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## The Perinatal Hospice: Ploughing the Field of Natal Sorrow

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*The opinions herein represent those of the authors, and not necessarily those of the United States Air Force, United States Army or Department of Defense*

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### CASE PRESENTATION

M.J. came to Madigan Army Medical Center (MAMC) as a referral patient for a possible fetus with short limbs. She arrived from her base as a 19-year old, married, nulligravida, dependent wife at 26 weeks



gestation and subsequently underwent diagnostic ultrasound in our unit. The measurements of the fetal long bones all demonstrated a baby with values well below 5 standard deviations from the mean and diagnostic of a congenital dwarfism. Further, the child's head size was above 3 standard deviations with a small chest noted by ultrasound. In fact, the child's chest was curved inward compared to the abdomen and gravely concerning for a presumptive diagnosis of thanatophoric dwarfism with probable maldevelopment of the lungs. This diagnosis is uniformly fatal due to compression of the chest with lack of lung function. M.J. was given her various options to include pregnancy termination and perinatal hospice. M.J. chose to continue her care at MAMC. Her pregnancy lasted until 36 weeks when she presented in active labor. The fetus had continued to show limb growth lag and significant chest wall compression. The baby delivered vaginally without difficulty and lived for a few minutes until it expired from respiratory failure. M.J. and her spouse were able to spend precious time with their newborn and have closure with him. Subsequently M.J. wrote a moving letter to our unit thanking us for our care and 'allowing her to choose life.'

## INTRODUCTION

Congenital anomalies now account for the majority of the causes of death in the first year of life.<sup>1</sup> Many lethal anomalies may now be diagnosed antenatally including anencephaly, bilateral renal agenesis, or acrania. Prenatal diagnostic capabilities continue to accelerate while thinking regarding hospice care for terminal perinates has lagged. We propose renewed thinking about how to approach the fetus that will die in utero or live a short time ex utero. We describe our method of approaching the 'perinatal hospice' at Madigan Army Medical Center (MAMC) under the perinatal hospice concept since July 1995.

## HOSPICE CARE FOR ADULT AND NEWBORNS

Madigan Army Medical Center provides tertiary and referral obstetrical/gynecologic care in the Department of Defense for TRICARE Region IV. There are twenty-four OB/GYN residents, three Maternal-Fetal Medicine Fellows (MFM), and fifteen staff. Military medicine provides a unique environment for obstetrics/ gynecology and neonatology since federal law restricts the provision of abortion services except where the life of the mother is at risk. Thus, infants with lethal congenital anomalies are frequently delivered at our facility. We have developed the concept of the perinatal hospice from our extensive experience with these patients and their families.

Adult hospice care began in the 1960s in Great Britain by Cicely Saunders when it was realized that end of life issues for terminally ill patients were not being addressed in a coherent, thoughtful, and supportive environment.<sup>2,3</sup> The hospice idea was particularly

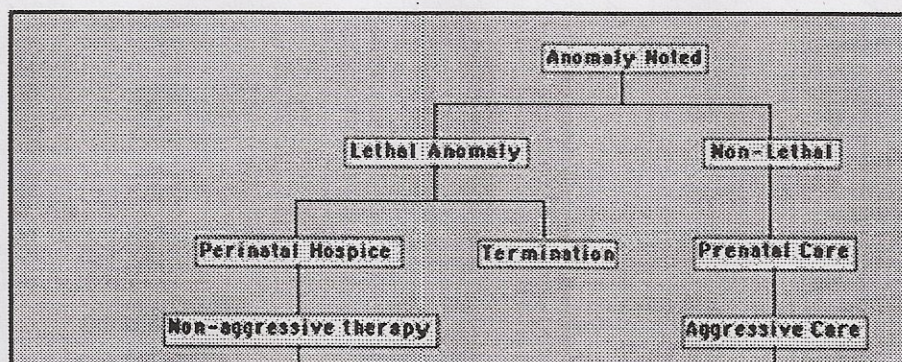


developed to provide nursing and medical care in an environment which addressed the common fear of pain and abandonment.<sup>4-7</sup> By the 1970s and 1980s, hospice care became increasingly available as an alternative. The work of Saunders laid the groundwork for awareness of end of life issues and hospice care became the focus of research and improved methods of care delivery. The hospice concept even developed further into childhood in the treatment of the terminally ill child.<sup>8</sup> Due to this work, Whitfield, et al, further refined Saunders' work with the implementation of the neonatal hospice concept at the Children's Hospital in Denver to support families of dying infants.<sup>9</sup>

### A NEW CONCEPT - THE PERINATAL HOSPICE

The neonatal hospice construct of care is no longer sufficient for our families' needs. Because of the increasingly common scenarios of the prenatal diagnosis of a lethal congenital anomaly, the process of providing care for a grieving family no longer begins at birth, but at the time of diagnosis. We, therefore, utilize the concept of perinatal hospice, one that implements a continuum of supportive care from the time of diagnosis until the death of the infant. The availability of perinatal hospice becomes important during prenatal counseling of families.

Upon prenatal diagnosis of a lethal anomaly, options for the parents include termination of the pregnancy versus the delivery of the fetus. Historically, the discussion often focused on what the delivery will be like, whether or not to resuscitate the infant, and, if so, what should be the level of care provided to the infant. The decision algorithm (Figure 1) may leave parents with the perceived dilemma of watching/allowing their infant to die versus an effort at futilely prolonging life which may lead to perceived increased suffering for their child. Parents may view this presentation of options as tacit counseling for termination of the pregnancy. Their decision may also be colored by the common fear of abandonment of themselves and their unborn child and the pain and suffering both may endure.<sup>12</sup> It is in this situation that an emphasis on perinatal hospice support throughout the pregnancy and the infant's life allows the parents full autonomy in coming to the best decision for their family.





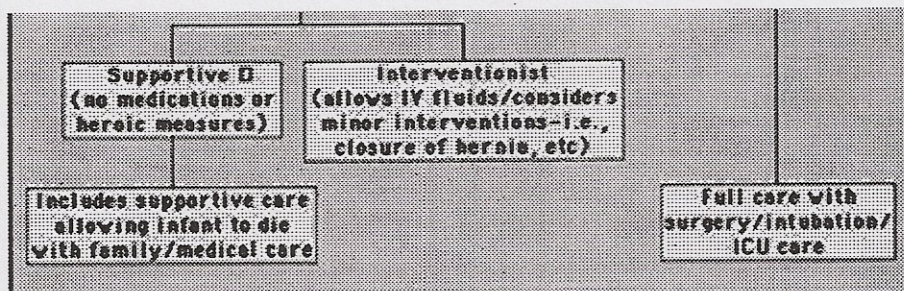


Figure 1. Sample Decision Algorithm.

Studies demonstrate that at least 20% of patients choose to deliver their children with known severe chromosomal or anatomic anomalies.<sup>7,10,11</sup> If we consider that roughly 0.5% to 1% (30,000 to 50,000 per year) of all live births have defects severe enough to cause fetal death, approximately 6,000 to 10,000 patients a year are possible candidates for perinatal hospice.<sup>13</sup> Patients who choose to deliver their infants rather than terminate the pregnancy had a perceived less severe anomaly on ultrasound or genetic amniocentesis.<sup>7,11</sup> Perinatal hospice care provides these patients and their children a compassionate, supportive, and desired alternative.

### ANTEPARTUM CARE

The burden of effort in perinatal hospice resides in the antepartum counseling and preparation. Patients need to see the baby on ultrasound and be allowed to grieve. Most birth defects are not as gruesome in appearance at birth as patients imagine.

We believe it essential to our management of these difficult pregnancies that we solicit input from the various services that will be involved in the terminal care of the infant. In concert with the hospice ideals, this allows for open communications and prevents derailment of carefully crafted care plans by lack of information. In our hands, the perinatal hospice includes the combined efforts of the maternal-fetal medicine sub-specialists, obstetricians, neonatologists, anesthesia services, chaplains/pastors/social work services, labor and delivery nurses, and neonatal intensive care nurses.

We participate in the ultrasound evaluation, amniocentesis, if desired, birth planning and on-going medical management in the antepartum, intrapartum and postpartum periods. Patients are given the fetal diagnosis and the expected prognosis during extensive time with the maternal-fetal medicine and neonatology staff. Patients are allowed to grieve, explore life issues, and prepare for the precious time they may be allowed to spend with their very special child.



## INTRAPARTUM CARE

Extensive support is also provided in labor through encouragement by the nursing staff and pain relief is administered by the anesthesia service. Labor management is conducted as other labors with the exception of fetal heart rate monitoring in lethal fetal conditions including anencephaly, trisomy 13, or trisomy 18 where an abnormal fetal heart patterns is expected.<sup>14</sup> Patients and staff find ignoring an abnormal heart tracing difficult. Fetuses with conditions not expected to be lethal, such as Down's or Turner's Syndromes, are managed with fetal heart rate monitoring in the same fashion as other labors.

When the time of delivery approaches, nursing staff who will be involved with the parents and the infant become increasingly involved in support and planning of delivery and postpartum care. The early and consistent involvement of the staff with the family prevents the "withdrawal" of care by the professional staff that Elizabeth Kübler-Ross so elegantly described in her work *On Death and Dying*.<sup>12</sup>

## POSTPARTUM CARE

Method of delivery is based on obstetrical indications and the infant is handed immediately to the parents to share in the baby's life or death. Many of these infants are stillborn, but some may live for minutes or days. The parents are allowed to stay in the delivery suite with the child as long as they wish. We encourage dressing the baby, pictures of the baby and holding the baby by all family members, including children if appropriate. We emphasize non-anomalous features of the baby to the parents. Descriptions of cute hands and/or soft skin give the parents a positive focus for their child's life and death.

Neonatologists and nursing personnel comfort the baby as needed. The infant is kept warm and cuddled. Some of these babies may even feed. Those infants who survive for longer periods may be kept comfortable in the nursery during the postpartum period, if the parents are feeling overwhelmed. Comfort measures are emphasized to the family. Our chaplain service and social services provide key spiritual and emotional support as needed.

## CONCLUSIONS

This supportive environment has been offered in our antenatal service for several years. Parents, when given loving support, freedom from abandonment and careful counsel as to clinical expectations, will choose the alternative of perinatal hospice, however brief that time may be. That our patients have access to comprehensive health care benefits in the Department of Defense facilitates this decision. However, none of the delivery or prenatal care expenses would be obviated by



termination. Delivery of the fetus is still necessitated. Other academic and private practice settings could arrange to ensure financial concerns are not prohibitive. Physicians and hospitals must be willing to waive or adjust fees, help set up payment plans and assist in the establishment of a perinatal hospice.

Parental responses have been overwhelmingly positive. These parents are allowed the bitter-sweetness of their child's birth and too soon departure. Grief lessens as time passes and parents can rest, secure in the knowledge that they shared in their baby's life, and treated their child with the same dignity as afforded a terminally ill adult.

*As you do not know the path of the wind or  
how the baby is formed in the mother's  
womb,*

*So you cannot understand the work of God,  
the Maker of all things:*

ECCLESIASTES 11:5 (15)

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**News From the National Institute of Child Health and Human Development  
and the National Institute on Alcohol Abuse and Alcoholism**

## **Stress Hormone Linked to Increased Alcohol Consumption in Animal Model**

**NATIONAL INSTITUTES OF HEALTH, USA**

Researchers at the National Institute on Alcohol Abuse and Alcoholism and the National Institute of Child Health and Human Development report in the current issue of *Alcoholism: Clinical and Experimental Research* (Volume 24, Number 5) results from the first study to determine whether future drinking may be predicted by response to stress during infancy. Monkeys that responded with high cortisol concentrations to stress during infancy were more likely than their peers to drink alcohol as adults, the research team found.

"Both drinking behavior and an individual's response to stress are determined by multiple genetic and environmental factors," said National Institute on Alcohol Abuse and Alcoholism Director Enoch Gordis, M.D. "If borne out in humans, these findings elucidate the alcohol-stress relationship in two ways: They confirm that early life stress can influence later alcohol consumption, and they offer a promising biological marker of risk for excessive drinking."

"This research may one day lead to ways to prevent alcohol abuse in adults, as well as prevent the devastating effects of alcohol on the developing fetus," said Duane Alexander, M.D., Director of the National Institute of Child Health and Human Development (NICHD). "It is indeed a promising finding."

Led by J. Dee Higley, Ph.D., Laboratory of Clinical Studies-Primate Unit, NIAAA, and Stephen Suomi, Ph.D., Chief, Laboratory of Comparative Ethology, NICHD, and funded by NIAAA, NICHD, and the Swedish Medical Research Council, the researchers followed 97 rhesus macaques from birth to young adulthood. Forty monkeys were separated from their mothers at birth and placed in a neonatal nursery for the first month of life. After 30 days, these monkeys were caged