



Bringing Perinatal Palliative Care to the Forefront

One Nurse's View

You may ask: "Why would I be interested in an issue with articles on newborns and children? I only care for adults in my practice." The movement to include fetal loss and newborns in hospice and palliative care is relatively new. At every step, we are learning from our adult care colleagues. Although you may not have cared for newborns in the past, the movement to join obstetrics, neonatology, and hospice care is a growing field. With the advent of technological advances for newborns, many children who in previous years would have died at birth now are being supported and kept alive. Many of these children have lethal anomalies or extreme low birth weight prematurity, and despite ongoing treatment, they will later die at home. Those of us in the perinatology field will look to you as leaders in providing these families a supported and dignified death for their children.

This edition of *Journal of Hospice and Palliative Nursing* takes a leadership position in neonatal and pediatric hospice and palliative care by showcasing three noteworthy articles: *Children and Adolescents Participating in Research and Clinical Care Decisions at the End of Life*, by Pamela Hinds; *Understanding Grief: A Component of Neonatal Palliative Care*, by Tricia Romesberg; and *The Impact of Hippotherapy on Grieving Children*, by Hilda Glazer. With the publication of these articles, those of us in neonatal and pediatric end-of-life care can join our adult hospice and palliative care colleagues and share the importance of the work we do.

I have been privileged to work in this field for nearly 20 years, and it was within the context of my experience that Editor-in-Chief Leslie H. Nicoll asked me to write this guest editorial. Realizing that many readers might not be aware of some of the key turning points in this field, I wanted to share a few highlights from history:

- 1973: Raymond Duff and Alex Campbell¹ publish a landmark paper in the *New England Journal of Medicine* questioning whether dying newborns



must be supported in the nursery and voicing that they should be allowed to die. This study receives controversial worldwide attention.

- 1981: Nurses Teresa Rambo and Sara Wheeler of Gunderson Lutheran begin an organization to train nurses in supporting women who lose babies called Resolve through Sharing (RTS). RTS continues its work to become known nationally as the standard of care for obstetric nurse training in providing support for families who lose a baby.
- 1982-1984: The late President Ronald Reagan, with the assistance of Surgeon General C. Everett Koop, initiates strict regulation (known as the "Baby Doe" laws) disallowing physician decision making for newborn end-of-life care and requiring technological support for newborns.
- 1983: *The Long Dying of Baby Andrew*,² describing a child who is kept alive despite parental requests, is published and causes reconsideration of requiring support for all newborns.
- 1986: The Baby Doe regulations are ruled unconstitutional by the US Supreme Court on the grounds that the autonomy of the states had been violated and that the Rehabilitation Act did not apply to the medical care of infants who are handicapped. Despite being ruled illegal, allowing newborns to die becomes extremely difficult.
- 1986: Kristin Swanson^{3,4} publishes her first in a series of qualitative studies about miscarriages and the needs of women with critically ill and dying children in the neonatal intensive care unit.
- 1987: *Hastings Center Journal*⁵ publishes a study on support of impaired newborns.
- 1988: Joy Penticuff⁶ publishes work supportive of parental decision making. Sherokee Isle⁷ and Deborah Davis⁸ begin authoring a series of texts on pregnancy and newborn loss.
- 1992: William Silverman,^{9,10} father of American neonatology, continues to publish nonstop in his retirement against the excesses of neonatal resuscitation of babies who should be receiving palliative care. Silverman becomes champion of the palliative care for newborns movement.
- 1993: Sociologist Rene Anspach¹¹ studies end-of-life decision making in the neonatal intensive care unit.
- 1995: Two books, *Sylvie's Life*¹² and *Lost Lullaby*¹³ are published by mothers writing about their fight to allow their newborns to die. The books state that physicians controlled decision making for their dying newborns.
- 1997: American Academy of Pediatrics funds study¹⁴ to investigate physician decision making for end-of-life care in severely premature newborns.
- 1997: Several states and cities (Wisconsin, Denver, and Sacramento)¹⁵ hold public hearings to make recommendations about intensive care technology for newborns and palliative care.
- 1998: International parents of impaired newborn graduates from neonatal intensive care units band together and begin the Narof support group. Moderated by Helen Harrison, one of the themes is: "Children should be allowed to die when extremely premature."
- 1998: The notion of palliative care for newborns gains strength. Physicians and nurse members of the American Society of Bioethics and Humanities (Steven Leuthner, Brian Carter, Marcia Levetown, Suzanne Toce, Byron Calhoun, Winnifred Pinch, Elizabeth Pector, and Kristina Orfali) work together to plan studies and mutual support. University Press and Johns Hopkins Press begin to sponsor journal editions and texts written by our group.
- Elizabeth Sumner, Director of the Children's Division of the San Diego Hospice, teaches nationally about her work with dying newborns.
- 2000: A study is conducted on end-of-life care for newborns removed from ventilatory support.¹⁶ Many of the infants received no pain or symptom management when removed from the ventilator, and some lived up to 10 days before dying.
- 2000: Neonatologist Brian Carter and I conduct a national Delphi study on end-of-life care needs for newborns.¹⁵ Funded by the American Nurses Foundation, 101 participants during an 18-month period help develop a protocol for neonatal end-of-life care. The protocol is published in the *Journal of Perinatology and in Neonatal Network* and inserted into many of Carol Kenner's neonatal publications.¹⁷
- 2000 to present: Physicians and nurses worldwide e-mail requests to me for the end-of-life protocol. Those of us supporting neonatal palliative care continue to meet, talk, and write. We receive invitations nationally and internationally to help facilities incorporate hospice care into the neonatal area.

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families. Hospice and palliative care nurses can play a vital role in the recognition and treatment of depression.

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- 2000: The End-of-Life Nursing Education Consortium (ELNEC) project is funded by The Robert Wood Johnson Foundation. This partnership between the American Association of Colleges of Nursing and the Los Angeles-based City of Hope National Medical Center begins to train nursing leaders throughout the country in both adult and pediatric palliative care. Nurse Cynda Rushton continues as national leader for access to hospice for children.
- 2002: The National Perinatal Association recognizes the Palliative Care Protocol for Newborns as the Model of Care Award winner.
- 2002: Nurse Patti Lewis opens Alexandra's House, the nation's first freestanding neonatal hospice, in Kansas City.
- 2003: Last Acts, a Robert Wood Johnson-sponsored national campaign, gathers nursing leaders from the Society of Pediatric Nurses, National Association of Neonatal Nurses, Association of Pediatric Oncology Nurses, Institute of Medicine, and National Leadership Academy in End of Life Care to create a joint document: *Precepts for Palliative Care for Children, Adolescents, and Their Families*.
- 2003: Sutter Alta Bates Hospital in Berkeley, CA, begins a neonatal palliative care program.
- 2003: American Academy of Pediatrics Perinatology Subsection Meeting chaired by Deborah Campbell hosts session on neonatal ethics and palliative care.
- 2004: The National Institute of Health holds a two-day meeting to discuss limits of viability and when palliative care might be appropriate.

These are just highlights; there are many more influential people and events that have occurred in the movement for palliative care for newborns. The movement for adult access to hospice and palliative care has set the standard. It

is with pleasure and humility that those of us in pediatrics will continue to learn from the readers, writers, and editors of the *Journal of Hospice and Palliative Nursing*.

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