

CNE

Continuing Nursing Education (CNE) Credit

A total of 1.4 contact hours may be earned as CNE credit for reading "A Proposed Model for Perinatal Palliative Care" and for completing an online posttest and evaluation.

AWHONN is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

AWHONN holds a California BRN number, California CNE Provider #CEP580.

<http://awhonn.org/?OnlineLearningCenter>

Correspondence

Joanna C. M. Cole, PhD, Center for Fetal Diagnosis and Treatment, The Children's Hospital of Philadelphia, 34th St. and Civic Center Blvd., 5th Floor Wood Center, Philadelphia, PA 19104. colej3@email.chop.edu

Keywords

multidisciplinary care team
palliative care
perinatal loss
trisomy 13

Joanna C. M. Cole, PhD, is an assistant professor in the Perelman School of Medicine, University of Pennsylvania and a clinical psychologist and Manager in the Center for Fetal Diagnosis and Treatment, Children's Hospital of Philadelphia, Philadelphia, PA.

(Continued)

A Proposed Model for Perinatal Palliative Care

Joanna C. M. Cole, Julie S. Moldenhauer, Tyra R. Jones, Elizabeth Shaughnessy, Haley Zarrin, Aimee L. Coursey, Q5 and David A. Munson

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.

JOGNN, ■, ■-■; 2017. <http://dx.doi.org/10.1016/j.jogn.2017.01.014>

Accepted January 2017

Congenital anomalies are the leading cause of infant mortality and account for approximately 20% of neonatal deaths (Matthews, MacDorman, & Thoma, 2015; Wool, Repke, Woods, 2016). 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, Ortigoza-Escobar, Escribano, & Argemi, 2012; Boss, 2010).

The goals of perinatal palliative care are to anticipate the needs of the mother, her partner, and her family at all points in the perinatal period, including (a) the time of diagnosis and pregnancy decision making, (b) throughout birth planning, (c) during the birth process, (d) during the newborn's life and death, and (e) during the early

postpartum and postmortem periods (Balaguer et al., 2012; Boss, 2010; Kobler & Limbo, 2011; Leuthner & Lamberg-Jones, 2007). Perinatal palliative care providers partner with expectant mothers and their families to develop individualized, seamless, and compassionate care plans that address their emotional, social, and familial needs. All the while, providers help the family celebrate the life of the fetus in utero and honor their grief in preparation for the impending loss (Kobler & Limbo, 2011; Munson & Leuthner, 2007). In 2002, Catlin and Carter described perinatal palliative care:

...the prevention and relief of physical pain and suffering for the infant and on relief of existential suffering of the family. It is a planned intervention by trained interdisciplinary staff members who support with dignity the infant's time on earth and support the family's experience with empathy and culturally sensitive respect. (p. 185)

In 2001, Hoeldtke and Calhoun formally proposed the concept of perinatal hospice. Both noted that little guidance was available for clinicians caring for a woman who chose to carry her pregnancy to term after learning of a fetal diagnosis incompatible with life. They made a compelling argument that advances in prenatal diagnosis, understanding of perinatal grief, and training in hospice care could be combined to create a perinatal hospice program. Such formal programs have since been described by other

Q2 The authors and planners of this activity report no conflict of interest or relevant financial relationships. No commercial support was received for this educational activity.



AWHONN

<http://jognn.org>

© 2017 AWHONN, the Association of Women's Health, Obstetric and Neonatal Nurses. Published by Elsevier Inc. All rights reserved.

Perinatal palliative care clinicians initially help families explore goals and then help them contemplate choices about medical treatment within that context.

Julie S. Moldenhauer, MD, FACOG, FACMG, is an associate professor in the Perelman School of Medicine, University of Pennsylvania; Medical Director of the Garbose Family Special Delivery Unit; and an attending maternal–fetal medicine physician in the Center for Fetal Diagnosis and Treatment, Children’s Hospital of Philadelphia, Philadelphia, PA.

Tyra R. Jones, MSN, CRNP, is a faculty member in the School of Nursing, University of Pennsylvania and a women’s health nurse practitioner in the Center for Fetal Diagnosis and Treatment, Children’s Hospital of Philadelphia, Philadelphia, PA.

Elizabeth Shaughnessy, MS, CCLS, is the Child Life Supervisor for the Barbara Bush Children’s Hospital, Maine Medical Center, Portland, ME.

Haley Zarrin, BA, CD(DONA), is a clinical research assistant in the Center for Fetal Diagnosis and Treatment, Children’s Hospital of Philadelphia, Philadelphia, PA.

Aimee L. Coursey, BSN, RNC-OB, is a registered nurse and clinical nurse expert in the Garbose Family Special Delivery Unit, Children’s Hospital of Philadelphia, Philadelphia, PA.

David A. Munson, MD, is an associate professor in the Perelman School of Medicine, University of Pennsylvania; Medical Director of the Harriet and Ronald Lassin Newborn/Infant Intensive Care Unit, Children’s Hospital of Philadelphia; and an attending neonatologist, Children’s Hospital of Philadelphia, Philadelphia, PA.

authors (Leuthner & Lamberg-Jones, 2007; Sumner, 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 multidisciplinary 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; Kowalcek, Muhlhoff, Bachmann, & Gembruch, 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

متن کامل مقاله

دریافت فوری ←

ISIArticles

مرجع مقالات تخصصی ایران

- ✓ امکان دانلود نسخه تمام متن مقالات انگلیسی
- ✓ امکان دانلود نسخه ترجمه شده مقالات
- ✓ پذیرش سفارش ترجمه تخصصی
- ✓ امکان جستجو در آرشیو جامعی از صدها موضوع و هزاران مقاله
- ✓ امکان دانلود رایگان ۲ صفحه اول هر مقاله
- ✓ امکان پرداخت اینترنتی با کلیه کارت های عضو شتاب
- ✓ دانلود فوری مقاله پس از پرداخت آنلاین
- ✓ پشتیبانی کامل خرید با بهره مندی از سیستم هوشمند رهگیری سفارشات