The Perinatal Hospice: Hope for the Helpless

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Impetus (Or My Story)

Obstetrics is not just a place of joy, it may also be a place of great grief. The most touching and devastating moments wrench your heart out and reaffirm your vulnerability before the Lord. A specific couple enters my mind named McGloughlin. He drove trucks for a living and she was a full-time mother to their other two children, a 6-year-old girl and 8-year-old boy. Mr. McGloughlin stood 6 feet 3 inches in his stocking feet and she was a petite 5 foot 2 inches. Their pregnancy had been a happy one initially until it became clear that her screening test called the Maternal Serum Alphafetoprotein (MSAFP) returned positive. Further ultrasound workup at 21 weeks revealed a badly deformed infant with a gastroschisis (bowel outside the infant's abdomen), cleft lip, club-foot, and a small head. The amniocentesis returned Trisomy 18. The McGloughlin's chose to carry the pregnancy, much to my surprise. The Perinatal Hospice did not yet exist so we just provided supportive care. Mrs McGloughlin entered labor at 36 and 1/2 weeks and delivered her son Jonathan. Jonathan barely moved and he had only small gasping breaths. Both parents, with his brother and sister, hugged and loved Jonathan for his short life. I truly understood at that time that "abnormal" babies come from God. Further, I realized we did not deal well with them or their families needs. This sowed the seeds for what has become "The Perinatal Hospice." The full-blown debate on "partial birth abortion/infanticide" in 1995-96 gave the final impetus to provide a cogent, loving, pro-life response of how to deal with babies with lethal in utero anomalies.

Introduction

Congenital anomalies now account for the majority of the causes of death in the first year of life.[1] Many lethal anomalies may now be diagnosed antenatally including anencephaly, bilateral renal agenesis, or lethal skeletal dysplasias. 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 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 XI. There are sixteen OB/GYN residents, three Maternal-Fetal Medicine Fellows (MFM), and nine 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 1960's 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.[2, 3] The hospice idea was particularly developed to provide nursing and medical care in an environment that addressed the common fear of pain and abandonment.[4,5,6,7] By the 1970s and 1980's, hospice care became increasingly available as an alternative. The work of Saunders laid the foundation for awareness of end of life issues and hospice care became the focus of research and improved methods of care delivery. The hospic concept even developed further into childhood in the treatment of the terminally ill

child.8 Due to this work, Whitfield, et al, further refined Saunder's work with the implementation of the neonatal hospice concept at the Children's Hospital in Denver to support families of dying infants.[9]

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 "The Perinatal Hospice" which allows for a continuum of supportive care from the time of diagnosis until the death of the infant. The availability of "The 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 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.[12] 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.

Studies demonstrate that at least 20% of patients choose to deliver their children with known severe chromosomal or anatomic anomalies.[7.1,10,11] If we consider that roughly 0.5 - 1% (30,000 - 50,000 a year) of all live births have defects severe enough to cause fetal death approximately 6-10,000 patients a year are possible candidates for perinatal hospice[12.1]. Patients who choose to deliver their infants rather than terminate the pregnancy had a perceived less severe anomaly on ultrasound or genetic amniocentesis.[7.2,11.1] "The 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 at 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, chaplains/pastors/social work 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 pattern is expected.[13] Patients and staff find it difficult to ignore an abnormal heart tracing. 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 involved with the parents and the infant become increasingly aware and assist in the 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 Kubler-Ross so elegantly described in her work On Death and Dying.[14]

Care

Method of delivery is based on obstetrical indications. Primary elective cesarean section may be an acceptable alternative for the patient and family who desire a live born infant.15,16 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. Non-anomalous features of the baby are emphasized 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 post-partum period, if the patents 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. 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 may arrange to ensure financial concerns are not prohibitive. Physicians and hospitals must be willing to waiver 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 rest secure in the knowledge that they shared in their baby's life, treating the child with the same dignity as 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)[17]

Footnotes

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