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Evalotte Morelius
Edith Cowan University

Kajsa Kling

Eva Haraldsson

Siw Alehagen

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You can't flight, you need to fight—A qualitative study of mothers' experiences of feeding extremely preterm infants

Evalotte Mörelius PhD, RN, Professor^{1,2}  | Kajsa Kling RN³ | Eva Haraldsson RN³ |
Siw Alehagen PhD, RN, RM, Associate Professor³

¹School of Nursing and Midwifery, Edith Cowan University, Joondalup, Western Australia, Australia

²Perth Children's Hospital, Nedlands, Western Australia, Australia

³Division of Nursing Sciences and Reproductive Health, Department of Health, Medicine and Caring Sciences, Faculty of Health Sciences, Linköping University, Linköping, Sweden

Correspondence

Evalotte Mörelius, School of Nursing and Midwifery, Edith Cowan University, 270 Joondalup Drive, Joondalup, Western Australia 6027, Australia.
Email: e.morelius@ecu.edu.au

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Abstract

Aim: To describe mother's experiences of feeding their extremely preterm infant.

Background: When an infant is born extremely preterm, there is a long rocky road for the mother if she wants to breastfeed. Some manage to reach their goals, others do not. Studies of feeding extremely preterm infants in the neonatal intensive care unit (NICU) are scarce.

Design: A qualitative method with an inductive approach.

Methods: Nine mothers giving birth to extremely preterm infants were interviewed by telephone after discharge from the NICU. The interviews were transcribed verbatim and analysed with qualitative content analysis. The COREQ checklist was followed.

Results: The overall theme was "you can't flight, you need to fight." The theme reflects the mothers' will to do the best for their infants even if the struggle with milk expression and breastfeeding practice evoked feelings of helplessness, exposure, worry and disappointment. The categories forming the theme were as follows: The wish to provide own breastmilk; For the infant's best; Loss of control; and Help to reach the goals.

Conclusion: The mothers had a strong will to provide breastmilk to their infants but requested more support in order to be successful.

Relevance to clinical practice: There is a need for evidence-based support programmes for mothers of extremely preterm infants to encourage them to persevere with milk expression and breastfeeding over time.

KEYWORDS

breast milk, breastfeeding, lactation, milk expression, milk production, neonatal intensive care unit, parents, premature, preterm

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1 | INTRODUCTION

The World Health Organization (WHO) recommends human milk exclusively until the infant is six months old (WHO, 2018a). Whilst breastfeeding physiology is the same for mothers of full-term and preterm infants, the conditions are vastly different. Depending on several factors as gestational age at birth, health condition, possibilities to practice skin-to-skin contact and ethnicity, it may take many weeks before the preterm infant can fully breastfeed (Bonet et al., 2011; Maastrup et al., 2014a; Merewood, Brooks, Bauchner, MacAuley, & Mehta, 2006). During this time, the infant receives milk through a nasogastric tube, the mother expresses milk, and the dyad practice breastfeeding if the goal is to eventually breastfeed. Even though this time can last for several months when the infant is born extremely preterm, few studies focus exclusively on mothers of extremely preterm infants.

2 | BACKGROUND

After an unexpected birth, mothers are actively encouraged to stimulate lactation in order to initiate milk production through early and regular milk expression (Maastrup et al., 2014b). Expression within six hours of partus favours breastfeeding for mothers to preterm infants, while delayed initiation of milk expression negatively affects breastfeeding (Maastrup et al., 2014b). The reported proportions of mothers of preterm infants that initiate breastfeeding vary in the literature but have shown to be up to 99% (Maastrup et al., 2014a). The proportion is usually lower among infants born at a lower gestational age (GA) (Demirci, Sereika, & Bogen, 2013; Merewood et al., 2006). Bonet et al reported that less than 30% of the infants born extremely preterm (<28 weeks GA) received mothers' milk exclusively or partially at discharge from the neonatal intensive care unit (NICU) (Bonet et al., 2011). A report from Sweden shows a decline in the prevalence of exclusive breastfeeding among extremely preterm infants from 55%–16% between 2004– 2013 (Ericson, Flacking, Hellstrom-Westas, & Eriksson, 2016).

The benefits of human milk include better mental development, emotional regulation, and fewer re-hospitalisations when the infant is 30 months (Vohr et al., 2007), and greater neurological development at five years (Roze et al., 2012). Breastmilk also decreases the risk of necrotising enterocolitis in the NICU (Colaizy et al., 2016) and is associated with long-term health benefits such as lower risk of hypertension and obesity (Binns, Lee, & Low, 2016). Feeding is also a critical part of the relationship between an infant and its parents, an opportunity for closeness, interaction, and to give comfort and show affection (Ikonen, Paavilainen, & Kaunonen, 2015; Medina et al., 2018).

Antenatal stress is associated with premature birth (Staneva, Bogossian, Pritchard, & Wittkowski, 2015), and there is an increased risk for post-traumatic stress and postpartum depression symptoms among mothers of preterm infants (Beck & Woynar, 2017). Being a parent in the NICU is often described with feelings such as

What does this paper contribute to the wider global clinical community

- Breastfeeding rates are low especially among mothers of extremely preterm infants.
- This study describes mothers' experiences of expressing milk and practicing breastfeeding in the NICU when the infant is born extremely preterm.
- The mothers need more support to persevere with milk expression and breastfeeding practice during the long NICU stay associated with having an extremely preterm infant.

anxiety, distress, stress and worry (Abuidhail, Al-Motlaq, Mrayan, & Salameh, 2017; Kantrowitz-Gordon, Altman, & Vandermause, 2016). Still, mothers of preterm infants have described that their highest priority is to maintain sufficient milk production (Boucher, Brazal, Graham-Certosini, Carnaghan-Sherrard, & Feeley, 2011). The ability to believe in oneself and support have been described as important factors for mothers of preterm infants to maintain sufficient lactation (Swanson et al., 2012).

According to the World Health Organization, 15 million infants are born preterm (<37 weeks GA) every year. The survival rate of preterm infants depends on the GA and country of birth. In high-income settings, it is estimated that approximately 90% of extremely preterm infants survive the first days (WHO, 2018b). The one-year survival rate ranges from 6% (22 weeks GA)–94% (28 weeks GA) (Anderson et al., 2016). Extremely preterm infants are at higher risk of morbidity, are subject to advanced intensive care for survival and are usually not discharged before they reach the time of expected birth (Glass et al., 2015). Taken together, extremely preterm infants fight for survival at the same time as their mothers face a period of high stress and vulnerability, not knowing whether their infant will survive. Moreover, the breastfeeding process must start through early initiation of milk expression. Despite this difficult situation, there are few qualitative studies involving exclusively mothers of extremely preterm infants and their experiences of feeding their baby in the NICU. An understanding of this unique breastfeeding situation is crucial for developing good support and care for mothers and it might lead, ultimately, to a better feeding situation for the child. The aim of this study was to describe mothers' experiences of feeding their extremely preterm infant.

3 | MATERIALS AND METHODS

3.1 | Design

The design used was a qualitative method with an inductive approach.

3.2 | Setting

This study was performed in Sweden where parents have the right to longer paid parental leave than in many other countries, which promotes breastfeeding and breastfeeding duration. Parents are also allowed to take sick leave in order to stay with the infant in the NICU 24 hr a day. The nurses working in the NICUs provide breastfeeding support, and psychological support is available for parents in need.

3.3 | Inclusion criteria

The inclusion criteria were that the infant was born before the GA of 28 weeks, families had been discharged for a minimum of one month from the NICU prior to being interviewed or had been home for a maximum of 12 months at the time of the interview, and that the mother spoke Swedish. Exclusion criteria were mothers whose infants had been admitted to an additional hospital besides the hospitals included in the study.

3.4 | Procedure

Head of departments and nurse managers from the six NICUs that care for extremely preterm infants in Sweden were contacted to gain permission for the study and approval to contact potential respondents. Five of the six NICUs opted to participate. After approval, a contact person, a nurse at the clinic, was selected for each NICU. Mothers who fulfilled the inclusion criteria were conveniently identified and contacted face-to-face by the contact person. They received verbal and written information about the study and the interviewers and signed consent if they chose to participate.

3.5 | Data collection

Data were collected and recorded through telephone interviews (KK and EH). The mothers decided the time so that the interviews could be prioritised. All mothers were at home for the interviews. The interviewers were experienced female nurses working in a neonatal and paediatric units, respectively. The interviews took place between October 2013–February 2014 and lasted between 38–70 min (mean 53 min). Data saturation was reached after nine interviews.

3.6 | Interview guide

The interview guide comprised of semi-structured open-ended questions. The mothers were informed that food and feeding were inclusive of milk expression, gavage, breastfeeding, breastfeeding practice and bottle-feeding. The conversation began with a question

about the mother's thoughts around feeding prior to birth. After this, a general question was asked "Can you describe how you experienced/experience your infant's feeding on the neonatal ward and later at home?" Thereafter, the mothers were asked about positive and potential problems they had experienced related to feeding both on the neonatal ward and at home. During the interviews, probing questions were used, for example "How was that?", "Can you describe that more?" and "How did you feel about that?"

3.7 | Analysis

The interviews were transcribed verbatim, and content analysis was undertaken (Elo & Kyngas, 2008). First, the transcriptions were read several times to make sense of data and create an overview. Second, statements and phrases, which had similarities and answered the study's aim, were extracted. Third, the phrases were condensed to units of meaning, in which the phrases were shortened while still maintaining their content. In the fourth stage, the units were condensed and sorted into categories, sub-categories derived from the data, and finally into an overall theme. Stages one to four were performed by two of the authors (KK and EH). However, under the whole analysis process, there was a back and forth discussion in the team, to ensure agreement.

3.8 | Ethical considerations

The research was carried out following the Declaration of Helsinki (World Medical Association, 2008) and the Consolidated criteria for reporting qualitative research checklist, COREQ (Supplementary File 1). The Regional Ethical Review Board approved the study (Dnr 2012/162-31).

4 | RESULTS

Thirteen mothers were approached, and ten consented to participation. One family had been discharged for more than 12 months at the time of the interview, and the mother was therefore excluded. In total, nine mothers participated. Their ages varied between 25–38 years (mean: 32.4 years), and the infants were born between GA 24–27 weeks (mean: 26 weeks). Four of the mothers had children previously, and one of them had experienced giving birth preterm. Three had previous breastfeeding experience.

The overall theme that emerged was "You can't flight, you need to fight". The theme was developed from four categories and nine sub-categories. All categories were permeated by the mothers' wish and will to do their best for their infants no matter how difficult it was (Table 1). Citations from the respondents were used to strengthen the categories, and they are numbered from one–nine. A bilingual NICU nurse, originating from UK, carefully performed translation of the citations from Swedish to English.

TABLE 1 Summary of categories, sub-categories and theme

Sub-categories	Categories	Theme
Striving for breastfeeding to function Feelings of not being good enough	Wish to provide their own breastmilk	You can't flight, you need to fight
You do what you have to do A need for mutual closeness	For the infant's best	
Feeling exposed Feeling excluded Lack of support	Loss of control	
Participation Encouragement	Help to reach the goal	

4.1 | Wish to provide own breastmilk

4.1.1 | Striving for breastfeeding to function

The mothers had a strong desire to breastfeed their infants and a hope that they would breastfeed successfully. Breastfeeding was seen as a natural part of motherhood, something that mothers were expected to do and manage, and something that could be simple. If it was not successful, it caused disappointment.

"The first time I tried to give him the breast was in week 30 and he was very, very tiny... he did suckle a couple of times and it was so fantastic to see that he new exactly what to do" (6).

However, they also described an understanding of the difficulties that could arise, for instance when an infant was born prematurely, but despite that a will to aim for the goal of fully breastfeeding their newborns.

The knowledge that their infants were receiving their own mother's milk in the nasogastric tube gave them the strength and motivation to continue breastfeeding and expressing milk.

"When she was in the incubator completely helpless I could at least feed her, so that was something that somehow drove me forward, that I didn't think of giving up that easy" (4)

Rationally, the mothers could understand that the supply of breastmilk would probably decrease over time, but still, they visualised that their infants would receive their own mothers' milk the whole time. One mother experienced the introduction of formula as a symbolic act; that from now on, it was only going to go downhill with the breastmilk. The wish to be able to give their own breastmilk and hope to be able to breastfeed at a later stage helped the mothers continue and strengthened their efforts.

4.1.2 | Feelings of not being good enough

The feeling that breastfeeding was expected and the best for the infant evoked emotions of worry and guilt among the mothers who

could not breastfeed their extremely preterm infants. The mother's expectations of herself led to the feeling that a premature delivery was worth less than a full-term delivery. They felt they had to fight for the breastfeeding. This was in a way not what they had expected before giving birth, which brought about a grieving process for what could have been.

"She was going to start [to breastfeed], you know, maybe, and everything would have been so much better, she would start to suck and I would start to produce milk again, but she didn't have the energy, she was too little, so she didn't manage to suck and that was that, that was just another sorrow that one had to get through" (8).

Eventually many mothers gave up. However, this was not easily done; those who finally quit had fought until the end to at least try everything before they stopped expressing milk and practice breastfeeding.

"Because I gave up, I felt as a bad mother who couldn't manage to get it going" (7)

Not being able to produce enough breastmilk or manage to breastfeed were two main reasons for feeling guilt. The general feeling was that a mother provides food for her infant, which means own breastmilk. The mothers found that there were too few discussions about how it is to not want to, or not be able to breastfeed. They thought that it would benefit the community to have more knowledge about problems related to breastfeeding, even with full-term infants.

4.2 | For the infant's best

4.2.1 | You do what you have to do

The mothers experienced that the infant required a lot of specialist care the days immediately after birth, with mostly the staff taking care of the infant. Right there and then, the mothers felt that milk expression was the only thing they were able to do for their infant.

“But well it was a little so-there, it's incredibly boring and hard work to keep at it [expressing milk], but at the same time there was this small feeling that it was the only thing I could do for my baby” (4).

The mothers' standpoint to milk expression can be described as something that the mothers felt compelled to do, that it was natural to fight with milk expression. Difficulties surrounding milk expression, tube feeding and practicing breastfeeding were overshadowed by the emotional obligation they felt towards their infants. Their focus was to do everything they could for their infants.

“But sometimes I felt that I was super-human to have managed it all, especially in the beginning, but you just have to do it, so you do” (1)

The milk expression was tiring and time-consuming, especially in the beginning before it became routine. Knowledge and information about what is best for infants motivated the mothers to continue the fight with milk expression, tube feeding and breastfeeding practice. Some wondered how it eventually could become so obvious to feed their infants via the nasogastric tube.

“But well it became natural, it was the way we could feed him, it didn't feel so frightening, it was more that this was the way we could feed him” (6)

The security of knowing that their infants received the nutrition they required was more important than if they were fed through breastfeeding, intermittent tube feeding or food pump.

4.2.2 | A need for mutual closeness

The mothers had a will to be physically close to their infants, even if it meant just sitting beside the incubator. It was important for them that the infants felt their presence and closeness, especially when the infants received food from a food pump instead of breastfeeding or intermittent tube feeding.

“We were there, with her, basically all the time. We left one time, an afternoon, an evening, we took some time off and went out to get some air” (8)

The mealtimes were emotionally charging; the feeding situation was described as moments when they formed a closer relationship with their infant. When an infant was fed continuously through a food pump they lost that natural moment of building a relationship that comes with intermittent tube feeding.

“Maybe you don't get that first connection with your baby [because of the premature birth], then it feels good

to, at least, get connected during feeding [intermittent tube feeding]” (5).

The closeness to the infant during milk expression facilitated milk expression. If that was not possible, a photo of the infant that they could look at during expression was helpful, acting as a substitute for real closeness.

4.3 | Loss of control

4.3.1 | Feeling exposed

Mothers described how they felt exposed and omitted to strangers in an alien environment, particularly regarding milk expression. The environment was experienced as too open and accessible for staff or other parents. The uncertainty that other people could enter the room at any time was both awkward and stressful and entailed feelings of insecurity and vulnerability in such a private situation.

“It was embarrassing when you slept there with your breast out in front of people that you didn't really know” (3)

When the infants were fed continuously with a pump, several mothers felt that their role had been taken away from them. When the infant had intermittent tube feeding, their role to feed the infant was important but when the machine took over the feeding, their role disappeared and they were no longer in control of the feeding.

“But you know, the day they told that he was going to be fed by a pump, I became..., I was a bit sad, because that was what I wanted to do, I wanted to feed him” (5)

The breast pump could not be left aside; the machine was a constant companion the mothers could never flight from. One mother described how she perceived that she was constantly holding the breast pump shields to her breasts, how she felt pain in her body and how trapped she felt in that strange situation.

4.4 | Feeling excluded

Feelings of exclusion were common among the mothers. To not be included in important situations or decisions surrounding the infant's nutrition and feeding methods evoked different emotions such as powerlessness, helplessness and loss of control.

“It became frustrating that we have a child, but we weren't allowed to decide completely for him...If we'd had a full-term infant we would have decided everything just like every other parent, except we weren't every other parent (6)”

Some mothers described the decision that their infant would receive formula as a compliment to their dwindling supply of breastmilk occurred without warning or their consent. This led to a feeling of losing control. They felt helpless when after a long period of creating a breastmilk supply, it was suddenly deemed insufficient. When staff decided to change the infants' food without consulting the mothers, they felt powerless over being unable to influence, especially if they felt the decision was incorrect and did not consent because they thought the infant needed something else.

"It was several times at the ward, the staff working there, fed him with a bottle when I came in, and I took that very hard" (3)

The perception that the staff was not meticulous with every drop of breastmilk was seen as frustrating. They felt the effort they put into expressing milk was not always appreciated by the staff. Every single drop of milk was important to them, something they had been fighting for, and they found it hard to see when the staff wasted milk, no matter how little.

4.4.1 | Lack of support

The mothers described disappointment in not receiving sufficient practical or emotional support with breastfeeding.

"It worked fine with the pumping and so but sometimes when I was sad or so I forgot to pump and there were days when I didn't know when I last expressed milk, I didn't know what time it was and how many hours that had past" (2).

They revealed they had to search on the internet to learn more about how to breastfeed. Even though breastfeeding practice took place under a longer period, the staff neither discussed nor planned how the breastfeeding practice should come about.

They also perceived a lack of support when the staff gave the impression that the result regardless would be bottle-feeding in the end, as the infant was born extremely preterm.

"Maybe I should have asked more, looking back, I should have asked more questions about it, but I had, you know, it felt as they took for granted it shouldn't work"(5)

4.5 | Help to reach the goal

Participation

Mothers felt they participated in the care around the infants' nutrition when the staff listened to their wishes, explained what they were planning and asked about their wishes and

opinions. This was seen as a mutual staff–mother relationship, which helped to build a meaningful participation in the infant's nutrition.

"We've always felt that we've participated, but needed to put our foot down and show that it was us who steered the ship. You don't want to feel as though just a passenger either; it's after all our decision" (9).

It was critical that the information on feeding was adequate and empathically given in relation to how exposed the family was and how vulnerable the situation was to have an extremely preterm infant. They wished for information in a neutral tone without being criticised.

"Their [staff] advices gave me a lot. I learned to take it easy, not be frustrated when he didn't eat, and give it [the feeding] some time" (7)

Feeling confident that the staff was competent provided understanding and acceptance of decisions, which also led to a feeling that the staff and parents were working towards the same goal. When the staff, together with the parents, calculated how much the milk amount should increase each day and invited the parents into these discussions, it presented feelings of involvement.

4.5.1 | Encouragement

The partner was seen as the greatest support, and together they made a good team. To receive encouragement from ones partner was important and highly appreciated especially while expressing milk. It was reassuring for the mothers to know they could take turns with practical things during the long hospital period. For instance, the partner did the tube feeding while the mother was expressing milk, or the partner helped to remember the time schedule for milk expression.

Positive encouragement from staff to get confirmation in the role as a mother was important and empowered the mothers. To be recognised, and asked, polite questions like "How is it going?" infused support and strength to keep fighting.

"I was so happy just to get something [expressed breast milk], so they encouraged me and said I was good which was a big thing, which really gave me more energy to continue" (1)

Other parents in the NICU were supportive for mothers, both during and after the hospitalisation. Having people around them who had similar experiences to what they themselves were going through gave a feeling of security. For example, to be encouraged to express milk by another parent was described as both strengthening and motivating. The socialisation with other parents was a meaningful support for the mothers.

"It was so important ... togetherness, that we had been through something similar. Then we all have our different journeys. But we had in any case a common theme" (5)

To provide support to other parents in the same situation was also experienced as positive and increased the motivation to reach the goal for those giving support.

4.6 | "You can't flight, you need to fight"

Throughout the mothers' stories, the theme "You can't flight, you need to fight" became obvious. It mirrors the mothers' struggles and fights to do what they could to support and help their vulnerable extremely preterm infants. Even if they found it very hard, draining and tearing to express breastmilk day and night and practice breastfeeding, there was no option to flight. The mothers' strong wish to give their own breastmilk and eventually breastfeed and the desire to do the best for the infants strongly motivated and encouraged them to continue the fight. In this fight, they needed to be empowered by support from their partners, the staff and other parents in similar situations.

5 | DISCUSSION

The mothers' stories of "You can't flight, you need to fight" are about a demanding journey to be a mother to an extremely preterm infant. Even if the mothers were aware of potential difficulties when having a preterm infant, they were unprepared for the emotional journey that came with the desire to breastfeed their child; the fight for every single drop of breastmilk and the unpredictability with the extremely preterm infants' immaturity and fluctuated health status that make every breastfeeding practice a struggle. Their preunderstanding was that breastfeeding was easy, natural and obvious. Even so, the mothers rationally could understand the difficulties with breastfeeding a preterm infant, but were unprepared when suddenly facing it themselves. This finding is in congruence with an earlier study of mothers to infants born extremely preterm in Australia, where the mothers thought of breastfeeding as obvious, natural and something you just do (Sweet, 2008a) and also, in a Swedish study of mothers to very preterm infants (Flacking, Ewald, Nyqvist, & Starrin, 2006). Information about potential preterm birth is usually provided during antenatal care. It might be that the information for becoming parents concerning breastfeeding of premature children has to be more realistic as well as hopeful. Moreover, to increase awareness in the community about the fight these mothers are going through.

Not being able to breastfeed was described as both a grief and a failure. The common understanding that breastmilk is the best option for an infant, increased guilt and feelings of failure of not being good enough as a mother. This is in congruence with a previous study where mothers described feelings of not being a good mother when there was not enough breastmilk to feed the infant

(Sweet, 2008b). These feelings are probably strengthened by the mothers' impression of what they believe is expected from them. Since negative feelings tend to decrease breastfeeding duration (O'Brien, Buikstra, & Hegney, 2008), it is important to highlight this issue. The mothers in this study suggested more discussions about how it is being a mother and not wanting to breastfeed or not being able to breastfeed in order to decrease stress and guilt. Information is important but also support from partners, experienced staff, other parents and the extended family. In a previous study, grandmothers have expressed that they want to help their grown-up children who give birth prematurely but they do not know how to be supportive without being intrusive (Frisman, Eriksson, Pernehed, & Morelius, 2012). Therefore, studies investigating how the extended family can be included in a structured way, in order to support parents in the NICU, are desirable.

The breastmilk was highly valued by mothers and something they had been fighting to achieve. A similar finding is also reported in another study where the mothers described the breastmilk as valuable and healing for the infant (Rossman, Kratovil, Greene, Engstrom, & Meier, 2013). If the infant was in need of continuous feeding instead of intermittent tube feeding, the mothers' perceptions were that they lost the only task they had and that they were no longer needed to feed their infant. The only thing left to do was milk expression. During expression, the mothers' described that they felt exposed, insecure and vulnerable. They often found the environment to be too open and unpredictable. This is in congruence with a study of mothers with breastfeeding problems, who felt forced to expose themselves and give the staff access to their bodies (Palmer, Carlsson, Mollberg, & Nystrom, 2012). This was also described by obese women breastfeeding their children (Claesson, Larsson, Steen, & Alehagen, 2018).

The mothers often mentioned the essence and importance of communication, information, involvement and participation. They wanted to be included in decisions around the infant's feeding, to know the planning for the infant's feeding, and about the next step. In a study by Wigert et al, mothers of full-term infants describe a feeling of being withheld from the staffs' decisions, which negatively affected their dignity. Moreover, the absence of information made the mothers worried and triggered speculation (Wigert, Johansson, Berg, & Hellstrom, 2006). More than twenty years ago, Eriksson wrote that staff's neglect creates a suffering and loss of dignity for the patient. To not include the patient was explained as a misuse of power (Eriksson, 1997). Moreover, a study by Ward showed the importance of including parents in the infant's nursing care plan because it decreased parents' worries and increased their confidence towards the staff (Ward, 2001). Information to parents in the NICU needs to be repeated several times and preferably given as both written and oral information in order to avoid misunderstandings (Broedsgaard & Wagner, 2005). According to the mothers in our study, the information also needs to be relevant, up to date, provided by staff with knowledge and more individualised. Because feeding an extremely preterm infant is such a delicate subject and the mothers are extra vulnerable, the guidance and information should be

delivered with caution and only by staff with special certification in the subject. The feeding care plan needs to be a written document performed in collaboration with the parents and the rationale for any discrepancies from the plan need to be clearly stated.

One limitation with present study is that the interviews were conducted 5 years ago which may affect clinical and scientific significance. However, few studies have addressed exclusively mothers of extremely preterm infants; moreover, the topic and the mothers' struggles are still significant in the NICUs. The participating mothers represent five out of six NICUs that care for extremely preterm infants in Sweden but no claims are made for wider transferability of the results. However, the transparency of the content analysis method should help establish trustworthiness.

6 | CONCLUSIONS

The mothers described a fight with milk expression and breastfeeding practice they could not flight. A fight for the infant's best, no matter what. Feeding was an opportunity for closeness that energised the mothers. When the food pump took over the feeding, they lost their role. Much of the wear and tear for the mothers concerned lack of information, care plans, support and involvement in the infant's care. The mothers had a strong will to provide breastmilk to their infants but requested more support and encouragement from staff in order to be successful.

7 | RELEVANCE TO CLINICAL PRACTICE

The findings in this study are similar to what has been described previously among mothers to preterm infants. However, what is important with mothers of extremely preterm infants is that the journey from giving birth to discharge is longer, the infants have a more immature feeding behaviour and are at higher risk of medical problems. If mothers are tired and exhausted from fighting with milk expression and breastfeeding practice, they may also be more vulnerable and at higher risk for stress. Since breastfeeding rates are declining for extremely preterm infants (Ericson et al., 2016), it is important to consider how information concerning nutrition and feeding is delivered, that parents are included in decisions around the infants feeding and that integrity and autonomy is respected in relation to breastmilk and milk expression in order to prevent stress. Moreover, there is still a need for evidence-based support programmes for mothers of extremely preterm infants to empower them in their journey to express breastmilk and maintain breastfeeding over time. Further studies are recommended to test the significance of support from peers, partners or professionals.

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CONFLICTS OF INTEREST

The authors declare no conflict of interest.

ORCID

Evalotte Mörelius  <https://orcid.org/0000-0002-3256-5407>

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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