Taking Palliative Care into Pregnancy and Perinatal Loss

A Model for Community Collaboration

by Lizabeth H. Sumner, RN, BSN.

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“There is a beginning
and an ending for everything
that is alive.
In between is living.”

These touching words are from the book Lifetimes: The Beautiful Way to Explain Death to Children, by Bryan Mellonie and Robert R. Ingpen, which offers children and their parents simple wisdom that crystallizes the message that sometimes things go wrong, through sickness, injury or age, and creatures, plants, people—and even babies—die.

Regardless of the length of a baby’s life or duration of illness, it is their lifetime. Both the infant and family deserve skilled and compassionate attention to their plight; a safety net throughout the experience; a palliative care approach, which emphasizes living fully those days, hours, and even moments.

Palliative care is a lifespan issue, not secluded to only the elderly or the infirm, or to patients who have been seriously ill for many months or years. Palliative care can be needed at the beginning of life as well, when life and death share each other’s company, in settings where the norm is joy and celebration. The death of an infant or child is a special sorrow leaving a devastating and enduring impact that demands of us the very best we can offer to prevent and relieve suffering for the child as well as the family.

The Institute of Medicine Report: “When Children Die: Improving Palliative and End of Life Care for Children and Families,” cites that “we can and must reduce the number of those who fail to receive consistent, competent care that meets not only their physical needs but their emotional, spiritual, and cultural ones as well.” The report, released in 2002 by the National Academy of Science, gives an in-depth look at the current deficiencies and unique characteristics of the palliative care needs of children. “Perinatal hospice” as a framework for an anticipated perinatal loss is mentioned often in the text.

When the report was published, the authors stated: “While we cannot alleviate all suffering, we can help prepare these children and families for what is to come. It is hard to imagine a situation that has a greater moral imperative for humane care giving, yet, far too often today, it is not provided. It is time to correct this situation. We hope this report will serve as a call to action.

The major themes of the report include:

1. Too often, children with fatal or potentially fatal conditions (i.e. prenatal diagnosis) and their families fail to receive competent, compassionate, and consistent care that meets their emotional, physical and spiritual needs.
2. Better care is possible now, but current ways of organizing and financing services complicate the provision of needed care. Sometimes families are forced to choose between curative or life-prolonging care for their child and palliative services, in particular hospice care.
3. Inadequate data and scientific knowledge impede efforts to deliver effective care, educate caregivers, and design supportive public policies.

The principles of palliative care

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Don’t Miss it...

Lizabeth H. Sumner, RN, BSN, is a Keynote Presenter at NPA’s Annual Conference, “Humanity, Technology, & Perinatology: Good Ethics Based on Good Information” – October 14 – 16, 2004, San Diego, CA

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advocate that efforts focus on striving for optimal quality of life, and for individualized care planning and decision-making to foster a more humane and meaningful approach to advanced illness and end of life, even at the beginning of a life. These principles have been integrated into a new realm of health care delivery—pregnancy. Perinatal hospice is an organized strategy to address the needs of the fetus/newborn, family and the health care providers.

Through a successful model of collaboration with an experienced pediatric hospice program, San Diego Hospice and Palliative Care, and community obstetricians, perinatologists, labor and delivery centers, genetic counselors, and NICUs, multiple specialists have come together to create a seamless continuum of support and skill to help families gain control over their circumstances, and orchestrate their major life event in a very personalized way. The program has received local and national recognition for its innovative response to an unmet need, including receiving the American Hospital Association’s prestigious Circle of Life Award. It has been replicated across the country by many hospice programs already serving children.

With this model in place, parents have direct input into a plan for how their baby’s birth, living and dying will be handled, consistent with and respectful of their own unique beliefs, goals and values. This continuum of support is sustained among the various medical caregivers during pregnancy, delivery and beyond, whether the baby survives initially or not.

Families can realize they made a difference in shaping the choices and memories that will sustain them for years to come, even as they heal from the death of their infant.

This new-found home for palliative care services was initiated by the clear voice of parents who came directly to the San Diego Hospice program desperate for help during their troubled pregnancies. Having already named their babies and made the decision to continue their pregnancy despite the anticipated fatal outcome of the prenatal diagnosis, each family had found themselves facing the rest of this journey alone. Their experience of rejection and lack of compassion from the medical system was troubling. Knowing fully that their babies would most likely die at birth or soon after, they were often chastised and criticized for continuing the pregnancies. They chose not to terminate the pregnancy based on personal and religious beliefs. These families had made a choice for which a continuum of care did not exist.

Seeing the gap when faced with these very intimate encounters, the San Diego Hospice began admitting parents whose unborn babies had life threatening conditions to the Children’s Program. It fit consistently within the broader mission of preventing and relieving suffering, neither hastening death nor prolonging suffering. The overall goal is to offer educational, emotional, and spiritual support for the whole family, and prepare them for decisions that will need to be made regarding intensity of care for the baby once born, their wishes for resuscitation, diagnostics, and what specific rituals, keepsakes and goals they desire for the baby’s potentially brief time with them.

The perinatal hospice program has a rare duality in that the planning is intentionally geared towards both birth and the possibility of death, not only on planning for death. NICUs and labor and delivery areas have made enormous efforts to respond to fetal demise and infant death, and provide grief resources to parents. However, in many situations the grieving and major adjustments began at the time of prenatal diagnosis and a need for preserving some thread of support and hope prevails for many parents. It is important to help establish some realistic hopes and goals and help parents focus on the remaining normal aspects of their pregnancy, delivery and preserving the strength and integrity of relationships through this experience.

The hospice team meets with parents at appointments with their physician, at their home, or at the hospice center during the remaining weeks or months of pregnancy. The counselors also work with siblings to prepare them for the possible scenarios to come. They coordinate the tour of the birthing hospital with the inpatient staff and then, as delivery approaches, they coordinate and disseminate the documented “Birth Plan” with all those to be involved in the care upon arrival for delivery. The Birthing Plan is a specific document that captures the advanced planning decisions of the parents for the delivery room, postnatal care, discharge options, and community resources.

Implementing components of this type of program in a hospital setting involves using an interdisciplinary team, including spiritual support, and identifying existing resources within the community, such as an existing home care pediatric hospice service for discharge planning and expertise in palliative care. Through complimentary services and combining the availability of professional staff, more options become open. For example, many families would like to take their baby home for the first and last time if they had help to support them at home. Often there are ways to enhance the continuum of services when collaborative models are developed between home and inpatient providers. Each have elements that when combined can make the care more comprehensive. Anticipation and then prevention of symptoms may ameliorate any anxiety regarding taking the baby home if adequate planning precedes the discharge.

A perinatal loss should in itself be a catalyst for attention, but sadly there is little formal recognition of this very real death experience. It is true that in 1988, October was designated Pregnancy and Infant Loss Awareness Month by President Reagan. And, on the first Sunday in December, a candlelight vigil takes place around the world to remember and honor the lives of children who have died. But each year nearly 900,000 families experience birth tragedies, including 800,000 miscarriages, 33,000 stillbirths, and 19,000 neonatal deaths. Of the 53,000 children between the ages of zero and 19 who die every year, half die during their first year of life; half of those during their first month. Clearly there is a need for more organized approaches to support these many families.

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A significant obstacle to creating the needed momentum was the lack of any centralized means of gathering the many individuals, organizations and programs that could care for the varied children who would benefit from palliative care. To provide that needed centerpiece, Drs. Dan Tobin, Joanne Hilden, Bruce Himmelstein, Kathleen Foley and others recently began the process of bringing together individual and organizational leaders to create an agenda for advancing palliative care for children.

Thus was created The National Alliance for Children With Life Threatening Conditions (NACWLTC), a coalition of organizations and individual leaders dedicated to improving palliative, end of life and bereavement services for children with life-threatening conditions and the loved ones who care for them. Its membership includes clinicians, administrators, educators, researchers, advocates, policy makers, funders and community organizers and parents. Organizations include: the National Hospice and Palliative Care Association, NACHRI, Children’s Oncology Group, Compassionate Friends, Children’s Hospice International, Midwest Bioethics, Association of Pediatric Oncology Social Workers; and Initiative for Pediatric Palliative Care. Parents are a central part of NACWLTC’s efforts and are integrated throughout its structure.

Initial funds for NACWLTC were provided by The Project on Death in America of the Open Society Institute, The Charitable Leadership Foundation, The Robert Wood Johnson Foundation, Last Acts, Rallying Points and The Kirk and Anne Douglas Foundation.

NACWLTC is managed by The Life Institute/Center for Advanced Illness Coordinated Care (CAICC) in Albany, NY, White River Junction, VT, and Washington DC. The executive director for NACWLTC is Dan Tobin, MD, of the Life Institute. The Life Institute and CAICC are non-profit 501(c)(3) organizations dedicated to the integration of advanced illness and end-of-life care into mainstream medicine. The project director is Liz Sumner, RN, BSN, who is executive director of the Children’s Program at San Diego Hospice.

NACWLTC offers a searchable National Resource Center database through its website to help every community in America access, develop, implement and evaluate services for children with life-threatening conditions. The domains of the NRC include a network of pediatric physicians, social workers and nurses; a parent network and a directory of pediatric clinical programs offering palliative care services and community resources that support these children and families. NACWLTC supports work groups that network in five priority areas: clinical models, education, research, advocacy and policy and community resources.

You can contact NACWLTC at (202) 336-8397 or by email at info@nacwltc.org. Visit us on the web at www.thelifeinstitute.org. Liz Sumner can be contacted at: lsumner@sdhospice.org or at www.sdhospice.org.

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FDA mandate represents the biggest single step to date in the effort to reduce birth defects.

This article was reported in several news outlets, including The New York Times and on the NCFA Web site in the “Headline News” section at www.folicacidinfo.org.

For a copy of the article, please contact Mary Mitchell, Director, Professionalism and Gynecologic Practice, ACOG (202) 863-2502, mmitchel@acog.org.

Wall Street Journal

The March 2nd edition of the Wall Street Journal reported on the benefits of folic acid beyond birth defects. The article states that while emerging research indicates that folic acid may reduce the risk of heart attacks, strokes and certain cancers as well as cleft lip and cleft palate, more randomized clinical trials are needed to conclusively prove that increased folic acid intake will lower the incidence of these risks.

If you subscribe to the Wall Street Journal you can access the article at their Web site: http://online.wsj.com/public/health?mod=0%255f0005