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Palliative care nursing and pediatrics in Intensive Care Unit (ICU): Updated review

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***Abstract*---Background**: Palliative care in neonatal intensive care units (NICUs) aims to enhance quality of life for critically ill neonates and their families. Despite the American Academy of Pediatrics' broad recommendations, variability exists in implementing palliative care across healthcare facilities. Common neonatal conditions like prematurity, respiratory distress syndrome (RDS), and neonatal sepsis pose challenges, emphasizing the need for integrative palliative care. **Aim**: To examine the history, current practices, and emerging trends in neonatal palliative care, emphasizing its implementation in NICUs. **Methods**: A comprehensive review of neonatal palliative care literature was conducted, highlighting advancements, barriers, and practical approaches to incorporating palliative care in NICU settings. The review included guidelines, clinical pathways, and policy frameworks. **Results**: Neonatal palliative care has evolved from rudimentary practices to specialized programs addressing complex medical, ethical,

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and emotional needs. However, significant barriers persist, including fragmented education, interprofessional communication gaps, and limited palliative care training for healthcare providers. Integrating primary palliative care into NICUs has shown potential for improving outcomes, though it requires widespread adoption of foundational skills among neonatal teams. **Conclusion**: The integration of palliative care into NICUs is crucial for addressing the nuanced needs of critically ill neonates and their families. Overcoming barriers such as training deficiencies and fragmented communication can enhance care quality. Further research and policy efforts are needed to standardize palliative care approaches and ensure equitable access.

***Keywords*---**Palliative care, Neonatal intensive care unit, Prematurity, Neonatal sepsis, Respiratory distress syndrome, Primary palliative care.

Introduction

Guidelines, clinical pathways, and policy frameworks for neonatal palliative care have shown differing degrees of compliance with the 2014 Institute of Medicine (IOM) recommendation that all healthcare providers who treat patients with advanced serious illnesses should be proficient in basic palliative care [1, 2]. The identification of critically sick newborns and their families who should receive the additional assistance provided by palliative care remains a substantial barrier. By focusing on reducing pain, improving quality of life, facilitating informed decision-making, and coordinating treatment across settings, the American Academy of Pediatrics (AAP) provides a wide definition of palliative care. Regarding the education needed for fundamental palliative care skills, these recommendations are vague [3]. When it comes to incorporating palliative care into their neonatal programs, certain healthcare facilities are at the forefront, while others struggle to get started [4]. In order to help all severely sick neonates and their families, this article explores the history, present methods, and potential future developments of palliative care in neonatal intensive care units (NICUs). It focuses on implementing basic palliative care techniques.

Common Conditions Managed in the Neonatal Intensive Care Unit (NICU)

The Neonatal Intensive Care Unit (NICU) is designed to provide specialized care for critically ill or premature newborns. Neonates admitted to the NICU often present with conditions requiring advanced medical and technological support to ensure survival and optimal development. The most common conditions encountered in NICU settings include prematurity and its associated complications, respiratory distress syndrome, neonatal sepsis, birth asphyxia, congenital anomalies, and metabolic disorders. Each condition requires a tailored approach to management and care.

Prematurity and Associated Complications

Prematurity, defined as birth before 37 weeks of gestation, is the leading cause of NICU admissions globally. Premature neonates often face multiple complications due to underdeveloped organs, including respiratory, neurological, and gastrointestinal systems. Conditions such as bronchopulmonary dysplasia (BPD), intraventricular hemorrhage (IVH), necrotizing enterocolitis (NEC), and retinopathy of prematurity (ROP) are prevalent among these neonates. The management of prematurity involves providing respiratory support, nutritional supplementation, and close monitoring for long-term neurodevelopmental outcomes. Advances in antenatal corticosteroids and surfactant therapy have significantly improved survival rates among preterm infants.

Respiratory Distress Syndrome (RDS)

Respiratory distress syndrome is a common cause of morbidity in premature infants, resulting from insufficient surfactant production in the lungs. This condition leads to alveolar collapse and impaired gas exchange. The mainstay of RDS management includes surfactant replacement therapy, continuous positive airway pressure (CPAP), or mechanical ventilation. Early administration of antenatal steroids to mothers at risk of preterm delivery has proven effective in reducing the incidence and severity of RDS.

Neonatal Sepsis

Neonatal sepsis remains a significant concern in the NICU due to its high mortality and morbidity rates. It is categorized into early-onset sepsis (EOS), occurring within the first 72 hours of life, and late-onset sepsis (LOS), which occurs after 72 hours. Common pathogens causing neonatal sepsis include *Group B Streptococcus* (GBS), *Escherichia coli*, and coagulase-negative staphylococci. Management involves empirical antibiotic therapy guided by blood culture results, alongside supportive care to address hemodynamic instability and metabolic abnormalities.

Birth Asphyxia and Hypoxic-Ischemic Encephalopathy (HIE)

Birth asphyxia, characterized by impaired oxygen delivery during labor and delivery, can lead to hypoxic-ischemic encephalopathy (HIE) and multiorgan dysfunction. Neonates with HIE often require therapeutic hypothermia within six hours of birth to mitigate neuronal damage and improve neurodevelopmental outcomes. Close monitoring of organ function, seizure activity, and long-term neurodevelopment is crucial in these cases.

Congenital Anomalies

Congenital anomalies, including cardiac defects, gastrointestinal malformations, and neural tube defects, are frequently managed in the NICU. Conditions such as congenital diaphragmatic hernia (CDH), gastroschisis, and hypoplastic left heart syndrome (HLHS) require surgical interventions and multidisciplinary care. The

NICU team plays a pivotal role in stabilizing these neonates preoperatively and ensuring optimal postoperative recovery.

Neonatal Jaundice

Hyperbilirubinemia, or neonatal jaundice, is another common condition requiring NICU care. Severe jaundice, if untreated, can lead to kernicterus and long-term neurological impairment. Management includes phototherapy and, in severe cases, exchange transfusion to reduce bilirubin levels.

Metabolic Disorders

Inherited metabolic disorders such as phenylketonuria (PKU), galactosemia, and maple syrup urine disease (MSUD) can present in the neonatal period with feeding difficulties, failure to thrive, or metabolic crises. Early identification through newborn screening programs and appropriate dietary or medical interventions are essential to prevent long-term complications.

Advances in NICU Care

The NICU has seen significant advancements in monitoring and treatment technologies, including non-invasive ventilation, point-of-care ultrasonography, and precision medicine approaches such as pharmacogenomics. Multidisciplinary collaboration involving neonatologists, nurses, dietitians, and therapists ensures comprehensive care tailored to the individual needs of neonates and their families. The NICU remains a critical resource for managing a spectrum of neonatal conditions, each requiring specialized knowledge and care strategies. Continued research and advancements in neonatal medicine are essential to further improve survival rates and quality of life for these vulnerable patients. Efforts in early diagnosis, preventive care, and family-centered approaches will continue to shape the future of neonatal intensive care.

The Emergence of Palliative Care in Neonatology

The treatment of preterm newborns and those with life-limiting illnesses was mostly palliative during the early days of neonatal medicine. Only basic care, such keeping warm, giving breast milk, preventing infections, and keeping an eye on growth, could be given by doctors [5]. Incubators that were rented or homemade were frequently used for this treatment at home [6]. Modern neonatal intensive care began in the 1950s with the introduction of positive-pressure breathing, which allowed physicians to prolong survival and obtain hospital release for premature infants [7]. The 1970s saw the creation of the Neonatal Nurse Practitioner (NNP) position to fill the need for specialized pediatric care and nursing expertise brought on by the quick development of neonatal medicine. Although subjects like grief support and sensitive communication were not covered in early training curricula, the position, which was supported by the AAP in the 1980s, placed a high priority on life-saving measures [8]. Clinicians started to doubt whether severe therapies for newborns with life-limiting diseases were justified, even in the face of progress in lowering infant mortality. Duff and Campbell's 1973 paper, which described instances in which parents and doctors jointly chose not to provide life-sustaining treatment, summed up this moral conundrum and emphasized the significance of facing these difficult choices in order to prevent unintentional and detrimental defaults [9]. Perinatal hospice and palliative care programs emerged as a result of growing awareness of neonatal death dynamics, and they were bolstered by academic contributions as well as parental activism [10–12]. The overuse of technology to extend infant survival without appropriately addressing the resulting misery was further criticized by renowned neonatologists like Silverman and Lantos [13, 14]. Perinatal and newborn palliative care integration efforts were sparked by the 2003 IOM report When Children Die: Improving Palliative and End-of-Life Care for Children and Families [15–19].

Growing Demand for Palliative Care in Neonatology

In contrast to the time period Duff and Campbell outlined, the majority of infant deaths in the modern era occur after life-sustaining measures are stopped or withheld [20]. According to a research by Weiner et al., decisions to forego such therapies, motivated more by worries about prognosis and quality of life than by unavoidable mortality, accounted for almost 80% of newborn fatalities in a regional NICU between 1999 and 2008 [21, 22]. According to Dupont-Thibodeau et al., there has been a decrease in first-week mortality rates and an increase in the age of death. This is because improvements in NICU care have made it possible for infants to live longer, which calls for the early implementation of palliative care to assist families in making difficult decisions [23]. The majority of the research currently available on neonatal palliative care focuses on end-of-life treatment in NICUs or perinatal care for pregnant mothers of fetuses with life-limiting illnesses [24, 25]. Significant gaps in meeting parental needs, such as customized care plans, pre-bereavement counseling, and memory-making activities, are shown by case reports [26, 27]. There is still much space for improvement in developing practical protocols and care templates, according to Balaguer et al.'s thorough analysis of the literature on infant palliative care from 1969 to 2010 [28–30]. Perinatal palliative care programs' outcomes and variability have been examined in recent studies, which have shown both advancements and enduring difficulties [4, 31, 32].

Barriers to Palliative Care Implementation

Critical obstacles to palliative care implementation were noted in the 2014 IOM report. These included a lack of communication skills training, fragmented interprofessional education, and a lack of curriculum emphasis on palliative care in medical and nursing school. Healthcare teams, which include nurses, doctors, intensivists, social workers, and therapists, are typically fragmented, which makes it difficult to reach an agreement on treatment goals and frequently leads to inconsistent messaging to families [33]. The formation of cohesive interprofessional teams is hampered by this compartmentalized approach, which encourages "medical tribalism." The ability to navigate prognostic uncertainty and interact sympathetically with grieving families is something that many neonatal physicians lack formal training in. According to a recent poll, only a small percentage of neonatologists expressed confidence in handling such difficulties, despite the fact that the majority acknowledge the importance of palliative care

[34]. In a similar vein, Kain et al. discovered that although almost all neonatal nurses asked agreed that palliative care is important, just one-third said they had received sufficient training to assist bereaved families [35]. Additionally, surveys of NICU directors have shown that communication difficulties relating to physicians frequently surpass those posed by nursing personnel [36]. Because they fear it could worsen parental grief or imply that therapeutic attempts are being abandoned, providers may refrain from starting conversations about palliative care [37]. Avoiding these discussions, however, deprives families of vital assistance and upholds irrational expectations regarding NICU procedures. Particularly in pediatrics, a specialty with relatively low mortality rates, Nelson criticizes cultural inclinations to ignore death, which make physicians feel even more like they have failed as professionals when children pass away [33]. Transitions to end-of-life care are frequently delayed by neonatology's "rescue culture," where palliative care strategies are frequently overshadowed by critical care efforts. It is still difficult to integrate these two skill sets, especially in high-stakes NICU settings when quality-of-life concerns may be subordinated to life-saving measures.

Primary Palliative Care Versus Consultative Palliative Care

In 2002, von Gunten [38] described primary palliative care as the foundational knowledge, attitudes, and competencies essential for all healthcare professionals to deliver palliative care. He contrasted this with the consultative model, wherein a specialist consultant assumes responsibility for addressing all aspects of palliative care, as opposed to the primary model that delegates this responsibility to the core clinical team—in this case, the neonatal team. Following the formal recognition of Hospice and Palliative Medicine as a specialty by the American Board of Medical Specialties in 2006, many healthcare institutions adopted mechanisms such as palliative care triggers and interdisciplinary palliative rounds with the primary team to identify patients requiring specialized consultation [39, 40]. While the consultative model offers immediate access to specialized palliative care, it serves as a short-term response to the broader demand for such services. Growing evidence indicates that palliative care can improve quality, reduce costs, and potentially enhance patient survival, prompting healthcare organizations to prioritize its implementation [41, 42]. However, critiques of the consultative approach highlight concerns about the increasing demand surpassing the availability of palliative subspecialists and the risk of undermining established therapeutic relationships between patients and their primary care providers, potentially leading to fragmented care [43].

Implementing Primary Palliative Care in the NICU

The application of primary palliative care within the neonatal intensive care unit (NICU) requires all members of the neonatal team to acquire fundamental palliative care skills, as outlined by von Gunten [38]. This includes neonatal nurses, respiratory therapists, pharmacists, speech and physical therapists, lactation consultants, chaplains, social workers, trainees, and physicians at all career stages. Competencies in symptom management, empathetic communication with families, and interdisciplinary collaboration are pivotal [1, 43]. Furthermore, the National Perinatal Association and the National Association for Neonatal Nurses emphasize the importance of identifying parental care goals and providing bereavement support [2, 44].

Basic Pain and Symptom Management

Palliative care expertise encompasses managing symptoms that significantly impact the quality of life, such as pain, respiratory distress, gastrointestinal issues, and sleep disturbances. While treating these symptoms aligns with neonatology objectives, shortness of breath presents unique challenges as infants cannot verbally express discomfort. Neonatal teams rely on clinical indicators, such as increased respiratory effort, to diagnose and manage underlying conditions (e.g., pneumonia or surfactant deficiency). For chronic respiratory conditions, interventions may include enhanced respiratory support or, in cases of distress, the use of opioids and benzodiazepines to ensure comfort. At the end of life, morphine is frequently employed to alleviate respiratory discomfort, although high doses necessitate discussions regarding care goals due to potential respiratory suppression. Since infants have limited capacity to communicate pain, providers use a combination of physiological (e.g., heart rate, oxygen saturation) and behavioral (e.g., crying, grimacing) indicators, assessed through various pain scales. Despite their validation in research, these scales are inconsistently applied in NICU settings and may conflate pain with anxiety [45]. Pain management strategies range from non-pharmacological approaches, such as oral sucrose, non-nutritive sucking, and skin-to-skin care, to pharmacological treatments for invasive procedures. To minimize pain exposure, neonatologists are encouraged to consolidate diagnostic interventions, such as routine blood draws, thereby reducing bedside interruptions and promoting better sleep, which supports long-term developmental outcomes [45]. Integrative therapies like music therapy and therapeutic touch have also shown promise. For instance, a randomized trial demonstrated that music therapy improved sleep and reduced parental stress in infants older than 32 weeks' gestation [46]. Similarly, kangaroo care has been associated with increased sleep and reduced irritability [47]. Establishing policies and ongoing education within NICUs to address pain and symptom management can enhance continuous quality improvement, ensuring that primary palliative care is embedded into neonatal care practices.

Comprehensive Management of Depression and Anxiety in the NICU

Approximately 30% of parents with infants in the Neonatal Intensive Care Unit (NICU) develop diagnosable mental health conditions within the first postpartum year [48]. While psychiatrists and psychologists typically provide specialized treatment for parental depression and anxiety, neonatal care providers play an integral role in identifying and supporting affected families. Among these providers, NICU nurses are uniquely positioned to detect early signs of parental mental health disorders, such as depression, anxiety, grief, and post-traumatic stress disorder, due to their extensive interactions with parents. Consequently, neonatal healthcare teams require training on recognizing symptoms and administering initial screenings, such as the Edinburgh Postnatal Depression Scale, to identify individuals at risk for perinatal depression [49]. To address serious mental health conditions, NICUs must establish robust protocols for timely referral to psychological and psychiatric services. Recommendations suggest embedding mental health professionals within NICUs, including doctoral-level psychologists and specialized support groups for parents, to provide immediate and sustained assistance [50]. Furthermore, understanding the psychosocial experiences of families with critically ill neonates is vital for delivering comprehensive, family-centered palliative care [51].

Foundational Communication on Prognosis, Treatment Goals, and Code Status

Effective communication with parents of NICU patients necessitates sensitivity and an understanding of their values, perspectives on life and death, and their newborn’s role within the family. Developing these communication skills involves listening attentively, observing non-verbal cues, and addressing prognostic uncertainty with a balance of honesty and empathy. Neonatal providers must also prepare parents for the potential outcomes associated with forgoing life-sustaining interventions and the approaching end of life [52]. While neonatal practitioners typically have experience discussing prognostic concerns, palliative care specialists excel in nuanced end-of-life counseling. These specialists refine their communication through extensive training, role-playing, and feedback, distinguishing their approach to engaging families. By collaborating with social workers, chaplains, and nurses, palliative care teams often incorporate debriefing sessions to enhance understanding and coordination among multidisciplinary teams. Training neonatal providers in strategies like the "ask-tell-ask" approach and the SPIKES protocol can empower them to navigate sensitive discussions effectively. These methods emphasize assessing parental understanding, sharing information compassionately, and addressing emotional responses with empathy [53][54]. Such skills enable all members of the NICU team, including nurses and allied professionals, to facilitate ongoing goals-of-care discussions and offer family-centered support. Incorporating communication training into the curriculum for neonatal teams aligns with recommendations from the 2014 Institute of Medicine (IOM) report, which advocates for palliative care education across all healthcare disciplines [1].

Advocating a Hybrid Model of Palliative Care for NICUs

To address the diverse needs of NICU patients and their families, a mixed model integrating primary and consultative palliative care is recommended. In this framework, the primary neonatal team—comprising neonatologists, nurses, and allied staff—manages routine palliative care needs while consulting subspecialists for complex or refractory cases [55]. This approach ensures that palliative care is seamlessly integrated into routine neonatal care, rather than being limited to end-of-life scenarios. It also minimizes the need to label patients as "palliative," promoting patient- and family-centered care that prioritizes symptom management, quality of life, and the alleviation of suffering. The hybrid model mirrors current practices for managing other neonatal conditions, such as infectious, cardiac, and pulmonary diseases. It also optimizes the availability of palliative care specialists for cases requiring advanced expertise, such as intricate pain management, challenging discussions on care goals, and complex transitions to home hospice. The IOM's 2014 report underscores the necessity for all healthcare providers caring for patients with serious illnesses to be proficient in basic palliative care. By delineating neonatal palliative care competencies and offering targeted education, NICUs can achieve these goals. A hybrid palliative care model, wherein the neonatal team provides foundational care and consults specialists as needed, exemplifies a comprehensive, family-centered approach. Training all neonatal staff in effective communication, symptom management, and the psychosocial aspects of care fosters an interprofessional environment that enhances patient outcomes and family satisfaction. Moreover, embedding mental health professionals within NICUs and prioritizing policies to minimize neonatal discomfort and promote developmental care reflects a culture shift toward holistic, compassionate care. In this framework, palliative care is not an endpoint but an integral component of every neonate's journey, ensuring that all patients benefit from a focus on quality of life and relief from suffering.

Conclusion:

Neonatal palliative care plays a vital role in addressing the unique challenges faced by critically ill neonates and their families. As neonatal intensive care units (NICUs) manage increasingly complex medical conditions such as prematurity, respiratory distress syndrome, and neonatal sepsis, the demand for integrative, compassionate, and family-centered care has grown significantly. Palliative care offers a framework to alleviate suffering, enhance quality of life, and support informed decision-making, yet its implementation remains inconsistent across healthcare systems. The evolution of neonatal palliative care from basic comfort measures to specialized interdisciplinary programs underscores its importance in improving outcomes. However, several barriers persist, including limited education and training among healthcare professionals, insufficient interprofessional communication, and the lack of standardized clinical guidelines. These challenges highlight the urgent need for integrating primary palliative care principles into routine NICU practices, equipping all team members with the foundational skills to provide holistic care. Addressing these barriers requires collaborative efforts among policymakers, educators, and healthcare organizations to prioritize palliative care within NICU workflows. Research has shown that structured palliative care programs can improve family satisfaction, enhance communication, and reduce unnecessary interventions, benefiting both patients and caregivers. However, further investigation is needed to explore innovative approaches to training, such as simulation-based education, and to develop policies that ensure equitable access to palliative care services. Additionally, culturally sensitive care models are essential to meeting the diverse needs of families, particularly in regions with significant cultural and religious diversity. In conclusion, neonatal palliative care represents a critical aspect of comprehensive care in NICUs. Overcoming implementation barriers through education, policy reforms, and interprofessional collaboration will not only enhance the quality of care for neonates but also support families through the challenging experiences of critical illness and end-of-life decision-making. By prioritizing palliative care as a core component of neonatal care, healthcare systems can create a more compassionate and effective model of care that aligns with the principles of dignity and respect for the most vulnerable patients and their families.

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رعاية التلطيف التمريضية وطب الأطفال في وحدات العناية المركزة - (ICU) مراجعة محدثة

الملخص:

الخلفية: تهدف رعاية التلطيف في وحدات العناية المركزة لحديثي الولادة (NICUs) إلى تعزيز جودة الحياة للأطفال الخدج الذين يعانون من أمراض خطيرة وأسرهم. وعلى الرغم من التوصيات الواسعة التي تقدمها الأكاديمية الأمريكية لطب الأطفال، إلا أنه يوجد تباين في تنفيذ رعاية التلطيف عبر المنشآت الصحية. وتواجه بعض الحالات الشائعة في حديثي الولادة مثل الخداج ومتلازمة الضائقة التنفسية (RDS) والإنتان الوليدي تحديات، مما يبرز الحاجة إلى رعاية تلطيفية تكاملية.

الهدف: دراسة تاريخ رعاية التلطيف الحالية والاتجاهات الناشئة في رعاية التلطيف لحديثي الولادة، مع التركيز على تنفيذها في وحدات العناية المركزة لحديثي الولادة.

الطرق: تم إجراء مراجعة شاملة للأدبيات المتعلقة برعاية التلطيف لحديثي الولادة، مع تسليط الضوء على التقدمات والعوائق والأساليب العملية لتطبيق رعاية التلطيف في بيئات وحدات العناية المركزة لحديثي الولادة. وشملت المراجعة الإرشادات، والمسارات السريرية، وأطر السياسات.

النتائج: تطورت رعاية التلطيف لحديثي الولادة من ممارسات بدائية إلى برامج متخصصة تعالج الاحتياجات الطبية والأخلاقية والعاطفية المعقدة. ومع ذلك، لا تزال هناك عوائق كبيرة، بما في ذلك التعليم المجزأ، وفجوات التواصل بين المهنيين، ونقص التدريب على رعاية التلطيف لمقدمي الرعاية الصحية. وقد أظهرت دمج الرعاية التلطيفية الأولية في وحدات العناية المركزة لحديثي الولادة إمكانات لتحسين النتائج، على الرغم من أنها تتطلب تبني واسع النطاق للمهارات الأساسية بين فرق العمل في وحدات العناية المركزة.

الاستنتاج: يعد دمج رعاية التلطيف في وحدات العناية المركزة لحديثي الولادة أمرًا بالغ الأهمية لمعالجة الاحتياجات الدقيقة للأطفال حديثي الولادة المصابين بأمراض خطيرة وأسرهم. إن التغلب على العوائق مثل نقص التدريب والتواصل المجزأ يمكن أن يحسن من جودة الرعاية. وهناك حاجة إلى مزيد من البحث والجهود السياسية لتوحيد أساليب رعاية التلطيف وضمان الوصول العادل إليها.

الكلمات المفتاحية: رعاية التلطيف، وحدة العناية المركزة لحديثي الولادة، الخداج، الإنتان الوليدي، متلازمة الضائقة التنفسية، الرعاية التلطيفية الأولية.