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Primary palliative care in neonatal intensive care

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ABSTRACT

This article explores the 2014 Institute of Medicine's recommendation concerning primary palliative care as integral to all neonates and their families in the intensive care setting. We review trends in neonatology and barriers to implementing palliative care in intensive care settings. Neonatal primary palliative care education should address the unique needs of neonates and their families. The neonatal intensive care unit needs a mixed model of palliative care, where the neonatal team provides primary palliative care and the palliative subspecialist consults for more complex or refractory situations that exceed the primary team's skills or available time.

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Introduction

Neonatal palliative care guidelines, clinical pathways, and policy statements have varied in their response to the 2014 Institute of Medicine (IOM) recommendation that all health care providers who care for people with advanced serious illness should be competent in basic palliative care.^{1,2} Uncertainty exists regarding which seriously ill babies and their families deserve the added support that palliative care provides. While the American Academy of Pediatrics (AAP) recommendation includes the definition of palliative care as relieving suffering, improving quality of life, facilitating informed decision-making, and assisting in care-coordination between sites of care, these recommendations are broad and nonspecific regarding education for the clinical skills needed to provide basic primary palliative care.³ Many centers sit on the cutting edge of integrating palliative care for patients and their families, while others still struggle to implement palliative care programs in their settings.⁴ This article discusses the past, present, and future of palliative care in the neonatal intensive care unit (NICU) and explores how to integrate primary palliative care skills in neonatal

intensive care for all infants with serious illnesses and for their families.

The origins of palliative care in neonatology

In the beginning of neonatal medicine, medical care for premature babies and infants with life-limiting conditions was essentially palliative care. Physicians could do little more for these babies than keep them warm, feed them breast milk, isolate them from strangers and each other, weigh them daily, and hope for the best.⁵ Many of these infants received care at home in homemade or rented incubators.⁶ After the invention of positive pressure ventilators in the 1950s, substantive neonatal intensive care began and physicians developed the ability to prolong infants' lives and achieve discharge for babies born prematurely.⁷ The role of the Neonatal Nurse Practitioner (NNP) developed in response to the rapid advances in neonatal care in the mid-1970s, a shortage of specially trained pediatricians, and the need for caregivers with skills beyond those of most bedside nurses. The NNP role, endorsed by the AAP in the mid-1980s,

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followed medical education with an emphasis on life-saving interventions.⁸ However, death of a newborn, sensitive communication with families, and bereavement care, did not appear in the early curricula for NNPs.

Despite improving infant mortality, physicians began to question the goals of neonatal care for infants identified with life-limiting conditions and extreme prematurity. The question became, “because we can, should we?” In their 1973 article, “Moral and Ethical Dilemmas in Special Care Nurseries,” Duff and Campbell described 43 out of 299 (14%) consecutive infant deaths occurring in a special-care nursery at Yale University after withholding treatment.⁹ Parents and physicians decided together to forgo further life-sustaining treatment. Although difficult, the authors commented, “The issue has to be faced, for not to decide is an arbitrary and potentially devastating decision of default.”⁹

Increased awareness of the reasons for and manner of newborn deaths led to recognition of the need for perinatal hospice and palliative care. Parents wrote books describing their struggles to advocate for their children's right to die.¹⁰⁻¹² In 1992, Silverman,¹³ a highly regarded academic neonatologist, warned against overtreating babies who could receive palliative care instead. Lantos later explained that clinicians' interest in using the technology they had developed to prolong the life of newborns at the limits of viability may have prevented their understanding of the human suffering of infants and parents.¹⁴ The Institute of Medicine report of 2003, *When Children Die: Improving Palliative and End-of-Life Care for Children and Families* motivated some clinicians to focus on perinatal and neonatal palliative care in their respective settings.¹⁵⁻¹⁹

Growing need for palliative care in neonatology

In contrast to what Duff and Campbell described in their seminal paper, the majority of neonatal deaths today occur after withholding or withdrawing life-sustaining treatment.²⁰ During a 10-year period from 1999 to 2008, Weiner et al.²¹ reported that withholding or withdrawing life-sustaining treatment constituted the primary mode of death for over 80% of infants in a regional referral NICU. Because changes in neonatal care have led to more babies surviving, reasons for withholding or withdrawing life-sustaining interventions have shifted away from dying despite intensive care to concerns about poor prognosis and/or quality of life.²² Dupont-Thibodeau et al.²³ showed a reduction in mortality in the first week of life and an increase in age at death. Babies who would have died soon after birth in the early days of NICU care can now live substantially longer, providing opportunities to introduce palliative care and support families in complex decision-making.

Most publications about neonatal palliative care focus on perinatal palliative care for women carrying fetuses with potentially life-limiting conditions and their families or on end-of-life care in the NICU.^{24,25} Case reports of perinatal palliative care often illustrate a need for more comprehensive obstetrical and neonatal care.²⁶ Authors highlight unmet parental needs, including an individualized decision-making approach, pre-bereavement counseling, and memory

making.²⁷ In a comprehensive analysis of neonatal palliative care literature from 1969 to 2010, Balaguer et al.²⁸ identify a total of 101 articles about neonatal palliative care and of them, 27 articles about perinatal palliative care. These include published birth plan templates and end-of-life care protocols.^{16,29,30} More recently, the literature has focused on the variation and impact of these perinatal palliative care programs.^{4,31,32}

Barriers to implementing palliative care in neonatology

The 2014 IOM report lists three major barriers to palliative care implementation: educational silos that impede the development of inter-professional teams; deficits in equipping physicians and nurses with sufficient communication skills; and insufficient attention to palliative care in medical and nursing school curricula. Health care teams are fragmented into silos or separate groups of nurses, doctors, surgeons, intensivists, social workers, and therapists. Working solely within our own respective disciplines increases the risk of providing inconsistent or conflicting information to patients and families and fails to facilitate achieving consensus about the goals of care among professionals and between clinicians and families.³³ The fragmentation of care increases stress for families as well as caregivers.³³ Furthermore, training in silos breeds medical tribalism, a tendency to be more loyal to the tribe (i.e., doctors who view their subspecialty as superior), inhibiting, if not preventing inter-professional teamwork.

Many neonatal providers have developed their communication styles without the benefit of sufficient education on how to convey prognostic uncertainty or respond to suffering and bereaved parents. In a recent study, nearly all surveyed neonatologists felt that palliative care constitutes an essential part of training, but only one-third of surveyed neonatologists very strongly agreed that they felt comfortable dealing with issues surrounding palliative care.³⁴ In surveying 645 nurses, Kain et al.³⁵ found that 98% of nurses somewhat or strongly agreed that palliative care is a necessary part of neonatal nursing education, though only 34% of nurses somewhat or strongly agreed that they had received education to support and communicate with parents of dying babies. In nursing and physician national intensive care unit director surveys, each group agreed that physicians pose a greater barrier to providing effective palliative care than nurses, particularly regarding communication between clinicians and patients or families about end-of-life issues.³⁶ Neonatal providers may fear that discussing sensitive issues or introducing palliative care may add to parental distress and hopelessness or suggest to parents that the neonatal team has given up on their infant.³⁷ Ironically, the failure to initiate communication about palliative care deprives newborns and families of the opportunity to receive the added support that palliative care may provide.

Neonatal providers' and families' inflated expectations of NICU interventions can create barriers to discussing prognostic uncertainty and exploring parents' goals of care. Nelson writes, “We—clinicians, patients, families—live in a death-

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