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Committee on the Judiciary,
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Chairman Franks and distinguished members of the subcommittee, I am Byron C. Calhoun. I serve as a professor and as vice chair of the Department of Obstetrics and Gynecology at West Virginia University-Charleston. I am pleased to have this opportunity to testify on current issues that may arise during your consideration of the District of Columbia Pain-Capable Unborn Child Protection Act (H.R. 3803).

As you know, this legislation would prohibit abortion within the federal jurisdiction that it covers, beginning at 20 weeks fetal age, which is 22 weeks in the system of dating that is commonly employed in obstetrics, which counts pregnancy as beginning at the time of the last menstrual period (the "LMP" system). The bill contains an exception for certain cases in which an abortion is deemed necessary because of danger to the mother's life.

Objections have been raised to this legislation by some who say that abortion should be permitted even after 22 weeks LMP (20 weeks fetal age) because it is the necessary and appropriate way to deal with a fetus with significant physical anomalies including lethal anomalies. I do not agree. There are other alternatives that are far more humane for both parents and child.

My training, as noted in my biography, involves maternal-fetal medicine, which is the care of high risk pregnancies. This includes the care of pregnancies with lethal anomalies. In my almost 25 years of practice, I have never found it necessary to terminate a pregnancy to save the life of the mother for a fetal anomaly. I have had to deliver patients prematurely and had babies die from prematurity, but never had to take the life of a fetus to save the mother's life.

In the case of a fetal anomaly, we advocate patients be offered the option of the perinatal hospice, which 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. Prior to the development of perinatal hospice, the counseling provided to parents facing such a diagnosis generally assumed abortion as the expected intervention, and offered no other alternative. There 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 ill-informed desire to avoid complications of pregnancy, and an unsubstantiated fear of increased maternal mortality.

Research in grief after termination of pregnancy paints a much different landscape. Early, small studies provided an initial glimpse 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.¹ 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, 2005 found that pathologic grief persisted in 3% of patients (2/253) and that 17% (33/253) suffered from symptoms of posttraumatic stress.² Finally, Korenromp et al, 2009 found persistent and significant grief responses at 4,8, and 16 months.³ 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.³ In contrast, 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.⁴ The first 6 months showed an increased level of depression, anxiety, and somatization in the miscarriage group, but by one year there was no difference between the 2 groups.⁴

With regard to the fear of increased maternal mortality, 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.^{5,6} So, essentially the mortality rates are the same for either of the management choices.

We utilized the seminal work of Kubler-Ross on modern medicine's understanding of death and dying to assist to shape our concept.⁷ At the same time Kubler-Ross transformed the discussions around death, Saunders transformed the care of the dying with her modern hospice movement.⁸ The unifying concept in hospice was the holistic approach to the physical, emotional, and spiritual support for dying patients and their families. The essence remained treating the dying with dignity and as if they really were alive and not yet dead. The patient and family's fear of abandonment could then be met. 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.

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. There was an emphasis on affirming life by care for the loved one while regarding dying as a normal process; a conscious effort to neither hasten death nor prolong dying; stressing values beyond the mere physical needs of the dying individual; allowing the parents to "parent" their child for whatever 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. Its 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. It agrees with Knapp et al, that "dying involves real people, even unborn fetuses [and that] significant relationships are disrupted and familiar bonds are severed".⁹ 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*,¹⁰ 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."¹¹

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 they are allowed to "parent" their child how they would like to do so. We discuss the support of and care for them during their pregnancy, delivery, and death of their child. Parents also fear their baby might have pain. If they desire comfort measures for their baby: oxygen, feeding, medications, pain relief if indicated, and wound dressings; they are assured these will be provided. Some parents want to be seen 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 ways to relate to other children in the family, friends, and family members. Often there remains a hope that the diagnosis is incorrect 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. The lack of physical contact with, and minimal amount 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.

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 will provide this service.

Diagnosis is validated 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. The neonatal team may continue hospice care as well.

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.^{12,13} Our first series published in 2003 review our experience with a military population where we discussed 33 patients eligible for perinatal hospice care. Out of the 33 patients, 28 (85%) chose hospice care.¹² 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).¹² In our subsequent paper at a civilian tertiary care center we had 28 patients eligible for perinatal hospice with 75% (21/28) choosing hospice.¹³ 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. All our live born babies lived in the combined series (33 total live born) from 20 minutes to 256 days (one trisomy13). The majority of the neonates expired within 24 hours.^{12,13} There were no maternal morbidities or mortalities in either of our series. This replicates previous authors' experience.¹⁴

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, 125 perinatal hospices in 34 of the United States and 13 international hospices have been created.¹⁵ What started as a small, simple 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.

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