# End–of–Life Care for Children and Families in Pediatric Intensive Care: Thai Nurses' Perspectives

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**Abstract:** End-of-life care is the activity or practice that helps to support children at the end stage of life, as well as their families. However, in pediatric intensive care units, there is a lack of well-defined practices for nurses about how to provide such end-of-life care. This qualitative descriptive study aimed to explore nurses' perspectives on providing end-of-life care for children and their families. Purposive sampling was used to select 24 nurses in a pediatric intensive care unit of a tertiary hospital in northern Thailand. Participant observation and in-depth interviews were used to collect data, from October 2016 to November 2017. The content analysis was used to analyze data.

The findings identified six themes from the perspectives of nurse informants regarding end-of-life care for children: 1) assessing for entering end-of-life stage; 2) decision-making for end-of-life care; 3) alleviating suffering at end-of-life period; 4) providing spiritual care; 5) continuity of end-of-life care, and; 6) receiving inadequate policy support. The study provides essential knowledge about how end-of-life care is provided by nurses for children and families in intensive care which could help nurses gain a better understanding of end-of-life care provision and also utilized to generate end-of-life care interventions for these children in Thailand.

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## Introduction

The pediatric intensive care unit (PICU) offers intensive care and advanced technologies to save the lives of ill infants, children, and teenagers, and is also a place with an inevitable confrontation with dying and death.[1] In 2016, a regional hospital in northern Thailand reported the overall mortality rate in PICU was 11.4%. The hospital study also revealed that of 42 deaths, 78.8% patients had died whilst under intensive life–sustaining treatments, 7.1% were identified with brain death, and 12% received a resuscitation endeavor. It was also found that many of the deaths had an unpredictable and short phase before death.[2] Nurses have dramatic demands in this short phase when providing care for children with a terminal illness and their families. Thus, an intimate understanding is required for nurses regarding how to provide such care.[3]

End-of-life care involves activities that support terminally ill children, during and immediately after death to attain the quality of mortality.[4] To achieve this goal, in a previous study there was recommended that end-of-life care should comprise seven domains: patients' and families' autonomy in decision making, communication within the team and with patients and families, providing continuous care, psychological support for patients and families, symptom administration and easing care, spiritual support for patients and families, and mental and policy support for ICU providers.[5] Evidence suggests that such care can guarantee a higher value of dying and death for patients,[4,6] decreased suffering and complicated grief, and increased family satisfaction after death.[7, 8] Therefore, the role of nurses needs to incorporate dealing with the process and care for the dying child and recommending the families, aimed at physical, mental, and spiritual support for the children and families, including the management within the nursing team.

Western studies have demonstrated that the situation of nurses' engagement in a terminal care for children and parents in PICU is still problematic in the areas of patient and parent involvement in decision-making,[9] communication with patients and parents,[10,11,12] providing continuous care,[11,13] symptom administration and comfort care,[14,15] psychological support,[10,8,12] spiritual support,[7,16,17] and mental and policy support for ICU providers.[10,18] Thai studies have focused on nursing care at a terminal stage delivered outside the PICU unit,[19] and also on adult ICUs, which face similar issues to those in the Western countries.[20, 21] Such problems have led to a decrease in quality of mortality in children and their parents in the PICU.[6, 22] Although there are studies about the experience of ICU nurses when serving end-of-life care in both qualitative and quantitative studies, little is known about end-of-life nursing for children and their parents in PICU. Thus, this study attempted to help fill this knowledge gap.

## Review of Literature

Children at end-of-life are determined by physicians as having an incurable illness and unavoidably dying, or being in the final stage of that illness.[1,4] The indicator of impending death is children's poor physical functions, and they received many intensive treatments. Whenever children show signs of impending death, they are in the active dying process.[23] Therefore, these children require care for the end stage of their lives to support them through the moribund and death periods,[6] and so PICU nurses have to change the goal of care from saving lives to letting children die with peace.[11]

A previous western study regarding nurses' involvement in PICU revealed that some nurses were not involved in the planning care at the last period of terminally ill children and their parents but these nurses provided daily care to the children.[9] Communication was limited because PICU nurses had inadequate knowledge regarding how to communicate in caring at the terminal stage.[10] Nurses took care of children with terminal illness as security guards and often had no meetings with parents, which led to a lack of providing continuous care for dying children and families, causing families to feel unfamiliar,[11, 13] and to fear asking questions when confused about their child's situation. In turn, these issues resulted in stress and anxiety,[12] and suboptimal support for problems and patients' and families' needs.[24, 25] Nurses also lacked knowledge to assess the spiritual desires of patients and families,[10,16] compassion providing spiritual support, and competence regarding spiritual practices.[7] In terms of symptom management, several children died with pain, fatigue, swelling of arms and legs, dyspnea or air hunger,[26] and around 45% received insufficient comfort care in their final days, as pain management was insufficiently administered alongside invasive procedures continuing until death.[14] The comfortless death of a child also leads to increased suffering of parents.[7, 8, 27] After losing their loved one, 40% of bereaved family members reported having psychological distress including feelings of anxiety, major depression, or complicated grief, and no one received proper emotional support.[28] These problems can be stressful for nurses, who do not know what to do in the circumstance, how to tell the family members certain matters, and how to deal with children at end of life.[10] Nurses also identified the need for protocols or guidelines for providing terminal care.[18]

According to literature in Thailand, end-of-life care services exist mainly in cancer centers, while such care in the intensive care units, especially in pediatric intensive care units, is limited. Nurses and other providers engaged in care of dying persons have not been well prepared and trained in a terminal care. [19] As the previous studied reveal that ICU nurses lacked knowledge about end-of-life care. [29] They tried to avoid caring for dying patient and their families due to heavy workloads and discomfort in contacting the families of the terminally ill patients.[30] Such problems caused decreased quality of mortality in terminally ill children as well as their parents. [19, 22] Moreover, most studies were conducted in adult ICU, which might have different perspectives of caring compared to PICU. The death of an adult may sometimes be understood as a natural conclusion, whereas the death of a child should not happen because society expects children to live longer than adults. [31] PICU can be seen as more sensitive and reflecting a larger degree of hope than adult ICUs [6]. In addition, previous studies also identified that most adult ICUs have a private room and sufficient space to spend time together with a dying patient and the family, and where the patient can fulfill peaceful death,[20] but PICU has no such private room for children at end-of-life, which can be cause of decreasing quality of dying and death.[19] It can be concluded that existing knowledge from adult ICUs might not be sufficient to understand how PICU nurses provide end-of-life care for children and families. It is essential to understand how nurses deliver end-of-life care since nurses are recognized as the backbone of providing such care. They collaborate with various stakeholders as well as managers, policy makers and planners.[32] Therefore, understanding of nurses regarding end-of-life care for children in PICU is required.

## Study Aim

The aim was to explore Thai nurses' perspectives on providing end-of-life care for children and their families in PICU.

## Methods

**Design:**

A qualitative descriptive approach was employed to explore the phenomenon of interest in its natural setting.[33] This approach enabled the researcher to gain better understanding of facts about behaviors, attitudes, beliefs, values, feelings, and thoughts of nurses in serving a terminal care for children within the PICU.

**Study setting and Participants:**

The PICU of a tertiary hospital in Northern Thailand was selected because of its capacity to service a terminal care for children and their families. Participants were recruited by purposive sampling based on inclusion criteria of: being professional nurses who have experience in serving end-of-life care for children and their family members, and willing to participate in the study. Participants were recruited until data saturation occurred.

**Ethical Considerations:**

Ethics approval was obtained from the Ethics Review Board of the Faculty of Nursing, Chiang Mai University and the participating hospital (Approval number Full-030-2016). All participants were informed verbally about the purpose, methods, potential risks and benefits of participation, and duration of the study. Their participation was autonomous and they had the right to deny or disengage from the study at any time without effects. All participants signed an informed consent agreement after deciding to join in the study. Participants' confidentiality and anonymity and other rights were guaranteed from beginning to end of the research.

### Data Collection

Participant observation with field notes and in-depth interviews were used to collect data from October 2016 to November 2017. After ethics approval, the principal investigator (PI) introduced herself to the head nurse of PICU and asked permission to work as a volunteer nurse in the palliative care team of the PICU. Then, a head nurse introduced her to nurses who provided nursing care in terminally ill children and their parents, established rapport, and then asked for their willingness to be nurse informants. During working as a volunteer nurse, the PI undertook participant observation using an observation guide, to see how nurses provided terminal care for children and their parents and how they interacted with physicians and the palliative care team within PICU. The observation was conducted on week days, weekends, and holidays, on the day, evening, and night period. The PI jotted down field notes during or immediately after observation.

In-depth interviews were conducted with 24 nurses, between 60-90 minutes, varying in each case. Each participant was interviewed 1-2 times. Interviews were arranged in private rooms or meeting rooms in PICU to maximize convenience for participants and protect their rights and confidentiality. Each interview began with general questions to ascertain the demographic characteristics of informants, and then asked questions to explore end-of-life care for children with impending death in PICU by following the in-depth interview guide, which was developed from a literature review and were reviewed by the PI's advisory committee for accuracy and comprehensiveness. This process started with questions such as, "What do you think about providing terminal care in PICU?", and "Why?", then continued with specific/probing questions for further clarity and insight into the participant's experience on terminal care for children at end of life, such as, "Based on your experience, how did you provide care for patient with impending death and their families in PICU?". All interviews were digitally audio-recorded. The PI transcribed and analyzed the data simultaneously, and then prepared the questions for the next interviews. In-depth interviews were stopped when the data saturation indicated that no new information was emerging from the interviews.

### Data Analysis

Qualitative data were analyzed through the content analysis process proposed by Creswell,[34] consisting of six steps: all data were organized and transcribed verbatim; to deeply understand the meaning of the information gained, the researcher read and re-read, then wrote notes with short phases, ideas, or key concepts in the margin, and started forming an initial code; coded the data using interpretive codes, arranged these codes as categories, and labeled the categories with terms based on the actual language of the participants; used the coding of the data to generate the categories or themes; interpreting the data; and represented the data and described themes.

### Rigor and trustworthiness

This study employed the four conceptual elements of trustworthiness according to Lincoln and Guba.[35] Credibility was ensured with prolonged engagement, triangulation, and peer debriefing. Transferability was accomplished through thick description. In order to achieve dependability, field notes and reflective diaries were made from beginning to end of the study, and the expertise of dissertation advisory committee is provided as auditors. Confirmability was achieved by handing method triangulation and an audit trail.

## Findings

There were 24 Thai and Buddhist nurses who participated in this study. Their ages ranged from 27 to 49 years (mean = 40.3). Most were married (n = 17) and held a bachelor's degree (n = 18). Their experience in terminal care practice was between 5 to 26 years (mean = 13.38).

Findings are presented in six themes: *assessing for entering end-of-life stage, decision-making for end-of-life care, alleviating suffering at end-of-life period, providing spiritual care, continuity of end-of-life care, and receiving inadequate policy support* (Table 1).

**Table 1** Themes and sub-themes of end-of-life care for Thai children in PICU

| Themes | Sub-theme |
|---|---|
| Assessing for entering end-of-life stage | Assessing for need of end-of-life care |
| | Waiting for making decision of entering end-of-life stage |
| Decision-making for end-of-life care | Coordinating for parent involvement |
| | Parents' decision for end-of-life care |
| Alleviating suffering at end-of-life period | Relieving pain at end-of-life stage |
| | Relieving families' grief during the dying and death period |
| Providing spiritual care | Assessing the needs for spiritual practices |
| | Supporting spiritual beliefs and practices |
| Continuity of end-of-life care | Managing for providing continuous care |
| | Providing care in the same direction |
| Receiving inadequate policy support | Obtaining insufficient preparation to provide end-of-life care |
| | Lack of policy for providing emotional support |
| | Unsupported environment for peaceful death |

**Theme 1: Assessing for entering end-of-life stage**

Nurses mentioned that assessing for entering the end-of-life stage was the initial step of end-of-life care, which included PICU nurses assessing the needs for care and waiting for making decisions for entering this stage stage based on the patient's survival. There were two sub-themes in this theme:

**Sub-theme 1.1: Assessing for need of end-of-life care.** Nurses used the Palliative Performance Scale of Children (PPSC) on a daily basis to assess the needs for care at the last stage of all children, who admitted into the PICU. A PPSC result below 30% indicates a patient has entered the end-of-life stage and requires end-of-life care.

> *"...Nurses use PPSC to assess patients every day, once a day. Then, the result shows the percentage lower than 30%. Such cases will become patients at end of life and need end-of-life care."* (Nurse, 27 years old)

After that, nurses used the PPSC result to identify a tentative plan for caring at a terminal stage. This plan included providing comfort care, giving psychological care to the children and their parents, supporting children's and parents' beliefs, and providing information about the children to parents.

> *"... After assessment with PPSC, we will provide terminal care in which we make the patients comfortable, give as much psychological support, ask about the needs and beliefs of the patient and parents, and allow them to do things according to their beliefs. We plan to provide care accordingly after assessment."* (Nurse, 43 years old)

**Sub-theme 1.2: Waiting for making decision of entering end-of-life stage.** Nurses could not provide care as planned because they had to wait for physicians' decisions. Physicians had their own ways of assessment for making decisions about end-of-life stage. They made the final decision based on patient's response after receiving treatments and chance of survival. If patients had little chance of survival, physicians identified them as entering the end-of-life stage.

> *"We have to wait for doctor's diagnosis and decision that the patient doesn't look good, the medication does not lead to a very good result, and the child's condition still does not improve. The doctors calculate the survival rate. If the patient has very little chance of survival, they will conclude that the patient is currently in end-of-life stage."* (Nurse, 48 years old)

After PICU physicians made the decision for entering end-of-life stage, they consulted all involved in patient care, in order to make a final consensus about entering treatment.

> *"…. the doctor in PICU discusses with hematology or neuro unit. Doctors mostly talk about the chance for survival of patients. Once they reach consensus that the patients have very little chance of survival, they will together conclude that the patients are currently in end-of-life stage."* (Nurse, 43 years old)

**Theme 2: Decision-Making for End-of-Life Care**

After physicians had decided about patient's end-of-life stage, nurses took responsibility to coordinate parent involvement in a meeting with physicians. Then, decisions about caring for children at the terminal stage are made by parents. This theme had two sub-themes:

**Sub-theme 2.1: Coordinating for parent involvement.** Nurses contacted the parents, made the appointment, and invited them to talk to physicians, including managing time and place for the meeting between parents and physicians.

> *"…I called parent and invited them to the ward. After talking to the parent, we will inform the doctor again to confirm the appointment. We coordinate between the doctor and the parent, and arrange the area where they can talk in the meeting."* (Nurse, 40 years old)

During the family meeting, physicians informed the parents about their child's current conditions and the treatment options. This helped the parent to understand the child's situation before making the appropriate decision for their children.

> *"…The doctor informs parent that the patient is in a critical condition. The current treatments do not do any good. So, he gives the choices of treatment (but) if the parent wants to go on with the usual treatments, the doctor can do it. Another option is terminal care to make a child comfortable. Then, the doctor will ask the parent what they want to do. It depends on their decision."* (Nurse, 44 years old)

**Sub-theme 2.2: Parents' decision for end-of-life care.** After the family meeting, most of the parents agreed that their child was in a severe condition and had immense suffering. They required end-of-life care to make their children more comfort. Thus, nurses enabled parents to make decisions for their children based on their needs. However, a few parents needed more time to accept this end-of-life stage, and nurses allowed them to have more time for decision making:

> *"After doctor tells the mother that her child is close to dying then the mother told me that she sees her child so weak and unconscious, and understands about doctor's information. When the doctor asks her to choose end-of-life care, she decides to select this. She does not want her child in pain anymore, and expects that this care can make her child comfortable until death."* (Nurse, 48 years old: K09)

> *"…One mother told me that she still hasn't made a final decision whether to choose end-of-life care or not. She wanted to think and find more information because her child is her first child, she doesn't want him to die right now. …I understand and allow her to stay with her child all the time. Eventually, this mother accepts end-of-life stage of her child and requires the palliative care."* (Nurse, 44 years old)

**Theme 3: Alleviating suffering at end-of-life period**

To alleviate suffering at this stage, nurses provided care to relieve the child's pain and reduce the family's grief. This theme had two sub-themes:

**Sub-theme 3.1: Relieving pain at end-of-life stage.** Nurses stated that pain was the main symptom of children at end of life. To relieve minimal pain, nurses used distraction methods such as touching, playing with dolls, drawing, and giving games or books. Then, dying children could get some rest.

> *"When the children feel pain and cry, I will console them or use toys to distract them and talk to them, they will stop crying. In older children who are conscious, I will give them comic books, play games or let them draw in their bed. This is when the children don't look very much in pain. These activities help calm them so they can get some rest."* (Nurse, 44 years old)

For children with severe pain, nurses used pharmacological methods to relieve pain. After receiving drugs, these children felt more comfortable during the dying period.

> *"... The doctor will prescribe pain relievers, MO, dormicum, or fentanyl in some cases which have severe pain and restlessness. In some very agitated cases, the doctor will also add more chloral hydrate to enable the patients to be as calm as possible before death."* (Nurse, 49 years old)

Nurses also followed physicians' prescriptions to relieve pain by eliminating unnecessary treatments in children at end of life, following the parents' decision for discontinuation of treatments. This could ensure more comfort for dying children.

> *"...The doctor will reduce pain by withdrawing some treatments that have been administered but no effects on the condition of the patient. However, this is up to the parents' decision."* (Nurse, 49 years old)

**Sub-theme 3.2: Relieving families' grief during the dying and death period.** Nurses shared their experiences of trying to reduce families' sadness after perceiving their child's end-of-life stage by staying close, giving inhaler drugs and tissue papers, asking about their needs, and being willing to listen and respond.

> *"...I will ask parent and relatives how they are feeling after knowing a child has entered end-of-life stage. We are willing to listen to whatever they say. We have to devote one staff to accompany them, to console, give inhalers and tissue paper, talk or stand quietly be side. We have to stick around until they feel better."* (Nurse, 43 years old)

Moreover, nurses allowed families to participate in daily care for children at end of life such suctioning, cleaning the kid's body. Then, nurses sensed children's happiness and their parents felt able to contribute to their child's comfort:

> *"I allow parents to be involved in patient care. If the mother wanted to perform suction, or to brush the patient's teeth, we would let her do it. We allowed the mother to do everything she wanted. I could see that she was so happy to be able to care for her own child by herself."* (Nurse, 43 years old)

During impending death period, nurses encouraged the family's presence in order for them to see their child alive and stay together before death. This helped to reduce families' guilt after the child's death.

> *"If the patient's vital sign is not so good and the condition has exacerbated, we try to hold the situation so that the parent and relatives can see the patient while he/she is still living so they can say good-bye before the patient dies. Thus, the relatives would not feel guilty because they can make it in time and say goodbye before the patient dies."* (Nurse, 46 years old)

**Theme 4: Providing Spiritual Care**

Nurses revealed that providing spiritual care for children with impending death and their families involved assessing needs for spiritual practices, and supporting spiritual beliefs and practices in order to support children with impending death die in peace. It was thought that the family would feel no guilt if their spiritual needs were fulfilled. Again this theme had two sub-themes:

**Sub-theme 4.1: Assessing the needs for spiritual practices.** Nurses assessed the needs for spiritual practices by asking the parents about children's and families' needs for religions beliefs and the needs to practice families' personal beliefs with terminally ill children, after a family meeting.

> "*After meeting with the doctor, I meet parents and ask what are your religious beliefs? Do you want to make merit in this setting? What special things do you want to do for your child?. If you need me to help, please tell me what you want to do.*" (Nurse, 49 years old)

**Sub-theme 4.2: Supporting spiritual beliefs and practices.** Nurses supported spiritual beliefs and practices by arranging rituals related to families' needs, contacting a priest if appropriate for the child's and family's religious beliefs, arranging the ritual of making merit, and providing chanting books for the families.

> "*...The father wants to make the dispelling ceremony. We facilitate by preparing the space at bedside to make this ceremony. Or some relatives require putting the Buddha statue and the chanted thread above the patient's head. We follow to the relatives' need to make this pleasant.*" (Nurse, 37 years old)

> "*The relatives want us to help by inviting the monk to come into the ward. Nurses will invite the monk to come and inform the relatives about preparing the crucial things for making merit. If the mother wants to read the chanting book for the patient, we prepare many chanting books for them.*" (Nurse, 44 years old)

When the impending death comes, nurses fulfill the last desires of the child and their family by responding to their needs.

> "*...the mother wants her dying child to wear a teen outfit with short pants and teen shirt. She thinks that if her child wears those clothes before death, the child will be very happy. After hearing, I go to the shop to buy that kind of clothes, and put it on the girl. I can feel that that mother is satisfied and looks calm.*" (Nurse, 46 years old)

**Theme 5: Continuity of End-of-Life Care**

Nurses mentioned that end-of-life care was continually supported for children and their parents by managing nurses to provide continuous care in the same direction, as described in the two sub-themes below:

**Sub-theme 5.1: Managing to provide continuous care.** This was done by assigning nurses as the primary nurses for patient care. The primary nurses provided care for children under their own responsibility continually until the child was transferred or died, and followed up children's conditions periodically. This could help them understand children's situations and provide continuous care appropriate for each patient.

> "*...I as a primary nurse have the patient as my own responsibility. I provide care for patient until they move or die. I always update child's conditions. If the conditions are worse, I will tell an in-charge, who will report to physicians later. This assignment helps me to provide the appropriate care continually for patient.*" (Nurse, 49 years old)

**Sub-theme 5.2: Providing care in the same direction.** The nurse forwarded the information of family's decision and end-of-life care plan within the nursing team. By doing this, nursing team would understand the current situation of terminally ill children and their parents and be able to follow the steps of providing care consistently.

> "*... we take the information of parent's decision about plan for the patient to forward within the nursing team when the duty has shift. The aim of forwarding this information is that the nursing team needs to provide care with the same direction as the parent's decision.*" (Nurse, 44 years old)

After handing over the information within the nursing team, the current primary nurse would provide all previous information of the children and families along with the end-of-life care plan to the primary nurse in the next shift.

> *"After finishing handing over within the nursing team, the current primary nurse transfers all information of patient to the next primary nurse such as what the severity of patient's conditions, what has been the treatments for the patient, what we have to do next for the patient. The next primary nurse will give the same care as the plan in every duty"* (Nurse, 33 years old)

**Theme 6: Receiving inadequate policy support**

The nurses stated that they received inadequate policy support from the organization as they obtained insufficient preparation to provide end-of-life care, experienced lack of policies for providing emotional support, and had an unsupportive environment for peaceful death. These inadequacies led nurses to have no confidence to provide care for children at end of life and their families, and believed they failed to achieve good deaths for patients along with failure to ensure satisfaction of families.

**Sub-theme 6.1: Insufficient preparation to provide end-of-life care.** Nurses mentioned that they had received the training course regarding end-of-life care a long time ago, and then they had not obtained it again. Nurses also stated that if they received updated training, they would have confidence to provide end-of-life care for children and their families.

> *"At present, we were not trained about terminal care. Some nurses went to training organized a long time ago. The palliative care board of the hospital should organize training sessions to boost the knowledge of end-of-life care for the nurses. With learning, nurses will be confident in caring for the patients."* (Nurse, 43 years old)

**Sub-theme 6.2: Lack of policy for providing emotional support.** Participants revealed that they did not know how to support the families' sadness after receiving the bad news from physicians and there was a lack of policy about this. When families showed sadness, nurses did not contact the families and instead let them console each other.

> *"... I don't know how to talk to them after the meeting, I don't know how to deal with these situations. No one has shown me. Most of the time, I just watch them and let the relatives console each other."* (Nurse, 44 years old)

> *"... the relatives are very sad when the patient dies. I don't know what to say to the relatives, how to comfort the relatives when they are sad and cry. We just end up watching them quietly and let the relatives console each other."* (Nurse, 27 years old)

In addition, a primary nurse had to manage documents and also provide emotional support to the family on her own; nobody provided assistance to her. Eventually, the primary nurse could not provide adequate psychological care to the family.

> *"Now I am not fully able to provide psychological care for the relatives after the patient dies because I have to take care of a lot of documents. I can't find another nurse to comfort them because she is also busy with her case. No one is specifically in charge of doing this."* (Nurse, 44 years old: N04)

**Sub-theme 6.3: Unsupported environment for peaceful death.** Nurses disclosed that the environment in PICU hardly supported a peaceful death for dying children due to a lack of tranquility, caused by noises from staff working along with sounds of monitors and ventilators.

> *"...The PICU is full of noises all the time because the staff are talking to each other; the doctors come to check on the patients while teaching residents; the sounds of the alarms, monitors or ventilators. There are always noises and impossible to have quiet in PICU."* (Nurse, 44 years old)

Nurses also try to provide a private space for children and their families by closing the curtains to cover patients' beds. However, if another patient on the bed next to the end-of-life case was very critical, they could not close the curtains for the patient and family. Thus, the chance to have peace was reduced.

> *"... in PICU, there are no separate rooms for end-of-life cases. We solve this problem by closing the curtains but it's difficult to have privacy because sometimes we have to open the curtains so that we can see other cases. So, it's not very peaceful."* (Nurse, 43 years old)

## Discussion

From nurse participants' perspectives regarding care in PICU, assessing for entering the end-of-life stage. This step was undertaken following a PPSC result below 30%, then waiting for making decisions for entering end-of-life stage based on patient's survival. This finding is congruent with that from another study which reported that when a patient had a PPSC score below 30%, the patient was transitioning into the end-of-life stage, and the destination should focus on the terminal stage.[36] The patient's survival was determined by their prognosis. If their symptoms worsened, the chance for the patient's survival also decreased, and this indicated transitioning to the end-of-life stage.[37]

After that, nurses took responsibility to coordinate between physicians and family members in the family meeting by arranging time and place, and providing the authority to family for decision-making about terminal care for their children. This action aligned with a previous study in that whenever the doctor wanted to talk with parents or family members, nurses took the role as coordinators and managers for arranging the family meeting session, and enabling parents to make appropriate decision about end-of-life care for their child.[38] Moreover, the decision-making for selecting the pattern of care at the last stage for children should come from family-centered.[5] Nevertheless, this finding differed from some studies, which revealed that some parents were excluded from or had little-to-no involvement in decision making, with physicians trying to persuade parents into making a similar decision as themselves.[10] These differences may be due to the participants' experiences following the hospital's end-of-life care guideline, which stated that the care decision should be patient and family-centered.

In response to suffering at the last life periods, nurses provided care to relieve patient suffering using distraction methods, administering medication to relieve pain, and eliminating unnecessary treatments. This finding was similar to previous studies, which found that health care providers prescribed many drugs to relieve pain, increase comfort, and eliminated unnecessary treatments for children at end of life. Then, dying children could die in peace.[5, 8,14, 15] Families suffered from grief and sadness after losing their loved ones and nurses tried to provide support to relieve family suffering and sadness. This finding was similar to previous studies, which revealed that emotional support could help to relieve psychological distress and ensure more comfort for families after losing their loved ones. [5,8, 10]

Providing spiritual care at the terminal stage of children and their parents involved responding to needs regarding spiritual beliefs and practices. This fulfillment could help reduce family guilt after the loss of their child and also help the child to die peacefully. This finding was congruent with some studies, which revealed that spiritual support in the last period of life involved providing support based on the needs, beliefs, and values of children and families. Nurses and physicians could help them feel at peace, prevent parents' guilt, and promote family satisfaction after children's death.[5, 7, 11, 39]

End-of-life care was continually provided for children through the assignment of primary nurses, and communicating patient and family information within the nursing team. This helped the team provide care in the same direction. This finding was congruent with studies revealing that continuity of care meant providing constant care for terminally ill children and their parents in order to achieve quality of death.[5, 13]

However, in terms of hospital policy regarding end-of-life care, nurses revealed that they received inadequate organizational support regarding knowledge of end-of-life care. With this inadequacy, nurses felt less confident to provide terminal care for children and their parents. Previous studies also indicated that health care providers lacked knowledge about providing such care; nurses did not know what to do, or how to deal with dying children and their families.[10,32] Similarly, Crump and colleagues[18] reported that nurses felt insecure in caring for dying patients because they lacked knowledge and had low confidence to care for children at a terminal stage. The findings also revealed that the PICU environment was unsupportive to facilitate patients' peaceful death or for families to be together with their child during dying and death periods. This finding was congruent with previous studies, that revealed that limited space for privacy in PICU could lead families to feel more stressed and anxious due to a lack of a private goodbye, and which made their children's death without peace. [11, 23]

## Limitations

This study was conducted with nurses in the tertiary hospital of a large city, which may decrease the validity of the study findings to nurses who work within hospitals in rural areas.

## Conclusions and Implications for Nursing Practice

The findings offer rich insights on those nurses who provided end-of-life care in PICU for children and their families. PICU nurses could utilize the findings to establish end-of-life care interventions. Moreover, nursing administrators and education can apply these findings to establish training sessions for nurses to improve their competence and confidence to provide end-of-life care in PICU. Guidelines of providing end-of-life care nursing in PICU can be enhanced using information from these findings, and this study can generate the foundation for further research. This is warranted in other settings in the other parts of Thailand to determine the aspect of nurses, clinicians, and caregivers regarding how end-of-life care is provided in PICU across the nation, and needs to involve a number of research methodologies.

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# การดูแลระยะสุดท้ายสำหรับผู้ป่วยเด็กและครอบครัวในหอผู้ป่วยหนักกุมารเวชกรรม: มุมมองของพยาบาลไทย

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**บทคัดย่อ:** การดูแลระยะสุดท้าย คือ กิจกรรมหรือการปฏิบัติดูแลที่ช่วยเหลือสนับสนุนเด็กที่มีความเจ็บป่วยอยู่ในระยะสุดท้ายของชีวิตและครอบครัว แต่อย่างไรก็ตามในหอผู้ป่วยหนักกุมารเวชกรรมในประเทศ พบว่า การให้การดูแลระยะสุดท้ายสำหรับเด็กป่วยในระยะสุดท้ายของชีวิตยังมีแนวทางที่ไม่ชัดเจนในการปฏิบัติทางการพยาบาล การวิจัยนี้มีวัตถุประสงค์เพื่อค้นหามุมมองของพยาบาลต่อการดูแลระยะสุดท้ายสำหรับเด็กป่วยในระยะสุดท้ายของชีวิตในหอผู้ป่วยหนักกุมารเวชกรรม คัดเลือก กลุ่มตัวอย่างแบบเฉพาะเจาะจง กลุ่มตัวอย่าง คือ พยาบาลในหอผู้ป่วยหนักกุมารเวชกรรมของโรงพยาบาลระดับตติยภูมิในภาคเหนือ จำนวน 24 คน เก็บข้อมูลโดยการสังเกตแบบมีส่วนร่วมและสัมภาษณ์เชิงลึก จากเดือนตุลาคม 2559 ถึงเดือน พฤศจิกายน 2560 การวิเคราะห์ข้อมูลใช้วิธีการวิเคราะห์เชิงเนื้อหา

ผลการวิจัยพบว่า การดูแลระยะสุดท้ายสำหรับเด็กป่วยในระยะสุดท้ายของชีวิตในหอผู้ป่วยหนักกุมารเวชกรรม ตามมุมมองของผู้ให้ข้อมูล ประกอบไปด้วย 6 ประเด็นดังนี้ 1) การประเมินการเข้าสู่ระยะสุดท้าย 2) การตัดสินใจในการให้การดูแลระยะสุดท้าย 3) การบรรเทาความทุกข์ทรมานในช่วงวาระสุดท้าย 4) การให้การดูแลด้านจิตวิญญาณ 5) การให้การดูแลระยะสุดท้ายอย่างต่อเนื่อง และ 6) การได้รับนโยบายสนับสนุนไม่เพียงพอ การศึกษานี้ให้ความรู้ที่เป็นประโยชน์เกี่ยวกับการให้การดูแลระยะสุดท้ายสำหรับเด็กป่วยในระยะสุดท้ายของชีวิตในหอผู้ป่วยหนักกุมารเวชกรรม ที่ซึ่งสามารถช่วยพยาบาลให้มีความเข้าใจในการให้การดูแลระยะสุดท้ายในหอผู้ป่วยหนักกุมารเวชกรรมได้มากขึ้น และผลการศึกษานี้ยังสามารถใช้เป็นข้อมูลพื้นฐานในการพัฒนารูปแบบการดูแลระยะสุดท้ายสำหรับเด็กป่วยในระยะสุดท้ายในหอผู้ป่วยหนักกุมารเวชกรรมในประเทศไทย

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**คำสำคัญ:** การศึกษาเชิงคุณภาพ การดูแลระยะสุดท้าย เด็กและครอบครัว หอผู้ป่วยหนักกุมารเวชกรรม ประเทศไทย

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