CRITICAL CARE NURSES’ PERCEPTIONS OF QUALITY OF DYING AND DEATH, BARRIERS, AND FACILITATORS TO PROVIDING PEDIATRIC END-OF-LIFE CARE IN THAILAND

by

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DEDICATION

This dissertation is dedicated to

My beloved parents
Lukjun and Pratum Mesukko,

and

All my wonderful family members,

who made all of this possible,

for their never-ending love, support and contributions

Additionally my dissertation is dedicated to
the memory of my beloved aunt, Bunme Wattage, and my grandparents

who would have been so proud of my accomplishment,

They all are forever in my heart.
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Little evidence exists regarding best practices for pediatric end-of-life care in Thailand. Most studies from Western cultures focus on adult patients; available studies in pediatrics focus on care delivered outside the intensive care unit (ICU). Nearly all pediatric deaths in Thailand occur in ICUs. This study aimed to explore nurses’ perceptions of the quality of dying and death, barriers and facilitators to providing pediatric end-of-life care in Thai ICUs and examine relationships among these variables. The study framework was based on Donabedian’s structure, process and outcome model. A descriptive correlational design was used on a convenience sample of 129 neonatal and pediatric ICU nurses from two university hospitals in Thailand. Data were collected using self-administered anonymous versions of the Modified Quality of Dying and Death and the Modified National Survey of Critical Care Nurses regarding End-of-Life Care surveys. Open-ended questions were used to elicit data on additional barriers and facilitators not addressed by the standardized instruments and to obtain suggestions to improve pediatric end-of-life care. The results revealed that critical care nurses perceived a moderate quality of dying and death for infants and children in Thai ICUs (Mean = 52.89, SD = 15.43). The overall
model demonstrated all three barrier and facilitator predictors (patient-family-related, healthcare-professional-related, and organizational-related) significantly affected the quality of dying and death ($p < .001$) with 33-34% of the variance explained. Barriers and facilitators related to healthcare professionals significantly contributed to quality of dying and death. The highest ranked of these healthcare-professional-related barriers were having disagreement among physicians about direction of care, time constraints, and insufficient knowledge of end-of-life care. The three highest ranked healthcare-professional-related facilitators were agreement of physicians about direction of care, the provision of a peaceful and dignified bedside scene once the patient has died, and having physicians put hope in real tangible way for the family. The content analysis results identified several additional barriers and facilitators related to healthcare professionals. The empirical evidence obtained from the study provides valuable information for Thai national healthcare policy, nursing and hospital administrators, nursing education, nursing practice and future research.
CHAPTER I

Introduction

Optimal quality of dying and death for children who die in intensive care settings depends heavily on end-of-life care. Improvements in providing pediatric end-of-life care processes are associated with improved quality of dying and death outcomes (Meyer, Ritholz, Burns, & Truog, 2006). Conversely, barriers to delivery of such care negatively affect quality outcomes and a variety of effective strategies is needed to overcome those barriers. Identifying barriers and seeking valuable facilitators are the first steps in determining the direction to improve pediatric end-of-life care in the intensive care unit.

There is compelling evidence that many children dying in an intensive care unit have unmet physical, psychological, emotional and social needs (Burns, Mitchell, Griffith, & Truog, 2001; Carter, Hubble, & Weise, 2006). In spite of the fact that providing end-of-life care is already established in such settings, considerable debate continues regarding the quality of care. Previous studies reveal that dying children in the intensive care unit continue to suffer from pain and other distressing symptoms because of inadequate symptom management (Carter et al., 2006; Meyer et al., 2006; Rushton et al., 2006; Wolfe, Grier, Klar, Levin, & Jeffreyc, 2000). Some studies have shown that parent satisfaction with their child’s pain control is worse in intensive care units than in other hospital settings (Burns et al., 2001; Copnell, 2005). Parents and other family members also report poor quality of communication with critical care providers (Copnell, 2005; Meyer et al., 2006). They often experience feelings of being abandoned and overwhelmed while suffering emotional and sometimes financial consequences from their child’s illness (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Meyer, Burns,
Griffith, & Truog, 2002). These observations are signs of failure to deliver effective pediatric end-of-life care in intensive care settings.

Barriers to providing optimal pediatric end-of-life care may reside in three areas: patient-family-related factors, healthcare-professional-related factors, and organizational-related factors (Anghelescu, Oakes, & Hinds, 2006; Moss, Demanelis, Murray, & Jack, 2005; Nelson, 2006). Patient-family-related barriers include prognostic uncertainty, family tension and denial, discomfort with death, unrealistic hope and misinformation (Beckstrand, Callister, & Kirchhoff, 2006; Beckstrand & Kirchhoff, 2005; Davies et al., 2008; Kirchhoff & Beckstrand, 2000; Nelson, 2006). Healthcare-professional-related barriers include inadequate education and training in the management of pain and other symptoms, philosophy of care toward terminally ill patients, poor communication, time constraints, and inappropriate attitudes and beliefs about end-of-life care and legal issues (Anghelescu et al., 2006; Beckstrand & Kirchhoff, 2005; Burns et al., 2001; Kirchhoff & Beckstrand, 2000; Michelson & Steinhorn, 2007; Nelson, 2006). Organizational-related barriers include unclear policies and lack of institutional resources including adequate staffing, and financial resources (Anghelescu et al., 2006; Beckstrand & Kirchhoff, 2005; Burns et al., 2001; Kirchhoff & Beckstrand, 2000; Michelson & Steinhorn, 2007; Nelson, 2006). These barriers can be conceived as negative resources associated with poor quality of dying and death.

Different strategies are required to address each barrier. Although many barriers and facilitators of providing end-of-life care have been identified in various studies, the majority of investigations have been conducted in the West, primarily in the United States, the United Kingdom, Israel, the Netherlands and Australia (Hales, Zimmermann,
A few studies were conducted in Asian countries: Japan, China and South Korea (Hales et al., 2008). No studies investigating barriers and facilitators regarding such care have been conducted in Thailand where the healthcare system, culture, organization and end-of-life care practices are different from previously studied countries.

In Thailand, the standards and proven methods regarding end-of-life care have not yet been adequately developed. End-of-life care in Thailand has slowly improved and numerous challenges remain to the development of such care (Nilmanat, 2006). Nimanat (2006) reveals that end-of-life care services in Thailand exist mainly in cancer centers, while such care in areas such as intensive care units, especially in pediatric intensive care units, is limited. Physicians, nurses and other providers involved in care of dying persons have not been well prepared and trained in end-of-life care. Methods of monitoring and evaluating end-of-life services are poorly developed (Nilmanat, 2006). Therefore, quality of dying and death, potential barriers and facilitators of providing end-of-life care that are specific to Thailand need to be identified in order to gain a fuller understanding of the important factors required to provide high quality end-of-life care. Because quality of end-of-life care is especially elusive to objective measurement, perceptions of others is one of the few viable options to elicit information on how an infant or child was cared for at the end of life. Thus, the primary aim of this study was to elicit the perceptions and views of Thai critical care nurses regarding the quality of dying and death, barriers to optimal end-of-life care, and perceived facilitators to improve such care for infants and children.
Problem Statement

It is estimated that worldwide over seven million children die from illnesses and injuries every year (WHO, 2003). In the United States alone, one million children are very seriously ill; approximately 500,000 children cope with life-threatening conditions, and approximately 50,000 children die annually from congenital malformations, low birth weight, sudden infant death syndrome, malignant neoplasms, heart disease, respiratory diseases, accidents and other unintentional injuries, and suicide-related causes (Martin et al., 2008).

In Thailand, with 14.5 million children in the population, more than 174,000 children die annually as a result of life-threatening illnesses such as cancer, congenital anomalies, heart disease, neonatal complications, and infections (Thailand Health Profile Report, 2007). Cancer and HIV/AIDS are especially prevalent in Thai children. About 17,000 children were living with HIV infection, and at least 4,000 children were newly HIV infected in 2007 (UNAIDS, 2008). In 2006, more than 13,000 Thai children under 15 years old were living with cancer (National Cancer Institute, 2007). Beyond these life-threatening illnesses, motor vehicle accidents and accidental drowning are also leading causes of child death, causing 37% of all deaths in Thai children (Thailand Health Profile Report, 2007).

With this prevalence, dying children and their families require comprehensive, compassionate, and developmentally appropriate end-of-life care. End-of-life care is an important method of care for infants and children with terminal illness and should be emphasized to ensure the best possible quality of life for dying children and their families through the prevention or alleviation of physical, emotional, social, and spiritual suffering.
Studies have documented a high prevalence of symptoms such as pain, dyspnea, agitation, and fatigue that may affect the quality of dying of infants and children (Howell, 2007; Jones et al., 2007; Kane, 2006; Korones, 2007). Some evidence suggests that many dying children in the intensive care unit experience considerable suffering with pain and other symptoms without adequate relief, despite the fact that modern medicine has the means to relieve their pain and improve most symptoms (Fujii et al., 2003; Hongo et al., 2003; Sirkia, Hovi, Pouttu, & Saarinen-Pihkala, 1998; Wolfe et al., 2000). Approximately 89% of dying infants and children experience substantial suffering from at least one symptom including fatigue, pain, and dyspnea, and treatment for these symptoms is seldom successful (Copnell, 2005; Devictor, Latour, & Tissieres, 2008; Hechler et al., 2008; Wolfe et al., 2000). Some studies demonstrated that up to 25% of dying children experience moderate to severe pain in the last three days of their life and less than 30% of parents reported that the treatment of pain was successful (Copnell, 2005; Devictor et al., 2008; Hechler et al., 2008; Wolfe et al., 2000).

Findings from previous studies suggest that communication with families of dying children is deficient and they are often abandoned to confront with the shock, sadness, anger and guilt of a child’s grave illness alone (Widger & Picot, 2008; Wolfe et al., 2000). Some studies reveal that families rarely were involved in meetings and were informed of a decision for consensus on care management options. Many times, they received insufficient information to make a decision (Copnell, 2005; Devictor et al.,
2008). Such situations lead to failure to deliver effective end-of-life care that meets physical, emotional, and spiritual needs of dying children and their families.

Setting of Care

Unlike adult patients who may prefer to be cared for and die at home, about 80% of pediatric deaths in developed countries occur within hospital settings, especially in the area of acute care settings in both the pediatric intensive care unit (PICU) and the neonatal intensive care unit (NICU) (Brandon, Docherty, & Thorpe, 2007; Carter et al., 2006; Feudtner, Silveira, & Christakis, 2002). In developing countries, like Thailand, about 90% of pediatric deaths occur in acute care settings (Maharaj Nakorn Chiang Mai Hospital, 2007). It is expected that the frequency of pediatric death following intensive care hospitalization is likely to remain high, since families of children with serious and even terminal illness continue to select hospital-based care at the end of life for their children (Carter et al., 2006; Ramnarayan, Craig, Petros, & Pierce, 2007). Families often have difficulty accepting the inevitability of their child’s death. Thus, they try to seek any hope they can find that their child’s life will be extended even for a short time.

Many providers debate whether the approach of inevitable death is an appropriate criterion for admitting a child to the intensive care unit. Traditionally, the ICU is not a place for the dying; the primary goal of such units is to provide maximum effort to sustain life and promote healing in children experiencing life threatening injuries or illness (Truog, Meyer, & Burns, 2006). However, the presentation of these children to such settings unavoidably arises because society does not routinely accept the death of children as natural. Aggressive treatments are often provided until clinicians and family become convinced that further treatment is futile (Carter et al., 2006). The advantage of
this approach is that children are offered every treatment that may benefit them. Parents are also reassured that healthcare providers have fully tried to save their child’s life (Doroshow et al., 2000; Giannini et al., 2008). Conversely, the disadvantage of this approach is that little regard is given to the suffering of children and their families. Hospitalization in the ICU also engenders false hope and high medical cost that is inconsistent with good outcomes (Doroshow et al., 2000; Giannini et al., 2008). Such situations challenge healthcare providers to provide comprehensive end-of-life care for these children and their families in intensive care settings.

Possible Barriers to Quality End-of-Life Care

Failure to provide optimal end-of-life care comes from several existing barriers in intensive care settings. These barriers can be categorized into three main areas including patient-family-related factors, health care professional-related factors and organizational-related factors (Anghelescu et al., 2006; Moss et al., 2005; Yabroff, Mandelblatt, & Ingham, 2004).

**Patient-family-related factors.** Patient-family-related factors are considered among the most important barriers to providing effective end-of-life care. The most common patient-family-related barriers include uncertain prognosis, a lack of family readiness to acknowledge an incurable condition and intra-family conflict. Several studies have documented uncertain prognosis as a main barrier to delivery of optimal care in children with life-limiting illness (Hilden et al., 2001; Himelstein, 2005; Himelstein, Hilden, Boldt, & Weissman, 2004; Jalmsell, Kreicbergs, Onelov, Steineck, & Henter, 2006). In a survey of pediatric healthcare providers’ perceptions of end-of-life care in an academic children’s hospital, approximately one half of respondents identified uncertain
prognosis as the most important barrier, and reported that it almost always occurs in situations of providing pediatric end-of-life care (Davies et al., 2008). In the same study, 51% of respondents agreed that lack of family readiness to acknowledge an incurable condition resulted in encounters where families had unrealistic expectations and were unwilling to participate in end-of-life care (Davies et al., 2008). Although this study investigated end-of-life care in pediatric patients, the study was conducted in a single tertiary care institution in the U.S., which limits generalizability to care of pediatric patients in Thailand. In another survey of obstacles to providing end-of-life care in adult patients, critical care nurses reported that family lack of understanding of the term “lifesaving measures” lead to unrealistic expectations (Beckstrand & Kirchhoff, 2005). Results from several studies support that intra-family conflict (conflict between family members) also served as a barrier to effective end-of-life care (Beckstrand et al., 2006; Beckstrand & Kirchhoff, 2005; Davies et al., 2008). Consequences of intra-family conflict include increasing distress or tension for patient, family and healthcare team and delays in redirection to more appropriate end-of-life care (Kramer, Boelk, & Auer, 2006).

*Healthcare-professional-related factors.* Factors that present barriers to the provision of effective end-of-life care related to healthcare professionals include beliefs and attitudes; lack of adequate training and education; poor communication between the healthcare professional and patient, family and other healthcare professionals; poor pain and symptom management for the patient; and staff shortage and time constraints (Beckstrand & Kirchhoff, 2005; Davies et al., 2008; Institute of Medicine, 2003; Kirchhoff & Beckstrand, 2000; Medicine., 2003; Miyashita et al., 2007). Negative attitudes regarding end-of-life care have been widely reported among healthcare
professionals. Many providers report they were uncomfortable providing care for
dying patients (Dunn, Otten, & Stephens, 2005; Ferrell et al., 2007; Lange, Thom, &
Kline, 2008; Rooda, Clements, & Jordan, 1999).

Inadequate education of healthcare professionals is noted as another major barrier
to delivering effective pediatric end-of-life care. In a survey of pediatric oncologists,
approximately 90% reported using trial and error when making decisions about pediatric
end-of-life care (Hilden et al., 2001). Only 10% of pediatricians report any formal
training in pediatric end-of-life care, although some had learned to care for dying children
informally through palliative care role models (Hilden et al., 2001). Similarly, practicing
nurses rate their knowledge of end-of-life care as fair or poor (Ferrell et al., 2007;
Puntillo et al., 2001) or feel their level of knowledge regarding end-of-life care is lower
than desired (Proctor, Grealish, Coates, & Sears, 2000; Raudonis, Kyba, & Kinsey,
2002). Commonly reported knowledge deficits include issues related to communication,
pain management, symptom alleviation, and information about the philosophy and
principles of end-of-life care (Manworren, 2001; Proctor et al., 2000; Puntillo et al.,
2001).

Deficiencies in knowledge may result from lack of end-of-life content in both
school curricula and nursing and medical textbooks used in the U.S. (Ferrell, Virani, &
Grant, 1999; Ferrell, Virani, Grant, & Juarez, 2000; Rabow, Hardie, Fair, & McPhee,
2000; Rabow & McPhee, 2002). Curricula and textbooks include little or no emphasis on
care of dying patients and their families (Ferrell, Virani, & Malloy, 2006; Rabow et al.,
2000; Rabow & McPhee, 2002). Most education training programs for healthcare
providers reveal a strong focus on preventive and curative aspects of care, partnered with
clinical experiences that expose students to curative-oriented rather than comfort-oriented care (Meier, Morrison, & Cassel, 1997). In Thailand, schools for healthcare professionals primarily use textbooks from Western countries; consequently, this barrier may also exist in Thailand.

Inadequate staffing levels and lack of time also are considered to be barriers to delivering effective end-of-life care (Beckstrand et al., 2006; Davies et al., 2008). Inadequate staffing levels and lack of time may be interdependent; nurses in one study felt the shortage of nurses was responsible for their lack of time to care effectively for dying patients (Beckstrand et al., 2006).

Although past studies have identified several healthcare professional-related barriers, these studies were conducted in the U.S. and findings may not apply to barriers in Thailand. Additionally, most studies evaluated end-of-life care for adult patients and the pediatric studies (Davies et al., 2008; Hilden et al., 2001) did not evaluate care provided in the ICU setting. No studies have evaluated healthcare-professional-related factors influencing pediatric end-of-life care in ICUs in Thailand.

Organizational-related factors. Organizational-related factors having a negative impact on provision of effective end-of-life care include financial barriers, restricted visiting policies, and inappropriate ICU environments (Burns et al., 2001; Carter et al., 2006; Ferrell et al., 2007; Institute of Medicine, 2003; Kirchhoff & Beckstrand, 2000; Roland, Russell, Richards, & Sullivan, 2001). The various health insurance options for children make it difficult to obtain a full picture of financing coverage for pediatric palliative and end-of-life care services (Institute of Medicine, 2003). Explicit reimbursements for palliative care and end-of-life care services for children do not exist
in the U.S. (Capello, Meier, & Cassel, 1998) or in the Thai health insurance system (Mustafa & Yee, 1997).

Limited visiting hour policies are another barrier that interferes with the needs of dying patients and their families leading to poor quality of care. One study noted that family members of critically ill patients expressed the greatest dissatisfaction with the visitation policy; a major concern was the desire to be able to perform personal care for their loved one (Roland et al., 2001). In Thailand, visiting hours for ICU patients are typically limited to 1 hour intervals at 11 am and 3 pm and limits visitors to only two persons at one time. Regarding the ICU environment, past investigations in Western countries have noted that the ICU environment is designed for utilizing high-tech equipment and is not designed for holistic family-centered care (Burns et al., 2001; Carter et al., 2006). Currently, ICU beds in Thailand are arranged in a common large space with little privacy or room between occupied bed spaces. The separation of dying patients from their families and the ICU environment contribute to the lack of a comfortable atmosphere for family members in a crisis situation (Simpson, 1997).

Possible Facilitators to Quality End-of-Life Care

A number of specific interventions, programs, and resources have been suggested to improve care for dying children in intensive care units. In a national survey of ICU directors in the U.S., more than 80% of respondents identified helpful strategies to improve end-of-life care in intensive care units (Nelson, 2006). These strategies included training of ICU health professionals in end-of-life communication skills, role modeling and supervision of trainees by clinicians experienced in end-of-life care, and regular meetings of a senior ICU physician and nurse with the patient’s family to help reduce
conflict about appropriate care goals (Nelson, 2006). Furthermore, ICU directors also offered other strategies including access to consultants with expertise in palliative care, incorporation of end-of-life care within the ICU, hospital and health system quality monitoring programs, and bereavement services (Nelson, 2006). Other studies identified possible facilitators to providing end-of-life care to dying patients and their families including providing a peaceful, dignified bedside scene for the family after a patient’s death, acceptance of the family toward the dying patient, and allowing the family adequate time alone with the patient (Beckstrand & Kirchhoff, 2005; Kirchhoff & Beckstrand, 2000). However, few of these strategies were widely availability in intensive care units (Beckstrand & Kirchhoff, 2005; Kirchhoff & Beckstrand, 2000).

The Quality of Dying and Death

Past research has examined the quality of dying and death in both non-ICU and ICU settings. A study by Curtis and colleagues identified that death at home, better symptom treatment, better communication, and higher satisfaction with care were all associated with higher quality dying (Curtis et al., 2002). The study also found provider accessibility, having a familiar person available at night or on the weekends, and having a designated member of healthcare team be responsible for overseeing good quality care were significantly associated with better quality of dying and death scores (Curtis et al., 2002). In a study where family members rated the quality of dying and death in an ICU setting, 88% of family members reported their loved ones had received either mechanical ventilation or hemodialysis in their last week (Mularski, Heine, Osborne, Ganzini, & Curtis, 2005). The rating for the quality of dying and death scores in the last week of life was low (32 of 100 points) and family members reported that their loved ones
experienced substantial physical symptoms, especially suffering from lack of adequate pain control most or all of the time (47%) (Mularski et al., 2005). Two studies asked critical care nurses to rate the quality of dying and death. One study revealed that not having CPR performed in the last 8 hours of life and having someone present at the time of death were related to higher total scores of quality of dying and death (Hodde, Engelberg, Treece, Steinberg, & Curtis, 2004). In the second study, 78% of critical care nurses reported that dying ICU patients received inadequate analgesia (Puntillo et al., 2001). The study by Levy and colleagues points to significant discrepancies in the perceptions of families and ICU clinicians related to the quality of dying and death; attending physicians provided higher scores of quality of dying and death than did nurses and resident physicians (Levy et al., 2005). No studies have evaluated the quality of dying and death from the perspective of nurses who care for pediatric patients in Thailand.

Significance of the Study

Effective end-of-life care is judged as a necessary service in neonatal and pediatric intensive care settings for several reasons. First, many children have a significant risk of dying during an intensive care unit admission. Second, a majority of patient care prior to death involves extremely invasive and painful procedures. Third, children and their families inevitably encounter crisis situations to a greater degree in an ICU than during admission to a general unit. Finally, many children who survive with significant morbidity are often returned to intensive care units and die later (Carter et al., 2006). Such situations challenge critical care health professionals to effectively provide quality end-of-life care that addresses the physical, psychological and spiritual needs of children and their families.
In Thailand, limited evidence exists for best practices to provide high-quality end-of-life care for children in the intensive care setting. Most studies have been conducted in adult ICUs and cannot be applied to children in this setting (Nilmanat, 2006; Wisesrith & Khungern, 2007). Clearly, children are not small adults; their relationship with family members and their attributes of physical, psychological, and spiritual development and needs are entirely different from those of adults (Weidner, 2007). All of this uniqueness can influence the provision of pediatric end-of-life care.

In the pediatric field, several end-of-life studies were centered on children in non-intensive care settings such as oncology and general units (Browning & Solomon, 2005; Wolfe et al., 2000). There have been attempts to develop practice guidelines to provide effective end-of-life care; however, such guidelines cannot be transferred to children in intensive care settings. There are multiple ways that deaths in the ICU differ from deaths in other settings and require better understanding. Furthermore, parents of children who die in critical care settings are more anxious, suffer more grief and are more traumatized than those of children who die in non-critical care settings (Meert, Thurston, & Thomas, 2001). Improving end-of-life care in the intensive care unit must therefore be based on an understanding of the unique issues and problems that cannot be simply applied from what is known in other settings.

Findings from the current study reveal descriptive information regarding the quality of dying and death, and identify barriers and facilitators to providing pediatric end-of-life care in intensive care settings in Thailand. Quality of dying and death is an important indicator for health care service that reflects aspects of the process of end-of-life care. In addition, measuring quality of dying and death can generate the necessary
data to support the benefits of end-of-life care. These data can be powerful tools to support both the effectiveness and success of end-of-life practices.

Studying the barriers that stand in the way of providing optimal end-of-life care in the newborn and pediatric intensive care units while also determining the facilitators that support increased quality of such care to dying children can improve end-of-life care. In addition, the current study examined the frequency of occurrence of these barriers and facilitators to help prioritize which barriers have the largest impact or magnitude and need to be reduced or eliminated and which facilitators need to be supported to optimize care at the end of life.

Information gathered from this study provides empirical evidence that may serve multiple purposes. Findings from this study support the need for educating healthcare professionals, hospital administrators, policy makers and the public about the current status of quality of dying and death for children in critical care units in Thailand. Study findings reflect the care of dying children and their families, and also assist those who are directly responsible for end-of-life care to continuously evaluate and improve practice. Findings from the study have helped to identify barriers in systems of care for dying children and suggest strategies to correct them. Finally, findings from this study serve to generate new hypotheses that can be tested subsequently by the researcher or others to fill the gaps which exist in pediatric end-of-life care.

Conceptual Framework

The conceptual framework guiding the current study was based on The Structure-Process-Outcome Model proposed by Avedis Donabedian (Donabedian, 1988) and on the literature review of factors that affect provision of end-of-life care and quality of care.
outcomes. Donabedian was extensively recognized for his structure-process-outcome approach for quality assessment activities. Most of his professional works centered on the systemization of knowledge throughout health care organizations, especially with respect to quality assessment and monitoring (Best & Neuhauser, 2004). Donabedian’s model has been universally accepted and used as the basis for much of the work addressing quality and outcomes in the health care system. The model includes three main concepts: structure, process and outcome, which are essential for quality assessment activities. Within the framework, structure of care is defined as the physical and organizational attributes of settings, and attributes of human resources that can be associated with provision of care. Process of care is referred to as a series of operations or activities that are performed on patients. Outcomes of care refer to what happens to patients and their families that result from structure and process of care (Donabedian, 1988).

The interrelationship of structure and process dictates the final outcome (Donabedian, 1988). Structural characteristics of the settings directly influence the process of care. Subsequently, change in the process of care can affect the outcome of care. It can be, therefore, implied in Donabedian’s model that when good structural inputs are in place, better outcomes will be produced.
Figure 1. Quality of the end-of-life care based on the structure-process-outcome model (Donabedian, 1988)
Conceptual Framework of the Current Study

The Structure-Process-Outcome model was specifically applied to the conceptual framework for the current study as shown in Figure 1. The current model was based on the premise that the outcomes of quality dying and death are necessary and vital aspects of delivering effective end-of-life care. In order to achieve quality of care, barriers and facilitators must first be identified. Within this framework, structural elements of care refer to healthcare professionals, education, organizational mission and values regarding end-of-life care, physical environment and other characteristics of organizations that may relate to providing end-of-life care in the intensive care setting. Structural elements also include patient and family characteristics that may influence the provision of end-of-life care such as patient conditions, underlying disease, supports, preference and expectation of care. The structure of care may either facilitate or hinder optimal quality of end-of-life care (Stewart, Teno, Patrick, & Lynn, 1999).

Based on this concept, structure of care in the current study focused on both facilitators and barriers organized into three primary factors including patient-family-related factors, healthcare-professional-related factors, and organizational-related factors. Patient-family-related factors within the framework of the study refer to issues of the dying patient and family members such as expectation and acceptance of patient conditions. Healthcare-professional-related factors refer to staff factors such as knowledge, attitude and skills regarding end-of-life care. Organizational-related factors refer to policies or rules in health care system that may have a negative or positive impact on end-of-life care such as visiting policies, privacy and philosophy of care (Gross, 2006; Kirchhoff & Beckstrand, 2000).
Process of care refers to actions and activities regarding end-of-life care that healthcare professionals actually perform with patients and families. This process is based on Clinical Practice Guidelines for Quality Palliative Care authored by the National Consensus Project for Quality Palliative Care [NCP] (National Consensus Project for Quality Palliative Care, 2009). The NCP guidelines offer necessary domains to help clinicians provide quality care at the end of life that takes into account aspects of physical care, psychological care, social care, spiritual, religious, and existential care, cultural care, imminently dying patient care, and ethical and legal care (National Consensus Project for Quality Palliative Care, 2009). However, the current study did not specifically measure the process of end-of-life-care because there are currently no standard clinical practice guidelines for palliative care established in Thailand (Nilmanat, 2006). Because the healthcare system, culture, organization and end-of-life care practices are different in Thailand, applying the NCP guidelines, which were developed with Western countries in mind, may be problematic. Therefore, it would be difficult at the current time to assess the process of care for pediatric patients in Thailand’s ICUs. Furthermore, it is difficult to completely separate structure from process and some overlap does exist. However, the process of care is acknowledged within the framework to guide future efforts targeting specific interventions in the process of care that will affect outcome.

Outcomes of care are the consequences that result from structure and process of care. There are a number of outcome measures that are currently used to assess end-of-life care in the intensive care setting such as ICU length of stay, patient symptoms, and family and clinician satisfaction with care including the quality of dying and death (Curtis & Shannon, 2006). Among these promising measures, the measurement of the
quality of dying and death as perceived by Thai critical care pediatric nurses was used in the current study. Assessment of the quality of dying and death allows families and clinicians to evaluate the patients’ experience at the end of life as to how well or how poorly these experiences occurred (Patrick, Engelberg, & Curtis, 2001). The domains of this measure consists of experiences at the end-of-life, medical care at the end-of-life, experiences at the moment of death, and overall quality of care that patients received before they died (Patrick et al., 2001).

Based on relationships within the model, a strong supporting structure regarding the provision of end-of-life care is the basis of good processes to deliver such care. Effective processes in turn ultimately lead to good quality of dying and death. On the other hand, structure of care that is impeded or hindered to provide optimal care will result in poor processes that subsequently lead to poor quality of dying and death outcomes.

In summary, the Structure-Process-Outcome model provides an integrative way to explore not only the quality of dying and death but also the barriers and facilitators that may influence the quality of dying and death. In addition, it allows the researcher to examine the relationship among these variables to increase understanding.

**Study Purpose and Research Questions**

**Study Purpose**

The purposes of this study were to: 1) to describe the level of the quality of dying and death as perceived by Thai critical care nurses, 2) to describe the intensity and frequency of barriers and facilitators to providing pediatric end-of-life care in intensive care settings as perceived by Thai critical care nurses, 3) explore relationships among
levels of quality of the dying and death, intensity of barriers, and intensity of facilitators as well as identify which barriers and facilitators have the most influence on quality of dying and death; and 4) seek suggestions from critical care nurses to improve end-of-life care for pediatric patients in Thailand. End-of-life care, particularly for pediatric patients, is not well developed within the Thai healthcare system. This investigation represents the first step of an evidence-based approach to improving the nursing care for terminally ill infants and children in Thailand.

Research Questions

The research questions addressed in the current study were the following:

1. What is the level of quality of dying and death in the neonatal and pediatric intensive care settings as perceived by Thai critical care nurses?

2. Which barriers to providing pediatric end-of-life care do Thai critical care nurses perceive as most severe?

3. Which facilitators do Thai critical care nurses perceive as most helpful?

4. Which barrier category has the most influence on quality of dying and death in the neonatal and pediatric intensive care settings?

5. Which facilitator category has the most influence on quality of dying and death in the neonatal and pediatric intensive care settings?

Additionally, the researcher also included open-ended questions to obtain additional views of critical care nurses beyond the scope of the quantitative questions. The research questions addressed by these open-ended questions were:

6. What are additional barriers and facilitators to providing pediatric end-of-life care experienced by Thai critical care nurses?
7. What do Thai critical care nurses identify as changes needed (facilitators) to improve end-of-life care in neonatal and pediatric intensive care settings?

Summary

Although many aspects of quality dying and death, and barriers and facilitators to providing effective end-of-life care were revealed in several studies, none of the studies were conducted in Thailand and none have examined the relationship among these variables. To design and implement interventions that appropriately improve quality of pediatric end-of-life care in Thailand, it is important to first more clearly delineate the barriers and facilitators that actually exist in the context and environment of intensive care settings in this country. Thus, the purposes of the present study were 1) to describe the level of the quality of dying and death as perceived by Thai critical care nurses, 2) to identify barriers and facilitators to providing pediatric end-of-life care in intensive care settings as perceived by Thai critical care nurses, 3) to examine the relationships among quality of dying and death, barriers and facilitators to providing pediatric end-of-life care, and 4) to identify additional barriers and facilitators that influence the quality of dying and death.

Critical care nurses were appropriate subjects for the study because they are in a unique position to interact with dying children and their families at many levels and spend more time with these children than do other healthcare providers (Kirchhoff & Beckstrand, 2000; Raudonis et al., 2002). Although family members can provide beneficial information to improve quality end-of-life care, they tend to give uniformly high scores to quality of care (Heyland et al., 2002). This may limit usefulness of family members’ evaluations in identifying problems for quality improvement. Some studies
revealed that nurses provide the lowest score and the most negative scores for quality of care, however their perceptions are potentially the most useful evaluations of ICU care and the quality of patient’s death (Ferrand et al., 2003; Levy et al., 2005). Therefore, it is believed that critical care nurses can provide valuable insight into the current situation of quality of dying and death and assist in identifying factors that may support or hinder optimal end-of-life care in the intensive care setting.
CHAPTER II

Literature Review

Recent efforts have focused on the quality of pediatric end-of-life care in intensive care units, which is defined as care that prevents or relieves physical and psychosocial suffering associated with a serious medical condition or treatment (Burns et al., 2001). The Institute of Medicine (IOM) affirms that end-of-life care is not an alternative to curative therapies, but rather the two should co-exist throughout the course of an illness (Institute of Medicine, 2003). Curative therapies should be transferred to palliative care as soon as possible when patients have a poor prognosis and therapies become less effective (Institute of Medicine, 2003). Initiating such care early not only provides good quality of life for dying children and their families, but also helps reduce the extraordinary costs of burdensome and ineffective ICU treatments (Campbell & Guzman, 2003; Schneiderman et al., 2003). Unfortunately, the transition to end-of-life care is often late and abrupt in pediatrics (Devictor et al., 2008).

Although no studies directly reveal poor quality care, empirical evidence does exist that quality of care could be improved in this population. Several studies have described situations of uncontrolled pain and other lack of symptom management, poor communication and inappropriate transition to care at the end of life (Devictor et al., 2008; Houlahan, Branowicki, Mack, Dinning, & McCabe, 2006; Wolfe et al., 2000). One important method to improve the quality of end-of-life care in the ICU involves understanding the current status of quality of care and factors that may influence optimal experiences surrounding death in the ICU. The purpose of this chapter is to provide a literature review based on three main concepts for the study: what is known about quality
of dying and death and what is known about existing barriers to providing pediatric end-of-life care in intensive care units. It also presents facilitators and suggestions for strategies to provide more effective, compassionate, and reliable pediatric end-of-life care.

Quality of Dying and Death

Definition and Domain of Quality of Dying and Death

The quality of dying and death is defined as “the degree to which a person's preferences for dying and the moment of death are consistent with others' observations of how the person actually died” (Patrick et al., 2001). This conceptual definition is different from the definition of both quality of life and quality of care at the end of life. Quality of life at the end of life can be distinguished from the quality of dying and death by virtue of a focus on functional status or fulfillment of needs essential to living even when a patient is close to death (Hales et al., 2008; Patrick, Curtis, Engelberg, Nielsen, & McCown, 2003). Quality of care at the end of life focuses on care and satisfaction with the care received (Hales et al., 2008; Patrick et al., 2003). Several studies revealed that the constructs of quality of dying and death are multidimensional with broad domains consisting of physical experience, psychological experience, social experience, spiritual experience, the nature of health care, life closure and death preparation, and the circumstances of death. (Hopkinson & Hallett, 2002; Kim & Lee, 2003; Kristjanson et al., 2001; Leichtentritt & Rettig, 2000; Pierson, Curtis, & Patrick, 2002; Steinhauser et al., 2000). These broad domains pose challenges for researchers, healthcare professionals, and others involved with improvement of the end-of-life experience. Although the more abstract domains are especially important at the end of life, consensus is lacking.
regarding these constructs, their distinctions, and the best way to measure them (Hales et al., 2008).

Measuring Quality of Dying and Death

Measuring quality of dying and death involves the same procedures as assessing quality in any other service that is specifying criteria, norms, and standards indicating whether good care or bad care has been provided or received (Curtis et al., 2002; Donabedian, 1988). Similarly, the criteria, norms, and standards for assessing quality of dying and death are those indicating that dying patients experienced a good or bad death. High quality of dying and death contributes to what is called a good death, meaning one that is free from avoidable distress and suffering for patients, families, and caregivers that is in accord with patients’ and families’ wishes; and is reasonably consistent with clinical, cultural, and ethical standards (Emanuel & Emanuel, 1998; Institute of Medicine, 2003). On the other hand, poor quality of dying and death, considered a bad death, is characterized by needless suffering, dishonoring of patient or family wishes or values, and a sense among participants or observers that the norms of a good death have been offended (Emanuel & Emanuel, 1998; Institute of Medicine, 2003).

Quality dying and death outcomes are a reflection of the quality of end-of-life care and the quality of a patient’s life before death. These outcomes can provide worthwhile information for healthcare professionals, researchers, policy makers and others involved with dying patients to improve quality end-of-life care. There are a number of ways that quality of dying and death has been measured in the ICU. Strategies used in past studies to measure quality of dying and death in the ICU have included: patient’s ratings of quality of dying and death, abstraction of data from patients’ medical
records, family members’ ratings of quality of dying and death and healthcare professionals’ ratings of quality of dying and death (Curtis et al., 2002; Glavan, Engelberg, Downey, & Curtis, 2008; Hodde et al., 2004).

**Ratings of quality of dying and death by dying patients.** Although patients are considered the best source of data about their end-of-life experience, it is generally not possible that patients can rate the quality of their own dying and death in the ICU (Curtis & Engelberg, 2006). Dying patients are limited in several ways to respond to questions. First, there are difficulties in determining whether a patient is actively able to answer questions; second, many patients close to end of life are unwilling or unable to participate in research because they are too ill or too young; last, patients who can be interviewed near the end of life may be cognitively limited due to their conditions (Hickman, Tilden, & Tolle, 2001; Hilden et al., 2001). Studies have documented over 90% of ICU patients have an altered level of consciousness due to delirium, sedation, or both (Truog et al., 2006). In the last month of life, as many as 89% of dying children may have experienced substantial suffering from at least one symptom, most commonly fatigue, pain, or dyspnea (Wolfe et al., 2000). These limitations erode the validity of the scores obtained. As a consequence of these reasons, evaluating quality of dying and death in the ICUs heavily depends on reports from variety of surrogate markers including patients’ medical records, family members and healthcare professionals.

**Patients’ medical records.** Quality of dying and death can be identified retrospectively through medical records. As noted in Glavan and colleagues’ study of using the medical record to evaluate the quality of end-of-life care in the intensive care unit, data exist within medical records that are associated with families’ assessments of
the quality of dying and death (Glavan et al., 2008). Their study was designed to identify whether chart-based markers could be used as a measure for improving the quality of end-of-life care in the ICU. Patients’ medical records were reviewed using a standardized chart abstraction form and family perspective was assessed using quality of dying and death questionnaire (QODD-22) (Glavan et al., 2008). The results revealed that higher scores on the QODD-22 were correlated to documentation of living will, absence of cardiopulmonary resuscitation performed in the last hour of life, withdrawal of tube feeding, family presence at the time of death and discussion of the patients’ wish to withdraw life support during a family conference. The authors suggest that the medical record provides indicators for measuring and improving the quality of end-of-life care in the ICU (Cook, Rocker, & Heyland, 2004). Some experts feel that retrospective review of care can be adequate if medical records are accurate, appropriately detailed, and available from all sites where dying patients receive care (Cook et al., 2004; Donaldson & Field, 1998). However, retrospective medical record review is not sufficient to evaluate patients’ spiritual and psychological experiences (Donaldson & Field, 1998). Therefore, after-death surveys of other surrogates such as family members and healthcare professionals have emerged as potential indirect measures of the broader evaluation of quality of dying and death.

*Rating of the Quality of Dying and Death by Families and Healthcare Professionals*

*Satisfaction scales.* Measures of family satisfaction with intensive care may be useful to reflect quality of dying and death and quality of end-of-life care in the ICU (Baker, Torkildson, Baillargeon, Olney, & Kane, 2007; Heyland & Tranmer, 2001; Johnson et al., 1998). The Family Satisfaction in the ICU (FS-ICU) questionnaire was
developed and validated by Heyland and colleagues (Heyland et al., 2002; Heyland & Tranmer, 2001). The FS-ICU consists of 24 Likert-style items; 14 items are related to family satisfaction with care and 10 items are related to family satisfaction with decision making. A total score is computed as the average of all items, uniformly scored on a 0 to 100 scale. Criterion-related convergent validity of the FS-ICU was supported by significant correlation in the expected direction with scores on the Quality of Dying and Death (QODD) scale assessed by family members (Wall, Engelberg, Downey, Heyland, & Curtis, 2007). The FS-ICU also correlated significantly with nurse-assessed quality indicators. The authors concluded that using FS-ICU questionnaire to assess family members would obtain useful outcomes to improve care in the ICU (Wall et al., 2007).

*The Quality of Dying and Death (QODD) questionnaire.* Another instrument used to assess the quality of dying and death is the Quality of Dying and Death (QODD) questionnaire. This questionnaire was developed by Patrick and colleagues (Patrick et al., 2001). The main purpose of the QODD is to allow families and healthcare professionals to evaluate a patient's experiences at the end of life. The QODD questionnaire consists of 31 items across six domains: symptoms and personal care, preparation for death, moment of death, family, treatment preferences, and whole person concerns. The QODD items are rated on scale from 0 to 10. A total score is calculated by summing all items and dividing by the number of items answered. This mean score is divided by the range of possible scores and then multiplied by 100 to construct a scale ranging from 0 to 100.

The QODD was initially validated with after-death interviews of family members (Curtis et al., 2002). Family members of 204 deaths in Montana were interviewed and asked to rate the quality of dying and death for the deceased person’s last seven days. The
instrument has good internal consistency (Cronbach’s alpha 0.86) and construct validity is supported by significant correlations with measures of symptom burden, patient-clinician communication about treatment preferences, and several measures of quality of care (Curtis et al., 2002). Total QODD scores were not associated with patient demographic data such as age, sex, education, marital status or income. However, scores indicating high quality of dying and death were significantly associated with death at home, death in the desired location, lower symptom burden, and better ratings of symptom treatment (Curtis et al., 2002). The QODD has been used to evaluate the quality of dying and death in the ICU in several studies (Hodde et al., 2004; Levy et al., 2005; Mularski, Curtis, Osborne, Engelberg, & Ganzini, 2004; Mularski et al., 2005).

**Empirical Evidence for Current Quality of Dying and Death in the ICU**

*Quality of dying and death from family members’ perspective.* Family ratings of the quality of patients’ dying experiences in intensive care settings were described in one study. Mularski and colleagues (Mularski et al., 2005) asked family members to rate the quality of dying and death in university and Veterans Affairs Medical Center ICUs. Perspectives of 94 family members of 38 patients who died in the intensive care units were assessed with the Quality of Dying and Death questionnaire. A moderate quality of dying and death in ICU was revealed with the mean total QODD score of 60 out of 100 points. High QODD scores indicated feeling at peace with dying, having control of events, being unafraid of dying, keeping dignity and self-respect. Furthermore, the study confirmed the importance of pain management for quality of dying in the ICU. Changes in rating of pain control from some of the time to most of the time improved the overall rating of quality of dying by seven points. Similarly, a patient provided with his or her
dignity and self-respect was associated with a 4-point improvement in the overall rating of the ICU dying experience. The study also found that acquaintance between family members and the dying patient was related to ratings of quality of dying. The more years the respondent had known the dying patient, the higher the quality of dying rating. This finding of the study also suggests that respondents’ experience may influence family ratings of quality of dying. Further study is needed to better understand respondents’ characteristics that influence ratings of quality of dying.

Quality of dying and death from healthcare professionals’ perspective. The views and experiences of nurses caring for 178 patients who died in an intensive care unit during a 10-month period at one hospital were described in another study (Hodde et al., 2004). This study aimed to determine the possibility of using nurse ratings of quality of dying and death to assess quality of end-of-life care in the intensive care unit and to determine factors related to nurses’ evaluation of patients’ quality of dying and death. Nurses were asked to complete a 14-item Quality of Death and Dying questionnaire that was revised from the original 31-item version developed by Patrick and colleagues (Patrick et al., 2001). The new version of the questionnaire contained only items appropriate for a nurse’s assessment in the ICU setting. The 14 items were selected by two focus groups of critical care nurses. The results indicated that higher total scores reported by nurses were associated with several factors including not having CPR performed in the last 8 hours of life and having someone present at the time of death. Findings from the study suggested that the nurse-assessed 14-item QODD is a feasible tool for assessing ICU nurses’ perceptions of the quality of a patient’s dying experience.
Quality of dying and death from multiple surrogates’ perspective. Finally, quality of dying and death was addressed in a study of nurses, resident physicians, attending physicians, and family members who were involved with dying patients in the medical ICUs at an academic tertiary care medical center in the U.S. (Levy et al., 2005). The goal was to compare the perceptions among these surrogates who observe dying and death in the ICU. Within 24 hours of the time of death, the attending physician, nurse, and resident caring for the patient were asked to complete the 31-item QODD questionnaire. One month after the patient’s death, a family member was contacted to complete the 31-item QODD questionnaire. The results indicated that nurses, attending physicians, resident physicians, and family members evaluate the quality of dying and death differently. Resident physicians and nurses provided the lowest scores on individual questions of quality of dying and death. Family members and attending physicians provided higher scores than did nurses and resident physicians. The authors suggested that this variability may represent error in the instrument or real differences in the ratings of the same patient’s death. Real differences may be reported in the quality of death and dying because of observations at the patient’s bedside and witnessing different events. Nurses and resident physicians typically spend more time at the bedside and are more likely to witness an episode of severe pain or distress experienced by the patient, accounting for lower perceptions of quality of dying and death (Levy et al., 2005).

Barriers to Providing Optimal End-of-Life Care

Barriers to optimal end-of-life care have been well described in the literature (Beckstrand & Kirchhoff, 2005; Davies et al., 2008; Miyashita et al., 2007; Moss et al., 2005; Nelson, 2006; Van Vorst et al., 2006). Poor quality of dying and death is a
consequence of these barriers. Barriers can be divided into three main categories including patient-family-related barriers, healthcare-professional-related barriers and organizational-related barriers (Anghelescu et al., 2006; Moss et al., 2005; Nelson, 2006; Yabroff et al., 2004). In this section, existing barriers including research findings related to barriers that may influence optimal end-of-life-care are reviewed.

**Patient-Family-Related Barriers**

*Uncertain prognosis.* Uncertain prognosis is the most common barrier that impedes optimal pediatric end-of-life care and it is also cited more frequently in pediatric literature than in adult literature (Hilden et al., 2001; Van Teijlingen, Rennie, Hundley, & Graham, 2001). This is strongly confirmed in a survey study of pediatric healthcare provider perceptions of end-of-life care in an academic children’s hospital in the U.S. Approximately one half of the respondents reported uncertain prognosis as the most important barrier, and almost always occurs when providing pediatric end-of-life care (Davies et al., 2008). In addition, several reports have documented uncertain prognosis as a main barrier to delivery of care in children with life-limiting illness (Hilden et al., 2001; Himelstein, 2005; Himelstein et al., 2004; Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004). Children who are admitted to the ICU setting often have a tortuous trajectory of disease with unexpected reversals. Many times, advanced technology and medication may enable children to completely reverse their deteriorating health and return to a stable condition and even to good health for a while (Carter et al., 2006; Nelson, 2006; Van Teijlingen et al., 2001). Steele’s (2000) study points out that parents and healthcare professionals often share many experiences in which the children were not expected to recover, but they survived. These experiences offer parents an unrealistic
hope and leave them requesting curative treatment until they are convinced that survival of their child is not possible (Steele, 2000). In addition, uncertain situations impede a healthcare professionals’ ability to accurately predict the effectiveness of treatment and leaves them reluctant to limit future interventions for children (Hynson, Gillis, Collins, Irving, & Trethewie, 2003; Steele, 2000). Uncertain prognosis also affects decision making. As mentioned in a study describing the parental role in medical decision-making in a neonatal intensive care unit, discussion of a child’s uncertain prognosis was felt to be both helpful and difficult when making a decision to withhold or withdraw life-sustaining treatment (Orfali, 2004). In another study of pediatric patients with cancer, the certainty that a patient would not get better and discussions with the patient’s family figured most prominently in healthcare providers’ decision-making (Hinds et al., 2001). This situation may confuse the goals of care between cure versus palliative care rather than encourage them to coexist.

*Lack of family readiness to acknowledge an incurable condition.* In a death-denying society, children are viewed as being at the beginning of life and are expected to live long healthy lives (Rowse, 2006). Therefore, the death of a child is never easy to accept, and families may resist early explorations or discussions about end-of-life care, advanced decisions regarding the use of life-support interventions, or other preparations for a child’s anticipated death (Steele, 2000). Especially for parents, the death of a child means that they must give up their dreams and hopes for their child (Larson & Tobin, 2000; Sahler, Frager, Levetown, Cohn, & Lipson, 2000). Given high technology and advances in medication in the ICU, parents have an expectation that technology can fix their child even when informed that no extraordinary medical interventions and measures
are of value (Sahler et al., 2000). The unrealistic belief in technology promotes parents to be overly optimistic about the possibility of a cure and causes them to continue to demand that all be done. As a result, parents are often unwilling to participate in end-of-life care.

Lack of family readiness to acknowledge an incurable condition is reported to be the second most frequently reported barrier to providing optimal end-of-life care (Beckstrand & Kirchhoff, 2005; Davies et al., 2008; Hilden et al., 2001; Nelson, 2006). In a study of perceptions of pediatric healthcare providers regarding barriers to palliative care for children, approximately one half of respondents (51%) reported “family not ready to acknowledge incurable condition” as the second most frequent barrier following uncertain prognosis (Davies et al., 2008). Similar findings were noted in a study of attitudes and practices among pediatric oncologists regarding end-of-life care (Hilden et al., 2001). In another survey of critical care nurses’ perceptions of obstacles to providing end-of-life care in adult patients, patients’ families who did not understand the term “lifesaving measures” had unrealistic expectations that served as a significant barrier to the provision of effective end-of-life care (Beckstrand & Kirchhoff, 2005).

Lack of family readiness to acknowledge an incurable condition is also associated with avoiding discussion of a patient’s death. As mentioned in a study by Larson and Tobin (2000), families often attempt to keep providers away from death discussions regarding their dying family members because they refuse to accept the fact that the patients are dying. Sometimes the families wanted to have everything possible done for their dying family member even when those treatments were unnecessary (Larson & Tobin, 2000). These findings are consistent with a study by Ferrell and colleagues (2000)
in reporting that approximately 92% of nurses felt family members’ avoidance of death was a main barrier to providing end-of-life care. This situation can interfere with nurses’ ability to initiate end-of-life discussions with patients and their families (Ferrell et al., 2007).

*Intra-family conflict.* Family conflict was viewed as a salient challenge to be addressed at the end-of-life in several studies (Beckstrand et al., 2006; Beckstrand & Kirchhoff, 2005; Davies et al., 2008; Kirchhoff & Beckstrand, 2000). One study examining nurse perceptions of supportive nursing behaviors in a hospital-based palliative care program identified family conflict as hindering the effective provision of end-of-life care (Davies et al., 2008). In another study, family conflict about the best course of action was viewed by physicians as a major barrier to talking about preferences and providing quality end-of-life care (Beckstrand & Kirchhoff, 2005). A study investigating the impact of life-sustaining treatment decisions on families suggested that stress and conflict among relatives caused family members to delay formulation of an advance care plan for dying patients (Kramer et al., 2006). In addition to delaying or restricting care planning and implementation regarding end-of-life care, consequences of family conflict include increasing distress or tension for patient, family, and/or healthcare team (Kramer et al., 2006).

Causes of family conflict include the perception that family members received insufficient help, a lack of agreement regarding care coordination or patient needs, the nature of illness, and overflow from longstanding issues in the family. In some cases, the only thing that family members may have in common is each of them has unique perceptions. Patient and family members react to the stress of illness in different ways.
They process their emotions and thoughts at different speeds. Various family members have different perceptions, perhaps feel guilty, or try to make decisions without fully understanding the complete context of the situation. An approaching death in the intensive care unit often produces conflict. All family members must come together to make decisions in a highly stressful setting that they have never before experienced. Often, parents and other family members disagree about whether to continue or discontinue life support for their child when the child has an extremely poor chance of survival and/or probably has profound neurological damage (Kopelman, 2006). In some families, conflict may arise from who exactly comprises the family and/or who holds decision-making authority. These fragmentations absolutely impede optimal end-of-life care.

**Healthcare-Professional-Related Barriers**

Since nurses and physicians typically take part in the role of caretaker in end-of-life services, many barriers to end-of-life care related to healthcare professionals that have been documented are associated with nurses and physicians (Ferrell, Virani, & Grant, 1999; Kirchhoff, Beckstrand, & Anumandla, 2003; Yabroff et al., 2004). Given the role of interdisciplinary teams in end-of-life care, these barriers may apply equally to other healthcare providers such as social workers or psychologists (Yabroff et al., 2004). Main barriers identified with optimal end-of-life care related to healthcare professionals include lack of adequate training and education, poor communication between the healthcare professional and the patient, the family and other healthcare professionals, and poor pain and symptom management for the patient (Beckstrand & Kirchhoff, 2005;
Lack of adequate training and education. Caring for dying children and families requires special knowledge and skill to achieve the ultimate goals of caring at the end of life especially in an intensive care unit (Howell, 2007). Training programs for physicians, nurses and other healthcare professionals often fail to provide the attitudes, knowledge, and skills required to provide optimal care for the dying patient; this makes providers feel uncomfortable taking care of dying children and their families (Harper et al., 2007; McCabe, Hunt, & Serwint, 2008; Sheetz & Bowman, 2008).

Larson and Tobin (2000) reveal that healthcare-professional-related barriers to providing optimal end-of-life care stem from nurses’ fear in taking care of dying patients. Most nurses are inexperienced in pain and symptom management for dying patients. They also are not experienced in relating bad news to patients and families (Larson & Tobin, 2000). Ferrell and colleagues (2000) found that pain and symptom management were considered prominent concerns for healthcare professionals and families. In their study, approximately 93% of nurses reported that they lacked knowledge and experience in taking of dying patients and their families (Ferrell et al., 2007). Findings from these two studies are supported in a study in Wolfe and colleagues (2000) that first established healthcare providers’ knowledge deficiencies regarding end-of-life care while studying symptoms of dying children with cancer. In the study, the authors interviewed the parents of 103 children who died from cancer. Sixty percent of parents reported that their children suffered from pain, and in only 20% of the cases did the parents feel that the pain was treated adequately (Wolfe et al., 2000). This study suggested that the deficit
stems from inadequate knowledge of healthcare professionals. As noted in the same study, healthcare professionals themselves often admit their lack of knowledge and experience in providing pediatric end-of-life care (Wolfe et al., 2000). Contro and colleagues’ study (2004) revealed similar findings reporting that 30 to 60% of attending physicians, residents, and nurses claimed that they were inexperienced in managing pain and other symptoms of dying children (Contro, Larson, Scofield, Sourkes, & Cohen, 2004). Lack of interest, knowledge and skill of medical practitioners has been highlighted in a Japanese study as a significant barrier to providing optimal end-of-life care in adult patients (Miyashita et al., 2007). These knowledge and skill deficits may be responsible for inadequate pain and other symptom management. Consequently, the psychological and spiritual condition of patients and their families is often ignored (Miyashita et al., 2007).

Insufficiencies in knowledge and training regarding end-of-life care can cause healthcare professionals to feel less competent and often result in susceptibility to feelings of burnout, inadequacy and discomfort (Contro et al., 2004). Adverse behaviors may unintentionally occur when healthcare professionals have to deliver bad news to dying patients and their families (Hilden et al., 2001). It is assumed that insufficient preparation of healthcare professionals may contribute to patients’ and families’ negative experiences (Proctor et al., 2000). Some studies suggest that inadequate support for these healthcare professionals who provide end-of-life care can lead to depression, emotional withdrawal, and other symptoms in the healthcare professional (Contro et al., 2004; Van Teijlingen et al., 2001).
Educational barriers. As previously mentioned regarding lack of end-of-life care training and education of healthcare professionals, several studies reveal deficiencies involving the educational system (Ferrell et al., 2007; Ferrell et al., 1999; Hammel, Sullivan, Block, & Twycross, 2007; Kirchhoff et al., 2003; Kolarik, Walker, & Arnold, 2006; McCabe et al., 2008). These deficiencies are compounded by the lack of attention to end-of-life care in nursing and medical school curricula and textbooks (Ferrell et al., 1999; Ferrell et al., 2000; Kirchhoff et al., 2003; Rabow & McPhee, 2002).

Inappropriate curriculum. Without appropriate curriculum and role models, it is unrealistic to expect healthcare professionals to manage dying effectively. Evaluation of education and training programs for healthcare professionals reveals a strong focus on the preventive and curative aspects of care and clinical experiences that expose them to curative-oriented care rather than comfort-oriented care (Meier et al., 1997). Ferrell and colleagues (2007) reported that most nursing education curricula include little or no emphasis on the care of dying patients and their families. The American Psychological Association similarly concluded that no systematic efforts have been undertaken to educate psychologists about end-of-life issues. The organization now encourages psychologists to obtain training in ethics as applied to end-of-life decisions and care (Institute of Medicine, 2003).

Medical school curriculum and training programs similarly contain few formal courses on death and dying. As noted in a study describing the current status of end-of-life curricula in osteopathic and allopathic medical schools, nearly all respondents in osteopathic medical schools (95%) and all respondents in allopathic medical schools (100%) reported that end-of-life education is integrated into other courses, not ones
primarily focused on end-of-life care (Rothman & Gugliucci, 2008). This study is consistent with a nationally representative survey of medical students, residents, and faculty in which the respondents felt their education had not adequately prepared them to address issues surrounding death and palliation (Sullivan, Lakoma, & Block, 2003). The respondents also described a medical culture that was not supportive of end-of-life care education: they felt that faculty and residents valued end-of-life care education less than they themselves did, and that end-of-life care was not considered a core clinical competency (Sullivan et al., 2003).

Similarly, in Thailand, most healthcare providers do not receive specific training in their graduate education to prepare them for end-of-life care. The majority reported that they developed the knowledge and skills for their work while on the job (Nilmanat, 2006). Palliative and end-of-life care content had not been taught as a separate subject, but as a topic integrated into other subjects and into practical training (Nilmanat, 2006).

Lack of attention to end-of-life care in nursing and medical textbooks. In general, medical and nursing textbooks are deficient in content regarding end-of-life care (Ferrell et al., 2000; Kirchhoff et al., 2003; McCabe et al., 2008; Rabow & McPhee, 2002). These textbooks could support improvement in end-of-life and palliative care by functioning as educational resources and as reference material. Most medical and nursing students study textbooks, and practitioners rely on textbooks for guidance (Ferrell et al., 2000; Kirchhoff et al., 2003; McCabe et al., 2008; Rabow & McPhee, 2002). Textbooks not only provide concrete information but also shape practitioners’ concepts of how knowledge is best organized. However, the studies showed that general medical and nursing textbooks
provide little information that would help healthcare providers to care for a dying patient (Carron, Lynn, & Keaney, 1999; Ferrell et al., 1999; Rabow et al., 2000).

Studies of content in most nursing textbooks demonstrate an under-emphasis on the care of dying patients and their families (Ferrell et al., 2006; Kirchhoff et al., 2003). Analysis of 50 leading textbooks primarily used in nursing schools in the United States demonstrated a focus on pathophysiology of disease and nursing care plans for each illness; only 2% of content related to providing end-of-life care (Ferrell et al., 2000). Three pediatric textbooks were reviewed in this study and only two had chapters discussing end-of-life care for dying children and their families. A second study analyzed end-of-life content in 14 critical care nursing textbooks published from 1995 to 2003. None of the textbooks contained comprehensive end-of-life content; three of them did not contain any end-of-life content (Kirchhoff et al., 2003).

Two main studies regarding end-of-life content in medical textbooks demonstrated similar findings: one studied four commonly used medical textbooks and concluded that most content focused on the provision of medical interventions and prognostic factors, yet rarely mentioned decision making or the effect of death and dying on the patient’s family (Carron et al., 1999). In a more comprehensive review of 50 leading medical textbooks from multiple specialties, generally helpful information on caring for patients at the end of life was provided in only 24.1%; in 19.1%, essential end-of-life content received minimal attention; and in 56.9%, expected end-of-life content was absent (Rabow et al., 2000).

Poor communication. Communication and decision-making about end-of-life care can be difficult for healthcare professionals in many health settings, but may be
especially difficult in the ICU since the culture and mission of the ICU is focused on saving lives (Curtis & Rubenfeld, 2005). In addition, the majority of deaths in the ICU involve withholding or withdrawing multiple life-sustaining therapies (Burns et al., 2001). Thus, the ICU represents a setting where communication and decisions about the dying and death of patients are made more often than in other health settings. These decisions involve a determination of the goals of care, communication between healthcare professionals and patients and families, and communication among healthcare professionals (Curtis, 2004).

Communication between healthcare professionals and patient-family members in the ICU settings requires clear and empathetic discussion of the expected course of illness as well as risk and benefits of treatment such as withholding or withdrawing life support (Sturman & Cassidy, 2006). These discussions take place within the context of cultural and ethical attitudes toward the value of life including death and dying (Anselm et al., 2005; Feudtner et al., 2002). Still more than that, these discussions occur at a time when family members are under tremendous stress, with symptoms of anxiety and depression, as well as financial burdens and concerns about their child’s health (Curtis et al., 2001). Such situations may affect communication among healthcare professionals, patients and families in the ICU (Anselm et al., 2005; Feudtner et al., 2002).

Compelling evidence indicates that insufficient and inadequate communication between critical care healthcare professionals and family members is common and can have serious consequences. Studies have shown that families consistently rate communication with the critical care healthcare professionals as among their most important concerns and often report dissatisfaction with the patient’s treatment, the
manner in which they were informed about the diagnosis, prognosis and treatment and in general with the quality of communication with the critical care healthcare professionals (Curtis et al., 2001; Meyer et al., 2006; Treece, 2007). Furthermore, observational studies suggest that critical care healthcare professionals frequently do not meet families’ needs for communication. Studies of parents and families of pediatric patients in both intensive and palliative care settings have described the family’s need for honest and complete information as well as their general dissatisfaction with the quality of physician communication near the time of their child's death (Contro et al., 2002; Contro et al., 2004; Meyer et al., 2006). These findings are consistent with a study of families’ experiences of inadequate communication with physicians in the ICU (Azoulay et al., 2000), in which 54% of families of critical ill patients reported misunderstandings of diagnosis, prognosis, or treatment after meeting with the physicians.

End-of-life communication conflict often occurs between family members and critical care clinicians. Nearly half of the respondents in a study by Abbott and colleagues (2001) reported conflict during their family member's ICU stay; the majority reported that the disagreement existed between themselves and the medical staff. Two recurring themes identified responsible for the conflict were communication and unprofessional and disrespectful behavior by the physicians and nurses (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001). Discussions and decisions about withdrawal and withholding of care, which physicians approached with great anxiety, were the main source of conflict (Abbott et al., 2001).

Several studies reveal that these communication deficits result from inadequate skill training in communication among healthcare professionals (Fujii et al., 2003; Lee &
Jung, 2006; Meyer et al., 2006; Nelson, 2006). A study of oncology nurses by Vickers and colleagues (2007) found the majority were not sufficiently trained in communication skills particularly related to the imparting of bad news. This caused the nurses to encounter difficulty when initiating a conversation with patients and family members about a forthcoming death (Vickers, Thompson, Collins, Childs, & Hain, 2007). Even though many nurses believed that it is essential to tell the truth to patients and their families in order to accomplish a successful therapeutic relationship, they argued that detailed information might cause the patients and their families to experience disappointment, despair and isolation (Vickers et al., 2007). Similarly, studies related to physicians’ communication skills revealed that many physicians are reluctant and feel poorly prepared to provide information about expected prognosis. Frequently, survival estimates given to patients with incurable disease are inaccurate, with the majority being overly optimistic (Christakis & Iwashyna, 1998; Lamont & Christakis, 2001). This situation may lead to confusion on the part of patients and families and overestimation of prognosis, making it difficult for family members to support a decision to transfer the patient to end-of-life care.

Good communication among healthcare professionals is critical for the effective functioning of an end-of-life care team. However, communication appears to be less than optimal, especially in ICUs where fragmentation of care often prevails (Curtis & Engelberg, 2006; Curtis & Shannon, 2006; Nelson, 2006). Because ICUs care for seriously and critically ill patients, a multidisciplinary team approach to patient care is typically required. Each team member has their own viewpoint that often leads to
separated groups of healthcare teams who fail to communicate and collaborate effectively with each other (Curtis & Shannon, 2006).

An example of poor communication among healthcare professionals is illustrated in a study by Simmonds (1996). Using a grounded theory approach to understand experiences of ICU professionals who work with dying ICU patients and how this work affected them particularly when they believed patients were being overtreated, physicians reported that the daily routine of ICU allowed them to avoid or ignore death because of their trust in technology. Nurses spoke of feeling abandoned by the physicians. Fear of litigation caused many ICU physicians to avoid difficult decisions resulting in a practice of “decision-making by default” (Simmonds, 1996). By defaulting, physicians were able to continue treatments and avoid confrontations and ethical decision making, guarding them from the reality that the patient was going to die.

Studies that were conducted in Australia and Canada corroborate Simmonds’ findings. Cartwright and colleagues (1997) reported results from a postal survey of Australian critical care nurses about their knowledge, attitudes, and beliefs concerning death and dying in ICUs. A major concern expressed by these nurses was physician–nurse communication; nurses also noted that they frequently have intimate knowledge of the needs of patients and families, and this knowledge should be respected and sought at the time that end-of-life decisions were made (Cartwright, Steinberg, Williams, Najman, & Williams, 1997). The authors concluded that nurses have their own knowledge and scope of practice that supports their involvement in end-of-life discussions (Cartwright et al., 1997). In the Canadian study, nurses and physicians provided different perceptions on ethical issues associated with end-of-life care (Oberle & Hughes, 2001). Physicians
shoulder the burden of having to make decisions, whereas the burden of nurses is in having to live with practice decisions made by someone else. These different responsibilities and practice perspectives can serve as key barriers to optimal care at the end of life (Nelson, 2006).

Death anxiety and attitudes. Death anxiety and attitudes can have a profound effect on healthcare professionals’ ability to care for the dying. Several studies have examined the attitudes and anxieties of healthcare professionals towards death and dying; these studies have documented that death anxiety has a direct impact on the ability of the nurse to provide a high level of care to dying patients (Dunn et al., 2005; Lange et al., 2008; Rooda et al., 1999). Death anxiety can influence care by shaping behaviors, attitudes and creating job stress (Yam, Rossiter, & Cheung, 2001). Studies have indicated that higher levels of death anxiety experienced by healthcare professionals can translate into more negative behaviors and attitudes towards dying patients and their families (Dunn et al., 2005; Lange et al., 2008). Behaviors such as avoidance, withdrawal and withholding of information were displayed by nurses with higher levels of death anxiety and fear of death (Lange et al., 2008). Rooda and colleagues (1999) found that nurses with a greater fear of death had a less positive attitude towards caring for dying patients. The characteristics of death denial, suppression and repression displayed by nurses have been found to have a negative impact on the delivery of end-of-life care (Rooda et al., 1999).

Staff shortages and time constraints. Inadequate staffing levels and lack of time were the most frequent barriers to providing effective end-of-life care (Beckstrand & Kirchhoff, 2005; Davies et al., 2008). As noted in a study conducted in an academic
hospital, pediatric providers reported time constraints (47.2%) and staff shortage (31%) as frequent or almost always occurring barriers to providing good end-of-life care (Davies et al., 2008). Time constraints and staff shortage are barriers that may be simultaneously cause and effect. As mentioned in a qualitative study of critical care nurses regarding improving end-of-life care, some nurses blamed the shortage of nurses as the cause of their lack of time for nursing care of dying patients (Beckstrand et al., 2006).

Organizational-Related Barriers

Organizational-related barriers can have a negative impact on patient care and provision of quality end-of-life care. Health insurance barriers, reimbursement barriers, restricted visiting policies, the lack of privacy, and inappropriate ICU environments are discussed in this section.

Health insurance barriers. Most health insurance plans do not cover services that are necessary for good quality end-of-life care (Raphael, Ahrens, & Fowler, 2001). Usually, health insurances’ priorities of payment for care services are to cure disease, extend life, or restore functioning destroyed due to sickness or injury (Raphael et al., 2001). Thus, preventive services as well as extended care for long-term and chronic illness have traditionally been excluded. Unlike for older adults eligible for government sponsored programs, children are covered not by a single insurance program, but by a diverse set of private insurance companies that have differing eligibility and coverage policies (Institute of Medicine, 2003). The various sources of insurance for children make it difficult to obtain an entire picture of financing coverage for palliative and end-of-life care services for children. This situation leads to children being at risk for
undertreatment, inappropriate transitions between settings of care, inadequate coordination of care, and poor overall quality of care.

Reimbursement barriers. Another barrier relates to reimbursement. For most individuals who die in hospitals, no explicit reimbursement exists for palliative and end-of-life services (Capello et al., 1998). Physicians may be encouraged to limit their time spent with dying patients and their families because most payment systems do not recognize the resources which are needed to deliver optimal end-of-life care (Institute of Medicine, 2003). These payment policies may encourage hospitals to discharge dying patients quickly and limit beneficial services to provide end-of-life care (Raphael et al., 2001).

Limited visiting hours. In the pursuit of excellent end-of-life care, many critical care clinicians now focus on providing patient- and family-centered care. There is an increased appreciation of the important role played by families in a critically ill patient's improvement. Families share decision making, provide medical history, and offer a sense of security to their loved ones. These are natural roles for families of the critically ill that may be impeded by the chaotic, highly technological environment of intensive care units. An important barrier that may hinder families from fulfilling these roles at the bedside is a limited visiting hour policy in intensive care units. Intensive care units often have visiting hour policies that conflict with the needs of patients and their families leading to poor quality of care (Abbott et al., 2001; Henneman & Cardin, 2002; Roland et al., 2001).

As noted in studies both in the United States and Europe, family members and healthcare professionals report that limited visiting hours leads to unmet needs of patients and their families in intensive care units (Lynn et al., 1997; Roland et al., 2001; Simon,
Phillips, Badalamenti, Ohlert, & Krumberger, 1997). The study by Roland and colleagues (2001) revealed that family members of critically ill patients expressed the greatest dissatisfaction with the visitation policy. A major concern expressed by 95% of respondents was the desire to be able to perform personal care for their loved one and 80% of respondents reported a desire for more open visitation policies (Roland et al., 2001). In the same study only 46% of nurses and physicians supported a limited visiting hour policy, and 82% of nurses and physicians disagreed with existing policy and believed that visitors were beneficial to the patient (Roland et al., 2001). Overall, flexible or open visiting hours have been shown to help meet the family’s needs and have positive effects on the patient. Patients place a high value on the presence of visitors, and families of critically ill patients report increased comfort and decreased anxiety with open visiting hours (Leon & Knapp, 2008).

*Inappropriate ICU environment.* The ICU environment can be a barrier to providing effective care for dying patients and their families. Intensive care units are designed for saving life purposes (Burns et al., 2001; Carter et al., 2006; Docherty, Miles, & Brandon, 2007). As a result, most ICUs environments are created for utilizing high-tech medical equipment and are not designed for holistic family-centered care. Ulrich’s theory of supportive hospital design speculates that the hospital environment always influences the patient, staff and family; it has either a negative or a positive effect on the care (Ulrich, 1997). However, the ICU environment does not often provide a comfortable atmosphere for family members in crisis situations. In a qualitative study of the experiences of intensive care nurses, the ICU nurses described that ICU environments separate dying patients from their families (Simpson, 1997). The physical environment of
the ICU, such as the machines, tubes and wires, and the constant sounding of alarms contributes to the separation of dying patients from their families (Simpson, 1997). Privacy is another essential component of good end-of-life and family-centered care (Burns et al., 2001; Faber-Langendoen & Lanken, 2000). Privacy allows for personal conversations among the family, as well as conferences with the ICU team. Yet, studies show that when patients die in critical care units, they often do so in shared facilities (Street, Love, & Blackford, 2005). Families who have lost a loved one in an ICU report a lack of privacy and the need for improved physical space (Abbott et al., 2001).

Facilitators to Providing Optimal End-of-Life Care

Facilitators to providing end-of-life care are defined as any supportive issue that advocates the delivery of optimal end-of-life-care services (Kirchhoff & Beckstrands, 2000). Currently, there are few formally tested strategies to improve end-of-life care in the ICU. A number of investigators, however, have made an effort to contribute their research outcomes regarding facilitators, interventions, programs and resources that may improve end-of-life care for dying ICU patients at the patient-family levels, the healthcare-professional level and at the organizational-system level (Beckstrand & Kirchhoff, 2005; Beckstrand, Smith, Heaston, & Bond, 2008; Kirchhoff & Beckstrands, 2000; Nelson, 2006).

In a national survey of 600 adult intensive care units in the United States, more than 80% of nursing and physician directors rated 14 important strategies as possible facilitators for optimal end-of-life care (Nelson, 2006). The facilitators regarding patient-family and healthcare-professional levels included a series of strategies to improve communication between clinicians and patients and their families, training for ICU
healthcare professionals in end-of-life communication skills, role modeling and supervision of trainees by healthcare professionals experienced in end-of-life care, regular meetings of senior ICU physicians and nurses with the patient’s family, and a mechanism to help resolve conflict about appropriate care goals. The ICU directors also disclosed strategies in organizational-system levels that may help support better care for dying patients in the ICU. These strategies included providing accessible consultants with expertise in palliative care, bereavement services, incorporation of end-of-life care within the ICUs, and resources to accommodate hospital and healthcare system quality monitoring programs. The authors also reported that the availability of these potentially helpful strategies in the ICUs was limited. For example, less than a third of these ICU directors reported availability of bereavement programs, end-of-life care quality monitoring, or the incorporation of end-of-life care within ICU. Only a third of directors reported regular family meetings of a senior ICU physician and nurse with families, and less than half reported healthcare professional communication training and role modeling (Nelson, 2006).

In a survey of critical care staff nurses who were members of the American Association of Critical Care Nurses, respondents were asked to rate 23 items described as possible facilitators to providing effective end-of-life care to dying patients and their families (Kirchhoff & Beckstrand, 2000). On issues related to the patient-family, the most helpful facilitators identified by respondents included family acceptance that the patient is dying, having a single family member designated as contact person for all patient information, and allowing the family to have adequate time alone with patient. On issues related to healthcare professionals, approximately 200 of 300 critical care nurses
ranked agreement among physicians about end-of-life care at the top of the list. Other items rated as most helpful by respondents included providing a peaceful, dignified bedside scene for family after patient’s death, having enough time to prepare the family for patients’ death, teaching families how to act and what to say to the patient, having a family who showed appreciation for care of patients and formal training on end-of-life care for nurses. Organizational-related facilitators included care in units designed with a private family grieving place, a unit schedule allowing for continuity of care by the same nurse and flexibility that allowed families to adjust the environment in the room to please the dying patient such as playing music and bringing in pets (Beckstrand et al., 2006; Gross, 2006; Kirchhoff & Beckstrand, 2000).

In a second study, the same investigators reported results of larger-scale member survey of American Association of Critical-Care Nurses regarding supportive behavior or facilitators to improving optimal end-of-life care (Beckstrand & Kirchhoff, 2005). Of 1,500 potential respondents, 955 returned completed questionnaires. As a whole, the results in term of intensity and the rank order of items of supportive behaviors changed very little from the original study. Another survey from the same research group reported the findings of critical care nurses’ suggestions for providing a good death (Beckstrand et al., 2006). Of 1,409 nurses in the randomly selected sample, 861 returned completed questionnaires. Of the respondents, 53% of respondents were staff nurses with a mean of 16 years of critical care practice experience. Six main categories of suggestions were identified including making environmental changes, managing patients’ pain and discomfort, knowing and following patients’ wishes for end-of-life care, promoting earlier cessation of treatment or not initiating aggressive treatment at all, and
communicating effectively as a healthcare team. Regarding the organizational-system issue of making environmental changes to promote dying with dignity, respondents suggested providing private and quiet rooms for dying patients and having space allocated for showering facilities, food preparation, and ceremonies or rituals for the convenience and comfort of the patient and/or family. Remaining categories related to the issues regarding healthcare professionals.

Summary

The review of the literatures supports a definition of quality of dying and death that is different from the definition of both the quality of life at the end of life and from the quality of medical care at the end of life. Quality of dying and death is subjective and difficult to assess directly from a patient’s perspective. Thus, quality of dying and death is often measured from various surrogate sources such as the patient’s medical record or by the family and clinician ratings of the quality of dying and death using satisfaction scales or quality of dying and death questionnaires. Current evidence supports that a high quality dying and death experience in the ICU is characterized as being free from avoidable distress and suffering for patients, families and caregivers, is in accord with patients’ wishes such as not having CPR performed in the last 8 hours and having someone present at the moment of death. However, only a few studies assessing quality of dying and death have been conducted and most of these studies focused mainly on adult patients.

Past studies have identified many barriers to optimum end-of-life care for dying patients in the intensive care unit. First, there are patient-family-related barriers including prognostic uncertainty of dying patients, lack of family readiness to acknowledge an
incurable condition and intra-family conflict regarding end-of-life decisions. Second, there are healthcare-professional-related barriers including lack of adequate training and education regarding end-of-life care, poor communication between healthcare professionals and patient and family members, poor communication among healthcare team members, death anxiety and attitudes regarding end-of-life care, staff shortages and time constraints. Third, there are large-scale organizational-related barriers including financial system barriers (health insurance and reimbursement barriers), educational system barriers, limited visiting hour policies, and inappropriate ICU environments.

Emerging evidence supports ways in which barriers to high quality end-of-life care can be lowered. Possible facilitators to providing optimal end-of-life care in the ICU are beginning to be identified. At the patient-family level, facilitators include presence of a family who accepts that the patient is dying, having one family member designated as a contact person for all patient information, providing the family with adequate time alone with dying patient, and regular meetings between the healthcare team and family members. At the healthcare-professional level, facilitators include improvement and training in communication, education and skills regarding end-of-life care, role modeling and supervision of trainees by clinicians experienced in end-of-life care, training of ICU clinicians in symptom management, agreement among healthcare team members and teaching families how to act/what to say to patients. At the organizational-system level, identified facilitators include providing bereavement programs or services, quality end-of-life care monitoring, resources to accommodate diversity among patients and families at the end of life, and changing the ICU environment.
Gaps in the Literature

The most significant gap in the literature is the lack of evidence regarding quality of dying and death, barriers and facilitators to providing optimal end-of-life care for infants and children in Thailand. Most studies were conducted in Western countries where culture and healthcare systems are totally different from Thailand. Furthermore, the studies conducted in Western cultures mainly focused on adult patients. Little is known about current status of quality of dying and death, barriers and facilitators to providing optimal end-of-life care in dying children. This may be one of the possible explanations why interventional studies to improve end-of-life care in the neonatal and pediatric intensive care units are lacking. This deficiency is consistent with a recent report from the Institute of Medicine (IOM) highlighting the fact that system data on end-of-life care for children are unavailable and more studies are needed to guide the provision of effective end-of-life care (Institute of Medicine, 2003). In preliminary work for improving end-of-life care, more descriptive data are required to define the nature of the problems before engaging in large-scale projects to improve care. Intervention studies often fail because they are designed without adequate understanding of the problem (Solomon, 1995). The present study can help to fill this gap by providing descriptive data about quality of dying and death, barriers and facilitators to providing pediatric end-of-life care in the ICUs in Thailand.

Another gap revealed in the literature is the lack of examination of the relationship of barriers and facilitators to providing pediatric end-of-life care and quality of dying and death outcomes. Past studies have been limited to examining relationships between patient characteristics and quality of dying and death. In order to fill this gap, the present
study investigated the relationship of barriers, facilitators to providing end-of-life care and quality of dying and death. This type of research is extremely valuable to shape the development of interventions for improving the quality of pediatric end-of-life care in the intensive care unit that can be systematically tested in future studies.
CHAPTER III

Methodology

The purposes of this study were to: 1) describe the quality of dying and death, barriers and facilitators to providing pediatric end-of-life care in intensive care units from the perception of critical care nurses in Thailand; 2) explore relationships among levels of quality of the dying and death, barriers, and facilitators as well as identify which barriers and facilitators have the most influence on quality of dying and death; and 3) seek additional suggestions from critical care nurses to improve end-of-life care for pediatric patients in Thailand. This chapter presents the methodological approaches carried out in the study including: research design, sampling, data collection, instruments, data analysis plan, and protection of human subjects.

Research Design

A cross-sectional, descriptive correlational design using mixed method data collection was used to answer the research questions. The descriptive design was chosen because the perceptions of Thai critical care nurses regarding the quality of the dying and death, and barriers and facilitators to providing pediatric end-of-life care is relatively unknown. According to Burns and Grove (2007), a descriptive study is appropriate to identify problems in an unknown area and obtain information concerning current status of the phenomena of interest. In the current study, the phenomenon of interest is the quality of dying and death, the barriers impeding and the facilitators supporting effective pediatric end-of-life care in intensive care settings in Thailand.

The study design was also correlational because this design is useful to examine possible relationships among variables that exist in past situation or in a present situation
(Burns & Grove, 2007). In the current study, this design was used to examine and describe the relationships among three main variables: levels of quality of dying and death, barriers and facilitators to providing pediatric end-of-life care in Thai ICUs. No intervention or manipulation of variables was planned nor were there any attempts to establish causality. The model of the descriptive correlational design for the current study is shown in Figure 2.
Nurses’ perceptions of the barriers to providing pediatric end-of-life care in Thai ICUs. Measured by The Modified National Survey of Critical Care Nurses regarding End-of-life Questionnaire.

Nurses’ perceptions of quality of dying and death of infants and children in Thai ICUs. Measured by the Modified Quality of Dying and Death (QODD) Questionnaire.

Nurses’ perceptions of the facilitators to providing pediatric end-of-life care in Thai ICUs. Measured by The Modified National Survey of Critical Care Nurses regarding End-of-life Questionnaire.

Examination of relationships

Interpretation of meaning

**Figure 2.** Model of study descriptive correlational design (Burns & Grove, 2007).
Furthermore, a mixed method data collection strategy was used for collecting data in the current study. Mixed or triangulation methods involve collecting data using different techniques to bring clarity to single complex phenomena (Creswell, Fetters, & Ivankova, 2004). Incorporating both qualitative and quantitative data to answer the research questions allows for development of a rich and fuller understanding of the phenomena of interest.

In the current study, data obtained with quantitative questionnaires was principally used to explore the perceptions of critical care nurses regarding quality of dying and death, barriers and facilitators to providing pediatric end-of-life care including relationships among these variables. The qualitative technique of using open-ended questions was additionally used to gain additional insights beyond the scope of quantitative techniques. This last point is very important since the nature of quantitative research and its data collection tools allow the researcher to see only what is being examined, whereas qualitative methods can expand the key elements that are never reached using a quantitative approach (Creswell et al., 2004).

**Sampling**

*Specifying the Sample*

The target population in the current study was neonatal and pediatric critical care nurses who work in intensive care units at two university hospitals located in the north and central regions in Thailand. Inclusion and exclusion criteria were specified to obtain an appropriate sample for the study. Inclusion criteria are a set of conditions that are required for including a subject in the study; exclusion criteria are the standards defined for excluding a subject from the study (Burns & Grove, 2007). The inclusion criteria for
the current study were full-time registered nurses who cared for neonatal and pediatric intensive care patients at the selected university hospitals in Thailand. These nurses had work experience of at least 12-months duration caring for children in the intensive care setting and were willing to participate in the study. Thai registered nurses with less than 12-months clinical experience often have not been encouraged to take care of these patients because they have to demonstrate their nursing competencies before they accomplish permanent full time status in the neonatal and pediatric intensive care units.

Part-time registered nurses, directors of nursing, and assistant directors of nursing in each unit were excluded from participation in the study. The part-time registered nurses come from multiple settings and may not have enough opportunities to interact with dying infants, children or their families. The directors of nursing and assistant directors of nursing of each unit were excluded because their time is heavily focused on administrative responsibilities and they often have minimal patient contact.

Setting

The current study was conducted at two university hospitals in Thailand. Maharaj Nakorn Chiang Mai Hospital is a 2000-bed tertiary care and major referral hospital in northern Thailand. The hospital has a 12-bed PICU with 33 nurses and a 20-bed NICU with 29 nurses. Siriraj Hospital is 2600-bed, tertiary care and major referral hospital in central Thailand, located in Bangkok. The hospital has a 12-bed PICU with 40 nurses, a 16-bed NICU with 40 nurses, a 4-bed Cardiac Care Unit (CCU) with 11 nurses, and a 6-bed Respiratory Care Unit (RCU) with 18 nurses. Both university hospitals are large governmental hospitals under The Ministry of Education in Thailand. They serve as a tertiary care and specialty referral center for smaller hospitals in their region. Each
facility provides specialized care services to patients who are critically ill, and have multiple complications and/or conditions that require continued hospitalization and advanced treatments.

The neonatal and pediatric intensive care units were selected for the study because any infants and children with serious illness who need intensive care will be referred to critical care settings. Often, death is inevitable in these settings. Of all the children who die in Thai hospitals, 80 to 90% of them are cared for in the neonatal and pediatric intensive care units (Maharaj Nakorn Chiang Mai Hospital, 2007). Therefore, the nurses who work in these settings are assumed to have more experience in caring for dying children than nurses in other units.

**Sampling Plan**

Non-probability convenience sampling was used. Convenience sampling is a method used to collect data from subjects who are conveniently accessible to the researcher (Burns & Grove, 2007). Due to lack of random selection, convenience sampling may result in possible sampling bias in which the study sample is less representative of the target population. A biased sample limits generalizability of the results. However, convenience sampling provides the main advantages of convenience, economy and time savings (Burns & Grove, 2007). Therefore, such sampling is suitable for a study that samples subject from either a large population or a geographically diverse population. Additionally, convenience sampling also provides a means of acquiring information in new areas and is useful for descriptive and correlational studies conducted in unexplored areas of research (Burns & Grove, 2007; Polit & Beck, 2008).
Based on sampling theory and the researcher’s judgment, non-probability convenience sampling was used to reach subjects of the current study for the following reasons: First, all eight university hospitals in Thailand are geographically located in four main areas: north, south, northeast and central. It is difficult and expensive to obtain a random sample with limited time and resources. Second, pediatric end-of-life care in Thailand is a relatively new area of study; little is known about the unique issues about quality of dying and death including barriers and facilitators to provide such care. The current study, therefore, met the criteria of seeking information and examining relationships in a new area. Finally, although convenience samples are unlikely to provide perfect representations of the ideal population, generalization to large populations was not a main concern in the current study. Convenience sampling was designed to increase knowledge in the field of study so that the researcher can generate some initial insights rather than make any generalizations.

With convenience sampling, two of eight university hospitals, Maharaj Nakorn Chiang Mai Hospital and Siriraj Hospital, were chosen because of their convenient accessibility to the researcher. Both hospitals are located near the researcher, which provided easier approval of the study, and familiarity with the setting. They also are large hospitals that were able to afford the researcher sufficient numbers of neonatal and pediatric critical care nurses to reach the minimum number of subjects required for the study. Within the selected settings, all eligible critical care nurses were invited to participate in the study.
Sample Size Determination

The sample size of all participants was calculated using a power analysis with regard to the number of independent variables and the planned statistical tests to be performed. Power analysis, the most powerful method for indicating sample size, is a procedure that determines if the proposed sample size is large enough to allow a fair test for the proposed statistical hypothesis (Polit & Beck, 2008). To determine sample size by power analysis, three main parameters must be considered including the significance level, power level and effect size (Polit & Beck, 2008).

Significance level (\(\alpha\)) refers to the probability of making a decision to reject the null hypothesis even when the null hypothesis is actually true, a decision known as a Type I error (Polit & Beck, 2008). Generally, setting the level of significance is considered by determining how crucial it is to have accurate results (Polit & Beck, 2008). In the current study, the researcher set alpha level at the traditional level of .05 for a two-tailed test, allowing for both positive and negative results in terms of the influence of barriers and facilitators on the quality of dying and death. This value provides 5% probability of making a Type I error or means that the researcher is willing to be wrong only 5 times out of 100 in rejecting the null hypothesis when it should be accepted (Polit & Beck, 2008). Since results from this study were not being used to make critical decisions, an alpha of .05 was acceptable without being too stringent.

Power (1- \(\beta\)) is the probability of rejecting a false null hypothesis or Type II error (Burns & Grove, 2007). With Type-II errors, the researcher wrongly accepts the null hypothesis of no relationship when, in fact, there is a relationship between the independent variables and the outcome (Polit & Beck, 2008). Since this study did not
involve a potentially harmful intervention, a Type II error was considered as seriously as a Type I error. Therefore, the conventional power of .80 was set for the current study (Cohen, 1988).

Effect size (ES) is the magnitude of the relationship of the independent variables on the dependent variable (Burns & Grove, 2007). Several ways to determine effect size exist. These include previous studies, pilot or preliminary studies, dummy power table analysis, and conventional effect size (Burns & Grove, 2007). In the current study, effect size was determined using conventional effect size together with the planned statistical tests, multiple regressions. According to Cohen (1992), by convention, a medium effect size in behavioral science is appropriate when the new area of research is conducted and when instruments have not well been tested. A medium effect size of 0.15 for regression analysis was used for the current study because no previous studies were found to report the actual effect size explained for quality of the dying and death, barriers, and facilitators to providing pediatric end-of-life care.

Finally, the sample size was calculated using the G*Power 3 (Faul, Erdfelder, Lang, & Buchner, 2007) with four parameters, including six independent variables (patient-family-related barriers, healthcare-professional-related barriers, organizational-related barriers, patient-family-related facilitators, healthcare-professional-related facilitators, organizational-related facilitators), power = 0.80, alpha (α) = 0.05, and medium effect size = 0.15. A total of 98 subjects were required as a minimal adequate sample size to detect an effect size of 0.15 with 80% probability at α of 0.05 (two-tailed). Since poor response rates are typical in survey research, the researcher aimed to recruit 123 subjects in the current study to account for an expected 25% non-response rate based
on information from the Nursing Research Unit at Maharaj Nakorn Chiang Mai Hospital Thailand (P. Chanin, personal communication nurse researcher, December 24, 2008).

**Instruments**

Two questionnaires were used to measure nurses’ perceptions of the quality of dying and death, barriers, and facilitators of providing pediatric end-of-life care in the intensive care units. A demographic questionnaire also was used to collect data to describe the study sample. Each instrument is described below.

*The Quality of Dying and Death Questionnaire (QODD)*

Critical care nurses’ perceptions of the quality of dying and death for infants and children in intensive care units were measured by a modified form of the Quality of Dying and Death Questionnaire for Health Care Professionals version 3.2 developed by Patrick and colleagues (Patrick et al., 2001). The questionnaire is available at the website of the University of Washington (“Quality of Dying and Death, 2008”). The main purpose of this instrument is to assess patients’ experiences at the end of life through the viewpoint of healthcare professionals (Patrick et al., 2001). The original questionnaire consists of 31 total items with four sections: patient’s experiences during time in the ICU (15 items), medical care at the end of life (9 items), experiences at the moment of death (5 items), and overall rating of care (2 items). Total scores are calculated by summing the responses to the 24 items which are rated from 0 (terrible experience) to 10 (almost perfect experience). Then this score is divided by the number of answered items and multiplied by 100 to obtain a scale ranging from 0 to a 100 point scale. The score 0 indicates the worst perceived quality of dying and death and the score 100 indicates the best perceived quality of dying and death.
Reliability and validity for the original QODD instrument were tested in 205 family respondents who experienced a recent loss in Missoula County, Montana. The results revealed the QODD total score ranged from 26.00 to 99.62 with a mean of 67.4 ($SD = 15.06$) and Cronbach’s alpha of 0.86 (Curtis et al., 2002). Construct validity was demonstrated by significant correlations with measures of symptom burden, patient-clinician communication about treatment preferences, and several measures of quality of care (Curtis et al., 2002; Patrick et al., 2003).

However, the QODD for Health Care Professionals version 3.2 has not been tested in the pediatric population. The item statements used in the original instrument needed revision to reflect the nature of the neonatal and pediatric intensive care situation. In the current study, the researcher modified this instrument by removing some items and rephrasing other items to reflect more closely the experience of children and infants dying in intensive care settings. The Modified Quality of Dying and Death instrument used in the current study consisted of two sections including patient’s background information (4 items) and quality of dying and death (20 items). Of the twenty items, the quality of dying and death was divided into four domains including pediatric patient’s experiences at the end-of-life (7 items), medical care at the end of life (6 items), experiences at the moment of death (4 items), and overall rating of care (2 items). Eleven of 20 items were questions rated on 5-point Likert scales: 1= poor, 2=fair, 3=good, 4= very good, 5=excellent. For ease of interpretation, item responses were converted from a 1 to 5 Likert range to a 0 to 4 Likert range. Total scores were obtained by simple summation of the 11 Likert-style items. This summed score was divided by the number of items answered to obtain the mean score and multiplied by 100 to produce a scale
ranging from 0 to 100 points. The score 0 indicates the worst quality of dying and death and the score 100 indicates the best quality of dying and death.

The remaining nine items constituted patients’ clinical information. For instance, “Did your patient receive mechanical ventilation during his or her stay in the ICU?” and “Was anyone, including family, friends or staff, present at the moment of your patient’s death?” Six of the seven questions offered multiple choice responses including “yes”, “no”, and “don’t know”. One question provided the choices: “awake”, “asleep”, “in a coma or unconscious” and “don’t know” for the respondent. These answers are nominal scales that cannot be calculated into a score. They could, however, provide quantitative data that helped the researcher better understand characteristics of patients cared for by the critical care nurses who participated in the study.

The National Survey of Critical-Care Nurses Regarding End-of Life Care Questionnaire

Critical care nurses’ perceptions of barriers and facilitators to providing pediatric end-of-life care in the intensive care unit were measured using a modified version of the National Survey of Critical Care Nurses Regarding End-of-Life Care Questionnaire. Kirchhoff and Beckstrand (2000) developed this instrument through literature review and four focus groups of critical care nurses experienced in end-of-life issues (N = 21). The instrument is comprised of 56 items: 29 barrier items, 24 facilitator items and three open-ended questions. Reliability and content validity for the instrument were established through 45 critical care nurses in a single ICU. The mean time for completion of the questionnaire is 17 minutes. The Cronbach’s alpha was 0.89 for the barrier items and 0.86 for the facilitator items (Beckstrand & Kirchhoff, 2005). Content validity was
established though use of focus groups and previously published literature in the development of the initial items.

In the current study, the instrument was modified to be appropriate with Thai culture. Three barrier items were deleted from the original instrument including “Employing life sustaining measures at the family’s request even though the patient had signed advanced directives requesting no such treatment”, “the unavailability of an ethics board or committee to review difficult patient cases” and “continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.” Consequently, the modified questionnaire used in the current study consisted of 53 items: 26 barrier items, 24 facilitator items and three open-ended questions.

**Barrier subscale.** The 26 items for barriers were statements that assessed critical care nurses’ perceptions of possible barriers to providing end-life-care to dying patients and their families. Examples for the statements are as follows: “Families not accepting what the physician is telling them about the patients’ prognosis” and “Lack of education and training regarding family grieving and end-of-life care”. Separate responses are required for intensity and frequency. Barrier intensity is rated on 6-point Likert-type scale: 0=not a barrier, 1=minimum barrier, 2=little barrier, 3=moderate barrier, 4=large barrier and 5=the most barrier. In past studies of the original instrument, item intensity mean scores ranged from 1.62 to 4.03 with SD ranging from 1.10 to 1.69 (Beckstrand & Kirchhoff, 2005). For barrier frequency, the 6-point Likert-type scale for response choices are 0=never happens, 1=rarely happens, 2=sometimes happens, 3=often happens, and 4=frequently happens, and 5=consistently happens. Past use of the original
The instrument has reported item frequency means ranging from 2.61 to 4.59 and SD ranging from .56 to 1.49 (Beckstrand & Kirchhoff, 2005).

Mean scores were calculated for the intensity and frequency for each barrier item individually. Items were ranked on the basis of their mean scores to determine which ones were perceived as the most intense barriers and the most frequent barriers. As in previous uses of the original instrument, the intensity mean of each item was then multiplied by the item’s frequency mean to achieve a weighted overall perceived severity score (PSS) for each barrier item. The possible range for perceived severity scores for each item is 0 to 25. A previous study reported means for perceived severity scores ranging from 2.06 to 14.83 (Beckstrand & Kirchhoff, 2005). These weighted severity scores were ranked from highest to lowest score. For the purposes of this study, emphasis was placed on the overall severity scores to answer the research questions.

**Facilitators subscale.** The 24 items for facilitators were the positive statements that assessed critical care nurses’ perceptions of possible facilitators to providing end-of-life-care to dying patients and their families. Examples for the statements are as follows: “Having enough time to prepare the family for the expected death of the patient” and “A unit designed so that the family has a place to go to grieve in private.” Separate responses are required for intensity and frequency. Facilitator intensity is rated on a 6-point Likert-type scale: 0=not a help, 1=minimum help, 2=a little help, 3=moderate help, 4=large help and 5=the most help. In past studies using the original instrument, intensity mean scores ranged from 2.61 to 4.59 with SD ranging from .61 to 1.51 (Beckstrand & Kirchhoff, 2005). For facilitator frequency, the 6-point Likert-type scale for response choices are 0=never happens, 1=rarely happens, 2=sometimes happens, 3=often happens,
4=frequently happens, and 5=consistently happens. Past use of the original instrument reported frequency means ranging from 0.77 to 3.96 and SD ranging from 0.77 to 1.60 (Beckstrand & Kirchhoff, 2005).

Mean scores were calculated for the intensity and frequency for each facilitator item individually. Items were ranked on the basis of their mean scores to determine which ones were perceived as the most intense facilitator and the most frequent facilitator. As in previous uses of the instrument, the intensity mean of each item was then multiplied by the item’s frequency mean to achieve a weighted overall perceived help score (PHS) for each facilitator item. The possible range for perceived help scores for each item is 0 to 25. A previous study using the original instrument reported mean perceived help scores ranging from 2.63 to 17.58 (Beckstrand & Kirchhoff, 2005). These weighted scores in the current study were ranked from highest to lowest score. For the purposes of this study, emphasis was placed on the overall perceived help scores to answer the research questions.

Open-ended questions. In addition to the standardized questionnaire, three open-ended questions were asked regarding barriers and facilitators that critical care nurses face aside from items contained in the National Survey of Critical Care Nurses Regarding End-of-Life Care Questionnaire. Critical care nurses were asked to express their opinions to the following items: 1) Please provide additional barriers to providing pediatric end-of-life care that have not been mentioned in previous statements. 2) Please provide additional facilitators to providing pediatric end-of-life care that have not been mentioned in previous statements. 3) If you could change the care for the end of life patients in the ICU what would you do? These questions have been previously pre-tested with critical
care nurses to confirm readability, clarity, and meaning (Beckstrand & Kirchhoff, 2005). Responses to the three open-ended questions were analyzed using content analysis.

Demographic Data Questionnaire

An investigator-developed demographic questionnaire consisting of 11 questions assessed number of years of RN experience, the number of years of ICU experience, gender, age, highest completed level of education, position held on the unit, the number of dying patients that nurse had experience with, type of ICU, the number of beds in the unit, the number of work hours per week, and whether the nurse was certified as a Critical Care Registered Nurse. Six of eleven questions were in a multiple choice format. Five questions were fill-in-the-blank items to collect information on participant age, the number of beds in the unit, and the number of work hours per week. This information was used to describe characteristics of the sample.
Table 1

**Study variables, description, & reliability coefficients for instruments used in the study**

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Indicators</th>
<th>Instruments</th>
<th>Level of Measure</th>
<th>Reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic Variables</td>
<td>Years of work experience (as Registered Nurses)</td>
<td>Demographic Tool</td>
<td>Ratio</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Years of NICU/PICU experience</td>
<td>Demographic Tool</td>
<td>Ratio</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td>Demographic Tool</td>
<td>Nominal</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Age</td>
<td>Demographic Tool</td>
<td>Ratio</td>
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</tr>
<tr>
<td></td>
<td>Education</td>
<td>Demographic Tool</td>
<td>Ordinal</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Position held on the unit</td>
<td>Demographic Tool</td>
<td>Nominal</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The number of dying patients nurse has experience with</td>
<td>Demographic Tool</td>
<td>Ratio</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Type of ICU (NICU/PICU)</td>
<td>Demographic Tool</td>
<td>Nominal</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The number of work hours per week</td>
<td>Demographic Tool</td>
<td>Ratio</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Number of beds in unit</td>
<td>Demographic Tool</td>
<td>Interval</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Certified as a Critical Care Registered Nurse (yes/no)</td>
<td>Demographic Tool</td>
<td>Nominal</td>
<td></td>
</tr>
<tr>
<td>Quality of dying and death</td>
<td>- Score for quality of dying and death from 11 items regarding quality of the dying and death on 5-point Likert scale</td>
<td>The Modified Quality of Dying and Death Questionnaire for Health care Professional Version 3.2 (QODD).</td>
<td>Interval</td>
<td>Cronbach $\alpha = .86$</td>
</tr>
<tr>
<td></td>
<td>- Background information on 4 items</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Clinical information on 9 items</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Barriers to providing pediatric end-of-life care</td>
<td>Score for barriers to providing pediatric end-of-life care on 6-point Likert scale</td>
<td>The Modified National Survey of Critical-Care Nurses Regarding End-of Life Care Questionnaire</td>
<td>Nominal</td>
<td>Cronbach $\alpha = .89$</td>
</tr>
<tr>
<td>Facilitators to providing pediatric end-of-life care</td>
<td>Score on facilitators to providing pediatric end of life care on 6-point Likert scale</td>
<td>The Modified National Survey of Critical-Care Nurses Regarding End-of Life Care Questionnaire</td>
<td>Interval</td>
<td>Cronbach $\alpha = .86$</td>
</tr>
</tbody>
</table>
Instrument Translation Process

Accurate translation of instruments from one language to another is essential in conducting cross-cultural research with non-English speaking populations. The researcher must verify that the meaning of items in the translated version is equivalent to the original version. In the current study, the participants were Thai critical care nurses speaking the Thai language. All questionnaires planned for the current study were originally developed in English language and used on English-speaking populations. Hence, the English version of the Modified Quality of Dying and Death Questionnaire (QODD), and the Modified National Survey of Critical-Care Nurses Regarding End-of Life Care were translated into the Thai language.

Back-translation technique was selected to translate the instruments in the current study. Three techniques are often discussed: translation by committee, one-way translation, and the back-translation method (Carlson, 2000). Each method has different advantages and disadvantages. However, to achieve a culturally equivalent instrument, the back-translation technique is considered the most preferred approach (Brislin, 1970; Duffy, 2006).

The back-translation technique is the most well known method for achieving linguistic translations. Back-translation uses an iterative process of repeated independent translation and back translation by a set of translators (Brislin, 1970; Duffy, 2006). At least two bilingual experts are required. One expert translates the instrument from the source into the target language; the second expert translates the instrument back into the source language, and then a comparison is done between the original and translated versions for linguistic equivalency (Brislin, 1970; Kristjansson, Desrochers, & Zumbo,
In the current study, these steps were repeated until the two versions of each instrument were identical or contained only minor differences.

The researcher contacted three bilingual translators who were fluent in both English and Thai languages and familiar with end-of-life care issues including the content of the instruments. All translators were bilingual nursing professors with expertise in the content area. Before beginning the process of translation, the researcher explained the purpose and significance of the study to the three translators.

The steps of back-translation were as follows: first, the researcher was responsible for translating questionnaires from the English version into the Thai version. Second, three translators blindly translated the questionnaires from Thai version back into English version. This means that the translator did not see the wording of the original source language. Third, after the translation and back translation process were completed, the three bilingual translators and researcher compared each item on the original English questionnaire with each item on the back-translated English version. This process was held to discuss problems found during the translation process, to correct errors in grammar, to analyze discrepancies in meaning and to assure equivalence. In the event that discrepancies were noted, the problematic items were retranslated and again back translated by the three bilingual translators until no discrepancy of meaning was found. Finally, after all steps of the translation processes were accomplished, a pretest procedure or pilot study was conducted.

Pilot Study

A pilot study is a smaller version of a full study that is conducted to prepare for a main study (Burns & Grove, 2007). The pilot study is used for a range of different reasons
such as designing a research protocol, identifying logistical problems that may occur in the study, collecting preliminary data, and testing adequacy of the research instruments (Burns & Grove, 2007; Polit & Beck, 2008). For this study, a pilot study was conducted to determine the reliability and validity of the Thai version of the Modified Quality of Dying and Death Questionnaire (QODD), and the Thai version of the Modified National Survey of Critical Care Nurses Regarding End-of-Life Care Questionnaire. The pilot study also provided an opportunity for pretesting of the researcher-developed demographic questionnaire.

Although the standardized instruments had established sound psychometric properties in the original English language versions, it was important to re-establish reliability and validity for the translated versions. According to Burns and Grove (2007), when studying a population in a new context or with different cultural backgrounds, establishing reliability and validity of research instruments is necessary to ensure that the translated instruments are readable, understandable, clear and culturally acceptable. These are important reasons for doing a pilot study in order to reveal deficiencies in the questionnaires and allow errors to be addressed and modified before the main study is conducted.

The Thai version of the Modified Quality of Dying and Death Questionnaire and the Thai version of the Modified National Survey of Critical Care Nurses Regarding End-of-Life Care were piloted by Thai critical care nurses who worked at the adult critical care unit at Maharaj Nakorn Chiang Mai in Thailand. The nurses were conveniently selected into the pilot study using the same inclusion and exclusion criteria as the subjects in the main study. Additionally, these recruited subjects were not nurses working in the
neonatal and pediatric intensive care units at the two university hospitals selected for the main study. Thus, there was no concern regarding contamination of subjects. Findings from the pilot testing were used to make final editorial changes to the Thai language versions of all three instruments to ensure that the participants understood the items.

**Reliability.** Composite scales of each questionnaire were considered in terms of their internal consistency. This approach was conducted to examine the extent to which all the items in the questionnaires consistently measured the same trait. There are several methods for testing internal consistency including split-half reliability, Kuder-Richardson formula 20 and Cronbach’s alpha coefficient. According to Burns and Grove (2007), selection of empirical evidence for reliability depends on the characteristics of an instrument. Kuder-Richardson formula 20 is used for questionnaires with dichotomous items and Cronbach’s alpha coefficient is used for questionnaires with interval items (Burns & Grove, 2007). Thus, Cronbach’s alpha coefficient was selected to estimate the internal consistency in the study because the instruments were characterized with interval scales. Cronbach’s alpha is an index of reliability associated with the variation accounted for by the true score of the underlying construct. Alpha coefficient ranges in value from 0 to 1; higher values indicate a higher internal consistency. The value of .70 is the typically the minimum acceptable value (Houser & Joanna, 2006).

**Content Validity.** To address validity for the study, content validity index (CVI) for the items was calculated. Three Thai nurse experts in end-of-life care served as content specialists to assure adequate content coverage of the instrument. These experts were asked to independently rate each item in term of its relevance to the content domain. Each item was rated on 4-point ordinal scale: 1 = not relevant, 2= somewhat relevant, 3=...
quite relevant and 4= highly relevant. The index of content validity was calculated using the proportion of expert agreement on items given a rating of 3 or 4, divided by the total number of experts (Polit & Beck, 2006). The CVI of 1 indicates perfect interrater agreement among experts; for six or more experts, values of .78 are the acceptable minimum level of content validity (Polit & Beck, 2006). Because this project used three experts, an I-CVI of 1.00 was considered acceptable (Polit & Beck, 2006).

**Data Collection**

Self-administered questionnaires were used to collect data in the current study. Several types of survey approaches are acceptable as effective methods to collect data, including interviewer-administered questionnaires, face-to-face interview questionnaires and telephone questionnaires (Fowler, 2001). Each of them has different advantages and disadvantages. According to Fowler (2001), self-administered questionnaires have prominent advantages beyond other types. First, participants can independently complete the questions by themselves. Second, participants have potential anonymity leading to more truthful or valid responses. Third, questionnaires can be completed at the convenience of the participants. Finally, self-administered questionnaires allow the researcher to collect data from large numbers of subjects at the same time. This approach saves in time, personnel and travel costs compared to personal interviews.

After obtaining the Institutional Review Board approval from Maharaj Nakorn Chiang Mai and Siriraj Hospital in Thailand, and Case Western Reserve University, three key persons whom the researcher personally knows were contacted to coordinate the process of data collection. The first one was contacted for conducting the pilot study; she was a nursing instructor with experience in the adult intensive care unit at Maharaj
Nakorn Chiang Mai Hospital. Two other key persons were contacted for conducting the main study. One of them was a senior nurse who had worked in the general pediatric unit at Maharaj Nakorn Chiang Mai Hospital and now she works at the research unit in the same hospital. The other key person was a nursing instructor who had experience in a general pediatric unit at Siriraj Hospital. Next, the researcher delivered all the questionnaire packets to the key person at each selected hospital and clarified the sample inclusion and exclusion criteria to them. The key person at each hospital then personally distributed the questionnaire packets to eligible critical care nurses face-to-face. Each of the packets contained the following materials: a cover letter introducing and describing the study, The Thai version of the Modified Quality of Dying and Death Questionnaire for Health Care Professional-version 3.2, The Thai version of the Modified National Survey of Critical Care Nurses Regarding End-of-Life Care Questionnaire and the Demographic Data Tool. A small gift was also included as a token of appreciation in anticipation of their participation in the study. All pages of the questionnaires were coded with an identification number to ensure anonymity. Each participant was asked to individually complete the questionnaire on her own time and directly return it within two weeks to the postal box provided at each NICU and PICU unit at each selected hospital. This box was locked and only the key person could open it to gather the returned questionnaires.

Reminders for completing questionnaires are very important for survey studies because a primary disadvantage of self-administered surveys is their low response rate. To increase the response rate as suggested by Dillman (2007), ten days after questionnaires were delivered; the key person posted a reminder in each pediatric
intensive care unit area to encourage participants to complete the survey. Ten days after the first reminder was posted, the key person personally distributed a card to all participants to thank those who had already returned the questionnaire and to ask non-respondents to complete and return the questionnaires. This card also emphasized the importance of the study and the need for a high response rate. All returned questionnaires in the postal boxes were gathered by the key person in each unit. Then, all materials were directly sent to the researcher’s office in Thailand.

Data Analysis

Statistical Analysis

Data analysis for the current study was divided into two parts: quantitative data analysis and qualitative data analysis. Both types of these data were analyzed to answer the research questions. Quantitative data was analyzed using the Statistical Package for the Social Sciences (SPSS) to answer research questions 1 through 5. Qualitative data was analyzed using a content analysis approach to answer research questions 6 and 7.

Quantitative data analysis. Descriptive statistics were used to analyze and describe the demographic characteristics of the participants and clinical information regarding quality of dying and death of infants and children including previous experience in dealing with dying infants and children.

To answer research questions 1 through 5, statistical analyses used on the data were based on the characteristics of research questions and the level of measurement of the variables as follows:

Research question 1. What is the level of quality of dying and death in the neonatal and pediatric intensive care settings as perceived by Thai critical care nurses?
The level of the quality of dying and death was determined by calculation of frequency, percentage, mean and standard deviation of the QODD.

**Research question 2.** Which barriers to providing pediatric end-of-life care do Thai critical care nurses perceive as the most severe? A perceived severity score (PSS) of barriers to providing pediatric end-of-life care was calculated by multiplying each barrier item’s mean intensity by the item’s mean frequency. Barrier items were ranked separately from highest to lowest severity scores to answer the research question.

**Research question 3.** Which facilitators to providing pediatric end-of-life care do Thai critical care nurses perceive as the most helpful? A perceived help score (PHS) of facilitators to providing pediatric end-of-life care was calculated by multiplying each facilitator item’s mean intensity by the item’s mean frequency. Facilitator items were ranked separately from highest to lowest helpfulness scores to answer the research question.

**Research question 4.** Which barrier category has the most influence on quality of dying and death in the neonatal and pediatric intensive care settings? Barriers were grouped into three main categories according to the study’s conceptual framework: patient-family-related barriers, healthcare professional-related barriers and organizational-related barriers. Then, multiple regression analysis was used to determine the barrier categories that significantly influenced quality of dying and death.

**Research question 5.** Which facilitator category has the most influence on quality of dying and death in the neonatal and pediatric intensive care settings? Facilitators were grouped into three main categories according to the study’s conceptual framework: patient-family-related facilitators, healthcare professional-related facilitators and
organizational-related facilitators. Then, multiple regression analysis was used to
determine the facilitator categories that significantly influenced quality of dying and
death.

*Grouping barriers and facilitators.* Prior to performing multiple regression
analysis, barrier and facilitator items were grouped to identify and reduce underlying
dimensions of the large number of variables to a smaller number of variables for further
appropriate analysis. According to Hatcher (1994), an exploratory factor analysis is a
technique to identify potential dimensions of variables. However, this technique generally
requires a minimum of 150-300 subjects to ensure reliable results (Mertler & Vannatta,
2005; Tabachnick & Fidell, 2007). In order to conduct a factor analysis with as few as
150 cases, several high loading marker variables greater than .80 are required
(Guadagnoli & Velicer, 1988). Despite having only a sample size of 129, a trial factor
analysis was performed separately for the 26 barrier items and for the 24 facilitator items
in the data set. None of the 26 barriers items loaded at greater than .80 and only 2 or the
24 facilitator items (< 10%) had factor loadings above .80. Therefore, grouping of
variables in the study was performed conceptually using the framework that guided the
study. Discussion by the researcher and two bilingual clinical experts experienced in
pediatric palliative care provided content validity of the variable groupings. Studies
documenting barriers and facilitators to providing end-of-life care can be grouped into
three categories including patient-family-related, healthcare professional-related, and
organizational-related factors (Anghelescu et al., 2006; Moss et al., 2005; Nelson, 2006).
In the current study, twenty-six of the barrier items and twenty-four of the facilitators
were grouped into three categories outlined below.
First, the researcher grouped all items into three categories based on the definitions of categories. The items that related to characteristics, behaviors, beliefs and attitudes of patients and families were assigned to the patient-family-related category. Healthcare-professional-related-items were those that related to behaviors, beliefs, attitudes, and knowledge of providing end-of-life care of healthcare personnel. The items related to characteristics and responsibilities of organizations such as changing the environment of the workplace and policies were assigned to the organizational-related category. To prevent individual bias, the researcher enlisted two bilingual experts experienced in pediatric palliative care to review and discuss the grouping of items to categories. The experts were asked to review and modify the grouped items to achieve an optional conceptual fit. Finally, discussions among the panel experts were held until agreement was reached on all grouped items. Grouped items were tested for internal consistency using Cronbach’s alpha coefficient.

The grouped items functioned as independent variables (predictors) for further regression analysis. Linear multiple regression analysis with simultaneous entry of the predictors was employed to test the barriers and facilitators that had the most influence on quality of dying and death for infants and children in intensive care settings. There are three methods for conducting multiple regression analyses including linear multiple regression, hierarchical multiple regression and stepwise multiple regression (Tabachnick & Fidell, 2007). The decision between these methods depends on the purpose of the analysis; both linear and hierarchical multiple regression should be used in research based on theory or some previous knowledge; stepwise multiple regression is a predictor model not based on theory (Mertler & Vannatta, 2005). Hierarchical multiple regression is
useful when testing for mediation or identifying the significance in a block of variables within the model (Mertler & Vannatta, 2005). In the current study, Donabedian’s model posits that barriers and facilitators (the structure) affects the outcome of quality of dying and death. Thus, the linear multiple regression approach was selected. Independent variables to be entered are chosen based on theory and prior empirical evidence. In this procedure, independent variables were entered into the regression equation simultaneously. The effect of each independent variable (i.e. barriers and facilitators) on the dependent variable (quality of dying and death) was assessed based on what it contributes to the prediction of the dependent variable.

Qualitative data analysis. Content analysis was used to analyze to answer the following research questions:

Research question 6. What additional barriers to providing pediatric end-of-life care are identified by Thai critical care nurses?

Research question 7. What do Thai critical care nurses identify as changes needed (facilitators) to improve end-of-life care in neonatal and pediatric intensive care settings?

The content analysis process was performed as follows (Weber, 1990):

Step 1: Arranging data for content analysis. The raw data for content analysis in this study was from written responses to two open-ended questions. All written responses to each research question were typed and assembled into a Microsoft Word document. Each hard copy of the text was repeatedly read several times. This reading provided an initial understanding of the entire text.

Step 2: Defining coding units. A key word was assigned to each meaningful statement and noted in the text. Then, these written notes were carefully read through
again and necessary headings were written down in the margins to describe all aspects of the content. These key words were collected from the margin into a coding sheet. Codes with similar meaning were grouped together under three main barrier and facilitator categories.

Step 3: Checking coding consistency. Checking coding consistency was done to confirm that the same meaning was assigned to the codes. This process was very important because it affects the developing subcategories. According to Weber (1990), codes that are inconsistent may result in incorrect subcategory groupings.

Step 4: Generating subcategories. In this step, subcategories were inductively generated from the data codes. Similar subcategories were combined into the same headings. Then, these subcategories were developed and grouped into existing topics to answer research question 6 and 7.

All of the content analysis processes were performed and reviewed by the researcher and another doctorally-prepared ICU nurse fluent in both English and Thai until consensus regarding generated themes was reached.

Data Management

To perform data management effectively, the researcher first developed a data codebook for each instrument. The purpose of the codebooks was to capture data elements. Data coding in this study included three parts: 1) General information of nurses coded on the demographic data sheets; 2) Nurses’ perceptions of the quality of dying and death regarding pediatric end-of-life care coded on the Modified Quality of Dying and Death questionnaire (QODD); and 3) Nurses’ perceptions of barriers and facilitators regarding pediatric end-of-life care coded on the Modified National Survey of Critical
Care Nurses Regarding End-of-Life Care questionnaire. Each codebook consisted of an abbreviated variable name, variable type, a descriptive variable label, the range of possible numerical variables of each variable, non-applicable values, and missing values. All decisions made during coding were recorded in the codebook to guide judgments and to maintain consistency in decision-making.

The researcher next assigned an identification number on all of the returned questionnaires in order to ensure that the researcher was able to attribute all data to the correct participant. The returned questionnaires of each participant were carefully reviewed for completeness and clarity. Then, the researcher rechecked all data for accuracy in order that the data were corrected before a large amount of data were entered into the computer. Raw data recorded on research instruments were reviewed to verify if appropriate values were met. Data were entered into a computer database using SPSS for Windows software. To ensure the accuracy of the data file, the researcher double checked the computerized data file by proofreading it against the original data. All discrepancies were corrected following the original data. When data entry was completed, a back-up of the database was saved on the computer hard drive and flash drives for further data analysis. All questionnaires and data files were kept in a locked file in order to assure confidentiality and individual privacy. Only the researcher was able to access the data.

Data Screening Procedure

Prior to analysis, the data were examined for missing values and assumptions of multiple regression to ensure that they were not violated and to ensure proper use of parametric statistics.
Data screening for missing data. Data screening for missing values and univariate outliers were performed using descriptive statistics including frequency and calculation of measures of central tendency. Analyzing missing values are important step in helping the researcher address several concerns caused by incomplete data. In the current study, missing data may result when a subject refuses to respond to sensitive questions on a questionnaire or neglects to finish the survey because the length of the questionnaire is excessive. Problems with missing data may reduce the precision of calculated statistics because there is less information than originally planned (Mertler & Vannatta, 2005).

To deal with missing data in the current study, the researcher used listwise deletion technique that is set as a default in SPSS. Although there are several alternative methods to handle with these missing data such as listwise, pairwise, mean substitution and regression approach, listwise was considered the easiest and simplest method (Mertler & Vannatta, 2005). Listwise deletion is a method of dealing with missing data by removing incomplete cases or missing values for the cases that are critical to the variables being analysis (Mertler & Vannatta, 2005; Warner, 2008). Advantages in using listwise deletion are 1) all analyses are calculated with the same set of cases; 2) it can be used for any kind of statistical analysis; 3) no special computational methods are required (Warner, 2008).

Testing assumptions. Before conducting the analysis, all assumptions for all statistical tests were examined for violations. The primary statistic used in the current study was multiple regression analysis. Primary assumptions for testing multiple regression analysis include variability in the variables, absence of influential cases or
outliers, and linearity. Secondary assumptions include normality and constant error variance. Testing for multicollinearity was also done.

**Variability in the variables.** Variability in the variables is important for multivariate analysis; if a given variable does not vary, then it will display an attenuated association with other variables (Tabachnick & Fidell, 2007). This assumption was tested by using frequencies and the explore function in SPSS. If this assumption is met, the values of a variable will not fall predominantly at one or two consecutive scores.

**Outliers and influential outliers.** An outlier is a score which is very different from the majority of data (Mertler & Vannatta, 2005). The rationale for looking for outliers is that they may have a strong influence that can distort the results of a statistical test. To identify outliers and influential cases in regression equations, diagnostic statistics including Mahalanobis Distance, standardized residuals, and Cook’s Distance were utilized. Mahalanobis Distance was used to examine outliers on the predictor variables. A Mahalanobis Distance value was tested using chi-square criteria ($\chi^2$ at $p<.001$ with respect to degree of freedom). The degree of freedom is the number of variables being examined. Mahalanobis Distance value that exceeds the critical value of chi square (using a chi-square table) indicates a problem with outliers (Mertler & Vannatta, 2005).

Standardized residuals values greater than +3 and less than -3 indicate a problem with outliers on the outcome variable. Cook’s Distance was used to measure the combined influence of a case being an outlier on an outcome variable and the set of predictor variables. A Cook’s Distance value that is higher than 1.0 indicates a problem with outliers (Tabachnick & Fidell, 2007). Once outliers were identified, the researcher first determined whether the outlier was due to an error in data entry. In this situation, the
value would be corrected and the data would be reanalyzed. If the outlier was due to an instrumentation error or the subject was simply different from the rest of the sample, the case would be dropped from the analysis. If it cannot be determined that either of these situations resulted in the extreme value, the researcher would perform two analyses (one with the outlying case included and the other after the case has been deleted). If the two results are the same, outliers would be kept. If the two results are different, outliers would be removed (Mertler & Vannatta, 2005).

**Linearity.** This assumption presupposes that there is a straight line relationship between two variables. Linearity can be examined using simple and partial scatter plot (Mertler & Vannatta, 2005). Generally, a simple scatter plot provides a good indication when performing a linear regression with a single independent variable and partial scatter plot is useful for multiple independent variables (Velleman & Welsch, 1981). In the current study, there was more than one independent variable. Therefore, partial scatter plot was chosen. For the partial scatter plot method, the scattered points depict the partial correlation between the two variables, controlling for the effect of other independent variables (Velleman & Welsch, 1981). This assumption was assessed by comparing linear with quadratic and cubic lines of best fit based on differences in total $R^2$ values and checking for differences that exceeded 1 or 2% additional explained variance. If a change in $R^2$ between the quadric and cubic $R^2$ is more than .02, the relationship is nonlinear (Velleman & Welsch, 1981).

**Normality.** The normality refers to a normal sample distribution. This assumption was assessed by running frequencies for a histogram, normal probability plot, skewness and kurtosis. If the assumption of normality is met, a histogram displays a symmetric
bell-shaped curve and the normal probability plot shows most values fall along the diagonal line with no substantial departure (Tabachnick & Fidell, 2007). For the numeric, skew should be within the -3 to +3 range and kurtosis should be within the -8 to +8 range when a distribution is normal (Kline, 2004).

**Constant error variance.** Constant error variance is an assumption in regression analysis that the residuals at each level of the independent variables have similar variances (Mertler & Vannatta, 2005). This assumption was examined by using simple scatterplots to assess Studentized Deleted Residuals (Y axis) by Standardized Predicted scores (X axis). All scatterplots that showed a random and approximately equal scatter of points from the zero line of the residuals indicate the assumption of constant error variance is met.

**Multicollinearity.** Multicollinearity is a problem that occurs when there is a high degree of correlation among several independent variables (Mertler & Vannatta, 2005). It is because some of the variables may measure the same concepts or phenomena. The presence of multicollinearity may make it difficult to determine the importance of individual independent variables due to the overlapping information (Mertler & Vannatta, 2005). In addition, multicollinearity tends to increase the variances of the regression coefficients which results in an unstable prediction equation (Mertler & Vannatta, 2005).

Multicollinearity was assessed using bivariate correlations, tolerance, and variance inflation factor (VIF). A high correlation that is above 0.8 between predictor variables, tolerance that is below 0.1, and VIF that is larger than 10 indicates a problem with multicollinearity (Mertler & Vannatta, 2005). If multicollinearity is present,
problematic variables involved will be deleted from analysis to avoid overlapping information.

Protection of Human Subjects

To ensure protection of subjects’ rights and personal privacy, the researcher followed the standard code of ethics for nurses and the requirements of the Institutional Review Board as a guide for the study: self-determination, privacy, anonymity and confidentiality, fair treatment, and protection from discomfort and harm (American Association of Critical Care Nurse, 2001). All of these ethical principles were addressed in the cover letter that was attached as the first page of each questionnaire packet.

The right to self-determination refers to the ethical principle of respect for persons indicating capability of their destiny (American Association of Critical Care Nurses, 2001). Participants were informed that involvement in this study was completely voluntary. They had rights to end the process and to withdraw from the study at any time without any repercussions.

The right to privacy is defended as the freedom of an individual or group to protect their private information which may be shared with the public or other persons (American Association of Critical Care Nurses, 2001). This right always deeply involves the right to anonymity and confidentiality. The participants have the right to anonymity and the right to assume that individual responses are kept confidential (American Association of Critical Care Nurses, 2001). To protect these rights, the participants in the study were notified that their names were not posted on any parts of the research. All questionnaires were coded with only an identification number. Additionally, all data sets were analyzed and reported in the aggregate form. No written informed consent form for
the participant’s signature was required. Consent was implied by completion and return of the questionnaire packet to the researcher.

To protect confidentiality, participants were assured that completed questionnaires were kept in a locked cabinet in the researcher’s office. Computer files were password protected. Only the researcher accessed all of the data and knew the computer password. All of the information that participants provided to the researcher will be retained for five years, as per Thai law, and then be destroyed afterward.

The right to fair treatment is based on the ethical principle of justice that every person must receive equal and fair treatment during the research process (American Association of Critical Care Nurses, 2001). To ensure fair treatment, participants were informed that they were fairly treated without bullying, discrimination, harassment and vilification from the researcher or from the key person at each study site who assisted the researcher with the study. The researcher respectfully followed research procedures and no activities were performed that had not received IRB approval. Every participant in the current study was equally selected for reasons directly related to the problem of the study and not for individual benefit. The findings of the study were used for improving quality of care at the end of life for infants and children and their families in the future.

The right to protection from discomfort and harm is based on the concept of beneficence, which is focused on “do good and do no harm” (Burns & Grove, 2007). To protect from harm and discomfort, the participants were notified that there were minimal or no anticipated physical and psychological harm for participants. However, emotional discomfort may unintentionally result from some statements in the questionnaires. To
minimize this risk, participants could refuse to answer any question if it caused them discomfort.

Summary

This chapter provided comprehensive methods and procedures used for the study. A description of research design, sampling, instruments, data collection procedures, data analysis plan, and protection of human subjects were discussed. Because this study aimed to explore problems in an unknown area and identify information concerning current status of the phenomena of interest, using a descriptive correlational design was used. Convenience sampling was used to select Thai pediatric critical care nurses under specified inclusion and exclusion criteria. Power analysis technique was used to determine a sample size of 129 subjects to control for Type I error with alpha set at .05, beta set at 0.80, and a medium effect size. Three self-administered questionnaires, the Modified Quality of Dying and Death Questionnaire, the Modified National Survey of Critical-Care Nurses Regarding End-of Life Care Questionnaire, and an investigator-developed Demographic Tool, were translated into Thai language and were pretested to determine internal consistency reliability by conducting a pilot study. Data collection was managed by key persons at each selected hospital. The key person was responsible to distribute the questionnaires, collect returned questionnaires and remind participants to return their questionnaires. Data analysis included descriptive statistics, Pearson correlation coefficients and multiple regression analyses. Responses to open-ended questions were analyzed using content analysis. Protection of human subjects was assured by following the principles of self-determination, privacy, anonymity and confidentiality, fair treatment, and protection from discomfort and harm.
CHAPTER IV

Results

The purpose of the study was to describe and explore the relationship among quality of dying and death, barriers and facilitators to providing pediatric end-of-life care in intensive care units in Thailand. In addition, the study also determined barriers and facilitators that have the most influence on the quality of dying and death. This chapter details pilot study results, reliability of instruments used in the main study, preliminary data analyses for all study variables and for assumptions underlying statistical analysis, descriptive information of study participants, descriptive information related to dying infants and children whom nurses cared for, and the results of analyses corresponding to the research questions.

*Pilot Study Results*

The results of the pilot study indicated that the content of the Thai version of Modified Quality of Dying and Death (QODD) and of the Modified National Survey of Critical Care Nurses regarding End-of-Life Care questionnaires was clearly understood by the sample of 15 adult ICU nurses. Prior to use in the pilot study, all translated instruments were evaluated for content validity using three bilingual Thai nurse experts in end-of-life care. The content validity index was 0.95 for the QODD questionnaire and 0.92 for the total scale of the National Survey of Critical Care Nurses regarding End-of-Life Care questionnaire. The content validity index for the barrier scale was 0.96 and for the facilitator scale was 0.88. The internal consistency reliability was calculated in the pilot sample of 15 adult critical care nurses. Cronbach’s alpha coefficients were 0.95 for the QODD questionnaire, 0.93 for the total scale of the National Survey of Critical Care
Nurses regarding End-of-Life Care questionnaire, 0.85 for barrier scale and 0.94 for facilitator scale.

Reliability Analysis Results of Main Study

To assure quality and adequacy of the questionnaires, the internal consistency reliability was recalculated in the main study sample of 129 pediatric critical care nurses. Cronbach’s alpha coefficients were 0.87 for the Modified QODD questionnaire, 0.92 for the total scale of the Modified National Survey of Critical Care Nurses regarding End-of-Life Care questionnaire, 0.95 for barrier scale and 0.94 for facilitator scale.

Barrier and facilitator items were grouped into the three main categories (patient-family-related, healthcare-professional-related, and organizational-related) identified in the study’s conceptual framework and internal reliability coefficients were calculated. Standardized Cronbach’s alpha coefficients for patient-family-related (10 items), healthcare-professional-related (10 items), and organizational-related barriers (6 items) were .84, .83, and .66 respectively. Standardized Cronbach’s alpha coefficients for patient-family-related (4 items), healthcare-professional-related (12 items), and organizational-related facilitators (8 items) were .60, .85, and .64 respectively.

Pre-Analysis Data Screening Results

Data Screening

Prior to analysis, data screening was conducted to check accuracy, missing values, and assumptions underlying statistical analysis. Data entered in the computer were compared to raw data forms by the researcher and research assistants. Descriptive statistics and frequencies were computed to assess continuous data for the range of values to assure that no cases had values outside the range of possible values. Category data
were checked to confirm that all cases had values corresponding to the coded values for the categories. Through frequency analysis, missing values were found in less than 5% of cases and reflected a random pattern. According to Tabachnick and Fidell (2001), up to ten percent of missing data on a particular variable is acceptable and missing values scattered randomly through a data matrix pose less concern for bias. Consequently, no imputation was needed.

Statistical Assumptions

Primary and secondary assumptions underlying multiple regression analysis were examined to assure that no violation of the assumptions existed. A primary assumption of multiple regression analysis requires variation in independent and dependent variables, absence of influential cases, and linearity. Variation in the variables was determined by examining frequencies and histograms. All six independent variables (barriers and facilitators for patient and family, healthcare professionals, and organizations), and the dependent variable (quality of dying and death) had sufficient variance. No values of any main study variable fell predominantly at one or two consecutive scores. To identify outliers and influential cases, standardized deleted residuals, Mahalanobis Distance, and Cook’s Distance were examined through two regression analyses, one for the barrier model and one for the facilitator model. Observed values of standardized deleted residuals for the barrier model ranged from -3.05 to 2.51, and for the facilitator model ranged from .00 to .082. Accordingly, no values of standardized deleted residuals exceeded three standard deviations, suggesting that no outliers were present. Mahalanobis Distance values were calculated for each model and were compared with the critical values of chi-square distribution at $p < .001$ with respective degrees of freedom (the
number of variables being examined for outliers) (Tabachnick & Fidell, 2007). In the proposed study, the critical value of $\chi^2$ at $p < .001$ and $df = 4$ was 18.467. The lowest and highest Mahalanobis Distance values for the barrier model were between .058 and 15.55 and for the facilitators model were between .17 and 12.03. Accordingly, Mahalanobis Distance values did not exceed 18.467, indicating that no multivariate outliers were detected. For examining influential cases, Cook’s Distance of all independent variables was $< 1$, indicating the absence of influential data points. The assumption of linearity was tested using partial scatter plots of each independent variable on the dependent variable and comparing linear with quadratic lines of best fit for each partial plot based on differences in total R square values. There were no differences that exceeded 1 or 2% additional explained variance, indicating that the assumption of linearity was met.

Secondary assumptions of multiple regression analysis require normality and homoscedasticity. Normal distribution was evaluated by examining histograms, P-P plots, and values of skewness and kurtosis for each variable. The histogram revealed a normal distribution of the residuals with a symmetrical bell shape and the P-P plots that approximated straight lines. No variables had absolute skewness values that exceeded 3 or absolute kurtosis values that exceeded 8, suggesting normal distribution of the variables. Homoscedasticity of variance of the residuals was also evaluated by examining residual scatter plots for even distribution of points across the reference line. This assumption was not violated since there was an approximately even random scatter of values across the reference line. Multicollinearity, another concern for regression analysis, was examined by checking the tolerance and Variance Inflation Factors (VIF)
for both barrier and facilitator variables. All variables had tolerance values >.10 and VIF <10, indicating absence of multicollinearity.

_Demographic Characteristics of the Study Sample_

A total of 129 critical care nurses responded to the 150 distributed questionnaires (response rate 86%). Demographic characteristics of the participants are presented in Table 2. Of the 129 nurses in the sample, most (97.67%) were female, with an age range from 24 to 59 years old, and a mean age of 36.58 years ($SD = 9.09$). The highest completed level of education of the participants varied from bachelor’s degree to doctoral degree. The majority (86.82%) held a bachelors degree. Participants reported experience as a registered nurse for a range of 1 to 36 years, with a mean of 12.63 years ($SD = 9.06$). Mean years experience as a critical care nurse was 11.12 years ($SD = 8.0$). Weekly employment hours in the intensive care unit ranged from 27 hours to 72 hours, with a mean of 43.78 hours per week ($SD = 7.18$). Less than 50% of the participants held current Pediatric/ Neonatal Critical Care Nurse Certification.

The majority of participants worked in the Pediatric Intensive Care Unit or Neonatal Intensive Care Unit. The size of these units ranged from 4 to 15 beds, with a mean of 8 beds ($SD = 3.5$). Most participants were bedside staff nurses. All participants reported caring for patients at the end of life with approximately half reporting that they had cared for more than 30 dying children in their professional career.
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<td>Type of ICU</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PICU (Pediatric Intensive Care Unit)</td>
<td>60 (46.51%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NICU (Neonatal Intensive Care Unit)</td>
<td>52 (40.31%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RCU (Respiratory Care Unit)</td>
<td>11 (8.53%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CCU (Cardiac Care Unit)</td>
<td>6 (4.65%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Position held on the unit</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Head Nurse</td>
<td>7 (5.43%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff Nurse</td>
<td>118 (91.50%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse Specialist</td>
<td>3 (2.30%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>1 (0.77%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dying infants/children cared for</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 5</td>
<td>6 (4.65%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 -10</td>
<td>26 (20.16%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 - 20</td>
<td>18 (13.95%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21 -30</td>
<td>9 (6.98%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 30</td>
<td>64 (49.61%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>6 (4.65%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Certificate as a Pediatric/ Neonatal Critical Care Nurse</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>59 (45.74%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>68 (52.71%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>2 (1.55%)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
As shown in Table 3, more than half of the dying patients most recently cared for were infants. The majority of dying patients were male. The top three conditions were diseases related to the respiratory system (18.6%), cardiovascular system (12.40%), and hematologic system (11.62%). Although all nurses in the study had cared for a dying infant or child recently, the majority of respondents had not cared for the most recent dying child referenced for the purposes of the study at the time of death.

With regard to medical care received at the end of life, nearly all dying infants and children received mechanical ventilator support, almost one third were on dialysis, and most (75.2%) were felt to have received the right amount of sedation. In most cases, nurses reported discussion had occurred between family members and doctors. Nearly two-thirds of critical care nurses did not think that the dying child or infant was kept alive too long.

The majority of dying infants and children (79.1%) had family or staff present at the moment of their death. Most infants and children (73.6%) were thought to have been in a coma or unconscious at the moment of death, with 12.4% thought to have been sleeping. Only 6.20% of patients were thought by the nurses to be awake at the moment of death. Nurses in the sample reported that 69.8% of parents had adequate time to communicate an important message to their dying infant or child but only in 71% of cases did nurses feel that a parent actually communicated that message.
Table 3

*Characteristics of Most Recent Dying Child/Infant Cared for in the ICU (N = 129)*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant/Child age at death</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infant (&lt; 1 year old)</td>
<td>79</td>
<td>61.24%</td>
</tr>
<tr>
<td>Child (1-18 years old)</td>
<td>45</td>
<td>34.88%</td>
</tr>
<tr>
<td>Missing</td>
<td>5</td>
<td>3.88%</td>
</tr>
<tr>
<td>Infant/Child gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>72</td>
<td>55.81%</td>
</tr>
<tr>
<td>Female</td>
<td>35</td>
<td>27.13%</td>
</tr>
<tr>
<td>Missing</td>
<td>22</td>
<td>17.05%</td>
</tr>
<tr>
<td>Infant/Child diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>2</td>
<td>1.55%</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>16</td>
<td>12.40%</td>
</tr>
<tr>
<td>Neurologic disorder</td>
<td>11</td>
<td>8.53%</td>
</tr>
<tr>
<td>Hematologic disorder</td>
<td>15</td>
<td>11.62%</td>
</tr>
<tr>
<td>Gastrointestinal disorder</td>
<td>3</td>
<td>2.33%</td>
</tr>
<tr>
<td>Infection</td>
<td>12</td>
<td>9.30%</td>
</tr>
<tr>
<td>Respiratory disorder</td>
<td>24</td>
<td>18.60%</td>
</tr>
<tr>
<td>Renal disorder</td>
<td>3</td>
<td>2.33%</td>
</tr>
<tr>
<td>Premature baby</td>
<td>10</td>
<td>7.75%</td>
</tr>
<tr>
<td>Immunologic disorder</td>
<td>1</td>
<td>0.78%</td>
</tr>
<tr>
<td>Missing</td>
<td>32</td>
<td>24.81%</td>
</tr>
<tr>
<td>Respondent was personally caring for this child at time of death</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>51</td>
<td>39.53%</td>
</tr>
<tr>
<td>No</td>
<td>55</td>
<td>42.64%</td>
</tr>
<tr>
<td>Missing</td>
<td>23</td>
<td>17.83%</td>
</tr>
<tr>
<td>Medical care that infant/child received at the end of life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>On mechanical ventilator</td>
<td>126</td>
<td>97.7%</td>
</tr>
<tr>
<td>On dialysis</td>
<td>43</td>
<td>33.5%</td>
</tr>
<tr>
<td>Adequately sedated</td>
<td>97</td>
<td>75.2%</td>
</tr>
<tr>
<td>Discussion between family and doctors</td>
<td>116</td>
<td>89.9%</td>
</tr>
<tr>
<td>Kept alive too long</td>
<td>29</td>
<td>22.5%</td>
</tr>
<tr>
<td>Experiences of infant/child at the moment of death</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence of family, friend or staff</td>
<td>102</td>
<td>79.1%</td>
</tr>
<tr>
<td>Coma/unconscious</td>
<td>95</td>
<td>73.6%</td>
</tr>
<tr>
<td>Asleep</td>
<td>16</td>
<td>12.4%</td>
</tr>
<tr>
<td>Awake</td>
<td>8</td>
<td>6.20%</td>
</tr>
<tr>
<td>Parent had adequate time to communicate important message to dying infant/child</td>
<td>90</td>
<td>69.8%</td>
</tr>
<tr>
<td>Parent communicated important message to dying infant/child</td>
<td>92</td>
<td>71.3%</td>
</tr>
</tbody>
</table>
Results for Research Questions

Research Question 1

What is the quality of dying and death in the neonatal and pediatric intensive care settings as perceived by Thai critical care nurses?

The QODD items were rated on a scale from 1 (poor) to 5 (excellent). For ease of interpretation, item responses were recoded into a 0 (poor) to 4 (excellent) scale. A total score was calculated by adding the scores on 11 items and dividing this score by the number of items answered. This mean score was divided by the range of possible scores (4) and then multiplied by 100 to construct a scale ranging from 0 to 100. Zero represented the worst possible quality of dying and death, and 100 represented the best possible quality of dying and death.

As shown in Table 4, the total mean score for quality of dying and death in the neonatal and pediatric intensive care settings in Thailand was 52.89 ± 15.43 (range 13.64-86.36, median 52.27). Regarding characteristics of individual items comprising the total score, the top five items rated from highest to lowest score were 1) being treated with dignity and self-respect; 2) care received from nurses in the last several days while in the ICU; 3) the quality of medical care received at the end of life; 4) the care received from doctors in the last several days while in the ICU; and 5) experiences at the moment of death. The two items rated as the lowest score included having a spiritual service/ceremony before death, and having one or more visits from a religious/spiritual advisor.
### Table 4

**Detailed Results for Quality of Dying and Death Items**

<table>
<thead>
<tr>
<th>QODD Items</th>
<th>n</th>
<th>Poor n (%)</th>
<th>Fair n (%)</th>
<th>Good n (%)</th>
<th>Very Good n (%)</th>
<th>Excellent n (%)</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total QODD scores (0-100)</td>
<td>52.89</td>
<td>15.43</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being treated with dignity and self-respect</td>
<td>129</td>
<td>5 (3.9)</td>
<td>5 (3.9)</td>
<td>32 (24.8)</td>
<td>65 (50.4)</td>
<td>22 (17.1)</td>
<td>68.22</td>
<td>23.12</td>
</tr>
<tr>
<td>Rating care received from nurses in the last several days while in ICU</td>
<td>129</td>
<td>2 (1.6)</td>
<td>2 (1.6)</td>
<td>64 (49.6)</td>
<td>58 (45)</td>
<td>3 (2.3)</td>
<td>61.24</td>
<td>16.23</td>
</tr>
<tr>
<td>Rating quality of medical care received at the end of life</td>
<td>114</td>
<td>0</td>
<td>10 (7.8)</td>
<td>52 (40.3)</td>
<td>47 (36.4)</td>
<td>5 (3.9)</td>
<td>60.31</td>
<td>17.85</td>
</tr>
<tr>
<td>Rating care received from doctors in last several days in ICU</td>
<td>129</td>
<td>0</td>
<td>13 (10.1)</td>
<td>63 (48.8)</td>
<td>50 (38.8)</td>
<td>3 (2.3)</td>
<td>58.33</td>
<td>17.21</td>
</tr>
<tr>
<td>Rating experience at moment of death</td>
<td>123</td>
<td>2 (1.6)</td>
<td>15 (11.6)</td>
<td>56 (43.4)</td>
<td>47 (36.4)</td>
<td>3 (2.3)</td>
<td>56.91</td>
<td>19.29</td>
</tr>
<tr>
<td>Being touched or hugged by loved ones</td>
<td>129</td>
<td>9 (7)</td>
<td>24 (18.6)</td>
<td>34 (26.4)</td>
<td>49 (38)</td>
<td>13 (10.1)</td>
<td>56.39</td>
<td>27.29</td>
</tr>
<tr>
<td>Spending time with family or friends</td>
<td>129</td>
<td>8 (6.2)</td>
<td>28 (21.7)</td>
<td>38 (29.5)</td>
<td>47 (36.4)</td>
<td>8 (6.2)</td>
<td>53.68</td>
<td>25.79</td>
</tr>
<tr>
<td>Having pain under control</td>
<td>129</td>
<td>11 (8.5)</td>
<td>24 (18.6)</td>
<td>47 (36.4)</td>
<td>41 (31.8)</td>
<td>6 (4.7)</td>
<td>51.36</td>
<td>25.45</td>
</tr>
<tr>
<td>Breathing comfortably</td>
<td>127</td>
<td>27 (20.9)</td>
<td>12 (9.3)</td>
<td>48 (37.2)</td>
<td>32 (24.8)</td>
<td>8 (6.2)</td>
<td>46.45</td>
<td>30.00</td>
</tr>
<tr>
<td>Having a spiritual service/ceremony before death</td>
<td>129</td>
<td>20 (15.5)</td>
<td>28 (21.7)</td>
<td>52 (40.3)</td>
<td>27 (20.9)</td>
<td>2 (1.6)</td>
<td>42.83</td>
<td>25.42</td>
</tr>
<tr>
<td>Having one or more visits from religious/spiritual advisor</td>
<td>127</td>
<td>24 (18.6)</td>
<td>45 (34.9)</td>
<td>35 (27.1)</td>
<td>19 (14.7)</td>
<td>4 (3.1)</td>
<td>37.01</td>
<td>26.51</td>
</tr>
</tbody>
</table>

*Note.* The quality of dying and death response choices were 0 = poor, 1 = fair, 2 = good, 3 = very good, and 4 = excellent
Research Question 2

Which barriers to providing pediatric end-of-life care do Thai critical care nurses perceive as most severe?

Barriers were grouped into three main categories according to the study’s conceptual framework: patient-family-related barriers, healthcare-professional-related barriers and organizational-related barriers. Barrier items were rated for both intensity and frequency by the Thai critical care nurses who participated in the study. The scale utilized for barrier intensity ranged from 0 (not a barrier) to 5 (the most barrier). Similarly, the scale of 0 (never happens) to 5 (consistently happens) was used to indicate frequency. Descriptive statistics were computed for all barrier items. Items were ranked on the basis of their mean score to determine which ones were perceived to be the most intense barriers and which items were perceived to occur most often. In order to determine which barriers were perceived as the most intense and the most frequently occurring, a perceived severity score (PSS) was calculated by multiplying each barrier item’s mean intensity by the item’s mean frequency. The possible PSS score range was from 0 to 25.

Patient-Family-Related Barriers

Table 5 ranks the perceived severity scores (PSS) for patient-family-related barrier items from highest to lowest mean score. PSS ranged from 2.10 to 7.15. The top three patient-family-related barriers items perceived as the most severe barriers to providing pediatric end-of-life care were 1) dealing with distraught family members while providing care for the patient ($M = 7.15, SD = 1.50$); 2) families not accepting what the physician is telling them about the patient’s poor prognosis ($M = 6.17, SD = 1.19$);
and 3) inability of patients to communicate due to depressed neurological status or sedation ($M = 5.30$, $SD = 2.60$).

Table 5

*Item Means for Patient-Family-Related Barriers*

<table>
<thead>
<tr>
<th>Patient-Family-Related Barriers</th>
<th>Intensity*</th>
<th>Frequency**</th>
<th>PSS***</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Dealing with distraught family members while providing care</td>
<td>2.76</td>
<td>1.27</td>
<td>7.15</td>
</tr>
<tr>
<td>2. Families not accepting the patient’s poor prognosis</td>
<td>2.78</td>
<td>1.25</td>
<td>6.17</td>
</tr>
<tr>
<td>3. Inability of patients to communicate due to neurological status or sedation</td>
<td>2.55</td>
<td>1.68</td>
<td>5.30</td>
</tr>
<tr>
<td>4. Infra-family fighting about whether to continue or stop life support</td>
<td>2.46</td>
<td>1.44</td>
<td>4.72</td>
</tr>
<tr>
<td>5. Family and friends who continually call nurses for an update rather than calling designated family member</td>
<td>2.06</td>
<td>1.18</td>
<td>4.37</td>
</tr>
<tr>
<td>6. Dealing with angry family members</td>
<td>2.19</td>
<td>1.42</td>
<td>3.88</td>
</tr>
<tr>
<td>7. Family is not with the patient at the time of death</td>
<td>2.17</td>
<td>1.56</td>
<td>3.69</td>
</tr>
<tr>
<td>8. Family does not understand what &quot;life-saving measures&quot; really mean</td>
<td>2.21</td>
<td>1.34</td>
<td>3.54</td>
</tr>
<tr>
<td>9. Patient pain that is difficult to control</td>
<td>1.77</td>
<td>1.38</td>
<td>2.76</td>
</tr>
<tr>
<td>10. Dealing with family culture differences</td>
<td>1.44</td>
<td>1.06</td>
<td>2.10</td>
</tr>
</tbody>
</table>

*Note.* *Intensity* of barrier response choices were 0 = not a barrier to 5 = the most barrier; **Frequency of barrier response choices were 0 = never happens to 5 = consistently happens; ***Perceived Severity Score (PSS) = mean for intensity multiplied by mean for frequency.

*Healthcare-Professional-Related Barriers*

In Table 6, perceived severity scores (PSS) for healthcare-professional-related barrier items are ranked from highest to lowest mean score. PSS ranged from 1.38 to 4.32. The top three healthcare-professional-related barriers to providing pediatric end-of-
life care were 1) multiple physicians involved with one patient who differ in opinion about the direction care should go \( (M = 6.76, SD = 2.89) \); 2) not enough time to provide quality end-of-life care since the nurse is consumed with other activities to save the patient's life \( (M = 5.12, SD = 2.20) \); and 3) lack of nursing education and training regarding family grieving and quality end-of-life care \( (M = 4.32, SD = 1.32) \).

Table 6

*Item Means for Healthcare-Professional-Related Barriers*

<table>
<thead>
<tr>
<th>Healthcare-Professional-Related Barriers</th>
<th>Intensity*</th>
<th>Frequency**</th>
<th>PSS***</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Multiple physicians who differ in opinion about direction of care</td>
<td>2.23</td>
<td>3.03</td>
<td>6.76</td>
</tr>
<tr>
<td>2. Lack of time to provide quality EOL care because of other activities to save patient's life</td>
<td>2.35</td>
<td>2.18</td>
<td>5.12</td>
</tr>
<tr>
<td>3. Lack of nursing education and training on family grieving and quality EOL care</td>
<td>2.32</td>
<td>1.86</td>
<td>4.32</td>
</tr>
<tr>
<td>4. Continuing treatments for a dying patient that cause patient pain</td>
<td>2.09</td>
<td>1.96</td>
<td>4.10</td>
</tr>
<tr>
<td>5. Physicians are overly optimistic to family about survival</td>
<td>2.17</td>
<td>1.84</td>
<td>3.99</td>
</tr>
<tr>
<td>6. Physician won't allow patient to die from the disease process</td>
<td>1.87</td>
<td>1.35</td>
<td>2.52</td>
</tr>
<tr>
<td>7. When nurse's opinion about direction of care is not requested, valued, or considered</td>
<td>1.86</td>
<td>1.30</td>
<td>2.42</td>
</tr>
<tr>
<td>8. Nurses’ awareness of patient’s poor prognosis before family is told</td>
<td>1.31</td>
<td>1.58</td>
<td>2.07</td>
</tr>
<tr>
<td>9. Continuing intensive care for a patient because of real or imaged threat of legal action</td>
<td>1.46</td>
<td>1.12</td>
<td>1.64</td>
</tr>
<tr>
<td>10. Evasive physicians who avoid conversations with family members</td>
<td>1.73</td>
<td>.80</td>
<td>1.38</td>
</tr>
</tbody>
</table>

*Note.* *Intensity of barrier response choices were 0 = not a barrier to 5 = the most barrier; Frequency of barrier response choices were 0 = never happens to 5 = consistently happens; Perceived Severity Score (PSS) = mean for intensity multiplied by mean for frequency.*
Organizational-Related Barriers

Table 7 displays perceived severity scores for organizational-related barrier items ranked from highest to lowest score. PSS ranged from .72 to 6.42. The top three organizational-related barrier items were 1) poor design of units that do not allow for privacy of dying patients or grieving family members ($M = 6.42, SD = 2.32$); 2) unit visiting hours that are too restrictive ($M = 3.59, SD = 1.53$); and 3) no available support person for the family such as a social worker or religious leader ($M = 2.64, SD = 1.88$).

Table 7

<table>
<thead>
<tr>
<th>Organizational-Related Barriers</th>
<th>Intensity*</th>
<th>Frequency**</th>
<th>PSS***</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Poor design of units that do not allow for privacy</td>
<td>2.62</td>
<td>1.48</td>
<td>6.42</td>
</tr>
<tr>
<td>2. Restrictive visiting hours</td>
<td>1.90</td>
<td>1.23</td>
<td>3.59</td>
</tr>
<tr>
<td>3. No available support person for family (e.g. social worker, religious leader)</td>
<td>1.77</td>
<td>1.39</td>
<td>2.64</td>
</tr>
<tr>
<td>4. Being called away to help with a new admit or to help another nurse</td>
<td>1.69</td>
<td>1.45</td>
<td>2.32</td>
</tr>
<tr>
<td>5. Visiting hours that are too liberal</td>
<td>1.58</td>
<td>1.41</td>
<td>2.23</td>
</tr>
<tr>
<td>6. Pressure to limit family grieving to accommodate a new admit to that room</td>
<td>1.11</td>
<td>.65</td>
<td>0.72</td>
</tr>
</tbody>
</table>

Note. *Intensity of barrier response choices were 0 = not a barrier to 5 = the most barrier; **Frequency of barrier response choices were 0 = never happens to 5 = consistently happens; ***Perceived Severity Score (PSS) = mean for intensity multiplied by mean for frequency.

Research Question 3

Which facilitators do Thai critical care nurses perceive as most helpful?

Facilitators were grouped into three main categories including patient-family-related facilitators, healthcare-professional-related facilitators and organizational-related
facilitators. Facilitator items were rated for both intensity and frequency by the Thai critical care nurses who participated in the study. The scale utilized for facilitator intensity ranged from 0 (no help) to 5 (the most help). Similarly, the scale of 0 (never happens) to 5 (consistently happens) was used to indicate frequency. Descriptive statistics were computed for all facilitator items. Items were ranked on the basis of their mean score to determine which ones were perceived to be the most helpful facilitators and which items were perceived to occur most often. In order to determine which facilitators were perceived as both the most helpful and the most frequently occurring, a perceived help score (PHS) was calculated by multiplying each facilitator item’s intensity mean by the item’s frequency mean. The possible range for PHS was 0 to 25.

**Patient-Family-Related Facilitators**

Perceived help scores for patient-family-related facilitator items were ranked from highest to lowest mean score. As shown in Table 8, the PHS ranged from 8.55 to 14.66. The top three items perceived as the most helpful patient-family-related facilitators to providing pediatric end-of-life care were 1) having family members accept that the patient is dying ($M = 14.66, SD = .96$); 2) having family members thank you or in some other way show appreciation for your care of the patient who has died ($M = 12.28, SD = 1.31$); and 3) having one family member be the designed contact person for all other members regarding the patient’s information ($M = 9.99, SD = 1.15$).
Table 8

*Item Means for Patient-Family-Related Facilitators*

<table>
<thead>
<tr>
<th>Patient-Family-Related Facilitators</th>
<th>Intensity*</th>
<th>Frequency**</th>
<th>PHS***</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Having family members accept that patient is dying</td>
<td>3.92 .99</td>
<td>3.74 .97</td>
<td>14.66 .96</td>
</tr>
<tr>
<td>2. Having family members show appreciation for your care of the patient</td>
<td>3.54 1.16</td>
<td>3.47 1.13</td>
<td>12.28 1.31</td>
</tr>
<tr>
<td>3. Having one family member be the designed contact person for all other members</td>
<td>3.31 1.01</td>
<td>3.02 1.14</td>
<td>9.99 1.15</td>
</tr>
<tr>
<td>4. Having family physically help care for patient</td>
<td>3.05 1.40</td>
<td>2.87 1.51</td>
<td>8.75 2.11</td>
</tr>
</tbody>
</table>

*Note.* *Intensity of facilitator response choices were* 0 = no help to 5 = the most help; **Frequency of facilitator response choices were* 0 = never happens to 5 = consistently happens; ***Perceived Help Score (PHS) = mean for intensity multiplied by mean for frequency.

*Healthcare-Professional-Related Facilitators*

As shown in Table 9, perceived help scores for healthcare-professional-related facilitators ranged from 6.60 to 16.30. The top three healthcare professional-related facilitator items perceived as most helpful were 1) having physicians involved in the patient's care agree about the direction care should go ($M = 16.03, SD = 1.09$); 2) providing a peaceful, dignified bedside scene for family members once the patient has died ($M = 14.36, SD = 1.53$); and 3) having the physician put hope in real tangible terms for the family such as "only 1 out of 100 patients in this condition will completely recover" ($M = 13.54, SD = 1.70$).
Table 9  

**Item Means for Healthcare-Professional-Related Facilitators**

<table>
<thead>
<tr>
<th>Healthcare-Professional-Related Facilitators</th>
<th>Intensity* Mean</th>
<th>Intensity* SD</th>
<th>Frequency** Mean</th>
<th>Frequency** SD</th>
<th>PHS*** Mean</th>
<th>PHS*** SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Having involved physicians agree about direction of care</td>
<td>4.11</td>
<td>.99</td>
<td>3.9</td>
<td>1.10</td>
<td>16.03</td>
<td>1.09</td>
</tr>
<tr>
<td>2. Providing a peaceful, dignified bedside scene after patient has died</td>
<td>3.82</td>
<td>1.22</td>
<td>3.76</td>
<td>1.25</td>
<td>14.36</td>
<td>1.53</td>
</tr>
<tr>
<td>3. Having physician put hope in tangible terms for the family</td>
<td>3.69</td>
<td>1.34</td>
<td>3.67</td>
<td>1.27</td>
<td>13.54</td>
<td>1.70</td>
</tr>
<tr>
<td>4. Teaching family how to act around the dying patient</td>
<td>3.58</td>
<td>1.20</td>
<td>3.43</td>
<td>1.35</td>
<td>12.28</td>
<td>1.62</td>
</tr>
<tr>
<td>5. Having enough time to prepare family for the expected death</td>
<td>3.63</td>
<td>.96</td>
<td>3.37</td>
<td>1.03</td>
<td>12.23</td>
<td>.99</td>
</tr>
<tr>
<td>6. Talking with family about their feelings and thoughts about their dying child</td>
<td>3.52</td>
<td>1.12</td>
<td>3.39</td>
<td>1.22</td>
<td>11.93</td>
<td>1.37</td>
</tr>
<tr>
<td>7. Having other nurses in the team cover for you while you get away from the unit for a few moments after the death</td>
<td>3.45</td>
<td>1.46</td>
<td>3.43</td>
<td>1.54</td>
<td>11.83</td>
<td>2.25</td>
</tr>
<tr>
<td>8. Having other nurses in the team tell you that &quot;you did all you could …&quot; or other words of support</td>
<td>3.52</td>
<td>1.35</td>
<td>3.33</td>
<td>1.52</td>
<td>11.72</td>
<td>2.05</td>
</tr>
<tr>
<td>9. Ability to draw on nurse’s own previous experience with critical illness or death of family member</td>
<td>3.15</td>
<td>1.15</td>
<td>3.07</td>
<td>1.33</td>
<td>9.67</td>
<td>1.53</td>
</tr>
<tr>
<td>10. Having the physician meet in person to offer family support after the patient’s death</td>
<td>3.20</td>
<td>1.41</td>
<td>2.90</td>
<td>1.41</td>
<td>9.28</td>
<td>1.99</td>
</tr>
<tr>
<td>11. Having other nurses in the team hug you, pat you on the back or give some other kind of brief physical support after patient death</td>
<td>2.92</td>
<td>1.5</td>
<td>2.72</td>
<td>1.73</td>
<td>7.94</td>
<td>2.60</td>
</tr>
<tr>
<td>12. Having a support person outside of the work setting who listens to you after patient death</td>
<td>2.63</td>
<td>1.47</td>
<td>2.51</td>
<td>1.70</td>
<td>6.60</td>
<td>2.50</td>
</tr>
</tbody>
</table>

*Note.* *Intensity of facilitator response choices were 0 = no help to 5 = the most help;*  
**Frequency of facilitator response choices were 0 = never happens to 5 = consistently happens;*  
***Perceived Help Score (PHS) = mean for intensity multiplied by mean for frequency.*
**Organizational-Related Facilitators**

Perceived help scores for organizational-related facilitator items are ranked from highest mean score (16.89) to lowest mean score (3.44) in Table 10. The top three items perceived as most helpful organizational-related facilitators were 1) allowing family members adequate time to be alone with the patient after he/she has died ($M = 16.89$, $SD = 1.14$); 2) after patient's death, having support staff compile all necessary paperwork which must be signed by family before leaving the unit ($M = 14.74$, $SD = 1.23$); and 3) allowing family unlimited access to patient even if it conflicts with nursing care at the time ($M = 14.40$, $SD = 1.46$).

Table 10

<table>
<thead>
<tr>
<th>Organizational-Related Facilitators</th>
<th>Intensity*</th>
<th>Frequency**</th>
<th>PHS***</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Mean</td>
<td>Mean</td>
</tr>
<tr>
<td>1. Allowing family members adequate time to be alone with patient after he/she has died</td>
<td>4.13</td>
<td>1.09</td>
<td>1.05</td>
</tr>
<tr>
<td>2. After patient's death, having support staff compile all the necessary paperwork</td>
<td>3.91</td>
<td>1.04</td>
<td>1.18</td>
</tr>
<tr>
<td>3. Allowing family unlimited access to dying patient even if it conflicts with nursing care</td>
<td>3.85</td>
<td>1.2</td>
<td>1.22</td>
</tr>
<tr>
<td>4. Letting social worker or religious leader take primary care of grieving family</td>
<td>3.45</td>
<td>1.25</td>
<td>1.48</td>
</tr>
<tr>
<td>5. A unit designed for family to grieve in private</td>
<td>2.56</td>
<td>1.65</td>
<td>1.52</td>
</tr>
<tr>
<td>6. Having a unit schedule that allows for continuity of nursing care for dying patient</td>
<td>2.43</td>
<td>1.43</td>
<td>1.46</td>
</tr>
<tr>
<td>7. Having an ethics committee routinely round</td>
<td>2.19</td>
<td>1.65</td>
<td>1.71</td>
</tr>
<tr>
<td>8. Having un-licensed personnel available to help care for dying patient</td>
<td>1.91</td>
<td>1.73</td>
<td>1.71</td>
</tr>
</tbody>
</table>

*Note. *Intensity of facilitator response choices were 0 = no help to 5 = the most help;  
**Frequency of facilitator response choices were 0 = never happens to 5 = consistently happens;  
***Perceived Help Score (PHS) = mean for intensity multiplied by mean for frequency.*
Research Question 4

Which barrier category has the most influence on quality of dying and death in neonatal and pediatric intensive care settings?

Linear multiple regression analysis was conducted to determine which barrier categories of patient and family, healthcare professionals and organizations most influenced quality of dying and death. Pearson Product Moment correlation analysis demonstrated moderate significant inverse relationships of each category of barriers with quality of dying and death. As barriers in all categories increased, quality of dying and death for infants and children in Thai ICU decreased (Table 11).

Table 11

Bivariate Correlation Matrix for Barriers and Quality of Dying and Death

<table>
<thead>
<tr>
<th>Variables</th>
<th>Quality of Dying and Death</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Correlation coefficient (r)</td>
</tr>
<tr>
<td>Patient-family-related barriers</td>
<td>-.50</td>
</tr>
<tr>
<td>Healthcare-professional-related barriers</td>
<td>-.60</td>
</tr>
<tr>
<td>Organizational-related barriers</td>
<td>-.48</td>
</tr>
</tbody>
</table>

Note. *p < .001

Total quality of dying and death scores (following conversion to a 0-100 scale) were regressed on the three barrier categories (patient-family-related, healthcare-professional-related, and organizational-related). Results shown in Table 12 indicate that the overall model of three barrier categories significantly influenced quality of dying and death. Approximately 34% of adjusted variance in quality of dying and death was explained by patient-family-related barriers, healthcare-professional-related barriers and organizational-related barriers. However, only the category of healthcare-professional-
related barriers significantly contributed to the model ($\beta = -.50, p < .001$), indicating that barriers related to healthcare professionals have the most influence on quality of dying and death for infants and children in Thai ICUs.

Table 12

*Multiple Regression Analysis for Barriers to Providing Pediatric End-of-Life Care on Quality of Dying and Death*

<table>
<thead>
<tr>
<th>Variables</th>
<th>B</th>
<th>SE B</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient-family-related barriers</td>
<td>-.01</td>
<td>.06</td>
<td>-.03</td>
</tr>
<tr>
<td>Healthcare-professional-related barriers</td>
<td>-.33</td>
<td>.08</td>
<td>-.50*</td>
</tr>
<tr>
<td>Organizational-related barriers</td>
<td>-.06</td>
<td>.07</td>
<td>-.10</td>
</tr>
</tbody>
</table>

*Note.* $F (3, 126) =22.58**$; Adjusted $R^2 = .34$; * $p < .05$, ** $p < .001$

Research Question 5

Which facilitator category has the most influence on quality of dying and death in neonatal and pediatric intensive care settings?

Linear multiple regression analysis was also performed to determine which facilitator categories (patient-family-related, healthcare-professional related and organizational-related) most influenced quality of dying and death. Pearson Product Moment correlation demonstrated significant positive moderate correlations of each category of facilitators with quality of dying and death (Table 13). As facilitators in all categories increased, quality of dying and death for infants and children in Thai ICUs increased.
Table 13

**Bivariate Correlation Matrix for Facilitators and Quality of Dying and Death**

<table>
<thead>
<tr>
<th>Variables</th>
<th>Quality of Dying and Death</th>
<th>Correlation coefficient (r)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient-family-related facilitators</td>
<td></td>
<td>.50</td>
<td>.000*</td>
</tr>
<tr>
<td>Healthcare-professional related facilitators</td>
<td></td>
<td>.57</td>
<td>.000*</td>
</tr>
<tr>
<td>Organizational-related facilitators</td>
<td></td>
<td>.54</td>
<td>.000*</td>
</tr>
</tbody>
</table>

*Note.* *p* < .001

Total quality of dying and death scores (following conversion to a 0-100 scale) were regressed on the three facilitator categories (patient-family-related, healthcare-professional-related, and organizational-related). Results shown in Table 14 indicate that the overall model of three facilitator predictors significantly influenced quality of dying and death. Patient-family-related facilitators, healthcare-professional-related facilitators and organizational-related facilitators explained 33% of adjusted variance in quality of dying and death. However, only the category of healthcare-professional-related facilitators significantly contributed to the model (β = .34, *p* < .05), indicating that critical care nurses felt that the facilitators related to healthcare professionals have the most influence on quality of dying and death for infants and children in Thai ICUs.
Table 14

*Multiple Regression Analysis of Facilitators to Providing Pediatric End-of-Life Care on Quality of Dying and Death*

<table>
<thead>
<tr>
<th>Variables</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient-family-related facilitators</td>
<td>.11</td>
<td>.11</td>
<td>.11</td>
</tr>
<tr>
<td>Healthcare-professional-related facilitators</td>
<td>.09</td>
<td>.04</td>
<td>.34*</td>
</tr>
<tr>
<td>Organizational-related facilitators</td>
<td>.09</td>
<td>.07</td>
<td>.18</td>
</tr>
</tbody>
</table>

*Note. F (3, 125) =21.30**; Adjusted $R^2 = .33$; * $p < .05$, ** $p < .001$*

**Content Analysis Results**

Content analysis was used to answer research question 6 “What additional barriers to providing pediatric end-of-life care are identified by Thai critical care nurses?” and research question 7 “What do Thai critical care nurses identify as changes needed (facilitators) to improve end-of-life care in neonatal and pediatric intensive care settings?” The analysis proceeded as follows. First, the researcher typed and assembled the open-ended responses into a Microsoft Word document. Second, the researcher and research assistant performed multiple readings of all responses to gain initial familiarity with the data. Third, the researcher and research assistant independently assigned codes for the text. Codes assigned were based on the three main categories of barriers and facilitators (patient-family-related, healthcare-professional-related and organizational-related) from the study’s conceptual model. Next, subcategories under the three main categories were developed. Finally, subcategories were reviewed and redefined by the researcher and research assistant until 100% agreement was reached on each subcategory. Results are summarized in Tables 15 and 16.
Research Question 6

What additional barriers to providing pediatric end-of-life care are identified by Thai critical care nurses?

Of the 129 critical care nurses who returned completed questionnaires, 35 responded with information eliciting 56 phrases that were analyzed as additional barriers using content analysis. The results revealed both additional barriers or as well as duplicated barriers that had already been stated in the study instruments. As shown in Table 15, approximately 35.71% (4 subcategories) of additional barriers identified were in the category of patient-family-related including lack of family readiness to acknowledge when a patient is worsening, family lack of knowledge regarding end-of-life care, language problems, and uncertain prognosis. Nearly 45% of responses were classified into subcategories related to healthcare professionals. Of these, 23.22% were new subcategories including providing aggressive treatment, staff shortage, and conflict among healthcare professionals related to treatment plans. The remaining subcategories identified were organizational-related barriers. The two new subcategories included lack of standard guidelines, and lack of legal support.

Subcategories of Patient-Family-Related Barriers

Lack of family readiness to acknowledge when a patient is worsening. Four nurses identified lack of family readiness to acknowledge a patient’s condition as an important barrier to providing quality end-of-life care in Thai ICUs. As one nurse said “no family members were present at the hospital when the child’s condition worsened, so nurses could not immediately inform family members. Often, the child died without saying good bye to family members.” Another one stated that “some family members lived far away
from the hospital and also had financial problems. They weren’t able to visit their child very often. Nurses often had trouble informing family members to prepare for the child’s death.” Two others said “no family members were with the child. Physicians often encountered a dilemma regarding end-of-life decisions” and “family members often blamed nurses for not informing them until after the child’s death, so they had no chance to say good bye to their child.”

Family members’ lack of knowledge regarding end-of-life care. Two nurses believed that family members lacked knowledge about end-of-life care, leading to ineffective care at the end-of-life. As one nurse said “family members don’t know how to act when their child is near death. This made them ignore their child’s needs.” Another one said “often family members took care of their child based on the family’s wishes not on their child’s wish.”

Uncertain prognosis. Two nurses indicated uncertainty of the child’s condition impeded optimal end-of-life care. One nurse said “the child’s condition often is uncertain. Sometimes it improves in a short time, and then worsens again. Often the condition quickly worsened until we have not enough time to prepare patients and families at the end-of-life.” Another one said “uncertainty in an infant or a child’s condition makes physicians and nurses reluctant to give information to families.”

Language problems. One nurse perceived that language barriers influenced end-of-life care. The nurse said “our patients and families often are hill-tribe people who speak a different language, leading to communication difficulties and obstacles to end-of-life care. Nurses don’t understand the exact needs of patients and families.”
Subcategories of Healthcare-Professional-Related Barriers

Lack of knowledge and skill to approach dying patient and family. Nearly one-third of the 35 nurses who responded to the open-ended question highlighted Thai healthcare professionals’ lack of knowledge and skill regarding end-of-life care as a prominent barrier to providing end-of-life care in pediatric ICUs. Especially in the area of communication, several nurses stated that physicians are expected to first inform patients and families of bad news. However, most physicians do not possess the skills to do this. As one nurse said “physicians should be the first person to tell patients and families the truth. Often, they avoid this situation and decide to let nurses do it.” Another nurse said “some physicians talk to families with a short sentence that families often can’t understand.” Nurses also pointed out that deficient communication prohibits the ability to meet the needs of patients and families. As one nurse said “some families would like to take their child home to die but the physician already put the child on a ventilator. So, families cannot bring their child home.” Some nurses also mentioned that nurses themselves lack knowledge and skill to take care of dying patients. Another nurse said “nurses, especially new nurses, often are uncomfortable taking care of dying children because they don’t know how to approach them.” Another nurse said “I was not taught much about how to take care of dying patients in nursing school. Mostly, I informally trained from senior nurses in my unit.”

Providing aggressive treatment. Three nurses thought that some physicians could not accept a patient’s death in the ICU because it is considered a treatment failure. Often, physicians still provided full treatments for infants or children whose condition was hopeless. As one nurse said “I noticed that some physicians provided aggressive
treatments even though they knew it was not beneficial to an infant or a child. It seemed
that they hated admitting defeat.” One said “physicians want to increase their experience
in certain kind of treatment, so they sometimes provide aggressive treatment in futile
cases.” Another one said “in some cases, family members accepted that their loved one
was dying but physicians still provided full treatment. Family members unnecessarily
took care of expenses for those medical treatments.”

**Staff shortage.** Three nurses mentioned that staff shortage was an important
barrier to providing quality pediatric end-of-life care in ICUs. All of them expressed
frustration in their practice settings related to staff shortages. One nurse said “patients in
ICU are seriously ill and the nurse-patient ratio is not appropriate. So we have a busy
workload and have no time to provide special care for patients at the end-of-life.” The
other two stated “I would like to have more time to support dying children and their
families. However I cannot do that because of staff shortages” and “currently we don’t
have enough ICU staff to fully provide end-of-life care in the ICU.”

**Conflict among healthcare professionals related to treatment plans.** Two nurses
believed that conflict among healthcare professionals is another barrier to providing end-
of-life care in the ICU. As one nurse said “in the ICU, most patients were cared for by
several different specialties of physicians. Often, they have disagreement among them
regarding the treatment plan.” Another one said “I noticed that arguments among the
healthcare team often arise from physicians who have a big ego. They don’t really listen
to each other. As a result, patients and families don’t receive good care at the end-of-
life.”
Subcategories of Organizational-Related Barriers

*Lack of privacy.* Four nurses perceived lack of a private room as the greatest obstacle to providing end-of-life care in ICUs. They mentioned that ICUs lacked private rooms because the unit has a limited space and must accommodate high technology life-saving equipment. As one nurse said “there is no space in the ICU to care for dying children at all. I tried to look around the unit but I didn’t see any space that wasn’t used by life-saving equipment.” One nurse said “I cannot imagine how to provide end-of-life care in this limited space.” Two others said “I provided counseling to a family in front of the break room of the ICU, but it didn’t work well due to lack of privacy” and “although patients want to die peacefully, there is no quiet space for them.”

*Lack of standard guidelines.* Two nurses complained that lack of end-of-life care guidelines impedes optimal end-of-life care. They believed that standard guidelines are like a compass to guide the direction of care. As one nurse said “because we lack clear standard guidelines for end-of-life care, we don’t know when and how to provide effective care for dying children and families.” Another nurse provided an example that reflected the lack of standard guidelines: “physicians do not know when they should transfer patients from cure to care and when they should stop aggressive treatment.”

*Lack of legal support.* Two nurses expressed concerned about the law and lack of information about how its precise details influence clinical practice in providing end-of-life care in the ICU. The nurses reported that physicians often struggled to define their legal and ethical obligations to patients. As one nurse said “because of unclear laws regarding end-of-life care, healthcare teams are reluctant to make a decision in some situations. For example, physicians don’t dare perform extubations to let patients die at
home.” Another said “some physicians feared a lawsuit that made them reluctant to stop aggressive treatment even in futile cases.”

Table 15

**Summary of Additional Barriers to Providing End-of-Life Care (n=56 responses)**

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Subcategories</th>
<th>Responses (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient-family-related</strong></td>
<td>Lack of family readiness to acknowledge when a patient worsens*</td>
<td>7 (12.50%)</td>
</tr>
<tr>
<td>barriers</td>
<td>Family’s lack of knowledge regarding end-of-life care*</td>
<td>7 (12.50%)</td>
</tr>
<tr>
<td></td>
<td>Language problem*</td>
<td>4 (7.14%)</td>
</tr>
<tr>
<td></td>
<td>Uncertain prognosis*</td>
<td>2 (3.57%)</td>
</tr>
<tr>
<td><strong>Healthcare-professional-</strong></td>
<td>Lack of knowledge and skill to approach dying patient and family</td>
<td>12 (21.43%)</td>
</tr>
<tr>
<td>related barriers</td>
<td>Staff shortage*</td>
<td>7 (12.50%)</td>
</tr>
<tr>
<td></td>
<td>Providing aggressive treatment *</td>
<td>3 (5.36%)</td>
</tr>
<tr>
<td></td>
<td>Conflict among healthcare professionals related to treatment plan*</td>
<td>3 (5.36%)</td>
</tr>
<tr>
<td><strong>Organizational-related</strong></td>
<td>Lack of privacy</td>
<td>6 (10.71%)</td>
</tr>
<tr>
<td>barriers</td>
<td>Lack of standard guidelines*</td>
<td>3 (5.36%)</td>
</tr>
<tr>
<td></td>
<td>Lack of legal support*</td>
<td>2 (3.57%)</td>
</tr>
</tbody>
</table>

*Note. * = New barrier subcategory

**Research Question 7**

What do Thai critical care nurses identify as changes needed (facilitators) to improve end-of-life care in the neonatal and pediatric intensive care settings?

Of the 129 critical care nurses in the study sample, 33 nurses provided 73 suggestions related to what they would change to improve end-of-life care in neonatal and pediatric intensive care settings in Thailand. The results revealed both additional suggestions and suggestions that duplicated some included in the study instruments. As shown in Table 16, the need for cooperation from family members was the only new
subcategory identified under patient-family-related factors. Most suggestions (54.78%) were healthcare-professional-related factors. Three subcategories were new including need for more staff to care for dying patients and families, need to stop aggressive treatment, and need for cooperation among the team. The second most commonly made suggestions (42.48%) were subcategories of organizational-related factors. Only one of these subcategories was new; the need for end-of-life care guidelines.

Subcategories of Patient-Family-Related Factors

Need for cooperation from family members. Only one nurse suggested that participation of family members would help improve end-of-life care in ICU. She said that “we often don’t get cooperation from family members to participate in caring for the patient in the ICU. If they could join us, it would be better.”

Subcategories of Healthcare-Professional-Related Factors

Need for end-of-life education. Nine nurses suggested the need for education regarding end-of-life care. Three of them proposed that physicians, including medical students, need to be taught how to communicate and discuss end-of-life issues with patients and families. Two of them stated that physicians and medical students should know their roles and how to clearly explain medical conditions and treatment plans to patients and families. One nurse said “physicians are the persons who are fully responsible to continually update dying children and their families. Therefore, medical school should teach them to know their role and their responsibility.” Another one said “medical school should teach students about holistic palliative care.” Two other nurses proposed that physicians also should be taught more about controlling pain and symptom
management. One nurse commented “physicians should alleviate pain for patients even near the time of death.”

Two nurses also wanted education for themselves with regard to concepts of palliative care, techniques to discuss issues of death with patients and families, and skill to holistically provide for peaceful death at the end-of-life. One nurse said “nurses should know how to alleviate pain in dying infants and children.” Another nurse said “nurses should know how to talk with parents that their children are dying and how to approach dying children.”

Need for more staff. Five nurses suggested the need for more ICU staff to care for dying patients and families. Three of them stated “providing a nurse-patient ratio of 1:1 for both day and night shift would help nurses spend time with the patients and families.” Another said “if we have enough staff, we can assign the same nurse to take care of one patient through the course of illness.” Two of them blamed lack of time for nursing care of the dying on the nurse shortage. As one nurse said “administrators of the hospital should limit the number of patients to fit with the number of staff in cases when they cannot provide more staff.” Another one said “now the number of ICU patients is more than the number of nurses can handle. Nurses have no time to provide good care.”

Need to stop aggressive treatment. Three nurses suggested that physicians should stop providing aggressive treatments in futile cases to improve care at the end-of-life. As one nurse said “physicians should stop aggressive treatment in futile cases to reduce patient suffering.” One said “physicians should stop treatment for dying infants and children and move them to the general ward to provide care at the end-of-life.” Others said “painful treatment should be stopped when there is no way to improve the patient’s
condition,” “physicians should reserve ventilator use for patients who will benefit from them,” and “physicians should change their attitudes regarding aggressive treatments.”

Need for cooperation among the team. Two nurses believed that having a formal team meeting would facilitate communication among the healthcare team and families, thus improving patient care. As one nurse said “we need multidisciplinary teams to provide consultation for patients and families.” Another nurse said “I would like to have healthcare professionals work as a team and continuously evaluate an infant’s or child’s condition,” and “the healthcare team should meet with family members and give them regular updates regarding an infant’s or child’s condition and treatment plan.”

Subcategories of Organization-Related Factors

Need for environmental changes. Nurses noted the need for more space and private rooms to provide end-of-life care appropriately. They commented that the ICU environment is crowded with people (patients, families and healthcare providers) and equipment for saving lives. To provide effective end-of-life care, private rooms for patients and families are necessary. Suggestions regarding the need for private rooms were best exemplified by five nurses who said “I would like the ICU to have private rooms to encourage family members to stay with patients,” “ICUs should have quiet places for families to perform their spiritual rituals,” “ICUs should have a place for counseling families,” and “the ICU is so congested. It is not appropriate to provide end-of-life care. It would be nice to have a comfortable and quiet room for those who are dying.”

Need to change visiting hour policy. Five nurses reported that dying children often feel isolated and alone and felt that restricted visiting hours contributed to this
situation. Nurses suggested that unrestricted visiting in the ICU would encourage family members to stay with infants and children longer, thus improving end-of-life care. One nurse said “unrestricted visiting would provide the family a chance to spend more time with a dying infant or child.” Another nurse said “unrestricted visiting would allow families to participate in caring for dying infants and children.” Three other nurses stated “At the end of life, visiting hours in ICU should be flexible to let family members be with patients all the time.”

**Need for end-of-life care guidelines.** Three nurses suggested that having a standard guideline would help guide healthcare professionals to move in the same direction. One nurse said that “I would like administrators to develop standard guidelines for care of dying infants and children.” Two nurses concluded “I need end-of-life care guidelines in order that every healthcare provider is on the same page.”
Table 16

*Summary of Additional Facilitators and Change Needed to Improve End-of-Life Care in (n=73 responses)*

<table>
<thead>
<tr>
<th>Facilitators</th>
<th>Subcategories</th>
<th>Responses (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient-family-related factors</td>
<td>Need for cooperation from family members*</td>
<td>2 (2.74%)</td>
</tr>
<tr>
<td>Healthcare-professional-related</td>
<td>Need for education of healthcare professionals regarding end-of-life care</td>
<td>25 (34.25%)</td>
</tr>
<tr>
<td>factors</td>
<td>Need for more staff to care for dying patients and families*</td>
<td>9 (12.33%)</td>
</tr>
<tr>
<td></td>
<td>Need to stop aggressive treatment for hopeless dying patients*</td>
<td>3 (4.10%)</td>
</tr>
<tr>
<td></td>
<td>Need for cooperation among the healthcare team*</td>
<td>3 (4.10%)</td>
</tr>
<tr>
<td>Organizational-related factors</td>
<td>Need for environment changes</td>
<td>16 (21.92%)</td>
</tr>
<tr>
<td></td>
<td>Need for changing visiting hour policy</td>
<td>9 (12.33%)</td>
</tr>
<tr>
<td></td>
<td>Need for end-of-life care guidelines*</td>
<td>6 (8.23%)</td>
</tr>
</tbody>
</table>

*Note.* * = New facilitator subcategory

*Summary*

In summary, critical care nurses in the current study perceived a moderate quality of dying and death for infants and children in Thai ICUs. Statistical analysis supported that the greatest perceived barriers significantly contributing to quality end-of-life care were related to healthcare professionals, particularly difference in opinion among multiple physicians about the direction of care, insufficient time to provide end-of-life care, and lack of end-of-life care education and training.

Statistical analysis also supported that the greatest perceived facilitators that significantly contributed to quality end-of-life care were related to healthcare professionals, namely having physicians involved in the patient's care agree about the direction of care, providing a peaceful and dignified bedside scene for family members...
once the patient has died, and having the physician put hope in real tangible terms for the family.

The findings from the open-ended written comments revealed either duplicate or additional information. Regarding duplicate information, more than one third of response phrases of Thai critical care nurses were opinions that repeated what appeared in questionnaire items. Particularity, end-of-life care education for healthcare professionals was the most prominent category in terms of both barriers and facilitators. With regard to the additional information, Thai critical care nurses provided seven new subcategories of barriers. The new subcategories included lack of family readiness to acknowledge when an infant or a child is worsening, family lack of knowledge regarding end-of-life care, language barriers, uncertain prognosis, staff shortage, conflict among healthcare teams, lack of standard guidelines, and lack of legal support. The critical care nurses also suggested additional facilitators beyond items found in the questionnaires. They reported that cooperation of family members, collaboration among the healthcare professional team members and development of standard guidelines have the potential to improve end-of-life care for dying infants and children in Thai ICUs.
CHAPTER V

Discussion

A cross-sectional descriptive correlational design was used to describe and explore relationships among quality of dying and death, barriers and facilitators to providing pediatric end-of-life care in intensive care units in Thailand. The study also determined barriers and facilitators that have the most influence on the quality of dying and death. In this chapter, the major research findings from the study are organized, interpreted and discussed according to the research questions proposed in the study. In addition, limitations of the study, implications for Thai healthcare policy, nursing and hospital administrators, and nursing practice, and recommendations for future research are presented.

Discussion of Major Research Findings

Perceived Quality of Dying and Death

The first research question sought to describe the quality of dying and death of infants and children in Thai ICUs as perceived by critical care nurses. The quality of dying and death is the level of Thai critical nurses’ perceptions of the experiences of infants and children and the medical care they received at the end-of-life and at the moment of death, including the overall quality of care received in the ICU.

The findings revealed that critical care nurses in the study sample perceived a moderate level of overall quality of dying and death for infants and children in Thai ICUs. In a closer examination of individual items, level of quality of dying and death varied among response choices. The majority of respondents rated most items as good or very good. The two lowest rated items rated between fair and good included having one
or more visits from a religious or spiritual advisor, and having a spiritual service or
ceremony before death. Overall, the majority of respondents did not rate any one item at
the extreme ends of the rating scale (i.e. as poor or excellent).

It should be noted that the provision of palliative and end-of-life care has been
listed as a quality indicator by the National Hospital Accreditation System in Thailand
since 2000 (Institute of Hospital Quality Improvement and Accreditation, 2000; Matchim
& Aud, 2009). This requires a call to action for professionals in healthcare settings and
administrators to ensure the provision of palliative care. To achieve National Hospital
Accreditation requirements, the recruitment hospitals, as the highest ranked hospitals
both in Thailand and in the continent of Asia, have attempted to implement palliative and
end-of-life care programs into their practices although the government has not yet been
implemented a national palliative care policy (Nilmanat, 2006). The results of the current
study support room for improvement in the quality of care for dying infants and children
in these hospitals. However, they also suggest that other hospitals in Thailand may have
even more room for improvement to achieve high quality end-of-life care.

A particularly notable finding was that the top two highest rated items in the
quality of dying and death for Thai infants and children were areas dealing with situations
that fall under the purview of nursing practice. These items include being treated with
dignity and self-respect, and care received from nurses in the last several days while in
the ICU. Critical care nurses in the current study might have felt that in their daily work,
they provided the best possible nursing care with dignity and respect for dying infants
and children and their families. This finding is in line with prior studies in which nurses
place importance on dying with dignity and maintaining personal comfort and control for
patients as the end-of-life approaches (Coenen, Doorenbos, & Wilson, 2007; Doorenbos, Wilson, Coenen, & Borse, 2006; Rankin et al., 1998). Interdisciplinary teams may be necessary for providing dignified and respectful care for dying patients (Gallagher, Li, Wainwright, Jones, & Lee, 2008). Nurses, however, could take on this role independently through the manner in which they carry out their work in the ICU. Among healthcare professionals, nurses spend much time with and have the most intimate connection to patients and families. In every single nursing activity that nurses provide for patients and families, dignity and respectful care could always be integrated. According to the American Nurses Association (2001), respect for persons is a fundamental component of the first provision in the Code for Nurses which states that nurses are to provide services with respect for human dignity and the uniqueness of every individual. Dignity and respect for dying infants and children and their families could be promoted in several ways including maintaining personal comfort, giving honest information, prioritizing nursing activities, and providing a peaceful and quiet environment that is less disturbing to dying infants and children (Reidun, Birgitta, & Elsy, 2007).

Following the top two highest rated items, the next five items rated as medium to quite high included quality of medical care received at the end of life, care received from doctors in last several days in ICU, experiences at moment of death, being touched or hugged by loved ones, and spending time with family or friends. Among these items, it appears that nurses’ role is one that bridges interactions between patients, families, and physicians. This suggests that the quality of these interventions depend on not only individual nurses but also on the cooperation of physicians, patients and families. Interestingly, the overall ratings for quality of medical care, for care received from
doctors, and for experiences at the moment of death were in top five although the majority of dying infants and children referenced by nurses in the sample received invasive procedures such as ventilator support or dialysis at the end of their lives. Prior studies have found that more invasive treatments were associated with poorer quality of dying and death (Curtis et al., 2002; Hodde et al., 2004). However, this observation was not supported by the findings of this study. This contrast may reflect the consideration that nurses in the sample paid to the quality of other sub items rather than items related to invasive procedures. While nurses could not control aggressive treatment situations, they may have been satisfied that the dying infants and children whom they cared for were adequately sedated, not kept alive too long, and did not die alone.

Nurses in the study reported that more than half of parents discussed their wishes for their child with physicians, communicated with their child and were present with their child at the moment of death. These factors are all components of a good death. Previous studies support that the presence of family members at the time of death is strongly associated a high quality of dying and death score (Curtis et al., 2002; Hodde et al., 2004; Steinhauser et al., 2000).

Another interesting observation was that items referring to being touched or hugged by loved ones and spending time with family did not receive high mean scores but instead were only scored as very good. This may reflect that nurses in the current study recognized that the family members were the most important persons and tried to provide the opportunity for family members to be with their dying infants or children within the space constraints of the ICU. Consistent with the one prior study of nurses’ experiences of providing peaceful death in Thai ICUs, the nurses understood that the
family members were the most significant person to the dying patients because they know the dying person’s needs and wishes (Kongsuwan & Locsin, 2009). Findings of the current study support that increased access of family members to patients at the time of death is an important aspect of improving end-of-life care, but one that could be promoted more for infants and children in Thai ICUs.

The nurses in the sample perceived that the quality of pain control and promoting comfortable respirations were quite low for dying infants and children in Thai ICUs. This suggests that nurses in the sample felt that the pain and suffering experienced by dying infants and children in Thai ICUs may not be managed well enough to make patients comfortable at the end-of-life. Although nurses play a pivotal role in identifying and treating symptoms of dying infants and children (McCaffrey & Ferrell, 1997), they often cannot control this situation singlehandedly. As in past studies (Ferrell, Ferrell, Rhiner, & Grant, 1991; Gregoire & Frager, 2006; Pargeon & Hailey, 1999; Rieman & Gordon, 2007), management of these symptoms in Thai ICUs is likely affected by multiple factors including patient and family, healthcare providers, the care environment and hospital and national policy. Some Thai families may believe the use of opioids encourages addiction and may be reluctant to use opioids for analgesia (Forgeron et al., 2009). Thais who are devout Buddhists may refuse analgesics and sedatives as their child approaches death. They believe that before death, a person should have mindfulness and mental clarity and medications may make a person die with a clouded mind (Keown, 2005). Thai physicians are often reluctant to prescribe opioids, classified as a controlled medicine in Thailand, to patients in severe pain due to legal restrictions of opioid prescribing and its availability
(Chaudakshetrin, 1993; Spencer, 2003). Additionally, physician misconceptions and attitudes toward opioid use may also impede effective symptom management.

Being visited by a religious or spiritual advisor and having a spiritual service before death were the lowest rated items related to the quality of dying and death for infants and children in Thai ICUs. This suggests that spiritual advisor visits and spiritual care services were infrequent when infants and children died in Thai ICUs. Unlike most Western countries where chaplains work as team members in interdisciplinary teams and take an important role to address spirituality in healthcare systems (Puchalski, Lunsford, Harris, & Miller, 2006), the healthcare system in Thailand provides no special services to ensure patient access to spiritual care. Buddhist monks are key spiritual leaders for the majority of Thai people (Lundberg & Trichorb, 2001). When death is near, Buddhist monks play an important role by performing a religious ceremony at the bedside with the goal of assisting the dying person to be of peaceful mind, which is believed to lead to a good death (Keown, 2005; Kongsuwan & Locsin, 2009). Yet, the findings of this study imply that this important spiritual care is often absent for dying infants and children in Thai ICUs. One possible explanation is Buddhist monks are not a part of the Thai healthcare team. Unlike the hospital chaplains based in many Western healthcare institutions, there is no schedule for monks to visit patients regularly during a hospital stay. Monks are only present at the special request of the patient or family and may not necessarily be readily available when the timing of death is difficult to predict (Kongsuwan & Locsin, 2009). Another explanation is that some religious practices such as candle burning and monk praying could be unsafe in the presence of medical oxygen delivery and might disturb other patients; thus they may be not allowed to perform
spiritual rituals in ICUs (Kongsuwan & Locsin, 2009). A prior study found an association between spiritual and religious experiences and the quality of dying; the investigators of that study suggest that if hospital administrators support access to or at least do not create barriers to these services, the quality of dying may improve (Curtis et al., 2002). Promoting ways for dying patients to receive spiritual support offer the greatest potential for improving quality of dying and death in Thai pediatric ICUs.

Perceived Barriers

The second and the sixth research questions focused on barriers to providing pediatric end-of-life care. The perceived barriers are the specific issues that hinder the launching of end-of-life care for dying infants and children. Barriers were grouped into three main categories including patient-family-related, healthcare-professional-related and organizational-related barriers. Additional barriers identified from the open-ended question regarding optimal pediatric end-of-life care within each category are also discussed.

Patient-family-related barriers. According to the Thai critical care nurses, three primary patient-family related barriers thought to create the greatest barriers were dealing with distraught family members while providing end-of-life care, family members not accepting what the physician is telling them about the infant/child’s poor prognosis, and inability of patients to communicate due to depressed neurological status or pharmacologic sedation.

Distraught family. Dealing with a distraught family was rated as the largest patient-family-related barrier to delivering optimal pediatric end-of-life care in ICUs. This finding was similar to the results of prior studies that found the issue of dealing with
anxious family members ranked in the top ten barriers by critical care nurses (Beckstrand, Moore, Callister, & Bond, 2009; Beckstrand, Rawle, Callister, & Mandleco, 2009; Beckstrand et al., 2008; Gross, 2006). The time surrounding the death of an infant or child is extremely tense and stressful for parents and family members. Studies on parents with a critically ill child show that parents often experience increasing stress from seeing the child suffer and from fearing the death of the child, particularly because they are unable to protect their child (Balluffi et al., 2004; Miles, Funk, & Kasper, 1991). These stressors cause a sense of profound helplessness for parents and they need compassionate support from caregivers; nurses are well-positioned to provide such support (Kirchhoff & Faas, 2007; Meyer, Snelling, & Myren-Manbeck, 1998). However, it is challenging to deal with distraught families because they do not always have similar styles of experiencing or expressing their grief. Most nurses who work in acute care areas often feel helpless when dealing with distraught families. Nurses must make time to listen when family members need to express their feelings, to provide words of comfort and talk openly and honestly about grief (Engler et al., 2004). A study of neonatal nurses’ perceptions regarding care of families of critically ill infants found that nurses spend much time sitting and listening to parents’ expressions of grief and providing them support (Engler et al., 2004). However, such situations remove the nurse from the bedside of the critically ill or dying infant or child.

*Family’s lack of acceptance of infant’s/child’s poor prognosis.* Family members who do not accept what the physician is telling them about their infant’s or child’s poor prognosis was ranked the second most intense patient-family-related barrier. This finding was consistent with previous studies documenting the non-acceptance of a patient’s poor
prognosis as an important barrier to providing optimal end-of-life care (Gross, 2006; Heaston, Beckstrand, Bond, & Palmer, 2006). Three possible reasons can be attributed to this finding. First, the success of medicine and advanced technology in ICUs that improve survival rates among children with serious illness may have had the unintended consequence of offering false hope to parents (Himelstein et al., 2004). Another explanation is that physicians are often overly optimistic regarding the prognosis of infants and children or may avoid conversations regarding a poor prognosis with the family. In the words of one nurse in the study, “physicians often keep away from telling the truth to families and leave the nurses to clarify it.” Similar to findings of Kirchhoff and colleagues (2000), nurses perceived that physicians are much more optimistic than the nurses and often give the family false hope. The third reason relates directly to the uncertain prognosis of infants and children. This issue was cited by Thai critical care nurses in their written comments. Uncertainty of prognosis may be an important barrier to providing optimal end-of-life care because it makes healthcare providers reluctant to give information to the family (Davies et al., 2008). As a result, parents continue their false hope that the impending death of their child can always be reversed and they prefer curative treatments over acceptance of their child’s poor prognosis (Carter et al., 2006; Nelson, 2006).

*Inability of patients to communicate.* Inability of patients to communicate was ranked as the third largest barrier related to patients and families. This could be explained by the fact that the majority of dying patients whom nurses cared for in this study were infants. Over half of dying children referenced by nurses in this study received mechanical ventilation and were unconscious or comatose. Nurses might feel frustrated
when considering redirection of treatment efforts toward end-of-life care. Nurses rely heavily on family members to speak for infants and children when making decisions about treatment. However, nurses in this study noted additional barriers are present that may impact communication quality between nurse and family, such as lack of family readiness to acknowledge when the patients’ condition worsens, family lack of knowledge about end-of-life care, and language barriers. Nurses stated that some families were difficult to contact quickly to relay updated information regarding their child’s condition because they lived far away from the hospital. As a result, the infants and children often died without family members surrounding them. Some families do not know how to approach and support their child when death is imminent. Goold and colleagues (2000), agree that lack of knowledge and readiness of family members are barriers impeding discussion and the decision-making processes in end-of-life care.

Thai critical care nurses also voiced concern about language barriers that may impede quality end-of-life care, a similar finding to previous studies (Beckstrand et al., 2009; Davies et al., 2008). One of the hospitals used in this study is located in northern Thailand where 18.75% of hill tribe people live. Hill tribe Thais have their own customs and language (Chiang Mai Provincial Office, 2009). Thus, some nurses may struggle to communicate with these minority groups. With the language barrier, family members may be unintentionally excluded from discussions among the healthcare team, limiting the information they have available to make decisions regarding end-of-life care (Anselm et al., 2005; James & Dean, 2009).

Healthcare-professional-related barriers. The top three healthcare-professional-related barrier items identified by Thai critical care nurses were disagreement among
multiple physicians, insufficient time for the nurse to provide quality end-of-life care, and lack of nursing education and training regarding end-of-life care.

Disagreement among involved multiple physicians. Multiple physicians involved in the care of one patient who differ in opinion about the direction of care were rated as the largest barrier related to healthcare professionals. This finding is similar to a prior study in which critical care nurses perceived differences in opinion among physicians as one of the top three obstacles to providing end-of-life care (Beckstrand & Kirchhoff, 2005). Written comments from nurses in the current study noted that the conflict often occurred among physicians, and cooperation was needed to improve pediatric end-of-life care. Infants and children whom the critical care nurses mostly cared for confronted complex diseases that need involvement of several different specialties of physicians. Among these separate groups of specialties, there are frequent differences in opinion regarding the plan for a patient’s treatment. These separate specialists often fail to communicate or collaborate effectively with each other, further fragmenting care (Curtis & Shannon, 2006; Nelson, 2006). As in Western health care systems, Thai physicians also deliver care on parallel tracks that rarely intersect and lack collaborative communication. Communication among physicians is mainly provided through physician’s progress notes (Kongsuwan & Locsin, 2009). Consequently, ICU nurses confront the consequences of fragmented care-giving, including communication of inconsistent or conflicting information to patients and families, failure to achieve clarity about care goals, and a high level of stress for families and for healthcare providers themselves. According to Beckstrand and Kirchhoff (2005), critical care nurses perceive
multiple physicians as a barrier to providing optimal end-of-life care because they try to act as a mediator to resolve these conflicts.

**Staff shortage and time constraints.** The second largest healthcare-professional-related barrier identified by Thai critical care nurses was the lack of time nurses have to provide end-of-life care when they are consumed with other activities to save the patient’s life. The nurses also reported staff shortage as an additional barrier relating to time constraints. This finding is in line with previous studies that inadequate staffing levels and lack of time were the most frequent barrier to providing optimal end-of-life care (Beckstrand et al., 2008; Davies et al., 2008; Gross, 2006; Houlahan et al., 2006; Hughes et al., 2005; Kirchhoff & Beckstrand, 2000). Time constraints and staff shortages are barriers that simultaneously are both cause and effect. The quality of pediatric end-of-life care may be unsatisfactory when the workload is too heavy or there are too few nurses (Silen, Tang, Wadensten, & Ahlstrom, 2008). Several times the Thai critical care nurses in the current study wrote that because of the shortage of nurses, their workload prevented them from having enough time to take care of dying infants and children. The majority of Thai critical care nurses in the current study worked at pediatric and neonatal intensive care units where infants and children are seriously ill, are treated with multiple-technological supports, and require a nurse at the bedside continuously. With the higher level of patient monitoring, a nurse to patient ratio of at least 1:1 is required (Thailand Nursing Council, 1997). In practice, because of staff shortages, critical care nurses are often assigned to take care of two patients during day shift and perhaps two or three patients during night shift. It is notable that the two study hospitals had quite different staffing levels for relatively similar numbers of patient beds. The end result is insufficient
nursing staff in proportion to the patient care needs and a heavy workload that hinders optimal pediatric end-of-life care in the ICUs. A previous study noted that critical care nurses are often confused whether to spend time with a dying infant and child and family or focus on their other patients who are fighting to maintain life (Silen et al., 2008).

*Lack of end-of-life education and training.* The third largest barrier item related to healthcare professionals was lack of nursing education and training regarding end-of-life care. Interestingly, in prior studies, nurses cited lack of end-of-life care education as a moderate to small barrier to providing optimal end-of-life care (Beckstrand et al., 2009; Beckstrand et al., 2009; Beckstrand et al., 2008; Gross, 2006; Kirchhoff & Beckstrand, 2000). Perhaps nurses in these prior studies were either not aware of the benefit of having end-of-life care education as an ongoing part of their ICU competencies or they thought that they had enough knowledge or experience to take care of dying patients.

In the current study, Thai critical care nurses cited end-of-life care education as an important tool to deliver optimal pediatric end-of-life care in ICUs. They repeatedly mentioned this barrier in written comments even though the barrier item was contained on the questionnaire. The nurses also wrote in the need for end-of-life education as one suggestion to improve care. These comments referenced not only nursing education but also medical education. The majority of nurses in the current study held bachelors degree and less than half held Pediatric/ Neonatal Critical Care Nurse certifications. Little end-of-life care content is taught in the undergraduate curriculum in Thailand and end-of-life content, if included, was often integrated into other subjects and not taught separately (Phungrassami, 2006). Textbooks used in nursing courses in Thailand rely heavily on Western texts that are noted to underemphasize death and dying topics (Ferrell et al.,
No specific end-of-life care training is available for Thai critical care nurses. Informally, they develop their knowledge and skills for taking care of dying infants and children while on the job (Nilmanat, 2006). Thai healthcare providers do not receive specific training in their education to prepare them caring for dying infants and children. This lack of knowledge influences care at the end of life. As nurses in the current study mentioned, nurses and physicians are uncomfortable providing end-of-life care for a dying infant and child. Several studies concluded that nurses’ lack of knowledge is associated with fear, distress and reluctance to provide end-of-life care (Kim & Lee, 2003; McClement & Degner, 1995). Many nurses identify personal discomfort dealing with dying patients as a major barrier to quality end of life care (Ferrell et al., 2000). End-of-life care without knowledgeable skilled physicians and nurses is unable to guarantee the best quality of care for a dying infant or child.

Organizational-related barriers. The top three organizational-related barrier items identified by Thai critical care nurses were poor design of units that do not allow for privacy of dying infants and children or grieving family members, unit visiting hours that are too restrictive, and no available support person for the family such as a social worker or religious leader.

Poor unit design. The biggest barrier related to organizations was poor design of intensive care units that do not allow for privacy when providing end-of-life care. Several concerns regarding space constraints and ICU environment were expressed on written comments. Thai critical care nurses believed that the ICU physical space was not a private and quiet environment for a dying infant or child and their families. As a nurse in
the current study complained “there is no space in the ICU to care for dying children at all. I tried to look around the unit but I didn’t see any space that wasn’t used by life-saving equipment.” Similar findings related to poor unit design were found in several studies of critical care nurses’ perceptions of obstacles and supportive behaviors in end-of-life care (Beckstrand et al., 2006; Beckstrand & Kirchhoff, 2005; Beckstrand et al., 2009; Kirchhoff & Beckstrand, 2000). Nurses in these studies mentioned that the ICU was “no place to die” and “not quiet” for dying patients (Beckstrand et al., 2006). Most ICUs are multi-bed rooms designed for saving lives and surround patients with technology and alarming sounds (Jastremski, 2000). The ICU bedside is often crowded with healthcare team members who are caring for the critically ill patient (Jastremski, 2000). Such environments restrict the number of family members who can sit with a dying infant or child at the bedside and limit their opportunity to give full expression to their loved one in a peaceful environment (Fridh, Forsberg, & Bergbom, 2009). In Thai culture, family structure is extended and all family members need to be present at the bedside of a dying infant or child before the time of death (Kongsuwan & Touhy, 2009). A serene place is also a significant concept in approaching death in Thai Buddhism, especially in the last hours of life. It is believed that a peaceful mind leads to a good death and a better rebirth (Kongsuwan & Touhy, 2009). Consequently, the ICU environments become a place entirely against promoting a peaceful death in Thai society.

Restriction of visiting hours. Thai critical care nurses ranked restrictive visiting hours as the second largest organizational-related barrier. This barrier was also referenced as a suggestion to change visiting hour policies in the written comments. Nurses in the sample believed that unrestricted visiting hours in ICUs encourage families to spend
more time with a dying infant or child and promote optimal end-of-life care. This finding is in contrast to previous studies that reported restriction of visiting hours as the lowest ranked barrier (Beckstrand et al., 2009; Beckstrand et al., 2008; Gross, 2006). A possible explanation is that the previous studies were not conducted in ICUs. One was conducted in emergency units and another one was conducted in oncology units where visiting hours might be more flexible than found in ICUs. Although one other study was conducted in critical care units of a community hospital, the critical care nurses still ranked restrictive visiting hours as the lowest barrier to providing optimal end-of-life care (Gross, 2006). Perhaps the ICU visiting hours in this community hospital were more liberal than those in today’s Thai ICUs.

In Thai ICUs, visiting hours are too restrictive due to overriding hospital policy. For example, one of the studied hospitals allows visiting hours for 1 hour intervals at 11 am and 3 pm and limits visitors to only two persons at one time. Some critical care nurses are more rigid than others when enforcing this policy. The restrictive visiting hours result in several disadvantages for end-of-life care. Restrictive visiting hours isolate families from a dying infant and child at a time when families need to be close to their loved ones (Beckstrand & Kirchhoff, 2005). This greatly affects the dying process in Thai culture in terms of contentment. Buddhist family members and other significant persons want to visit and be with the dying person to provide happiness and a peaceful mind (Kongsuwan & Touhy, 2009). Some families may also invite Buddhist monks to come to the bedside to pray for dying patients (Kongsuwan & Touhy, 2009). Therefore, they need more time to spend with their loved one. Another disadvantage of restrictive visiting hours is that family members are not usually included in daily interdisciplinary rounds (Maxwell,
Stuenkel, & Saylor, 2007). Consequently, nurses or other healthcare professionals have limited time to share critical information with family members (Maxwell et al., 2007). Information is often shared by phone with only a designated family contact person. In conclusion, limited visiting hours in ICUs lead to unmet needs of dying infants and children and their families (Roland et al., 2001).

*Lack of support personnel for family.* No available support person for the family such as a social worker or religious leader was ranked as the third largest organizational-related barrier. Thai critical care nurses felt that lack of support personnel for the family was an important barrier hindering optimal pediatric end-of-life care whereas this finding received less attention in previous studies (Beckstrand et al., 2009; Beckstrand et al., 2009; Beckstrand et al., 2008; Gross, 2006). This can be explained in that previous studies were conducted in Western countries where interdisciplinary teams for end-of-life care are available. An interdisciplinary team, which consists of at least a nurse, physician, social worker and a religious leader, is a cornerstone to enhance the quality of end-of-life care (Sourkes et al., 2005). However, the interdisciplinary team concept does not function well in Thailand (Nilmanat, 2006). This situation plus staff shortages certainly increases the workload for Thai critical care nurses. They have to simultaneously deal with patients whose lives are being maintained and those whose lives are ending. The critical care nurses may feel it is too much to bear these situations alone. Therefore, they need support and assistance from others such as social workers or religious leaders in moving through the end-of-life care process with their patients.

*Additional barriers.* Two other organizational-related barriers emerged from written comments including lack of standard guidelines and lack of legal support.
Although not mentioned frequently, these comments still provide insight into Thai critical care nurses’ perceptions of continuing barriers to effective end-of-life care. Nurses in the study were deeply concerned about the lack of standard guidelines and called for the need to develop standard guidelines for end-of-life care. Palliative and end-of-life care are quite new concepts in Thailand and there are currently no standard clinical practice guidelines available for such care (Nilmanat, 2006). Nurses in the current study compared the guidelines to a compass to guide the direction of care. Standard guidelines are important tools to assist healthcare providers’ decisions about appropriate interventions in a way that reduces errors and provides consistent quality of care and utilization of resources throughout the system (Gibson, 2004).

Another concern was related to legal support for end-of-life care. Nurses in the study witnessed that physicians were reluctant in withdrawing life support from dying children because of unclear laws regarding end-of-life care. Thai laws on palliative and end-of-life care are not available yet; the draft National Healthcare Act proposed by the Health System Reform Office is still in process (Santivasa, 2006). This may be why physicians provide aggressive treatment until the last breath of infants and children. It is notable that the majority of infants and children whom nurses cared for in the current study received mechanical ventilator at the end of their lives. It could be implied that lack of legal support is an important barrier to providing optimal pediatric end-of-life care in Thai ICUs.

Perceived Facilitators

The third and the seventh research questions referred to facilitators of providing pediatric end-of-life care in Thai ICUs. In this study, facilitators were defined as
supportive issues that advocate delivery of quality end-of-life care for dying infants and children as perceived by Thai critical care nurses. The perceived facilitators were grouped under three main categories of patient-family-related, healthcare-professional-related and organizational-related. Additional suggestions within each category from the open-ended question are also discussed.

**Patient-family-related facilitators.** The three highest ranked facilitators suggested by Thai critical care nurses that were related to patients and families were having family members accept that an infant or a child is dying, having family members thank you or in some other way show appreciation for nursing care of the patient who has died, and having one family member be the designated contact person for all other members regarding updates on a patient’s status.

**Family’s acceptance that infants/children are dying.** Thai critical care nurses reported having family members accept that an infant or a child is dying as the greatest facilitator to providing optimal pediatric end-of-life care. The finding is consistent with the result of prior studies (Beckstrand et al., 2009; Beckstrand et al., 2008; Gross, 2006; Heaston et al., 2006; Kirchhoff & Beckstrand, 2000). Nurses need cooperation from families to stop aggressive treatment. It should also be mentioned that acceptance of a child’s poor prognosis (as measured in the modified instrument used in this study) and acknowledgement of a child’s poor prognosis (as used in Davies et al., 2008) have different meanings. Nurses who responded to this study are reporting their perceptions of family behaviors that may indicate to them that families are not accepting the child’s poor prognosis. However, it may be that families could be ready to acknowledge that their child is dying but are not ready to accept this outcome. Acknowledgement of family
members that their loved one is dying encourages them to accept palliative care earlier, leading to better quality of life and less suffering for the infant and child (Wolfe et al., 2000). Family members who realize the valued time that they have to spend with their loved one (Institute of Medicine, 2003) are more likely to facilitate an optimal experience for the dying child. This is important in Thai culture where family structures include extended families and a strong desire exists for patients to die with family members around them. Families need to stay together, providing care for their dying loved one and support for each other (Kongsuwan & Locsin, 2009).

Receiving words of appreciation from family members. Thai critical care nurses reported having family members thank you or in some other way show appreciation for nurses’ care of the patient who has died as the second highest patient-family-related facilitator of optimal pediatric end-of-life care. The finding is similar to the results in a prior study that documented this item as one of the top ten facilitators of end-of-life care (Gross, 2006). According to Contro and colleagues (2004), nurses involved in long term relationships with children have been noted to experience severe grief when these children die. It could be implied that the nurses in the current study may need thanks from family members’ in order to deal with their intense emotions that arise from a child’s death so they can return to care for other patients immediately.

Having a designated family member to contact. Thai critical care nurses suggested that having one family member be the designated contact person regarding a patients’ information could support optimal pediatric end-of-life care in ICUs. Similar to the results of prior studies, Thai critical care nurses perceived this item as a top-ranked facilitator to providing quality end-of-life care (Beckstrand et al., 2009; Beckstrand et al.,
It is possible that nurses in the current study were frequently interrupted by multiple calls from family members or other significant persons who were concerned about their critically ill infant or child. These calls and requests for updated information totally remove the nurse from the bedside and they are unable to provide care to patients during these calls. Designating one family member to be the representative for the rest of the family may reduce the number of times that information is conveyed and perhaps allow for greater consistency in the content of the information (Billings et al., 2006).

**Healthcare-professional-related facilitators.** Three facilitators related to healthcare professionals were having involved physicians agree about direction of care, providing a peaceful and dignified bedside once the infant or child has died, and having the physician put hope in real tangible terms for the family. Of these three items, two of them are related to physicians’ actions, similar to findings of previous studies of American critical care nurses (Beckstrand & Kirchhoff, 2005; Beckstrand et al., 2009; Beckstrand et al., 2008; Gross, 2006; Kirchhoff & Beckstrand, 2000). Several written comments from the Thai nurses referenced the need for physicians to stop aggressive treatment and called for physicians to cooperate with the healthcare team. These comments provide strong support that Thai critical care nurses perceive physicians as gatekeepers to delivery of optimal end-of-life care services.

**Having physicians agree with direction of care.** The need to have involved physicians agree about direction of care was ranked as the number one facilitator to providing optimal pediatric end-of-life care. As earlier mentioned, responsibility for the medical care of infants or children in ICUs does not belong to one specialist;
consequently conflict can always occur. The fact that the need for cooperation among physicians was also cited on written suggestions and the lack of physician agreement was cited as a top-rated barrier, despite being an item on the questionnaire demonstrates the desire of the Thai nurses in this study to call attention to this issue. In line with existing literature, collaboration among physicians should be the basis to providing quality of end-of-life care (Baggs, 1993; Baggs, Norton, Schmitt, & Sellers, 2004; Ciccarello, 2003). The advantages of collaboration are two fold: first, communication and sharing among experts allow treatment to proceed in the same direction leading to integrated care, and second, the consistency of information facilitates parental decision making (Puntillo et al., 2001). Nurses in the current study may often be dealing with involved physicians who are not keeping the direction of care on the same track. As patient advocates, nurses need to encourage collaboration to ensure that the care that patients and families receive from different specialties is connected in a coherent way.

*Having physicians put hope in real tangible terms.* Another item related to physicians’ actions is the need for the physician to put hope in real tangible terms for the family. This item was ranked as the third facilitator to delivery of optimal pediatric end-of-life care. Consistent with a previous study by Kirchhoff and colleagues (2000), Thai nurses suggested that it was important for physicians to give family members a clear, accurate and realistic prognosis. In the hierarchical structure of healthcare professions in Thailand, physicians are assumed by nurses to be the most knowledgeable regarding a patient’s condition, prognosis and treatment (Tyson & Pongruengphant, 2004). In Thai society, physicians are traditionally highly admired and respected by Thais, especially by rural family members (Holmes & Tangtingtavy, 1997). The decisions of family members
mainly hinge on information from physicians. Thus, a realistic prognosis from physicians can reduce the family members’ false hope and make it easier for them to make a decision regarding end-of-life care (Puntilllo et al., 2001). Physicians have an important role in assisting patients and family members to make a successful transition to palliative care (Feeg & Ingles, 2009).

*Providing a peaceful and dignified bedside scene.* Providing a peaceful and dignified bedside scene once infants or children have died was ranked as the second largest facilitator to providing pediatric end-of-life care in ICUs. This ranking is similar to prior studies of American critical care nurses (Beckstrand & Kirchhoff, 2005; Beckstrand et al., 2009; Beckstrand et al., 2008; Gross, 2006; Kirchhoff & Beckstrand, 2000). The current study finding reflects the desire of Thai critical care nurses to extend more emotional and spiritual support for family members and significant others after a child’s death. Thai critical care nurses regularly face end-of-life care and related issues, thus they focus and maximize family support through things over which they have control. Providing a peaceful and dignified bedside scene is a way for them to show sympathy that provides support for family members and promotes a satisfying experience. Providing emotional support immediately after a child dies may prevent feelings of abandonment and may help parents cope with their grief and emotional distress both short and long term (D'Agostino, Berlin-Romalis, Jovcevska, & Barrera, 2008).

*Organizational-related facilitators.* Three top-ranked facilitating factors dealing with organization support were allowing family members adequate time to be alone with a child after he or she has died, having support staff compile all the paperwork to be
signed by the family before leaving the unit, and allowing families unlimited access to
their dying child. The findings of this study reflect Thai critical care nurses call for
organizational support to provide psychological and spiritual support for dying children
and their families in the ICUs.

*Allowing time to be alone with infants’/children’s body.* The need to allow family
members adequate time to be alone with a child after he or she has died was ranked as the
most important facilitator to providing effective pediatric end-of-life care. This item has
also received the highest ranking in prior studies of American critical care nurses.
(Beckstrand & Kirchhoff, 2005; Beckstrand et al., 2009; Beckstrand et al., 2009;
Beckstrand et al., 2008; Gross, 2006). Prior evidence supports that psychological stress
after the death of a child could seriously affect health outcomes of parents (Li, Laursen,
adequate time alone after a child has died respects and preserves the parent-child
relationship and allows parents to fulfill their roles as a caregiver and protector for their
child (Beckstrand et al., 2009). Several prior studies document the compelling need for
parents to stay with their child’s body in an unhurried time (Davies et al., 2008; Finlay &
Dallimore, 1991; Meyer et al., 2006). This could help parents to cope with their early
grief and may positively affect long term bereavement (Meyer et al., 2006).

*Having support staff for paper work.* Related to allowing adequate time, nurses
also desire to be with the distraught family during the difficult time immediately
following the death of the child. This is reflected in the nurses’ desire to have support
staff prepare the paperwork for the family to sign before leaving the unit. This was rated
as the second highest facilitator. A need for more staff, reflecting the workload, was also
mentioned on written comments, implying that critical care nurses desire to spend more time providing emotional support to the family. Thus, they want other staff members to manage clerical activities for them. This finding is consistent with results of prior studies demonstrating that nurses appreciated help from co-workers who could gather necessary paperwork for families so that the nurse could increase her time with the family (Beckstrand et al., 2008; Gross, 2006).

Allowing families unlimited access to the dying infant or child. The need to allow families unlimited access to the dying infant or child was the third highest ranked facilitator to providing optimal pediatric end-of-life care in Thai ICUs. In support of this facilitator, nurses also mentioned the need for more liberal visiting hours and the need for environmental changes in the ICUs on their written comments. This reflects the strong desire of the Thai critical care nurses in this study to provide benefits for grieving families to be as comfortable as possible during such a stressful time. Consistent with the study of Meyer and colleagues (2006), many parents emphasized the need for private, quiet and unlimited time to stay with their dying children at the end-of-life. Interestingly, this item is given less attention by critical care nurses in other prior studies (Beckstrand et al., 2008; Gross, 2006). One possible explanation is that restrictive visiting policies are not an issue encountered by some previously studied nurses.

Influence of Barriers and Facilitators on Quality of Dying and Death

The fourth and the fifth research questions sought to identify barriers and facilitators that influenced the quality of dying and death of infants and children in Thai ICUs. The findings indicated the overall model of three barrier and facilitator predictors (patient-family-related, healthcare-professional-related, and organizational-related)
significantly affected quality of dying and death of infants and children in Thai ICUs. The best explanation of the findings could be based on Donabedian’s (1988) work composed of three interacting elements: structure, process and outcome. The study findings support the model that the three main categories of barriers were negatively correlated to the quality of dying and death, and these barriers explained a significant portion of the variance in quality of dying and death. This supports Donabedian’s model in that when structural inputs are poorly prepared, the outcomes will be worsened. The three main categories of facilitators were positively correlated to the quality of dying and death, and these facilitators explained a significant portion of the variance in quality of dying and death. This also supports Donabedian’s model in that when good structural inputs are in place, better outcomes will be produced. Although the current study did not measure process of care, the results support the importance of changing the structure of care that can subsequently influence process of care; together changes in both structure and process of care can affect outcome of care.

The study findings also revealed the significant barriers and facilitators which have the most influence on the quality of dying and death of infants and children in Thai ICUs were related to healthcare professionals. Nurses in the study identified that they themselves, as well as other healthcare professionals may either facilitate or hinder optimal quality of dying and death. Although no previous studies regarding the relationship between healthcare professionals and quality of dying and death exists, the findings imply that Thai nurses felt that they were not qualified to provide end-of-life care for infants and children. As found in several previous studies, inadequate education and staffing levels are major barriers to optimal end-of-life care (Beckstrand et al., 2006;
Davies et al., 2008; Ferrell et al., 2007; Paredes & Frank, 2000; Puntillo et al., 2001; Raudonis et al., 2002). On the other hand, nurses in the study thought that being better prepared to provide end-of-life-care might improve the quality of dying and death of infants and children. According to Radwin (1998), knowing how to care for patients is an important concept in nursing and an essential antecedent in planning and providing high quality care.

**Limitations and Strengths of the Study**

**Limitations of the Study**

There are a number of limitations of the current study including generalization, instrument translation, and psychometric properties of instruments. These limitations point out some major concerns that should be considered for further study. The first limitation is related to generalizability of research findings. The findings from the study could benefit the development of pediatric palliative care in Thai ICUs but may not be generalized to all university hospitals in Thailand. Although the study had a high response rate (86%), the study sample consisted of a convenience sample of critical care nurses from only two university hospitals located in the central and northern regions of Thailand. The perceptions of critical care nurses who might have had different experiences and views in end-of-life care from Thailand’s remaining university hospitals are not known. Thai university hospitals are geographically located in four main areas: north, northeast, central and south. In these different regions, people have different cultures that may influence end-of-life care issues and the provision of end of-life care. Thus, assembling subjects across a variety of settings in a future study will provide a representative sample of the target population.
The second limitation is related to instrument translation of questionnaires used in the current study from English to Thai language. Optimally, the panel of bilingual experts should include members who use English as a first language and Thai as a first language (Jones & Kay, 1992). In the current study, all bilingual experts were Thais who spoke English as a second language. Thus, interpretation of instruments from the original to the target language may encounter problems. Although the original instruments were modified and evaluated for content validity by an expert panel, the items were originally developed in Western cultures and might not be culturally appropriate for the Thai population.

The third limitation is related to psychometric properties of the study instruments. The original instruments were designed to measure perceptions of critical care nurses who had experience with adult patients. This study represents the first attempt to apply the items to obtain perceptions of critical care nurses who care for dying infants and children. Some items were refined to reflect more closely the experience of infants and children dying in intensive care settings. Although the content validity index and internal consistency reliability values were for the most part acceptable, the measures used in the current study are still relatively new and not extensively tested in the pediatric area. Thus, further use of the instruments is required. For the Modified National Survey of Critical Care Nurses regarding End-of-Life Care questionnaire, barrier and facilitator items were grouped into three categories based on theory and literature review. Some categories demonstrated weaker Cronbach’s alpha coefficients than others because they contained fewer items. Adding items gained from the open-ended responses and retesting the instruments may be helpful in improving psychometric properties. An additional
limitation related to measurement relates to the fact that the data reflect perceptions of quality of dying and death and perceptions of barriers and facilitators by the Thai critical care nurses who participated in the study. These perceptions may not completely reflect the reality of particularly the quality of dying and death experienced by infants and children in Thailand.

Many of the additional written responses to the open-ended questions were duplicative of items already addressed in the questionnaire such as inadequate end-of-life care education, need for private rooms and changes in visiting hour policy. The repetition of suggestions implies that the wording of the open-ended questions might be unclear or the length of the questionnaire might prevent nurses from remembering that they had already responded to a particular barrier or facilitator in previously scored items. These possibilities should be further investigated.

**Strengths of the Study**

The strength of the study was supported by use of a descriptive correlational design. A descriptive correlational design allowed the researcher to explore the problems and identify relationships between the quality of dying and death, barriers and facilitators to providing pediatric end-of-life care in Thai ICUs. In Thailand, end-of-life care issues are new and existing evidence for best practice of end-of-life care is limited. Initially, descriptive data were needed as basic information to improve end-of-life care in the next step. This design is appropriate to explore the nature of problems before engaging in the interventional research to improve the provision of end-of-life and palliative care for Thai infants and children including their families.
Perhaps most notably, this study represents the first empirical evidence of the quality of dying and death and the barriers and facilitators of end-of-life care for infants and children in Thailand’s ICUs.

Implications of the Study

The findings in the current study provide valuable information to direct national healthcare policy, nursing and hospital administrators, nursing practice, nursing education, and nursing research that will improve end-of-life care for pediatric patients in Thailand.

National Healthcare Policy

In order to implement the study findings into all practice levels including nursing and hospital administrators, nursing practice, nursing education, and nursing research, there is a fundamental need to first establish a national policy. According to the World Health Organization (2003), a national policy is like the umbrella for all health-related policies within a country and is needed to guide the planning, legislation and regulation of palliative and end-of-life care. Having a national policy is the best way to ensure quality standards, funding, and accessibility of adequate care for all patients and families. The study findings could raise awareness of end-of-life care issues to policy makers and have implications for national healthcare policy in Thailand.

Nursing and Hospital Administrators

The study findings are relevant to essential issues regarding features of intensive care units including restricted visiting hour policies, an ICU environment that is not conducive to provision of quality end-of-life care, and insufficient staff. These issues require effective interventions at the organizational level. Nursing and hospital
administrators play a vital role in making improvements to these issues to encourage the quality of end-of-life care in ICUs. One of the principles for optimal pediatric end-of-life care is allowing dying infants and children to be surrounded by their families until the last hours of their lives. To do so, visiting hours need to be extended to enable families to spend time with their loved one. Improving the ICU environment is also in the list for change. The findings of the study make clear that privacy, proximity, and a quiet environment are significant in promoting a peaceful death in ICUs. Thus, it is necessary for administrators to enact policies that ensure a proper environment to encourage effective care. Structural redesign of future ICUs is needed. For a short term solution, providing temporary space or a room for the dying in their last hours to be with their families is recommended. Regarding staff shortages, the study findings reveal many Thai neonatal and pediatric ICUs face understaffing, excessive workloads, and overtime, leading to time constraints for nurses to provide optimal care for dying infants, children and their families. Therefore, recruitment, empowerment, reward strategies and other significant incentives are needed to retain neonatal and pediatric ICU staff.

**Nursing Education**

Education and training of healthcare professionals is crucial in providing optimal pediatric end-of-life care. Findings from the current study revealed Thai critical care nurses call for end-of-life care education to better prepare nurses to provide care for dying infants and children. Several of their written comments regarding barriers and facilitators repeated the need for end-of-life education despite the fact that this item was already contained on the questionnaire. This could be a reflection of the frustration that nurses felt when dealing with dying infants and children with little preparation and may
point to a major deficiency in the curriculum of Thailand’s nursing programs. This study provides support to nursing educators to include palliative and end-of-life care in the curriculum at the undergraduate and graduate levels to prepare the next generation of nurses to be competent in caring for dying infants and children. It is proposed that the content of palliative and end-of-life care should be taught separately from other courses in order to emphasize the importance of the topic. Additionally, continuing education programs should be available for currently practicing nurses to improve their competency in providing optimal end-of-life care.

*Nursing Practice*

The findings of the current study indicate some ways in which interventions might be developed to improve quality end-of-life care in neonatal and pediatric intensive care units. In the transition from cure to care at the end of life, critical care nurses are challenged as patients and families struggle to understand when the goal of treatment changes. The unfamiliar environment of the ICUs, their child’s appearance, and difficulties in having conversations with healthcare providers are all sources of distress for families. Effective communication and care coordination with families is important. Nurses should collaborate with the team to develop a communication protocol to assure that everyone in the team is aware of and follows the plan for end-of-life care. Communication should include clarity about what patients and families have been told and consistency of the potential risks and benefits of various treatment options.

Some families maintain false hope due to an uncertain prognosis and have difficulty accepting that their child is nearing the end of life. Ongoing communication and regular updates are necessary to help families reach understanding of their loved
one’s condition. Nurses can work together with physicians and ask them to tell families the truth and present the child’s prognosis in a realistic and tangible way without removing all hope for their child. These approaches would be more effective if team meetings first were held among members of the healthcare team and if nurses were regularly included when physicians speak with the family. This would allow nurses to be aware of what families were told and allow them to better support the family. During both the team and family meetings, the infant or child’s condition is reviewed and updated, and the current treatment, plan of care and option for future treatment is presented. Thus, families could have a complete picture of relevant information and clinical judgment to prepare them for future situations.

Nurses often act as mediators to translate information from physicians to family members, yet are often disturbed with multiple concerned visitors and callers who are seeking updated information on an infant or child. It may be useful to appoint one family member to be the conduit for information for the rest of the family in order to increase the nurses’ time available for bedside care. At the end of life, nurses could consent to unlimited time for families to be with their child and provide the family with opportunities for meaningful participation in the child’s care. This can help parents to cope with grieving process. To promote peaceful death in ICUs, a comfortable, private, and quiet environment should be provided. Although most features of Thai ICUs are not conducive for preparing a peaceful death, it would at least be helpful to keep lights and noise at a minimum. During this time, some families may need a spiritual leader to come to the bedside to pray for their dying infant or child; nurses should understand and allow these rituals to be performed.
Once death has occurred, the focus of care should immediately shift from the patient to the family. Nurses should allow family members to spend time alone with their child’s body without rushing them. This can help family members to deal with acute grief.

Health and emotional well-being of healthcare providers should be recognized. In this study, nurses identified that a sign of appreciation from families for their nursing care facilitated quality of dying and death. This implies that nurses experience distress in caring for dying infants and children. Debriefing sessions for ICU staff should be provided to offer these staff the opportunity to express their feelings related to caring for dying infants and children.

Recommendations for Future Research

In Thailand, end-of-life care for infants and children is still in its infancy. Efforts to integrate such care to neonatal and pediatric intensive care units needs more study. The current study provides basic descriptive information regarding the quality of dying and death, barriers and facilitators to providing pediatric end-of-life care in Thai ICUs. Future research should include additional study to examine the psychometric properties of the Thai versions of the Modified Quality of Dying and Death, and the Modified National Survey of Critical Care Nurses regarding End-of-Life Care questionnaires. With the several limitations of the instruments previously mentioned, more valid and reliable measures are needed.

This investigation should be replicated using with a larger sample size recruited from other hospital settings. More descriptive studies are still needed to gain a comprehensive understanding of the quality of dying and death, barriers and facilitators
to providing pediatric end-of-life care in Thai ICUs. This is an important step before moving to interventional studies. Solomon (1995) advised that interventions often fail because they are designed without adequate understanding of the problem and the relationship between variables.

Study in other populations including physicians and family members should be conducted to compare their perceptions of the quality of dying and death, barriers and facilitators to providing pediatric end-of-life care in Thai ICUs. Other surrogates having experience with dying infants and children may have different perceptions of many aspects of end-of-life care than those of the critical care nurses.

**Conclusion**

In conclusion, pediatric end-of-life care in Thai ICUs is in an early stage. The study findings disclose a moderate quality of dying and death for infants and children as perceived by Thai critical care nurses and suggest room for improvement. Specifically pain and respiratory symptom management, and the provision of spiritual care are serious concerns. Findings from the current study suggest that efforts to decrease the top barriers and promote the top facilitators have the potential to improve the quality of dying and death for Thailand’s infants and children. Among these barriers and facilitators, healthcare professionals were considered to have the most influence on the quality of dying and death. Fortunately, this category is one in which the most opportunity exists to effect change.
APPENDIX A

Institutional Review Broad Approval

*Maharaj Nakorn Chiang Institutional Review Broad Approval*

Faculty of Medicine
Chiang Mai University
Chiang Mai 50200 THAILAND
Tel: 66-53-946144 Fax: 66-53-217144

September, 4 2009

Dear Associate Dean for Doctoral Education, and PhD Program Director,
Case Western Reserve University
10900 Euclid Avenue
Cleveland, Ohio 44106-4904
Phone 216-368-5356
Fax 216-368-8864

Dear Associate Dean for Doctoral Education, and PhD Program Director,

Regarding to your request for approval of conducting human subject research at Maharaj Nakorn Chiang Mai Hospital for Ms. Jutarat Mesukko’s dissertation project titled “Quality of Dying and Death, Barriers, and Facilitators to Providing Pediatric End-of-Life Care in Intensive Care Units in Thailand: Critical Care Nurses’ Perceptions”

I am pleased to inform you that the research project was certified by the Research Ethics Committee of the Faculty of Medicine, Chiang Mai University (REC FOM-CMU) and Ms. Jutarat Mesukko is authorized to begin data collection immediately. The length of time of the research project will be as specified in the certificate issued by the REC FOM-CMU.

Please note that, if Ms. Jutarat Mesukko wish to initiate any changes in the research protocol or the consent documents; she should submit the request to REC FOM-CMU in writing prior implementing any changes.

Sincerely,

[Signature]

(Associate Professor Nites Nantachit, M.D.)
Dean of Faculty of Medicine, Chiang Mai University
Certificate of Approval

No. 287/2009

Name of Ethics Committee: Research Ethics Committee 3,
Faculty of Medicine, Chiang Mai University

Address of Ethics Committee: 110 Intavaroros Rd., Amphoe Muang, Chiang Mai, Thailand 50200

Principal Investigator: Jutarat Mesukko
Frances Payne Bolton School of Nursing, Case Western Reserve University

Protocol title: Quality of Dying and Death, Barriers, and Facilitators to Providing Pediatric End-of-Life Care in Intensive Care Units in Thailand: Critical Care Nurses' Perceptions

Study code : 09JUL101017

Sponsor: -

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Opinion of the Ethics Committee/Institutional Review Board: PLS. CHECK ONE

- Approval

- Conditional approval (Specify on space below)

DECISION : By expedited review process

Date of Approval: September 4, 2009 Expiration Date: September 3, 2010

This Ethics Committee is organized and operates according to GCPs and relevant international ethical guidelines, the applicable laws and regulations.

Signed: ........................................
(Emeritus Professor Panja Kulapongs, M.D.)
Chairperson, Faculty of Medicine

Signed: ........................................
(Associate Professor Niwes Nautachit, M.D.)
Dean, Faculty of Medicine
GENERAL CONDITION OF APPROVAL:

- Please refer to [www.med.cmu.ac.th/research/ethics/inv_sop_announce.pdf](http://www.med.cmu.ac.th/research/ethics/inv_sop_announce.pdf) article 13.
- Please submit the progress report at least once a year except where required more frequent by the REC.
- In particular, approval of this study must be renewed at least one month before the expiration date if work is to continue.
- Prior Research Ethics Committee approval is required before implementing any changes in the consent documents or protocol unless those changes are required urgently for the safety of subjects.
- Any event or new information that may affect the benefit/risk ratio of the study must be reported.
- Any protocol deviation/violation must be reported to the IRB.
หนังสือยินยอมการวิจัย

คณะเวชศาสตร์ศิริราชพยาบาล มหาวิทยาลัยภูมิพล

คำขอรับอนุมัติใช้เครื่องมือพิเศษ

ชื่อโครงการวิจัย: การศึกษาคุณภาพของภาวะโลหิตขาดและภาวะขาดสารสินในระบบการดูแลผู้ป่วยที่มีผลต่อการรักษาหัวใจในประเทศไทย การรับรู้ของผู้ดูแลผู้ป่วย

ชื่อหน่วยงาน: มหาวิทยาลัยภูมิพล

รหัสโครงการ: 01/2552 (Exempt)

โครงการวิจัยนี้เป็นโครงการวิจัยที่ข้ามข่ายศูนย์ (Research with Exemption from IRB Review)

วันที่ยื่นย่อ: 22 กันยายน 2552

ผู้ยื่นเรื่อง: คณะเวชศาสตร์ศิริราชพยาบาล มหาวิทยาลัยภูมิพล

คณะเวชศาสตร์ศิริราชพยาบาล มหาวิทยาลัยภูมิพล ดำเนินการให้การรับรองโครงการวิจัยตามแนวทางหลักจริยธรรมการวิจัยในศัพท์ที่เป็นสากล โดยDeclaration of Helsinki, the Belmont Report, CIOMS Guidelines และ the International Conference on Harmonization in Good Clinical Practice (ICH-GCP).

ลงนาม: 24 กันยายน 2552

(ศาสตราจารย์พยาบาลผู้ช่วย ปลัดกระทรวง)

วันที่: ประทานกฎหมายวิจัยในศัพท์
Documentary Proof of Exemption
Sriraj Institutional Review Board

This document is a proof of the following study protocol.

Protocol Title : Quality of Dying and Death, Barriers, and Facilitators to Providing Pediatric End of Life Care in Intensive Care Units in Thailand: Critical Care Nurses’ Perceptions

Principal Investigator /Affiliation : Miss Jutarat Mesukko
Faculty of Nursing, Mahidol University

SIRB Protocol No. : 011/2552(Exempt)

This protocol complies with a “Research with Exemption” category.

Date of Proof : July 22, 2009

This is to certify that Sriraj Institutional Review Board is in full Compliance with International Guidelines for Human Research Protection such as the Declaration of Helsinki, the Belmont Report, CIOMS Guidelines and the International Conference on Harmonization in Good Clinical Practice (ICH-GCP).

July 24, 2009

(Prof. Jariya Lertakyamane, M.D.)
NOTICE OF EXEMPTION (N2)
Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior

If this protocol changes, the PI and/or CI must fully complete and submit an addendum request.

PLEASE BE CERTAIN TO DESTROY EMAILS OR ANYTHING ELSE THAT COULD POSSIBLY LINK DATA WITH PARTICIPANT

Responsible Investigator: Elizabeth Damato
Department: Nursing - General
IRB Protocol Number: 20090918
Title: Quality of Dying and Death, Barriers, and Facilitators to Providing Pediatric End-of-Life Care in Intensive Care Units in Thailand: Critical Care Nurses’ Perceptions
Co-Investigator: Jutarat Mesukko

Exemption Date: September 29, 2009

The Institutional Review Board (IRB) has deemed the above protocol EXEMPT under 45 Code of Federal Regulations (CFR) part 46.101(b)(2). The IRB will not conduct subsequent reviews of this protocol.

Any changes to the protocol that put it under the purview of the IRB would require a formal application to, and approval of, the IRB prior to implementation of the change. IRB applications are available at the CWRU IRB Pages, or from the Office of Research Compliance (ORC) at Sears Library Building, #660.

Questions? Please visit our website: http://fora.case.edu/orc_humansubjects_CWRU_IRB.asp
OR contact our administrative office...

Isabel Sanchez-Cummings, IRB Director
216.368.8983
Maureen Dore-Arshenovitz, IRB Assistant
216.368.8925
Fax: 216.368.3737

CASE Institutional Review Board
Office of Research Compliance
Sears Building 667
Cleveland, OH 44106-7230
APPENDIX B

Informed Consent Letter

Informed Consent Letter of Maharaj Nakorn Chiang Mai Hospital

To all participants,

My name is Jutarat Mesukko. I am a doctoral student in Nursing at the Frances Payne Bolton School of Nursing, Case Western Reserve University, in Cleveland, Ohio. This document was written to provide you important information for helping you making a decision to participate in the study. If you have any difficulties of understanding the contents of the document, please ask the student investigator or the representatives until you get comprehensive understanding. You may take this document to read at your own home or to consult your family or close friend before making a decision.

In partial fulfillment of my degree, I am conducting a study of Thai critical care nurses’ perceptions regarding quality of dying and death, barriers, and facilitators to providing pediatric end-of-life care in intensive care units. The purposes of this study are to explore current status of quality of end-of-life care for dying infants and children in Thailand, what barriers impede care and what facilitators help support the optimal care. Data will be collected in the intensive care units for infant and children at the two university hospital in Thailand: Maharaj Nakorn Chiang Mai Hospital, Faculty of Medicine, Chiang Mai University and Siriraj Hospital, Faculty of Medicine, Mahidol University, Thailand. A convenience sample of 123 nurses from the two university hospitals will be recruited.

The expected benefits of the study are to obtain descriptive information regarding the quality of dying and death, barriers and facilitators to providing pediatric end-of-life care in intensive care settings in Thailand. This important information will be powerful tools to improve effectiveness of end-of-life practices to take care of these patients. In addition, the findings will provide us more understanding regarding the relationship among three variables, quality of dying and death, and barriers. Evaluating the barriers and facilitators to providing pediatric end-of-life care will help the administrators and health care professionals prioritize which barriers have the largest impact or magnitude and need to be reduced or eliminated and which facilitators need to be supported to optimize care at the end of life. The study also provides preliminary evidence for further development and testing of new hypotheses and interventions to improve end-of-life care for dying infants and children.

I would like to request your assistance as a voluntary participant in my research project. You are being asked to participate as a subject because you are a critical care nurse who has direct experience caring for dying infants and children and for their families. Therefore, I expect that you will provide the best answer regarding quality of dying and death, barriers, and facilitators to providing end-of-life care for dying infants and children.

Participation in this study is completely voluntary and there is no cost to you. Your decision whether or not to complete the questionnaires will not affect your job benefits and your family. If you agree to be a part of this study, you will first be asked to fill out the three questionnaires: 11 - item Demographic Questionnaire, 24-item Quality of Dying and Death Questionnaire, 53-item Barriers and Facilitators to providing end-of-life care Questionnaire. Completion of the
questionnaires will take approximately 30 minutes of your time. To protect your privacy, **Please do not put your name on the questionnaires.** When your questionnaires are completed, please directly return them within two weeks to the postal box provided at your unit. This box will be locked and only the key person can open it to gather the returned questionnaires. To increase the response rate, ten days after questionnaires are delivered; the key person will post a reminder in each NICU and PICU area to encourage participants to complete the survey. Ten days after the first reminder is posted, the key person will personally distribute a card to all participants to thank those who have already returned the questionnaire and to ask non-respondents to complete and return the questionnaires. If you are not willing to participate in the study, you do not have to fill out the questionnaires. You can withdraw from the study any time without penalty or loss of benefits. You will be not asked to explain the reason for stopping or withdraw from the study. Your information will be immediately destroyed and cut off.

There are no physical risks associated with your participation. The risks or discomforts of filling out the surveys are minimal. Some of the questions may be upsetting as you remember the dying infants and children you have cared for. If you feel uncomfortable answering a particular question, you may leave it blank and go on to the next question. Information from individual questionnaires will be kept confidential. Returned questionnaires will be kept in a locked file cabinet and will be used for research purposes only. Your name will be not posted on any part of the research. All responses will be identified using a study identification number. Results will be reported aggregated and not in a way that personally identifies you. As per Thailand law, all completed questionnaires will be destroyed 5 years after the study has ended.

There are no direct benefits to you as a participant. However, your participation will provide value information which is useful for dying infants and children including their families. You will not receive monetary payment for participation. You will receive a small gift as a token of appreciation in anticipation of their participation in the study. The gift will be distributed along with questionnaire packet. If I have more information regarding either advantage or disadvantage of the study, I will promptly inform you all reliable information.

If you have any questions or concerns about this study, please feel free to contact the researcher by telephone or email any time. The researcher can be reached at 0861932422 or by email address: jmesukko@yahoo.com.

**Statement of Consent for Participants**
I understand the above information and have had all of my questions about participation on this research project. I voluntarily to participate in this research

Print Name of Participant ……………………………………………..

Signature of Participant………………………………………………

Print Name of the student investigator…………………………………..

Signature of the student investigator……………………………………….
Informed Consent Letter of Siriraj Hospital

To all participants,

My name is Jutarat Mesukko. I am a doctoral student in Nursing at the Frances Payne Bolton School of Nursing, Case Western Reserve University, in Cleveland, Ohio. This document was written to provide you important information for helping you making a decision to participate in the study. If you have any difficulties of understanding the contents of the document, please ask the student investigator or the representatives until you get comprehensive understanding. You may take this document to read at your own home or to consult your family or close friend before making a decision.

In partial fulfillment of my degree, I am conducting a study of Thai critical care nurses’ perceptions regarding quality of dying and death, barriers, and facilitators to providing pediatric end-of-life care in intensive care units. The purposes of this study are to explore about the current status of quality end-of-life care of dying children in Thailand, what barriers impede care and what facilitators help support optimal care. Data will be collected in the intensive care units for infant and children at two university hospital in Thailand: Maharaj Nakorn Chiang Mai Hospital, Faculty of Medicine, Chiang Mai University and Siriraj Hospital, Faculty of Medicine, Mahidol University, Thailand. A convenience sample of 123 nurses from the two university hospitals will be recruited.

The expected benefits of the study are to obtain descriptive information regarding the quality of dying and death, barriers and facilitators to providing pediatric end-of-life care in intensive care settings in Thailand. This important information will be powerful tools to improve effectiveness of end-of-life practices to take care of these patients. In addition, the finding will provide us more understanding regarding the relationship among three variables, quality of dying and death, and barriers. Evaluating the barriers and facilitators to providing pediatric end-of-life care will help the administrators and health care professional prioritize which barriers have the largest impact or magnitude and need to be reduced or eliminated and which facilitators need to be supported to optimize care at the end of life. The study also provides preliminary evidence for further development and testing of new hypotheses and interventions to improve end-of-life care for dying infants and children.

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Participation in this study is completely voluntary. Your decision whether or not to complete the questionnaires will not affect your job benefits and your family. If you agree to be a part of this study, you will first be asked to fill out the three questionnaires: 11-item Demographic Questionnaire, 24-item Quality of Dying and Death Questionnaire, 53-item Barriers and Facilitators to providing end-of-life care Questionnaire. Completion of the questionnaires will take approximately 30 minutes of your time. To protect your privacy, Please do not put your name on the questionnaires and on informed consent letter. All responses will be anonymous. Return of a completed questionnaire implies consent and voluntary participation. When your questionnaires are completed, please directly return them within two weeks to the postal box provided at your unit. This box will be locked and only the key person can open it to gather the
returned questionnaires. To increase the response rate, ten days after questionnaires are delivered; the key person will post a reminder in each unit area to encourage participants to complete the survey. Ten days after the first reminder is posted, the key person will personally distribute a card to all participants to thank those who have already returned the questionnaire and to ask non-respondents to complete and return the questionnaires. If you are not willing to participate in the study, you do not have to fill out the questionnaires. You can withdraw from the study any time without penalty or loss of benefits. You will be not asked to explain the reason for stopping or withdraw from the study. Your information will be immediately destroyed and cut off.

There are no physical risks associated with your participation. The risks or discomforts of filling out the surveys are minimal. Some of the questions may be upsetting as you remember the dying infants and children you have cared for. If you feel uncomfortable answering a particular question, you may leave it blank and go on to the next question. Information from individual questionnaires will be kept confidential. Returned questionnaires will be kept in a locked file cabinet and will be used for research purposes only. Your name will be not posted on any part of the research. All responses will be identified using a study identification number. Results will be reported aggregately and not in a way that personally identifies you. As per Thailand law, all completed questionnaires will be destroyed 5 years after the study has ended.

There are no direct benefits to you as a participant. However, your participation will provide value information which is useful for dying infants and children including their families. You will not receive monetary payment for participation. You will receive a small gift as a token of appreciation in anticipation of their participation in the study. The gift will be distributed along with questionnaire packet. If I have more information regarding either advantage or disadvantage of the study, I will promptly inform you all reliable information.

If you receive unequal and unfair treatment during the research process, please contact Siriraj Institutional Review Board Adulyadejvikom Building, 6th floor by telephone (02) 419-6405-6 or fax (02) 419-6405. If you have any questions or concerns about this study, please feel free to contact the researcher by telephone or email. The researcher can be reached at 0861932422 or by email address: jmesukko@yahoo.com. Thank you for your time and your consideration of participation in this study.

Sincerely,

Jutarat Mesukko
PhD Candidate, School of Nursing
Case Western Reserve University
Cleveland OH 44106-4904 U.S.A
APPENDIX C

Demographic Data Questionnaire (Thai Version)

เลขที่แบบสอบถาม............... แบบสอบถามข้อมูลส่วนบุคคล

คำแนะนำ: โปรดเติมข้อมูลเกี่ยวกับตัวของท่านเองลงในช่องว่างหรือทำเครื่องหมาย ✓ ในช่อง □ ที่ตรงกับท่าน

1. ประสบการณ์เป็นพยาบาลประจำการ.............................ปี
2. ประสบการณ์เป็นพยาบาลประจำการในหอผู้ป่วยหนัก...............................ปี
3. เพศ □ ชาย □ หญิง
4. ปี พ.ศ เกิด.................................
5. ระดับการศึกษาสูงสุด
  □ ปริญญาตรีพยาบาล □ ปริญญาโทอื่นๆ
  □ ปริญญาโทพยาบาล □ ปริญญาเอกอื่นๆ
  □ ปริญญาเอกพยาบาล □ อื่น ๆ (โปรดระบุ)...........................
6. จำนวนผู้ป่วยทารกและหรือเด็กใกล้ตายที่ท่านเคยให้การดูแล
  □ น้อยกว่า 5 คน □ 5 -10 คน □ 11 - 20 คน
  □ 21 - 30 คน □ มากกว่า 30 คน □ อื่น ๆ (โปรดระบุ)....................
7. ชนิดของหอผู้ป่วยหนักที่ท่านปฏิบัติงานอยู่
  □ หอผู้ป่วยหนักมรณะเวชกรรม (PICU)
  □ หอผู้ป่วยหนักการเกิดแรก (NICU)
  □ อื่น ๆ (โปรดระบุ)...........................
8. จำนวนเด็กในหอผู้ป่วย...........................
9. ตำแหน่งของท่านในหอผู้ป่วย
  □ หัวหน้าหอผู้ป่วย □ พยาบาลประจำการ
  □ พยาบาลเฉพาะทาง □ อื่น ๆ (โปรดระบุ)...........................
10. จำนวนชั่วโมงที่ปฏิบัติงานต่อสัปดาห์...........................ชั่วโมง
11. ท่านได้รับประกาศนียบัตรพยาบาลทหารหรือเด็กกุศลหรือไม่
  □ ได้รับ □ ไม่ได้รับ
แบบสอบถามการวิจัยของพยาบาลเกี่ยวกับคุณภาพของการได้รับการดูแลและการตายของผู้ป่วยทารกและเด็กในระยะสุดท้ายของชีวิตในหอผู้ป่วยหนัก

ตัวชี้วัด แบบสอบถามมีวัตถุประสงค์เพื่อสอบถามเกี่ยวกับประสบการณ์ที่ผู้ป่วยได้รับในระหว่างที่อยู่ในหอผู้ป่วยหนักในระยะเวลาการดูแลที่ผู้ป่วยหนักให้การระลึกถึงผู้ป่วยใกล้ตายรายล่าสุดที่จะสิ้นสุดลง แล้วและกุญแจตอบจากความคิดเห็นของพยาบาลในระหว่างการดูแลที่พบเห็นผลผลกระทบต่อคุณภาพการดูแลผู้ป่วยใกล้ตายอย่างไร

ไม่ได้ คิดว่าผู้ป่วยจะให้คะแนนประสบการณ์เรื่องนี้อย่างไร กรุณาตอบตามที่คิดว่าถูกต้องมากที่สุด

ก่อนที่จะตอบแบบสอบถาม กรุณาให้ข้อมูลพื้นฐานเกี่ยวกับผู้ป่วยใกล้ตายรายล่าสุดที่จะสิ้นสุดลง
1. อายุของผู้ป่วยทารกและเด็กขณะตาย:
   1. ทารกอายุ …….. สัปดาห์หรือ …….. เดือน
   2. เด็กอายุเป็น ……..

2. เพศของทารกหรือเด็ก: โปรดทำเครื่องหมายน่าที่เหมาะสม
   …….. ชาย (0)
   …….. หญิง (1)

3. การวินิจฉัยโรคของทารกหรือเด็ก:.................................................................

4. ท่านได้ดูแลผู้ป่วยรายนี้ขณะตายหรือไม่: โปรดทำเครื่องหมายน่าที่เหมาะสม
   …….. ใช่ (1)
   …….. ไม่ได้ (0)

ประสบการณ์ของผู้ป่วยทารกและเด็กในระยะสุดท้ายของชีวิต

คำถามต่อไปนี้จะเป็นคำถามเกี่ยวกับประสบการณ์ของท่านในการดูแลผู้ป่วยทารกและเด็กในระยะสุดท้ายของชีวิตในระหว่างที่อยู่ในหอผู้ป่วยหนัก ในความเห็นของท่าน ท่านจะประเมินคุณภาพประสบการณ์ของผู้ป่วยทารกและเด็กในระยะสุดท้ายอย่างไร โปรดทำเครื่องหมายของคุณความคิดเห็นของท่านมากที่สุด

<table>
<thead>
<tr>
<th>คำถาม</th>
<th>ไม่ดี</th>
<th>พอใช้</th>
<th>ดี</th>
<th>ดีมาก</th>
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<tbody>
<tr>
<td>1. การควบคุมอาการปวดของทารกและเด็กในระยะสุดท้ายของชีวิตตามข้อความต่อไปนี้อย่างไร</td>
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<td>2. การหายใจของทารกและเด็กในระยะสุดท้ายของชีวิต</td>
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<tr>
<td>การรักษาพยาบาลที่ผู้ป่วยทารกและเด็กได้รับในระยะสุดท้ายของชีวิต</td>
<td>ไม่ดี</td>
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<td>3. การใช้เวลาอยู่กับครอบครัวหรือเพื่อนของผู้ป่วยทารกและเด็กในระยะสุดท้ายของชีวิต</td>
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<td>4. การได้รับการสัมผัสหรืออบอุ่นจากคนที่รักของผู้ป่วยทารกและเด็กในระยะสุดท้ายของชีวิต</td>
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<tr>
<td>5. การได้รับการดูแลอย่างสม่ำเสมอและเคารพความเป็นบุคคลของผู้ป่วยเด็กในระยะสุดท้ายของชีวิต</td>
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<tr>
<td>6. การเยี่ยมจากผู้ให้คำปรึกษาด้านศาสนาหรือด้านจิตวิญญาณ (หนึ่งครั้งหรือมากกว่า) ของผู้ป่วยเด็กในระยะสุดท้ายของชีวิต</td>
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<tr>
<td>7. การบริการหรือพิธีกรรมทางด้านจิตวิญญาณก่อนการตายของผู้ป่วยเด็กในระยะสุดท้ายของชีวิต</td>
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</tr>
</tbody>
</table>

คำถามต่อไปนี้จะเกี่ยวกับการรักษาพยาบาลที่ผู้ป่วยที่ท่านดูแลได้รับในขณะที่อยู่ในหอผู้ป่วยหนัก โปรดทำเครื่องหมายที่เหมาะสมและทำตามที่เหมาะสม

8. ผู้ป่วยของท่านได้รับการรักษาด้วยเครื่องช่วยหายใจในขณะที่อยู่ในหอผู้ป่วยหนักหรือไม่
   - ใช่ (0)
   - ไม่ใช่ (1)
   - ไม่ทราบ (8)

9. ผู้ป่วยของท่านได้รับการรักษาด้วยการฟอกไตในขณะที่อยู่ในหอผู้ป่วยหนักหรือไม่
   - ใช่ (0)
   - ไม่ใช่ (1)
   - ไม่ทราบ (8)
10. ท่านคิดว่าผู้ป่วยของท่านได้รับระบบประสาทในจำนวนที่ถูกต้องหรือไม่ในขณะที่อยู่ในหอผู้ป่วยหนัก
   ___ ใช้ (0)
   ___ ไม่ใช้ (1)
   ___ ไม่ทราบ (8)

11. ครอบครัวของผู้ป่วยได้พูดคุยความประสงค์ของเขากับการดูแลผู้ป่วยเด็กในระยะสุดท้ายของชีวิตกับแพทย์หรือไม่ เช่น การช่วยฟื้นคืนชีพ
   ___ ใช้ (0)
   ___ ไม่ใช้ (1)
   ___ ไม่ทราบ (8)

12. ท่านคิดว่าผู้ป่วยของท่านได้รับการดูแลให้มีชีวิตอยู่นานเกินไปหรือไม่
   ___ ใช้ (0)
   ___ ไม่ใช้ (1)
   ___ ไม่ทราบ (8)

13. ท่านจะให้คะแนนคุณภาพการรักษาผู้ป่วยเด็กและทารกในระยะสุดท้ายของชีวิตอย่างไรบ้าง
   โปรดทำเครื่องหมาย O ในช่องที่ตรงกับความคิดเห็นของท่านมากที่สุด

<table>
<thead>
<tr>
<th>ไม่ดี</th>
<th>พอใช้</th>
<th>ดี</th>
<th>ดีมาก</th>
<th>ดีเลิศ</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

ประสบการณ์ของผู้ป่วยทางการและเด็กขณะตาย

คำถามต่อไปนี้จะเกี่ยวกับผู้ป่วยเด็กและทารกที่กำลังจะตายในหอผู้ป่วยหนัก โปรดทำเครื่องหมาย √ หน้าข้อที่เหมาะสม

14. มีบุคคลโดยเฉพาะบุคคลหนึ่ง เช่น ครอบครัว เพื่อนหรือบุคลากรทางด้านสุขภาพอยู่ด้วยในขณะที่ผู้ป่วยกำลังตาย
   ___ ใช้ (0)
   ___ ไม่ใช้ (1)
   ___ ไม่ทราบ (8)
15. ในขณะที่ผู้ป่วยเด็กและทารกกำลังตาย ผู้ป่วยอยู่ในภาวะ
   _____ตื่น (1)
   _____นอนหลับ (2)
   _____ไม่รู้สึกตัว (3)
   _____ไม่ทราบ (8)

16. พ่อแม่หรือบุคคลอันเป็นที่รักในเวลาที่เห็นพ่อในอาการที่จะกล่าวคำอ่อลากับผู้ป่วยทารกและเด็กในขณะที่ผู้ป่วยกำลังตาย เช่น พ่อและแม่ที่ทารก
   _____ใช้ (0)
   _____ไม่ใช้ (1)
   _____ไม่ทราบ (8)

17. พ่อแม่หรือบุคคลอันเป็นที่รักในเวลาที่เห็นพ่อในอาการที่จะกล่าวคำอ่อลากับผู้ป่วยทารกและเด็กในขณะที่ผู้ป่วยกำลังตาย เช่น พ่อและแม่ที่ทารก
   _____ใช้ (0)
   _____ไม่ใช้ (1)
   _____ไม่ทราบ (8)

18. ในภาพรวม ท่านจะให้คะแนนคุณภาพการดูแลผู้ป่วยขณะใกล้ตายอย่างไร โปรดทำเครื่องหมาย ในช่องที่ตรงกับความคิดเห็นของท่านมากที่สุด

<table>
<thead>
<tr>
<th>ไม่ดี</th>
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</tr>
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<tr>
<td>1</td>
<td>2</td>
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<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

การตอบในภาพรวม
คำถามต่อไปนี้จะเกี่ยวกับคุณภาพการดูแลที่ผู้ป่วยในระยะสุดท้ายของชีวิตได้รับขณะอยู่ในหอผู้ป่วยหนัก โปรดทำเครื่องหมาย ในช่องที่ตรงกับความคิดเห็นของท่านมากที่สุด

19. ให้คะแนนคุณภาพการดูแลที่ผู้ป่วยของท่านได้รับจากพยาบาลในระยะสุดท้ายของชีวิตในขณะที่อยู่ในหอผู้ป่วยหนัก

<table>
<thead>
<tr>
<th>ไม่ดี</th>
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</thead>
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<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
20. ให้คะแนนคุณภาพการดูแลที่ผู้ป่วยของท่านได้รับจากแพทย์ในระยะสองสามวันสุดท้ายของชีวิตในขณะที่อยู่ในหอผู้ป่วยหนัก

<table>
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</tr>
</thead>
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<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
APPENDIX E
The Modified National Survey of Critical Care Nurses’ Perceptions regarding End-of-Life Care (Thai Version)
<table>
<thead>
<tr>
<th>ข้อคำถาม</th>
<th>ความเข้าใจของอุปสรรค</th>
<th>ความถี่ของการเกิดอุปสรรค</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. การออกแบบหอผู้ป่วยที่ไม่เหมาะสมเป็นสิ่งที่ไม่เอื้อถึงความเป็นส่วนหนึ่งของผู้ป่วยที่ไกลเสี่ยงซึ่งทรัพยากรโรคเก่าเสี้ยงของสมาชิกครอบครัว</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>8. เวลาเยี่ยมของหอผู้ป่วยถูกจำกัดมากเกินไป</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>9. ผู้ป่วยมีความเจ็บปวดที่ยากจะควบคุมหรือบรรเทาอาการ</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>10. การรับมือกับความแตกต่างด้านวัฒนธรรมที่แต่ละครอบครัวใช้แสดงความเศร้าโศกต่อสมาชิกครอบครัวที่ใกล้เสียชีวิต</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>11. ไม่มีบุคคลที่เข้ามาให้บริการรักษาสนับสนุนครอบครัวเช่น นักสังคมสงเคราะห์ หรือผู้นำทางศาสนา</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>12. ให้การดูแลแบบวิถีที่ดีถูกจำกัดเนื่องเพื่อช่วยเหลือชีวิตของผู้ป่วยยังคงมีความเสี่ยงของการรักษาเสี่ยงเนื่องจากกลั่นแกล้งความมีศักดิ์ศรีและความเสี่ยงจากการเกิดขึ้นระหว่างหรือจากการชักช้าจากครอบครัวของผู้ป่วย</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>13. ไม่มีโอกาสให้ครอบครัวได้แสดงความเศร้าโศกเศร้าหลังการเสียชีวิตของผู้ป่วยอย่างเต็มที่เนื่องจากต้องเตรียมเตียงนั้นเพื่อรับผู้ป่วยรายใหม่</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>14. โดยมีการให้การรักษาอย่างต่อเนื่องสำหรับผู้ป่วยใกล้ตายถึงแม้ว่าการรักษาสั้นจะเป็นสาเหตุทำให้ผู้ป่วยเกิดความเจ็บปวดหรือไม่สุขสบาย</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>15. ครอบครัวและเพื่อนมีโอกาสสอบถามข้อมูลอาการของผู้ป่วยจากแพทย์มากกว่าจะสอบถามจากสมาชิกครอบครัวที่ดูแลผู้ป่วย</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>16. แพทย์มีความรู้และการฝึกอบรมเกี่ยวกับการดูแลครอบครัวที่มีอาการโรคเก่าและผู้ป่วยในระยะสุดท้ายของชีวิตต้องมีความ</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>17. แพทย์ไม่ยอมปล่อยให้ผู้ป่วยเสียชีวิตตามสถานการณ์ด้านหน้าของโรค</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>18. แพทย์มีการรับมืออย่างต่อเนื่องในการรับผู้ป่วยใหม่หรือช่วยเหลือผู้ป่วยคนเดิมและผู้ป่วยของช่วงที่มีน้ำตาเต็มที่ในการดูแลผู้ป่วยและครอบครัวที่ได้รับมอบหมาย</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>ข้อคําถาม</td>
<td>ความเข้าใจของอุปสรรค</td>
<td>ความถี่ของการเกิดอุปสรรค</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------------------</td>
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</tr>
<tr>
<td>19. ไม่มีการจำกัดเวลาเยี่ยมของหอผูป่วย</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>20. สมาชิกครอบครัวรับไม่เข้าใจว่า “อะไรคือความหมายที่แท้จริงของวิธีการช่วยชีวิต” ตัวอย่างเช่น เข้าใจว่าอบเชยมาตกลงที่จะให้เกิดความเจ็บปวดและดอก, การใส่สติกเกินหน้าหายใจที่จะให้ผูป่วยไม่สามารถพูดคุย หรือการอื่นซึ่งควรจะทำมันระหว่างการหมดหน้าอก</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>21. พยาบาลไม่ทราบความปรารถนาของผูป่วยว่าต้องการที่จะรักษาหรือไม่ เพราะไม่สามารถดีต่อต่อสายกับผูป่วย เนื่องจากผูป่วยอยู่ในภาวะที่ระบบประสาทถูกกดหรือได้รับยาสงบประสาท</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>22. พยาบาลมักต้องรับมือกับความเครียดของสมาชิกครอบครัว</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>23. ไม่ว่าเหตุผลใดก็ตาม ครอบครัวไม่ได้ยึดถือผูป่วยขณะที่เข้าร้องขอการช่วยเหลือชีวิต</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>24. แพทย์บอกปิดหรือหลีกเลี่ยงการสัมภาษณ์กับสมาชิกครอบครัว</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>25. มีแพทย์หลายสาขาที่เข้ามาเกี่ยวข้องในการดูแลผูป่วย หนึ่งคนซึ่งมีความคิดเห็นที่แตกต่างกันในเรื่องแนวทางการดูแลผูป่วย</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>26. ความคิดเห็นของพยาบาลเกี่ยวกับแนวทางในการดูแลผูป่วยไม่ได้รับความสนใจ ไม่เห็นคุณค่าหรือไม่ได้รับการพิจารณา</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
</tbody>
</table>

27. กรุณาให้ข้อมูลเพิ่มเติมเกี่ยวกับอุปสรรคในการดูแลผูป่วยทารกและเด็กระยะสุดท้ายเพื่อให้เอกสารจากข้อคําถามที่กล่าวมาข้างต้น

1.___________________________________________________________________________
2.___________________________________________________________________________
3.___________________________________________________________________________
ส่วนที่ 2: แบบสอบถามเกี่ยวกับปัจจัยสนับสนุนในการดูแลผู้ป่วยทารกและเด็กในระยะสุดท้ายของชีวิต

ค่าชี้แจง: ข้อความต่อไปนี้เกี่ยวกับการรับรู้ของท่านในเรื่องเกี่ยวกับปัจจัยช่วยเหลือสนับสนุนที่อาจจะเป็นไปได้ในการให้การดูแลในระยะสุดท้ายของชีวิตแก่ผู้ป่วยที่อยู่ในภาวะใกล้ตายและครอบครัวของพวกเขา เมื่อท่านอ่านข้อความแต่ละข้อความแล้วโปรดทำเครื่องหมาย✔ ใน O ตรงกับหมายเลขที่ใกล้เคียงกับการรับรู้ของท่านมากที่สุด จงเปรียบเทียบข้อมูลที่เก็บรวบรวมมาและทำเครื่องหมาย✔ ใน □ ตรงกับหมายเลขที่ไกลคือเก็บข้อมูลจากการรับรู้ของท่านมากที่สุดในเรื่องความถี่ที่ท่านพบประสบการณ์การได้รับปัจจัยช่วยเหลือสนับสนุนนั้นๆ และท่านให้การดูแลผู้ป่วยที่อยู่ในภาวะใกล้ตาย

<table>
<thead>
<tr>
<th>ข้อคำถาม</th>
<th>ความเข้มข้นของปัจจัยช่วยเหลือสนับสนุน</th>
<th>ความถี่ของการได้รับปัจจัยช่วยเหลือสนับสนุน</th>
</tr>
</thead>
<tbody>
<tr>
<td>28. มีสมาชิกครอบครัวหนึ่งคนที่ได้รับมอบหมายให้เป็นตัวแทนสมาชิกคนอื่นในการติดต่อเพื่อให้ข้อมูลผู้ป่วย</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>29. มีเวลาเพียงพอที่จะเตรียมครอบครัวเกี่ยวกับการเสียชีวิตของผู้ป่วย</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>30. ครอบครัวมีสามารถแสดงความเศร้าโศกอย่างเป็นส่วนตัว</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>31. มีแพทย์เข้าไปเกี่ยวข้องในชั้นของการตกลงเกี่ยวกับแนวทางการดูแลผู้ป่วย</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>32. มีการพูดคุยกับครอบครัวเกี่ยวกับความรู้และความคิดเกี่ยวกับการดูแลผู้ป่วย</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>33. พยาบาลมีการจัดการระบบดำเนินการให้ผู้ป่วยให้ได้รับการดูแลอย่างต่อเนื่อง</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>34. มีครอบครัวช่วยดูแลร่วมกับผู้ป่วยที่อยู่ในภาวะใกล้ตาย</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>35. การพูดคุยกับครอบครัวของผู้ป่วยเกี่ยวกับความสึกเสียและความคิดเกี่ยวกับการดูแลผู้ป่วยที่อยู่ในภาวะใกล้ตาย</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
</tbody>
</table>
ข้อคำถาม | ความเข้าใจของผู้ป่วย | ความถี่ของการได้รับ
ช่วยเหลือสนับสนุน | ช่วยเหลือสนับสนุน

<p>| 36. การอนุญาตให้นักสังคมสงเคราะห์หรือผู้นำทางท้องถิ่นให้การดูแลแก่บุคคลที่อยู่ในภาวะใกล้ตาย | 0 1 2 3 4 5 | 0 1 2 3 4 5 |
| 37. การสนองตอบข้อสงสัยหรือวิธีการที่จะปฏิบัติต่อผู้ป่วยที่อยู่ในภาวะใกล้ตาย | 0 1 2 3 4 5 | 0 1 2 3 4 5 |
| 38. อนุญาตให้ครอบครัวทำเรื่องคัดแยกยอดมันด้วย | 0 1 2 3 4 5 | 0 1 2 3 4 5 |
| 39. จัดสถานที่ทำเรื่องคัดแยกยอดมันด้วยกับกระบวนการเรียบร้อยและผสมกันดีหรือส่งผลสูตรครอบครัวเมื่อผู้ป่วยเสียชีวิต | 0 1 2 3 4 5 | 0 1 2 3 4 5 |
| 40. อนุญาตให้ครอบครัวทำเรื่องคัดแยกยอดมันด้วยกับการพยาบาลผู้ป่วยหลังจากที่เขาหรือเธอเสียชีวิต | 0 1 2 3 4 5 | 0 1 2 3 4 5 |
| 41. มีพยาบาลผู้ร่วมงานบอกท่านว่า “คุณได้ทำทั้งหมดที่คุณสามารถทำให้กับผู้ป่วยแล้ว” หรือคำพูดให้กำลังใจอื่นๆ | 0 1 2 3 4 5 | 0 1 2 3 4 5 |
| 42. มีพยาบาลผู้ร่วมงานบอกท่านว่า “คุณได้ทำทั้งหมดที่คุณสามารถทำให้กับผู้ป่วยแล้ว” หรือคำพูดให้กำลังใจอื่นๆ | 0 1 2 3 4 5 | 0 1 2 3 4 5 |
| 43. มีพยาบาลผู้ร่วมงานช่วยทำเรื่องคัดแยกยอดมันด้วยกับการพยาบาลผู้ป่วยหลังจากที่เขาหรือเธอเสียชีวิต | 0 1 2 3 4 5 | 0 1 2 3 4 5 |
| 44. มีการให้กำลังใจจากบุคลากรนอกจากที่ทำงานซึ่งรับผิดชอบงานของท่านหลังจากการเสียชีวิตของผู้ป่วย | 0 1 2 3 4 5 | 0 1 2 3 4 5 |
| 45. มีสมาชิกครอบครัว lokal ได้มีการให้กำลังใจเป็นอย่างมากกับการพยาบาลผู้ป่วยหลังจากที่เขาหรือเธอเสียชีวิต | 0 1 2 3 4 5 | 0 1 2 3 4 5 |
| 46. มีสมาชิกของคณะกรรมการจริยธรรมเข้ามาดูแลผู้ป่วยหลังจากที่เขาหรือเธอเสียชีวิต | 0 1 2 3 4 5 | 0 1 2 3 4 5 |
| 47. สมาชิกครอบครัวยอมรับว่าผู้ป่วยยังคงมีการใช้จ่ายทางด้านการดูแลผู้ป่วย | 0 1 2 3 4 5 | 0 1 2 3 4 5 |
| 48. หลังจากการเสียชีวิตของผู้ป่วย มีเจ้าหน้าที่ช่วยท่านในการรวบรวมเอกสารที่จำเป็นเพื่อให้ครอบครัวชื่นชื่น | 0 1 2 3 4 5 | 0 1 2 3 4 5 |</p>
<table>
<thead>
<tr>
<th>ข้อคำถาม</th>
<th>ความเข้มข้นของปัจจัยช่วยเหลือสนับสนุน</th>
<th>ความถี่ของการได้รับปัจจัยช่วยเหลือสนับสนุน</th>
</tr>
</thead>
<tbody>
<tr>
<td>ก่อนที่พวกเขาจะออกจากหอผู้ป่วย</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>49. แพทย์ที่ช่วยเหลือที่เป็นไปได้รับการสนับสนุน</td>
<td>0 0 0 0 0</td>
<td>0 0 0 0 0</td>
</tr>
<tr>
<td>ตัวอย่างเช่น ผู้ป่วยที่ถูกไปในสภาพพื้นที่ 1 ใน 100 ที่จะ</td>
<td></td>
<td></td>
</tr>
<tr>
<td>พื้นที่ดับมาเป็นปกติตามเดิม</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50. มีแพทย์มาพบทุกครั้งหลังจากการเสียชีวิต</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>ของผู้ป่วยเพื่อเสนอการช่วยเหลือและให้ความมั่นใจกับครอบครัวเกี่ยวกับความถูกต้องของการรักษาที่ได้ให้กับผู้ป่วย</td>
<td>0 0 0 0 0</td>
<td>0 0 0 0 0</td>
</tr>
<tr>
<td>51. มีบุคลากรที่ไม่มีใบประกอบโรคศิลป์คอยช่วยเหลือผู้ป่วยใกล้เสียชีวิต</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>0 0 0 0 0</td>
<td>0 0 0 0 0</td>
</tr>
</tbody>
</table>

52. ควรให้ข้อมูลเพิ่มเติมเกี่ยวกับปัจจัยสนับสนุนในการดูแลผู้ป่วยทารกและเด็กระยะสุดท้ายนอกเหนือจากข้อคำถามที่กล่าวมาข้างต้น

1. __________________________________________________________
2. __________________________________________________________
3. __________________________________________________________

53. หากท่านต้องการเปลี่ยนแปลงการดูแลผู้ป่วยทารกและเด็กในหอผู้ป่วยหนึ่งสิ่งสำคัญที่ท่านต้องการจะเปลี่ยนแปลงคือ

1. __________________________________________________________
2. __________________________________________________________
3. __________________________________________________________
APPENDIX F

Permission Letter for Questionnaires

Permission Letter for Quality of Dying and Death Questionnaire

Dear Professor Downey,

My name is Jutarat Mesukko. I am a PhD student in the Nursing School at Case Western Reserve University. My dissertation is about critical care nurses’ perception of quality of dying and death, barriers and facilitators to providing end of Life care in intensive care unit in Thailand. I found QODD questionnaire was used in several research papers. This questionnaire is very useful to collect the data for my dissertation and my country. I would like to ask your permission to use the QODD instrument in my dissertation. Thank you in advance for your consideration. I am looking forward to hearing from you.

Sincerely yours,
Jutarat Mesukko
PhD Student
Frances Payne Bolton School of Nursing
Case Western Reserve University
10900 Euclid Avenue
Cleveland, OH 44106

Jutarat --

The various QODD instruments are all available from our website at http://depts.washington.edu/eolcare/instruments/index.html. It’s my understanding that they are available free of charge to other researchers, but I am copying Ruth Engelberg, the Associate Director of our research program, so she can confirm that.

— Lois Downey

Yes, it is fine to use any of our instruments, including the QODD, that are available on our website. Good luck with your project!

Ruth Engelberg, Ph.D.
Associate Director, End-of-Life Care Research Team
University of Washington, Division of Pulmonary and Critical Care
Box 359765
Phone: 206-744-9523
Fax: 206-744-9982
email: rengei@u.washington.edu
Permission Letter for National Survey of Critical Care
Nurses’ Perceptions of End-of-life Care

Dear Dr. Kirchhoff,

My name is Jutarat Mesukko. I am a PhD student in the Nursing School at Case Western Reserve University. I am currently working on my proposal for dissertation: ‘The quality of dying and death, barriers and facilitators to providing end of Life care in PICUs in Thailand: Critical care nurses’ perceptions’. I have got QODD questionnaire. I am looking for barriers and facilitators questionnaires.

I have read your articles about critical care nurses' perceptions of obstacles and helpful / supportive behaviors to providing end of life care. I am very impressed with your works. I have found wonderful questionnaires which are very useful for my dissertation and my country. There are few researches about end of life care in Thailand. I think perhaps, I am the first one to focus on quality, barriers, and facilitators in end of life care in my country.

I consulted my committees about your questionnaires, everyone is strongly agree that they are very useful for my work. Moreover, one of my committee, Dr. Barbara Daly, personally appreciates your works.

Lastly, I would like to ask your permission to use these instruments in my dissertation. Thank you in advance for your consideration. I am looking forward to hearing from you.

Sincerely yours,
Jutarat Mesukko, PhD student
Frances Payne Bolton School of Nursing
Case Western Reserve University
10900 Euclid Aven.
Cleveland, Ohio, 44106-4904

Sure you have my permission. If I can be helpful as a reader of your dissertation or anything else that Case will allow, I am willing to do that. I am the most interested in trying to improve EOL in the ICU right now. I will retire in January and hope to have more time for what interests me. I will be receiving email at this address but will be living in Salt Lake City.

Karin
Dear Critical Care Nurses,

Ten days ago, a questionnaire packet was distributed to you seeking your opinion regarding the quality of dying and death, barriers and facilitators to providing end-of-life care for dying children and infants in the intensive care unit. If you have already returned your questionnaire, thank you for your help on this very important study. If you have not responded, please complete and return the questionnaire today in the locked box provided in your unit. I would greatly appreciate your participation.

Sincerely,
Jutarat Mesukko
PhD Candidate, School of Nursing
APPENDIX H

The 20 Day Follow-Up Reminder Card for Questionnaire

Dear Critical Care Nurses,

This card is to remind you that several weeks ago, a questionnaire packet was distributed to you seeking your input in an important study regarding the quality of dying and death, barriers and facilitators to providing end-of-life care for dying children and infants in the intensive care unit. If you have already completed and returned it, thank you very much for your participation.

If you have not yet responded, it would be highly appreciated if you would return the questionnaire today. Your information is extremely important for the results of the study. These results will help us to improve the quality of end-of-life care for infants and children and their families.

If you need a replacement questionnaire or did not receive one or have any questions about this study, please contact me at 0861932422 or email: jmesukko@yahoo.com.

Thank you very much for your time and participation

Jutarat Mesukko
PhD Candidate, School of Nursing
Case Western Reserve University
Cleveland OH 44106-4904 U.S.A
REFERENCES


education in palliative medicine and end-of-life care. *Journal of Palliative Medicine, 10*(2), 420-429.


communication about end-of-life care in the intensive care unit: Opportunities for improvement. *Critical Care Medicine, 29*(2 Suppl), N26-33.


