

Palliative Care Guidelines for Physicians and Nurses Caring for Children and Their Families in the Pediatric Intensive Care Units: A Participatory Action Research Study

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Abstract: Pediatric palliative care in intensive care units entails challenging tasks for healthcare professionals, and distressing times for parents and families of children around the world. It is vital that care is of the highest quality and is focused on the needs of the child and family members. Guidelines for such care were urgently needed in Thailand for physicians and nurses caring for the children and their families to enhance their quality of life, provide a good death for children, and appropriate support for families. A 5-phase participatory action research study was conducted in a university hospital in northern Thailand, and findings from the first three phases are reported here. Forty-four healthcare professionals, consisting of physicians, registered nurses and practical nurses, working at two pediatric intensive care units in a university hospital in northern Thailand were purposively recruited. In-depth interviews and focused group discussions were the primary means of collecting data. Data were analyzed by content analysis

Findings revealed five critical components that needed to be included in the Palliative Care Guidelines for Physicians and Nurses in Pediatric Intensive Care: Breaking bad news, Decision making, Care before death, Imminent death care, and Care after death. Nurses and physicians can use the guidelines to ensure a dignified death and quality of palliative care for a child in a pediatric intensive care unit. The benefit of the guidelines can be extended to support a child's family members through their difficult times and experiences. Our findings also help to inform the international community of nurses and physicians caring for children in palliation. The guidelines will be distributed to different locations for testing to ensure relevancy for practice and may be adapted for contextual and cultural relevancy elsewhere.

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Introduction and Literature Review

Pediatric intensive care units (PICUs) are designated hospital wards for providing care to critically ill children. Dependent on resources available, such wards are

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usually equipped with the latest biomedical engineering technology to ascertain delivery of the best healthcare services. When a child's condition worsens and the final stage of their life is inevitable, healthcare directives need to be changed from a curative basis to that of being palliative. The aim of care should focus on improving the quality of life of children and their families through preventing physical, psychosocial and spiritual suffering.¹ Globally, palliative care for children has substantial precedents for adults' end-of-life delivery of healthcare. The Thailand Healthcare Accreditation Institute identifies palliative care as one of the key indicators for quality of care delivered by health care professionals within a hospital system.²

Although the key indicators are needed, providing palliative care in PICUs still faces limited and inadequate care. These may be because of the cultural values and norms in PICU settings. In PICU the traditional focus has been on curative strategies with the objective of saving lives and death has been viewed as a limitation in skills of healthcare professionals and failure of technology.³ The practice of prolonging life, at any cost, may be viewed as the only acceptable method of delivery of care. This practice in turn increases the burden of medical interventions, for example, use of mechanical ventilators, or children dying despite the heroic interventions of healthcare professionals, as well as costs to the state, health care facilities, and to families. Several studies conducted in PICU settings indicate that most children lose their quality of life due to receiving aggressive interventions and some die during resuscitation, but few of them received comfort care before death.^{4,5} In Thailand, about 97% of children who died while in PICU had received ventilation interventions and 30% were treated with kidney dialysis.⁶

Family members, especially parents, can be overwhelmed and emotionally distressed when dealing with dying children. The sight of their child suffering from pain, or their inability to communicate with their child can be very stressful and it is not uncommon for

them to receive limited or unclear information about their child's prognosis.^{4,7} Their sense of little or no ability to join in a shared decision-making process about their child's treatment options can exacerbate the negative feelings of already emotionally distressed parents.^{4,7,8} Family members of dying children often report anxiety and distress as common psychological symptoms, while pain, fatigue, irritability and drowsiness are reported as physical symptoms.⁷ Most parents perceive that their children suffered "a great deal", or "a lot" or "somewhat" during the last stages of their lives.⁷ The most common reasons for suffering include pain, irritability, difficulty with feeding and breathing in children <two years and drowsiness, and fatigue and sleeping problems among older children.^{4,7,9,10} The majority of parents described the quality of life of their children during the last months of their lives as "poor" or "fair" and some reported care was not compassionate care by healthcare professionals and they excessively used technology during the final stages of their children's lives.^{4,7,9,10} Findings from a study conducted among Brazilian parents regarding their perceptions about deaths of their child in PICU revealed that unclear and low quality communication by the healthcare professionals as the primary source of their frustration.¹¹ Parents were dismayed because the healthcare professionals used technical terms when communicating with them.¹¹ They believed that use of medical and technical jargon by healthcare professionals prevented them from fully comprehending their child's health conditions and getting inadequate information to make a decision for their child.¹¹ Therefore, they were not able to fully participate in and make the appropriate decisions about their child's course of treatment. Other studies have found that parents believe that decisions are made based on medical perspectives rather than personal choices and values.^{7,8,9,12,13}

Parents with children in PICU often feel disempowered and stripped of their parental roles and rights. One study reported that parents were not allowed to remain in the room with their dying child

and were prevented from touching them.¹³ Additionally parents' satisfaction with care was influenced by the communication style of health providers and the limited information given, and lead to their lack of clarity about the course of treatment.^{11,12,13,14} Another study reported that physicians have the propensity to dominate parent-physician conferences, speaking 67%–73% of the time.¹⁴ And, in general, healthcare professionals are not prepared for the imminent death of a child and do not have communication dexterity to empathize with family members.^{13,14}

The traumatic issues described in the literature, our own experiences and that of our immediate colleagues, and reading of the literature about the current state of pediatric palliative care in PICUs in Thailand, were a strong indication for the urgent development of the palliative care guidelines to assist healthcare professionals to provide quality of care. A previous review of the literature over the last five years of the existing palliative care guidelines in PICU found no reports.^{15,16,17} Most of the existing evidence showed that pediatric palliative care guidelines were developed for pediatric oncology and general pediatric ward in which the context is much different from PICU.^{15,16,17} Hence these guidelines are of limited value to palliative care practice in PICU. Considerable advancements in the field of adult palliative care has made the concept of end-of-life quality of care a component of standard care practice in health settings. We believed that a similar standard should be established for pediatric end-of-life care in PICU, and so implemented this research project. A participatory action research study was conducted in five phases: preparation, situational analysis, plan development, implementation and evaluation phases but only the first three phases are reported here.

Study Aim

To develop a set of Palliative Care Guidelines for Physicians and Nurses in Pediatric Intensive Care

(PCGHPIC) caring for children and their families in a university hospital in Thailand.

Methods

Design: A qualitative study using participatory action research (PAR), a derivative of action research, with foundations in social psychology. PAR has a number of phases or cycles that empower participants to identify their research needs in the workplace, and to find ways of addressing issues.¹⁸ For this reason PAR was chosen for this study, as it was important for multidisciplinary staff to work collaboratively together to share ideas and opinions and make decisions with the research team about what should be in the new pediatric care guidelines, ultimately so that quality of care to the children and families was improved.

Participants and Setting: Study participants selected through purposive sampling comprised a total of 44 healthcare professionals (HCPs): three physicians, four senior registered nurses (SRNs), 25 registered nurses (RNs), and 12 practical nurses (PNs). Inclusion criteria were: employment with the university hospital; a minimum of two years' experience with providing pediatric end-of-life care; and willingness to participate in the study.

The setting was two PICUs at a university 1,400-bed hospital in Thailand. Each PICU houses 6 beds for children aged between 1 month to 15 years. Delivery of healthcare services is focused primarily on children requiring advanced respiratory support or support systems for two or more organs, and those with chronic impairment of one or more organs who also require support for an acute irreversible failure of another organ. The prioritized care goal in the PICU is to undertake all relevant medical interventions available to cure a child's illness. When cure is not possible, the provision of palliative care will be started which is based on individual practices of the lead physician. The team consisting of senior specialist, physician residents, medical students, and

a senior nurse will approach the family to discuss about child's prognosis and goal of care. Then the team gives the family members time to make a decision what choice they need to do for their children.

Ethical Considerations: This study was approved by Ethics Committee for Research in Humans, Faculty of Medicine, Chiang Mai University (Approval #NONE-2556-01911). Researchers protected all participants from potentially harmful consequences that might affect them as a result of their participation. They received clear verbal and written explanations about the purposes and processes of the study including that it was voluntary for participation; and their rights to anonymity and confidentiality and they could withdraw from the study whenever they desired without giving a reason, or fearing repercussions. All those participating signed a consent form.

Data Collection

The data collection processed through three phases consisted of preparation phase, situational analysis phase, and plan development phase.

1. Preparation phase

This involved establishing contact with and gaining cooperation of hospital staff. The principal investigator (PI) contacted hospital administrators and stakeholders including the head of the medical department, nurse supervisors of pediatric nursing division, and two head nurses of the PICUs to inform them of the research aim and processes, and the risks and potential benefits of the study, to ask for their research support, and especially to obtain their agreement to participate.

2. Situational analysis phase

This phase took three months. The objectives here were to analyze the situation of palliative care in the PICUs and to develop care guidelines. The PI and participants identified the conditions of pediatric palliative care in the PICU and the problems faced by healthcare professionals who took responsibility for

the children and family members needing palliative care. Two main activities during this phase were focus group discussions (FGDs) and in-depth interviews (IDIs). An interview guideline was used to conduct FGDs and IDIs of the participants. The interview guideline, founded on the existing literature, was developed by the PI. Question examples were: "Please tell me in the current situation about the communications between/among healthcare team and family?" and "What are your suggestions to improve communication". Probing questions were also used to obtain more in-depth data. Correlation between this guideline and the research questions was qualitatively assessed by three experts in palliative care: a physician, an RN, and a nurse instructor. During FGDs participants were prompted to share suggestions and opinions regarding the desirable palliative care services. Permissions were obtained to digitally record the FGDs and IDIs.

There were four FGDs for the 25 RNs divided into four groups according to years of work experience. Groups 1 (7 RNs) and 2 (8 RNs) had work experience between 2–10 years. Groups 3 and 4 (5 RNs each) had work experiences of 11–20 years duration. For the PNs, two FGDs were conducted with six PNs in each. Each group participated for around 60–minutes. The PI led the FGDs, aided by a research assistant (RA) who took notes and recorded the conversations. Seven IDIs were conducted with three physicians and four SRNs, with >20 years of work experience. Each interview lasted approximately 45–60 minutes.

3. Plan development phase

The PI shared with the participants the findings from data analysis of the situational analysis. They were encouraged to brain storm and share additional thoughts and suggestions about the present status of palliative care at the PICU and a tentative palliative care guideline was developed by the research team in consultation with participants. Three meetings were set to confirm appropriateness of the guideline using the spiral design of action research consisting of planning, acting, observing, and reflecting proposed

by Kemmis and McTaggart.¹⁹ In the planning step, the first draft of guideline was presented to all participants who discussed the plan for an implementation trial. Acting and observing occurred simultaneously. The first draft was distributed to participants to implement for 4 weeks. After this the PI and participants discussed and reflected on the result and drew conclusions for the next guideline revision. This process was conducted repeatedly through three meetings and the document was reshaped three times until confirmed as appropriate by participants. Next, a physician, an RN and a nurse instructor, all with expertise in pediatric palliative care, reviewed the revised guideline, offered suggestions and revised it again.

Trustworthiness

To achieve study trustworthiness, four criteria suggested by Guba and Lincoln were used, credibility, transferability, dependability and confirmability.²⁰ For credibility, the PI leveraged her extensive years of contributions in the field of pediatric palliative care to increase the validity of the study. This was accomplished by building trust with participants to verify potential information biases they introduced. Credibility was achieved through member checking to confirm interpretation of meaning of data. Transferability was achieved by describing a rich data base, with sufficient detail and description to enable to reader to understand the study processes and findings. Dependability was achieved by thick description of transcription and field notes. Confirmability was conducted through a spiral cycle within three meetings to sort out possible ideas and information that may have been overlooked. In addition, validation of findings were discussed and confirmed by the researchers and study participants.

Data analysis

Data was organized to identify and categorize topics of palliative care situations. Qualitative data collected during FGDs and IDIs were transcribed

verbatim and analyzed using content analysis, read several times, and then coded line-by-line. Key words or phrases were underlined and documented in the right-hand margin of the text and sections of the texts with similar words or phrases were classified and coded together. This step permitted clustering of similar responses and labeling them for a clear definition of the nature of each theme.

Findings

The findings are presented in two parts: 1) situational analysis of palliative care in PICUs and 2) components of Palliative Care Guidelines for Physicians and Nurses in Pediatric Intensive Care (PCGPHPIC). The latter section contains overall discussions about the guideline.

Part 1: Situational analysis of palliative care in PICUs

Five major themes emerged from data analysis and explained below:

Theme 1: Communication and Decision - making

Communication is a crucial tenet in delivering effective palliative care in PICU. Participants described communication with children and their families as one of the main responsibilities for both physicians and RNs. For example,

When a child's condition worsens, doctors should start to discuss [among themselves] within the doctor and team including nurses before talking to children and parents regarding the condition of the child. (FGD1, RN1)

Team discussion is important to make sure all healthcare members are on the same page and there is continuity of care and treatment. Family meetings should be held in the unit in private and conversation focused on the child's prognosis and the risk of adverse events. However, not all physicians and nurses need to be present at these meetings, for example,

... just only some of the pediatricians and nurses in day shift can join the meeting; in fact, [if] children were provided care by multidisciplinary team such as a cardiologist or a nephrologist, then specialists would not be invited to join the discussion. Practical nurses also should join because they are in the nursing team. (FGD1, RNs)

Nurses expressed their concerns about health professionals being absent from these meetings and missing important information about care delivery to the child. Medical notes and charts should be reviewed carefully to ascertain the appropriate delivery of healthcare and prevent any misunderstanding and conflicts among the team. When a child's condition deteriorates and all indications suggest a poor prognosis, the team should plan for bad news to be given to parents, a difficult task. Parents and family members often cannot accept the truth, and have difficulties with full comprehension of a situation and the necessity for making the right decision regarding withdrawing or withholding life-sustaining treatments. Therefore, senior physicians or RNs are assigned to carry out this responsibility:

When the dying comes closer, it is very difficult for us to explain any plan to the family. Healthcare professionals should comprehensively understand palliative care concepts, if not they cannot approach...and there are impacts on the family to make a decision for their child ... Staff cannot do this alone. (IDI1, doctor)

Participants suggested improving communication in PICU. The fragmentary and conflicted communication among multidisciplinary teams directly affects decision-making of both team members and a child's family:

If doctors cannot agree on the same page of treatment plans, children and their family also get affected. They cannot make a good decision for their children as well. (FGD1, 3, RNs 4,5)

Theme 2: Continuity of care

Continuity of care is necessary for palliative care in PICU. However, health care teams in PICU often experienced a deficiency in this because of the multiplicity of professional approaches, who often work separately within their own medical sphere. Sometimes care was fragmented, not only among individuals but also between hospital specialists. There was lack of continuity in referring for ongoing treatments and other related information among the team, causing issues with a consistent approach to manage health conditions and needs of children and family. Consequences of treatment and care were inadequately provided to the patient and family, affecting quality of palliative care, for example:

It was difficult to achieve continuity of care because the complexity of care required several specialty doctors such as cardiologist, chest specialist, and nephrologist and so on. They all did not talk together so the quality of palliative care became poor. (IDI2, doctor)

In four FGDs (4-5-6-7) SRN participants emphasized team members working together and communicating well, for example:

It would be good if multidisciplinary team can work together. The quality of palliative care cannot be done by one single doctor or nurse. This requires that all health care professionals effectively communicate and discuss about prognosis and treatment plans together in order that the patient and family needs and quality of care are met.

Theme 3: Symptom management and comfort care

Pain is number one of symptoms causing suffering at end-of-life for children. In palliative care in PICU, nurses take a major role to assess children's pain on a regular basis and other vital signs using standardized tools. Nurses explained:

We always assess pain every 1–2 hours using the standardized tools; NIPS (Neonatal Infant Pain Scale) for assessing infants' pain less than one-year-old and CHEOP for children one to six years old. For children older than six years who are conscious, we assess pain based on a self-report and in the case one who is intubated and unconscious or sedated we would use behavioral pain scales instead of self-report. (FGD1–4, RNs)

However, pain management in PICUs is still inadequate and often pain and other discomfort symptoms are often overlooked by physicians, for each physician has a different method of managing pain and mostly focuses on pain. Few physicians are concerned with other symptoms such as constipation, so they do not work in the same direction. Physicians also do not quite trust the pain score recorded by nurses; they make a decision on their own about whether children have pain. This may lead to poor pain management. A nurse mentioned that:

We would like the doctors to pay more attention about pain assessment and manage pain using the same guideline. (FGD3, RN1).

For pain management physicians take a responsibility for medication but some are reluctant to use opioid agents, and a reason for this is:

Some doctors still misunderstand about medication to relieve pain such as opioids because they are concerned about drug addiction, resulting in inadequate pain management. (IDI 4, SRN)

Dyspnea is another common symptom found in children with advanced disease and can severely impair their quality of life. Often it is thought to be a clinical marker for the terminal phase of their disease and management is still inadequate. This can make nurses and family feel frustrated and helpless that they cannot provide comfort care for children. A nurse mentioned that:

In the final stage, children mostly suffered from severe dyspnea and a doctor did not provide appropriate treatment. Some doctors give sedation medication for children but it seems the medication dose is not enough to alleviate dyspnea. Nurses don't know how to help and parents feel unhappy to see their child suffering. (FGD2, RN4).

However, non-pharmacological interventions should be integrated into pain management which is within the main role of nurses but mostly participants believed they did not use these kinds of intervention.

Theme 4: Spiritual support

Participants described that spirituality is like a strategy used by the family to protect and strengthen it to overcome crisis and the moments of losing their children. In current practice in Thailand, there is no guideline about how to provide spiritual care for children and family in PICU. Mostly providing spiritual care is nurses' role and they approach children and family depending on their understanding of this. They may act according to an individual belief or religion, influenced by family or culture, for example:

Nurses always ask about family beliefs and culture. Some respect God. We contact the pastor for them or they may contact them by their own if they have someone in mind. Some respect Buddhism. We contact the monk for them... (FGD4, RN5)

Although physicians do not take on the important role of providing spiritual care directly, they often perceive that what nurses do is not exactly spiritual care. One participant said:

I thought providing spiritual care nowadays was practiced individually and it is not a true spiritual care; it is just a superficial care without any guideline. (IDI1, Doctor)

Nurses were also concerned about the guideline and were not confident whether they undertook the right actions regarding spiritual care. One doctor reiterated this:

Nurses provide spiritual care on their understanding or experience; not based on any theory; hence the specific guideline is needed to implement spiritual care in PICUs contexts. (IDI 1, doctor)

Theme 5: Emotional and psychosocial support

All participants agreed that emotional and psychosocial support are extremely stressful to deal with for the dying child and grieving family. In current PICU practice, only the nurses recognized and paid attention to the need for such care, and this was not a multidisciplinary approach. Participants perceived that physicians will only take responsibility to update the family with factual information as quickly as possible on a regular basis. This may be because nurses have the most contact with both dying children and their family, and provide everyday support. However, providing emotional and psychosocial support is based on individual nurses' understanding. There was no practice guideline on how to approach a child and family during a period of grief, so this was considered problematic in terms of the lack of a multidisciplinary team approach, available time, and communication skills:

Currently, nurses take an important role to support dying children and family. However, I think it is the individual nurse in each shift. Have no pattern and guideline to give the direction of support, and no system or team to provide such care seriously. (IDI3, doctor)

The limitations of such care may be because physicians and nurses are not competent enough to provide emotional and psychological care for dying children and family or because of staff shortage:

Healthcare personnel in PICUs lack both knowledge and skill to provide such care. So, they follow their ideas to provide care as good as they can. (IDI1, doctor)

Although some healthcare professionals provided such care, it was not really considered comprehensive care. The participants also mentioned recognizing grief in healthcare professionals after a child's death. This is challenging, and such grief is a recognized cause of burnout and other forms of emotional distress:

...we would like to have an emotional support system for us. Sometimes we felt very sad after the child's death but no one cares for each other about this issue; it is important especially for new staff. They have no experience about the death of a child before. Some could not accept this situation at all and felt guilty. (FGD2, RN1)

Part 2: Components of the PCGPHPIC

The PCGPHPIC was developed based on findings from the situational analysis and literature review and consists of five components with the same names as the themes from the qualitative data: *Breaking bad news, Decision-making, Care before death, Imminent death care, and After-death care* as described below. (see also Table 1)

Table 1. the Guidelines for physicians and nurses caring for children and their families in the PICU

Component 1: Breaking of bad news

- Discussion among health care team members so that all care plans are in the same direction in order to avoid conflicting information
 - Asking for other family members whom parents would like to participate in the bad news communication.
 - Involving the children in the bad news communication as appropriate
 - A face-to-face discussion in privacy, timely, up to date, accurate and consistent information, and family should be treated with respect, honesty and sensitivity.
 - Assessing emotional state and coping of parents/family/children after the bad news communication
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Table 1. Guidelines for physicians and nurses caring for children and their families in the PICU (Cont.)

Component 2: Decision making

- Identifying and appointing surrogate who has the right by law to make decision for children.
 - Involving children in decision-making regarding medical treatments as appropriate to respect their autonomy
 - Assessing family understanding of children's disease and prognosis; repeating information if they do not understand.
 - Assessing the parents or legal surrogate's decision-making capacity, including conflict within family
 - Giving opportunities and support to parents to discuss and involve their children in expressing and sharing their wishes on decision about their treatments
 - Respecting decision of the children and family regarding either withholding or withdrawing life sustaining treatments.
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Component 3: Continuity of care

- Communicating among the health care professional team regularly (at least weekly or more often as required by the clinical situation) to plan, review, and evaluate the care plan based on the children and family, and documenting all plans over time.
 - Meeting the team regularly to discuss provision of quality care and to make sure for continuity of care.
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Component 4: Pain and symptom management

- Regular, ongoing assessment of pain and other symptoms such as shortness of breath, nausea, fatigue and weakness, anorexia using standard instruments as appropriate with the child's development and documenting the symptoms in the patient chart.
 - In case of cognitively-impaired children, assessing symptoms should be performed by appropriately trained professionals with appropriate tools.
 - Providing management of pain and other symptoms safely and timely using both pharmacological and non-pharmacological treatment.
 - Reassessing pain and other symptoms within one hour after administering medication and observing complications of medication provided and documenting in the patient chart.
 - Referral to healthcare professionals with specialized skills in symptom management as appropriate
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Component 5: Psychosocial care

- Regular, ongoing assessment of psychological reactions related to the illness of children and family such as stress, anxiety, fear, and anticipatory grieving using the standard tools.
 - Documenting information in the patient chart
 - Providing management for the psychological problems, both pharmacological and non-pharmacological treatment as appropriate
 - Reassessing psychological symptoms after administering medication and observing for any complications of medicine. Documenting this in the patient chart.
 - Referring to healthcare professionals with specialized skills in psychological management as appropriate.
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Component 6: Spiritual care

- Assessing and identifying religious / spiritual background and preferences related beliefs and rituals of the children and family
 - Assessing spiritual concerns regularly using standard tools with age-appropriate manner.
 - Encouraging and facilitating the patient and family to perform any ritual practices following their own religious/spiritual.
 - Referring to professionals or spiritual leader with specialized knowledge or skills in spiritual issues as appropriate.
 - Documenting all information in the patient chart.
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Table 1. Guidelines for physicians and nurses caring for children and their families in the PICU (Cont.)

Component 7: Imminent death care (4–48 hours)

- Recognizing and providing information about the signs and symptoms of approaching death to parents/ family members to make sure they can come to say goodbye on time.
 - Assessing and documenting symptoms at the end of life on a timely basis and providing management based on children–family preferences.
 - Revising the care plan appropriately to meet children–family needs and withdrawing all aggressive treatments to reduce suffering as much as possible.
 - Educating family members regarding the signs and symptoms of approaching death in a developmentally, culturally, and age–appropriate manner.
 - Facilitating privacy and quiet environment as much as possible in order that the family can express their feelings openly to the child for the last time.
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Component 8: Immediate after–death care

- Removing all medical equipment connected to a child such as ET tube, catheter lines, and urinary catheter.
 - Washing and dressing the child body; asking parents / family members for their possible involvement in these activities.
 - Encouraging parents/ family members to hold their child.
 - Allowing and encouraging parents to personally collect their child’s belongings and to retain important mementos such as photographs, clippings of hair, and hand and footprints
 - Providing time for parents/ family members to be alone with their child body in a private zone and facilitate their desire to undertake rituals based on their beliefs and culture.
 - Providing opportunities for parents/ family members to express their emotions openly.
 - Providing access to care whenever parents/ family members have questions, and supporting the family during the grieving time as appropriate
 - Nurses and physicians saying the words “Asking for forgiveness” in case they have done some trespass during the child’s admission in the PICU.
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Component 9: Bereavement care

For parents /family members

- Helping parents accept the reality of their loss.
- Expressing sincere sympathies to a grieving parents/family members such as participating in memorial services
- Connecting families to other parents who have experienced this loss, to self–help organizations, or to professional counseling or services that address this issue.

For Healthcare professionals

- Supporting each other via peer–to–peer discussions, group debriefings, psychological and spiritual counseling, and educational programs
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Discussion

Breaking bad news: This component is important in the guideline because it is the first step before moving into palliative care. The highlight of this component

is the difficult task to inform bad news to family by healthcare professionals working in the acute care settings where context is limited access to privacy and less time to establish a rapport with children and families.²¹ A recent study reported children and

families need sufficient time to ensure that they receive all necessary information and can ask questions.²¹ Skilled and effective communication is needed. Previous studies demonstrate inadequate communication can cause distress and dissatisfaction, and convey negative impacts on families throughout their life.^{14,21,22} Giving bad news to families should be done by senior physicians but in real practice, not many of them take this responsibility.^{14,21,22} Since patients and families may suffer when given bad news, especially in a poor fashion, the physician needs good training about how to do this better. This may enhance physicians and other healthcare team feel confident to talk with parents in a difficult situation.²³ Another highlight is about the dying children, whether to involve them in the bad news communication. This point is still controversial, “to tell?” or “not tell?”, however, the literature reports that if parents decide not to tell children about their impending death, the children will sense this for themselves.^{24,25} Children want to be told the truth, and not be told untruths about their illness.²⁶

Decision-making: After delivering bad news, healthcare professionals need to identify a legal surrogate decision-maker for children. Children do not have the capacity to do this on their own, either because they are too young or too sick to join in decision-making.²⁵ Generally, parents are the best ones to advocate in this role and most likely to decide based on the best interests of their children.^{27,28} Clear and honest information is needed for parents to make the best decision so assessing the family understanding of children’s disease and prognosis as well as repeating information is important.^{8,27,28} A paucity of information and lack of comprehensive understanding information reduces their decision-making capacity.^{14,29} Another important point is children can join in discussions even if there is no commonly agreed definition about what age they are competent to make decisions for themselves.^{27,28} The literature suggests that children should be allowed to participate in their treatments as a minimum as they can work together with their parents.^{27,28}

Care before death: this component is divided into four sections: continuity of care, physical care, psychosocial care, and spiritual care. Continuity of care is vital to help improve patient and family satisfaction and palliative care quality.³⁰ The health care team should meet regularly in discussions to review, evaluate and confirm that everyone is on the same page with care, treatment and strategies, and that all plans are based on the preferences of children and their family to maintain continuity of care.³⁰ Previous studies show that lack of continuity of care may affect end-of-life decisions.^{31,32} Assessing and managing pain and other symptoms during this time is also very important. There are common symptoms in the dying phase including pain, fatigue, irritability and drowsiness, and distress is commonly scored highly.¹⁰ Pain relief is the most essential treatment in palliative care before control of other problems in the physical, psychosocial and spiritual domains is achieved.³³ During the critical time, parents always experience a wide emotions; if their coping strategies are inappropriate they may behave in a negative way with PICU team members,³ who should assess psychological reactions regularly, and provide specific management or refer them to specialist care if necessary.

Spiritual care is also vital. Dying children and their families need appropriate spiritual care based on their beliefs and culture during this difficult time. A study showed that the parents of dying children have spiritual needs that need to be attended to and to be given an opportunity to perform rituals in PICU; they may also feel a desire a chaplain to have discussions with them and to pray for their child.^{34,35} Healthcare professionals can help them to contact clergy or pastoral support from their appropriate faith group and facilitate ritual practice.

Imminent death care: When children are approaching the final stage of dying, health care professionals need to recognize sign and symptoms of impending death as soon as possible. This is to enable the family members the opportunity to say

goodbye and they may want to perform some ritual practices based on their belief.^{36,37} In some cultures where the family structures are extended families, there is a strong desire for the patients to die with family members around them.^{3,11} Some families may express their wishes for the place of death. Previous studies reported most families preferred their child to die at home.^{37,38,39} However, most important is the need for privacy and achieving death of in a place of their choice.³⁹ PICU staff should provide privacy and a quiet environment as much as possible so that the family can express their feelings openly to the child for the last time.³⁹ Assessing and managing the symptoms during this time is also important. All suffering of children should be minimized as much as possible and this should help reduce parents' long-term distress.

After-death care: This component is divided into immediate after-death care and bereavement care. After a child dies, immediate care should be provided to include physical care of the body as well as care of the family. The first experience of death for families may be that of their own child, and so they need to be given the chance of viewing the body, and to be prepared for what they will see when they enter the room.⁴⁰ Every family should be allowed time and privacy with their child, and then nurses or physician remove all medical equipment connected to the child. Parents should be supported to feel in control and be able to make their own choices and encourage them to hold, bathe, and dress their dead child.⁴⁰ Some need to capture a memory of their child. Health care professionals can help them to keep important mementos like photographs, hair, hand and footprints.^{40,41} This is an individual choice, and nurses and physicians should inquire about their needs. Also siblings, grandparents or other significant persons should be included in this situation.⁴¹⁻⁴² Primary nurses and physicians need to stay at bedside in order that they can answer the questions and support the family during the grieving time appropriately.⁴⁰ In Thai culture, nurses and physicians may "ask for forgiveness from

the child who has died" in case they may have committed some trespass on the child during their admission to PICU. Providing the family with written information on the processes to be followed after death is important.⁴¹⁻⁴²

Bereavement care is essential in palliative care, not only for the family but also the healthcare professionals. Parents may want to have a continued relationship with staff in the hospital, and might think of this as extended caring and comfort, and acknowledgement.^{43,44} Bereavement care should be offered for as long as the family needs, and nurses and physicians can assist parents to come to accept their loss, by expressing sincere sympathy to a grieving family after the death and by participating in memorial services. They can help by introducing them to other families who lost a child, refer them to counselling or self-help organizations to help them deal with their loss.^{43,44}

Healthcare professionals may also need help to deal with their grief reactions which, if left untreated can cause distress and burnout.⁴⁵ This affects not only for individual healthcare professionals but also the health care system. Studies recommend attention, acknowledgment, and in-time support to assist healthcare professions to dealing with patient death.^{45,46} Several coping strategies can be used such as social support and religion, distraction by breaking their time to pay attention to grief like undertaking sports and recreational activities, spending time with own children and so on.⁴⁵ McDermott, Brook and Ben-Isaac⁴⁷ state that an effective way to reduce caregiver suffering is to provide support both clinically and emotionally. This will help caregivers to deal with their grief responses. A recent study reported three core concepts which can help healthcare professionals during the grief process: (1) how they perceive the death of patients; (2) their actual reactions to bereavement; and (3) accumulated changes. There is both a personal and professional dimension to each of these concepts.⁴⁸

Limitations

This study was undertaken in a pediatric intensive care unit at one university hospital using PAR. Therefore, findings may not fit widely because different settings may have specific challenges and problems in providing palliative care, however the guidelines produced need to be tested elsewhere for cultural relevance. The family members who had experience with dying children in PICU were not involved in this study and they would add valuable information for guideline revision in the future.

Conclusions and Implications for Practice

This study took place in a northern Thai university hospital with the participation of all healthcare professionals in the PICU setting, physicians, registered and practical nurses, to develop the palliative care guideline (PCGPHPIC) thus this adds value to the guideline because it was developed collaboratively. PAR was a useful qualitative method to employ in this study. Through PAR processes participants can take action to resolve workplace problems by being empowered to seek solutions through collaboration with others in a systematic way.¹⁸ The study participants gained benefit from the PAR approach to understand actual situation of palliative care in the PICU and designed their own solutions. As a result, the guideline was developed with the specific situation concerned in their settings. Through the focus group processes and in-depth interviews, all participants could express their ideas and share their experiences of providing palliative care for children and family in the PICU. They also provided suggestions to improve palliative care quality in the PICU.

All health care professionals working in PICUs need to be offered psychosocial and emotional support, including spiritual care. This is essential to both their

well-being and ability to work together for the benefit of children who have life-threatening illnesses, as well as their families. These supports should be proactively addressed by the palliative care team in PICUs via peer discussions, counselling of various kinds and educational sessions.

Providing palliative care in PICU is the unique challenge. Healthcare professionals face a transition from cure to caring for a child that addresses the end-of-life issues. They have to deal with the difficult tasks of breaking bad news to the child and family, decision-making, dealing with a wide range of emotions expressed, and burdensome symptoms. Our findings provide rich data about the palliative care situation in PICU and offer insights in the palliative care guideline development. Healthcare professionals especially nurses can use the guideline as a resource to reduce gaps in care and improve quality of palliative care in PICU. For future research, the guideline should be implemented and tested in the various setting for the possibility of improving the palliative care quality.

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แนวปฏิบัติการดูแลแบบประคับประคองสำหรับแพทย์และพยาบาลในการดูแลเด็กและครอบครัวในหอผู้ป่วยหนักกุมารเวชกรรม: การวิจัยเชิงปฏิบัติการแบบมีส่วนร่วม

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บทคัดย่อ: การดูแลเด็กแบบประคับประคองในหอผู้ป่วยหนักกุมารเวชกรรมเป็นความท้าทายสำหรับบุคลากรวิชาชีพสุขภาพ และเป็นช่วงเวลาแห่งความวิตกกังวลของบิดามารดาและครอบครัวในทุกหนทุกแห่งทั่วโลก สิ่งสำคัญในการดูแลแบบประคับประคอง เป็นการดูแลที่มุ่งเน้นคุณภาพสูงสุดและตอบสนองความต้องการของผู้ป่วยเด็กและครอบครัว ในประเทศไทยแนวปฏิบัติในการดูแลแบบประคับประคองมีความจำเป็นเร่งด่วนสำหรับแพทย์และพยาบาลที่ให้การดูแลเด็กป่วยระยะท้ายและครอบครัว เพื่อส่งเสริมให้เด็กและครอบครัวมีคุณภาพชีวิตที่ดี ตายดีและเป็นการช่วยเหลือสนับสนุนครอบครัวให้ผ่านภาวะที่หนักหน่วงได้อย่างเหมาะสม การศึกษาครั้งนี้เป็นการวิจัยเชิงปฏิบัติการแบบมีส่วนร่วม ในโรงพยาบาลมหาวิทยาลัย ภาคเหนือตอนบนของประเทศไทย แบ่งขั้นตอนการดำเนินงานวิจัยเป็น 5 ระยะ และในบทความนี้นำเสนอผลการดำเนินการวิจัยใน 3 ระยะแรก เลือกรุ่นเป้าหมายแบบเจาะจงจำนวน 44 คน เป็นบุคลากรที่มสุขภาพ ได้แก่ แพทย์ พยาบาลวิชาชีพ และผู้ช่วยพยาบาลที่ปฏิบัติงานในหอผู้ป่วยหนักกุมารเวชกรรมจำนวน 2 แห่ง ณ โรงพยาบาลมหาวิทยาลัยในเขตภาคเหนือตอนบน ประเทศไทย รวบรวมข้อมูลเชิงคุณภาพโดยการสนทนากลุ่มและการสัมภาษณ์เชิงลึก วิเคราะห์ข้อมูลโดยการวิเคราะห์เชิงเนื้อหา ผลการศึกษา ได้องค์ประกอบสำคัญของแนวปฏิบัติการดูแลแบบประคับประคองสำหรับแพทย์และพยาบาลที่ปฏิบัติงานในหอผู้ป่วยหนักกุมารเวชกรรม 5 องค์ประกอบ ได้แก่ การแจ้งข่าวร้าย การตัดสินใจ การดูแลในระยะก่อนตาย การดูแลในระยะใกล้ตาย การดูแลภายหลังการตายของผู้ป่วยเด็ก แนวปฏิบัติที่ได้จากการศึกษาครั้งนี้สามารถเป็นแนวทางที่ช่วยสนับสนุนแพทย์และพยาบาลให้การดูแลแบบประคับประคองแก่ผู้ป่วยเด็กและครอบครัวในหอผู้ป่วยหนักกุมารเวชกรรมได้อย่างมีคุณภาพ ผลการศึกษายังช่วยเป็นการเผยแพร่ข้อมูลการดูแลแบบประคับประคองให้แก่กลุ่มแพทย์และพยาบาลในระดับนานาชาติซึ่งอาจนำแนวปฏิบัติไปปรับใช้ในบริบทและวัฒนธรรมที่มีความแตกต่างกัน

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คำสำคัญ: เด็ก ครอบครัว พยาบาล การดูแลผู้ป่วยหนัก การดูแลแบบประคับประคองในเด็ก แนวปฏิบัติในการดูแลเด็ก แพทย์

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