End-of-life Decisions for Children in a Thai Pediatric Intensive Care Unit: A Qualitative Descriptive Study

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Abstract: The issue of healthcare decisions for terminally ill children is complex and presents a wide range of challenges and difficulties. This qualitative descriptive study was designed to investigate end-of-life decisions, based on health professionals' perspectives, for children admitted to the pediatric intensive care unit. The participants comprised two physicians and 17 nurses, sampled purposively. Data collection was performed from November 2018 to June 2019, adopting in-depth interviews. Data analysis was carried out using the process proposed by Creswell.

The main findings revealed that parents ultimately took responsibility for end-of-life decisions related to their terminally ill child. There were four main categories describing end-of-life decisions for a terminally ill child: *Making definite end-of-life diagnosis; Communicating to assure parental understanding; Allowing parents to choose end-of-life options; and Initiating end-of-life care*. The findings of this study provide an insight into parental decision for their terminally ill child during this critical stage. Such essential knowledge is useful as a foundation to improve end-of-life decisions in the pediatric intensive care unit, practically and effectively for nurses and other health professionals.

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Introduction

Advanced medical technology and pharmacology have created greater possibilities for sustaining bodily functions and prolonging lives.[1] Nevertheless, not all critically ill children with complex medical problems treated in the pediatric intensive care unit (PICU) will survive due to failures to respond to treatment, poor prognosis, or irrevocably progressive illnesses. When aggressive-curative therapies are not possible, end-of-life (EOL) care must be considered to prevent or relieve suffering of both pediatric patients and their families.[2] An American report stated that the mortality rate in the PICU was 2.3%, and 70% of those pediatric

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patients died following the withholding or withdrawal of life-sustaining treatment (LST).[3] Similarly, a Pakistani report demonstrated that the mortality rate in the PICU was 12.9%. Most commonly, cause of death was due to limitation of LST (63.7%) and failed cardiopulmonary resuscitation (CPR) (28.2%).[1] Maharaj Nakorn Chiang Mai Hospital is a large university hospital located in Chiang Mai Province, Thailand. This university hospital is a central setting for patient referral in Northern Thailand, providing care and treatment for complicated patients. A report from the hospital revealed that the PICU mortality rate was 6.69% in 2017.[4] This report did not identify whether pediatric patients died following either the withholding or withdrawal of LST. Though the mortality rates in the PICU are relatively low in contrast to other ICU settings, EOL care still remains a critical component for terminal pediatric patients.[5] This is due to healthcare professionals placing great concern on the quality of life for children during the terminal stage. The EOL decision and whether to withdraw or withhold LST in a complex situation during the terminal stage of a child's illness is a vital issue that needs to be considered seriously.

An EOL decision is defined as the process that healthcare professionals, patients, and their families collaboratively go through the consideration to select forgoing LST, withholding or withdrawing any treatment that may unintentionally or intentionally hasten death.[6,7] In case of pediatric patients in the PICU, parents must be the decision-makers on behalf of their child. This is due to three main reasons: a child's immature cognitive development, a child's legal status as an incompetent person[8], and the severity of the terminal illness.[9] Hence, the authority to consent or refuse medical treatment for critically ill children usually falls to the parents or a child's legal guardians.

Nevertheless, the existing evidence suggests that most parents do not act as decision-makers for their child.[6,10-12] Physicians typically provide information to parents about the child's prognosis or physicians' final decision, then take the main responsibility to be the decision-makers for EOL options. Most parents have limited or no opportunities to be involved in a decision to either withhold or withdraw LST, and some of them do not even have the chance to express their opinions or agreement/disagreement.[10-12] Based on scientific evidence, parents are treated mostly as information receivers. This position relies highly on healthcare professionals' attitudes[12-14], communication[10,13,15] and different medical cultures concerning parental involvement in EOL decisions.[16] Regarding healthcare professionals' attitude, there is evidence indicating physicians strongly believe parents could not be responsible for EOL decisions because parents lack the required knowledge[12,13] and their emotional burden leads to them being unable to effectively make decisions.[13] Protecting the parents from guilt related to taking part in the EOL decision might be another reason for the physicians' unwillingness to involve the parents.[14]

Communication between healthcare professionals and parents has proven to be a successful and critical component for encouraging parents to become involved in the EOL decision.[10] Practically, such communication in the EOL decision still remains a problem. Parents expect to be informed about all kinds of medical procedures and interventions[13], but parents find the information is often inadequate and the treatment rationale for their terminally ill child is still unclear. Moreover, it is difficult for parents to understand the medical terminology and technical language used by healthcare professionals. Such problems limit the parent's ability to make EOL decisions for their children.[10,13,15]

Regarding medical culture, some studies indicate that parental involvement in EOL decision differs among hospitals on each continent. In North America, patient autonomy and informed consent are strongly emphasized. It is common for parents to be involved and consulted in EOL decision about the withdrawal or limitation of LST. An EOL decision is based primarily on the patients' and family's wishes.[16] In Europe, physicians tend to play a more decisive role in making an EOL decision; there is little or no parental involvement in an EOL decision.[16] Physicians thus play the key role in such decision.[11-13] As a result of different medical cultures and contexts, it is difficult to generalize the existing evidence for EOL decision among parents. To improve parental involvement in an EOL decision, the initial and crucial step must be paid attention to healthcare professionals since their attitude, their communication with parents, and their medical culture are strongly influence an EOL decision. Exploring the perspectives among healthcare professionals regarding an EOL decision in a real PICU situation is needed.

Improving the quality of EOL care has become a healthcare priority worldwide[17], based on the principle of patient rights, specifically the right to 'know and to choose'.[18,19] The transition from aggressive curative treatment to palliative care is being focused on by many health institutions in order to avoid inappropriate prolongation of dying and balance the burdens and benefits for children.[18] Previous studies related to EOL decisions focus on decision-makers and communication between healthcare professionals and parents.[10-12,20] Such previous studies adopted a quantitative approach, using a questionnaire, and did not provide a detailed description of how an EOL decision occurs in the PICU. Thus, there is a dearth of data relating to decisions around EOL in the PICU, especially in Thailand, where the government has declared an agenda to focus on EOL care.[21] An exploratory study relating the situation of EOL decision for terminal pediatric patients in the PICU was therefore strongly required to illustrate the whole picture of such a decision. Such essential knowledge would also pave the way for nursing professionals to encourage parents to make an EOL decision effectively. This study thus aimed to investigate EOL decisions for children in PICU, based on the perspectives of health professionals.

Method

Study design

A qualitative descriptive approach was adopted, which aimed to comprehensively and intensively summarize specific events, which in this study was EOL decisions experienced by individuals or groups of individuals, and healthcare professionals.[22] This approach is grounded by naturalistic inquiry, which enabled researchers to investigate a specific event of an EOL decision for terminally ill children in a natural setting without any attempt to manipulate or interfere with the ordinary unfolding of circumstances.

Research setting and participants

The PICU of a major university hospital located in Chiang Mai Province, Northern Thailand, was chosen as the study setting. The PICU has six beds and permits visits to the critically ill children from noon to 1.30 PM and from 3 to 7 PM, with a restriction of two people per visit. This hospital addresses palliative care, providing an opportunity for parents to make decisions for terminally ill children at the end stage of life.

The selection of participants was performed using purposive sampling based on the inclusion criteria. It included healthcare professionals who had experiences in dealing with EOL decisions and were willing to participate in the study. The head nurse of the PICU assisted in recommending potential participants. Upon recruitment, it was found that all healthcare professionals in this PICU met all criteria.

Ethical considerations

This study was approved by the Research Ethics Review Committee, Faculty of Nursing (2018-FULL 001) and Faculty of Medicine (NONE-2018-05643), Chiang Mai University. All participants were informed regarding the objectives of the study, the data collection process, voluntary participation and the right of refusal or withdrawal for participation in the study at any time without any prejudice. In-depth interviews were conducted after participants signed informed consent forms. Moreover, all obtained information, transcripts, notes, and digitally recorded files were kept confidential.

Data collection

Data collection was performed from November 2018 to June 2019. Each in-depth interview was conducted at a convenient time in a private place based on the participant's preferences. Before conducting each interview, researchers asked for permission to audio-record and conduct in-depth interviews based on a guideline. The questions were as follows: *"What are the criteria for an EOL diagnosis?" "How do you handle the situation when pediatric patients arrive at an EOL? Why?" "Who are the EOL decision-makers for patients?" and "What are the options for EOL decisions and reasons for these options?"* Further, the technique of probing was utilized to clarify the completeness of information. The length of each interview was approximately 60-90 minutes. A second interview was also conducted for original information clarification. Two physicians and four nurses were invited for a second in-depth interview. The process of data collection was carried out until data saturation was reached.[23]

Data analysis

Data analysis was carried out using the process proposed by Creswell.[23] Researchers transcribed verbatim data from in-depth interviews as soon as possible. They spent time reading and re-reading transcriptions and took notes and marked ideas for initial coding. Then, they coded the data using interpretive codes and labeled the codes with terms based on the actual language of the participants. They used mind maps to organize codes into sub-categories and categories, then interpreted the data, and linked the interpretation of the data to the information gathered from the literature review.

Trustworthiness

Trustworthiness in this study was developed by credibility and confirmability. Credibility was established by member checking and peer debriefing. Regarding member checking, researchers took the research results back to key participants and asked them to affirm or assure the qualitative findings that represented their perspectives. All participants agreed with the findings. Concerning peer debriefing, the findings of this study were examined and approved by three experts in qualitative research and two experts in EOL care. All experts are nursing professors. To achieve confirmability, the researchers consulted their advisory committee in all steps of research to examine research processes and check the accuracy of coding during the analysis process. In addition, researchers provided rich quotes from participants to illustrate participants' responses.

Findings

There were 19 participants including two physicians and 17 nurses who were involved in EOL decisions for terminally ill children. Their ages ranged from 24 to 56 years old. Most participants held a bachelor's degree (n = 15). Professional experience in EOL care ranged from 2 to 28 years.

Based on obtained information, EOL decisions for terminally ill children in the PICU occurred as an ongoing process and were identified in four main categories (see **Table 1**), as described below.

Table 1 Categories and Subcategories of End-of-life Decision for Children in PICU

Categories	Subcategories
Making definite end-of-life diagnosis	Clinical symptoms of pediatric patients Consulting medical specialist for approval
Communicating to assure parental understanding	Querying parental perception about their children condition Explaining current status of pediatric patients Reviewing parental understanding
Allowing parents to choose end-of-life options	Informing end-of-life options Making end-of-life decision by parents Accepting parental end-of-life decision
Initiating end-of-life care	Appropriate supporting treatment based on parental decision Psychosocial and spiritual support based on parental needs

Category 1: Making definite end-of-life diagnosis

There was consensus among participants that physicians were responsible for making a definite EOL diagnosis before commencing the EOL decision for terminally ill children. To diagnose the EOL stage accurately, physicians took 2Cs into consideration; clinical symptoms of pediatric patients and consulting special experts for approval.

Sub-category 1.1: Clinical symptoms of pediatric patients. Physicians seriously considered clinical symptoms of pediatric patients who did not respond to medical treatment over a period of time (including worsening illnesses) to be indicators for an EOL diagnosis. Examples of these clinical symptoms included vital organ failure and lower standard vital signs.

> *To judge a child approaching the end stage, his condition does not get better even after providing advanced medical treatments for a period of time. ...I give the medication for reducing cerebral edema, all diuretics or even removing a blood clot. Cerebral edema still exists, and the child's condition is getting worse. He gets very serious signs, like fixed pupils, non-responsiveness to voice and deep pain, Glasgow Coma Score as* $E_1V_TM_2$*, and loss of brain stem reflex.* (Physician 02)

Sub-category 1.2: Consulting medical specialist for approval. The PICU physicians needed to consult relevant medical specialists such as neurologists, urologists, and endocrinologists, to confirm whether critically ill children had truly arrived at the EOL stage or could not be cured, even with advanced medical treatment for over a time period. This confirmation was of great importance since healthcare professionals need to reach a consensus before beginning EOL treatment and care.

> *...PICU physician will consult the neurologist for neuro cases. If the neurologist thinks that the child can be cured, it is not EOL stage. Nevertheless, if the neurologist confirms that the neuro problem cannot be cured, so it is EOL stage. ... This is an agreement that everyone has to approve for entering EOL stage. If someone thinks that patients can be treated, they do not enter to the end of their life.* (Nurse 11)

Category 2: Communicating to Assure Parental Understanding

Healthcare professionals considered communication to be a critical element in initiating the EOL decision. After reaching a definite diagnosis of EOL, communication was carried out in a formal way through a so-called "family meeting". This meeting was conducted to examine parents' understanding of their child's prognosis. In case of misunderstanding, physicians directly explained the child's status to parents, including adverse signs and symptoms, current medical treatment, and illness prognosis. Thereafter, physicians confirmed parental understanding of their child's status before a parental decision was made regarding EOL care.

Sub-category 2.1: Querying parental perception about their children condition. During the family meeting, the physician initially asked parents what they understood about their child's illness or condition as they had continuously obtained medical information about their child's status since his/her admission. This understanding was crucial since the physician could then assess whether parents accepted the reality of their child's illness prognosis and medical treatment to date.

> *Firstly, we need to ask parents regarding their understanding about their child's disease. Let parents tell all. ...Do they know about their child's symptoms? We want them to describe these symptoms before we explain their child's status.* (Physician 01)

Sub-category 2.2: Explaining present status of pediatric patients. After assessing the parents' perception of their child's status, the physician initially and gradually started to explain the EOL stage of the child. Such explanation directly included the current status of the child, such as that the condition was worsening or there was no response to advanced medical treatment, as well as the illness prognosis and chance for the child's survival. Throughout the meeting, this information was repeated in order to reinforce understanding. Physicians were asked for clarification by parents, as they often desired to understand precisely what was happening to their child and whether treatment was working or not. The purpose of this explanation was to ensure the parents' understanding of the pediatric patients' poor prognosis. In addition, some participants stated that it was essential for physicians to directly tell the truth to parents about their child's condition.

> *I will tell mother, hit to the point that today her child's symptoms are not good, loss of perceptions, dilated pupils ... loss of gag reflex. These symptoms showed that cerebral tissue is severely swollen and shifted to the brain stem. If the brain stem is compressed continuously, her child cannot breathe ... and the child's heart slowly stops. I already provided a maximum setting for the ventilator, but the oxygen is still down. Setting the ventilator more than this will induce complications such as pneumothorax. ... I calculate the chance for survival as 15-20%. This is a low chance for survival... I have to tell them exactly what is going on with their child.* (Physician 02)

During the explanation to parents, physicians used simple language, so the parents were able to understand the situation more easily and the use of medical terminology was avoided. Physicians communicated to parents in the appropriate language, based on the context and background of the parents.

> *Physicians use simple words, not using medical terms. For instance, medical ventilator or inotropic drugs, have to be translated into simple Thai language to be easily understood by the parents. If parents are Central Thai, the physician will speak Thai, if parents are Northern Thai, physicians will use the Northern dialect.* (Nurse 06)

Further, the physicians also used an X-ray film or computerized tomography scan as a visual tool to explain the child's condition to parents. Such a strategy could facilitate a better understanding for parents in terms of their child's current condition.

> *I invite the mother to see the results of a computerized tomography scan. First, I describe the normal characteristics of cerebral tissue. I describe that the blood clot in the brain is abnormal. Such technology would help the mother to gain a better understanding about her child's condition.* (Physician 02)

Sub-category 2.3: Reviewing parental understanding. After intentionally explaining the possibility of decline, survival or that the pediatric patients had arrived at the EOL stage, the physicians asked parents to summarize their understanding of their child's situation. This step was undertaken to ensure sufficient parental understanding of the critically ill child's condition in order to move to the next step of an EOL decision.

> *I ask parents: "Do you understand the information that I explained to you?". Parents must explain how they understand. This will lead to adequate understanding between us* (Physician 01)

Category 3: Allowing Parents to Choose End-of-life Options

Physicians informed parents of available EOL options based on parent enquiries before EOL decisions were made. Therefore, parents are considered to be the most significant people to make decisions on behalf of their child during the end stage of that child's life. Physicians and nurses took responsibility for supporting parents in providing core and sufficient information for making decisions regarding EOL treatment and care. Based on obtained data, physicians and nurses respected and accepted parental decisions, even if those decisions changed at a later time.

Sub-category 3.1: Informing end-of-life options. Physicians were the key people to provide information regarding EOL options, in terms of both treatment and care, based on parent enquiries and needs. There were three main EOL options for parents. These included maximum therapeutic care, withholding LST, and withdrawing LST. In case of choosing maximum therapeutic care, pediatric patients continued receiving existing treatment and essential medication, reducing any procedures that caused suffering but could receive cardiopulmonary resuscitation (CPR) if needed. If CPR was unsuccessful for 30 minutes, the physician would discontinue the procedure and provide a reasonable explanation to parents. For the option of withholding LST, pediatric patients continued receiving existing treatment but did not receive any additional treatment or CPR. In the case of withdrawing LST, a child's existing or additional treatment was discontinued, such as medication or use of a medical ventilator, and they did not receive CPR. The physicians deliberately explained to parents the treatment and care details in each EOL option for their consideration.

> *... There are three options of care. First, stop ... stopping is the end that removes medicine or medical ventilator. Second, supportive care, do not give more medicine, do not provide aggressive treatment, and let pediatric patients pass away peacefully. For instance, pediatric patients have received dobutamine at the maximum dose. Pediatric patients will be treated like that until they pass away. Lastly, maximum therapeutic care, we will consider what treatment we can provide continually to pediatric patients, we will continue existing treatment and do chest compressions at the end.* (Nurse 04)

Sub-category 3.2: Making end-of-life decision by parents. Upon the physicians' explanation of the three main EOL options, parents took responsibility for deciding their preferred EOL option on behalf of their child. Before making this decision, parents had ample opportunity to enquire and discuss with physicians regarding LST for other similar cases, including the final outcome and the best treatment based on the physicians' opinions. The physicians only provided honest information, giving details of previous cases without directing parents.

> *Medical treatment during EOL stage depends only on the parents' choice. The physicians have no right to make the decision. Physicians only provide information about the child to parents and make them to decide. ... Parents always ask me about other similar cases and how did the parents in those cases decide? ...What is the best treatment? .... I just told the story of previous cases to them.* (Physician 02)

Some parents preferred to select the maximum therapeutic care because they could not accept the loss of their child and remained hopeful that their child might get better or recover.

> *Parents are not prepared to lose their child. They ask to continue treatment, continue using medical ventilator, or even to do CPR. Thus, parents decide to choose maximum treatment including medicine and CPR.* (Nurse 11)

In case of parents who had sufficient understanding of their child's prognosis, almost all parents preferred to choose the option of withholding LST. They did not prefer any invasive procedures for saving their child's life, such as CPR or inserting an endotracheal tube, since such procedures induced more suffering for their child.

> *Parents explain that their child is so tired with his/her chronic illness. They do not want their child to suffer more. They asked to let their child go. No more additional medication and invasive procedure like intubate with endotracheal tube or CPR.* (Nurse 01)

Some parents decided to stop all treatments and preferred to take their child home. They believed that if their child died at home, the soul of their child would be at home.

> *Some parents ask physicians to stop any treatment. They want to bring their child back home to perform the rites and rituals at home. They do not want their child dying at a hospital. If their child is dying at home, the soul of their child will stay at home.* (Physician 02)

Sub-category 3.3: Accepting parental end-of-life decision. Healthcare professionals respected the decision of parents and followed medical management based on their chosen option without any prejudice.

> *The decision for children depends on their parents. I do not judge whether it is right or wrong. Though I think that it should be done another way, I try to understand parents at that moment. I respect the parental decision.* (Nurse 01)

Healthcare professionals also gave parents the chance to change their decisions, even when they had already signed the consent form. Almost all parents eventually changed the option of maximum therapeutic care to withholding or withdrawing LST. This was due to parents' realization that it was unreasonable to prolong their child's life with advanced medical treatment, as this was likely to induce more suffering for them.

> *Parents prefer to select this option* (withhold LST) *when their child is given full treatment for a while. The child does not get better, so parents have a clear insight that extending their child's life is not possible. Parents then end up with withholding LST, not using CPR and letting their child to die naturally.* (Physician 01)

While some parents initially chose the option to withhold LST, very few of them changed their decision to the option of maximum therapeutic care. The reason for the change related to parents' failure to accept the loss of their child or to parents' increased hope in extending their child's life.

> *First, parents prefer to choose full medicine but no CPR. Near the end stage, they see their child gradually breathing slowly, heart rate has decreased, parents cannot accept or make up their mind to lose their child so they ask us to help through CPR.* (Nurse 12)

Category 4: Initiating End-of-life Care

Upon reaching the decision to forgo LST, which is the end stage of the decision process, the process of EOL care would begin. Healthcare professionals started to manage EOL care with the therapeutic team and parents. Medical management of each EOL option was generally the main role and responsibility of physicians, while providing care for the terminally ill child was the responsibility of nurses. Care during the terminal stage strongly focused on spiritual and psychosocial support.

Sub-category 4.1: Appropriate treatment based on parental decision. The physicians started EOL management based on the parents' chosen EOL option. In order to ensure the quality of care and treatment, physicians and nurses again discussed planning for EOL treatment and care. Physicians and nurses began to reconsider which treatment or procedure should be continued or discontinued. At this stage, nurses reminded physicians about appropriate EOL management.

> *Plan together, like to discuss which procedure needs to be continued or discontinued. The nurse always reminds the physician through reviewing medical records whether the remaining procedure is fit or not with the selected option, such as X-ray or blood test tomorrow.* (Nurse 05)

Sub-category 4.2: Psychosocial and spiritual support based on parental need. Healthcare professionals, particularly nurses, assessed parental needs before facilitating support for psychosocial and spiritual well-being based on parental needs and wishes. There was a consensus that parents should be involved in caring for/supporting their child until the last minute of their life, allowing parents to perform their best parental roles and strengthening the parent-child relationship, thereby reducing feelings of guilt. Parents would be encouraged to be at their child's bedside, staying with their child 24 hours a day until they passed away. Moreover, nurses would arrange for parents to undertake religious rites and rituals according to their wishes at the hospital. Some parents preferred to make merit in the Buddhist way so as to pacify their child at the end-stage, before passing away.

> *In case of full med no CPR, we will give parents a chance to stay with their children 24 hours. There was no limit as per usual visit regulations. We also asked parents what they want or want to do. We allow parents to bring clothes or something to their child at PICU. Parents can change their child's clothes or place a doll on the bed. We must know the religion of the parents so we could arrange or offer some rites and rituals based their beliefs.* (Nurse 06)

Discussion

The first step for the EOL decision is making a definite EOL diagnosis, which is primarily performed by PICU physicians according to clinical practice guidelines. They adopt the 2Cs indicators of clinical symptoms of pediatric patients and consult medical specialists for approval. Regarding the clinical symptoms of pediatric patients, physicians considered the signs and symptoms of vital organ failure, such as brain death, which is universally approved as one indicator of the terminal stage.[24] This finding is congruent with a prior study which demonstrated that poor physical function of children after aggressive treatment was an important indicator of entering the EOL stage.[25] Another indicator, consulting medical specialists to confirm that pediatric patients had truly reached the EOL stage, is also important to gain second opinions from other specialists or repeated sub-specialist assessment to ensure the arrival of the terminal stage.[19] PICU physicians undoubtedly place great concern on a definite diagnosis of the EOL stage in children in order to take further steps of EOL planning and delivering of high quality and appropriate EOL care and treatment.[17]

Upon an accurate terminal diagnosis, physicians organized formal communication with parents and the healthcare team through a family meeting to share medical information regarding the pediatric patient's circumstances and prognosis. This sharing of information is parallel to the decision process of information exchange, referring to the provision of information regarding a patient's condition and the risks and benefits of various received treatments.[20] The current study indicated that, to initiate an EOL decision, physicians needed to be assured of the parents' understanding of their child's poor prognosis in order to avoid confusion. A previous study pointed out that parents confronted with many physicians providing different information about their child might become confused about their child's condition.[26]

Questioning parents' understanding of their child's status was first performed so as to subsequently explain actual information about a child's poor prognosis. This explanation, including complete, timely, and understandable information about the diagnosis, prognosis, and treatments, is considered to be effective physician-parent EOL communication that facilitates parents' comprehension of medical information.[27] Providing information, particularly regarding a child's poor prognosis, was done according to physicians' recognition of the right to know, referring to the parents' right to gain essential medical information regarding their child's condition.[19] Besides explaining a child's poor prognosis, parents were informed of the chance of their child's survival. This was congruent with the principle of right to information, whereby parents have the right to truthful and accurate information of a child's poor prognosis in a timely fashion[18], allowing them the opportunity to understand and later participate in an EOL decision.

Parental understanding of the terminal stage of their child's illness leads to the parents' decision to forgo LST. Such comprehension derived from formal communication may affect the choices parents make regarding EOL management for terminally ill children. This finding is congruent with some previous studies which demonstrated that discussion with healthcare professionals, along with essential information regarding the likelihood of a child's survival, facilitates parents to make a decision about their child's LST without too much difficulty.[28,29] Hence, physicians play a major role in informing parents of forgoing LST and care options, including providing a deliberate and detailed explanation of the treatment and care of each option for parents' consideration. This action was taken in view of the rights 'to know and to choose'; that is, a patient's right to know about available treatment options for their condition, along with their right to choose whether to accept or reject life-prolonging treatment.[19]

Findings indicated that parents played a major role in EOL decisions; this was parallel with the informed medical model, that is, healthcare professionals were information givers, while parents made their decisions based on given information.[30] Nonetheless, this finding differed from those in previous studies where parents were only information receivers. In these studies, physicians took responsibility to be decision-makers; they provided information about the child's condition or physicians' final decisions to parents. Most of the parents in prior studies had limited or no chances to be involved in the decision process. Some parents even did not have a chance to express their opinion, agreement, or disagreement.[10-12]

In addition to allowing parents to make EOL decisions, healthcare professionals also respected parents' decisions and provided EOL treatment based on parents' preferences without any prejudice, even if the chosen course of treatment did not correspond with the preference of the healthcare team. This finding, however, contrasted with previous evidence that healthcare professionals assumed parents should not take part in an EOL decision, as they lacked the required medical knowledge.[12,13] In addition, physicians thought that parents' emotional burden impaired their thinking and caused an inability to act as decision-makers.[13] In addition, physicians wanted to protect parents from any guilt related to involvement in EOL decisions.[14]

Regarding EOL choices, there were some reasons underlying each EOL option. For instance, we found that if choosing maximum therapeutic care, parents were unable to accept the loss of their child. This is similar to another study which indicated that parents preferred to continue medical treatment since they remained hopeful of their child's recovery.[20] In case of choosing to withhold LST, parents had a sufficient understanding of their child's prognosis. They wished to reduce any procedures which could induce more suffering to their child, such as CPR. Another study found that parents decided to withhold LST because they realized their child was not likely to recover and further medical treatment would be increasingly burdensome for their child. They preferred to forgo CPR for their child.[31] Parents with insight about their child's prognosis selected withdrawal of LST and preferred to take their child back home. This finding is in line with another study conducted in Asia which found that families wanted their terminally ill relative to die at home to allow the patient's soul to be at home.[32]

Following an EOL decision, healthcare professionals start to manage EOL care through informal collaboration with parents to strengthen the relationship between parent and child. Such management is performed under the concepts of working as a multidisciplinary team and being family-centered.[5] Physicians took responsibility for medical management of each EOL option, while nurses provided both spiritual and psychosocial support for the terminally ill child and their family. Care during the terminal stage applied the concept of a collaborative approach in which families and healthcare professionals worked together to provide kind and gentle care to the terminally ill child. Such care also followed the notion of appropriate EOL care; focusing on comfort, clear communication, and psychosocial and spiritual support.[5] Such collaborative care was carried out to enhance high quality and appropriate EOL care, referring to respect for life and death.[33] This is important as medical care prioritizes saving lives as a main goal; however, when it is not possible to save the life of a terminally ill child, the priority becomes ensuring the child's comfort and dignity during the terminal stage and providing necessary support to family members.[19]

This study found that the nursing staff at the PICU paid much attention to psychosocial and spiritual support, an essential dimension of holistic care for dying patients. Spirituality can be seen as a coping mechanism for families whereby crises and difficulties can be overcome through reliance on faith. When families are facing life-or-death situations, they may find comfort and strength in thinking about the meaning and purpose of life as it relates to a higher power.[34] Religion is one way that some people create a sense of spirituality and support a personal sense of self.[35] Hence, in this study nurses started to assess and implement religious practices based on spiritual needs, agreeing to perform rites and rituals either at the hospital or at home. This finding is congruent with some previous studies in which nurses assessed patients' and their families' wishes and followed such wishes. They allowed the family members of patients to stay bedside and encouraged religious traditions by advising the families to invite monks to conduct rituals for dying patients.[36]

Limitations of the Study

The findings of this study represent the healthcare professionals' perspectives at a given point in time. It should be noted that recollection might be a potential bias since all participants had to recall relevant events or situations retrospectively, indicating obtained information relied on participant memory. As the findings of this study are based on healthcare professionals' viewpoints, it might not reflect actual parents' reasons for choosing or changing an EOL option. Further studies if possible should recruit parents of terminally ill children, if possible, into the study, to reflect the real-life experiences of a key EOL decision-maker in a Thai PICU context.

Conclusion and Implications for Nursing Practice

This study provides a picture of the real-life situation of an EOL decision related to terminally ill children. The findings indicated that communication competence is of great importance to encourage effective EOL decision. Professional nurses and physicians working in the PICU should recognize the significance of communication skills, especially those related to listening, speaking, and clarification techniques during the family meeting to make an EOL decision. The findings could be beneficial for authoritative healthcare providers including nurse administrators working together to formulate guidelines for EOL decisions for children in the PICU, according to the roles of a multidisciplinary team.

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การตัดสินใจในระยะสุดท้ายของชีวิตสำหรับเด็กในหอผู้ป่วยหนักกุมารเวชกรรมไทย: การศึกษาเชิงคุณภาพแบบพรรณนา

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บทคัดย่อ:การตัดสินใจการดูแลผู้ป่วยเด็กวิกฤตในระยะสุดท้ายเป็นประเด็นความซับซ้อนทางการแพทย์ที่มีทั้งความท้าทายและความยากลำบาก การศึกษาวิจัยเชิงคุณภาพแบบพรรณนาครั้งนี้มีวัตถุประสงค์เพื่อศึกษาการตัดสินใจสำหรับผู้ป่วยเด็กวิกฤตในระยะสุดท้ายที่เข้ารับการรักษาในหอผู้ป่วยหนักกุมารเวชกรรมจากมุมมองของบุคลากรทางการแพทย์ ผู้เข้าร่วมในการวิจัยคัดเลือกแบบเฉพาะเจาะจง ประกอบด้วยแพทย์จำนวน 2 ราย และพยาบาลวิชาชีพจำนวน 17 ราย ดำเนินการรวบรวมข้อมูลระหว่างเดือนพฤศจิกายน 2561 ถึง มิถุนายน 2562 โดยใช้เทคนิคการสัมภาษณ์เชิงลึก วิเคราะห์โดยใช้หลักการวิเคราะห์ข้อมูลของเครสเวล

ผลการวิจัยพบว่า บิดามารดาเป็นบุคคลหลักรับผิดชอบตัดสินใจการดูแลสำหรับผู้ป่วยวิกฤตเด็กระยะสุดท้าย ข้อค้นพบ 4 ประเด็นหลักที่อธิบายการตัดสินใจสำหรับผู้ป่วยเด็กระยะสุดท้าย ได้แก่ การวินิจฉัยที่แน่ชัดของการเข้าสู่ระยะสุดท้าย การสื่อสารเพื่อยืนยันความเข้าใจของบิดามารดา การเอื้อให้บิดามารดาเลือกการดูแลในระยะสุดท้าย และการริเริ่มการดูแลระยะสุดท้าย ข้อค้นพบจากการศึกษาครั้งนี้ให้ความรู้สร้างความเข้าใจที่ชัดเจนเกี่ยวกับการตัดสินใจของบิดามารดาในช่วงระยะสุดท้ายชีวิตของบุตร สาระความรู้ที่จำเป็นของการตัดสินใจในระยะสุดท้ายมีประโยชน์ เป็นพื้นฐานที่สำคัญในการพัฒนาการตัดสินใจการดูแลในระยะสุดท้ายสำหรับผู้ป่วยเด็กในหอผู้ป่วยหนักกุมารเวชกรรมได้อย่างมีประสิทธิภาพและเหมาะกับบริบทการปฏิบัติงาน

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คำสำคัญ: การตัดสินใจในระยะสุดท้าย ผู้ป่วยเด็ก หอผู้ป่วยหนักกุมารเวชกรรม การศึกษาเชิงคุณภาพ ประเทศไทย

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