes worse and he/she cannot help himself/herself in his/her daily routines and has to be bedridden. It may be necessary for a tube to be inserted through his/her stomach to give food to him/her. Anti-biotic probably has to be administered for complications such as lung infection. If Mr. A or Ms. B stops breathing and his/her heart stops beating, the doctor will help making his/her heart beat again and the patient will have to be on a respirator.

If you were Mr. A (for a participant who is a male) or Ms. B (for a participant who is a female), how would you decide about life-sustaining treatments?

(   ) 1. Receiving treatment to prolong your life (Answer Questions 1-13)
(   ) 2. Refusing/terminating treatment that prolongs life (Answer Questions 14-30)
(   ) 3. Asking the doctor to make a decision (Answer Questions 31-36)
(   ) 4. Asking your family to make a decision (Answer Questions 37-43)
(   ) 5. Others (Please specify) ..............................................