ARTICLE IN PRESS

JOGNN

PRINCIPLES & PRACTICE

Ethical Considerations in Perinatal Palliative Care

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Keywords
clinical ethics
organ donation
perinatal bereavement
perinatal palliative care
shared decision making

ABSTRACT

Clinicians may face new ethical considerations when parents continue pregnancies after receiving life-limiting fetal diagnoses and desire palliative care. In this article we present four ethical considerations in perinatal palliative care: ambiguous terminology in relation to diagnosis or prognosis, differences between bereavement support and palliative care, neonatal organ donation, and postdeath cooling. In this article, we enable readers to consider current topics from different perspectives and reflect on care when confronted with sensitive clinical scenarios.

JOGNN, ■, ■–■; 2017. http://dx.doi.org/10.1016/j.jogn.2017.01.011

Accepted January 2017

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The boundary of palliative care has enlarged to include the needs of parents who are given a prenatal diagnosis of a life-limiting fetal condition (LLFC). An LLFC is one in which the fetus is expected to die in utero or shortly after birth. Clinicians all over the world interact with parents who desire to continue such pregnancies, and it is estimated that between 37% and 85% of families make this choice (Wool, 2013). Perinatal palliative care (PPC) is an approach to health care services that addresses the needs of the fetus and parents beginning at the time of diagnosis and extending through the birth, through the possible death of the infant, and into the bereavement period. PPC can be incorporated simultaneously with curative and disease-oriented treatments throughout the continuum of care (Institute of Medicine, 2014). The World Health Organization (2014) addresses palliative care for children and (a) advocates for an active, holistic approach in caring for the child while providing support to the family, (b) recommends beginning care when the condition is diagnosed and continuing it regardless of curative interventions, and (c) endorses a multidisciplinary approach that partners with community members so care can be given in the home or in health centers. Like palliative care for adults, the World Health Organization specifies that palliative care for children should be aimed to prevent suffering and address the physical, psychosocial, and spiritual needs of patients and family members.

The range of options available to parents who face LLFCs is dependent not only on parental preferences, expectations, and values but also on the broader health care culture, legal implications, and national policy. Professional organizations in the United States recommend that, for parents facing unexpected outcomes from prenatal testing,

> Counseling should include family education and preparation; obstetric management recommendations, including fetal surveillance, intrapartum monitoring, and mode of delivery; referral to pediatric specialists and a tertiary care center for delivery, if appropriate; availability of adoption or pregnancy termination; and perinatal palliative care services and comfort care for delivery of a child with a diagnosis or fetal presentation that is expected to be incompatible with long-term survival. (American College of Obstetricians and Gynecologists & Society for Maternal-Fetal Medicine, 2016, p.10)

Countries outside the United States may lack PPC options or have other approaches to

The authors report no conflict of interest or relevant financial relationships.

The use of vague terminology fosters confusion and frustration in parents and opens the door for speculation about the prognosis of a fetus or infant.

management, but advocating for universal access to palliative care services is considered a global priority throughout the life span (World Health Assembly, 2014). Palliative care is universally accepted as a human right (Open Society Public Health Program, n.d.; Schmidlin, Haut-Léman, Blonay, & Oliver, 2015), and every woman should be given the option to continue a pregnancy with planned palliative care when a fetus has a life-limiting condition (Together for Short Lives, 2017a).

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The purpose of this article was to identify emerging topics in perinatal palliative care and reflect on their ethical implications. The complexity of PPC is centered on the fact that the pregnant woman opts for pregnancy continuation, on behalf of her fetus, who is expected to die while in utero or shortly after the birth. The fetus is a fully dependent entity living protected inside the mother's uterus, and direct fetal interventions are rare. Until the birth, the palliative care focus is primarily on parents' emotional, psychosocial, and spiritual needs that include creating a safe place for parenting and supporting parents during the pregnancy. Additionally, clinicians share information and facilitate healthy coping by providing anticipatory guidance so parents can prepare for what is likely to transpire during the course of pregnancy and birth. The maternal–fetal dyad continues with prenatal care and is treated simultaneously during the pregnancy until birth occurs. After birth, the mother and newborn need physical care, including routine maternal postpartum and lactation support and education. Infant curative and palliative care interventions can coexist, and the transition to end-of-life (EOL) care is focused on emerging neonatal symptom control. Emotional and spiritual support continues for the mother, father, siblings, and other family members.

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Background

The Web site PerinatalHospice.org is an important international clearinghouse of information for providers and parents. The site was started in 2006 by Kuebelbeck, a journalist and parent advocate. To date, 280 PPC programs representing 22 countries are listed on the Web site. One aspect of the site is the opportunity to network through a private listserv of more than 400 members from all over the world who are parent advocates, clinicians, and researchers. The listserv provides interested parties with a platform to discuss policies and guidelines related to PPC, including sharing information about program start up, components of care delivery, and international educational opportunities. Occasionally, new or controversial ideas are presented on the listserv. Four complex issues were introduced and discussed in the first half of 2015. Content analysis of all of the listserv comments was conducted, and this represented the start point of ethical reflection. In this article, these four topics are defined and summarized, and insights about the ethical implications that surround them are offered.

Ethical Issues

Ambiguous Terminology

With technological advances and routine pregnancy follow up, it is now possible to diagnose a wider range of LLFCs and extrapolate prognostic considerations (Kidszun et al., 2016). However, sometimes clear prognostic information is not possible or is inconclusive until after birth. Given the breadth of organ system involvement and symptom severity that exists even with well-recognized syndromes, parents and providers need to honestly address and prepare for the range of outcomes that may exist at or after birth (Kidszun et al., 2016). Prognostic uncertainty can be seen as an invitation to begin difficult conversations, explore goals of care with families, and introduce a palliative care approach, but, in fact, prognostic uncertainty is one of most important referral barriers to a PPC program (Tosello et al., 2015).

The language and terminology that surround prognostication must be treated delicately and with importance. Ethically, clinicians must approach difficult conversations with veracity, compassion, and sensitivity. Communication is complicated by a lack of clearly defined terms. The variance in parental perceptions may result in a layered complexity in discussions of fetal prognosis. The use of broad labels such as *lethal malformation*, *fatal,* or *incompatible with life* conveys a hopeless prognosis and may be perceived by parents as disrespectful to their infants' lives. Whether because of chance, biology, medical interventions, or limitations of fetal surveillance or provider expertise, there are times when neonates unexpectedly survive.

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