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Facilitating Milk Donation in the Context of Perinatal Palliative Care

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ABSTRACT

The option to donate milk within the context of perinatal palliative care allows pregnant women to be involved in medical decision making before birth. In this article we examine how a perinatal bereavement program engages women and families in the process of milk donation when the deaths of their newborns are anticipated. We include two case examples to offer insight into the complexities within the patient experience of milk donation after perinatal loss.

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Milk banks operated by the Human Milk Banking Association of North America (HMBANA) are nonprofit entities that rely on mothers who are breastfeeding and/or pumping for their own children and have excess breast milk to share. Mothers undergo rigorous screening processes and laboratory testing to determine eligibility as donors. Milk is mixed from multiple donors, heat-treated, serologically screened, and bacterially cultured after pasteurization (Jones, 2003).

Azema and Callahan (2003) studied the motivations of donors and found that the two most commonly reported reasons for milk donation were an excess of milk that the donors did not want to waste and a desire to help others. A sense of altruism was identified as an important motivating factor for prospective donors in other studies as well (Alencar & Seidl, 2009; Azema & Callahan, 2003; Osbaldiston & Mingle, 2007). The decision to donate milk to a human milk bank is also influenced by the information women receive from providers during and after their pregnancies (Pimenteira Tomaz et al., 2008). Health care professionals can provide education to dispel myths, quell a woman's worries, and answer questions regarding the process and use of donor milk (Osbaldiston & Mingle, 2007; Pimenteira Tomaz et al., 2008).

Bereaved mothers are an emerging subgroup of donors to milk banks. When expectant parents are informed that their fetuses have life-threatening diagnoses, some may choose perinatal palliative care support at birth. In preparation for birth and death, families can determine how they would like to spend the limited time with their newborns, which may include breastfeeding. As part of their grieving processes, some women may choose to donate milk during the postmortem period. Lactation has strong value and meaning for many bereaved mothers (Welborn, 2012). Unfortunately, research and international policy discussions on the subject of breast milk donation before and after infant death and the role of human milk banks is scarce (Carroll et al., 2014). Nonetheless, collaboration with lactation professionals is essential to support mothers and families during the palliative care process (Spatz, 2016).

The purpose of this article is to examine milk donation in the context of perinatal palliative care.

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It is critical that pregnant women, including those carrying fetuses with life-threatening diagnoses, have the opportunity to make informed decisions about milk donation.

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Health care professionals are the primary sources of information about HMBANA milk banks and the process of becoming a milk donor. It is critical that pregnant women, including those carrying fetuses with life-threatening diagnoses, are able to make informed decisions about milk donation and understand how this process may become part of their perinatal palliative care birth plans. We also provide a model for other institutions that work with expectant mothers who anticipate the deaths of their newborns before or shortly after birth. We provide guidance on how to incorporate milk donation into the perinatal palliative care birth plan and offer two case examples from interviews with mothers that illustrate their experiences to better inform clinical care. Finally, we provide recommendations for clinical practice and future research.

The Center for Fetal Diagnosis and Treatment

The Center for Fetal Diagnosis and Treatment (CFDT), located at The Children's Hospital of Philadelphia (CHOP), is a specialized diagnostic and high-risk fetal center for healthy women carrying fetuses with congenital anomalies. Fetal diagnosis, ongoing prenatal care, and birth occur within CHOP to keep women, families, and newborns together (Howell, 2013). Each year, approximately 450 to 500 women carrying fetuses with birth defects and/or complex medical and genetic conditions give birth on the Garbose Family Special Delivery Unit (SDU).

Approximately 8% of the SDU's annual birth volume consists of palliative care births supported by the CFDT's Perinatal Palliative Care and Bereavement Program. Providers partner with expectant mothers and their families to develop individualized, seamless, and compassionate care plans that address their emotional, social, and familial needs (J. C. M. Cole et al., 2017). 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). 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. More detailed information about the program is described elsewhere (J. C. M. Cole et al., 2017).

Improvements in prenatal diagnostic techniques have expanded options for families who face pregnancies complicated by fetal anomalies. Some conditions may be improved with fetal or neonatal interventions (Adzick et al., 2011; Rychik et al., 2016). On the other hand, confirmation of a life-threatening diagnosis can allow families time to prepare for an anticipated loss. In such cases, the use of perinatal palliative care consultations allows families to engage in medical decision making and birth planning for their neonates. Collaboration with the medical care team positively affects the perinatal bereavement experience and can provide the necessary context for lactation support if a woman chooses to engage in milk donation in the postmortem period (Kendall & Guo, 2008; Spatz, 2016).

The Prenatal Care Visit

Regardless of the expected neonatal outcome, every woman seen in the CFDT meets with an advanced practice provider (APP; e.g., a women's health nurse practitioner or a certified nurse-midwife). During a woman's transfer-of-care visit, the APP obtains a detailed history of her pregnancy and previous prenatal care and medical, surgical, family, and social history. The APP also reviews in detail with the woman and her family the structure of outpatient prenatal care within the Center and takes them on a tour of the SDU where the birth and postpartum care will occur. Based on the recommendations of the maternal–fetal medicine and obstetric teams, the APP reviews the schedule for prenatal visits, follow-up ultrasonography, and consultations needed during the remainder of the pregnancy. During this discussion, the APP arranges for each woman and her family to have a personalized neonatal nutrition/lactation consultation as a standard of care before birth.

Women are informed that during the postpartum period, those who produce more breast milk than their newborns need can donate the surplus to the CHOP Mother's Milk Bank (MMB). All families planning births with perinatal palliative care support have the opportunity to discuss decisions about mode of birth, memory making, and milk donation. Providing women with a choice about lactation can be empowering during a time of grief (M. Cole, 2012). For some women, lactation

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