

## CLINICAL OPINION

### Perinatal hospice

Nathan J. Hoeldtke, MD,<sup>a</sup> and Byron C. Calhoun, MD<sup>b</sup>

Honolulu, Hawaii, and Tacoma, Washington

When the prenatal diagnosis of a lethal fetal anomaly has been established, some patients choose to continue their pregnancy. Currently, there is a paucity of medical literature addressing the specific management of families in this unique circumstance. We propose a model of care that incorporates the strengths of prenatal diagnosis, perinatal grief management, and hospice care to address the needs of these families. We discuss the identification of candidates for this form of care; the multidisciplinary team approach; and the aspects of antepartum, intrapartum, and postpartum care. Finally, we discuss some barriers that might need to be overcome when attempting to implement perinatal hospice care. (*Am J Obstet Gynecol* 2001;185:525-9.)

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Congenital anomalies are now the leading cause of death through the first year of life.<sup>1</sup> Many congenital defects, such as anencephaly or bilateral renal agenesis, are lethal conditions that may be diagnosed during the antenatal period. Generally, when a diagnosis of a lethal anomaly has been established, parents are confronted with 2 options: termination of the pregnancy or expectant management, "letting nature take its course." Although much has been written about the management of those choosing termination of pregnancy under these circumstances, there is little in the medical literature to specifically guide clinicians caring for families choosing to continue these pregnancies.

We believe that the strengths of 3 medical and social advances of the past 4 decades can be integrated in an organized program to comprehensively and effectively address

the needs of these families. These advances include the capability for accurate prenatal diagnosis, a new understanding and appreciation of perinatal grief, and the advent of modern hospice care. Uniting key features of these disciplines and applying them to the care of these families results in a model that we refer to as *perinatal hospice*.

#### The current situation

Prenatal diagnosis of fetal pathology was virtually impossible before the last half of the 20th century. The first prenatal diagnosis of a significant congenital anomaly was the sonographic diagnosis of anencephaly, reported in 1964.<sup>2</sup> This was followed by the prenatal diagnosis of a fetal karyotype abnormality in 1968.<sup>3</sup> Subsequently, the revolutions in diagnostic imaging and molecular genetics have resulted in a rapidly expanding roster of conditions that can be detected in the prenatal period. New uses for maternal serum analyte screening and the increased application of routine prenatal sonography ensure that many cases of fetuses with lethal conditions will continue to be uncovered during the prenatal period. Accumulated experience and refinements in diagnostic technique are also enabling better prognostication about the severity of many prenatal diagnoses, including those with potentially lethal consequences.

Unfortunately, despite some hopeful advances in fetal therapy, the ability to accurately diagnose a fetal condi-

*From the Department of Obstetrics and Gynecology, Tripler Army Medical Center,<sup>a</sup> and the Department of Obstetrics and Gynecology, Madigan Army Medical Center.<sup>b</sup>*

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*Reprint requests: Nathan J. Hoeldtke, MD, Department of Obstetrics and Gynecology, Tripler Army Medical Center, Honolulu, HI 96859.*

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tion frequently outstrips the ability to effectively prevent or treat that condition. Likewise, prenatal diagnostic advances have not always been accompanied by equivalent advances in knowledge about the management of familial needs arising from foreknowledge of a significant fetal disorder. It has previously been observed that although the science of prenatal diagnosis has rapidly expanded, the art of caring for these patients is poorly understood and taught.<sup>4</sup>

The tragedies of stillbirth and neonatal death are common, but the first report of maternal reactions to stillbirth did not appear until 1968,<sup>5</sup> and the first study investigating parental response to neonatal death was not published until 1970.<sup>6</sup> Before that, these losses were generally viewed and handled as "non-events."<sup>5</sup> Fortunately, once this topic had been broached in the medical literature, a growing awareness of the grief associated with perinatal loss led to research, culminating in the practical management strategies routinely employed with these patients today.<sup>7, 8</sup>

Yet, nearly simultaneously, the prenatal diagnosis of lethal anomalies was creating a new situation for many families. These families now learned of the terminal condition of their fetus weeks, or even months, before death occurred. What once resulted in an unexpected stillbirth or neonatal loss became an expected event. The suddenness of a surprise death was replaced by the suddenness of a surprise diagnosis. Termination of pregnancy became the management of choice for many of these families, since legal abortion became broadly available concurrent with prenatal diagnostic advances. It took more than a decade before it was widely recognized that parents electing this course of action grieve with the same intensity as those experiencing a stillbirth or neonatal loss.<sup>9, 10</sup> Subsequently, a body of literature detailing bereavement management for these families appeared, contributing to a commendable advance in their care.<sup>11, 12</sup>

On the other hand, little has been systematically done to comprehensively provide for the unique needs of those families choosing to continue pregnancy under these circumstances. This clinical scenario is not adequately addressed by simply resorting to traditional perinatal bereavement management, which was developed to care for parents experiencing sudden and unexpected perinatal loss. Nor can these pregnancies be managed as other pregnancies, for the psychosocial dynamics surrounding them are clearly different than those in which the fetus is believed to be healthy. For these families, instead of anticipating the arrival of a new baby, there is contemplation of the impending death of a loved one. Despite the significant increase in awareness and understanding of both prenatal diagnosis and perinatal grief, there remains a great deal of ambiguity, uncertainty, and misunderstanding about how to approach and care for these particular families.

Some researchers, noting this group of patients as a phenomenon, have made laudable, although cursory, recommendations for their management.<sup>13, 14</sup> Outside of these brief descriptions, there is virtually no literature dealing with the specific care of these patients. This current situation may be analogous to the one in which Bourne<sup>5</sup> found himself 30 years ago, when he noted that although stillbirth was not an infrequent condition, it seemed to represent a "professional blind spot," as evidenced by a paucity of medical literature regarding its management. When he sought to bring attention to this matter, his work was initially rejected by the major medical journals with the explanation that it had already been adequately addressed.<sup>15</sup>

### Proposal for perinatal hospice

The modern medical community's understanding of end-of-life issues was profoundly challenged by Kubler-Ross<sup>16</sup> in her seminal work on death and dying. Her contemporary, Saunders,<sup>17</sup> championed the modern hospice movement and forever changed medicine's approach to the dying. The hallmark of this new understanding and method of care was the provision of holistic physical and emotional support for dying patients and their families. The philosophy of hospice has been embodied in a variety of forms and institutions, and various manifestations of hospice care can be found in almost every community today. This care has been further adapted for use with the families of terminally ill children, and Whitfield et al<sup>18</sup> used these same principles to create a program for dying infants and their families—the neonatal hospice.

Families who choose to carry pregnancies in which the fetus has a lethal condition share many similarities with the families of a terminally ill adult or child member, clinical situations in which hospice has become an increasingly accepted and successful methodology of care. Many tenets of hospice can be applied directly to the circumstances of these families: an emphasis on neither hastening nor prolonging death; affirming life by caring for the loved one while regarding dying as a normal process; stressing values that go beyond the physical needs of the dying one; and meeting the medical, emotional, and spiritual needs of the family by providing a multidisciplinary team that continues to follow them even after the death of the loved one, during the period of bereavement. Therefore, we propose that the hospice paradigm be extended to the care of families anticipating a perinatal loss as a logical step in the evolution of hospice.

Perinatal hospice differs in emphasis, though not necessarily in kind, from other modes of perinatal health care. It focuses on the persons involved, rather than on the fetal pathology, and places the family in the central arena of care. It provides a continuum of support for the family from the time of diagnosis until death and beyond. It is marked by a cognizance that "dying involves real peo-



ple, even unborn fetuses; [and that] significant relationships are disrupted and familiar bonds are severed."<sup>19</sup> Hospice allows time—time for bonding, loving, and losing; time so that the entire course of living and dying is a gradual process that is not jarringly interrupted.

What follows is a brief description of what we have done in caring for these families. This is provided as a framework example and is offered with the anticipation of further refinement and improvement.

### Identifying candidates

Families who are candidates for perinatal hospice are identified through a variety of prenatal diagnostic techniques. A simple and clear explanation regarding the nature of the diagnosis and lack of curative therapy is provided in an honest and kind manner. This is followed by a discussion of the options of pregnancy termination versus continuing the pregnancy with management under the hospice paradigm. Parents are unlikely to choose a management plan that has not been presented to them in a clear and positive fashion. The importance of understanding the psychology and framing of choices cannot be underestimated when counseling these patients.<sup>20</sup> Parents must understand that they are not choosing between "actively" terminating the pregnancy and "passively" doing nothing. We do not allow the impression that because the fetus has a terminal condition, there is nothing that can be done—there are a great many things that can be done to care for these families. Hospice care is an interactive, and at times intense, form of care. Rather than simply "letting nature take its course," this approach empowers the family to take control of some of the consequences of their unfortunate situation. Those who choose to continue their pregnancy can avail themselves of as much, or as little, of the hospice program as they desire. Simply having a viable, compassionate, and structured program in place offers them a tangible alternative, providing a context in which they can work out the ramifications of the birth and death of their offspring.

### The hospice team

Hospice care in the perinatal period (as in any other period of life) is, of necessity, team care, because no single profession can meet all the needs of the family anticipating the death of a fetus or neonate. The core hospice team includes the family, the physician or physicians primarily caring for the pregnancy, a social worker, and a nurse care manager with training in bereavement issues. To this core team, other members are added as the situation warrants and may include neonatologists, anesthesiologists, psychiatrists, psychologists, chaplains, bereavement counselors, labor nurses, and neonatal nurses. Some parents will choose to use many of these resource personnel, whereas others may prefer to interact with a smaller group of team members. Services are provided at

the intervals and intensity needed by the family. Members of the team specifically involved with the family meet at preset intervals and on an as-needed basis to discuss management and coordinate efforts.

### Antepartum/intrapartum care

A major focus of hospice care lies in allaying fear. Those who are dying fear loneliness and abandonment in their time of need, and in a similar way, these families fear isolation and abandonment during the loss of their baby. They also fear the prospect of pain for their baby. We reinforce that they will be supported and cared for throughout the gestation and delivery and that their infant, if live born, will be kept comfortable until the time of death. Frequent contact with the physician is desired by many of these families. Some parents will want to be seen on "off-hours," when there are no other pregnant women in the clinic, whereas others may prefer to be seen along with other pregnant patients. Generous flexibility with the parents' desires and schedules is key to successful management of these pregnancies. All attempts are made to reduce feelings of isolation and abandonment through continuous multidisciplinary services and the ready availability of providers to address concerns as they arise.

Anticipatory guidance is provided, both for grieving and for interacting with their other children, family members, and friends. These parents often hold on to some hope that the diagnosis is wrong or that their baby will somehow beat the odds and be a "miracle" baby. This is not unlike the hope experienced by dying adults,<sup>16</sup> except in this case it is the parents who are holding on to hope for the fetus. Great care is taken to be realistic with them, while at the same time not utterly shattering this normal hope, which allows them to continue functioning in their daily lives.

The psychologic tasks of grieving may be more difficult for parents experiencing a perinatal loss, compared with the grieving associated with other losses.<sup>21</sup> Limited experience with, and limited memories of, the fetus or neonate can interfere with the integration of this particular loss into the ongoing life of the family. Because building memories of their loved one is important for the grieving process, we provide parents with frequent ultrasonographic visualization of the fetus. We also encourage the presence of other family members, including grandparents and children, so they may visualize the fetus. The clear delineation of the existence of the "baby" helps not only the parents but also other family members to develop a concrete memory of the fetus, facilitating their grieving. This way of preparing other family members, and even close family friends, enables them to more adequately support the grieving couple.

Delivery contingencies are discussed with the parents, including management of the infant in the event of a live birth. Although we do not recommend fetal monitoring



or other interventions in labor, there are occasionally families who want monitoring and even cesarean delivery if intrapartum death seems imminent without it. Usually the rationale of the parents is that they want to see the infant alive, if at all possible, before he or she dies, and they are willing to assume the increased maternal risks of cesarean delivery to achieve this goal. We accommodate these patients in this request, as have others.<sup>22</sup>

At delivery, the diagnosis is confirmed and the infant is kept with the parents to maximize their time together. We again encourage the presence of other family members, including children, during this time. Being able to care for the newborn in even the smallest way allows parents to feel that they contributed something special to their offspring.<sup>23</sup> Some infants will have conditions that are not immediately fatal and may go home to be with the family before death. Hospice care continues during this time, with increased input from the neonatal team.

### **Postpartum care**

Care does not end with the death of the fetus or neonate. Grief counseling continues. The team may help the parents make arrangements for a funeral or memorial service and attend when possible. Genetic counseling and anticipation of concerns regarding future pregnancies are discussed when the parents are ready. Initially, frequent contact by telephone is maintained to assure that the family is coping adequately. This contact is slowly tapered over time, but this is not always the end of care for the family, as the onset of a new pregnancy often brings a renewed relationship with some members of the team. These patients understandably carry a significant burden of anxiety in any subsequent pregnancy. This concern may be unspoken and requires increased physician, or other provider, contact during this pregnancy.

### **Overcoming resistance to perinatal hospice**

Any proposal to structure the care of these families into a hospice approach is likely to be greeted with some skepticism. It may take some effort to overcome resistance to changing prevailing modes of care for these patients. It might be argued that a simple, common sense approach to these families should suffice. However, the complex issues related to death that are involved in these pregnancies can result in reluctance on the part of health care providers to deal with the family in a straightforward manner. They may believe that they have no further skills to offer and distance themselves from the family, just when the family needs them the most. A focused multidisciplinary program can serve as a guide for all involved, including the family, to overcome the natural aversion to dealing with these difficult issues. Further, a structured program will foster an environment conducive to consistent quality of care and provide involved professionals

the extra measure of confidence needed in dealing with these families.

The purposes of a given institution and the attitudes and belief systems of the professionals involved in the care of these patients may also have a profound impact upon the extent to which hospice concepts in perinatal care will be accepted or instituted. Termination of pregnancy has become the de facto management of choice for lethal fetal conditions, and health care providers as a group may be more favorably disposed to this method of management than either the general public or pregnant women.<sup>24</sup> Others have speculated,<sup>14</sup> and our own experience has suggested, that if a specific model of prenatal care for these patients is instituted and explicitly presented as an option, the number of parents choosing this form of management may increase. Therefore, some providers may question the wisdom of committing resources to an approach possibly encouraging what they perceive as a "less than optimal" parental choice. We contend, however, that the lack of a consistent, organized, and comprehensive plan for providing these families professional support throughout pregnancy has often been a deficiency in modern prenatal care and that just such a structured and explicit approach is needed if we truly want to enhance patient autonomy and provide these parents with tangible options when it comes to choosing a method of pregnancy management.

Instituting such a program in any system requires at least one physician willing to champion this care. A small group of individuals, representing a portion of the disciplines necessary for a perinatal hospice, must also be willing to provide their input and support at the outset. Personnel already involved in caring for patients experiencing perinatal loss are those most likely to be interested in expanding and applying their skills to meet the needs of these families. A variety of approaches to overcoming resistance to a perinatal hospice can be envisioned, but we have found that the most effective approach is simply to put these concepts to work in the context of caring for several families electing to carry a pregnancy in which the fetus has a lethal condition. Those providers who have shown an interest in the idea of perinatal hospice and a willingness to provide support can be recruited to join in the care of these families. Ultimately, nothing overcomes resistance more effectively than the direct observation of families coping with these difficult pregnancies in a dignified manner through the assistance of these providers. Other providers will inevitably become interested in, or at least curious about, this service, and individual members of the core team can then provide education through both formal multidisciplinary symposia and informal exchanges with their colleagues. In this way, the benefits of perinatal hospice can be gently introduced to prenatal care.