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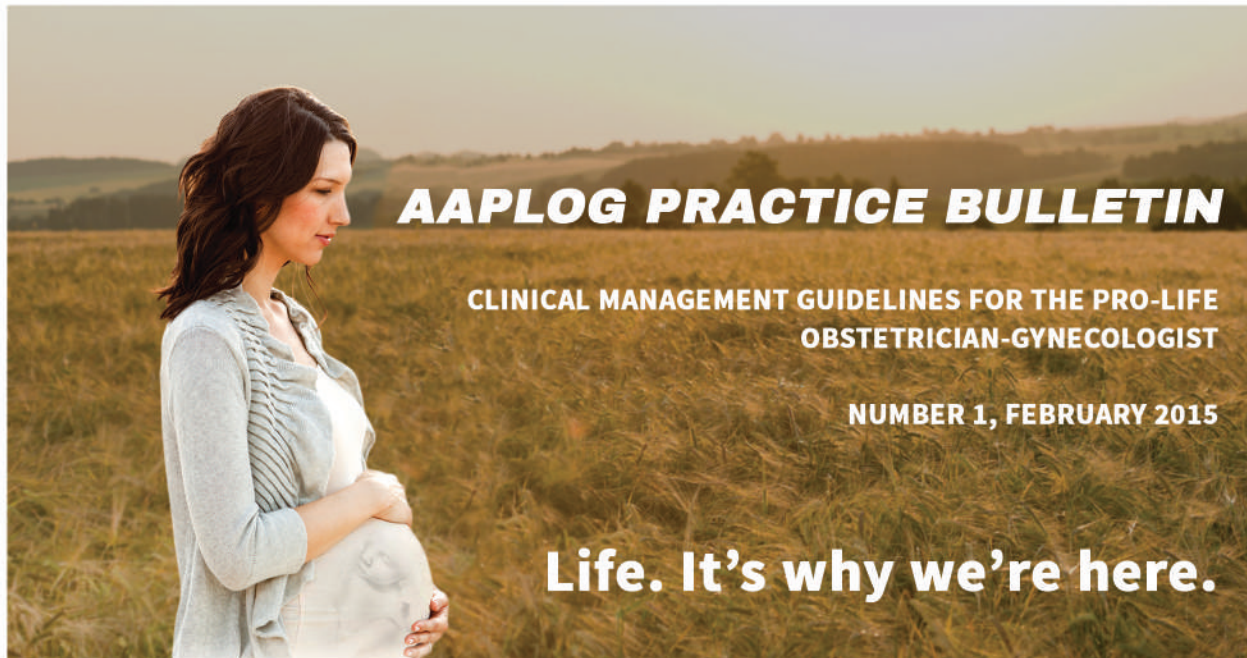
A pregnant woman with long brown hair, wearing a light blue cardigan over a white top, stands in a field of tall golden grass. She is looking down at her belly with her hands resting on it. The background shows rolling hills under a warm, golden light, suggesting a sunset or sunrise.

CLINICAL MANAGEMENT  
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*This Practice Bulletin was developed by the Board of the American Association of Pro Life Obstetricians and Gynecologists with the assistance of Byron Calhoun, MD. The information is designed to aid practitioners in making decisions, relating to obstetric and gynecologic care, which reaffirm the unique value and dignity of individual human life in all stages of growth and development from fertilization onward.*

# **Perinatal Hospice: Care with Compassion for Families with an Adverse Prenatal Diagnosis**

## **Background**

The objective of this paper seeks to introduce to physicians and the public a novel concept in perinatal care called the “perinatal hospice”. The origin of the concept began in 1996 with the original controversy in the United States over “partial birth abortion”. This procedure involved the barbaric act whereby the baby would be delivered to the shoulders as a breech, deliberately held in place by the operator while a scissors or other sharp

instrument was inserted into the baby’s posterior skull, and the brain removed by a suction catheter resulting in death. We believed this procedure so horribly inhumane that we sought to find a cogent and moral alternative for the hardest cases so we might have a better way to care for our patients.<sup>1,2</sup>

Our original article in ILM by Calhoun, et al., 1997 presented the ethical and moral framework of the treatment of infants with a lethal anomaly

consistent with the dignity afforded humans.<sup>1</sup> We now present an updated discussion of the state of perinatal hospice including maternal outcomes and management of the fetus.

The incidence of affected infants includes 0.2-0.3% of neonatal deaths as a result of lethal anomalies.<sup>3</sup> Lethal anomalies now represent the leading cause of neonatal death at term.<sup>4</sup> These findings, linked with our enhanced ability to identify and diagnose fetal anomalies before birth has led to a dearth of management choices for families.

Prior to perinatal hospice, the traditional counseling generally involved only termination of the pregnancy. Often heard and touted were the well-intentioned desires to “spare the mother and family” a distressing experience; a need to “get it over with”; an obstetrical provider’s need to “do something” and deal with the discomfort of bereaved patients; an unsubstantiated desire to avoid complications of pregnancy; and an undocumented fear of increased maternal mortality.

Research in grief after termination of pregnancy presents a different perspective. Previous small studies provided preliminary information that termination losses were as intense as spontaneous losses. Zeanah, et al, 1993 reported a case-control study of 23 individuals and found a 17% (4/23) depression rate and 23% (5/23) seeking psychiatric counseling at two months when compared to stillbirths.<sup>5</sup> A much larger study of 253 women encompassing 2-7 years duration after termination of pregnancy for fetal anomalies prior to 24 weeks by Korenromp et al, 2005, found that pathologic grief persisted in 3% of patients (2/253) and that 17% (33/253) suffered from symptoms of posttraumatic stress.<sup>6</sup> Finally, Korenromp et al, 2009 found persistent and significant grief responses at 4, 8, and 16 months.<sup>7</sup> 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.<sup>7</sup> Women simply do not “*get over with it*” in regard to the termination of their pregnancies for anomalous babies, including those with *lethal anomalies*.

In contrast to termination of pregnancy, Janssen et al, 1996 published a study of 227 women with first trimester losses compared to a control group of 213 women matched for live births.<sup>8</sup> The first 6 months after miscarriage women showed an increased level of depression, anxiety, and somatization, but, by one year after a spontaneous

miscarriage there was no difference between the miscarriage group and the live-birth group with regard to mental health issues.<sup>8</sup>

In response to the ungrounded fear of increased maternal mortality, the actual mortality rates with induced abortion from 16-20 weeks are quoted from CDC data as 9.3/100,000 live births and the rate for pregnancy related mortality is 10/100,000 live births.<sup>9,10</sup> So, essentially the mortality rates at 16-20 weeks gestation, when most terminations are done for anomalies, are *equal* for either abortion or live-birth.

## **Definition**

Into this clinical void, we offer the new concept of the perinatal hospice: the institution of perinatal hospice care as part of the continuum of end-of-life care. Thus, perinatal hospice is offered in cases where there is prenatal diagnosis of a terminally ill fetus in-utero.

## **Frequency of Occurrence**

Prenatal diagnosis of fetal anomalies was unheard of and virtually impossible until the 20<sup>th</sup> century with the advent of radiologic and sonographic techniques. The first sonographic diagnosis of a lethal anomaly was anencephaly in 1964.<sup>11</sup> Subsequent to ultrasound followed the first prenatal diagnosis of fetal aneuploidy in 1968 through amniocentesis.<sup>12</sup> Rapid advances in diagnostic ultrasound, molecular genetic testing, and maternal serum screening provide increased ascertainment of fetuses with lethal conditions. Advancing research and publication of outcomes in patients with a previous lethal diagnosis allows better clinical prognosis for fetuses with serious anomalies.

In contrast, fetal therapy does not necessarily keep pace with prenatal diagnostic abilities. Also, the clinical care of families and patients has not been as well studied or taught in the past.<sup>13</sup> The first attempts to study the effects of stillbirth and neonatal death on mothers did not surface until 1968.<sup>14</sup> The parents’ perspective on neonatal death did not appear in the literature until 1970.<sup>15</sup>

Prior to our work in perinatal hospice, there were limited attempts to address the complex issues of perinatal loss.<sup>16,17</sup> Laudable as these attempts

were, they did not reflect a cogent, systematic approach to patients and families--especially in the light of some 20% of patients desiring to carry their pregnancy no matter the prognosis.<sup>18</sup> The care of these patients does not fit in with simple bereavement counseling paradigms. These original care pathways were developed for stillbirth, or sudden, and, unexpected fetal losses. Nor can these patients receive simply routine-care since the psychosocial dynamics of anticipatory grief, dashed dreams, and loss of expectations are significantly different than those of normal patients expecting a healthy and normal child. For these families it was not the joyful arrival of a new, healthy baby, but, rather, the sorrow of the too soon loss of a loved child.

In spite of the new published data in the area of perinatal grief and better prenatal diagnosis, many clinicians face a significant amount of uncertainty, mixed emotions, ambiguity, and, lack understanding of precisely how to counsel and care for these families. Until our salient work, there was no significant literature on how to care for these specific patients and their families.

## ***Perinatal Hospice Concept***

We employed the seminal work of Kubler-Ross on modern medicine's understanding of death and dying to assist to shape our model.<sup>19</sup> As Kubler-Ross transformed the conversations around death, Saunders transformed the care of the dying with her modern hospice movement.<sup>20</sup> The unifying idea in hospice was the holistic approach to the physical, emotional, and spiritual support for dying patients and their families. The core care consisted of treating the dying with dignity--acknowledging that they really were alive, and, not yet dead. The patient and family's fear of abandonment could then be alleviated. The philosophy of hospice has spread throughout the world. Its care may be found in various forms, institutions, and hospice, in some manner, may be found in almost every community today. Hospice has even been adapted to provide palliative care to terminally ill neonates. Whitfield, et al used the hospice principles to found the neonatal hospice movement in 1982.<sup>21</sup>

In the author's experience, 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 acknowledged as a useful method of care. Many of the hospice principles were successfully applied in perinatal hospice. There was an emphasis on affirming life by providing care for the loved one while regarding dying as a normal process of life; a conscious effort to neither hasten death nor prolong dying; a stressing of values beyond the mere physical needs of the dying individual; by allowing the parents to "parent" their child for whatever precious time they are allowed, and, supporting the medical, emotional, and spiritual needs of the family through an organized multidisciplinary team that cares for the family after the death of the loved child during the period of grief.

The care in perinatal hospice differs in emphasis, not type of care from other modes of perinatal care. The primary focus is on the family and not the fetal diagnosis. The family is placed in the center of the care and there is a continuum of support from the diagnosis, through death, and grief. We agree with Knapp et al, that "dying involves real people, even unborn fetuses [and that] significant relationships are disrupted and familiar bonds are severed".<sup>22</sup> Hospice preserves time for the bonding, loving, and loss; time for parents to adjust to the dying process. Amy Kuebelbeck, author of *Waiting with Gabriel*,<sup>23</sup> 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."<sup>24</sup>

## ***Eligible patients***

Patients, and families, who participants in perinatal hospice access care through multiple prenatal diagnostic pathways. A gentle and clear explanation of the diagnosis and lack of ability to physically heal the child is given to the patient and family. This is followed by a discussion of their legal access to termination of pregnancy versus management of the continued pregnancy with hospice care. Patients generally will not choose a plan that has not been presented in a concise and affirming manner. The framing of choices and psychology of decision making must be taken into

account. The parents ought 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 will be intense and personal. Those who continue the pregnancy may engage as much, or 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.

## ***Hospice team***

The care of terminally ill perinates requires a team of professionals, since no single group of professionals will be able to meet all the needs of the grieving family of a terminally ill child. The primary hospice team consists of the patient, her unborn child, her family, her physician or team of physicians providing primary care, a social worker, and a nurse with training in bereavement issues. Usually, as the care progresses, neonatologists, anesthesiologists, psychiatrists, psychologists, chaplains, local priest/pastor, bereavement counselors, labor nurses, sonographers, and neonatal nurses may be added. Depending on the family and situation, patients will utilize resources as needed. Care is provided at the timing and intensity of the family desires. Those team members most intimately involved in the care of the patient meet at regular intervals, or as needed, to review management and coordinate care.

## ***Antepartum/intrapartum care***

One of the major clinical issues in 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 allowing patients to “parent” their child in their own style. Discussion with the parents concentrates on the support of, and care for the family during their pregnancy, delivery, and death of their child. Parents sometimes fear their baby might have 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. Some parents want to be seen in clinic when other patients are not

present, and, some parents want to be with other pregnant women. Flexibility to the parents’ wants and schedules is critical to the management of these pregnancies. Reduction of feelings of isolation and abandonment, through multidisciplinary and easy accessibility to the hospice team, are the mainstays of perinatal hospice care.

Instruction is given in anticipatory grief as well as tools of how to relate to other children in the family, friends, and family members. Often there remains a hope that the diagnosis is in error and that their child will be the miracle baby who somehow survives. Gentle sharing of the realistic outcome of the pregnancy is balanced with the hope for simplified dreams for their baby.

The grief accompanying a wanted child in the perinatal loss may be more intense than those with other losses.<sup>25</sup> The lack of physical contact with, 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 are provided of their baby, and, other family members are invited to attend; particularly grandparents and siblings, to come and see the baby. Seeing the baby cements the relationship and bond with the family and the child. Video tapes may be recorded for the family as the only living memories of their child.

- **What are the options for fetal monitoring of patients with lethal anomalies?**

## ***Fetal Monitoring***

Antepartum monitoring in patients with aneuploidies and anomalies are not well understood and there is little information regarding the application of antepartum testing in these pregnancies. However, we do know that patients carrying a fetus with Trisomy 13 or Trisomy 18 are at increased risk for stillbirth. Stillbirth rates at term (> 37 weeks) for a normal pregnancy are approximately 1/1,000 or 0.001%.<sup>26</sup> The stillbirth rates in a recent 20 year experience in Europe found the stillbirth rate for Trisomy 21 (DS) to be in order of 5% without enough data to report the T13/T18 rates.<sup>27</sup> The American College of Obstetricians and Gynecologist in their Practice Bulletin Number 9 from 1999 (reaffirmed in 2012)<sup>28</sup> state categorically in their summary that:

“Women with high-risk factors for stillbirth [like a Trisomy 13/18 fetus or other anomalies] should undergo antepartum fetal surveillance using the NST (nonstress test), CST (contraction stress test), BPP (biophysical profile), or modified BPP.

and:

Initiating testing at 32-34 weeks of gestation is appropriate for most pregnancies at increased risk of stillbirth, although in pregnancies with multiple or particularly worrisome high-risk conditions, testing may be initiated as early as 26-28 weeks of gestation.

and:

When the clinical condition that has prompted testing persists, a reassuring test should be repeated on a periodically (either weekly or, depending on the test used and the presence of certain high-risk conditions, twice weekly) until delivery. Any significant deterioration in the maternal medical status or any acute diminution in fetal activity requires fetal reevaluation, regardless of the amount of time that has elapsed since the last test.”

Clinical application would, therefore, in light of these ACOG guidelines and the increased risk for stillbirth in patients with a fetus with either a Trisomy or other anomalies, declare that antepartum testing *may* be initiated. Discussion with the patient and her family regarding the options of management of the pregnancy is suggested. Below is a possible antepartum monitoring regimen:

- Initiate antepartum testing with weekly NST's and weekly Amniotic Fluid Index (AFI) at 28-30 weeks gestation.
- Advance to twice weekly NST's with weekly AFI's at 34-36 weeks.
- Add fetal umbilical artery Doppler systolic/diastolic ratios (S/D ratios) if indicated or weekly beginning with antepartum testing at 28-30 weeks.
- BPP's may be added if NST's are not reassuring or Doppler S/D ratios added as well.
- Delivery is based upon gestational and obstetrical indications for mother and baby.

There is no evidence that antepartum steroids could not be offered to patients with aneuploidy or anomalies for fetal lung maturation at the usual clinical ages of 24-34 weeks in the usual clinical situations (i.e. preterm labor, early onset preeclampsia needing delivery, etc). Discussion with the patients' obstetrical provider regarding antepartum assessment and steroids is encouraged.

### ➤ **What delivery options should be offered to patients?**

## ***Delivery***

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 as noted above, which we usually do not recommend in labor for lethal anomalies, 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; desire baptism of the living child; or, request other religious ceremony. If the parents are adequately counseled regarding the increased maternal risk for cesarean delivery, we will provide this service.

Diagnosis is confirmed at delivery and the family allowed to spend maximum time with their child. This 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. The neonatal team may continue hospice care as well.

## ***Postpartum care***

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 the their child. The team may help with funeral arrangements, pictures, a memorial service, and may attend services when available. Postpartum visits encourage the discussion about future pregnancies, grieving, and genetic counseling may be needed. Future pregnancies may carry anxiety about the previous loss.

- **What are the clinical outcomes for perinatal hospice patients?**

## ***Clinical outcomes***

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.<sup>29,30</sup> Our first series published in 2003 reviewed our experience in a military population with 33 patients eligible for perinatal hospice care. Out of the 33 patients, 28 (85%) chose hospice care.<sup>29</sup> 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).<sup>29</sup> In our subsequent paper at a civilian tertiary care center we had 28 patients eligible for perinatal hospice with 75% (21/28) choosing hospice.<sup>30</sup> Out of our 21 patients who chose hospice we had a 76% live birth rate (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. In the combined series of 33 live-born infants, the survival times ranged from 20 minutes to 256 days (one trisomy13). The majority of the neonates expired within 24 hours.<sup>29,30</sup> There were no maternal morbidities or mortalities in either of our series. This replicates previous authors' experience.<sup>31</sup>

## ***Barriers to Perinatal Hospice***

The institutional vision along with the attitudes and beliefs of the professionals who care for the patients and families will have a significant effect on whether or not the perinatal hospice concepts will be accepted or allowed to take shape. Termination of pregnancy remains the tacitly 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.<sup>32</sup> There are concerns that patients, once offered perinatal hospice, will desire these services (as in our series). Some providers might wonder why resources should be wasted on a fetal demise. However, if patients are to be offered true choices and exercise of autonomy, then *real* options need to be given. It is the lack of a cogent, consistent, organized, and

thorough planning that has been a deficiency in modern prenatal care. A structured and patient centered approach is necessary if we truly desire to give tangible options with real autonomy for patients to manage their pregnancy.

In order to be successful, there must be at least one physician champion. A dedicated small group of professionals from each segment of the disciplines is critical for perinatal hospice. They must be willing to give input and support from the beginning of the process. Usually those professionals already involved in the care of these patients are a great resource and most likely willing to stretch clinically and utilize their skills. There might be a diversity of approaches used to overcome nay-sayers. The most effective 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 sojourning with their children in a dignified manner with their providers transforms the most hardened of heart. As others become curious and interested, the pioneering team can educate others through multidisciplinary meetings or symposiums.

## ***Present Environment for Perinatal Hospice***

Significant resistance existed to perinatal hospice when first proposed.<sup>1,33</sup> 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”, an obstetrical provider’s 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 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 provider's 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 provided the necessary clinical support for perinatal hospice demonstrating no increase in either maternal mortality or morbidity. A number of educational presentations have also been presented in various venues in support of the development of perinatal hospice. To date, over 230 perinatal hospices in the United States and 39 international hospices, have been created.<sup>34</sup> What started as a small, simple idea to promote patient-centered choice and humanity honoring care, 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.

## **Summary of Recommendations and Conclusions**

*The following recommendations and conclusions are based on good and consistent scientific evidence (Level A):*

- **Women with termination of pregnancy for lethal anomalies have significant persistent psychological problems.**
- **Delivery of patients with lethal anomalies have similar maternal mortality (10/100,000) as do abortions at same gestational age (16-20 weeks) [9.3/100,000].**

*The following recommendations and conclusions are based primarily on limited or inconsistent scientific evidence (Level B):*

- **When explicitly offered comprehensive perinatal hospice care, 75-85% of patients will preferentially choose perinatal hospice.**

- **There is no increased maternal mortality with perinatal hospice care.**

- **Fetal monitoring may be offered perinatal hospice patients to insure a desired live birth.**

*The following recommendations and conclusions are based primarily on consensus and expert opinion (Level C):*

- **Primary cesarean delivery may be offered to patients who desire a live-birth just in any other instance of patient autonomous choice for cesarean delivery.**
- **Patient psychological outcomes are superior with hospice care compared to termination of pregnancy.**

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