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Title: *"It's like you're feeding your child twice." Barriers and facilitators to human milk feeding children with cystic fibrosis*

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Running Head: Human Milk Feeding Experiences in Early CF care

Abstract

Background: Cystic Fibrosis Foundation guidelines recommend human milk (HM) as the ideal source of nutrition for children with CF (cwCF). Despite known pulmonary and nutritional benefits, fewer cwCF ever receive HM compared to the general population. Early nutrition choices are preference-sensitive, yet little is known about the factors that impede or sustain HM feeding among parents of cwCF.

Objectives: Explore perceptions and experiences of mothers of cwCF who initiated HM feeding.

Methods: Mothers of cwCF aged ≤10 years completed audio-taped, semi-structured interviews describing their experiences with HM feeding. Interviews were transcribed

This is the author manuscript accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1002/ppul.27497.

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and two researchers independently coded the transcripts and conducted content and thematic analysis using an inductive approach.

Results: Participants included 28 mothers who initiated HM feeding. Major themes included 1) the impact of a CF diagnosis on HM feeding plans 2) CF-specific challenges to HM feeding 3) mixed perceptions of the CF care team's support for HM feeding and of the role of formula in CF nutritional care and 4) the benefit of lactation consultants as part of the CF care team.
Conclusion: Many parents prioritize HM for their cwCF given the well-established health benefits. However, CF-specific barriers to HM feeding are common and nutritional challenges necessitating fortification add additional barriers to sustained HM feeding efforts. While HM may improve long-term pulmonary outcomes, our findings demonstrate the need for personalized support for mothers desiring to HM feed to facilitate shared decision-making around options to optimize early nutritional status among cwCF.

Keywords: cystic fibrosis (CF); HM; pediatrics; caregiver; decision-making

Abbreviations:

CF = cystic fibrosis; cwCF = children with CF; human milk = HM; Cystic Fibrosis Foundation=CFF

Word count: 240

1. Introduction

Human milk, or breastmilk, is recommended as an ideal source of nutrition for children with CF (cwCF) for the first six months of life.[1–3] Human milk (HM) has antimicrobial, anti-inflammatory, and immunomodulatory properties, and cwCF who receive HM have reduced rates of lung infections requiring intravenous antibiotics,[4,5] increased time to first CF exacerbation,[6,7] and similar or decreased rates of *Pseudomonas aeruginosa* acquisition[7,8] compared to cwCF who are exclusively formula fed. Despite the known benefits, there are many well-established barriers to HM feeding for both mothers and babies, including limited and unpaid parental leave, rigid work schedules, and lack of workplace support for expressing HM.[9] Additional challenges exist for parents of children with chronic diseases who wish to HM feed, including increased medical responsibilities, providing HM to hospitalized infants, and stress related to an unknown disease course.[10,11] Therefore, unsurprisingly, only 50-70% of cwCF ever receive HM,[4,6,12] as compared to 83% of the general population.[12,13] By 6 months of age most cwCF exclusively receive formula or either supplement or fortify HM with formula, and rates of exclusive formula feeding increase regardless of exocrine pancreas function by 12 months.[12,13]

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While concerns about providing enough HM to meet a growing infant's nutritional demands are common among chestfeeding parents,[*14] families of cwCF face additional pressures to optimize nutritional status as growth trajectories at or above the 50th percentile are associated with improved health outcomes.[15,16] Given the frequency of nutritional challenges in early CF care and known parental stress associated with not meeting CFF nutritional benchmarks,[17] we hypothesize these factors may impact rates of any HM feeding among cwCF. Recently, a prospective study by *Lai et al.* demonstrated that among cwCF requiring fortification, those receiving predominantly fortified HM at 6 months of age had less early onset lung disease than cwCF who predominately received fortified formula, with benefits persisting through age 3 years.[12] The authors suggested a proactive fortification of HM after CF diagnosis to minimize the risk of postnatal growth faltering and early-onset lung disease, but did not explore challenges to sustained HM feeding for cwCF.

Despite the known pulmonary and nutritional benefits of HM, and emerging evidence around potential benefits of early adoption of fortified HM, little is known about the experiences of chestfeeding parents of cwCF that may contribute to lower rates of initiation and sustained HM feeding. This study sought to explore: 1) preferences and individualized experiences of mothers of cwCF who initiated HM feeding 2) factors that impacted discontinuation of HM feeding and 3) perceived support from CF care teams for chestfeeding parents of cwCF.

2. Methods

We report this study following Consolidated Criteria for Reporting Qualitative Research guidelines.[18]

2.1 Participants and Recruitment

Between November 2019 and September 2020, we recruited English-speaking parents and primary caregivers (>18 years) of cwCF, aged 1-10 years. Recruitment has been previously described.[19] Additional inclusion criteria for this analysis included mothers who initiated HM feeding for their cwCF. Recruitment occurred at the Johns Hopkins Pediatric CF Center, with 4 other pediatric CF centers informing potentially eligible individuals about the study using IRB-approved recruitment materials and

[*]While all participants in the sample self-identified as mothers, gender-inclusive language in healthcare is important. The terms "human milk" and "chestfeeding" are gender-neutral alternatives inclusive to transgender and nonbinary individuals who could experience pregnancy and chestfeed. However, to accurately represent our data, we have maintained the term "breastfeeding" in all direct quotes.

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methods. Interested caregivers contacted the senior author, a post-doctoral pediatric pulmonary fellow with qualitative research training (K.M.D.) who obtained consent and conducted the interviews. The original study explored the influence of socioeconomic status (SES) on early CF nutrition. After conducting many of the planned 40 interviews, early feeding preferences and experiences, specifically around chestfeeding, emerged as a salient major theme, while there were no novel themes relevant to SES. This study was approved by the Johns Hopkins University Institutional Review Board (IRB00210225).

2.2 Data Analysis

All interview transcripts were content-analyzed for recurring themes in a ground theory method using NVivo Pro v.12 (QSR International). The study team (KMD, BMS, and KAR) defined initial codes via group consensus and the codebook was derived inductively. To ensure consistency, the study team met weekly to review emerging themes and co-develop the codebook. Next, KMD and BMS, also a post-doctoral pediatric fellow, independently coded transcripts, identified coding discrepancies, and resolved discrepancies via verbal discussion with KAR. Saturation was achieved for a theme when no new codes emerged in the prior five participant interviews. Final review of themes was completed by the team to ensure clarity of definitions.

3. Results

Forty-three primary caregivers were interested in participating; four fathers and three grandparents were excluded. Of the 36 mothers interviewed, 28 initiated HM feeding for their cwCF. Of the eight excluded mothers, two were adoptive parents, five mothers never planned to HM feed, and one was unable to do so due to personal medical issues. Most participants self-reported as White (n=25, 89%), 7% (n=2) as Black/African American, 4% (n=1) as Asian, and 4% (n=1) as Hispanic. Six mothers (21%) had more than one cwCF, and 32% (n=9) met with a lactation consultant after their cwCF's birth. Caregiver-reported demographic information of the cwCF is reported in **Table 1**. One interview included a spouse for a portion of the interview, otherwise non-participants were not present. The interviews lasted an average of 40 minutes (range 17-69 minutes). All enrolled participants completed the study, and none dropped out after screening.

We identified four main themes related to early feeding choices in CF care. Representative quotations are included below. Quotations have been selected to be representative of the diversity of participants and perspectives.

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3.1 CF diagnosis can change "the plan"

Many mothers expressed an initial desire to exclusively HM feed, including exclusively chestfeed. "*I was hoping that he would be completely breastfed and that it would be successful.*" (Participant 7) Most mothers viewed HM as the ideal early feeding option "*it was just something I really wanted to do just as a mom, because breast is best"* (Participant 20) and many mothers wanted to provide their cwCF with HM due to the perceived health benefits for cwCF. *"We were just fully committed to breastfeeding her to make sure she had that strong immune system and all the goodness from milk*." (Participant 15) Notably, knowing a child's CF diagnosis prenatally solidified one mother's desire to chestfeed. "*I think being able to prepare for what we were going to experience really helped me to be aware of things that were going to benefit him…I became very much more invested in breastfeeding because I knew that weight challenges could be an issue, it was always on the forefront of my radar*." (Participant 19)

Conversely, several mothers expressed that after their child's CF diagnosis, they no longer viewed exclusive HM feeding as the best option. "*I did it (chestfeed) at first before they diagnosed him with CF…but then after I found out about everything, with him having CF, I didn't really care...even though breast milk would be the best…I just felt [formula] looked like it was better for him*." (Participant 40) A few mothers reported combination feeding their cwCF before their diagnosis, however the diagnosis of CF prompted them to stop all HM. *"Before her diagnosis, it was a combination. And then after, it was just formula…when she got her diagnosis, she needed the extra calories… it was better to just go straight to formula.*" (Participant 6) For many, the decision to transition to formula was difficult, requiring consideration of both their cwCF's needs and their own. "*I was just going to try and be the best mom I could…I really imagined myself trying to breastfeed longer, but it just didn't seem like that was really what he needed or really what I needed*." (Participant 3) One mother described feeling stigmatized by her decision to stop chestfeeding. "*In the Latino community, it's such a stigma, like "oh you can't breastfeed?"…but I didn't let that get to me because I was already on another worry, like this guy has CF, that's my main concern*." (Participant 22)

3.2 CF-specific challenges to HM feeding are common and stressful

Nearly 90% of the cwCF in our study had pancreatic insufficiency requiring pancreatic enzyme replacement therapy (PERT) with each feeding to address malabsorption and support weight gain. Many mothers noted that dosing of PERT added

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stress to chestfeeding. "*Since I was breastfeeding, you can't really measure the amount [of HM] that they were getting, so it was hard. Do I need to give him just a quarter of a cap…when he wasn't really staying awake and eating a whole lot, it was hard to tell, do I need to give it to him*?" (Participant 2) One mother noted giving PERT with each chestfeeding session was challenging. "*When she started to take enzymes, it was a little bit frustrating. They [CF care team] wanted her to have enzymes with every breastfeeding session, which was near impossible because they would happen in the middle of the night and kind of dream-feeding, and to wake a sleeping baby to shove enzymes in their mouth was not the easiest thing*." (Participant 15)

Many mothers started expressing HM, or pumping, soon after their cwCF's diagnosis, to better assess their cwCF's intake and ensure they were meeting their increased caloric needs. *"I started pumping instead of breastfeeding so that I would know how much she was getting and just for peace of mind that I could tell them [CF care team] she drank this many ounces."* (Participant 33) The ability to provide their cwCF with HM through pumping was viewed by some mothers as worth the effort, despite the challenges. *"I'm pumping like a maniac at the hospital [child had meconium ileus] because that was the one thing that I felt like I could control and help her with…even though I was getting such a little amount out, it meant the world to me*." (Participant 39) However, balancing the demands of caring for their cwCF and pumping was difficult. One mother was successful in exclusively pumping for one year but noted "*it's so time-consuming…it's like you're feeding your child twice, because first you're pumping and then you give them what you pump…I would not be able to do that if she was my second child*." (Participant 20). Several stated that the burden of pumping became unsustainable. "*They [CF care team] were encouraging that I was doing a good job pumping, but they could tell that I was getting worn out.*" (Participant 16) Many women identified pumping as a major factor in their decision to stop providing HM to their cwCF. "*I personally couldn't keep up with pumping…So it was just better just to go straight to formula*." (Participant 6)

3.3 CF care team feeding recommendations: supportive but may be perceived as pressure

Overall, most mothers felt supported by their CF care teams to HM feed. "*The doctors were very understanding that I had originally wanted to continue breastfeeding…they were supportive in ways that I could do that*." (Participant 4) Notably, a few mothers perceived the messaging around HM feeding added stress to

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their cwCF's nutritional challenges. "*They [CF care team] were a little too supportive…because it becomes pressure. And it's "this is the best way, if you can't do it this way, I guess we'll go another way*." (Participant 38) Additionally, several mothers acknowledged the benefit of CF care teams providing anticipatory guidance about the potential to supplement with formula. "*They [CF care team] were really supportive of breastfeeding, but they were also very realistic in terms of "You might need to supplement with formula. You can do both, and that's perfectly acceptable and not lose the calories in your own breast milk." It just really helped the perception of it all*." (Participant 42)

For many mothers, fortifying HM or supplementing with formula relieved stress related to the weight trajectory of their cwCF and was commonly viewed as "*a nice support where it doesn't make you feel like a failure but also, able to meet the needs of your baby*." (Participant 42) Some found the addition of formula provided practical advantages over exclusive chestfeeding. "*I nursed for the first six months. But I didn't produce enough, so I had to supplement, which was actually great because it helped adding her medicines and [salt] because I could hide it in the bottle*." (Participant 23) However, for many mothers who planned to exclusively HM feed, the recommendation to supplement or fortify with formula was challenging. "*I just burst into tears. It was just not what I wanted to hear. But ultimately, it's what we had to do because it was better for him and I eventually just abandoned trying to feed him breast milk…breast is best really messed with my head a lot.*" (Participant 24) Another noted *"I was super-against it…Don't ever say that to me. I work so hard to breastfeed. This is such a struggle. I want to continue doing this*." (Participant 35) Mothers recognized that recommendations to consider formula to increase calories were made to improve nutritional status, however some felt it affected their relationship with their CF care team. *"[CF care team] said "You might want to stop breastfeeding because he could have more calorie intake…it kind of hurt my feelings a little bit, because I was like, "I'm sorry. He's too young. Up to six months to a year. That's what you do." I mean, let's point out that God didn't make breastmilk for no reason...they could tell that it kind of bothered me a little bit*." (Participant 21)

3.4 Lactation consultants play an important role in the CF care team

Lactation consultants (LC) were predominantly seen as a source of support for chestfeeding mothers, particularly for mothers who were exclusively pumping. "*Having that lactation consultant really kept me encouraged to do what I can, and just even that*

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message of "a little bit of breast milk is better than no breast milk," kind of thing… to really keep encouraging and helping us with the whole pumping only kind of thing." (Participant 42) Unfortunately, it was difficult for many mothers to find continued LC support after hospital discharge. "*When we were at the hospital with my CFer, there were lactation consultants there, but then they just send you home…nobody hooks you up with a lactation consult."* (Participant 34) Notably, some mothers interacted with LC who were not knowledgeable about CF. *"My LC was, "No, breast is best, breast is best"…just pushing it and not really taking into consideration his health needs and growth needs with his disease… It was awful." (*Participant 24*)* While not all LC will have experience with CF, experience with failure to thrive was viewed as beneficial. "*She didn't have experience specifically with CF, but she did have experience with kids who had failure to thrive, which helped.*" (Participant 35)

Most mothers wished their CF center included LC as part of the multi-disciplinary care team during clinic visits. "*They [CF care team] never said "Let's bring a lactation consultant in on a clinic day"…that honestly would have been so helpful.* (Participant 20). One mother wished LC support was better incorporated into early CF nutritional counseling. *"I wish that they [CF care team] just would've educated me more on how to increase my breast milk supply, from the clinic itself...since I was the nutrition for the baby, focusing on my nutrition, focusing on how I could make my milk fatty or ways to pump, things like that.*" (Participant 7)

4. Discussion

Emerging research has demonstrated pulmonary and nutritional benefits of sustained HM feeding for cwCF in the first year of life.[12] Despite these important potential benefits, there are lower rates of HM feeding among cwCF compared to their peers. To our knowledge this is the first study to explore parental experiences with HM feeding for cwCF, including motivations and reasons for discontinuation. While many cwCF exclusively chestfeed or never initiate fortification, our results demonstrate significant challenges to exclusive or sustained HM feeding of cwCF, including the burden of expressing HM to facilitate fortification, difficulties with administration of PERT, and difficulty identifying lactation support with CF-specific knowledge. These findings illustrate that mothers wishing to HM feed their cwCF would benefit from tailored support to reach their personal HM feeding goals, as well as support when their preferences evolve as their cwCF grows or if nutritional challenges develop. To best provide this

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support, CF providers should assess parental feeding preferences and goals, provide tailored anticipatory guidance surrounding the unique barriers to HM feeding for cwCF and partner with families to navigate challenges. Lastly, our findings highlight the importance of acknowledging the emotional, physical, and logistical toll that CF-specific nutritional recommendations may have on chestfeeding mothers.

Within our study, maternal views on HM feeding commonly aligned with CFF guidelines as the "best" initial option for cwCF, with some mothers noting that the diagnosis of CF increased their motivation to HM feed due to the known health benefits.[20] The majority of parents felt their CF care teams supported HM feeding, which mirrors findings from a survey of CF center directors and mothers with CF regarding HM feeding practices.[21] Importantly, a few mothers perceived that their CF care team's promotion of HM and the concept of "breast is best" added pressure to their cwCF's nutritional journey. Emerging data has demonstrated similar pulmonary and nutritional outcomes among cwCF without growth challenges who received exclusive non-fortified formula or exclusive non-fortified HM,[12] and our findings highlight the need for care teams to be mindful of the impact of early feeding recommendations on parents as pressure to HM feed for mothers who are unable to or do not desire to has been associated with negative perceptions of mothering abilities,[22] which may impact the therapeutic alliance. While two mothers in our study exclusively HM fed for 12 months, nearly all cwCF in our study received formula, either supplemental or fortified feeds, by three months of age. Presently, the median age of diagnosis for cwCF is 3 months,[16] and thus it is important to acknowledge how a CF diagnosis and accompanying medical advice may change feeding preferences and practices. For many mothers, modifications to their preferred feeding plan evoked mixed emotions, including guilt and sadness that they were not able to feed their child in the way they imagined. For some mothers, the recommendation to introduce formula led to conflict with their care teams. This emotional discord has broader implications for early CF care, as not meeting chestfeeding goals is associated with increased rates of maternal depression and grief.[23] Overall, our findings demonstrate that most parents have feeding preferences that are established before their first appointment with their care team. While a CF diagnosis may solidify or change these preferences, care teams should routinely assess feeding preferences and goals from the earliest visits to inform nutritional recommendations and support shared decision-making if nutritional challenges arise. Acknowledging the potential emotional impact of changing plans is important and can allow for a greater sense of partnership

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between chestfeeding parents and care teams, which can foster co-production of other important decisions in their cwCF's care.

Our study uncovered several CF-specific barriers to sustained HM feeding of cwCF. Study participants noted that the need to provide PERT with each feeding is logistically challenging and stressful, due to inconsistent feeding schedules and uncertainty regarding milk intake with chestfeeding. These findings support prior studies demonstrating rates of HM feeding are higher among cwCF who are pancreatic sufficient,[6] which differed from findings by *Lai et al.* Given concerns about milk supply, many mothers reported initiation of pumping soon after their cwCF's diagnosis to closely monitor intake given concerns about weight gain or to be able to fortify their milk. Several mothers viewed the efforts needed to sustain pumping as worthwhile, but pumping commonly added another significant stressor for already overwhelmed mothers. Given that HM must be expressed prior to being fortified, many mothers described feeling that they were "feeding their cwCF twice". This additional burden, on top of other CF treatments, contributed to discontinuation of any HM feeding for many mothers in our study. Additionally, many mothers expressed perceptions that formula would better meet their cwCF's nutritional needs when nutritional challenges arose. *Lai et al.* suggest that proactive fortification of HM may be the ideal feeding plan for cwCF to minimize the risk of postnatal growth faltering and early-onset lung disease. However, our findings suggest it is possible that recommendations to pre-emptively fortify HM, may contribute to unneeded stress and added pressure on chestfeeding mothers that could ultimately decrease rates of HM feeding. Given the unique feeding challenges faced by chestfeeding parents of cwCF and the inability to predict growth trajectories in CF,[24] care teams should strive to support the efforts of mothers desiring to exclusively HM feed while also providing anticipatory guidance on the potential role of fortification of some HM feeds and/or supplementation to ensure families feel supported as the needs of their cwCF and family evolve.

Finally, mothers in our study who worked with a knowledgeable LC viewed this support as a positive experience that helped sustain efforts to provide HM to their cwCF. These findings support prior research demonstrating a professional support system, such as an LC, is associated with greater rates of initiation and maintenance of HM feeding through age 6 months.[25,26] Unfortunately, many parents had difficulty accessing LC, or worked with those who were not knowledgeable about the needs of cwCF. A few parents identified that the availability of a LC in CF clinic would have been beneficial to

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support their goal to HM feed. Notably, Miller at al. found a significant increase in duration of any chest feeding of cwCF when hospital-based international board-certified lactation consultants (IBCLC) were incorporated into early CF care.[27] Taken together, these findings suggest that knowledgeable postnatal lactation support is effective and desired by families of cwCF. Support for CF dietitians/nutritionists or international equivalent as well as other interested team members to receive Certified Lactation Counselor or IBCLC certification may help with early identification of modifiable feeding challenges and provide hands-on guidance on pumping or navigating PERT either in clinic or via telemedicine.[3,28] Additionally, given the increasing frequency of prenatal CF diagnosis, nearly 18% of cwCF in our study population were diagnosed prenatally, LC could potentially be included during prenatal consultations to help interested families prepare for potential barriers to initiating or sustaining HM feeding.

There are several strengths and limitations of this study. First, it was not advertised to be about HM feeding. While the need for caregivers to opt-in to participation may have led to over-enrollment of parents of cwCF with nutritional challenges during early childhood, it beneficially included caregivers with different perspectives and experiences with early nutrition choices and allowed HM feeding experiences to arise organically. Study participants were disproportionately mothers who identified as White, which may limit the generalizability of our results to all mothers of cwCF. Potentially relevant maternal health or demographic data was not obtained, and interviews did not ask about pre-pregnancy or pre-birth perspectives on chestfeeding, which may have elicited additional information regarding prenatal chestfeeding preferences. Finally, many interviewees were several years past the infant feeding period, which may have affected their recall of events and associated emotions. That noted, parents were eager to talk about their experiences and had strong memories of their perceived struggles and victories with chestfeeding.

HM feeding is the recommended first feeding option for cwCF, yet factors that prevent initiation or sustained HM feeding remain poorly understood. This qualitative study elicited perceptions and experiences of chestfeeding mothers of cwCF, explored the impact of a CF diagnosis on HM feeding preferences, and elucidated CF-specific challenges to sustained HM feeding. Our findings demonstrate the importance of eliciting parental preferences and goals related to early feeding options, the need for tailored support for CF-specific barriers to HM feeding, and the potential beneficial role of an LC as part of the CF care team. While “breast is best” may help some mothers sustain their

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HM feeding efforts, growth challenges remain common in early CF care and anticipatory guidance may need to evolve to recognize that fortified HM may be “the best of both worlds” for cwCF. Future studies are needed to evaluate the impact of shared decision-making when nutritional challenges arise in early CF care to support HM feeding efforts for as long as desired and beneficial for both the cwCF and their family.

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Table 1. Caregiver Report of Child's Characteristics

	(n =28)
Gestational Age	
≤ 36 weeks	5 (17.9)
≥ 37 weeks	23 (82.1)
Age at Diagnosis, N (%)	
Prenatally	5 (17.9)
≤ 4 weeks	17 (60.7)
After 4 weeks	6 (21.4)
Hospitalization After Birth, N=7	
Meconium Ileus	5 (17.9)
Congenital Anomaly	1 (3.6)
Prematurity	1 (3.6)
***CFTR* Genotype, N (%)**	
2 *F508* Variants	17 (60.7)
1 *F508* Variant	10 (35.7)
0 *F508* Variants	1 (3.6)
Pancreatic Status, N (%)	
Insufficient	25 (89.3)
Sufficient	3 (10.7)
Duration of human milk feeding, N (%)*	
Exclusive human milk feeding, 12 months	2 (7.1)
Any human milk feeding, 7-12 months	9 (32.1)
Any human milk feeding, 4-6 months	9 (32.1)
Any human milk feeding ≤ 3 months	8 (28.6)

*Exclusive human milk feeding information not available for all groups

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