A Proposed Model for Perinatal Palliative Care

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ABSTRACT

Perinatal palliative care allows for an active partnership among a pregnant woman, her family, and her multidisciplinary treatment team and addresses her specialized medical care, emotional, social, and familial needs when a life-limiting fetal diagnosis is confirmed. The purpose of this article is to highlight the multidisciplinary care model used within a perinatal palliative care program. A case study provides a unique perspective on support needed for parents who anticipate that their newborn may die before or shortly after birth.

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Congenital anomalies are the leading cause of infant mortality and account for approximately 20% of neonatal deaths (Matthews, MacDorman, & Thoma, 2015; Wool, Repke, Woods, 2017). When expectant parents are told that their fetus has a life-limiting diagnosis or is at risk for intrauterine death, obstetric providers may discuss termination of pregnancy as a management option. However, because of social, cultural, or spiritual beliefs or gestational age limitations, termination of pregnancy may not be a viable option for many parents. For parents who choose not to terminate their pregnancies, support through perinatal palliative care at birth may be a preferable choice.

In response to advances in fetal imaging and diagnosis (Denney-Koelsch et al., 2016; Kobler & Limbo, 2011; Wax et al., 2014), perinatal palliative care programs are beginning to emerge in high-risk obstetric and fetal care centers across the United States. These programs are usually located in perinatal medicine departments and consist of multidisciplinary teams (Balaguer, Martin-Ancel, Ortigosa-Escobar, Escribano, & Argemi, 2012; Boss, 2010).

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authors (Leuthner & Lamberg-Jones, 2007; Summer, Kavanaugh, & Moro, 2006).

In this article, we describe the Perinatal Palliative Care and Bereavement Program within the Center for Fetal Diagnosis and Treatment (CFDT) at The Children’s Hospital of Philadelphia. We use a case study to describe the proposed best clinical practices and to serve as a resource for other institutions with similar programs. We address initial diagnostic confirmation, palliative care consultation, birth planning, and postmortem care. Details related to the case illustrate the steps taken by the staff to support the mother and her family throughout the perinatal period.

The CFDT

The CFDT’s Perinatal Palliative Care and Bereavement Program located at The Children’s Hospital of Philadelphia is a collaborative multi-disciplinary program established to care for families who face anticipated loss. Prenatal diagnosis, ongoing prenatal care, and birth all occur within the Center to keep women, families, and newborns together and to facilitate ongoing access to many related subspecialists. Most fetal diagnoses made in the CFDT are amenable to neonatal care, and the infants maintain potential for long-term survival. However, certain diagnoses are not compatible with survival despite all available technology, including skeletal dysplasias, severe congenital diaphragmatic hernia in conjunction with heart disease, and some genetic conditions. Parents are counseled regarding pregnancy management options including continuation with a palliative care plan and termination. Some choose termination, but a growing number of expectant parents choose palliative care. In fact, up to 8% of the annual birth volume within our institution consists of palliative care births. Since the inception of the program in 2012, the CFDT has provided perinatal palliative care consultation and support to more than 120 women and their families.

Perinatal Palliative Care Process

Fetal Diagnosis

After an initial evaluation in the CFDT, a confirmed fetal diagnosis is given to the woman and her family by the maternal–fetal medicine physician. Parents who may benefit from palliative care consultation are connected to the CFDT’s Perinatal Palliative Care and Bereavement Program by a nurse coordinator or advanced practice registered nurse (APRN). The nurse coordinators and APRNs support the family in the decision-making process, communicate with all specialists to streamline care, and facilitate clinical access for the family (Leuthner & Lamberg-Jones, 2007). In addition, the APRNs also provide continued family support, continuity of care, and anticipatory guidance and education during subsequent prenatal visits.

The Perinatal Palliative Care Consultation

Perinatal palliative care involves many of the principles of traditional palliative care models to address a severe illness diagnosed in a fetus (Boss, 2010; Kobler & Limbo, 2011; Munson & Leuthner, 2007). For expectant parents and families, the diagnosis of a life-limiting fetal abnormality can be a traumatic event that elicits strong emotions. Without proper attention, these emotions may develop into symptoms of perinatal depression, anxiety, and traumatic stress (Cole et al., 2015; Kowalczyk, Muhlhoff, Bachmann, & Gemburck, 2002; Whynes, 2002). Ongoing grief support services are needed to help expectant parents as they grieve the loss of a typical, healthy pregnancy and an imagined child (Kasl-Godley, King, & Quill, 2014; Kavanaugh, Roscigno, Swanson, Savage, Kimura, & Kilpatrick, 2013; Leuthner & Lamberg-Jones, 2007). Psychosocial team members (e.g., social workers, psychologists, chaplains) should be an integrated part of the palliative care team to support grieving parents, connect them with community grief resources, and provide continuity of services throughout the perinatal period and ongoing assessment for emotional and social risk factors that may potentially challenge a family’s grief process.

The perinatal palliative care consultation is focused on navigating medical choices and validating good parenting, which derives directly from the broad view that palliative care acknowledges the very idea of parenthood. The expectant couple will always be the parents, whether the fetus dies in utero, the newborn dies shortly after birth, or the newborn survives to hospital discharge. The goal of a palliative care team is to manage emotional and existential distress in all members of the family, not just the pregnant woman. Consequently, memory making, making
meaning of the pregnancy, and validation that the parents are making loving choices as good parents are needed (Kavanaugh et al., 2013; Munson & Leuthner, 2007).

Clinicians involved in perinatal palliative care should have a good understanding of the clinical paths a newborn might follow once born. If appropriate, the physician should describe what intensive care would entail, including which interventions might be considered and how likely they would be to extend life or improve quality of life. In addition, the physician should describe what to expect if the family and team elect to protect the newborn from such interventions (Boss, 2010; Munson & Leuthner, 2007). Once this context has been provided, perinatal palliative care clinicians can help the family explore their goals and then help them contemplate choices related to medical treatment.

Therapeutic Birth Planning
As the team and family “hope for the best while preparing for the worst” (Back, Arnold, & Quill, 2003, p. 439), one way to enhance the family’s sense of control is to help them develop a palliative care birth plan. Similar to end-of-life hospice planning, the act of therapeutic birth planning allows expectant parents the emotional space to discuss their needs with one another and plan for the anticipated death of their child. In the context of perinatal palliative care birth planning, Munson and Leuthner (2007) outlined a framework that includes engaging families in the exploration of their wishes, providing options, and allowing choice. Families vary in their ability to communicate effectively about their distressing thoughts and feelings to make decisions collaboratively and may need support from staff to do so (Kasl-Godley et al., 2014). One way to facilitate healthy grief is to help families create meaningful pregnancy memories and use the prenatal time period for bonding with their unborn child (Côté-Arsenault & Denney-Koelsch, 2011; Leuthner & Lambreg-Jones, 2007; Munson & Leuthner, 2007).

Expectant parents often avoid difficult or sensitive discussions about the fetus, but within the therapeutic context of birth planning, they are supported to face their fears. A systematic and intentional review of the birth plan is completed at a couple’s pace as a cognitive-behavioral exposure technique to effectively address their worries and concerns without the elicitation of traumatic stress. The specific elements of birth planning have been described elsewhere (Kuebelbeck & Davis, 2011; Munson & Leuthner, 2007). At each step in the birth planning process, additional team members (e.g., social worker, lactation consultant, chaplain, anesthesiologist, etc.) are introduced depending on the family’s needs and interests. Therapeutic birth planning capitalizes on evidence-based methods of family assessment to help families develop resiliency regarding the impending death (Kasl-Godley et al., 2014; Kobler & Limbo, 2011). Research shows that good advanced-care birth planning is associated with increased parent and family satisfaction; better sense of control; and less fear, anxiety, and emotional distress (Kasl-Godley et al., 2014; Kavanaugh et al., 2013; Wool et al., 2017).

Sibling Support
The child life specialist collaborates with parents to create and implement a personalized care plan for other children during the prenatal and postpartum periods. With expertise in child development and family systems, child life specialists focus on the optimal development and well-being of children by promoting coping skills and minimizing the adverse effects of hospitalization or other potentially stressful experiences through therapeutic play, preparation, and expressive modalities (Brown & Chitkara, 2014). In a consultation, child life specialists can help to gain an overview of family dynamics; introduce available services; and assess the parents’ hopes, fears, and concerns for themselves and their children. The inclusion of siblings in the grief process in developmentally appropriate ways is an important part of healing (Desai & Pandya, 2013; Howard, 2006; Ulanowski, McGee, & Giambra, 2011). Parents are encouraged to include the newborn’s life, however short, as a part of their family narrative, which includes honoring the big brother and big sister role.

Multiple authors described the importance of providing age-appropriate, honest, and concrete explanations to young children to help them understand the finitude of death and begin coping with the loss. Parents are advised to avoid euphemisms, such as she’s gone or she passed away, and instead use the word dead to increase a child’s understanding (Desai & Pandya, 2013; Kuebelbeck & Davis, 2011; Pearson, 2009). Because young children often engage in magical thinking (Bibace & Walsh, 1980; Desai & Pandya, 2013; Turner, 2009), they often believe that they may be the ones who caused the fetus to die, or they may fear that something is wrong with their mother. Therefore, it is important for parents to
clarify with statements similar to the following: We are sad that our baby died, but we know that nobody did anything wrong and mommy and daddy are okay. Siblings who are well-prepared and present at the time of death, who participate in family rituals, and who are supported by the family in their grief process are better able to integrate their loss (Desai & Pandya, 2013; Ulanowski, et al., 2011).

The Prenatal Course

Once a decision to continue the pregnancy is made, prenatal care must be tailored to each unique woman and her family (Catlin & Carter, 2002; Kobler & Limbo, 2011; Wool, 2013). Prenatal palliative care necessitates involvement of physicians, APRNs, other clinicians (e.g., genetic counselors, lactation specialists, etc.), and psychosocial team members (e.g., social workers, psychologists, psychiatrists, chaplains, child life specialists, music and creative arts therapists, etc.). Provision of palliative care throughout the perinatal period may be complicated by the wide array of emotions experienced by the expectant parents as the pregnancy progresses and death becomes imminent (Wool, 2013). The patient—provider relationship is cultivated during routine prenatal visits and enables APRNs to support pregnant women as they attend to their physical and emotional health. Normalization of the pregnancy is a key component of the care provided by the APRNs during prenatal visits. Calling attention to normal aspects of the pregnancy may provide additional emotional support and comfort to a woman as she gets closer to birth. Such normalization may be enhanced by three-dimensional ultrasonographic photos of the fetus or audio recordings of the fetal heartbeat; these also serve as mementos after death (Kuebelbeck & Davis, 2011).

It is imperative to encourage parents to discuss their grief during routine prenatal visits (Kavanaugh et al., 2013; Kobler & Limbo, 2011; Williams, Munson, Zupancic, & Kirpalani, 2008). Advanced practice registered nurses allow women and families time to express their feelings during their care visits. Nurses also review specific education regarding the fetal diagnosis and clarification of the birth plan in collaboration with women, families, and the medical team. A palliative care birth plan should remain available in the woman’s electronic medical record so that medical and nursing providers can use the document to gather additional information, such as decisions related to fetal monitoring, preference for mode of birth and surgical birth for fetal distress, or the wish to donate breast milk after the newborn’s death.

The Birth and Postpartum Course

Obstetric nurses are guided by the philosophy of family-centered care to empower families to make informed choices and to spend time with and parent their infants, however brief the time may be (Wool, 2013). Nurses should recognize that all families process fetal or neonatal death differently. By building rapport with the family, a nurse can more easily tailor appropriate care. When nurses and the support team embrace a being with rather than a doing to philosophy (Milstein, 2005), they can help enhance the healing experience and sense of familial connection. Collaboration with psychosocial colleagues has great potential to strengthen the level of care for parents and generate an atmosphere of mutual professional support (Boss, 2010; Wool, 2013; Wool et al., 2017). In addition, members of a multidisciplinary team can support one another throughout the woman’s perinatal period to reduce the emotional burden on any one provider.

A well-documented birth plan allows nurses immediate engagement with a family upon admission and prevents awkward conversations while attempting to establish rapport. For many laboring women, the maintenance of normalcy in routine care is important and can be calming, despite awareness of the anticipated death (Boss, 2010). The prioritization of physical care during labor and after birth allows the woman to focus on something concrete and may help give her a sense of control. Nurses are often the health care providers who have the most presence at the bedside during labor and throughout the woman’s hospital stay. During labor, the obstetric nurse can focus not only on the provision of physical care but also on full engagement in patient advocacy, protecting the woman’s wishes throughout the palliative care birth process.

After birth, nurses can model bonding behaviors and encourage families to become more comfortable with holding, seeing, and touching their newborns before and after the death and calling the newborn by name. Nurses assist the family in newborn care, based on the family’s wishes. Ample time is needed for a gradual goodbye to promote healthy grief and potentially reduce the risk of trauma at the time of birth (Leuthner & Lambrecht-Jones, 2007). Taking photographs, hands-on bonding, bathing, and dressing are all important activities that can help to
Therapeutic birth planning allows expectant parents the emotional space to discuss their needs with one another and plan for the anticipated death of their child.

normalize the experience and celebrate the birth (Boss, 2010; Catlin & Carter, 2002; Kuebelbeck & Davis, 2011; Munson & Leuthner, 2007).

Throughout the inpatient admission, the obstetric nurse has the opportunity to discuss discharge teaching in anticipation of leaving the hospital without the newborn. Based on the established rapport, the nurse can begin to include discharge teaching throughout the provision of care, introducing small and concrete pieces of information so as not to overwhelm the woman but to raise awareness on what physical and emotional challenges she may face upon hospital discharge. The following case highlights the unique elements of the perinatal palliative care model used within the CFDT at The Children's Hospital of Philadelphia.

Case
A 38-year-old gravida 3, para 1 woman presented with her husband for an evaluation to the CFDT at 22 weeks gestation. She was referred by her primary obstetrician for multiple findings during the fetus's ultrasonographic examination. She opted to proceed with invasive fetal diagnostic testing through amniocentesis, which showed trisomy 13. The structural findings through imaging at our Center were consistent with this diagnosis. The couple was counseled regarding the poor prognosis associated with trisomy 13, a well-described chromosomal disorder associated with multiple organ malformations that includes congenital heart disease. They were alerted to the high rate of intrauterine fetal loss of at least 50%. The maternal–fetal medicine physician explained that approximately 90% of individuals with trisomy 13 do not survive past the first year of life, and only 5% to 10% survive to the first birthday (Rasmussen, Wong, Yang, May, & Friedman, 2003). The couple was committed to continuation of the pregnancy but felt that heroic intervention for the neonate might go against their wishes. They were referred to the CFDT's Perinatal Palliative Care and Bereavement Program for a palliative care consultation.

At the perinatal palliative care consultation, clinical pathways were presented to the couple that clearly defined the services that would be available at birth if they chose to pursue aggressive interventions, and there was a thorough discussion about the options for palliative care. The consulting neonatologist discussed the profound apnea that most often results in early mortality for newborns with trisomy 13 within hours to days after birth, and it was acknowledged that some neonates with trisomy 13 do not have this problem. Because the apnea status is unknown until birth, the newborn would be given routine care, which would allow the family to have precious moments with their daughter immediately after birth.

Upon the departure of the neonatologist, a brief risk assessment was performed by the clinical psychologist. Because the woman's medical record confirmed a history of depression, it was important to offer immediate emotional validation and psychoeducation about relapse prevention. The clinical psychologist met with the couple at each subsequent prenatal care visit to assess for risk, address daily coping and self-care strategies, and discuss components of their palliative birth plan. The revised drafts of the birth plan were always read aloud, line by line, for the couple to verify the accuracy of their wishes, safely increase exposure to the traumatic stimuli, and create a dialog for problem solving. After each session, updated drafts were documented in the electronic medical record and used as a guide for nursing and medical staff at prenatal follow-up appointments and upon inpatient admission.

A primary concern for this couple was how to best prepare their 4-year-old son for the birth and death of his sister. As a result, a referral to the Child Life Specialist was made, which offered developmentally appropriate, supportive, and honest language choices and therapeutic interventions that fit the unique needs of their family. Strategies were provided on how to best talk to their son about his sister's diagnosis and impending death, how to support his emotions and grief, and how to include him in the process of effective memory making.

It was recommended that the couple use the words growth or lack of growth instead of more abstract words such as sick or something's wrong. When their son naturally asked about his sister, they said, "The doctors are watching our baby grow in mom's belly, and our baby's brain may not grow big enough." This language
allowed the parents to build a foundation for their son regarding the birth and eventual death. He also benefited greatly from learning language to support his own understanding of the emotions he was experiencing and those witnessed in the adults around him.

Periodically, the parents brought their son to the prenatal visits, which allowed for one-to-one therapeutic play interventions. While the parents met with the clinical psychologist to discuss birth planning, the child life specialist allowed safe opportunities for play (Jessee & Gaynard, 2009; Thompson & Stanford, 1981). The child-directed play sessions allowed for a sense of control and mastery (Gaynard, Wolfer, Goldberger, Thompson, Redburn, & Laidley, 1998) as the boy built a new supportive relationship with the specialist and became more familiar with the labor and delivery environment.

The woman transitioned prenatal care to the CFDT at 29 weeks gestation and was scheduled for monthly ultrasonographic examinations to assess fetal well-being. The maternal-fetal medicine physician discussed the ultrasonography findings and plan of care with the family at each visit. The woman was also scheduled to have routine prenatal care visits with an APRN during which prenatal education was reviewed, and the couple was given the opportunity to discuss their birth plan and their daily struggles.

The woman’s care was unremarkable until 35 weeks 5 days gestation, when she called the office to report decreased fetal movement. She was instructed to immediately come to the office for an ultrasonographic examination that confirmed an intrauterine fetal demise. The woman was admitted per routine nursing process and prepared for an elective cesarean birth that evening.

Obstetric nursing staff supported the family overnight and assisted with holding and bonding according to the woman’s wishes. On the first postoperative day, nurses continued to assist her with important self-care while the psychosocial support team assisted with memory making: taking photos, making hand and foot molds, and eventually introducing their son to his sister.

When their son arrived, the parents chose to talk to him alone, without the newborn present, and requested that the child life specialist be in the room for support. The couple used the predetermined language to explain to their son that his sister died: “Remember when we told you that our baby’s brain may not grow big enough? Your sister was born but because her brain did not grow big enough, she died.” After explaining that she died, the couple gave their son the choice to meet his sister and to be involved in the memory-making process. He spent his time in the postpartum recovery room shifting between getting to know his sister, playing with toys, and openly expressing his emotions to describe his current experience, such as “It’s really sad that my sister died.”

The psychosocial support team partnered with nurses to help the couple develop a structure for each day of the 3-day admission that allowed for continuity and emotional containment. Minimal interruptions from hospital staff (e.g., environmental services, food services, etc.) allowed for family bonding, honest grieving, and intimacy that minimized traumatic stress and aided in the beginning stages of integrating the loss into their family narrative. On the second postoperative day, obstetric nurses assisted with bathing, redressing, swaddling, and cutting a lock of the newborn’s hair. Frequent bedside consultation with the clinical psychologist supported the couple’s grieving process and helped prepare them for discharge. On the day of discharge, the team assisted the couple with the newborn’s release; the family was accompanied off the unit by the psychosocial team, and nursing staff remained in the room with the newborn according to the family’s wishes before transport to the pathology department.

The woman chose to return to the CFDT for her 6-week postpartum visit. She and her husband met with the clinical psychologist to continue to process the birth experience, time on the unit, and re-integration back home. They were engaged in grief counseling in the community, which proved effective, and they reflected on how they felt more connected in their relationship with each other in response to their shared loss. They also met with the child life specialist to discuss the ongoing support of their son. The couple expressed that it was hard to witness their son’s sadness, but they felt comfortable in continuing to validate and support his emotions and grief response. They also continued to talk about their daughter at home and were thoughtful in trying to find ways to honor the sibling relationship.

During the postpartum visit, the woman had a normal physical examination result, and the
The clinical focus of perinatal palliative care is directed toward honoring, witnessing, validating, and celebrating the humanity inherent in the process of becoming a parent.

couple wished to spend time during their visit conversing with their APRN about their emotional well-being. At the end of the visit, self-care measures and instructions were reviewed, and the woman was transitioned back to her primary provider for well-woman care.

Discussion
Upon initial diagnosis of a lethal fetal anomaly, women often reveal that they feel unable to speak honestly about their thoughts and feelings regarding their pregnancy to other providers, friends, and family members. It is imperative that providers discuss all options with families once a life-limiting diagnosis is confirmed, make referrals to perinatal palliative care programs when warranted, and support the decisions that families make regarding their pregnancies. Integration of palliative care services within the prenatal setting provides a natural infrastructure to support the grieving process for women and their families.

The multidisciplinary approach to perinatal palliative care birth planning helps to encompass all aspects of care and ensures that the woman and family are well cared for from a mind-body-spirit perspective. By advocating for the woman and protecting her desired wishes for the birth experience, the obstetric nurse can help provide peace of mind in an otherwise high-stress, emotional time. Through commemoration of the experience and celebration of the birth and life of the infant, no matter how short, the team can help provide long-lasting memories for the woman and her family. Wool and colleagues (2017) found that parents identified greater satisfaction with perinatal palliative care when the team was compassionate, cared for medical needs, supported spiritual customs, helped them cope with emotions, provided a comfortable and caring environment, helped with decision making, and provided care in a consistent manner.

This case illustrates the concrete work used in one multidisciplinary perinatal palliative care model to meet the needs of expectant parents confronted with their worst fears. Because there are a variety of ways to create teams and processes, it is our hope that the reader feels empowered by this description to engage in this work.

Conclusion
As illustrated throughout this case study, perinatal palliative care requires considerable expertise, compassion, and time. The clinical focus is directed toward witnessing, honoring, validating, and celebrating the humanity inherent in the process of becoming a parent (Kasl-Godley et al., 2014). The collaboration between nurses, physicians, and members of the psychosocial team is critical to provide comprehensive woman- and family-centered bereavement care. Although the outcomes of these cases are tragic, there is nonetheless room for peace and beauty for families and providers alike.

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REFERENCES


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