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The Perinatal Hospice:
Allowing Parents to be
Parents

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Introduction

“A person is a person no matter how small.” *Horton Hears a Who*, Dr Seuss

Perinatology—also known as maternal fetal medicine—is that branch of obstetrics concerned with the care of mother and fetus and the handling of high-risk pregnancies.

In recent years, perinatologists have been incorporating into their practice a new concept in perinatal care called the “perinatal hospice.” This care originated in 1996 with the controversy over “partial-birth abortion.” This abortion method involved the surgical procedure where the baby would be delivered to the shoulders as a breech, then deliberately held in place while a scissors or other sharp instrument was inserted through the baby’s posterior skull into the brain resulting in death. Many perinatologists believed this procedure so horrible that they sought to find a better way to care for our patients facing the hardest circumstances.⁽¹⁾

Approximately 0.2-0.3% of newborns die as a result of lethal anomalies.⁽²⁾ Lethal anomalies now constitute the leading cause of newborns’ deaths at term.⁽³⁾ This, in concert with our new abilities to find and diagnose fetal anomalies before birth, has led to limited management choices for families.

Previous counseling prior to perinatal hospice generally involved only the recommendation to terminate the pregnancy. Doctors did so for a number of reasons: a desire to “spare” the mother and family a distressing experience, the family’s perceived need to “get it over with,” the physician’s felt need to “do something” and deal with the discomfort of bereaved parents, misinformation about avoiding complications of pregnancy, and a fear of increased maternal death.

The literature regarding termination of pregnancy for anomalies finds a different picture. Early, small studies provided an initial glimpse that termination losses were as intense as spontaneous losses. Zeanah, et al., in 1993 reported a case-control study of 23 individuals and found 17% (4/23) suffering depression and 23% (5/23) seeking psychiatric counseling at two months.⁽⁴⁾ A more recent study of 253 women from 2-7 years after termination of pregnancy for fetal anomalies prior to 24 weeks by Korenromp et al., in 2005 found that pathologic grief persisted in 3% of patients (2/253) and that 17% (33/253) suffered from symptoms of posttraumatic stress.⁽⁵⁾ Finally, Korenromp et al., in 2009 found persistent and significant grief responses at 4, 8, and 16 months.⁽⁶⁾ At 4 months 46% of women revealed pathologic levels of posttraumatic stress symptoms and at 16 months 21% still had pathologic levels of posttraumatic stress symptoms.⁽⁶⁾

Comparing grief from miscarriages with live birth, Janssen et al., in 1996 published a study of 227 women with first-trimester losses compared to a control group of 213 women who had a live birth.⁽⁷⁾ The first 6 months after miscarriage showed an increased level of depression, anxiety, and physical symptoms in the miscarriage group, but by one year after the miscarriage there was

no difference between the women who delivered a live baby or those who suffered a miscarriage — thus demonstrating recovery to baseline mental health with early miscarriages.⁽⁷⁾

The much-touted increase in maternal mortality in hospice care does not exist. In fact, the mortality rates with induced abortion from 16-20 weeks are quoted as 9.3/100,000 live births and the rate for pregnancy-related mortality is 10/100,000 live births.^(8,9) Essentially, the mortality rates are the same for either of the management choices.

In this context we offer the new concept of the “perinatal hospice”: perinatal hospice is the prenatal diagnosis of a terminally ill fetus in-utero leading to perinatal hospice as part of the continuum of end-of-life care.

Prenatal diagnosis of fetal anomalies was virtually impossible until the 20th century with the advent of radiologic and sonographic techniques. The first sonographic diagnosis of a lethal anomaly was anencephaly in 1964.⁽¹⁰⁾ Soon after came the first prenatal diagnosis of fetal aneuploidy in 1968 through amniocentesis.⁽¹¹⁾ Rapid advances in diagnostic ultrasound, molecular genetic testing, and maternal serum screening increased diagnosis of fetuses with lethal conditions.

Unfortunately, fetal therapy does not necessarily keep pace with prenatal diagnostic abilities. Also, how to care for families and patients has not been as well studied or taught in the past.⁽¹²⁾ The first studies of the effects of stillbirth and neonatal death on mothers’ health did not surface until 1968.⁽¹³⁾ Parental thoughts on neonatal death did not appear in the literature until 1970.⁽¹⁴⁾

Prior to the introduction of perinatal hospice, there were limited attempts to address the complex issues of perinatal loss.^(15,16) Admirable as these attempts were they did not reflect a systematic approach to patients and families, especially in the light of some 20% of patients desiring to carry their pregnancy to term no matter the diagnosis.⁽¹⁷⁾ The care of patients carrying children with a lethal fetal anomaly is not adequate with simple bereavement counseling protocols. These care pathways were developed for stillbirth or sudden and unexpected losses. Nor can these patients receive simply routine care. The attendant psychosocial dynamics of anticipatory grief, extinguished dreams, and loss of future life events are much different from those of parents expecting an uncomplicated pregnancy and a healthy and normal child. Not for these families the joyful arrival of a new baby, but, rather, the sorrow of the too-soon loss of a loved child.

In spite of the new findings in the area of perinatal grief and better prenatal diagnosis, many clinicians face a significant amount of uncertainty, mixed emotions, ambiguity and misunderstanding about how to counsel and care for these families. Until our work, there was scant literature on how to care for these specific patients.

We employed the seminal concepts of Kubler-Ross on modern medicine’s understanding of death and dying to aid us in shaping our care model.⁽¹⁸⁾ While Kubler-Ross transformed the

discussions around death, Saunders revolutionized the care of the dying with her modern hospice movement.⁽¹⁹⁾ The unifying concept in hospice remains the holistic approach to the physical, emotional, and spiritual support for dying patients and their families. The core belief in hospice is to offer treatment of the dying that respects their dignity and sees them as truly alive and not yet dead. The patient and family's worst fears of abandonment could then be met. Hospice care may be found in various forms and institutions, and hospice in some manner may be found in almost every local community today. The care has even been adapted for use with terminally ill neonates. Whitfield, et al., used the hospice principles to found the neonatal hospice movement in 1982.⁽²⁰⁾

Perinatal hospice families who choose to carry their pregnancies in which the fetus has a lethal condition possess many of the same characteristics of families with a terminally ill adult or child, a clinical scenario in which hospice has been well accepted and a useful method of care. Many of the hospice principles were successfully applied in perinatal hospice. The emphasis is on affirming life by care for the loved one, yet regarding dying as a normal part of life. A conscious effort is made to neither hasten death nor prolong dying. The team stresses values beyond the mere physical needs of the dying individual and allows the parents to "parent" their child for whatever time they are allowed. The family is supported in their medical, emotional, and spiritual needs through an organized, multidisciplinary team that cares for them after the death of the loved child during the period of grief.

The care in perinatal hospice differs in emphasis, but not in type of care from other modes of perinatal care. Its primary focus is on the family — not the fetal diagnosis and attendant anomalies. The family is placed in the center of the care and there is a continuum of support from the diagnosis, through death, and grief. As Amy Kuebelbeck, author of *Waiting with Gabriel*,⁽²¹⁾ a book about her own experience with her son who had a fatal form of hypoplastic left heart, notes, "I know that some people assume that continuing a pregnancy with a baby who will die is all for nothing. But it isn't all for nothing. Parents can wait with their baby, protect their baby, and love their baby for as long as that baby is able to live. They can give that baby a peaceful life – and a peaceful goodbye. That's not nothing. That is a gift."⁽²²⁾

Participants in perinatal hospice access care through multiple prenatal diagnostic pathways. A kind and clear explanation of the diagnosis and lack of ability to physically heal the child is given to the patient and family. The framing of choices and the psychology of decision making must be taken into account. The parents should not think they must choose between an "active" choice of termination versus a "passive" choice of inaction. Nothing could be further from the truth in perinatal hospice. The families are empowered to enter into an interactive process that may be intense and personal. Those who continue the pregnancy may engage as much, or as little, of the hospice care as they need or want. The presence of a viable, compassionate, organized program gives the parents a place to "be parents" and an opportunity to work through grief and dashed expectations.

The care of terminally ill perinates requires a team of professionals, since no single group of professionals will be able to meet all the desires of the grieving family of a terminally ill child. The central hospice team consists of the patient, her unborn child, her family, the physician or team of physicians providing primary care, a social worker, and a nurse with training in bereavement issues. Generally, as the care evolves, neonatologists, anesthesiologists, psychiatrists, psychologists, chaplains, a local priest/pastor, bereavement counselors, labor nurses, sonographers, and neonatal nurses may be added.

The major clinical issue in much of hospice care remains fear. The patients who are dying fear abandonment, and in the same way, the perinatal hospice families fear abandonment and loss of relationships during the loss of their child. Hospice emphasizes that they are allowed to “parent” their child how they would like to do so. A birth plan is often written to elaborate the family’s wishes. Many parents also fear their baby might feel pain. If they desire comfort measures for their baby — oxygen, feeding, medications, pain relief (if indicated) and wound dressings — parents are assured these will be provided. Flexibility in meeting the parents’ needs and schedules is critical to the management of these pregnancies. Reduction of feelings of isolation and abandonment, through easy accessibility to the multidisciplinary hospice team, is the mainstay of perinatal hospice care.

Instruction is given in anticipatory grief as well as ways to relate to other children in the family, friends, and other family members. Gentle sharing of the realistic outcome of the pregnancy is balanced with the hope for simplified dreams for their baby.

The grief accompanying perinatal loss of a wanted child may be more intense compared with loss of another family member. The lack of physical contact and minimal amount of time with the fetus may prevent connection within the family and minimize the feelings of loss. Memories built around the child are important in the grieving process. Frequent ultrasounds of their baby are provided and other family members, particularly grandparents and siblings, are invited to attend and to see the baby. CD’s or videos may be recorded providing the family living memories of their child.

Delivery plans are covered in detail with the parents. It is especially necessary for the parents to design their own birthing plan, including a possible live birth. This may include fetal monitoring which we usually do not recommend unless the parents agree to possible cesarean delivery. Cesarean delivery may be offered in the event the parents want to see and hold their living child. If the parents are adequately counseled regarding the increased maternal risk for cesarean delivery, we would provide this service.

Diagnosis is confirmed at delivery and the family allowed to spend maximum time with their child. The time allows parents to contribute something special to their child’s life and to let family members hold the infant and even perform its first (and maybe only) bath.

Hospice care does not cease with the death of the child. Grief counseling continues throughout the postpartum time frame. Usually the patients are contacted 72 hours after delivery, monthly thereafter for one year, and on the first anniversary of the death of their child. The team may help with funeral arrangements and a memorial service and may attend services when available. Postpartum visits encourage the discussion about future pregnancies and genetic counseling may be needed.

We have published two previous case series in perinatal hospice in diverse medical environments: a military medical center and a community-based tertiary care medical center.^(23,24) Our first series published in 2003 reviewed our experience with a military population where we discussed 33 patients eligible for perinatal hospice care. Of the 33 patients, 28 (85%) chose hospice care.²³ We had a 61% (17/28) live birth rate: 12 vaginal deliveries with 4 preterm (< 37 weeks) and 8 term; and 5 cesarean deliveries (18% or 5/28).²³ In a follow-up paper at a civilian tertiary care center we had 28 patients eligible for perinatal hospice with 75% (21/28) choosing hospice..²⁴ Of our 21 patients who chose hospice, 76% had a live birth (16/21) with 15 vaginal deliveries. Four of the deliveries were preterm (before 37 weeks) and 11 were full term. We had one cesarean section (1/21 or 5%) for maternal request of a live-born baby. All our live-born babies lived in the combined series (33 live born) from 20 minutes to 256 days (one trisomy 13). The majority of the neonates expired within 24 hours.^(23,24) There were no maternal morbidities or mortalities in either of our series. This replicates previous authors' experience.⁽²⁵⁾ A recent review of the literature by Balaguer et al. in 2012 found 27 articles with clinical data on perinatal hospice and noted that “. . . in light of the significance and complexity of Palliative Care (Perinatal Hospice), it seems desirable for obstetric and neonatal units to have available an active and efficient PPC (Perinatal Palliative Care) programme.”⁽²⁶⁾

The institutional attitudes and belief frameworks of the professionals who care for the patients and families will have a huge effect on whether or not the perinatal hospice concepts will be initiated. Termination of pregnancy remains the approved solution for lethal fetal conditions, and health care providers as a group, unless trained otherwise, seem to be more in favor of termination than either the public or pregnant women.⁽²⁷⁾ Some are concerned that patients, once offered perinatal hospice, will desire that these services be provided (as in our series). Some providers might even ask why resources should be wasted on a lethal anomaly. However, this really begs the question. If hospice concepts are valid, and patients are to be offered true choices with exercise of true autonomy, then *real* options need to be given. The deficiency, then, seems to be a cogent, consistent, organized, and thorough planned model of prenatal care for lethal anomalies.

In order to be successful, there must be at least one physician champion. A dedicated small group of professionals from each of the disciplines involved is critical for perinatal hospice. These individuals must be willing to give input and support from the beginning of the process. There might be a diversity of approaches used to overcome negative reactions. Perhaps, the most direct means is to put the perinatal hospice concepts to work in caring for several families who choose to carry their child with a lethal anomaly. The direct

observation of these families moving through the process with their children in a dignified manner with their providers transforms the most hardened of heart.

Significant resistance existed to perinatal hospice when first proposed.^(1,28) Much of this was based on the erroneous beliefs elaborated in the introduction of the article: well-intentioned desires to “spare” the mother and family a distressing experience, a need to “get it over with,” obstetrical providers’ need to “do something” and deal with their discomfort with bereaved patients, an ill-informed desire to avoid complications of pregnancy, and an unsubstantiated fear of increased maternal mortality.

The whole idea of perinatal hospice was initially greeted with skepticism. The challenge became overcoming the reluctance of health care providers to deal with families in an ambiguous situation. The complex issues of death related to these pregnancies often left the providers feeling they had nothing to offer the patients in terms of therapy, so they would withdraw from the family just when the family needed them most. The focused, multidisciplinary perinatal hospice program served as a template for everyone involved in the patients’ care and allowed providers to deal with their aversion to caring for patients in difficult and painful situations. A clinical template allowed an environment of quality metrics to emerge with professionals at all levels finding the comfort necessary to care for these families.

The publication of our two case series (now 27 articles) provides the necessary clinical support for perinatal hospice demonstrating no increase in either maternal mortality or morbidity. A number of educational presentations have also been made in various venues in support of the development of perinatal hospice. To date, 127 perinatal hospices, including one in 35 of the 50 United States, and multiple international hospices have been created.⁽²⁹⁾ What started as a small, humble idea to promote patient-centered choice and humanity-honoring care has blossomed into a national and international movement for compassionate care for families. We look forward to the day when all parents will be allowed to “just be parents” and love their children for however long they may tarry.

I shall be telling this with a sigh
 Somewhere ages and ages hence:
 Two roads diverged in a wood, and I—
 I took the one less traveled by,
 And that has made all the difference.-

Robert Frost, *Mountain Interval*. 1920.

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