

ADVANCING PALLIATIVE CARE TO PERINATAL AND NEONATAL SETTINGS

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The needs of parents anticipating a short life span for their infant have driven the advancement of perinatal and neonatal palliative care. Expanded fetal and neonatal diagnostic capabilities, the growing base of evidence, and the experiences of healthcare professionals are key factors in the holistic care of women electing to continue pregnancy after diagnosis of a life-limiting fetal condition and guide the care of the newborn infant. Perinatal palliative care is clinically unique because the two patients embodied in the maternal–fetal dyad are assessed simultaneously, with plans of care tailored to the needs of each. In the aftermath of an emotionally devastating diagnosis, women seek information, participate in prenatal and postnatal consultations, make difficult decisions, and ultimately prepare to give birth and care for an infant with significant physical needs or who may require thoughtfully rendered comfort measures. Regardless of where along the childbearing trajectory women and their families interact with providers, they are vulnerable and in need of support and anticipatory guidance. Foundational in all palliative care settings, advance care planning allows providers to give guidance, share clinical wisdom, and administer compassionate care throughout the remainder of the pregnancy, birth, and neonatal period. In this chapter, we highlight some historical developments in palliative care and its progression into the perinatal and neonatal domains. We review cornerstones of palliative care delivery, as well as feature the importance and benefits of educational initiatives benefiting patients, providers, and other stakeholders.

CASE STUDY

Healthcare providers planning to initiate palliative care services for expectant parents or families whose infant is admitted to the neonatal intensive care unit (NICU) need evidence-based resources and strong cooperation across disciplines.

Dr. Manning, an OB/GYN resident physician, attended a palliative care symposium that sparked her interest in palliative care for families in the medical center where she was

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CASE STUDY (*continued*)

doing her resident training. She realized that support from administration and colleagues from other disciplines would be critical to successful implementation.

Dr. Manning sought palliative care champions from the perinatal high-risk units and the NICU. Two RNs agreed to partner with her to appraise available evidence on the implementation of palliative care beginning at prenatal diagnosis and extending through neonatal care. Using guidelines from organizations, they brainstormed how the philosophy and principles of palliative care could be embedded into their health system and respective units. They sought cooperation from professionals within and outside the organization who would refer patients for palliative care services. Primary goals were (a) to create a consistent way to communicate patient encounters among the team and (b) to provide formal education to providers across disciplines.

Case Questions

1. What resources would be most useful when implementing palliative care into perinatal units and the NICU?
2. What would need to occur in your organization to ensure seamless communication among team members and across disciplines?
3. What are three approaches, from least expensive to most expensive, to providing formal palliative care education for providers in the perinatal unit and the NICU?

OBJECTIVES

- Discuss the history of palliative care and its progression to neonatal and perinatal populations
- Define terms related to neonatal and perinatal palliative care
- Describe educational initiatives available to improve practice in perinatal and neonatal palliative care
- Examine the benefits of ongoing education for providers and administrators
- Consider future opportunities in perinatal and neonatal palliative care

BACKGROUND AND SIGNIFICANCE

Care of children of all ages with serious chronic or life-limiting illnesses poses significant challenges for families and healthcare providers. Recognizing the needs of families facing the tremendous challenge of their child's life-limiting illness prior to birth and during childhood is an expansion of the field of palliative care, the goal of which is to maximize quality of life in persons of all ages with significant threats to their health and comfort

across physical, social, spiritual, intellectual, and emotional domains.¹ Not simply “little adults,” children vary widely in their developmental needs, as well as in their physical care. Care of children, the ages of whom in this context range from the prenatal period to age 21 years, is very complex. Children respond to treatments differently from adults, so they might receive treatment for cure even as their disease appears to be progressing. Known as *concurrent care*, this complex situation requires provider expertise to help families who seek continuing treatment to effect a cure for their child, to manage symptoms associated with treatment and with the illness itself, and simultaneously to prepare for the end of life if treatments prove ineffective.

Palliative care as both a philosophy and practice is “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”^{2(p1)} The attributes of palliative care according to the World Health Organization (WHO) are:

- Provision of relief from pain and other distressing symptoms
- Affirmation of life and a regard of dying as a normal process
- Intentions to neither hasten nor postpone death
- Integration of the psychological and spiritual aspects of patient care
- Support system to help patients live as actively as possible until death
- Support system to help the family cope during the patient’s illness and in their own bereavement
- A team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- Enhancement of quality of life, which may also positively influence the course of illness
- Application of palliative care early in an illness, in conjunction with other therapies intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

The expansion of fetal diagnostic evaluation coupled with widespread use of ultrasonography during pregnancy has led to the increased diagnosis of fetal congenital defects, with a wide variation in severity. Antenatal care is administered to the maternal–fetal dyad because both the expectant woman and the fetus require assessments and a potentially wide range of healthcare services. In the presence of life-limiting fetal conditions (LLFC)—for example, acrania, bilateral renal agenesis, or thanatophoric dysplasia—women face difficult choices regarding continuation of pregnancy. Women choose to continue the pregnancy for a variety of reasons, and according to a recent study, 97% of 405 parents who did so expressed no regrets, citing their rich experiences of spending time with their expected baby or newborn infant to bond, and to give and receive love and comfort, if even for a short time.³ Families whose infants have severe congenital

problems are likely to face crucial decisions about the extent to which they want intervention for their child. These interventions range from comfort therapies to curative treatments, as in the case of some cardiac and other structural defects. While facing these circumstances, families, including their newborn infants, benefit from palliative care services.

The WHO definition provides a sound foundation for expanding palliative care to the perinatal and neonatal periods. *Perinatal* refers to the interval between 22 completed weeks of gestation and 7 completed days after birth,⁴ and *neonatal* refers to the first 4 weeks after birth. Palliative care in the perinatal period refers to care of pregnant women whose expected infant is diagnosed with an LLFC and the women's families, while neonatal palliative care (NPC) refers to supportive care (curative and/or comfort), of infants with a life-limiting condition, such as renal agenesis, certain cardiac defects, severe genetic conditions, and extreme prematurity. Perinatal palliative care (PPC) and NPC involve a distinct focus on the care of families and their infants who are facing severe illness, and even death, during the childbearing period, typically considered a time of joy and hopefulness.

PURPOSE OF THIS CHAPTER

In this chapter, we introduce the historical development of palliative care, including its roots in the hospice movement, the expansion of palliative and end-of-life care to the pediatric population, and then, by extension, to perinatal and neonatal populations and settings. We introduce readers to common terms and definitions in palliative care. For healthcare providers interested in offering palliative care to patients in their communities and healthcare systems, expertise and guidance are available from numerous organizations, some of which are listed in the appendix to this book. Finally, because of the critical importance of structuring palliative care on best practices supported by evidence, we include information to encourage participation in ongoing education opportunities.

HISTORY OF PALLIATIVE CARE

The mid-20th century was a time of tremendous social change during which two important and seemingly unconnected movements took place: (a) the transition of dying and death into comfortable settings outside the confines of hospitals and (b) the women's movement, which included, among other societal changes, an insistence that birth practices become less paternalistic and more family-centered. Specifically, women began to demand that their spouses be included in the birthing process, that they learn about and have natural childbirth options, and that they have a voice in creating a birth plan that included opportunities to access support measures they preferred. These two important movements served as background for practices embedded in the sociocultural context of today: the inclusion of and guidance by family, with the support of providers, in two of the most meaningful and intimate occasions across the life span—death and birth.

In 1967, after working for a decade toward the goal, Dame Cicely Saunders opened the St. Christopher's Hospice in Sydenham in South London, UK, which would become "a model for emulation, embellishment and adaptation."^{5(p60)} Between 1958 and 1967, Dame Saunders, sometimes referred to as the "mother of the hospice movement," published numerous papers and a book chapter on dying of cancer, care for the dying, and management of cancer-associated symptoms, the first written while still a medical student. Moreover, Saunders's important work was not done in isolation but reflected a growing interest internationally in care for the dying. Although the opening of St. Christopher's Hospice is often noted as the sentinel event marking the start of the hospice movement, it in fact reflected the extensive effort of the previous decade by Saunders and others in England, the United States, Australia, and Europe devoted to an alternative to death in hospitals, where death was "sanitized, sequestered and removed from public gaze."^{5(p45)} Elizabeth Kübler-Ross, whose work is well known in the United States, reflected a similar view of care of the dying—that is, to be respectful and honest in communication, and to move discourse about dying out of the shadows and into the public.

Saunders died at the St. Christopher's Hospice in 2005. The *BMJ* (formerly the *British Medical Journal*) published an extensive obituary describing Saunders as "more than anybody else . . . responsible for establishing the discipline and the culture of palliative care."⁶ She advocated not simply for a comfortable setting for dying patients, but also for the relief of pain in its various manifestations (physical, emotional, and spiritual) of patients dying from cancer.

The term *palliative care* was first used in 1974 by Balfour Mount, a Canadian surgical oncologist, to offset what had become a negative connotation of the word *hospice* and its close alignment with dying and death. Despite foregoing the word *hospice*, Mount continued to promote Saunders's view of holistic care, extending these principles to care of persons with chronic or life-limiting illnesses and their families.⁷

In the United States, in 1997 the Institute of Medicine (IOM; now the National Academy of Medicine) published *Approaching Death: Improving Care at the End of Life*. In 2003, it published a second report focusing on children: *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. And in 2015, a third report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, was published. Recognizing that persons of all ages encounter death, the report notes that the goal of care should be "person-centered, family-oriented, and evidence-based," with a palliative approach offering "the best chance of maintaining the highest possible quality of life for the longest possible time."^{8(p1-2)} The authors of *Dying in America* noted that persons can and do live with life-limiting illnesses over long periods; thus, palliative care is ideally suited for management of symptoms to improve and sustain quality of life for those patients. The report also noted that hospice care is a form of palliative care for patients and their families as the patient approaches death;⁸ thus, palliative care is not necessarily hospice care, but all hospice care is palliative care. Palliative care for children and their families is woven throughout the *Dying in America* report, underscoring the perspective that serious illness and death occur at all ages and that human needs for dignity, respect, and comfort transcend age.

Although the human needs of children with chronic, complex, or life-limiting illnesses are the same as those of adults, distinct differences characterize palliative care for the pediatric population. The age range of children with palliative care needs crosses widely diverse developmental stages, extending from the prenatal period in the event of a diagnosis of a life-limiting fetal condition to beyond age 21 years in the case of persons with long-term illnesses and conditions managed by pediatricians.⁹ Illness trajectories may be less predictable in pediatric conditions; moreover, fulfillment of the social needs of school-age children and teenagers is an important determinant of quality of life. Families facing the illness and eventual decline of their children with a life-limiting condition have tremendous challenges in creating a sense of normalcy and balance in their day-to-day lives and in the lives of their other children. Quality palliative care requires the resources and talents of providers across healthcare disciplines, whose expertise may need to be focused on other members of the family affected by the child's illness.

Progression of Palliative Care to the Youngest Patients and Their Families: Perinatal and Neonatal Palliative Care

The childbearing period is a time typically associated with hope and expectations for a healthy baby born full term; however, the increasingly widespread use of prenatal technologies assessing the health of the developing fetus has resulted in an increasing number of pregnant women faced with diagnoses of a fetal defect, the meaning or prognosis of which may be unclear until after the infant's birth. Although the absolute number of congenital defects has not increased, the prenatal diagnosis of fetal defects has increased, meaning that some pregnant women and their families face the difficult prospect of choosing whether to continue the pregnancy and, if they choose to continue, planning for the birth and uncertain outcome for their newborn.

Complex issues surround prenatal diagnoses, decisions regarding treatment in the presence of severe or life-limiting fetal defects, and care of women and families in these difficult circumstances. PPC offers a means to assist these families in significant ways and has been endorsed by a variety of professional groups and stakeholders. In 2019, the American College of Obstetricians and Gynecologists (ACOG) Committee on Obstetric Practice and Committee on Ethics published an opinion on perinatal palliative care which was endorsed by The American Academy of Pediatrics and the Society for Maternal-Fetal Medicine.¹⁰ In this publication they expanded women's right to choose by presenting the need for providers to give patients faced with a LLFC information about palliative care, of "sufficient depth and breadth to make an informed voluntary choice."^{10(p84)} The ACOG committees noted specifically that "perinatal palliative comfort care is one of several options along a spectrum of care, which includes pregnancy termination (abortion) and full neonatal resuscitation and treatment."^{10(p84)} For women who choose to terminate, bereavement support may be beneficial. Women should be informed that, depending on the nature of the termination, some bereavement interventions—infant remembrance photography, for example—will not be possible.

In 2015, the National Association of Neonatal Nurses (NANN) published a position statement on palliative and end-of-life care for newborns and infants in which they affirmed that palliative and end-of-life care are integral to neonatal care and that neonatal nurses should be trained to provide essential services and assist families in setting goals of care.¹¹ The introduction to the statement affirms the concurrent use of palliative care and curative treatments, emphasizing the importance of ongoing assessment in order to recognize when it is necessary to shift goals of care to comfort rather than cure. This point of emphasis underscores the need for neonatal nurses to be exceptionally skilled in providing care across a wide range of conditions affecting infants admitted to the NICU and their families—from those otherwise healthy infants needing a few days of supportive care before discharge home to those for whom limitations of gestational age, congenital conditions, or birth trauma limits their lives to hours or days.

In 2017, the American Academy of Nursing (AAN) published a policy brief in which it made six recommendations regarding PPC as a collaborative effort across several disciplines: (a) development of effective models of PPC providing for ongoing communication with the pregnant woman and family when the fetus has a life-limiting condition; (b) allocation of adequate resources by healthcare organizations to ensure adequate training of PPC team members; (c) congressional mandate for funding of PPC advance care planning services and evaluation of quality; (d) recognition of nurses as key members in the PPC team, including as care coordinator and advanced practitioner across care settings; (e) PPC credentialing mechanism; and (f) increasing public awareness of the role of PPC using a variety of media.¹² As a newer form of palliative care, PPC has yet to become widely and consistently implemented; however, application of these policies has potential to advance the mission of PPC providers to implement comprehensive, supportive care to women and families for whom pregnancy is likely to end in fetal or neonatal death.

PPC, the importance of which is increasingly being recognized, is then distinct in its focus on emotional, social, and functional support of pregnant women and their families and is provided by a team of providers across various disciplines. These may include maternal–fetal medicine physicians, who typically make and convey the diagnosis and follow fetal development over the course of the pregnancy and often are the primary maternity care provider for the pregnant woman. Neonatologists or pediatricians are often part of the PPC team, or at a minimum consult with the family in advance of birth to discuss potential management and care of the neonate, and consultations with genetic counselors and medical and surgical specialists are not uncommon. Depending on the composition of the PPC team, social workers, RNs in the prenatal clinic and in the birthing suite, childbirth educators, and lactation consultants may be involved in the care of the families. Some PPC teams include pastoral care and child life specialists.

Functional support occurs in the form of birth planning and contingencies related to the outcome of the pregnancy. Because prognostication related to fetal and neonatal outcomes can be difficult, answers to questions of “What is going to happen?” may be vague or simply “We don’t know.” The lack of certainty accompanying the diagnosis of an LLFC heightens parents’ vulnerability, which is typically coupled with worry and

anxiety throughout the remainder of the pregnancy. Effective PPC requires providers to be skilled in assessing family responses to the diagnosis, prognosis, and potential range of outcomes and to provide anticipatory guidance throughout the pregnancy trajectory. PPC serves uniquely as a bridge from pregnancy to parenthood, and from fetus to newborn.

NPC and PPC overlap in the immediate aftermath of a live birth. Although for some parents the answer to “What is going to happen?” is stillbirth or neonatal death soon after birth, for others the infant might remain with the family while the mother is hospitalized or until discharge. Still other parents’ infants might require supportive care in the NICU to ensure his or her comfort or for intensive life-support measures. PPC typically includes care of the mother and family at the time of birth, including comfort care of the live-born infant expected to die soon after birth. Most PPC teams work to keep dying newborns with their mothers and family members as long as the parents desire, and their care is administered by RNs in the birthing suite, many of whom have training in bereavement support.

The need for NPC is not always anticipated. Sometimes infants born with congenital, life-limiting conditions live beyond their expected short life span, surviving to be discharged home with their families after supportive care in the hospital. Some pregnancies end unexpectedly in the presence of maternal complications requiring obstetric intervention or when a woman goes into labor prematurely, giving birth to a neonate on the edge of viability. For others, congenital defects or metabolic disorders may have been undetected prenatally, or maternal trauma or obstetric accidents such as umbilical cord prolapse may result in conditions necessitating the use of both intensive care services and palliative care focusing on preparation for the end of life in the event of an irreversible injury or untreatable condition.

No longer an either/or choice of curative treatment or palliative care, NPC current best practices suggest concurrent curative treatments and palliative care as the gold standard. Because palliative care encompasses symptom management, its early adoption for fragile infants facing a long recovery and potential developmental challenges introduces families to its benefits for their child. Moreover, once an infant is discharged home, the family may benefit from community-based pediatric palliative care services. If the infant has a life-limiting condition, palliative care provided in the home by expert healthcare providers can prepare a family for the use of hospice services when the infant’s health declines. Unfortunately, community-based neonatal and pediatric palliative care services are not uniformly available across the United States. Thus, care for an infant at home with a life-limiting condition can pose a challenge to families and their local providers in the absence of adequate professional palliative and end-of-life support.

Define Terms

Conceptual clarity is important for ensuring that healthcare professionals, researchers, and other stakeholders define and interpret phrases and terms in a similar manner. As such, Table 1.1 presents a glossary of common palliative care terms and their definitions.

TABLE 1.1 Glossary of Palliative Care Terms

TERM	DEFINITION
Advance care planning	Informed and shared decision-making about the care parent(s) wish to have during the birth process and for their infant after birth. Plans should be documented and shared with the healthcare team. Neonatal assessment findings, or parents who alter their decisions may require re-examination of the plan and flexibility in implementation
Anticipatory guidance	Information given by a healthcare provider to assist parents in understanding the expected range of physical and psychosocial experiences they may encounter for themselves and their infant during pregnancy, birth, and postnatally. Information should be shared at appropriate times in a compassionate and understandable manner. Prior to anticipatory guidance conversations, parental needs and understanding should be assessed
Holistic care	A philosophy that guides patient care based on an understanding of personhood that includes physical, psychological, emotional, and spiritual dimensions of health and healing. Holistic care draws from the biological, psychological, sociological, and spiritual dimensions of health, with an aim to achieve harmony that transcends physical wellness ¹³
Hospice, adult	In the United States, older adults using hospice services use a Medicare Hospice Benefit Funding mechanism Attending physician and hospice medical director certify that an individual is expected to die within 6 months, assuming normal disease progression
Hospice, pediatric	Requires physician certification that child is within the last 6 months of life, assuming normal disease progression <ul style="list-style-type: none"> • Hospice is a Medicaid benefit limited to end of life BUT can be offered in conjunction with curative measures • Hospice and curative measures can be offered concurrently, and services will be paid for <ul style="list-style-type: none"> • The Patient Protection and Affordable Care Act (ACA) requires all state Medicaid programs, or children insured through the Children’s Health Insurance Program (CHIP) to pay for both curative and hospice services for children under 21 years of age who qualify¹⁴ • Some states offer additional benefits that include benefits to children with life-limiting conditions rather than terminal illness with a 6-month life expectancy¹⁵
Life-limiting condition	An incurable condition that will shorten a child’s life, categorized as follows: <ul style="list-style-type: none"> • Potential for cure: Conditions in which treatment may be feasible but may fail • Period of normality with diagnosis incompatible with extended life: Conditions in which premature death is inevitable, but periods of participation in activities occur • Unremitting deterioration from or before the time of diagnosis: Progressive conditions without curative treatment options; palliative care is common and may extend over time • Unpredictable course: Irreversible but nonprogressive conditions causing a likelihood of premature death through complications¹⁶

(continued)

TABLE 1.1 Glossary of Palliative Care Terms (*continued*)

TERM	DEFINITION
Palliative care, neonatal	Neonatal palliative care focuses on the infant and his or her mother and family members. Palliative care is holistic and can be combined with cure-oriented, disease-modifying care and intensify when curative therapies are no longer beneficial or appropriate. Interventions aim to prevent and relieve infant suffering and improve the conditions of the infant's living and dying. An interdisciplinary team approach enables providers to relieve the physical, psychological, social, emotional, and spiritual suffering of the dying infant and the family ¹⁷
Palliative care, perinatal	Comprehensive and holistic services for expectant parents who receive a diagnosis of a life-limiting fetal condition and choose to continue the pregnancy ¹⁸
Patient-centered care	A model of healthcare services in which an individual's specific health needs and desired health outcomes are the driving force behind healthcare decisions and quality measurements. The patient is an active participant and partner with the healthcare team. Providers tailor interventions and consider clinical needs as well as holistic dimensions of health. Elements include shared decision-making, tailored care, timely updates, and a focus on patient needs, not those of the providers or system ¹⁹
Team-based care, interdisciplinary	Interdisciplinary teams are composed of members from more than one discipline who work interdependently with one another to achieve a common patient-centered goal. A respect and understanding of the roles of each team member allow for unique contributions. Processes are in place to ensure seamless communication and ongoing collaboration ²⁰
Team-based care, multidisciplinary	Multidisciplinary teams are composed of members from more than one discipline who work independently when providing patient care. Patient assessments and consultations are conducted separately in parallel efforts with each provider responsible for only his or her own area. Intentions to create a common plan are limited, as is communication across the disciplines ²⁰

Preparing Providers: Educational Initiatives to Improve Practice in Perinatal and Neonatal Palliative Care

Nurses, physicians, and others working in perinatal settings such as prenatal clinics, birth suites, and postpartum units may have chosen these settings for the typically good outcomes of a healthy baby born at term to a healthy mother. Poor outcomes are difficult and painful reminders that death occurs anywhere across the life span. Providers in NICUs may be more accustomed to dying and death because of the nature of the population admitted to those units; however, being accustomed to these difficult situations does not mean that one is necessarily well-prepared to meet the challenges posed when an infant dies.

For a long time, nurses in labor and birth settings have participated in what have become routine acts associated with stillbirth, including taking photos, saving locks of hair, armbands, foot prints, and other memorabilia associated with the baby's birth. These kind and well-meaning actions in fact are important: They are efforts to ritualize and make meaning of the short moments a family has with their child. Furthermore—even if inadvertently—these actions are consistent with the continuing bonds theory, which describes bereaved persons maintaining bonds of attachment even after the death of their loved one. Although describing various grief and bereavement theories is beyond the purpose of this chapter, we mention this as an example of an intervention well-entrenched in current maternity care practices and with a sound theoretical basis. Many maternity units have had for decades a mentor/mentee model of bereavement care, in which practices are handed down from experienced to novice nurses. As formal educational initiatives have expanded, providers have become increasingly knowledgeable about loss, grief, and bereavement, with an improved understanding of the complexities of loss in perinatal and neonatal settings. Providers in childbirth settings are now better positioned to implement effective care for families suffering these losses and their aftermath.

Dying in America includes a section on professional education and development in which the committee notes that, although education for providers has improved since the first report was published, “serious problems remain.”^{8(p13)} These problems are two-fold: (a) improved education has not been fully applied to clinical settings and (b) the number of end-of-life and palliative care specialists is inadequate to the need, such that clinicians in primary settings and other specialties (e.g., cardiology and oncology) continue to provide much of the care for patients approaching the end of life.⁸ These shortcomings are a function of three patterns of clinical education: (a) absence of hospice and palliative care in medical and nursing curricula; (b) single-profession educational silos, especially troublesome because end-of-life and palliative care are interdisciplinary fields; and (c) continuing lack of education, especially among physicians, regarding effective communication with patients and families in this population.⁸

Recognizing that most healthcare providers reading this chapter will be products of the educational system the IOM described as problematic, we will present ways in which clinicians can enhance their practice through education in order to provide quality, evidence-based care for patients in perinatal and neonatal settings. We begin by describing the most general education related to death and dying, end of life, and palliative care.

Death Education

In the broadest sense, loss, grief, and bereavement are located theoretically in the broad field of thanatology, the study of death and the various losses associated with death. Thanatology involves both the physical aspects of death and the psychological, emotional, and social responses to death. Practitioners across healthcare disciplines can study thanatology formally and receive certification from the Association for Death Education and Counseling. Thanatology programs often grant master's-level degrees and can be found online. The study of thanatology is not specific to any one clinical setting or practice; it does, however, provide an in-depth study of the complex aspects of death

and dying and theoretical perspectives related to grief and bereavement. Perinatal and neonatal clinicians may find the general focus of thanatology to be highly beneficial in deepening their understanding and broadening their communication skills in care for patients and families.

Many colleges and universities offer formal courses on death and dying. Increasingly popular, these courses may be interdisciplinary and provide the benefit of perspectives across disciplines that will work together on end-of-life and palliative care teams. For clinicians with limited time or inflexible schedules, courses offered through Massive Open Online Courses (MOOCs) hold an advantage over classroom-based courses with specific meeting times, especially if the MOOC content is asynchronous, meaning that students work at their own pace on their own schedule. The advantage to in-person (or hybrid online/in-person) courses is the opportunity to interact with classmates and faculty about the difficult topics undertaken in courses on death and dying. Finding courses through university continuing education centers or through search engines is not difficult; however, prospective students should explore the course objectives and faculty expertise carefully to determine the usefulness of the content for one's own practice.

Clinical Education in End-of-Life and Palliative Care

More specific to clinical care, education in end-of-life and palliative care provides clinicians with knowledge and skills more directly applicable to patient situations. This form of education may take place in medical residency programs and fellowships in palliative care. RNs can study at the graduate level for advanced practice or can become certified as palliative care nurse practitioners. Although this type of education may perpetuate the educational “silos” the IOM discouraged, clinicians trained in these programs may be highly skilled and prepared to work in hospices and palliative care settings and have a broad knowledge base about physical care and well-developed communication skills.

Interdisciplinary education for providers interested in PPC and NPC is available from a variety of organizations (see Appendix A at the end of this book). Healthcare systems and organizations nationwide coordinate conferences and symposia with highly regarded and trained speakers who present current best practices and lead discussions into a wide variety of PPC and NPC topics. Benefits of such interdisciplinary events are many—for example, increasing communication among disciplines, fostering opportunities for brainstorming within and across healthcare systems, sharing clinical practices that are effective but not yet published, practicing effective team communication skills for use with parents, and enhancing understanding of one another's challenges, among others.

Maintaining Quality Practice: Benefits of Ongoing Education

Ongoing education among healthcare providers is a professional responsibility regardless of practice setting. Providers typically think of ongoing education in terms of continuing education, that is, learning activities related to one's profession providing continuing education units (CEUs) for participation. Although requirements for continuing education and accrual of CEUs vary across healthcare disciplines and state regulatory boards, providers

committed to excellence in practice engage in ongoing continuing education beyond the minimum standards set forth by their profession and regulatory boards. Furthermore, continuing education equips providers with evidence-based tools for practice.

Evidence-based practice is a three-pronged approach to clinical care that is broader than simply the awareness of scientific evidence in the extant and developing literature, although that is crucial. Provider expertise and patient preference are the other two sometimes-overlooked prongs of evidence-based practice. Clinical expertise is enhanced through ongoing education, providing exposure to new thinking and developments in one's field. Patient preference, although sometimes easy to discern, may be less obvious when patients and/or families are highly vulnerable, such as those times when expectant or new parents encounter the prospect of early death of their child. It is at this point that well-developed communication skills are extremely valuable in assisting families to determine what they prefer and to implement a tailored yet flexible plan of care accordingly. Ongoing education is a means of shaping all three prongs of evidence-based practice in order to ensure quality care.

A clinical staff that values and participates in ongoing education benefits not only patients (the first priority) but also the healthcare organization. Quality care rendered expertly has the best chance for good outcomes. Educational offerings often identify and address potential barriers to implementation of new models of care. Providers have opportunities to recognize organization-specific barriers and to create strategies to manage them. Comprehensive palliative care education also includes how to measure baseline and outcome metrics. The current trend of linking reimbursement to outcomes or value-based care means that it is in the best interest of the healthcare organization to support clinical staff development through ongoing education to maximize clinical skills and optimize outcomes. Success of any program rests on the ability of health professionals to demonstrate results meaningful to themselves, patients, and administrators. Data are necessary to monitor patient outcomes and program impact, as well as to facilitate ongoing quality improvement processes.

In addition to these benefits, organizational support of ongoing education creates a work environment with potential for efficiency and increased productivity and is thus an investment in both the clinical staff and the organization itself. Well-run organizations tend to retain employees, which reduces costs. Importantly, an administration that values ongoing education for its clinical staff means that administration values clinicians' work and professional development and can promote shared purpose and mission. Support for ongoing clinical education then becomes a win-win-win situation across three important stakeholders: patients, providers, and administrators.

THE FUTURE OF PERINATAL AND NEONATAL PALLIATIVE CARE

The history of perinatal and neonatal palliative care continues to unfold. As diagnostic technologies become increasingly more sophisticated, the integration of palliative care with prenatal counseling is likely to increase. Postnatally, NICU providers will continue

to work toward expanding access to palliative care interventions for infants with prognostic uncertainty, those born at the cusp of viability, infants with life-limiting conditions resistant to curative treatments, and those for whom curative interventions are considered burdensome. Opportunities to forge strong interdisciplinary alliances will emerge as palliative care specialists, geneticists, maternal fetal medicine physicians, neonatologists, obstetricians, and nurses develop models of care that target best practices for patient-centered services. Palliative care training is likely to become increasingly incorporated and standardized into the educational training for physicians, nurses, and geneticists, who will then be able to lead teams and capture important metrics.

The future of PPC and NPC will rely upon researchers who are willing to conduct carefully designed studies that examine the breadth of interventions common in palliative care in careful partnership with healthcare providers who can speak to the very real needs of the patients and systems-level challenges. Although knowledge gaps still exist, the palliative care field will continue to grow as we determine how to minimize communication problems and care fragmentation, and to enhance patient-centered models of care.

CONCLUSION

In 2002, Catlin and Carter published results from a Delphi survey addressing the creation of a neonatal end-of-life protocol still in use today by providers caring for neonates.¹⁷ Since this early work was published, a body of research for perinatal and neonatal palliative care has emerged to guide practice. A national survey of palliative care programs in the United States confirmed that the number of PPC programs has increased and that the coordinators of these programs aim to provide tailored, patient-centered, exceptional care. Although attributes such as continuity of care, reimbursement models, and quality assessment vary,²¹ stakeholders continue to work to improve delivery systems. Carter, several years after publication of the neonatal protocol, noted that neonatologists, who typically manage the care of newborns likely to die from sequelae of prematurity or congenital defects, continue to have opportunities to “comprehensively address the continuum of interdisciplinary palliative, end of life, and bereavement care” needed in the NICU.²² In the last decade, PPC and NPC have notably improved, with parents having more opportunity to participate in shared decision-making and advance care planning. Parents are recipients of care from providers, who examine the eight domains of palliative care and consider innovative ways to bring comprehensive services to bereaved parents. Care of neonates is focused on pain and symptom management and facilitation of family bonds; these efforts honor their brief lives.

In this chapter, we have shown the benefits to women, their infants, and families when perinatal and neonatal palliative care are delivered seamlessly by providers whose abilities are closely aligned and evidence-based. Furthermore, we have shown the importance of education to keep one’s practice up to date with current developments in the field of palliative care. Although the field of palliative care is still developing, many providers have collaborated to move a new model of care forward that respects and gives dignity to parents’ choices and the lives of their infants for whom life is fleeting.

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