

Perinatal Hospice: Family-Centered Care of the Fetus with a Lethal Condition

Michelle D'Almeida, D.O.
Roderick F. Hume, Jr., M.D.
Anthony Lathrop, C.N.M.
Adaku Njoku, M.D.
Byron C. Calhoun, M.D.

ABSTRACT

Twenty-eight newborns prenatally diagnosed with lethal anomalies were eligible for a pilot hospice program at Rockford Memorial Hospital (RMH). Comprehensive care in a comforting community setting was provided to the 75% of families who chose this option. No maternal morbidity resulted. In the 76% of infants who were born live, survival ranged from 20 minutes to 256 days. Further study of psychological outcomes is warranted.

This study, a follow-on to previous experience with perinatal hospice,^{1,2} was carried out at Rockford Memorial Hospital (RMH), a community tertiary hospital and an Illinois state-designated perinatal referral center for northwest Illinois. There are approximately 2,500 deliveries per year at RMH, and 13,000 deliveries per year in its referral area. RMH also serves as one of the four clinical training sites for 50 senior University of Illinois medical students per year.

Congenital anomalies now account for the majority of neonatal deaths in the United States.³ Significant numbers of congenital anomalies, such as anencephaly, renal agenesis, and lethal trisomies, may be diagnosed prenatally. Pregnant patients have been presented with offers of abortion in such circumstances. Patients who do not want abortions have been left to manage their pregnancies expectantly, but without recognition of, and support for, the likelihood of loss of their infants, and their attendant grief.

Capacity for prenatal diagnosis continues to expand with the advent of real-time 3D ultrasound, but prognosis for many of the diagnosed conditions remains as poor as if they had not been diagnosed prior to birth. Likewise, the need for comprehensive, especially psychological, care for families of infants who will die in utero, or live for only a short while after birth, has been underestimated. The family's experience with these pregnancies is analogous to that of families with a terminally ill child. Their needs are best fulfilled with a comprehensive end-of-life approach. Perinatal hospice has been proposed as a comprehensive structured approach for the care of these families.¹

Modern hospice care for adults originated in the 1960s in response to a realization that end-of-life issues for terminally ill patients were inadequately addressed by traditional approaches.^{2,4,5}

Hospice care rapidly expanded over the ensuing three decades, to include care of terminally ill children and their families.⁶

Whitfield et al. developed the idea of a neonatal hospice, but with the now common scenario of prenatal diagnosis of a lethal condition, the families involved need a special type of hospice care.⁷ We recognize that when a prenatal diagnosis portends perinatal death of the family's newest member, hospice care must start at the time of diagnosis. The perinatal hospice furnishes caring support to families who do not want abortion, whatever their moral, psychological, religious, or other reasons may be.

Material and Methods

After prenatal diagnosis of a lethal fetal condition, parents were presented with the option of a multidisciplinary program of supportive care until the time of spontaneous labor, or until delivery was required for obstetric indications, or referral for abortion per Illinois state guidelines. For those parents choosing the perinatal hospice, a significant portion of their care occurred as antepartum counseling and preparation.

The maternal-fetal medicine staff coordinated initial and follow-up ultrasound evaluation; amniocentesis and other diagnostic procedures; birth planning; and management in the antepartum, intrapartum, and postpartum periods. To provide adequate understanding, especially while exploring anticipatory grieving, parents were carefully counseled regarding the fetal diagnosis and probable prognosis. Families were allowed to grieve, explore life issues, and prepare for the precious time they might have to spend with their child. Antepartum consultation with the neonatology service included development of a postnatal plan for the eventuality of a live birth.

Local hospice services were engaged for those neonates who would go home. The usual template plan involved evaluation at the time of birth to confirm the prenatal diagnosis where possible, and if a lethal condition was confirmed, interventions were performed for the infant's comfort. Referral to chaplain services was offered as desired.

Consultations with social services were planned to help with financial issues related to the pregnancy and the funeral.

Each family's status and plan was reviewed at regular perinatal conferences, in which physicians in maternal-fetal medicine and neonatology, medical students, sonographers, antepartum/intrapartum and neonatal nurses, social workers, and chaplains participated. Our goal was patient/family-centered care, and patients and family members had easy access to members of the multidisciplinary team.

We encouraged medical students to participate in giving emotional support during labor to the patient and her family, with the assistance of nursing staff trained in perinatal bereavement. The family designed a birth plan covering their expectations for the care they desired during labor and delivery (Figure 1).

We carefully reviewed each plan to meet both patient and institutional expectations. The patient's labor management was similar to that of other labors, and was individualized based on the parents' moral/religious, social, and cultural background, and personal desires. Care might include listening to fetal heart tones, or deleting continuous fetal heart rate monitoring if an abnormal heart rate or pattern was expected. The anesthesia service managed pain relief in the usual manner.

The mode of delivery was based on obstetric indications, with exceptions when the family requested a caesarean delivery in order to see the infant alive or to baptize a live infant. Patients were extensively counseled about the additional maternal morbidity, the unchanged ultimate prognosis for the neonate, and our reasons for advising vaginal delivery. If the family showed an understanding of these facts but insisted on a caesarean delivery, the request was usually granted. Our medical students were encouraged to attend preoperative counseling, participate in surgery, and provide postoperative care with our team.

At each birth, the attending neonatologist carefully examined the infant, confirmed the diagnosis, and if desired gave the infant to family members to share in their baby's life and death.

Bereavement care began at the infant's delivery. Bonding of the infant with family members was encouraged, and the parents' desires directed the medical, nursing, pastoral, and social-work staff in their interactions. Unlimited time with the infant was allowed, before and after the infant's death. The staff encouraged family bonding by providing privacy, assisting the parents with bathing and dressing of the infant, helping all family members hold the infant, and emphasizing non-anomalous features of the infant. The infants were kept warm, cuddled, and some even fed. If the parents desired, infants who lived for prolonged periods were occasionally cared for in the nursery during the postpartum period. Chaplain, nursing, and social services provided spiritual and emotional support during this time as needed.

Medical students learned how mementos of the infant were created and given to the parents, and how these represented meaningful gifts to the grieving families. Mementos might include a baby outfit, a newborn knitted hat, the blanket the baby was received in at birth, foot and handprints, a lock of the infant's hair, the blessing or baptismal bowl, photographs, and a hand-painted memory box.

After discharge, parents were offered bereavement support for one year after the death of their infant. A sympathy card signed by the staff was sent to the parents, and a committed member of the perinatal bereavement team called the parents right after discharge, at one month, three months, six months, and one year. The parents were also invited to participate in a parent support group facilitated by social and nursing services.

During the period from Jan 1, 2000, to Jul 1, 2004, 28 families whose pregnancies were complicated by a lethal fetal condition

were eligible for participation in the RMH perinatal hospice program. The criteria for participation included any patient with the diagnosis of a fatal fetal in utero anomaly diagnosed by our clinic. We assessed the following outcomes: number who chose perinatal hospice; number experiencing an intrauterine fetal demise; number of live births; number of preterm births; mode of delivery; and length of survival of the live-born neonate. Maternal morbidity was examined, including infection, operative complications, need for blood products, and postpartum readmission.

Results

As shown in Table 1, 21 (75%) of the 28 patients with a clearly defined lethal fetal anomaly chose to participate in the perinatal hospice program. Of the seven aborted infants, five had anencephaly, and one each had trisomy 18 and triploidy.

In the remaining patients, 5 (24%) of 21 had an intrauterine fetal demise and 16 (76%) delivered live-born infants. All who experienced an intrauterine fetal demise had a vaginal delivery. There were 15 vaginal deliveries of live-born infants, of which four were preterm and 11 full-term. One caesarean delivery was done for obstetric indication and one on maternal request, the latter of an infant with acrania. The live-born infants lived between 20 minutes and 256 days.

There were no maternal infections, operative complications, blood transfusions, or postpartum admissions.

Discussion

Perinatal hospice care has now been offered on the RMH perinatal service for a number of years. During the pilot program, 75% of patients chose to continue their pregnancies in this environment of care, despite prenatal diagnosis of a lethal condition. The care of this group of patients was accomplished without any notable maternal morbidity.

Table 1. Characteristics of Patients Eligible for Perinatal Hospice

Case	Diagnosis	Gestational at Dx	Age at delivery	Delivery method	Life-span/ demise
1	Trisomy 18	22 wk	40 wk	SVD	48 days
2	45 X, hydrops, cystic hygroma	19 wk	23 wk	SVD	IUFD
3	Trisomy 18	17 wk	39 wk	SVD	177 days
4	Acrania	31 wk	37 wk	C-section	16 hrs
5	Trisomy 18	22 wk	40 wk	SVD	IUFD
6	Multiple: ASD, ventriculomegaly, craniosynostosis	38 wk	39 wk	SVD	7 days
7	Anencephaly	23 wk	42 wk	SVD	< 60 min
8	Trisomy 18	20 wk	35 wk	SVD	24 hrs
9	Anencephaly	30 wk	32 wk	SVD	3 hrs
10	Body stalk anomaly	14 wk	37 wk	SVD	53 min
11	Anencephaly	22 wk	41 wk	Repeat C-section	4 days
12	Ancephaly, ectopia cordis	19 wk	34 wk	SVD	IUFD
13	Renal agenesis	24 wk	36 wk	SVD	< 60 min
14	Anencephaly	18 wk			Aborted
15	Trisomy 18	22 wk			Aborted
16	Anencephaly	20 wk			Aborted
17	Acrania, anencephaly	14 wk			Aborted
18	Anencephaly	21 wk			Aborted
19	Anencephaly	16 wk			Aborted
20	Triploidy	14 wk			Aborted
21	Trisomy 13	24 wk	37 wk	SVD	256 days
22	Trisomy 18	24 wk	41 wk	SVD	IUFD
23	Triploidy	23 wk	28 wk	SVD	IUFD
24	Achondroplasia type III	21 wk	31 wk	SVD	3 days
25	Thanatophoric dwarf	21 wk	37 wk	SVD	20 min
26	Anencephaly	15 wk	32 wk	SVD	< 60 min
27	Trisomy 13	20 wk	39 wk	SVD	15 days
28	Complex CHD, syndactyly, cleft lip	18 wk	39 wk	SVD	10 days

ASD, atrial septal defect; SVD, spontaneous vaginal delivery; IUFD, intrauterine fetal demise; CHD, congenital heart disease

Family Birthing Plan

To the staff of the Hospital:

Our beloved baby, sadly, has been diagnosed with _____. However imperfect he/she appears, this is our child, whom we love deeply. This love compels us to revere and treasure every moment of our baby's life to its fullest natural extent. Your compassion and understanding during this bittersweet and difficult time are appreciated deeply. We believe that the memories of our actions during this sacred time with _____ will later console us.

We understand that after the birth, situations may arise that were not anticipated and decisions will need to be made. We simply ask you to keep us informed so we can participate in the decisions as to what is best for _____. We ask that no intervention be taken without our approval, other than what is outlined below. We trust you will respect our wishes.

Please call our baby _____. Ask us how we feel, if he/she has been active, and what special stories we have from this pregnancy. This validates and honors our baby's life.

During labor and delivery, we would like (special music, shower, foot back massage, etc.) _____.

We would like to remain in the same room for labor, delivery, and recovery.

Regarding fetal monitoring, we would like ___ none; ___ external; ___ internal.

We might like to hear our baby's heartbeat early, before labor progresses. If our baby's heart stops prior to delivery, ___ we do/ ___ we do not want to be informed.

We would like these people in attendance: _____; _____; _____;

We ___ want/ ___ do not want, the birth videotaped.

Any drugs given during labor to _____ should be given in doses to provide maximum comfort while allowing her to remain alert. Our other preferences regarding management of pain for _____ include _____.

Please allow _____ to cut the umbilical cord.

We would like oral/nasal suctioning for _____'s comfort only and *NO* intubation without our permission.

After our baby is born, we ask that he/she be wiped, suctioned (if indicated), wrapped in a blanket and, if alive, handed to _____; if stillborn, handed to _____. We wish to cuddle our baby immediately and ask that vital signs, weight, medications and labs be postponed, if possible.

If our baby has fewer or more problems than expected, please discuss all options with us.

Other than routine post-delivery care, we wish for private time with our baby. We will discuss exceptions that should be made: _____.

We prefer that our liaison _____ periodically give updates to our waiting family and friends and that he/she escorts visitors to our room, at our request, and helps us with phone calls.

If our baby can't suck or nurse, we wish to provide comfort with drops of breast milk or formula.

We have planned a ___ baptism/ ___ (other) _____ to be performed by _____, or we wish to enlist the services of the hospital chaplain. Godmother/parents are _____.

Memorial/funeral plans ___ have been/ ___ have not been made for our baby. If our baby is placed in the NICU, we request as much privacy as possible as we care for him/her.

Please discuss any medications and/or procedures with us before giving or performing.

We wish to hold our baby as he/she is dying or has died and want to keep their precious body with us as long as possible.

We would like to bathe and dress our baby. ___ We have/ ___ we need a burial garment.

We would like to keep the following items as keepsakes: cord clamp, lock of hair, ID bracelet, tape measure, crib card, hand and foot prints (molds, if possible) baptismal certificate, weight card, bulb syringe, hat/blanket/clothes, family handprints, and photographs color and black and white.

Please give instructions to _____ (mother) on comfort measures/ milk suppression.

Please allow _____ (my husband) or _____ to spend the night in my room.

Regarding our other children we: _____

Other considerations: _____

Parent(s): _____

Date: _____

Our doctor is: _____

Figure 1. Sample Birth Template

Criticisms of the perinatal hospice program at RMH include the lack of perinatal grief evaluation, tools to measure anxiety, and surveys of the incidence of depression in patients and their families. However, the intent of this pilot study was to demonstrate the feasibility of establishing such a program in a community perinatal referral center. Further study of psychological outcomes of patients, families, physicians, nurses, chaplains, and ancillary personnel is indicated.

Typically, the options presented to the parents at the time a lethal condition is diagnosed include abortion of the pregnancy versus continued pregnancy with routine maternal care, and non-intervention for the neonate at the time of labor and delivery. A bare presentation of these options may leave parents with the perceived choice of futilely watching their infant die, which they may also interpret as increasing the suffering of their child,

versus actively doing something to end this sudden, emotionally wrenching dilemma.

Although this counseling is presented with the intention of being nondirective, it may be viewed by parents as a tacit recommendation for aborting the pregnancy. Parental decisions may also be strongly colored by the common fear of abandonment of themselves and their unborn child, and the anticipation of pain and suffering that all may endure.

Nevertheless, some studies note that up to 20% of parents of a fetus with known severe chromosomal or anatomic anomalies choose to continue their pregnancy.⁸ Previous experience with perinatal hospice confirms that finding, and also finds that more than 80% choose hospice when it is offered in a supportive environment.²

In the United States, 0.2-0.3% (6,000-10,000) of all live births each year are afflicted with defects severe enough to cause neonatal death,⁹ and there are also significant numbers with conditions severe enough to cause intrauterine demise. Thus, there are a significant number of families who are candidates for perinatal hospice, a compassionate intervention for which there seems to be an unmet demand.

The RMH population represents a cross-section of the U.S. population, so we would not expect acceptance of neonatal hospice to be different from that in other facilities based on demographics. Some RMH patients, however, might have chosen hospice based partially or wholly on financial considerations. While RMH does not oppose counseling abortion when maternal life is endangered by continuing a pregnancy (i.e. chorioamnionitis or severe preeclampsia), the hospital does not perform elective abortions. Thus, RMH patients who desire to abort their pregnancy electively must have it done elsewhere, most likely at their own expense.

The comprehensive nature of prenatal care at RMH has fostered a medical environment that is more likely to anticipate and treat a decision to carry a fetus with a lethal anomaly to term as a normal occurrence. This well-organized program might be expected to act synergistically with the compassionate care of these patients in the perinatal hospice to increase the patient acceptance rate.

However, these considerations do not totally explain the high pregnancy continuation rate in the military population at Madigan Army Medical Center (85%), and the present high rate of 75% in the Rockford population.²

Some of our patients had diagnoses made later in gestation (Table 1). Patients appearing later in gestation are possibly more likely to continue their pregnancies, given the problems that they may encounter in obtaining late-term abortions. However, even among the patients with a diagnosis before 22 weeks (16 of 28 patients), 10 (62%) of 16 chose perinatal hospice, compared to 21 (75%) of the 28 total.

Commitment and tireless effort is required from a dedicated staff to carry out perinatal hospice care, and a multidisciplinary approach is essential. Through the experience of participating in every step necessary to take care of these patients, and through coming to an understanding of the nuances and complexities in these difficult pregnancies, the medical students assimilate key lessons essential to their success as physicians.

In keeping with hospice ideals, open communication among patients and their families, and all the physicians, nurses, and support personnel, is essential to prevent problems in even the most carefully crafted plans. In addition, early and consistent involvement of the staff, residents, and medical students with the family in this multidisciplinary setting can help to prevent the unintentional withdrawal of care by professional staff observed by Kubler-Ross in end-of-life settings.¹⁰

Early salient work by Lewis in patients with stillbirth emphasized the importance of patients seeing their dead infant as part of the grieving process.¹¹ Parents of infants with external congenital defects are not repulsed by the appearance of their infant, and most emphasize the normal aspects of the child. A major advantage of perinatal hospice is that a significant majority of these infants may be live-born, allowing the parents and family a chance to share precious time with their infant, even if the infant's life is exceedingly brief.

It is imperative not to underestimate the importance of the antepartum consultation with the neonatal service. The neonatology staff must be thoroughly informed of the diagnostic findings in each case, and meet with the parents during the antepartum period. During this consultation, neonatology staff and the parents agree on the plan of management at birth. The plan is documented in writing and placed in the prenatal record.

Antepartum counseling allowing for dialogue and documentation leads to a mutual understanding that alleviates any pressure on the part of the neonatology staff to give the appearance of doing "everything possible" at the time of birth. Parental response to antenatal planning was overwhelmingly positive, and our patients voiced gratitude for the special time they were able to spend with their infants, regardless of whether the infant was alive or dead.

Conclusions

When parents are given comprehensive, multidisciplinary, individualized, and informed counsel, including clinical

expectations, in the setting of a lethal fetal condition, they often choose the option of perinatal hospice care. This can be safely accomplished with current methods of obstetric care, and demonstrated successfully to medical students. These parents are thus enabled to fully experience the birth of their child and the bonding that occurs during the antepartum and immediate postpartum period.

This experience helps parents reach a more peaceful acceptance of the death of their offspring. They may rest secure in the knowledge that they shared in their baby's life, and treated their child with the same dignity afforded other terminally ill individuals under the best of circumstances.

Further study of psychological and emotional outcomes of patients, families, physicians, nurses, chaplains, and other personnel is indicated.

Michelle D'Almeida, D.O., FACOG, and **Anthony Lathrop, C.N.M.**, are affiliated with the Division of Maternal-Fetal Medicine, Rockford Memorial Medical Center, Rockford, IL. **Roderick F. Hume, Jr., M.D., FACOG**, is a member of the Department of Obstetrics and Gynecology, Hutzel Hospital/Detroit Medical Center, Wayne State University, Detroit, MI. **Adaku Njoku, M.D.**, is affiliated with Cook County Medical Center, Chicago, IL. **Byron C. Calhoun, M.D., FACOG, FACS, MBA**, is a member of the Department of Obstetrics and Gynecology, West Virginia University, Charleston, WV. Contact Dr. Calhoun: 830 Pennsylvania Ave., Suite 304, Charleston, WV 25302. Tel.: (304) 388-1599. Fax: (304) 388-2915. Email: byron.calhoun@camc.org

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REFERENCES

- 1 Hoeldtke NJ, Calhoun BC. Perinatal hospice. *Am J Obstet Gynecol* 2001;185:525-529.
- 2 Calhoun BC, Napolitano P, Terry MV, Bussey C, Hoeldtke NJ. Perinatal hospice: comprehensive care for the family of the fetus with a lethal condition. *J Reprod Med* 2003;48:343-348.
- 3 MacDorman MF, Atkinson JO. Infant mortality statistics from the 1996 period linked birth/infant death data set. *Monthly Vital Statistics Report* Vol 46, No 12, Suppl. Hyattsville, Md.: National Center for Health Statistics; 1998.
- 4 Saunders C. The last stages of life. *Amer J Nurs* 1965;65:70-75.
- 5 Saunders C. Terminal patient care. *Geriatrics* 1966;21:70-74.
- 6 Saunders C. The management of fatal illness in childhood. *Pro Royal Soc Med* 1969;62:550-553.
- 7 Whitfield JM, Siegel RE, Glick AD, et al. The application of hospice concepts to neonatal care. *Am J Dis Child* 1982;136:421-424.
- 8 Schechtman KB, Gray DL, Baty JD, Rothman SM. Decision-making for termination of pregnancies with fetal anomalies: analysis of 53,000 pregnancies. *Obstet Gynecol* 2002;99:216-222.
- 9 CDC. Trends in infant mortality attributable to birth defects—United States, 1980-1995. *MMWR* 1998;47:773-778.
- 10 Kubler-Ross E. *On Death and Dying*. New York, N.Y.: Macmillan; 1969:122-126.
- 11 Lewis E. The management of stillbirth: coping with unreality. *Lancet* 1976;2 (7986):619-620.