JOGNN

IN FOCUS

Making Meaning of Pumping for Mothers of Infants With Congenital Diaphragmatic Hernia

Elizabeth B. Froh, Janet A. Deatrick, Martha A. Q. Curley, and Diane L. Spatz

Correspondence
Elizabeth B. Froh, PhD, RN, The Children's Hospital of Philadelphia, Office 2W78, 34th Street and Civic Center Blvd., Philadelphia, PA 19104.
frohe@email.chop.edu

Keywords
human milk
oral care
mouth care
neonatal intensive care unit
breastfeeding
congenital diaphragmatic hernia

ABSTRACT

Objective: To describe the process of initiation and maintenance of milk supply and potential transition to direct breastfeeding among mother/infant dyads with infants with congenital diaphragmatic hernia (CDH).

Setting: A Level-III neonatal intensive care unit.

Participants: Eleven mother/infant dyads with infants with CDH.

Methods: Prospective, longitudinal qualitative descriptive design. Semistructured interviews were conducted over the course of the NICU stay. Conventional content analysis was used.

Results: Human milk oral care emerged from the interview data as a strong facilitating factor to encouraging mothers to continue pumping during hospitalization. Four main themes emerged regarding the importance and value of human milk oral care for the mothers in relation to pumping and maintenance of milk supply: (a) *It motivates me*; (b) *I'm a part of my baby getting better*; (c) *We do it together*, and (d) *We're getting somewhere*.

Conclusions: The findings of this study reflect the importance and value of human milk oral care as a driving factor to motivate mothers to maintain milk supply during the critical time when the infant with CDH is not able to take in enteral nutrition and throughout the hospital stay.

JOGNN, 44, 439-449; 2015. DOI: 10.1111/1552-6909.12564

Accepted October 2014

Elizabeth B. Froh, PhD, RN, is a clinical supervisor, Lactation Team and Human Milk Management Center, The Children's Hospital of Philadelphia, Philadelphia, PA.

Janet A. Deatrick, PhD, RN, FAAN, is the Shearer Endowed Term Chair in Healthy Community Practices professor of nursing, University of Pennsylvania School of Nursing, Philadelphia, PA.

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Congenital diaphragmatic hernia (CDH) is a congenial anomaly in which there is an anatomical malformation of the diaphragm in which the visceral abdominal contents herniate into the thoracic cavity via a discontinuity of the musculature of the diaphragm. The prevalence of CDH is one case in every 2,000 to 4,000 live births, a similar prevalence to spina bifida (Colvin, Bower, Dickinson, & Sokol, 2005; Gallot et al., 2006; Mah, Chiu, & Kim, 2011; Peetsold et al., 2010). Medical and surgical advancements have contributed to improved survival rates with mortality rates now estimated between 30% and 50%. In the United States, newborn infants diagnosed with CDH are immediately separated from the mother and following stabilization are subjected to multiple medical and surgical interventions. Many of these interventions require the withholding of enteral nutrition.

An abundance of literature exists regarding the health benefits of human milk for vulnerable infants. However, outside of case reports, the science surrounding the relationship of human milk and/or breastfeeding for the mother/infant dyad with an infant with CDH is limited (Spatz, Raphael, & Froh, 2012). Most commonly, infants with CDH are affected by respiratory morbidities (respiratory distress, 68.8%) and gastrointestinal morbidities (gastroesophageal reflex disease, 27.8%), both of which are shown to decrease when an infant (healthy or preterm) receives human milk instead of artificial nutrition (Abdullah et al., 2009; American Academy of Pediatrics Section on Breastfeeding, 2012; Ip et al., 2007). The relationship between a human milk diet and the associated morbidities of the infant with CDH has been examined, and the authors described how a human milk diet may significantly affect the health outcomes (short- and long-term morbidities) of this infant population (Froh & Spatz, 2012).

For the mother who desires to breastfeed her infant, the diagnosis of CDH presents several barriers. An essential component to providing a human milk–based diet revolves around the mother of the

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

All of the mothers felt included in their infant's care and knew that oral care could only be done if they had fresh milk to use.

infant with CDH initiating and maintaining lactation during the hospital stay and postdischarge. Following the birth of the infant with CDH, the mother and infant are immediately separated from one another. In the case of an undiagnosed CDH, if the birth hospital cannot manage the infant's diagnosis, the infant is transported to a facility that has a Level-III NICU with the capabilities to care for the infant. Of particular concern, the treatment modalities required necessitate that the infant with CDH not be stimulated for prolonged periods of time. Therefore, mothers of infants born with CDH may not touch or hold their infants for days to weeks. Furthermore, depending on the treatment modalities used, it may be days to weeks before an infant is able to receive enteral feeds.

Human milk oral care is a process by which fresh human milk is applied to the oral mucosa of the infant with a swab (Rodriguez, Meier, Groer, & Zeller, 2009). In doing so, the healthy breastfeeding infant/mother dyad is replicated. The components of human milk, such as proteins, amino acids, cytokines, lactoferrin, and secretory immunoglobulin A, work to protect the infant by lining the mucosa of the orogastric and respiratory tracts and warding off pathogenic bacteria (Lawrence & Pane, 2007; Rodriguez et al., 2009).

The science surrounding the clinical implementation of human milk oral care continues to emerge. In a recent synthesis, Gephart and Weller (2014) concluded the practice of human milk oral care poses little to no risk and is cost-effective, safe, feasible, and well tolerated by preterm infants. However, in the available published research, none of the infants had congenital anomalies, and all of the study samples comprised preterm infants (McFadden, 2012; Montgomery, Baer, Lanbert, & Christensen, 2010; Rodriguez et al., 2010, 2011). Additionally, the published research is focused on the immediate benefits of human milk oral care to the hospitalized infant.

The experience of having an infant with CDH may or may not be similar to the experiences of mothers of preterm infants hospitalized in the NICU. It is unknown how a mother of an infant with CDH is able to initiate lactation and maintain her milk supply in the context of the hospitalization period. The aims of this study were to describe the mother's experience surrounding the initiation of lactation via expression and/or mechanical pumping and the process of transitioning to direct breastfeeding from her perspective, describe facilitators and barriers that influence the mother's decisions to initiate and continue breastfeeding throughout the hospital stay, and describe the mother's subsequent emotions related to initiating and maintaining lactation and potential transition to direct breast feeds during hospitalization.

Martha A. Q. Curley, PhD, RN, FAAN, is the Ellen and Robert Kapito professor in nursing science, University of Pennsylvania School of Nursing, Philadelphia, PA.

Diane L. Spatz, PhD, RN-BC, FANN is a professor of perinatal nursing and the Helen M. Shearer Professor of Nutrition at the University of Pennsylvania School of Nursing and is a nurse researcher and the director of the Lactation Program, Children's Hospital of Philadelphia, Philadelphia, PA.

Methods

A prospective, longitudinal, qualitative, descriptive design was chosen for the study to better understand the lactation experiences of mothers of infants diagnosed with CDH and cared for in the NICU. With little known in this specific area of inquiry (provision of human milk and/or breastfeeding the CDH infant), qualitative descriptive design allowed us to draw from naturalistic inquiry with no a priori commitment to any one theoretical view. The initiation of lactation and potential transfer to direct breastfeeding among mother and infant dyads with infants with CDH was studied in its immediate natural state: the NICU. The University of Pennsylvania and the hospital's Institutional Review Boards approved the study.

Sample and Setting

Purposive sampling for phenomenal variation was used to enroll mother/infant dyads of various ages, parity, ethnicity, prior breastfeeding experience(s), time of prenatal diagnosis of CDH, and position of the infants' CDH (Table 1) (Coyne, 1997; Sandelowski, 1995). Eleven dyads were recruited from a 95-bed Level-III NICU in a large northeastern urban children's hospital. Inclusion criteria included all mothers of infants with CDH age 21 years or older (due to the age parameters of children defined by the National Institutes of Health) who made a decision to initiate pumping. The informants were English speaking due to the design and methodologies of the study. Exclusion criteria were defined by the American Academy of Pediatrics (AAP) for conditions that would prohibit a mother from giving her child human milk (mothers who are HIV positive, use illicit street drugs, positive for human T-cell lymphotropic virus type I or II, have untreated tuberculosis, or untreated brucellosis) (American Academy of Pediatrics Section on Breastfeeding, 2012).

The setting for the study is unique in that it serves as an international referral center for a prenatal diagnosis of CDH. Within this children's hospital