



# Decision to Withdraw Life- Sustaining Treatments: The Experience of Thai Family Caregivers

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## Abstract

End-of-life decision-making is a complex process and more challenging when decisions are made for others. Little is known about Thai family members' involvement in decision-making to withdraw life sustaining treatments (LSTs) from loved ones with serious illnesses. This qualitative study explores the experiences of family caregivers in Southern Thailand regarding decisions related to LST withdrawal. In-depth interviews were used to gather data from fifteen primary caregivers, who were involved in LST withdrawal decision-making. Content analysis was applied, and several techniques, such as member-checking and peer debriefing, were used to enhance trustworthiness. Four main themes were identified: facing dilemmas, weighing up options, making a consensual decision, and accepting the reality of life. The findings pointed out the significant roles played by family meetings and early end-of-life discussion in the process of decision-making to withdraw LSTs from loved ones. Further research on communication among patients' family members and health care providers is recommended.

## Keywords

end of life decision, family caregivers, Thailand, withdraw life-sustaining treatments

## Introduction

The decision to withhold/withdraw life-sustaining treatments (LSTs) is widely accepted in intensive care units (ICU) and accounts for a significant part of hospital mortality (Lobo et al., 2017). However, a considerable variability in the prevalence and pattern of LST withdrawal has been found around the world, ranging from 0% to 84.1% (Mark et al., 2015). Several clinical factors, such as greater disease severity, presence of  $\geq 2$  organ failures, severe comorbidities, medical and trauma admissions, and admission from the Emergency Department (ED), have been found to be independent predictors of a decision to withhold/withdraw LSTs (Lobo et al., 2017). Furthermore, this variability may be explained by sociocultural influences, including religious, statutory, or health provider-related factors (Bain et al., 2017; Mark et al., 2015; Phua et al., 2016). As reported by Guidet et al. (2018), LST limitations are more common in countries with a high gross domestic product (GDP) and less common in religious countries. Phua et al. (2016) has also found that physicians with Islamic, Hindu, Buddhist, and Christian faiths were more likely than those without

religious affiliations to withhold cardiopulmonary resuscitation in end-of-life care. Also, those from a low-middle-income country and region were more likely to decide to withdraw LSTs in a given case scenario, while medical physicians of Islamic, Hindu, Protestant, and Shinto faiths were independently less likely to do so. Notwithstanding, the studies being referred here were mainly conducted among health care providers. Due to societies becoming increasingly multicultural and diverse in terms of religious belief, an adequate understanding of end-of-life decisions regarding LST withholding/withdrawal from the perspective of family caregivers would help health care providers tailor individualized care based on patient and family preferences, beliefs, values, and religious/cultural backgrounds (Manalo, 2013). The failure to recognize or facilitate cultural values surrounding end-of-life decision-

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making can lead to conflict between the patient/family and the health care staff (Kim et al., 2018). In addition, Wallace (2015) has addressed the need for further studies on the process of decision-making during end-of-life care among the patients' family members.

## Background

End-of-life decisions, particularly the decision to withdraw LSTs, involve a complex process and can be emotionally challenging to all involved in care, particularly when patients are comatose or lack decision-making capacity. Such patients may be unable to participate in the decision-making process; thus, families are usually expected to take the substitute's role in making decisions on their behalf. The study of Lind et al. (2013) explored how relatives of ICU patients experience their involvement in the end-of-life decision-making processes. They found a variety of ways that family members are involved in end-of-life care decisions regarding conscious patients in ICU; they range from active participation in the decision-making process to the acceptance of the physicians' decisions or just passively receiving information. Similarly, a recent systematic review of qualitative evidence reported varied levels of family involvement in decision-making, particularly related to the withdrawal of LSTs (Anderson et al., 2019). Also, there is evidence that families take this heavy responsibility with a great burden (Braun et al., 2008; Githaiga & Swartz, 2017; Wendler & Rid, 2011). They are aware of its gravity and consequences. Previous research findings illustrate that families view withdrawing LSTs as the most difficult decision they have ever made (Githaiga & Swartz, 2017; Schenker et al., 2012; Wiegand, 2008). Families tend to express a profoundly emotional conflict between the desire to act in accordance with the patient's preferences and in line with their conscience (Schenker et al., 2012). A study by Miller et al. (2016) found that family members expressed considerable uncertainty about decisions made on patients' behalf. They were concerned that the decision they made might be potentially ineffective. Feelings of stress, guilt, and doubt have been commonly reported as negative emotional consequences on family members when making treatment-related decisions for critically and terminally ill patients (Miller et al., 2016; Wendler & Rid, 2011).

End-of-life decisions are bounded in a clinical, social, political, economic, and ethical context (Cain et al., 2018). Thailand is a middle-income country with a family-centric and hierarchical society. Family plays a key role in care-related decisions. Regarding end-of-life decisions, they value physicians as being both clinically competent and knowledgeable when it comes to medical treatments, while family members, particularly those with more

seniority, are regarded as being best suited to understand the needs and concerns of both the patients and the other family members. For this reason, Thai persons with chronic conditions often choose to transfer their decision-making authority to either their physicians or family members (Manasurakarn et al., 2008; Sittisombut & Inthong, 2009). Furthermore, religious faith plays a crucial role in shaping the Thai way of living and dying. In southern Thailand, although the majority of the population are adherents of Buddhism, nearly one-third are Muslims. Previous studies have indicated that religious faith influences end-of-life decisions. Some authors have found that Thai Buddhist family members mobilize religious resources to accommodate the suffering incurred from the decision to withhold or withdraw LSTs for critically ill patients in the terminal stage of the disease (Vattanaprasan et al., 2019). Similarly, Thai Muslim family members, who are assigned to act as substitute decision-makers for dying patients, make end-of-life decisions based on their religious beliefs, that is, that both one's death and place of death are determined by God (Jehloh et al., 2019).

Establishing end-of-life discussion and decision-making among relevant stakeholders is not a common practice in Thai culture. Although Thais believe that death is a natural part of life and inevitable, talking about death is a taboo subject. Conversations around dying and death are viewed as a curse or bad luck that can hasten the progression of one's health deterioration and which extinguishes the hope for a cure. Therefore, discussions on death are rarely undertaken while the ill person remains alive, even when he/she is at the end stage of life. Consequently, both health care providers and family members often feel reluctant to talk about death and dying (Sinthuprasit & Kangsadanpor, 2019). Most patients do not formally communicate their wishes to either their family or physicians. Thus, family members, particularly family caregivers, are affected by situations related to needing to make end-of-life decisions for their relative, especially the decision to withhold or withdraw LSTs when the patient lacks the decision-making capacity to do so on his/her own. The majority of research studies on end-of-life decisions have been undertaken in Western countries, where patient autonomy is highly valued in medical practice. Meanwhile, many non-Western cultures place a higher priority on family involvement in end-of-life decisions than on patient autonomy (Kim et al., 2018). The investigation of decision-making processes regarding LST withholding or termination from the point of view of Thai family caregivers has been scarcely undertaken and remains inadequately elucidated. Therefore, the aim of this study was to describe the Thai family caregivers' experiences related to their involvement in deciding to withhold or withdraw LSTs for their loved ones.

## Methods

To gain a better understanding of the Thai family caregivers' experiences involving decision-making related to LST withdrawal from their loved ones, a qualitative descriptive design based on a naturalistic approach was employed for the data collection and analysis. The naturalistic approach aims to generate a thorough understanding of a phenomenon by accessing the meanings individuals attach to it, with a focus on literal description (Sandelowski, 2010) as well as on the analysis and interpretation of the meaning people assign to events (Bradshaw et al., 2017). According to Colorafi and Evans (2016), qualitative descriptive research provides true understanding to inquiries about how people feel about a space, why they utilize certain elements of the space, who uses specific services or functions of the space, and the factors that help or impede their use.

## Setting

A tertiary provincial hospital with more than 500 beds in Southern Thailand was selected as the research setting to recruit potential participants. This hospital has a palliative care center. One family medicine physician and an advance practice nurse provide palliative care consultations for attending physicians and nurses in the hospital. This palliative care center has implemented a protocol for the withdrawal of LSTs since 2015. This project was developed based on extensive discussions among the first author, who is a nurse educator, and health care providers involved in end-of-life decision-making and care for both patients and their families after the decision to withhold/withdraw LSTs was made. Both the medical physicians and nursing staffs mentioned that they would like to hear the voices of their clients, which could help them improve their end-of-life care practices. Data collection was undertaken at the participants' homes between March 2019 and October 2019.

## Participants

The participants were purposively selected based on their experiences with care for patients at the end stage of their life and their involvement in LST withdrawal decisions. To be eligible, the participant had to be a primary caregiver and involved in decision-making concerning LST withdrawal for a critically and terminally ill patient; at or above the legal age of consent or at least 20 years of age; and able to read, speak, and understand the Thai language. These did not include paid caregivers, who were hired by families to provide care, as their relationships with the patients could not be assumed to have been the same as those of family caregivers. In this study, the recruitment

ended once data saturation was reached; this was indicated by information redundancy or the lack of new information emergence (Morse, 1991). It appeared that code saturation was met at 9 interviews. Additional 6 interviews were conducted to reach meaning saturation, in order to help the researchers develop a comprehensive understanding of the phenomena of interest (Hennink et al., 2017). The total number of participants comprised 15 family caregivers, who underwent 16 interviews.

## Ethical Consideration

Prior to undertaking the study, ethics approval was sought and received from the Prince of Songkla University's Centre for Social and Behavioural Sciences Institutional Review Board (Approval no. PSU IRB 2017 – NL 012) as well as the ethics review board of the health institution where the study took place (Approval no. 316/10/61). Participants were informed that they had the right to decline answering any of the questions of the interview or terminate the interview at any time if they so chose. We were aware that some of the interview questions could cause unanticipated emotional discomfort. For this reason, during the interviews, we observed the participants' facial expressions and non-verbal behaviors in order to assess their emotional states. In cases when emotional discomfort was noticed, the protocol for distress management was followed. Participants were informed that they could request to stop the interview in case of any such eventuality, and that a referral to a mental health professional was available to them free of expense. Also, the decision to pursue the interview any further was left to the discretion of the participants. In addition, they were assured that the collected data would remain anonymous, and that a code number would be assigned to each participant instead of using real names in order to protect his/her privacy. The audio recordings contained interview files that were stored on the lead author's computer and secured with a password. All identifiable information of the participants was kept in a locked filing cabinet separate from interview transcripts, field notes, and reflective diary. Access to the data was restricted to the lead author only. No participants withdrew from the study, but two participants expressed feeling guilty and cried when sharing their experiences related to making the decision to withdraw LSTs from their dying loved one. However, they elected to continue the interview. After providing psycho-emotional support according to the distress management protocol, one participant completed the interview on the same day, while the other one preferred to continue the interview 1 week later. This participant indicated later that the interview had helped her share her emotions that she had internalized since her husband had passed away.

**Table 1.** Sample Interview Questions.

Guide questions
How did you perceive the patient's health condition at that time?
What were your concerns at that time?
How was the decision made?
What were the things that you valued the most in that situation?
How did this decision affect your life and the family?
What was the experience of being involved in the decision to withdraw this type of treatment like?
How would you describe it?

### Data Collection

After receiving ethical approval and permission to collect data from the selected hospital, the second author initially reviewed the records of palliative care patients and listed the names of patients for whom the decision to withdraw LSTs was made more than 6 months before the study was undertaken. The rationale behind this is the finding that the level of stress among bereaved family caregivers who had decided to discontinue or decline life-sustaining treatments for their loved ones decreases gradually 6 months after the patient's death (Tilden et al., 2001). The second author, then, phoned potential participants to inform them about the study and invited them to participate. Once they agreed, an appointment for the interview was made at the participants' convenience regarding both time and place. On the appointed day and at their preferred place, the second author introduced the lead author to the participant. After building rapport with the participants, she provided them with information about the study and its purpose, informed them about their rights as it regards their participation in this study, and assured them that all their disclosed information would be kept confidential. Informed consent was then obtained from each participant.

Face-to-face in-depth interviews were used to elicit the experiences of family members, who were involved both in the care for and the decision to withdraw treatments from their relative suffering from a critical and terminal illness. A semi-structured interview guide was developed based on published literature and the researchers' experience related to palliative care research and care of terminally ill patients and their families during their transition to the end of life. Open-ended questions, for example, "Can you tell me about your experience regarding the last hospitalization of your loved one, who had a critical and terminal illness?" were used to initiate discussions. The participants were encouraged to talk freely. Probing questions followed based on the emerging

key issues related to the participants' experiences as well as the study's objective. Sample interview questions are presented in Table 1. In addition, descriptions of the atmosphere during the interview, facial expressions, gestures, voice, and the behaviors of the participants during the interview were noted soon after the lead author returned to her office.

All the researchers involved are native speakers of Thai. However, the interviews were conducted solely in Thai by the lead author. She is a nurse educator at a university and an experienced qualitative researcher, who has been involved as a principal investigator in several qualitative studies on the end-of-life experiences of patients and their families. Furthermore, she serves as a clinical instructor to nursing students in both medical wards and ICUs, but she did not have any clinical relationship with the participants of this study. All interviews were audio-recorded with the participants' permission, and transcribed verbatim in Thai. Fourteen participants engaged in one in-depth interview session. Only one participant, who experienced emotional discomfort and requested to postpone the continuation of the interview until the following week, underwent two interview sessions. The interviews lasted approximately 30 to 60 minutes.

### Trustworthiness

In accordance with the guidelines of Lincoln and Guba (1985), several techniques aimed at enhancing the trustworthiness of the study were employed. Efforts were made to establish a trusting relationship by ensuring the participants that our professional values corresponded with those of our institution and by adhering to its governing body's standards and regulations in a transparent manner (Guillemin et al., 2018). As the authors shared the same cultural background with that of the participants, we were aware that our level of education and professional background could inevitably place us in a higher position within the hierarchical social ladder of the Thai cultural context compared to them. To minimize such power relation during the interview and to promote a trust relationship between the parties, the interviews were undertaken at the participants' homes, the researchers dressed casually and behaved with humility in order to make the participants aware that they were sincerely valued as the experts of their lived experiences. Before ending the interview, the data were verified with the participants. We summarized the key issues raised and asked whether they were complete, reflected the participants' thoughts adequately, and if there was anything they wanted to add or discuss further. In addition, the lead author kept a reflective diary during her fieldwork in order to describe her thoughts and feelings related to the

interactions between herself and the participants as well as between herself and the collected data. Peer debriefing was established through regular meetings among the research team members during the fieldwork and data analysis phases of the study. Furthermore, the audit trail approach was applied (Amankwaa, 2016). All research documents were kept and available for the auditor to review. Finally, coding, sub-coding, and content analysis were maintained, so others could examine and verify the researchers' decision-making and interpretation of the findings.

### Data Analysis

An inductive content analysis was conducted according to the guidelines of Elo and Kyngäs (2008). The initial data analysis was performed concurrently with the data collection during the interview process. A final qualitative analysis was undertaken manually after data saturation by the lead author. During the analysis process, the interview recordings were listened to and considered the original source of the data. The field notes and reflective diary were also reviewed. This process allowed the lead author to not forget the feelings associated with the data collection and recall the situations related to that process vividly. The transcripts were read and reread over and over in order to gain as thorough an understanding of their contents as possible. Doing so helped the researcher immerse herself into the data. Sentences or word groups as well as key phrases were coded and carefully considered in terms of how they managed to describe the phenomenon or experience studied. All coding was categorized and grouped. At this stage, the lead author also revisited the field notes and reflective diary again. These steps improved data reduction by connecting disparate pieces of information into conceptual clusters (Colorafi & Evans, 2016). Then abstraction was performed to formulate a general description. Dialogue and discussions among the research team members were held regularly during the analytic process until all researchers reached an agreement on the codes and categories. After that, the lead author translated the participants' accounts into English. Since language is a vital aspect of social conventions and interactions, translation and transmission are closely linked to not only words and grammar but also culture (Filep, 2009; Wongsee, 2021). With this in mind, we consulted and discussed the translated contents of the recorded accounts with native English speakers with the aim of verifying the most appropriate and/or equivalent English words that conveyed the exact meanings (or as close as possible to them) of their counterparts in the Thai context.

### Results

We interviewed fifteen primary caregivers; twelve of them were female. The majority was Buddhist ( $n = 9$ ). The participants' ages ranged from 32 to 65 years, with an average of 44 years. Most of the participants were aged over 40 years old; 2 were about 65 years old. They represented a diverse range of relationships to the patient; 6 were children, 3 spouses, 3 granddaughters, and the remaining 2 were a relative and a mother. None had any underlying health concerns. Thirteen participants had secondary family caregivers. The interviews occurred at an average of 6.9 months after the LST withdrawal decision was made. Thirteen patients had passed away, while the other two were still alive with a bed-ridden status. The mean time to death for the thirteen deceased patients was 20 hours after the withdrawal of mechanical ventilation and/or other LSTs.

Four main themes related to the decision-making process to withhold/withdraw LSTs from critically and terminally ill patients cared for by family primary caregivers were identified: (1) facing the dilemma to make the decision; (2) weighing up the available treatment options and their consequences; (3) making a consensual decision; (4) accepting the reality of life or *Thum-jai* (in Thai).

#### Facing the Dilemma to Make the Decision

Before the treatment withdrawal decision was made, the caregiver participants experienced the dilemma of whether to withhold/discontinue or continue life-prolonging treatments for the relative under their care and reported being indecisive. Many participants stated that initially, although the patients were critically ill, they strongly believed that the physicians and nurses would be able to restore the patient's health. They hoped that their family member would survive their illness and be able to return home. Yet, as time went on, the participants did not see any positive changes in the patient's health condition. Therefore, when the attending physician asked for their consent to pursue further aggressive treatments such as a tracheostomy procedure or acute hemodialysis, the participants felt uncertain to decide either way. They could not decide whether to try with the new treatments or decline them. The 36-year-old daughter of a comatose patient with an acute hemorrhagic stroke recalled:

*At that time, everything was so chaotic...When thinking about my father's health situation, I thought that his condition could turn any way...There were lots of questions in my mind, for which I did not have an answer. I didn't know whether it was the right or the wrong decision to receive or refuse new treatments.*

The lack of understanding regarding medical treatments and their consequences was the main cause of such indecisiveness. The caregiver participants recalled their lives at that time as being in turmoil and darkness. A 52-year-old participant reported being stressed when the physician informed her about the need for a new treatment plan, that is, a tracheostomy, for her mother.

*I had been under stress for several days since the physician told us about the plan to perform a tracheostomy. ...The most stressful thing at that time was that I did not understand (what the physicians said). Perhaps this was because I didn't understand what a tracheostomy was. ...At that time, my thoughts were in-between the two sides of the decision... On the one hand, I thought that if we decide to continue the medical treatments for her, she might stay with us longer. On the other hand, I knew four persons in my community, who had passed away after undergoing this procedure. In the end, we could not make the decision in favor of the procedure because we didn't understand it clearly.*

In this instance, the stated dilemma stemmed from a lack of clarity about the patient's health condition and the recommended treatment for it. This participant did not understand the medical term "tracheostomy" and how this medical procedure would benefit the patient. Ultimately, she was fearful of making the wrong decision.

### Weighing Up the Available Treatment Options and Their Consequences

During the period of indecisiveness, the participants had sought further information from several sources, such as physicians, nurses, relatives of other patients, their own relatives as well as the internet. Also, they used their own observations and experience in order to reason through their decision-making process. Then they processed the obtained information and used it to weigh up the pros and cons of the available options before reaching the LST termination decision. A 36-year-old participant had taken care of her mother with dementia, who had suffered a cardiac arrest and brain anoxia, for a week. She explained how she arrived at the final decision of treatment withdrawal.

*It does not mean that we didn't consider things...like, we made the decision without any consideration...No..., we asked the physician what would happen if we decided one way or the other. In addition to the information obtained from the attending physicians, my father's friend, who is a retired medical physician, always provided us with adequate information; we asked him questions all the time.*

The aspects that were weighed up before making the decision were: (1) there being no hope for a cure; (2) honoring the patient's wishes; (3) ceasing the patient's suffering (4) acting in line with the patient's and/or the family's religious beliefs, and (5) considering the family burden resulting from the care provided to their loved one.

### There Being No Hope for a Cure

The perception or determination that there was no hope for a cure was addressed by several participants as being one of the factors for the decision to withdraw treatments. These participants said that although the patient had received aggressive treatments via advanced medical technologies to sustain his/her life, it seemed like their loved one did not respond positively to them. Hence, their hope for a cure had gradually disappeared, and it was replaced by a feeling of hopelessness. When asked about their reasoning they followed to arrive at their decision, a 33-year-old participant shared that although her grandfather had received renal replacement therapy, he did not get any better. Eventually, she realized that her grandfather's illness was very severe, and that she was going to lose him.

*We observed that his body did not respond to what the physician treated him with. Therefore, attempting to prolong his life meant that we would have caused him to suffer more....because undergoing hemodialysis didn't bring about any better outcome.... We did not have the hope for even a 10% chance of him surviving his illness. ....When we realized that there was no hope, we decided that it was pointless to continue with the dialysis. Why prolong life when we did not have any hope for a cure...the hope that he could return to us?*

This account indicates the participant's loss of hope for the full recovery of her grandfather. She and her family members had realized that the treatments the patient was receiving were merely for either sustaining or prolonging his life.

### Honoring the Patient's Wishes/Preferences

Close to half of the participants spoke of the patients' preferences as being an important reason to make the decision to terminate LSTs. A 49-year-old participant said that her mother became acutely sick with breathing difficulty—and was taken urgently to the hospital. At some point during the hectic events of this medical emergency, she was asked to make an abrupt decision for the administration of lifesaving procedures to her mother. She mentioned that everything happened so fast. The health care team then performed cardiopulmonary

resuscitation (CPR), and intubated and transferred her mother to the ICU. After being hospitalized for 2 weeks, the physicians and nurses informed her that her mother's health condition remained severe and was worsening. They also asked her for the possibility to make the decision of discontinuing and/or withholding life-preserving treatments. This participant shared that it was the most difficult decision she had to make for her unconscious mother. At that time, she recalled what her mother had informally told her children regarding her wishes related to end-of-life care before her health condition worsened.

*My mom told us (the participant and her brothers) that when it was the time, she would prefer to die at home. She also said that if she was going to die, she would rather not be intubated...she instructed us this way since the time she was well.*

This participant mentioned that had her mother been conscious, she would have disapproved of being put on a breathing machine at the ED. The participant explained that she consented to the health care team to intubate her mother at that time because her family hoped that it would save her mother's life and help restore her to good health. Later on, she realized that things did not go as well as she had expected. Ultimately, the family members relied on her mother's wishes to guide the final decision-making.

### Ceasing the Patient's Suffering

The patient's suffering was repeatedly highlighted as another reason for the decision to withhold/withdraw LSTs. While taking care of their family members at the hospital, the participants had witnessed how much suffering critically ill patients experienced. A 53-year-old mother of a patient with hepatic coma and prolonged intubation recalled:

*We considered terminating treatments. We didn't want to see him suffer anymore. It was such a pity to see him suffer; therefore, we decided to discontinue using the ventilator and withdraw the other treatments. Intubation caused him much agony, so we made the difficult decision to end his suffering.*

### Acting in Line with Religious Belief

Religious belief was used to explain the patients' life destinies by some participants. In the face of a hopeless prognosis, these participants relied on their religious beliefs to guide their decision-making. Some participants believed that dying while using life-support technologies is an unnatural way to die. In addition, according to their beliefs, living and dying are directly related to the good

and bad karma one has accumulated over one's lifetime. A 49-year-old Buddhist caregiver recounted:

*We reasoned we should let her go naturally. If she had any merits remaining, she would have lived longer. However, if her merits had run out, she would die at that time. We made the decision to let her go naturally and peacefully. We knew we could not bring her back (restore her health)...so, it was best to let her die peacefully.*

Similarly, after taking care of her grandfather for 3 weeks, a 33-year-old Muslim participant realized that the patient was dying and believed that he was going journey toward God. This led her family to the final solution they determined for the patient's life.

*It was like his body didn't respond any longer to treatment...He was ready to return to Allah...as we say in our language...At that point, we knew the patient would not return to us anymore.... It was obvious to us that he was on his way (to Allah).*

### Considering the Family Burden

Most participants mentioned the family burden as one of the factors that played a role in the decision-making to withhold/withdraw LSTs. Some participants talked about the financial burden the family incurred as a result of caring for their dying loved one. These participants lived from hand to mouth. As they spent most of their time taking care of their relative at the hospital, they could not continue earning a living as usual, which resulted in a loss of family income. Therefore, family financial concerns were a significant part of the decision-making. The 43-year-old wife of a patient with acute hemorrhagic stroke and hepatic coma explained the impact of caregiving on her family's livelihood:

*If we had not decided to withdraw the treatment, what would have been the alternative? Could I have left him at the hospital and forgotten about it? Since I could not have left him there alone, how would I have been able to do my job? I had stopped working for many weeks already...I kept thinking over and over about this ...*

Furthermore, two participants reported having the responsibility of taking care of other older relatives with chronic conditions at home. When considering that their hospitalized relative was more likely to die than survive, they preferred to allocate more time to providing care for the other sick relatives at home instead. In addition to taking care of her sick mother at the hospital, a 58-year-old participant also had a dependent grandmother, who required care at home. Therefore, she weighed up the



option of caring for her hospitalized mother, who suffered from hopelessly irreversible conditions, against caring for another elderly person at home, that is, her grandmother, who was completely dependent on her care but enjoyed a much better prognosis. This 58-year-old participant explained:

*We determined that instead of devoting our time to caring for the one who would not last long, it would be better to spend that time looking after the other sick elderly person at home.*

### Making a Consensual Decision

All participants reported that their relative had neither designated a legal document that delegated authority to a family member to make medical decisions on their behalf, nor completed a legal document outlining their preferences related to medical treatments if they were unable to make decisions for themselves when care was needed. Despite being the primary caregiver, our participants stated that they could not make such a decision solely on their own. They pointed to the need to ask other family members for their opinions. Therefore, the decision to discontinue or withdraw LSTs was made in a consensual agreement between all family members, particularly the older persons. A 52-year-old participant who was the brother of a patient with upper gastrointestinal bleeding and alcoholic cirrhosis explained:

*One day, a nurse came and organized a meeting between us, the family, and the medical personnel. We talked among ourselves and discussed the question of whether we should consent to additional treatments or decline to pursue them. It was apparent to me that he could not stand it (further aggressive treatment). He was seriously ill... Although I am his brother and in the position to make such a decision, I asked his son and daughter for their opinions regarding whether to take him back home or keep him in the hospital and continue the treatment...They agreed to take him back...so we took him home.*

Similarly, a 33-year-old participant was told by the physician that her grandfather had renal failure and needed hemodialysis. After a family meeting with the palliative care nurse case manager, all family members consented to the hemodialysis with the hope that the patient would get better and recover. However, the outcome of the dialysis therapy was not what was expected. Consequently, they all agreed to withdraw all treatments and took the patient back home.

*I could not make the decision alone. ...I had to ask my father and his relatives. When all his (grandfather's) children come together, we decided to try the dialysis; we thought that,*

*perhaps, he could recover and return to normal. But after undergoing the dialysis, he got worse. His blood pressure started fluctuating, so we decided to take him back home. After the dialysis, we saw that nothing improved...he did not respond to the treatment at all.*

### Accepting the Reality of Life or Thum-jai

Accepting the reality of life or "thum-jai" in Thai, was mentioned during interviews by all participants. They stated that they had made up their minds to face and accept the anticipated loss since their family member had been hospitalized with life-threatening conditions. The participants explained that accepting the reality of life or thum-jai helped them move on. Many participants used religious teachings or beliefs to make sense of the situation they encountered and to accept that their loved one would not return to normal and might pass away after the decision to withhold/withdraw LSTs was made.

*We must "thum-jai." Like Buddha stated, birth, old age, sickness, and death make up the normal cycle of human life. In my life, I have learned to "thum-jai". Putting it in Buddha's words, there should be no sorrow, anger or joy in what happens to us in life. For me, it is like that...Departing from this world is normal.*

As can be seen from the above example, this 53-year-old participant used Buddhist teaching to reflect on his life situation. He mentioned that thum-jai helped him accommodate the suffering that resulted from the loss of his comatose mother. This participant elaborated further that the words "no sorrow, anger, or joy" pointed to the attainment of emotional detachment from the material world, which would lead him to achieving spiritual peace and well-being. He was able to let go of his attachment to the deceased mother. Accepting this truth helped him move on in life.

Similarly, the Muslim participants believed that death is a part of life, and that the time of one's death was a matter that should be left to God. A 62-year-old Muslim participant stated that the life and death destiny of a person was determined by God's decrees. She didn't know how to help her brother out of her own resources and, instead, she left it up to God to determine her brother's life's end. This participant explained:

*Let's think about it in these terms; this life belongs to God. Leave it up to God.... One's life and death are matters decided by God. Even for myself, I don't know when my appointed time to die will be. Certainly, we are sad when a loved one passes away... but if we keep thinking too much about it, we will then develop a headache. "Thum-jai" is the best way*



*for us in such situations.... Just think that we will not live in this world for long; we all will return to God, sooner or later.*

After the decision to discontinue LSTs was made, all but two participants shared that they felt comfortable with the decision and did not feel any regret or guilt. Thirteen of the patients involved died peacefully, while two others survived and lived well with their families at home. Seven of the 13 deaths happened in the hospital. In those cases, nurses had facilitated the process and provided a quiet environment for the family, so that they could be with the dying patient until the last moments. The participants whose family members passed away at the hospital stated that the patients looked calm and peaceful at the moment of their departure from this world. They believed that their family member had experienced a good death. As a 45-year-old participant shared:

*I have no regrets regarding his passing away. I saw my grandpa at the last minute of his life. I reckon it was just like what I thought it would be (referencing a good death). ... Lucky me that I was at his bedside at the moment of his last breath. I felt we had performed our duties perfectly and completely. We turned on Dharma chants for him to listen to until his last breath. The nurses even asked whether we preferred that the ritual of pouring the dedication water be performed. We did it all. At cremation, I felt happy and had no regrets*

Eight families elected to take their loved ones back home. For them, a palliative care physician had prescribed medications to provide adequate symptomatic relief, while palliative care ward nurses had instructed the participants how to provide care for the patients at home. The participants who had taken the patients home stated that they had not felt abandoned by the nurses. At home, the families had performed religious activities for the patients. Buddhist families had invited Buddhist monks to visit the dying patients. The dying patients had been given the chance to offer food to the monks as a way of merit-making. Meanwhile, Muslim families had prayed and asked for blessings as well as for forgiveness from Allah for the dying patients. In addition, relatives who lived both nearby and far away had come to visit the patients at home. A 53-year-old participant reflected that he was at peace with the LST withdrawal decision.

*My feelings now? ...I can "thum-jai" ... "thum-jai" that her time with us has ended. I think it was the right decision. I had taken care of her for 7 years, and I knew it was her time to go. As far as I am concerned, I did my absolute best to care for her. I never left or neglected her while she was alive. For me, there is nothing to feel guilty about....no sorrow or sadness...*

Two patients were still alive at the time of the interviews. The participants caring for them stated that it was the right decision to discontinue the treatments and take the patients back home. By doing so, they could continue earning a living while taking care of the patients at home.

*A few days after coming back home, grandma got better. She could recognize the relatives who came to visit her. It was like a miracle. It was so good that she got better...everything is good now...we can also continue to earn a living.*

On the contrary, two other participants expressed feeling guilty for having made the decision to withdraw LSTs. These caregivers shared that there remained lingering questions as to whether they had made the wrong decision. The 43-year-old wife of a patient with acute cerebrovascular hemorrhage started crying when recalling the time she was asked to decide to discontinue the LSTs her husband was receiving. Although the decision was discussed with and supported by her son and daughter, she was blamed for having made the wrong choice by her husband's relatives, who lived in another city.

*At cremation, his relatives raged and blamed me for making this decision. I have been suffering since that time. Nowadays, whenever I think of the moment of LST withdrawal, I just cry alone....I feel as if I killed him....At his last breath, my kids watched the monitors and saw the heart rate went down. This scene makes me feel even more guilty.... I think I should have not made that decision....I feel like I have committed a sin....At that time, I just thought that if we withdrew the treatments, he would die comfortably, and I would be able to concentrate on earning a living and nurturing our kids.... I wonder whether it was the right or wrong decision...but I have never asked my kids whether I was wrong for making it....I am afraid of what they would say.*

At that point, the researcher asked the participant whether she wanted to continue the interview or not. She confirmed her willingness to continue. At the end of the interview, she thanked us for listening to her story and helping her express her emotional suffering she had harbored on the inside. On the follow-up interview, the same participant stated that she had shared her feelings with her children and had informed them about her suffering. She said that all of her children had supported her decision and had ensured her that they thought that she had done the right thing. She reported that, at last, she felt relieved and ready to move on, and that she felt less insecure in her mind about her decision to withdraw the LSTs.

Similarly, a daughter caring for her 83-year-old mother with acute myocardial infarction and several other comorbidities also shared her experiences of feeling guilty

about the decision to discontinue LSTs. After 2 weeks of intubation, the physician had informed her about the possibility of performing a tracheostomy procedure with the view of improving her mother's breathing and preventing potential infection. Based on her experience of taking care of her mother at the hospital for almost 24 hours a day for approximately 2 weeks, she believed that her mother would not tolerate the procedure and that it would not cure the disease. This participant decided to reject the procedure. When conveying her thoughts to her family, the participant was accused by her daughter of acting irresponsibly.

*I sometimes wonder whether she may be upset with me for having decided to not go on with the tracheostomy for her. I often ask, "was I wrong?" A part of me wanted her to receive the tracheostomy. By the same token, another part of me thought that it would be better to not go ahead with the treatment as we knew that her health condition could not get better anymore....she was 83 years old, and the physician stated that she had several serious diseases. I agreed with the physicians, but my daughter got angry at me. She was unhappy with my decision. She asked what my reasons were. She said that my decision was as if I was refusing to assume the responsibility of caring for my mother any further. She accused me like that. I felt very down....I know I am not like what my daughter was portraying me to be. ...I still think sometimes whether I was wrong about the decision, although our family eventually came to an agreement about the decision to withdraw the LSTs. I felt guilty and kept asking myself whether I was wrong. The feeling of guilt and these lingering questions were with me for several months. Thankfully, over time, I started to gradually feel better. Now, I have Thum-jai.*

## Discussion

The aim of this study was to elicit the experiences of family caregivers involved in making the decision to withdraw or withhold LSTs in Thailand. Based on the analysis of data obtained from in-depth interviews with 15 family caregivers, who had experiences with caring for patients at the end stage of life, four themes were identified: facing the dilemma, weighing up the advantages and disadvantages of treatment options and their consequences, obtaining a consensual decision among family members, and accepting the reality of life or *Thum-jai*. The descriptions of their experiences elicited from our participants highlighted a number of significant issues for the advancement of the care provided to family members of patients with life-threatening conditions during end-of-life decision-making and thereafter.

The withdrawal/withholding of treatments, particularly LSTs, is a crucial decision with tremendously important

consequences; therefore, it naturally creates moral dilemmas for the family of the patient. The family caregivers in our study were aware that their decision would affect the life of another person directly. To them, it was a decision that would change everything as it regards the person for whom the decision was made. They considered that the result of their decision might mean the end of their beloved family member's life. Before the LST withdrawal decision was made, the participants described their experiences as being in a situation of indecisiveness, which caused moral distress. They all reported feeling they lacked the necessary confidence to make such a decision since no legal documents for care preferences at the end of life had been established by any of the patients. Previous studies have found that early discussions about the end of life among family members could ease the decision-making process (Batteux et al., 2019, 2020). With such documents in place, relatives and family members tend to gain more confidence in making the right decisions that align with the patient's preferences. Thereby, without previous discussions, end-of-life decision-making becomes a significant burden for the family. Participating caregivers in our study reported being unsure what to do next because the future seemed uncertain and vague. They were also not sure whether the patients would be able to recover from their illness. On the one hand, they hoped deeply that the patient's condition might improve due to the new medical interventions or therapies they were being offered as treatment options by the medical staff. On the other hand, they remained uncertain about their outcomes. The family caregivers partaking in this study wondered whether, by consenting to further aggressive therapy, the patients would return to normal as they wished. Hence, when medical physicians asked them to make end-of-life decisions for their kin, the caregiver participants felt fearful of making the wrong decision. The results of our study are consistent with those of other studies, which have shown that families describe the experiences related to the decision to withdraw LSTs as the foremost burden they have ever faced (Githaiga & Swartz, 2017; Schenker et al., 2012; Wendler & Rid, 2011; Wiegand, 2008).

In addition, this study found that a lack of understanding about treatments and their consequences among the family caregivers was at the root of their feeling of uncertainty regarding the future of the patients' health conditions. A poor understanding of treatment options results in an inability to make rational decisions (Wilson et al., 2014). Our findings confirm previous evidence addressing the problematic communication that exists between health care providers and families in relation to the decision-making process in such cases (Noome et al., 2016). A previous study reported that family caregivers of critically ill patients who had acted on the patient's behalf

felt overwhelmed by the medical terms typically used by health care providers (Kalocsai et al., 2018). Furthermore, family caregivers often receive insufficient information and are made to wait for considerable lengths of time before physicians or nurses provide them with information about the patient's progress (Kisorio & Langley, 2016). Consequently, they tend to not make good sense of the situation they face and develop an emotional burden related to the fact that they bear the responsibility for the patient's life.

In our study, the LST termination decision was justified in several different ways. Some participating family caregivers rationalized this end-of-life decision by seeking to honor the patient's wishes that were discussed prior to the time the patient was rendered unconscious. These participants shared that the patients had informally communicated with them about their last wishes and care preferences at the end of their life. Thus, they simply tried to remain true to the patients' wishes and preferences. Furthermore, freedom from suffering was raised as another reason for deciding to withhold/withdraw LSTs by our participants. The caregivers viewed that the medical treatments administered to their family members prolonged not only their lives but also, and unnecessarily so, their suffering. Moreover, they realized that the treatments the patients received were no longer beneficial toward their recovery. What is more, they also increased and prolonged the suffering of their caregivers, who witnessed the anguish of their dying kin for whom they were responsible to provide care. The caregiver participants also stated that the longer the patients stayed in the hospital, the worse their health condition became and the greater their suffering was. All these created a sense of hopelessness in relation to medical treatments, which led the caregivers to view further treatments as futile. Alongside the hopelessness regarding the patient's recovery, the family burden due to the care required to provide for their loved one was also mentioned by some participants as a factor in their decision-making. The family caregivers participating in this study played multiple roles in their families. They usually spent most of their time taking care of their seriously ill relative at the hospital. As a result of having to fulfill this caregiving role, some had to abandon other dependent elders at home, while others could not continue to earn a living. Consequently, these caregivers encountered not only physical and emotional burdens but also financial ones. These factors were pooled together and weighed at the end. The results of our study support previous findings that seeking the opinions of other family members, pondering the prognosis and wishes of the patient, and considering the financial situation of the family were some of the factors that played meaningful roles in the end-of-life decision-making process related to

the care provided for critically ill family members (Kimura & Kidachi, 2019).

Interestingly, in the face of a hopeless prognosis, religious belief was used to inform the family caregivers' decision to withdraw LSTs and also cope with their life situation. The participants of this study believed that dying without the application of technological support is the natural way to die, and that the patient's life and death were determined by either their karma or God's ordinances. These findings are supported by those reported by Bain et al. (2017), who found that the desire for and the use of life-sustaining treatments was significantly related to religious belief. In addition, the findings of our study are similar to those described by Fritsch et al. (2013) in the way that religion is a factor that plays a significant role in making decisions related to end of life; however, the current study expands further the understanding of the role of religion in such situations, that is, it also helped the participating family caregivers to accept the reality of life.

As it has been reported, the decision to withdraw LSTs brings about psychological and emotional distress to those involved in the process of decision-making (Kisorio & Langley, 2016; Miller et al., 2016; Schenker et al., 2012; Wendler & Rid, 2011). Nevertheless, caregivers attempt to cope with these psychological and emotional consequences. In our study, accepting the reality of life, or "*thum-jai*" in Thai, was repeatedly mentioned by all participants as a way to explain how they dealt with this life-and-death situation. *Thum-jai* is culturally embedded in Thai society; it is a religious coping strategy used by Thai people when confronting a stressful and unescapable event (Mills et al., 2017). Furthermore, *Thum-jai* is a subjective concept of acceptance that necessitates conscious thought, a willingness to live in the moment, the realization that one cannot alter an unpleasant or undesirable reality, and the need to come up with strategies for thriving (Mills et al., 2019). For our participants, the decision they had to make for their relatives' health care at the end of their life constituted a major and irreversible life event. Our Thai family caregivers drew on their religious beliefs when making end-of-life decisions for the patients under their care and seeking to live with the consequences of their decisions. The religious teachings enabled them to understand that their present suffering stemmed from the anticipated loss of and the emotional attachment to their dying loved one. Furthermore, religious beliefs helped them "*thum-jai*" or accept the natural law of human life and/or God's plan for the patient. They realized that they could not make any changes to the patient's life journey. Practicing "*thum-jai*" helps an individual calm his/her mind, endure suffering by understanding the reality of life, and consequently, have a positive outlook in life (Mills et al., 2017). This study suggests that care provided to

patients and family caregivers should be tailored based on their cultural background and religious affiliation.

In our study, the families' decisions at the end of life of their loved ones were reached by consensus among relevant family members. Due to the hierarchical nature of the Thai family, even though the participating family caregivers were the main persons who had provided care for their relatives at their bedside, they were not assigned to act as substitute decision-makers by the family. Our caregivers were the daughters, wives, brothers, or grandchildren of the patients. They felt uncertain about what decision to make in relation to the lives of their loved one. Therefore, they sought support from other more senior family members. Our study confirms the results of a previous investigation, which reported that family consensus was used as a means of making what they thought was the right decision or as a way to preclude themselves from responsibility (Fritsch et al., 2013). It also underscores the significance of the family-oriented approach to making care decisions at the end of one's life (Bellamy & Gott, 2013; Venkatasalu et al., 2011).

The findings of our study also highlight the significant role of family meetings in facilitating the communication between health providers and the family of patients, who are at the end of their life (Meeker et al., 2015; Sullivan et al., 2015). In our study, during the decision-making process, the participants were referred to a palliative care team. All of them had a palliative care consultation with the advance practice nurse. A family meeting was organized after that. Other significant family members were invited to join the meeting. After gathering sufficient information related to the patient's condition, treatments, and disease progression from the advance practice nurse, the key family members discussed and weighed up what would be the best course of action for the patient. Eventually, a consensual decision to withdraw LSTs was made.

Despite gaining a consensual decision, it was evident from this study that two participants reported negative experiences during the decision-making period, which continued on even after the withdrawal decision had been made. The feeling of guilt was rooted in the family conflict that ensued such a decision. One of these family caregivers was the wife of one of the patients. After getting married, they had relocated to and settled in the South, where she was from, for several years. As a result, she did not have a close relationship with her husband's family. During the time the decision was made, she sought further information from the attending health care personnel and asked her children and relatives, who lived with her, for their opinions and expressed her desire to arrive at a consensual agreement among them. However, she was blamed for the decision she had made by the patient's side of the family, who were not involved in the end-of-life

decision-making process. A previous study found that the relationship that caregivers have with their family members has a significant impact on decision-making. Strong family ties are generally reported as having a beneficial effect, but impaired family ties are generally recognized as a source of stress (Sanford et al., 2011). Furthermore, the understanding of the patient's medical conditions influenced the decision-making of the family. Unclear and inadequate information about the seriousness of the patient's medical conditions and a lack of communication among family members may lead to family conflict. These 2 primary caregivers were accused by the patients' relatives of not wanting to take on the responsibility of caring for the dying kin under their care. The families in this study reflected on the importance of a decision-making process with a family-centered approach, which is consistent with the findings from an earlier study (Parks et al., 2011). It is suggested that during the end-of-life decision-making process, medical professionals and nurses should examine family discord. If this is the case, health care teams should explore addressing the conflict and finding solutions. A previous study has shown that encouraging discussions about the end of life among families would ease the decision-making process. Nevertheless, interventions that are designed to foster these discussions between family members would still be useful to relieve the burden placed on the decision-maker, particularly for those without previous experiences of illness and death, who are, therefore, less likely to be keen about having such discussions (Batteux et al., 2019).

### *Strengths and Limitations*

The participants in this study came from diverse social and religious backgrounds. Such a variety of perspectives helps to not only capture a more comprehensive view of a phenomenon of interest, that is, the family's involvement in the LST withdrawal decision, but to also investigate a given issue from different angles. However, in this study, there was no participant from the Christian religious background. Therefore, the interpretation of its findings may be limited in their transferability to this religious group.

### *Conclusion and Implications*

Based on our empirical data, family involvement in the end-of-life decision-making is more complex when decisions are made for others. Accordingly, a comprehensive assessment that includes the socio-cultural and religious background of the patients and their families would help nurses and other health care providers in tailor-making and offering culturally-sensitive care during

this crucial time in the life of the patient as well as facilitate the process of decision-making with the aim of ensuring a smooth transition to end-of-life care. Furthermore, on a regular basis, health care providers should provide adequate information to both patients and their families about the patients' health condition, prognosis, and all available treatment options while avoiding medical jargon. The implementation of end-of-life discussion with a family-oriented approach at the early stage of critical illness is also essential. Successful end-of-life discussion leads to informed decisions and the obtainment of documentation of care preferences, which would, consequently, prevent potential conflicts related to such decision-making. Moreover, care should be extended to the patient's family both during and after the decision is made. Future research needs to focus on communication issues between patient relatives and health providers during the transition to end-of-life care as well as the development of interventions related to such communication, the management of grief experiences, and bereavement care for the family members of the deceased patient.

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