AAPLOG
PRACTICE GUIDELINE
Number 1, November 2014, Updated 2017, 2021

Perinatal Palliative Care and Perinatal Hospice

Families who receive a life-limiting fetal diagnosis may choose perinatal palliative care, an active approach that manages symptoms of anxiety and isolation, and openly manages anticipatory grief. Perinatal palliative care has similar rates of maternal complications and maternal regret as abortion, which is not an effective way to curtail or prevent grief. Retrospective cohort studies demonstrate that perinatal palliative care is readily taken up by patients and providers; limited prospective evidence suggests that perinatal palliative care may improve maternal anxiety, communication, and family relationships. Offering perinatal palliative care should be part of every obstetrician/gynecologist's counseling when adverse prenatal diagnoses are made.

Background

Vocabulary

Perinatal palliative care (PPC), previously known as perinatal hospice (PH), is a plan of care for women and families who have been given a life-limiting fetal diagnosis. PPC refers to a multidisciplinary approach that aims at decreasing the burden of the condition by emphasizing anticipatory grief management and communication.[1,2] "Life-limiting" describes fetal conditions that are associated with intrauterine death, neonatal death, or death within a short number of years of life. This term is more accurate than the historical terms "lethal" or "incompatible with life," given that fetal life *is* life, and that those terms can predispose toward treating the fetus as if he or she is "as good as dead."

History

PPC began in the United States in the 1990s, twenty or thirty years after the first ultrasound and genetic diagnoses of fetal anomalies.[3,4] One significant motivator for the development of PPC was intact dilation and evacuation (D&E) or dilation and extraction (D&X), colloquially termed "partial birth abortion." PPC was promoted in response to this procedure, variations of which include delivery of a

AAPLOG Practice Guideline. This document was developed by [number] authors on the Research Committee. Practice Guidelines are evidence-based documents informing pro-life providers with high-quality, peer-reviewed literature.

breech fetus to his or her shoulders, inserting a sharp instrument into the fetus' skull, causing death by removing the brain or collapsing the skull, and removing the fetus. PPC in part began as a cogent alternative care pathway to late-term gestations with life-limiting anomalies.[5]

The development of PPC has been slow, from nursing-based calls for "a reasonable plan for patient support and care" after prenatal diagnosis, to publication of a bulletin from the American College of Obstetricians and Gynecologists (ACOG) in 2019, twenty-five years after PPC was developed.[2,6] PPC is now coming of age as a field,[7-9] and several clinical trials have now been published.[10-12]

Population

As many as 20,000 persons die each year due to life-limiting fetal conditions.[13,14] This number of yearly deaths is greater than the number of yearly deaths from all childhood cancers combined.[15]

Approximately one in five women desire to continue pregnancy regardless of the fetal prognosis.[16] However, women who have received a life-limiting fetal diagnoses are more likely to terminate pregnancy than the general population.[16,17]

The loss of a pregnancy to abortion may be grieved intensely as a stillbirths: a case-control study of 23 individuals with fetal anomalies found the prevalence of depression among women who elected to terminate pregnancy for fetal anomaly was 17% (4/23), and the rate of psychiatric counseling was 23% (5/23) at two months when compared to stillbirths.[18] Although grief responses fade, they persist in some patients for over a year,[19] which is different from some studies of spontaneous first trimester miscarriage.[20] One study of 253 women between 2 and 7 years after termination of pregnancy for fetal anomalies found that 3% experienced complicated grief and 17% experienced symptoms of posttraumatic stress.[21] Grief may begin at diagnosis, and persist regardless of management choice.[22] Termination of pregnancy, thus, is not an effective measure to curtail or prevent grief.

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.[9,10] So, essentially the mortality rates at16-20 weeks gestation, when most terminations are done for anomalies, are *equal* for either abortion or live-birth.

Patients and families who participate in PPC do so after being given a gentle and clear explanation of the diagnosis, and medical technology's inability to treat the life-limiting diagnosis. This is followed by a discussion of their legal access to termination of pregnancy, and the active management option of PPC. PPC is rightly portrayed as a patient- and family-driven opportunity to interact with as much (or little) of PPC services as they want. Ideally, a PPC program is a viable, compassionate, organized setting to give parents the tools to "be parents" and work through anticipatory grief.

PPC Components and Team

PPC is more than simple bereavement counseling or routine obstetric care. The care of terminally ill fetuses and grieving families requires a multidisciplinary team, including the maternal patient, her pre-born child, her family, and her team of providers. As care progresses, these providers may include her obstetrician or midwife, a maternal-fetal medicine specialist, a neonatologist, a mental health professional (psychiatrist, psychologist, or bereavement counselor), sonographers, and labor and delivery personnel.

Depending on the family and situation, patients may also utilize child life, social work, case management, and spiritual leaders or chaplains. Care is provided at the timing and intensity of the family desires. Team members who are central to the care of the PPC patients meet at regular intervals to review management and coordinate care.

PPC allows patients to "parent" their child in their own style. Some PPC families wish to be seen in clinic when other pregnant patients are not present; others want to be among other pregnant women. Some PPC families desire frequent ultrasounds for memory-making; others wish to minimize occasions where they may discover their pre-born child has died. At birth, some parents desire comfort measures for their neonate if born alive (e.g. oxygen, feeding, pain relief, or wound dressings); others may only wish to hold the infant, or may decline to see the infant at all. Flexibility, an attitude of non-judgment, and easy accessibility to PPC team members can reduce anxiety and isolation associated with the life-limiting fetal diagnosis.

Barriers to Perinatal Hospice

Although AAPLOG and ACOG both maintain that PPC should be offered,[2] it is not offered in all centers. Significant resistance existed to PPC when first proposed,[1,23] especially because providers tended to prefer abortion to

pregnancy continuation in the 1990s.[24] However, there are now over 200 programs in the United States that offer this as an active management solution for pregnancies complicated by life-limiting fetal diagnosis.[25]

Clinical Questions and Answers

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

Antepartum monitoring, an intervention made to prevent stillbirth, is not well characterized in patients with aneuploidies and anomalies.

Fetuses with trisomies 13, 18, and 21 are at increased risk for stillbirth. Approximately 1 in 160 fetuses are stillborn each year in the United States (0.006% of all deliveries),[26] in fetuses with trisomy 21 this number is as high as 1 in 20.[27] The risk of stillbirth is even higher with trisomy 13 (5 in 10 may be stillborn) and 18 (7 in 10 may be stillborn).[28] While ACOG advocates for increased antenatal surveillance for pregnancies at risk of stillbirth,[29] it is not clear that this type of surveillance can prevent stillbirths like it can in other conditions that are commonly monitored. More research is needed to investigate whether antenatal surveillance changes outcomes in fetuses with life-limiting conditions.

For families interested in frequent monitoring, perhaps for memory-making if not for stillbirth prevent, a possible antepartum monitoring regimen is:

- Initiate antepartum testing with weekly NST and weekly amniotic fluid index (AFI) at 28-30 weeks gestation.
- Advance to twice weekly NST with weekly AFI at 34-36 weeks.
- Add fetal umbilical artery Doppler systolic/diastolic ratios in the case of fetal growth restriction.
- Biophysical profile (BPP) may be added if NST is not reassuring
- Delivery timing is based on obstetric indications or value-consistent goals of the maternal patient.

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).

Q *What delivery options should be offered to PPC patients?*

The maternal patient and her family designs a value-consistent birth plan in PPC. This may include fetal monitoring, which should only be undertaken after

a carefuly discussion of the maternal risks of cesarean delivery. Cesarean delivery may be offered in the event the parents want to see and hold a living child. Given that cesarean delivery may be offered for no medical indication,[30] its availability in this setting is not in violation of standard of care.

At delivery, the life-limiting diagnosis should be confirmed. Following this, the family should be allowed to spend maximum time with the neonate, allowing them to contribute to their child's life by holding or bathing him or her, taking photos, or performing religious ceremonies. PPC may be continued by neonatal teams if pain management or wound care is applicable.

Q *How is postpartum care different for perinatal hospice patients?*

PPC does not cease with the death of the child. Grief counseling continues throughout the postpartum time frame, for instance, by phone or office visits within one week of delivery and monthly thereafter until the first anniversary of the child's death. The PPC team may help with funeral arrangements, pictures, and memorial services. Postpartum visits should encourage discussion about mental health, diagnostic workup or genetic counseling, future pregnancies, and other caregivers.

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

In two small cohorts, the majority (75-85%) of parents chose PPC rather than abortion.[31,32] Only one patient in these early cohorts had a cesarean delivery to meet a liveborn neonate. The majority of neonates expired within 24 hours, and there was no maternal morbidity or death. Another small cohort had similar findings.[33]

More recently, a retrospective cohort of 430 PPC families showed an increase in uptake of PPC over the nine years since data collection began (1 family in 2019 to 85 in 2018), such that it became the "norm" in a secular Midwest hospital.[10] PPC in this setting addressed a broad range of diagnoses and prognoses addressed by PPC, with some children living over one year.

Another retrospective cohort confirms that most neonates die within one year, adding that most patients who are referred to PPC continue with this service, potentially suggesting satisfaction (84/85 patients).[11]

The only randomized controlled trial of PPC was for prenatally diagnosed congenital heart disease, and was associated with decreased maternal anxiety,

improved maternal positive reframing, and improved communication and family relationships.[12]

Summary of Recommendations and Conclusion

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

1. Perinatal palliative care is associated with rates of regret and complicated grief similar to termination of pregnancy.
2. Delivery of patients with lethal anomalies have similar maternal mortality (10/100,000) as do abortions at 16-20 weeks (9.3/100,000).

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

1. When explicitly offered comprehensive perinatal hospice care, 75-85% of patients will preferentially choose perinatal hospice.
2. Perinatal palliative care is associated with decreased maternal anxiety and improved communication and family relationships for congenital cardiac disease.

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

1. Cesarean delivery in the setting of life-limiting fetal diagnosis is consistent with standard of care when the maternal patient gives informed consent.
2. Antepartum surveillance and intrapartum fetal monitoring may be offered in the setting of life-limiting fetal anomaly.

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