PALLIATIVE/END-OF-LIFE CARE IN THE NEWBORN
INTENSIVE CARE UNIT

by

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ABSTRACT

Advances in neonatal critical care in the past 3 decades have dramatically improved the life-saving capability of medical providers in the care of critically ill infants. However, a population of infants exists whose lives cannot be saved despite the most advanced medical therapies. Neonatal palliative/end-of-life care protocols provide guidance for medical providers in giving care to infants and their families at the end of life.

This descriptive study determined the presence of palliative/end-of-life care protocols in two newborn intensive care units (NICUs). The study also explored the experiences and attitudes of NICU registered nurses (RNs) and neonatal nurse practitioners (NNPs) in providing care to infants at the end of life. This study served as a basis for exploring the current practices and attitudes of RNs and NNPs about neonatal end-of-life care in order to assess the need for the institution of a formalized palliative/end-of-life care protocol in these particular NICUs.

An absence of palliative/end-of-life care protocols was found in both NICUs in this study. The majority of RNs and NNPs indicated that they believed the addition of a palliative/end-of-life care protocol would be at least somewhat helpful to them in providing care to infants and their families at the end of an infant’s life. The respondents reported that providing palliative/end-of-life care was a positive experience overall. RNs with more years of NICU experience reported being more
comfortable than RNs with fewer years of NICU experience in providing care to infants at the end of life. Comfort in providing care at the end of life was also increased with higher numbers of infants cared for at the end of life. Several common themes regarding RN and NNP perceptions of skills, concerns, and rewards in providing neonatal palliative/end-of-life care were found.
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INTRODUCTION

Advances in technology, medicine, and pharmacotherapy have led to dramatic improvements in the life-saving capabilities of practitioners who care for critically ill infants. The life-saving care of extremely low birth weight infants and those with morbidities such as sepsis, necrotizing enterocolitis, meconium aspiration syndrome, and congenital heart disease occurs on a daily basis in newborn intensive care units (NICUs) in industrialized countries throughout the world. Despite the phenomenal advances in neonatal care in the past few decades, a population of infants exists whose lives cannot be saved regardless of the most intensive therapies (Nelson, 2001). Some parents choose elective withdrawal of treatments in cases of lethal congenital anomalies or morbidities such as severe hypoxic ischemic encephalopathy or intraventricular hemorrhage when neurological devastation has occurred (Cook & Watchko, 1996). Discontinuing life-extending treatment or aggressive cure-oriented care is considered to be ethical as well as medically appropriate in cases when infants are deemed to be extremely premature, have lethal birth defects, or have complicated neonatal courses (Carter & Bhatia, 2001).

An emerging issue in neonatal care is the creation of palliative/end-of-life care protocols. Palliative care focuses on providing comfort care to patients who have diseases that are not responsive to curative treatment and also focuses on
prevention, reduction, or soothing of symptoms at the end of life. Palliative care is also used to help patients and families reconcile conflicts and to derive meanings from end-of-life experiences (Ferrell & Coyle, 2002). Palliative care is different from end-of-life care, which focuses on care of the patient when death is imminent (Ferrell & Coyle, 2002). Death often occurs acutely in the NICU, leaving little time for the transition from palliative care to end-of-life care. Palliative care and end-of-life care are generally provided simultaneously in the NICU because death often occurs acutely (Catlin & Carter, 2002). The combination of neonatal palliative/end-of-life care differentiates it as a separate entity from the palliative and end-of-life care of older children or adults. Palliative/end-of-life care protocols that are designed specifically for the NICU offer guidelines for medical providers on the care of dying infants, family support, and the ongoing support of NICU staff (Catlin & Carter, 2002). Palliative/end-of-life care protocols do not exist in many NICUs throughout the United States (Carter & Bhatia, 2001).

A paucity of research exists about the experiences of palliative/end-of-life care in the NICU from the perspective of registered nurses (RNs) and neonatal nurse practitioners (NNPs). Several recently published articles have discussed the need for end-of-life care protocols in the NICU (Catlin & Carter, 2002; Glicken & Merenstein, 2002; Peirucci, Kirby, & Luethner, 2001). These protocols for palliative/end-of-life care are recommended to ensure that in the case of the death of an infant certain steps are taken to make the experience one of comfort, dignity, and respect for the infant and the family (Glicken & Merenstein, 2002).
Research Questions

Despite the availability of published protocols for end-of-life care in the NICU, there appears to be a lack of education and standardization of palliative/end-of-life care protocols in the NICU. The first purpose of this descriptive study was to determine the presence of palliative/end-of-life care protocols in two NICUs in the intermountain west. The second purpose of this study was to explore the experiences and attitudes of NICU RNs and NNPs in providing care to infants at the end of life. The research questions are:

1. Do the NICUs that employ these RNs and NNPs have palliative/end-of-life care protocols?
2. What types of educational preparation have these RNs and NNPs had in order to provide palliative/end-of-life care in NICUs?
3. How do neonatal RNs’ and NNPs’ experiences in providing palliative/end-of-life care compare to the experiences of RNs in other intensive care unit (ICU) settings?

Background and Significance

In 2000, there were 18,776 neonatal deaths in the United States (Anderson, 2002). A majority were due to prematurity and congenital anomalies. Other major contributors to neonatal death were maternal and placental complications, respiratory distress, sepsis, asphyxia, hemorrhage, and necrotizing enterocolitis (Anderson, 2002). The idea of palliative care for dying infants was first recognized in the literature more than 30 years ago (Duff & Campbell, 1973). A relative lack
of literature in the 1980s about the withdrawal of life support and management of end-of-life care in infants led to a lack of consistency among providers in initiating palliative/end-of-life care in the NICU, particularly with advances in neonatal care leading to the use of life-saving measures of more extremely low birth weight infants and infants of decreasing gestational age. The inconsistency of the care of dying infants has also led to ethical debates in hospitals and court rooms (Carter & Bhatia, 2001).

A policy statement by the American Academy of Pediatrics (1995) asserts that a definite treatment dilemma has come into existence with respect to initiation of the treatment of high-risk newborns (including the extremely premature and those with potentially lethal congenital anomalies), since it is difficult to determine what type of treatment is in the best interest of the infant at birth. Not providing immediate resuscitation to these infants may result in poor neurologic outcomes if they do survive, but providing extensive resuscitation efforts when the life cannot be saved may result in prolongation of dying or iatrogenic illness (American Academy of Pediatrics, 1995).

The ethical dilemmas of when to resuscitate extremely low birth weight or premature infants and when to continue life-sustaining measures in severely ill infants continue. The most common protocol in resuscitation of potentially nonviable infants is to resuscitate and offer technological support to all infants and then to determine whether or not the infant will benefit from treatment (Abe, Catlin, & Mihara, 2001). The practice of aggressive resuscitation followed by the
decision to discontinue life support leaves little time for palliative care to occur, since death often occurs acutely.

Studies conducted during the past decade suggest that approximately 82% of deaths in the neonatal population occurred after decisions were made by medical providers and parents to withdraw or withhold life-sustaining treatment (Cook & Watchko, 1996). Peirucci and colleagues (2001) conducted a study at the Children’s Hospital of Wisconsin. They found that even in the presence of a palliative care service, a majority of infants who had died over a 3-year period died while undergoing aggressive support in their last 48 hours of life. Abe and colleagues (2001) conducted a study on ventilator withdrawal in end-of-life care in the NICU. They found a lack of consistency in the chart documentation of end-of-life care in infants who died after ventilator removal. Clinical implications of the study were that there is a need for improved provision and documentation of certain aspects of neonatal end-of-life care, including pain and symptom management, orders for ventilator withdrawal, parent participation in decision making, and staff support to parents of dying infants (Abe et al., 2001).

The process of changing the focus of care from an aggressive and cure-oriented approach to a palliative or care-oriented approach is difficult for providers (Glicken & Merenstein, 2002). One reason palliative care is underutilized in infants is the general philosophy of medical providers to often opt for all medical therapies before allowing an infant to die (Peirucci et al., 2001). Many health-care professionals do not receive formal palliative care education (Ferrell, Grant, &
Virani, 1999; Glicken & Merenstein, 2002). In addition, they may not cope well with their own emotional, spiritual, and psychological feelings about the process of death that leaves them at a disadvantage in providing palliative services (Catlin & Carter, 2002).

A paucity of research about palliative/end-of-life care protocols in the NICU exists that specifically relate to the formation, initiation, and efficacy of palliative/end-of-life care protocols in the NICU. The relative lack of literature about the initiation of such protocols in the NICU is disturbing, considering the fact that approximately half of the deaths of children (birth to 19 years) occurs in infants up to 1 year of age (Institute of Medicine, 2003). In 2003, the Institute of Medicine published *When Children Die: Improving Palliative and End-of-life Care for Children and Their Families*, which gives many recommendations for the care of dying children. Unfortunately, similar to the general body of palliative/end-of-life care literature, the text gives few recommendations specific to palliative/end-of-life care of infants in the NICU. Studies that describe the experiences of RNs and NNPs in providing palliative/end-of-life care in the NICU were also absent in the literature.

Although there is a lack of research about RNs' experiences with palliative/end-of-life care in the NICU, several studies have examined the experiences of RNs with end-of-life care in other ICU settings (Kirchhoff, Spuhler, Walker, Hutton, & Cole, 2000; Miller, Forbes, & Boyle, 2001; Puntillo et al., 2001). RNs experience moral and ethical tensions while caring for patients at the
end of life (Puntillo et al., 2001). In the midst of these tensions, RNs have stated that variables such as improved education about end-of-life care and better communication not only among staff members but with patients’ families as well would improve end-of-life care (Kirchhoff et al., 2000).

Catlin and Carter (2002) formulated an end-of-life palliative care protocol for the NICU. They developed the protocol using Delphi methodology to create a consensus statement outlining the essentials of a neonatal palliative care program. They used 16 palliative care protocols and the consensus of 101 professionals (e.g., physicians, nurses, ethicists, researchers, and social workers) from throughout the world in developing an alternative care model for dying infants. The approach developed was to provide palliative care to dying infants by emphasizing compassionate and culturally sensitive care to the infants, their parents, their family members, and the health-care professionals involved in their care. The protocol gives guidelines and recommendations for a variety of issues in the end-of-life care of infants (e.g., a palliative care model for parents, an optimal environment for infant death, a location for the provision of palliative care, ventilator removal, pain and symptom management, discussion of organ procurement and autopsy, family care, and ongoing staff support) (Catlin & Carter, 2002).

The death of an infant can be an emotionally taxing and devastating experience for all caregivers involved. The creation and institution of a neonatal palliative/end-of-life care protocol in the NICU is essential in providing care to
infants who cannot be saved, despite the most intensive medical care. Education about palliative care and the self-reflection of medical providers on the feelings and beliefs about death are essential elements that must be present for the provision of appropriate, supportive, and culturally sensitive end-of-life care in the NICU.

**Conceptual Framework**

Several variables affect the provision of palliative/end-of-life care to infants by RNs and NNPs. Some of those variables are an individual’s experience in providing palliative/end-of-life care, his or her comfort level in providing palliative/end-of-life care, and his or her cultural beliefs and values about death. The provision of care by RNs and NNPs to infants also affects the parents and extended family of these infants during and long after death. The care that these RNs and NNPs provide also affects them in subsequent experiences in providing palliative/end-of-life care. The use of a palliative/end-of-life care protocol influences the provision of care by RNs and NNPs that affects not only the dying infant but the infant’s parents and extended family as well (see Figure 1).

An assumption of this study is that a written protocol for providing palliative care to infants would assist practitioners in providing better care for infants and their families at the end of life. The presence of a protocol and education on how to use the protocol before having the experience of providing end-of-life care allows practitioners to explore their feelings, beliefs, and values about death in advance. This exploration may improve their comfort level by providing palliative/end-of-life care at a later date. Palliative/end-of-life care
Protocols provide guidance when working with families at the end of an infant's life; specifics of caring for the infant (e.g., pain management, ventilator withdrawal, and comfort care); and recommendations for practitioners in dealing with their own feelings about the death of an infant. A second assumption of this study is that a palliative/end-of-life care protocol would increase the comfort level of practitioners in providing palliative/end-of-life care and would lead to an improvement in the provision of palliative/end-of-life care.

Figure 1. Variables affecting the provision of palliative/end-of-life care to infants by nurses and NNPs in the NICU.
METHODS

Design

A descriptive retrospective survey was used to evaluate the experiences and attitudes of NICU RNs and NNPs in providing care to infants at the end of life. The survey was also used to determine if palliative/end-of-life care protocols were being used in two Level III NICUs in the intermountain west. The first NICU (NICU A) was located in a regional high-risk perinatal center specializing in the care of extremely low birth weight infants. The second NICU (NICU B) was located in a regional children’s hospital that offers neonatal surgical services and treatments such as extracorporeal membrane oxygenation.

Sample

The NICUs were selected by convenience. The respondents were RNs and NNPs employed (full or part time) at the two sites at the time the surveys were distributed. Three hundred thirty-five surveys were distributed. At NICU A, 132 surveys were distributed to RNs and 20 surveys to NNPs. At NICU B, 158 surveys were distributed to RNs and 25 surveys to NNPs.

Instrument

Data were collected by a confidential survey to examine the RNs’ and NNPs’ experiences and attitudes about palliative/end-of-life care in the NICU (see
Appendix A). The survey also examined if the unit that the RNs and NNPs were employed in had an established protocol for palliative/end-of-life care. The survey included a majority of multiple-choice questions about the RNs’ and NNPs’ education, NICU experience, number of infants cared for at the end of life, and comfort level in providing palliative/end-of-life care. Four open-ended questions were asked to evaluate the attitudes and experiences of the participants in palliative/end-of-life care in the NICU. Participants were asked a series of demographic questions at the end of the survey.

Procedure

Approval by the Institutional Review Board was obtained prior to data collection. Participation in the study was voluntary. The survey was pilot tested on 10 volunteers (5 RNs and 5 NNPs) and modified for clarity and grammar prior to distribution to the potential participants. The cover letter (see Appendix B) and survey (see Appendix A) inviting the RNs and NNPs to participate in the study were placed in the participants’ mailboxes at each site. The participants were given a 2-week time period to complete and return the survey. The surveys were collected from a return box that had been placed in each unit. A reminder note was placed in each of the NICU staff lounges 1 week after initial distribution of the surveys and cover letters in an attempt to improve the response rate.
Analysis

Data were analyzed using SPSS® 12.0.1 for Windows (SPSS®, Inc., 2003). Descriptive statistics that included measures of central tendency and dispersion were computed. Qualitative analysis of open-ended questions was completed by reading and reviewing written responses of the participants and tallying similar responses. The related participant responses were assigned into groups of common themes.
RESULTS

The number of returned surveys at the end of the 2-week period was 140 out of 335 distributed for a response rate of 42%. The number of RN respondents was 121 (87%), and the number of NNP respondents was 18 (13%). No significant difference was found between RN and NNP responses. The educational preparation of respondents was bachelor’s degree (46%), associate’s degree (35%), diploma (3%), master’s degree (14%), and postbachelor’s certificate (1%). Respondents reported reading *Advances in Neonatal Care* (67%) and *Neonatal Network* (8%).

A majority of respondents (75%) reported working 36 or more hours per week, ranging from 12 to 72 hours per week. The experience of RN respondents providing care for infants in the NICU ranged from less than 1 year to more than 20 years (see Table 1). The experience of NNP respondents providing care for infants in the NICU ranged from less than 1 year to between 11 and 20 years. A majority of NNP respondents (61%) providing care for infants in the NICU had between 11 and 20 years of experience.

Neither NICU had a written palliative/end-of-life care protocol. When asked if the NICU where the respondents were employed had a written palliative/end-of-life care protocol, a majority were unsure (66%), 23% reported not having a protocol, and 11% reported having a protocol. Sixty-six percent of respondents stated that a palliative/end-of-life care protocol would be very helpful, 31%
Table 1

*Years of Experience of Respondents as NICU RNs Providing Palliative/End-of-life Care to Infants (N = 140)*

<table>
<thead>
<tr>
<th>Years of experience</th>
<th>n</th>
<th>%</th>
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<tbody>
<tr>
<td>Less than 1</td>
<td>19</td>
<td>13</td>
</tr>
<tr>
<td>1 to 3</td>
<td>30</td>
<td>21</td>
</tr>
<tr>
<td>4 to 10</td>
<td>43</td>
<td>31</td>
</tr>
<tr>
<td>11 to 20</td>
<td>26</td>
<td>19</td>
</tr>
<tr>
<td>Greater than 20</td>
<td>22</td>
<td>16</td>
</tr>
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somewhat helpful, and 3% not helpful.

Forty-four percent of respondents reported receiving education on neonatal palliative/end-of-life care. Forty-seven percent of respondents who received education on neonatal palliative/end-of-life care reported that they received it at nursing orientation. Respondents also reported receiving neonatal palliative/end-of-life care education at in-services (26%), conferences (24%), nursing school (2%), and on-the-job training (1%). Of those who received neonatal palliative/end-of-life care education, 51% stated that it was somewhat helpful, 26% very helpful, and 1% not helpful. The remainder of respondents were neutral whether or not their education on neonatal palliative/end-of-life care was helpful.

Seventy-two percent of respondents (n = 102) reported caring for an infant in the NICU at the end of his or her life. The number of infants cared for at the end of life varied, ranging from 0 to 1 infant (7%), 2 to 5 infants (40%), 6 to 10
infants (13%), 11 to 20 infants (13%), and more than 20 infants (28%).
Respondents identified multiple members of the health-care team who gave them assistance in providing palliative/end-of-life care (e.g., other RNs and NNPs, neonatologists, respiratory therapists, social workers, unlicensed assistive personnel, clergy, unit clerks, discharge planners, patient care coordinators, family care coordinators, and hospice personnel). Ninety-two percent of respondents stated that two or more members of the health-care team assisted them with palliative/end-of-life care, the most common being a combination of RNs, NNPs, neonatologists, and unlicensed assistive personnel (18%). Overall experiences in providing neonatal palliative/end-of-life care were reported as positive (70%), very positive (14%), neutral (15%), and negative (2%).

The level of comfort in specific aspects of providing palliative/end-of-life care was explored (see Table 2). Respondents reported being less comfortable overall in caring for the infant’s family and being more comfortable overall in working with other members of the health-care team; their nursing skills in caring for the infant at the end of life; and dealing with their own feelings, values, and beliefs when caring for the infant at the end of life. Comfort levels of RNs and NNPs in specific aspects of providing palliative/end-of-life care were compared to the number of infants cared for at the end of life. Only 46% of respondents who cared for 6 to 10 infants reported feeling completely comfortable in their nursing skills in caring for infants at the end of life. In a subgroup of respondents who cared for more than 20 infants at the end of life, 71% reported feeling completely
Table 2

Comfort Levels of RNs and NNPs in Aspects of Providing Neonatal End-of-life Care (N = 102)

<table>
<thead>
<tr>
<th>Aspects of providing neonatal end-of-life care</th>
<th>Comfort level (n of respondents reporting)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Completely</td>
</tr>
<tr>
<td>Caring for infant</td>
<td>28</td>
</tr>
<tr>
<td>Caring for family</td>
<td>18</td>
</tr>
<tr>
<td>Working with the health-care team</td>
<td>58</td>
</tr>
<tr>
<td>Nursing skills</td>
<td>44</td>
</tr>
<tr>
<td>Dealing with own beliefs, feelings, and values about death</td>
<td>60</td>
</tr>
</tbody>
</table>

*Note.* The percentage of respondents was not reported due to the n being close to 100; therefore, the percentage would be redundant.
comfortable in their nursing skills in caring for infants at the end of life. When comparing the number of infants cared for to the comfort level of caring for the infant’s family, 32% of respondents who cared for 2 to 5 infants reported feeling uncomfortable in caring for the infant’s family. Only 1% of respondents who cared for more than 20 infants reported feeling uncomfortable in caring for the infant’s family at the end of the infant’s life.

Experience measured by years working in the NICU was also compared to comfort in providing palliative/end-of-life care. In the group of RNs with 3 years or less experience in the NICU, none stated that they were comfortable in caring for the family at the end of an infant’s life compared to the group with more than 20 years of NICU experience in which 86% reported being comfortable in caring for the family at the end of an infant’s life. RNs who had more experience in the NICU also reported feeling more comfortable in working with the health-care team than RNs with less experience.

Respondents who had experience in providing end-of-life care to an infant were asked four open-ended questions. The respondents were asked what two skills they believed were most important for a nursing professional to have in the care of an infant at the end of life. The most common responses were compassion (38%) and empathy (22%). Other skills listed as important for a nursing professional to have while caring for an infant at the end of life were listening, being sensitive, having verbal/nonverbal communication skills, understanding the physiologic process of death in infants, understanding the cause of death, being supportive,
showing care and concern, being calm and patient, showing respect for
cultural/religious practices, knowing one’s own values, giving personal comfort
with death/self-awareness, expressing patient advocacy, being in tune with parents’
needs, having tact, being gentle, and having an ability to show emotion.

The second open-ended question asked was if the respondents had concerns
about providing end-of-life care to infants. The two most common themes were
concerns about providing adequate pain management (18%) and knowing how to
react/relate to the family of the dying infant (10%). Other themes involved
conscerns about care of the infant (e.g., having time and staff limitations, giving
life-prolonging care to infants when palliative care is more appropriate, waiting too
long to start end-of-life care, having medical staff agreement on the decision to
withdraw support, observing inconsistencies in the way end-of-life care is
provided, knowing how to do postmortem care and complete paperwork after
death, and receiving inconsistent orders by practitioners and physicians such as do
not resuscitate orders, discontinuing medications, and discontinuing equipment such
as heart and oxygen saturation monitors).

Themes that involved concerns about the care of the family of the infant
included when and how to present to families that end-of-life care is an option,
inconsistency of options offered to families, meeting the family’s religious and
cultural needs, ensuring that both parents agree on withdrawing support, providing
emotional support, and ensuring that the family is comfortable with the decision.
Themes identified by participants involving the participants’ own actions or
reactions included concerns about saying the wrong words, providing emotional support, meeting emotional needs of everybody, controlling one's own emotions, feeling deserted by team members, and dealing with their own psychological issues/recuperation from the experience.

When asked if there were rewards in providing end-of-life care to dying infants, 64% of respondents stated that a reward was knowing that they had provided support to the infant's family during a difficult time. In addition, 29% of respondents reported that ending suffering and providing comfort to the infant also made the provision of end-of-life care a rewarding experience. Other responses included providing the family with good memories, providing a peaceful end of life to the infant, witnessing a spiritual experience, providing closure, and assisting with the transition of life to death.

Respondents were also given the opportunity to list any additional comments about palliative/end-of-life care in the NICU. Several common themes about palliative/end-of-life care were identified. One theme identified concerns about legal aspects of providing palliative/end-of-life care in the NICU. For example, respondents stated: "I am concerned about legal aspects of caring for infants at the end of life." "When does [the infant] become DNR [do not resuscitate]?

A second common theme found when asking respondents to list any additional comments about palliative/end-of-life care was that they believed palliative/end-of-life care was important to families. For example, some respondents stated: "It is important to honor families with the decision to withdraw
support.” “Bathing and dressing the infant before removing life support is often helpful for families.” “Infant death after a code situation is much more difficult for families than a planned death.” “Palliative care is important to families later on.”

Another theme identified was the respondents recognized the potential emotional strain placed on staff caring for infants and their families at the end of life. For example, respondents stated: “The death of infants is difficult emotionally.” “One must be familiar with their own feelings, beliefs, and values before they can be effective at palliative care.” “We often prolong life when death is imminent because we feel like we have failed.” A final theme in the comments section was that a palliative/end-of-life care protocol would be helpful in providing guidance to RNs and NNPs who care for infants and their families at the end of life.

In summary, many themes were identified as a result of the open-ended questions on the survey. Themes extracted about palliative/end-of-life care were comprised after asking open-ended questions about skills important for nursing professionals to have and what rewards or concerns, if any, were present in the provision of palliative/end-of-life care. Themes were also identified after allowing the participants to list any additional comments.
DISCUSSION

One purpose of this study was to determine the presence of palliative/end-of-life care protocols in two select NICUs. The absence of neonatal palliative/end-of-life care protocols in these units was consistent with the findings of other studies that concluded that many NICUs throughout the United States do not have palliative/end-of-life care protocols (Abe et al., 2001; Carter & Bhatia, 2001; Catlin & Carter, 2002). Eleven percent of respondents stated that the NICU in which they worked had a palliative care protocol when the unit did not have a protocol at the time of the survey. The reason for the perception that the NICU had a protocol when it did not is unclear; however, the confusion may be related to end-of-life care education at nursing orientation that was misinterpreted as a protocol. A majority of participants (66%) in this study were unsure if the units where they worked had protocols, but almost all participants (97%) indicated that a palliative/end-of-life care protocol would be at least somewhat helpful in providing care to infants and their families at the end of life.

The second purpose of this study was to examine the experiences and attitudes of neonatal RNs and NNPs in providing palliative/end-of-life care in the NICU. Experiences of RNs and NNPs in providing palliative/end-of-life care in the NICU were evaluated by determining if they had previous education on neonatal palliative/end-of-life care and also by examining the number of infants who they
have cared for at the end of life. Many of the respondents (72%) had provided care to an infant at the end of life, but the majority had no education on neonatal palliative/end-of-life care (66%). Only 2% of respondents received education on neonatal palliative/end-of-life care in nursing school, which is similar to the findings of other researchers who concluded that health-care professionals are not receiving palliative/end-of-life care education in their general educational preparation (Ferrell et al., 1999; Glicken & Merenstein, 2002). In the absence of a neonatal palliative/end-of-life care protocol, the findings of the present study suggest that comfort in working with infants and their families at the end of the infants’ lives increases with experience. RNs and NNPs who cared for more than 20 infants at the end of life were more comfortable overall than practitioners who had cared for fewer than 5 infants. In the group of RNs with 3 years or less experience in an NICU, none stated that they were completely comfortable in caring for the family at the end of the infant’s life. However, in the group of RNs with more than 20 years of experience, 86% stated that they were either completely or at least somewhat comfortable with caring for the family at the end of the infant’s life. These data support the idea that a protocol that includes recommendations on caring for the family at the end of the infant’s life may be most helpful to less experienced nurses. Mentorship of less experienced nurses by RNs or NNPs with more palliative/end-of-life care experience may also be valuable in implementing palliative/end-of-life care protocols in the NICU.
The attitudes of RNs and NNPs in providing palliative/end-of-life care in the NICU were positive overall. Several themes about rewards in providing neonatal palliative/end-of-life care were found: “Knowing that you have provided support to a family during a difficult time.” “Stopping suffering.” “Providing comfort to the infant.” The experiences that RNs had in providing palliative/end-of-life care in this study were similar to RNs in other ICU settings (Kirchhoff et al., 2000; Miller et al., 2001; Puntilllo et al., 2001). The main concerns of RNs in both studies were pain management and communicating with family members. The analysis of adult ICU end-of-life care may have further value in organizing and implementing neonatal palliative/end-of-life care protocols.

Another common theme among respondents was concern about the “legal implications” of providing end-of-life care. One nurse stated that there are often “inconsistent orders by practitioners/physicians.” A second RN stated:

Sometimes it isn’t specified what the orders are—when to discontinue drips, when to give medications, when and what equipment to discontinue. Up to what point are we saving the baby and when exactly does he [or she] become DNR [do not resuscitate] and we let him [or her] go?

These concerns were consistent with the findings of Abe and colleagues (2001). These researchers studied ventilator withdrawal and end-of-life care in the NICU. They found a need for improved provision and documentation of certain aspects of neonatal end-of-life care, including pain and symptom management and orders for ventilator withdrawal.
Palliative/end-of-life care protocols are not just aimed at providing support to the dying infant and the infant’s family. Palliative/end-of-life care protocols also provide guidelines for ongoing staff support to all health-care professionals involved in the care of an infant at the end of life (Catlin & Carter, 2002). A theme about the potential emotional strain on staff caring for infants and their families at the end of life was recognized by respondents in several statements. Some of these statements include: “The death of infants is difficult emotionally.” “I am afraid I will say the wrong thing.” “I am concerned about meeting the emotional needs of everybody.” “I am concerned about my own psychological issues/recuperation from the experience.” These statements validate the need for staff support guidelines in neonatal palliative/end-of-life care protocols.

The findings of the present study validate those of other studies that found a lack of palliative/end-of-life care protocols in many NICUs (Abe et al., 2001; Carter & Bhatia, 2001; Catlin & Carter, 2002). The lack of established protocols may not be related to a complete lack of information on the institution of palliative/end-of-life care protocols in the literature. Recommendations for the creation of a neonatal palliative/end-of-life care protocol were published in the *Journal of Perinatology* (Catlin & Carter, 2002). The recommended protocol addresses many of the themes and concerns of respondents within the present study (e.g., a palliative care model for parents, an optimal environment for neonatal death, a location for the provision of palliative care, ventilator removal, pain and symptom management, family care, ongoing staff support, and compassionate and
culturally sensitive care of the dying patient and the patient’s parents, family members, and health-care professionals involved in their care). One nurse out of the 48 RNs who reported reading journals regularly stated that he or she read the journal in which Catlin and Carter’s recommendations were published. The paucity of recommendations for instituting palliative/end-of-life care protocols in the literature may be related to the lack of the presence of such protocols in many NICUs; however, more research needs to be conducted to determine why palliative/end-of-life care protocols continue not to be utilized in many NICUs.

Limitations

One limitation of this study was that it was confined to two hospitals in one geographic area of the United States. Generalizability was affected; in other words, results may vary from NICUs in different geographic areas based on the demographics of the sample. The relatively low response rate of 42% may have impacted the overall data by not representing a majority of RNs and NNPs. Another limitation was that neither unit has a palliative/end-of-life care protocol; consequently, respondents may not recognize the value of a palliative/end-of-life care protocol in providing guidance to RNs and NNPs caring for infants and their families at the end of life. A final limitation is that the nature of the data collection in questionnaire format did not allow for further exploration and discussion of open-ended responses.
Recommendations

Recommendations for further research include a nationwide multicenter study that examines the presence of palliative/end-of-life care protocols and the attitudes that RNs and NNPs have about such protocols in assisting them in providing palliative/end-of-life care. A comparison of the experiences and attitudes of RNs and NNPs in units that have or do not have palliative/end-of-life care protocols may be helpful as well. A study describing the institution of a palliative/end-of-life care protocol in the NICU may serve as a model for other units to replicate. A mentorship program in which RNs who have experience in providing palliative/end-of-life care and who assist inexperienced RNs in providing end-of-life care may also be a useful adjunct to a palliative care protocol in the provision of end-of-life care to infants and their families.

Further research to evaluate exactly what about experience makes nurses more comfortable with providing palliative/end-of-life care to infants is needed. Additional research is also needed to examine if comfort in providing palliative/end-of-life care is an indicator of competency. Finally, parental interviews may be valuable in identifying essential components of neonatal palliative/end-of-life care protocols from the families’ perspectives.

In summary, improvements in the life-saving capabilities of critically ill infants have led to the ability of practitioners in the NICU to save infants with morbidities that would have been fatal 3 decades ago. Although advances in the life-saving measures of infants have continued, progression of the provision of
palliative/end-of-life care to infants who cannot be saved has not advanced at such an exponential rate despite its acknowledgment in the literature as early as 1973 (Duff & Campbell, 1973). The institution of palliative/end-of-life care protocols in the NICU is essential in providing optimal care to the thousands of infants who die in the NICU every year in the United States. Palliative/end-of-life care supports dying infants as well as their families and health-care providers involved in the care of these families. Palliative/end-of-life care protocols are essential for the provision of appropriate, supportive, and culturally sensitive end-of-life care in the NICU. Palliative/end-of-life care protocols provide valuable guidance to medical providers in optimally supporting the infant, family, and other NICU staff members when infant death occurs.
APPENDIX A

SURVEY
Neonatal Palliative/End-of-Life Care Survey

Despite extraordinary advances in neonatal care, a population of infants exists in the neonatal intensive care unit (NICU) whose lives cannot be saved. Many NICUs have well-developed bereavement programs to provide grief support for parents after the death of an infant. There are few palliative/end-of-life care protocols (written guidelines or standards of care) that provide guidance for neonatal nurses and neonatal nurse practitioners who care for infants at the end of life. Palliative/end-of-life care protocols assist providers in caring for infants at the end of life (e.g., what orders should be written before discontinuing life support, standardized pain management doses, and procedures for ventilator removal). In an effort to determine the access to palliative/end-of-life care protocols and your experience in end-of-life care in the NICU, please answer the following questions.

Please circle one answer code number for each question unless otherwise instructed.

1. Have you had education on palliative/end-of-life care in the NICU?
   a. Yes ................................................................. 1
   b. No (Please skip to Question 4.) ................................. 0

2. Where did you receive your education on neonatal palliative/end-of-life care? (Circle all that apply.)
   a. Nursing school .......................................................... 1
   b. Nursing orientation ....................................................... 2
   c. Unit inservice ............................................................. 3
   d. Educational conference ................................................ 4
   e. Other (Please specify): .............................. 5

3. Please rate how useful the palliative/end-of-life care education you received was in providing care to infants at the end of life.
   a. Very useful ................................................................. 1
   b. Somewhat useful ......................................................... 2
   c. Neutral ................................................................. 3
   d. Not useful ................................................................. 4

4. Does the NICU where you are employed have a written palliative/end-of-life care protocol?
   a. Yes ................................................................. 1
   b. No ................................................................. 2
   c. Unsure ................................................................. 3

Go to next page.
5. How helpful would a written protocol that could be referred to while caring for infants at the end of life be to you in providing end-of-life care?
   a. Very helpful ............................................................... 1
   b. Somewhat helpful .......................................................... 2
   c. Not helpful ............................................................................. 3

6. Have you cared for an infant in the NICU at the end of his or her life?
   a. Yes (Please continue to Question 7.)................................. 1
   b. No (Please skip to Question 19.)....................................... 2

The following questions pertain to your end-of-life experiences in the NICU.

7. How many infants have you cared for at the end of an infant’s life?
   a. 0-1 ............................................................................... . 1
   b. 2-5 ................................................................................ . 2
   c. 6-10 ................................................................................ . 3
   d. 11-20 ............................................................................... . 4
   e. More than 20 ........................................................................ . 5

8. Did other NICU staff members assist you in caring for the dying infant? (Circle all that apply.)
   a. Registered nurse ............................................................... 1
   b. Neonatal nurse practitioner .............................................. 2
   c. Neonatologist ...................................................................... 3
   d. Unlicensed assistive personnel ............................................ 4
   e. Social worker ....................................................................... 5
   f. Other (Please specify.).......................................................... 6

9. When caring for an infant at the end of life, how comfortable are you?
   a. Completely comfortable .................................................. 1
   b. Somewhat comfortable ....................................................... 2
   c. Neutral .................................................................................. 3
   d. Somewhat uncomfortable ................................................... 4
   e. Very uncomfortable .............................................................. 5

10. How comfortable are you with caring for the family of an infant at the end of life?
    a. Completely comfortable .................................................. 1
    b. Somewhat comfortable ....................................................... 2
    c. Neutral .................................................................................. 3
    d. Somewhat uncomfortable ................................................... 4
    e. Very uncomfortable .............................................................. 5

   ➤ Go to next page.
11. How would you characterize your comfort with nursing skills in caring for an infant at the end of life.
   a. Completely comfortable ........................................... 1
   b. Somewhat comfortable ........................................... 2
   c. Neutral ........................................................................ 3
   d. Somewhat uncomfortable ........................................... 4
   e. Very uncomfortable .................................................. 5

12. How comfortable are you in working with other members of the health care team while caring for an infant at the end of life.
   a. Completely comfortable ........................................... 1
   b. Somewhat comfortable ........................................... 2
   c. Neutral ........................................................................ 3
   d. Somewhat uncomfortable ........................................... 4
   e. Very uncomfortable .................................................. 5

13. Please rate your comfort level of dealing with your own beliefs, feelings, and values about death.
   a. Completely comfortable ........................................... 1
   b. Somewhat comfortable ........................................... 2
   c. Neutral ........................................................................ 3
   d. Somewhat uncomfortable ........................................... 4
   e. Very uncomfortable .................................................. 5

14. Please describe your overall experience in caring for an infant at the end of life.
   a. Very positive ......................................................... 1
   b. Positive ....................................................................... 2
   c. Neutral ........................................................................ 3
   d. Negative ....................................................................... 4
   e. Very negative ............................................................ 5

15. List two skills you believe are most important for a nursing professional to have in the care of an infant at the end of life.
   a. _______________________________________________________
   b. _______________________________________________________

16. What are your concerns, if any, in providing palliative/end-of-life care to infants? (Please provide a written answer.)
17. What rewards are there, if any, in providing palliative/end-of-life care? (Please provide a written answer below.)

18. Please write any further comments you would like to add about palliative/end-of-life care of infants below.

* If needed, please affix an additional sheet of paper to answer Questions 16, 17, and 18.

The next few questions are about your demographic information. Please circle one code number for each question.

19. Specify your educational background.
   a. Registered nurse (diploma prepared) .............................................. 1
   b. Registered nurse (associate’s prepared) ........................................... 2
   c. Registered nurse (bachelor’s prepared) ........................................... 3
   d. Registered nurse (master’s prepared) ............................................. 4
   e. Neonatal nurse practitioner (certificate) ........................................... 5
   f. Neonatal nurse practitioner (MS, MSN, MN prepared) ....................... 6
   g. Other (Please specify): ...................................................................... 7

20. How many years of experience do you have as a registered nurse providing care for infants in the NICU?
   a. Less than 1 year ............................................................................. 1
   b. 1-3 years ....................................................................................... 2
   c. 4-10 years ..................................................................................... 3
   d. 11-20 years ................................................................................... 4
   e. More than 20 years ......................................................................... 5

Go to next page.
21. How many years of experience do you have as a neonatal nurse practitioner providing care for infants in the NICU? (Please answer if applicable.)
   a. Less than 1 year ............................................................... 1
   b. 1-3 years ........................................................................ 2
   c. 4-10 years ....................................................................... 3
   d. 11-20 years ..................................................................... 4
   e. More than 20 years ........................................................... 5

22. How many hours per week do you work? ________ hours/week.

23. What nursing organizations do you belong to?

24. What journals do you read regularly?

THANK YOU FOR YOUR PARTICIPATION IN THIS SURVEY!
APPENDIX B

COVER LETTER
Dear Colleague:

Advances in technology, medicine, and pharmacotherapy have led to dramatic improvements in the life-saving capabilities of practitioners who care for critically ill neonates. Despite the phenomenal advances in neonatal care in the past few decades, a population of neonates exists whose lives cannot be saved regardless of the most intensive therapies. The discontinuance of life-extending treatment or aggressive cure-oriented care is now considered to be ethical as well as medically appropriate in cases when newborns are deemed to be extremely premature, have lethal birth defects, or have complicated neonatal courses.

An emerging issue in neonatal care is the creation of palliative/end-of-life care protocols. Palliative care focuses on providing comfort care to patients who have diseases that are not responsive to curative treatment, focusing on the prevention, reduction, or soothing of symptoms at the end of life. Palliative care is also used to help patients and families reconcile conflicts and derive meaning from end-of-life experiences. End-of-life care focuses on care of the patient when death is imminent. Palliative/end-of-life care is different than bereavement care, which is the care of the family after the death of the infant and includes follow-up phone calls, pictures, and hand/foot molds of their deceased infant.

A five-page questionnaire is enclosed that asks for information about your practice specific to the care of infants at the end of life. The purpose of this questionnaire is to determine the presence of palliative/end-of-life care protocols in the newborn intensive care unit (NICU) where you are employed and to examine the experiences and attitudes of NICU nurses and nurse practitioners in providing care to infants at the end of life. It will take approximately 10 to 15 minutes to complete. The questionnaire contains a code number for follow-up only. The code list will be destroyed when data analysis is complete. Any data reported will be aggregated for the entire group, and no individual will be identified. You may omit any question you prefer not to answer. The information from this questionnaire will be used to develop and improve palliative/end-of-life care protocols in the NICU. A red-labeled box has been placed in the staff lounge of the NICU where you work. Please return the questionnaire no later than February 25, 2004.

This project has received approval from the Institutional Review Board at the University of Utah. There are no risks to participating in this study. If you have questions regarding your rights as a research subject, or if problems arise that you do not feel you can discuss with the investigator, please contact the Institutional Review Board office at (801)581-3655. Your participation is voluntary, and return of the questionnaire implies consent to participate. I look forward to hearing from you and thank you for sharing your experiences and thoughts in this important aspect of neonatal care.

If you have any questions or concerns, you may reach me at (801)446-8808.

Yours sincerely,

Fawn N. Clark, RN, BSN, NNPS
Enclosures

February 16, 2004
REFERENCES


