

**Providing breast milk for a very low birth weight infant –
organisational and individual challenges from the mothers' perspective**

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Zusammenfassung

Hintergrund: Die Weltgesundheitsorganisation empfiehlt ausschließliches Stillen aufgrund der positiven Auswirkungen auf die Gesundheit für Mutter und Kind für mindestens die ersten sechs Lebensmonate. Für Frühgeborene, insbesondere solche mit sehr niedrigem Geburtsgewicht (<1.500g), ist die Ernährung mit Muttermilch aufgrund ihres frühen Entwicklungsstadiums entscheidend. Mütter von Frühgeborenen stehen jedoch vor strukturellen, soziokulturellen und individuellen Herausforderungen, wenn sie ihr Kind mit Muttermilch ernähren wollen. Da sehr kleine Frühgeborene häufig nicht voll gestillt werden können, muss die Muttermilch durch Abpumpen gewonnen werden, was Kontinuität erfordert. Darüber hinaus können psychosoziale Herausforderungen durch die vorzeitig beendete Schwangerschaft und die Situation auf der neonatologischen Intensivstation die Laktation negativ beeinflussen. Bislang liegen kaum Erkenntnisse zu den organisationalen Determinanten der Stillförderung auf neonatologischen Intensivstationen in Deutschland sowie zu den individuellen, psychosozialen Herausforderungen aus mütterlicher Perspektive vor.

Zielsetzung: Diese kumulative Dissertation hat zum Ziel, organisationale und individuelle Barrieren und Chancen für die Ernährung mit Muttermilch aus der Perspektive der Mütter von Frühgeborenen zu untersuchen. Hierfür wird zunächst der Status quo der Still- und Laktationsförderung auf deutschen neonatologischen Intensivstationen dargestellt. Darüber hinaus wird mithilfe der Theorie der mütterlichen Rollenfindung die Wahrnehmung der Mütter hinsichtlich des zur Verfügung Stellens von Muttermilch als Stressor oder als Bewältigungsressource analysiert.

Methoden: Zwei Datenquellen werden innerhalb der zugrunde liegenden Forschungsarbeiten genutzt. In allen drei Publikationen werden quantitative und qualitative Daten trianguliert. Die erste Datenquelle stammt aus einer quantitativen, querschnittlichen Befragung von Müttern von sehr kleinen Frühgeborenen (n=533), welche validierte Skalen, selbst entwickelte Items, und schriftliche Kommentare enthält. Als zweite Datenquelle werden Interviews mit Müttern von sehr kleinen Frühgeborenen (n=12) genutzt. Die Daten wurden durch deskriptive und multivariate Analysen, sowie mittels qualitativer Inhaltsanalyse ausgewertet.

Ergebnisse: Auf der organisationalen Ebene zeigen sich deutliche Defizite in der Still- und Laktationsförderung, welche die Initiierung der Laktation, Haut-zu-Haut Kontakt, und anhaltende Unterstützung betrifft. Unter Anwendung der Theorie der mütterlichen Rollenfindung werden komplexe Zusammenhänge auf der individuellen Ebene hinsichtlich der psychosozialen Herausforderungen sichtbar. Nachdem der Prozess der mütterlichen Rollenfindung durch die Frühgeburt unterbrochen wird, beschreiben die Mütter das zur Verfügung stellen von Muttermilch als eine Fortführung ihrer versorgenden Rolle, welche

sowohl als Stressor, als auch als Bewältigungsressource wahrgenommen wird. Die Empfindung, inwiefern das zur Verfügung stellen von Milch als stressvoll oder als Bewältigungsressource wahrgenommen wird ist demnach insbesondere von dem Erreichen einer ausreichenden Milchmenge abhängig.

Schlussfolgerung: Die Ergebnisse machen deutlich, dass ein ganzheitlicher Ansatz nötig ist, welcher strukturelle, soziokulturelle und individuelle Ebenen einbezieht, um Mütter bei der Laktation optimal zu unterstützen und damit die Ernährung von Frühgeborenen zu verbessern. Diese Dissertation erweitert das Wissen zur Still- und Laktationsförderung auf neonatologischen Intensivstationen in Deutschland und ermöglicht die Entwicklung gezielter Interventionen. Sie erforscht zudem die komplexen Zusammenhänge der mütterlichen Wahrnehmung bei dem zur Verfügung stellen von Muttermilch. Dieses Wissen ermöglicht es den Versorgenden, die Bedürfnisse der Mütter besser zu verstehen und sie damit während der Laktation zu unterstützen. Darüber hinaus zeigt diese Dissertation das Potenzial für weitere Forschung zur Erweiterung der Kenntnisse zu den Herausforderungen der Mutterrolle nach einer Frühgeburt auf.

Summary

Background: Exclusive breastfeeding positively impacts maternal and child health and is recommended by the World Health Organization for at least the first six months of life. For sick and preterm infants, especially those with a very low birth weight (VLBW, <1.500g), this nutrition is crucial due to their early developmental stage. However, mothers of VLBW infants face structural, socio-cultural, and individual challenges. Since the infants can often not be fully breastfed, mothers have to express breast milk, which requires continuity. Furthermore, individual challenges in terms of the prematurely ended pregnancy and the hospitalisation of the infant in a neonatal intensive care unit (NICU) can negatively affect lactation. To date, there is a lack of information on organisational determinants of lactation support in NICUs in Germany, as well as on the individual, psychosocial challenges behind the mothers' perceptions of providing breast milk.

Objectives: This cumulative dissertation aims at investigating organisational and individual barriers and opportunities for the provision of breast milk from the VLBW mothers' perspective. First, the status quo of lactation support in NICUs in Germany is illustrated. Second, the mothers' perceptions whether providing breast milk is perceived as a stressor or coping resource is elaborated by applying the theory of maternal role attainment.

Methods: Two data sources are used within the research papers underlying this dissertation. All three research papers triangulate quantitative and qualitative data. The first data source comprises a quantitative cross-sectional survey with mothers of VLBW infants (n=533), which includes validated scales, self-developed items, and an option for written comments. Furthermore, interviews with mothers of VLBW infants (n=12) are utilised. Descriptive and multivariate analysis, as well as content analysis of the written comments and qualitative interviews were performed.

Results: On the organisational level, considerable deficits in lactation support, covering the initiation of lactation, skin-to-skin contact, and continuous support are shown. By applying the theory of maternal role attainment, complex interdependencies emerge concerning the individual level of psychosocial challenges. Following the interruption of the process of developing the maternal role after premature birth, mothers describe the provision of breast milk for their infants as a continuation of their caregiving role, while perceiving it as both stressful and a coping resource. Therefore, to what extent it is recognised as stressful or as a coping resource is particularly dependent on achieving sufficient milk supply.

Conclusion: The results indicate that a multifaceted approach, which includes structural, socio-cultural and individual levels, is necessary to optimally support mothers in the provision

of breast milk and thus improve the nutrition of preterm infants. This dissertation contributes to the state of knowledge of lactation support in NICUs in Germany, thereby enabling the development of targeted interventions for improvement. Furthermore, it identifies the vulnerability of mothers after premature birth, who experience a complex emotional response to the provision of breast milk. This knowledge enables healthcare providers to gain a deeper understanding of maternal needs and thus to support them during lactation. Additionally, this dissertation indicates the potential for further research on maternal role challenges after premature birth to expand upon these findings.

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List of abbreviations

WHO	World Health Organization
NICU	Neonatal Intensive Care Unit
UNICEF	United Nations International Children's Emergency Fund
VLBW	Very Low Birth Weight
ELBW	Extremely Low Birth Weight
BPD	Bronchopulmonary Dysplasia
ROP	Retinopathy Of Prematurity
NEC	Necrotizing Enterocolitis
MOM	Mother's Own Milk
ICD	International Statistical Classification of Diseases and Related Health Problems
P1	Research Paper 1
P2	Research Paper 2
P3	Research Paper 3

1. Introduction

Breastfeeding is essential for the nutrition, survival and development of infants as well as for the health of mothers. In an infant's first six months of life, the World Health Organization (WHO) recommends exclusive breastfeeding. This should be continued with complementary food for up to two years or beyond (World Health Organization, 2020). One of the global nutrition targets until 2025 is to increase the rate of exclusively breastfed children in the first six months from 38% in 2014 up to at least 50% in order to reduce mortality in children (World Health Organization, 2014a, 2014b). In Germany, the majority of mothers (90%) have the intention to breastfeed, but only 68% exclusively breastfeed their infant after birth and only 40% continue until four months of age. Reasons for this mainly stem from lacks in support during lactation and breastfeeding, which highlights the necessity not only for international, but national interventions on breastfeeding promotion (Bundesministerium für Ernährung und Landwirtschaft, 2023). However, these reported rates refer to healthy mother-infant dyads. For mothers of sick or prematurely born infants, these gaps can increase even more due to the unique challenges they face. Especially, when the infant needs specialized medical care in a neonatal intensive care unit (NICU). At the same time, the health promoting effects of breast milk are of great relevance for this highly vulnerable group of infants. However, depending on the infant's and mother's health status, they are confronted with altered and often additional challenges to achieve breastfeeding. These include the initiation of breastfeeding, respectively lactation and establishing prolonged lactation and continued breastfeeding at home after discharge from the hospital (Parker et al., 2021).

These challenges lead to a significantly lower number of prematurely born infants who are exclusively fed with breast milk than that of healthy newborns. Compared to the rather low prevalence of about two-third of healthy infants being exclusively breastfeed, it can be assumed that only 30% of premature infants are fed exclusively with breast milk during their hospital stay (Scholten et al., 2022). This indicates the high need for support in preterm mothers. Nevertheless, breastfeeding is not only beneficial for infants, but also has a profound impact on the well-being of mothers, both as individuals and for the mother-infant relationship (Lau, 2018). Consequently, although the central objective is often the feeding outcome of the infants, the focus should be on their mothers as those who decide, initiate and maintain breastfeeding. To achieve this, different dimensions of breastfeeding, which include societal, organisational, and individual levels should be considered (Rollins et al., 2016). The objective of this dissertation is to elaborate the obstacles and opportunities of lactation for mothers after preterm birth on a macro level by first encompassing organisational conditions. Second, on a micro level, it aims to examine the rather unexplored maternal psychosocial (role-)challenges utilising Rubin's (1967) and Mercer's (1981) theory of maternal role attainment. To illustrate

the relevant background, preterm birth and its following outcomes on mothers and infants, as well as the importance of the infant's nutrition are described. Then, the organisational and individual, psychosocial challenges of lactation and breastfeeding after preterm birth are examined and the two research questions of this dissertation are derived from this. After presenting the results, which include three published research papers, the discussion triangulates the findings of the papers according to the research aims of this dissertation and elaborates implications for practice and research.

2. Preterm birth

2.1 Definition and prevalence

Preterm birth can be defined by a certain gestational age and/or through birth weight. The WHO defines preterm infants as children who are born before 37 weeks of gestation are completed and low birth weight infants as infants under 2500g (World Health Organization, 2022). To distinguish between different stages of prematurity, subcategories of preterm infants and low birth weight infants are made (Table 1). This dissertation focuses on the group of very low birth weight infants (VLBW), which also include extremely low birth weight infants (ELBW). To describe this group, the term VLBW is used, as most of the relevant studies addressing this issue refer to this definition and the underlying data sources used this as inclusion criteria.

Table 1: Subcategories of preterm infants (WHO, 2022, 2023)

Low birth weight/(late) preterm	<2.500g	32-37 weeks
Very low birth weight preterm/very preterm	<1.500g	<32-28 weeks
Extremely low birth weight preterm/extremely preterm	<1.000g	<28 weeks

The prevalence of preterm birth varies across low, middle and high-income countries. Globally, preterm birth occurs in 10.6% of all livebirths. In Europe, reported preterm delivery rates are 8.7%, which accounts for 5.7% of all livebirths worldwide. Ranked according to birth weight, 84.5% of the preterm births in Europe are late preterm infants, 10.9% are VLBW and 5.1% are ELBW (Chawanpaiboon et al., 2019). In 2021 the preterm delivery rate of all births was 7.9% in Germany, differentiated in 6.5% late preterm, 0.8% VLBW and 0.6% ELBW. This represents a total number of 10.664 VLBW infants born with a gestational age under 32 weeks (IQTIG, 2022). Overall, the number of preterm births in Germany is slightly decreasing, with previous rates of 8.5% in 2015 and 8.2% in 2019 (Euro PERISTAT, 2020).

The reasons for preterm birth are multifaceted and only partially explored. It is suggested that high systemic inflammation might explain the association of preterm birth with diverse risk factors, including maternal and fetal characteristics (Goldenberg et al., 2008). In general, factors on demographical and gynaecological levels and factors arising from complications related to the current gestation can be differentiated (Cobo et al., 2020). Maternal demographics, such as maternal socioeconomic and educational status, racial or ethnic disparities, and maternal age are associated with prematurity (Goldenberg et al., 2008). Until now, in most cases the mechanisms behind these associations remain unclear. Maternal age and educational level, for example, both showed to be associated with prematurity, but are

highly associated with each other. Therefore, caution should be taken in the interpretation of significant pathways when examining correlations.

Preterm birth itself and following complications are the leading cause of death in children under five years of age and, therefore, represent 35% of deaths across all new-born infants worldwide (UN, 2017). Among children younger than five years, preterm birth complications cause 17.7% of deaths (Perin et al., 2022). This complication rate differs among high-income and low-income countries and is dependent on the gestational age and birth weight of the infant. Lower gestational age leads to higher mortality, which indicates the vulnerability of VLBW and ELBW infants (Platt, 2014). Therefore, the rather small group of VLBW infants accounts for slightly half of all infant deaths and medical complications, leading to high health system costs in high-income countries (Barfield, 2018). Prematurity, however, is the leading cause of morbidity and mortality in both preterm infants and mothers (Green & Arck, 2020). To receive a better understanding of the relevant risk factors, the central medical outcomes of mothers and infants after preterm birth are illustrated in the following.

2.2 Outcomes after preterm birth

Maternal outcomes

In the case of prematurity, VLBW infants are mostly delivered through caesarean section, with one-fourth being primary caesarean section (decision made before birth began) (24%) and slightly half a secondary caesarean section (decision during birth) (46.4%) in Germany (IQTIG, 2022). Caesarean section leads to a higher number of complications compared to spontaneous delivery, which is only the case in one-fourth (26.5%) of VLBW births (IQTIG, 2022; Reddy et al., 2015). Research indicates that the risk for maternal morbidity is even higher, the lower the gestational age of the infant (Romagano et al., 2020). However, maternal morbidity after preterm birth remains rather unexplored, demonstrating that much more research is still needed (Raju et al., 2014). Apart from the physical consequences of preterm birth, some psychological outcomes are worthwhile to be considered as well.

Mothers who deliver prematurely have an increased risk for mental health issues (Anderson & Cacola, 2017). Childbirth as well as the postnatal period can be traumatic or distressing for mothers, leading to post-traumatic stress disorder and/or postpartum depression (Ayers et al., 2016). Studies have shown, that severe mental health issues occur particularly in mothers after preterm birth, including depression, post-traumatic stress disorder, anxiety and high levels of distress (Roque et al., 2017). In case of giving birth to a VLBW infant, that needs to be admitted to the NICU, 40% to 50% of mothers report anxiety and symptoms of depression,

which corresponds to a significantly higher rate than in term-mothers. Although the symptoms usually decline over time, they slowly attenuate and often remain longer than six months after birth (Pace et al., 2016). Furthermore, preterm mothers experience an unique kind of parental stress due to the special situation in the NICU, where the infant has special needs in care and taking part of it is often limited (Caporali et al., 2020; Miles et al., 1993). Stress will be defined, and the existing literature and measurements will be reviewed in greater extension during the examination of the interdependence of stress and lactation (Chapter 3).

Infant outcomes

Preterm infants with a very low birth weight have a higher risk of morbidity in both short- and long-term. In the following, an example of outcomes, which are directly associated with prematurity are reviewed for a better understanding of the vulnerability of those infants. VLBW infants are at risk for respiratory problems, including infectious and non-infectious problems, such as bronchopulmonary dysplasia (Farstad et al., 2011). Bronchopulmonary dysplasia (BPD) is a chronic lung disease that affects preterm infants who need an oxygen therapy more commonly. Infants with BPD are at risk for pulmonary hypertension, neurological complications and other developmental problems (American Lung Association, 2023). Moreover, a lower gestational age is correlated with the prevalence of retinopathy of prematurity (ROP), which can lead to visual impairment, blindness and implies a higher risk of myopia, hypermetropia, and hearing impairment (Sabri et al., 2022). There are many more complications which are directly linked to preterm birth such as cerebral palsy, cognitive impairment and neonatal jaundice (Platt, 2014). One of the most common gastrointestinal emergencies, which is highly dependent on birth weight and gestational age is necrotizing enterocolitis (NEC). Due to the advances in neonatal care, more VLBW infants survive the early postnatal period and are, therefore, at a risk of NEC. It arises postnatally and in most cases after infants received enteral feeds. Depending on the study, mortality rates range from 15% to 30%. Even though the treatment of NEC is challenging, improving the VLBW infants diet showed to be crucial in prevention and therapy (Lin & Stoll, 2006). Besides the physical outcomes after preterm birth, the neurological and especially long-term psychological outcomes remain rather unclear. However, VLBW infants are at higher risk for psychotropic medication than healthy newborns in later life (Robinson et al., 2020).

In summary, preterm infants have an increased risk for many complications and especially compared to term newborns, VLBW infants show higher mortality rates, prolonged hospital stays, rehospitalisation rates, as well as physical and psychological limitations in their later life. The increased risk of the discussed vital threatening infections and developmental impairments in VLBW infants make them a particularly vulnerable group. As already mentioned, one

relevant factor in preventing some of these outcomes is the optimal nutrition for VLBW infants. Therefore, the different options for nutritional diet of VLBW infants including their benefits are reviewed in the following.

2.3 Nutrition in preterm infants

Human milk

The term “human milk” includes mother’s own milk (MOM) and donor milk. MOM describes the milk of the infant’s own mother and donor milk is donated milk expressed from another mother (Parker et al., 2021). Besides the macronutrients which contain proteins, fats and carbohydrates, human milk includes biologically active bacteria strains which vary between women and over the stage of lactation (Bode et al., 2020). Therefore, it contains an individual microbiome, for instance probiotic bacteria, which contribute to the establishment of the infant’s gastrointestinal microbiome (Witkowska-Zimny & Kaminska-EI-Hassan, 2017). However, even though many constituents of human milk are known already, it’s composition and biological function is only partly explored yet and requires more research (Christian et al., 2021). Furthermore, many differences occur in the case of donor milk, depending on whether and how the milk is processed, for example whether pasteurization takes part or not (Parker et al., 2021).

Due to the various components of human milk which contribute to the infants’ positive development, it is seen as the best nutrition for VLBW infants. It prevents many of the potentially vital-threatening diseases mentioned before. An exclusive human milk diet decreases the risk for BPD and protects against NEC (Cacho et al., 2017; Quigley et al., 2018; Sisk et al., 2007; Villamor-Martínez et al., 2018). Concerning the prevalence of late-onset sepsis and ROP, a nutrition with human milk may be protective, but more evidence for this is needed (Bharwani et al., 2016; Miller et al., 2018). In some outcomes, however, the distinction between MOM and donor milk becomes relevant. Studies have shown different health effects of MOM compared to donor milk, where donor milk is suggested to be beneficial, but not equivalent to the nutrition with MOM (Cartagena et al., 2022; Parker et al., 2021). This may be based on the assumption that MOM differs in composition from donor milk and matches the infant’s individual stage of development (Dingess et al., 2017; Marx et al., 2014). Nevertheless, especially long-term outcomes of an exclusive nutrition with human milk and potential differences to an exclusive diet with MOM remain rather unclear. One study, for example, indicates better growth and body composition two years after birth with increased MOM-feedings compared to donor milk (O’Connor et al., 2016). Concerning neurodevelopmental outcomes, no differences occurred 18 months after birth in case of an exclusive nutrition with

human milk, compared to a nutrition with MOM and preterm formula (industrially processed milk) (Patra et al., 2022). However, due to the many benefits of an exclusive diet with MOM, the WHO recommends the usage of donor milk only in case of MOM being not or not yet available, ideally bridges the gap until the infant can be exclusively fed with MOM (World Health Organization, 2022).

Infant formula

When preserving nutritional management, infant formula is the only alternative if human milk is not available. The first commercial milk formula was developed and marketed in 1865 (Stevens et al., 2009). Aggressive advertising, especially in developing countries, led to globally declining rates of breastfeeding. Even though in the 1970s, the promotion of breastfeeding was focused and higher breastfeeding rates were established, they declined again in the 21st century (Stevens et al., 2009). The development and marketing of infant formula can be reflected from different point of views, such as socioeconomical, sociological and individual, as well as medical perspectives.

From a socioeconomical point of view, the commercial milk formula industry benefits from the developments with increasing sales of more than 50 billion US\$ in the last years (Rollins et al., 2023). Globally, slightly less than half of all infants (48%) were breastfed within an hour of birth, while just 44% of infants under six months were exclusively breastfed (United Nations Children's Fund & World Health Organization, 2021). In Germany, even though breastfeeding rates show to be about 72% to 97% after birth, they decline shortly within the first two months, leading to only 50% of infants who are still (partly) breastfed by the age of six months (Weissenborn et al., 2016). These numbers collide with the fact that MOM is the best choice of nutrition for all newborns, but especially for preterm infants due to its various aforementioned positive effects (World Health Organization, 2020). However, the multilevel marketing of infant formula, which influences not only families, but also health professionals, science, and policy, contributes to the already discussed low remaining rates of infants who are fed with MOM (Rollins et al., 2023).

On a sociological level, the mothering role, including the role of a nourisher, could be blurred after the development of formula. Women had no longer either the role of a mother or a working woman but were able to incorporate both. Thus, the emancipatory and feministic movements, which already started decades before, argue for the opportunity of mothers to control their activities not being tied to the infant's feeding needs. Furthermore, this enabled mothers to choose to get back in the job shortly after giving birth (Pelto, 1981). It is undisputed that the development of food substitution freed women from the allocation of roles and, therefore, promoted their emancipation. Whether these role expectations may still play an important role

in the mothers' perceptions of providing breast milk to the infant is discussed later in this dissertation.

When considering the medical point of view, it should be specified that VLBW infants have special nutritional requirements. In the last century, it was figured out that the components of MOM do not meet these requirements of preterm infants, as especially preterm infants with a very low birth weight did not achieve growth rates. Therefore, preterm formula was designed and became the nutrition of choice in neonatal units in the 1990s (van Goudoever, 2018). Although donor human milk was also common, the occurrence of HIV led to using preterm formula even more frequently, as human milk was known to transmit the virus. However, only a few years later, the nutrition with preterm formula was criticized due to higher rates of NEC and infections. In order to reduce the risk of NEC by addressing the micronutrient requirements of infants, the fortification of human milk became important (van Goudoever, 2018). Still, a lot of research is running on the advantages of different fortifiers in order to minimize the risk of morbidities in VLBW infants (Picaud et al., 2021). In summary, the development of preterm formula and the subsequent recognition of its impact on morbidity, particularly in VLBW infants, led to a renewed interest in the human milk diet. However, since preterm formula was seen as standard nutrition for preterm infants in neonatal units a few years ago, exclusive feeding with MOM or donor milk is still often not established today (Quitadamo et al., 2023; Scholten et al., 2022). Reasons for this stem from various factors, including structural, organisational, and individual levels. Moreover, mothers of preterm infants face specific barriers in achieving lactation, which are described as follows.

3. Lactation after preterm birth

3.1 Breastfeeding the very low birth weight infant

Giving birth to a VLBW infant affects breastfeeding due to interruption of maternal secretory differentiation and the infant's immaturity. In general, lactation is established within two phases of secretory differentiation (lactogenesis). The first initiation stage (lactogenesis 1) already occurs within the 20th week of pregnancy, where the unique colostrum is produced. This is followed by secretory activation (lactogenesis 2), which occurs four to six days after birth. It activates a phase of transitional milk secretion for five to ten days, resulting in the copious milk production (Truchet & Honvo-Houéto, 2017).

Prematurity can lead to impaired lactation, as the development of the mammary glands is interrupted. Further, the VLBW infant's early stage of growth leads to an impaired ability to suck, which requires enteral nutrition (Dutta et al., 2015; Farah et al., 2021). Therefore, VLBW infants' mothers face specific and multifaceted challenges in establishing lactation. First, lactogenesis is often delayed after preterm birth which may contribute to low milk production. Second, lactation initiation and maintenance require milk expression by hand and/or a (electric) pump. Third, the VLBW infant's early stage of development and need for medical interventions result in the NICU admission, which separates mother and infant. This separation may negatively influence mother-infant attachment, further impeding the provision of MOM (Bergman, 2019; Hofer, 2005).

Besides, more factors, such as sociological, structural, political, and individual issues have an impact on breastfeeding. In the case of prematurity, the provision of MOM becomes particularly challenging, due to the earlier mentioned barriers. Rollins et al. (2016) elaborated a conceptual model to describe relevant factors in society to enable breastfeeding for mothers. These determinants are crucial to enable and promote breastfeeding. However, the vulnerable group of mothers of preterm infants may need even more support on the individual level of this model. To be more specific, prematurity causes distinctions in the mother-infant attributes and affects their relationship negatively due to the separation of the mother from the infant in the NICU and the obligation to express milk rather than breastfeeding (Parker et al., 2021). Thus, especially early lactation initiation must be supported by professional counsellors to enable mothers to provide breast milk to their infants. Apparently, all determinants, such as the health care system, family and community are necessary to create a basis from which the special needs of those vulnerable groups can be addressed. This dissertation focuses on the individual level of VLBW mothers and their perceived (emotional) challenges in establishing lactation (Figure 1).

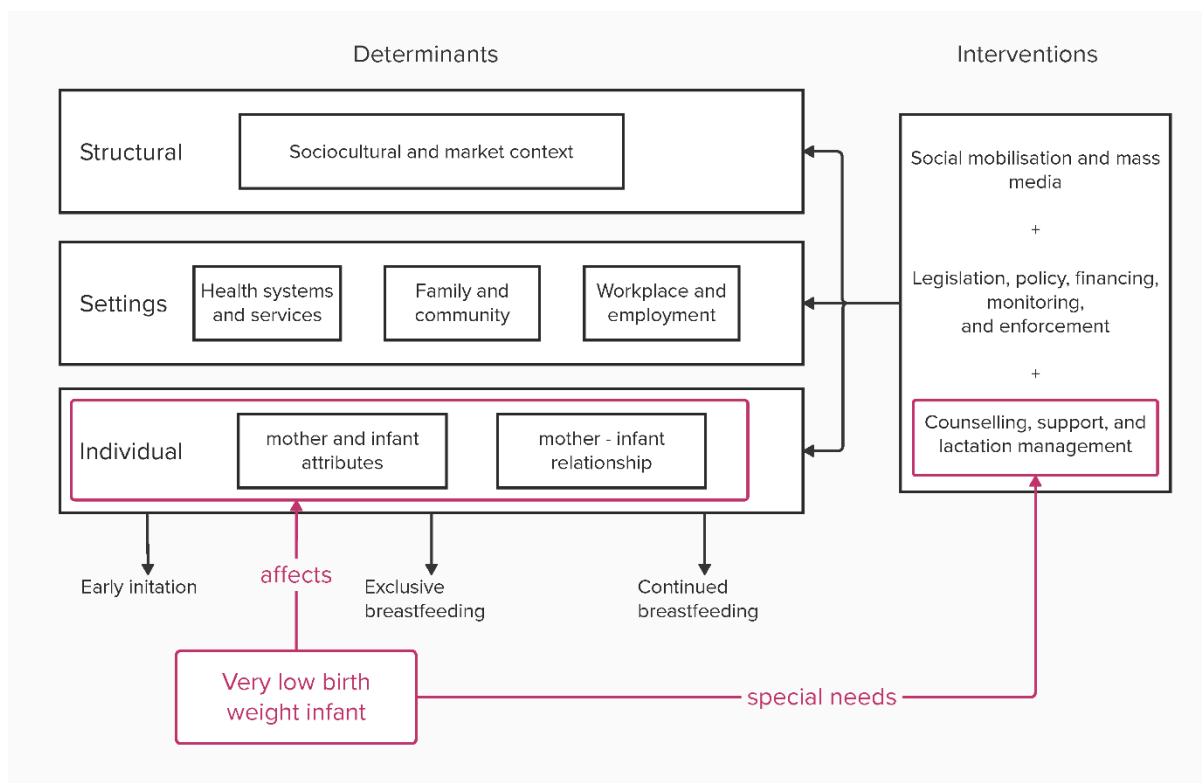


Figure 1: The conceptual model for a breastfeeding enabling environment: Special needs during lactation having a VLBW infant (Rollins et al., 2016, own editing)

In order to realise early lactation in preterm mothers, exclusive and continued breastfeeding, respectively exclusive nutrition with MOM, some interventions and recommendations on lactation support showed to be crucial for the NICU setting, which are illustrated below.

3.2 Establishing maternal milk supply after prematurity: evidence-based interventions

Maternal milk supply after preterm birth is dependent on many factors, including organisational, physical, and psychosocial challenges. Therefore, structured lactation support by trained lactation consultants, which includes an option of psychological counselling, should be implemented. Some evidence-based interventions are eminent in promoting human milk feedings in NICUs. Overall, a hospital culture which supports lactation and breastfeeding showed to be beneficial for the provision of MOM (Hallowell et al., 2014; Ward et al., 2021). This includes that consistent, evidence-based information is given to the mothers to enable an informed decision about feeding the infant with human milk (Meier et al., 2017; Ward et al., 2021). After delivery, mother and infant should have skin-to-skin contact immediately, latest within the first hour after birth, as both mother and infant widely benefit from it (Linnér et al., 2022; Mehler et al., 2020). This should further be enabled daily and continuously during the

hospital stay in order to raise maternal oxytocin levels, which play a crucial role in bonding and breast milk ejection (Arrowsmith & Wray, 2014; Geddes et al., 2013; Mörelius et al., 2015; Vittner et al., 2019). Recent meta-analyses highlighted the relevance of skin-to-skin contact in terms of lactation and presumably also the infant's growth (Sharma et al., 2019; Song et al., 2023). In addition, the option for parents and infants to stay together day and night, preferably with the option of rooming-in in a single family room in the hospital, showed to be beneficial for breastfeeding (Grundt et al., 2021). After giving birth, mothers should initiate lactation within the first hours, best by applying a combination of manual milk expression and the use of an electric pump (Meier et al., 2008; Parker et al., 2021). Manual milk expression is particularly important to win colostrum which has shown to be immensely beneficial for the infant's immune development (Haase et al., 2018). Furthermore, it is assumed, that the combination of manual milk expression and pumping contributes to maternal milk supply (Morton et al., 2009). Establishing sufficient milk supply is reached through coming to volume (CTV), which is defined as a breast milk supply of more than 500ml per day on day 14 postpartum (Hoban et al., 2021). VLBW infants of mothers who reach this milk amount are more likely to be fed with MOM at the time of discharge from the NICU (Hoban et al., 2018). In order to reach CTV, the frequency of pumping showed to be important, but research indicates different frequencies of around four to seven times within 24 hours being optimal, depending on the varying cut points in recent studies (Parker et al., 2021). However, when facing the infant's exclusive nutrition with MOM in the NICU as the outcome, a recent study indicates a higher pumping frequency of seven to nine times per day being supportive (Scholten et al., 2022). When the infant is ready to be (partially) fed at the breast, this transition should be already made in the NICU, as it leads to longer breastfeeding duration (Briere et al., 2016; Meier et al., 2017).

As mentioned before, a hospital culture which promotes the nutrition with MOM is crucial for increasing feedings with MOM in neonatal units. Various studies have shown the positive effect of structured interventions in NICUs on maternal lactation and breastfeeding rates of VLBW infants (Gharib et al., 2018; Meier et al., 2013; Nyqvist et al., 2013). However, there is limited data available on the current state of lactation support in NICUs in Germany from the mothers' perspective. One study indicates that lactation support is suboptimal in German NICUs, as lactation initiation is delayed and pumping frequency is rather low (Scholten et al., 2022). However, more data on lactation support in German NICUs is needed in order to identify barriers and opportunities to promote the nutrition with MOM in VLBW infants. Therefore, this represents the first research aim of this dissertation.

3.3 Establishing maternal milk supply after prematurity: psychosocial challenges

The implementation of the evidence-based interventions mentioned above is essential in promoting lactation and thus feeding VLBW infants with MOM. These should include psychosocial support for mothers during lactation, as psychosocial challenges occurring after preterm birth may influence lactation, as well as they may be influenced by lactation itself (Nagel et al., 2022). The previously elaborated psychological outcomes after preterm birth (Chapter 2), including a higher risk for distress, postpartum depression, anxiety, and post-traumatic stress disorder in preterm mothers than term-mothers, indicate their special needs for support (Malouf et al., 2022; Pace et al., 2016; Roque et al., 2017). Furthermore, mothers of infants admitted to a NICU showed to score high in parental stress. Within three subscales, parental stress can be measured through the situation in the NICU (sounds and sights), limited possibilities of caregiving (parental role alteration), and the fragility of the infant (appearance and behaviour) (Miles et al., 1993). Different studies indicate, that parental role alteration is the biggest of all stressor components when measuring parental stress, compared to the infant's appearance and behaviour, or the sounds and sights in the NICU (Caporali et al., 2020; Pavlyshyn et al., 2022). Whereas many studies evaluated parental stress in the NICU, some focused on possible differences in the experiences of parental stress between mothers and fathers. They found out that mothers report higher levels of parental stress and especially stress due to parental role alteration after preterm birth (Ahn & Kim, 2007; Caporali et al., 2020; Matricardi et al., 2013). These findings indicate not only the different perception of stress due to the parental role but suggest that different coping strategies may be used by mothers. Some explorative studies aimed to elaborate further reasons why mothers often experience negative feelings and stress, indicating that this may be due to the prematurely ended pregnancy, unexpected birth, and not being able to care for the infant as expected (Al Maghaireh et al., 2016; Reid, 2000). Moreover, the own vulnerability in combination with the VLBW infant's hospitalisation in the NICU may increase these negative feelings. The limited possibilities of caregiving and, therefore, building up the maternal identity may further aggravate the development of coping strategies (Caporali et al., 2020). However, there are still many gaps in our knowledge, particularly regarding the mothers' individual perceptions of the challenges encountered during the process of lactation after prematurity. A better understanding of maternal experiences after preterm birth may help caregivers to adapt their support to the mothers' needs. In order to describe the process of establishing a maternal identity after premature birth and whether this may lead to stress among preterm mothers, the theoretical framework of the maternal role attainment is illustrated in the following. Then, the current knowledge about the interdependence of maternal stress and lactation is illustrated.

Maternal role after preterm birth

In sociology, roles are focused on societal and cultural specified behavioural patterns, thus conceive social structures as an interplay of roles. From an individual perspective, a role can be seen as a concept of how to behave in a particular situation. Therefore, roles structure and support behavioural expectations (Bosak, 2018). In general, role theory includes the two aspects of role-taking and role-making, which emerge from different sociological approaches. Both aspects are based on the thought that the interpretation of a role includes the assumption that prescribed behavioural expectations exist for this role. When the expectations are clearly defined and overall accepted and the person is able to behave as expected, role-taking (structural functionalism) is dominant. If this is not the case and a person is further engaged with intra- and inter-role conflicts without institutional pathways to follow, role-making (symbolic interactionism) is the major component. In this case, roles have to be interpreted in a process which is dependent on role partners. A role is always linked to the interpretation of the relationship with a partner role and vice versa. Therefore, an ongoing process of interactive adjustment of these interpretations lead to role behaviour, which is both modified and standardised (Schulz-Schaeffer, 2018).

When a woman becomes pregnant, a new social role arises for her. This can be considered as a major event which comes along with a new reality in life (Mercer, 1985). In 1967, Rubin examined the construct of the maternal role attainment to describe the process of developing maternal role identity. This construct is based on the previously described approach of the symbolic interactionism, where roles are continuously created and modified. Mercer (1981, 1985) further examined it to the theory of maternal role attainment, which describes a women's transition to motherhood. Within this, fetal attachment, reaching confidence in mothering behaviours, and gratification in maternal-infant interactions are the main components of establishing the mothering identity (Mercer & Ferketich, 1995). However, maternal role attainment already starts during pregnancy, where the future mother starts to address the upcoming changes (Mercer & Ferketich, 1995). In this concept, the whole process is covered by four stages of maternal role attainment: anticipatory (during pregnancy, when the future mother seeks for information and builds expectations of the new role), formal (starting with birth, where maternal behaviour is learned and replicated), informal (learning infant's cues and finding a mothering style), and personal (integrating the role of mothering into life, reaching self-confidence in mothering) (Mercer, 1981). The transition between stages to reach the own mothering identity, however, is assumed to be challenged by several factors, such as personal and societal conditions, role strain, and social stress (Mercer, 1981, 1986). Later, Mercer (2004) stated to replace the term "*maternal role attainment*" into "*becoming a mother*", since she stated that this process, which includes life-transforming experiences and continuing growth, is not adequately described in the theory of maternal role attainment. However, the

four stages only slightly differ in their names and content: the first stage (a) includes commitment, attachment and preparation which occurs during (and sometimes also before) pregnancy, (b) is learning, acquaintance and physical restoration (following birth), (c) moving toward the new normal and (d) achievement of the maternal identity. Mercer points out, that these stages may overlap and are highly dependent on factors such as maternal and infant characteristics, or social environment (Mercer, 2004). The differences in the description of the stages may be neglected, as they outline a comparable process and both terms are used in current research on this topic (Alinejad-Naeini et al., 2021; Spinelli et al., 2016; Zdolska-Wawrzekiewicz et al., 2019).

In this dissertation, the transition to motherhood is understood as a process of different stages and challenges on various levels as described in the term “*becoming a mother*”. However, due to the focus of this dissertation, which aims to explain various interrelationships based on role expectations and fulfilment, the term “*maternal role*” is used when describing these mechanisms. According to Mercer (2004), the first stage in particular has long-term implications on the mothers’ positive adaption to motherhood. In the case of prematurity, especially this stage may be influenced by the prematurely ending pregnancy and the unexpected birth. Further on, the second stage, when the mother recovers, but also begins to get to know her infant and incorporates caregiving practises, highly differs in the case of premature birth and with a VLBW infant admitted to a NICU in comparison to term birth. Therefore, the third stage, where the mother learns about her infant’s cues and what’s best for it, may be delayed (Mercer, 2004). Figure 2 shows the theoretical framework of developing the maternal role adapted to this situation.

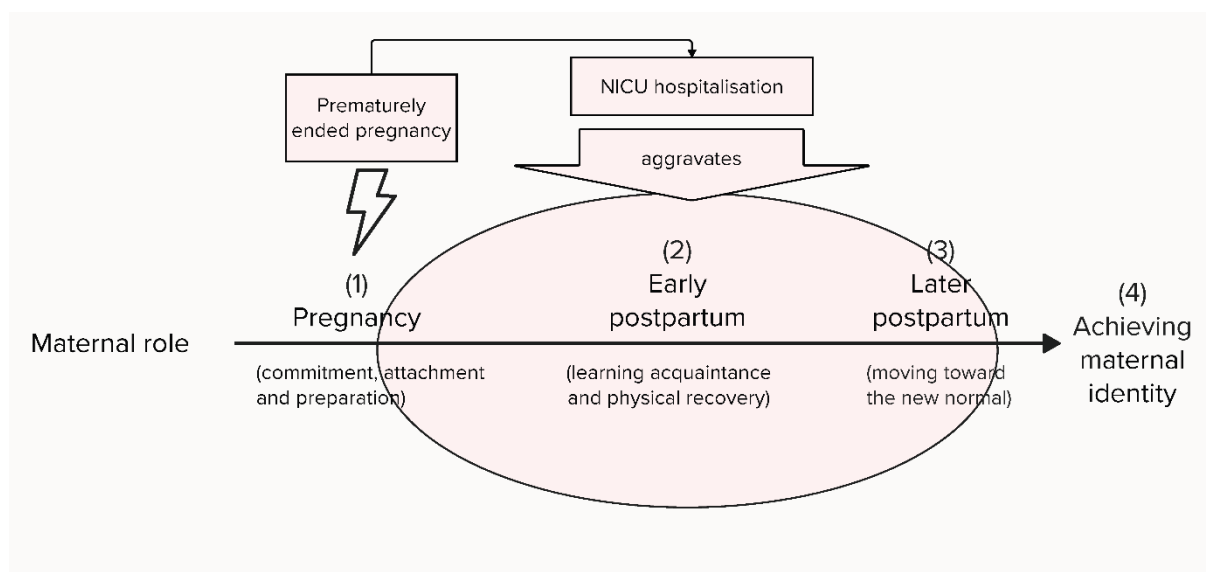


Figure 2: Maternal role attainment in the situation of prematurity (own illustration)

As already mentioned, preterm birth can be suggested being a disruptive life event, which can lead to different negative feelings (Roque et al., 2017). Many studies have observed, that mothers of preterm infants report feelings of guilt, loss, and anxiety (Bower et al., 2017; Rafael-Gutiérrez et al., 2020; Thivierge et al., 2023). Thereby, mothers describe providing breast milk to their infant as a mechanism to relieve guilt and to maintain a connection to the infant after the prematurely ended pregnancy (T.-Y. Lee et al., 2009; Sweet, 2008b). The loss of connection after preterm birth may be aggravated when the infant is hospitalised in a NICU, where developing the mothering and caregiving role may hardly be possible due to medical complications and separation of mother and infant (Baum et al., 2012; Boucher et al., 2011). C.-K. Lee & Huang (2022) identified a core category while elaborating the psychological processes regarding the maternal role in postpartum mothers with an infant admitted to an intensive care unit. It consists of worrying about their infants' conditions and striving to fulfil their maternal responsibilities. In those terms, any dimension of possible caregiving may contribute to developing and fulfilling the maternal role. One of these dimensions may be breastfeeding, respectively providing breast milk to the infant. At least, this can be assumed when the mother decides to initiate lactation. Indeed, research shows, that mothers of preterm infants are more likely to initiate lactation than mothers of term-infants (Colaizy et al., 2012; Jonsdottir et al., 2022). Some explorative, mostly qualitative studies previously suggested that expressing and providing breast milk to the infant may be supportive for mothers developing their maternal role and, therefore, coping with the situation in the NICU (Abu Bakar et al., 2019; Bower et al., 2017; Ikonen et al., 2015). However, concerns about milk supply showed to be common among preterm mothers (Ikonen et al., 2016). If sufficient lactation is not reached, the upcoming demands may exceed the mother's resources, thus hindering coping mechanisms by providing breast milk. Knowledge about the importance of breast milk to the vulnerable infant may further put psychological pressure on mothers to reach sufficient lactation. A study with term-mothers showed, that this pressure can be incorporated by both external factors through e.g. the hospital staff or internal factors by the mothers themselves (Korth et al., 2022). To approach the possible relevance of these factors for lactation, the relevant literature on this indicated interdependency of lactation and stress is examined as follows.

Lactation and maternal stress after preterm birth

Psychological distress can be described as a rather vague concept of a distressing emotional state with non-specific symptoms, often involving depression and anxiety (Drapeau et al., 2012; Ridner, 2004). If a situation is experienced as stressful, it can be evaluated as challenging, threatening or harming. In order to cope with this situation, different strategies are used and assessed. The experience of stress, as well as assessing coping strategies are

dependent on various individual and societal factors (Lazarus R. S. & Folkman S., 1984). This process is structured in different phases. After persons are exposed to a stressor from the environment, they initially evaluate it as positive, dangerous or irrelevant. If the stressor is assessed as dangerous within the first appraisal, the resources available to reduce stress are analysed as part of the secondary appraisal. If these are not sufficient, the person perceives the situation as stressful and utilises coping strategies to overcome stress. Then, within the reappraisal, the person learns and paces its perception restarting with the primary appraisal (Lazarus R. S. & Folkman S., 1984). Therefore, this model focuses on the stress experience as an individual process. In the case of preterm birth, many stressors may be experienced by mothers, including the prematurely ended pregnancy, which may trigger stress due to role challenges, and the stressful situation of a vulnerable infant hospitalised in the NICU.

Indeed, these possible stressors may impact lactation, as well as lactation outcomes may raise stress in mothers who want to provide breast milk to their infants. The association between stress and lactation has been investigated several times. Depending on the study and measurement which was used, different results are reported. Most studies have shown that stress can affect lactation, however, the suggested pathways of this association differ. One study found out, that different sources of stress, such as postnatal depression or anxiety are correlated to breastfeeding in mothers of late preterm infants (Zanardo et al., 2011). Another study reported depression being negatively correlated to milk supply, while higher stress due to the parental role shows no association with milk supply, but with the decision to decline milk expression (Lau et al., 2007). A recent study further emphasises the relationship between stress and establishing lactation, respectively breastfeeding, being bidirectional (Nagel et al., 2022). Indeed, expressing milk may further increase stress in mothers, when they are not able to meet their goals in feeding their VLBW infant (Dowling et al., 2012; Mörelius et al., 2020). Strategies such as early and prolonged skin-to-skin contact were found to reduce stress levels of both infant and mother, adding positive effects on breastfeeding outcomes (Feldman et al., 2002; Handlin et al., 2009; Mehler et al., 2020). Creating positive experiences with lactation are particularly relevant since they have shown to be beneficial for upcoming breastfeeding events and maternal self-efficacy (Hankel et al., 2019; Huang et al., 2019). Although the recent results vary depending on the used frameworks, there is consensus that the mechanisms between stress and lactation are still rather unexplored, and more research is needed. For instance, since stress may be one reason why mothers struggle to achieve lactation after prematurity (Geddes et al., 2013; Lau, 2002, 2018). More knowledge about these mechanisms may be particularly important in mothers of VLBW infants who experience higher levels of stress than term-mothers and are at higher risk for postpartum depression (Roque et al., 2017; Zhao & Zhang, 2020).

4. Research questions

Current research shows, that both the mother and the VLBW infant benefit from lactation, respectively the nutrition with MOM is crucial for infant health outcomes. In order to reach the nutrition with MOM in VLBW infants, mothers need support to achieve sufficient lactation. This lactation support should include the evidence-based interventions, such as skin-to-skin-contact, early and frequent pumping, and the transition from pumping to breastfeeding as mentioned before. Although the positive effects of these factors on lactation outcomes are already known, many mothers still struggle to achieve sufficient lactation or reaching their goals in feeding their infant with breast milk. Given the interrelation between stress and lactation as indicated in the aforementioned studies, there is a gap in research considering the psychosocial challenges for mothers in providing breast milk to a VLBW infant. This dissertation aims at two main objectives to address these knowledge gaps, by 1) illustrating the VLBW mothers' perceptions of lactation support in German NICUs in order to describe the current state of practice, thus identifying potentials for improvement and 2) exploring the previously rather underestimated emotional challenges mothers are confronted with when providing breast milk for a VLBW infant using the theory of maternal role attainment. For instance, how mothers perceive this as stressful or potentially helpful in coping with prematurity is to be elaborated. These findings should contribute to a better understanding of mothers' perceptions of lactation and, therefore, enable health care providers to adapt lactation support even better to the (emotional) needs of mothers.

The research questions of this dissertation are:

- 1) What is the current state of lactation support in German NICUs from the mothers' perspective?
- 2) How do mothers' perceptions of developing the maternal role by providing breast milk as a source of pressure or as a resource for coping with prematurity interact with lactation?

Aim of the first publication:

To reach effective lactation support, the aforementioned key objectives, such as early and frequent skin-to-skin contact and initiation of lactation, psychosocial support and the transition from pumping to breastfeeding should be implemented in NICUs. However, no data is available on the current state of lactation support and, for instance, how it is perceived by mothers with

an infant admitted in a NICU in Germany. In order to identify room for possible interventions by interference, the status quo of lactation support needs to be illustrated. Therefore, the first publication focuses on describing the current state of lactation support in German NICUs. By using quantitative data and qualitative interviews with mothers of VLBW infants, the mothers' perceptions are illustrated. The actual research question of the first publication is:

How do mothers perceive lactation support in NICUs in Germany by means of the key objectives recommended to support and promote lactation?

This study was published in the journal "BMC Pregnancy and Childbirth" with the title "Lactation support in neonatal intensive care units in Germany from the mothers' perspective – a mixed-method study of the current status and needs" (Chapter 6) (Schwab et al., 2024b).

Aim of the second publication:

Mothers of preterm infants experience more stress, anxiety, and depression than term mothers, especially when their infant is admitted to a NICU (Malouf et al., 2022; Treyvaud et al., 2019). This may impact lactation and, therefore, aggravates difficulties establishing sufficient milk supply. Given the fact, that MOM is crucial for the infant's medical outcome, mothers may perceive a high level of pressure to provide breast milk. Furthermore, incorporating the parental role, respectively developing the own maternal role, may be difficult due to the situation in the NICU, where caregiving to the infant is not possible as expected. Recent studies lead to the idea that providing breast milk to the infant may be one factor which supports mothers in their transition to motherhood by enhancing their maternal role after prematurity (C.-K. Lee & Huang, 2022; Spinelli et al., 2016). However, if lactation is not established sufficiently and milk supply remains low, mothers who want to feed their infant with breast milk may perceive the provision of milk as stressful and a source of pressure. The aim of the second publication is to explore the pressure to provide milk among mothers of VLBW infants and its interdependence with lactation.

The research question of the second publication is:

How is pressure to provide breast milk perceived by mothers of VLBW infants and which factors are correlated to it?

This study was published in "BMC Pregnancy and Childbirth" with the title "Pressure to provide breast milk among mothers of very low birth weight preterm infants - an explorative study" (Chapter 6) (Schwab et al., 2024a).

Aim of the third publication:

In addition to the question, whether mothers perceive pressure to provide breast milk to their infants, it can be suggested that mothers may perceive the provision of breast milk as a coping resource in terms of restructuring motherhood. Research indicates that providing breast milk being both supportive and obstructive in helping mothers to cope with their prematurity, which may depend on their lactation experience (Ikonen et al., 2015). Therefore, the aim of the third publication is to elaborate whether mothers perceive providing breast milk as supportive in coping with their prematurity.

The research question of the third publication is:

How is expressing breast milk perceived as a resource for coping with premature birth?

This study was published in “Acta Paediatrica” with the title “Achieving sufficient milk supply supports mothers cope with premature birth” (Chapter 6) (Schwab et al., 2024c).

5. Methods

Research in health sciences is characterized by a high level of complexity due to the various structures and professions involved (Mayring, 2017). Mixed-method approaches can be a suitable instrument to address these complex research questions by including both qualitative and quantitative data (Creswell & Plano Clark, 2018). As elaborated before, many considerable dimensions can be eminent in the mothers' perceptions on lactation after giving birth to a VLBW infant (Figure 1). Therefore, all research papers in this dissertation adapted a triangulation of qualitative and quantitative data. Different mixed-method approaches were featured depending on the triangulation of results (Creswell & Plano Clark, 2018). According to the previously defined research aims of the three research papers of this dissertation, the data basis and methods are described as follows. Further information on the data basis and methods is given in Table 2. Full research papers are provided in the appendix. All data was conducted within the project Neo-MILK (funding code: 01NVF19027) at the University of Cologne (duration: 2021-2024).

Quantitative questionnaire

A cross-sectional, retrospective survey with mothers of VLBW infants (n=533) was analysed. A positive ethical vote from the University Hospital Cologne was received for the study (20-1547). Data was conducted from June to August 2021 in cooperation with four statutory health insurance companies (AOK Rhineland/Hamburg, TK, DAK, Pronova BKK). The questionnaire was sent to mothers who had given birth 6 to 24 months before and were identified through the following International Statistical Classification of Diseases and Related Health Problems (ICD)-10 Codes: P07.00, P07.01, P07.02, P07.10, and P07.11. The questionnaire was developed based on the current literature, including validated scales and self-developed items. The development process was supported by an interdisciplinary team of health services researchers, neonatologists, psychologists, and behavioural economists to enable multidimensional content to answer various research questions. Accordingly, the questionnaire covered questions on the birth setting, experiences with lactation support in the NICU, challenges due to lactation, psychological strain after preterm birth, experiences with milk expression and breastfeeding, and sociodemographic factors. In addition, an option to leave written comments at the end of the survey was given to enable mothers to share any further experiences. This dataset was the basis of all three publications of this dissertation. Descriptive and bivariate analysis, as well as multivariate analysis were performed, depending on the research aim of the publication. Furthermore, the written comments at the end of the survey were analysed using qualitative content analysis (Mayring & Fenzi, 2014). These were

examined in the second research paper. For the first and the third research paper, data from the quantitative questionnaire was combined with qualitative data from interviews with mothers of VLBW infants.

Qualitative interviews

Semi-structured interviews with mothers of VLBW infants (n=12) were conducted. The study received a positive ethical vote from the University of Bielefeld (2020-147). Mothers had been recruited through social media and were interviewed 3 to 12 months after their infants were discharged from the hospital. Due to the COVID-19 pandemic, the mothers were interviewed online via GoToMeetings and the audio was recorded. The interviews were conducted by a psychologist to alleviate experiences with psychological strain and reduce the risk of re-traumatization during the interviews. To depict a wide variety of the mothers' experiences, the interview guide covered topics of breastfeeding intention, breastfeeding and milk expression attitude, behaviour and norms, as well as questions on the hospital stay in the NICU, lactation support, psychological factors, and previous experiences with milk expression and breastfeeding. Data was analysed through qualitative content analysis after the audio files were transcribed and anonymised by a transcription office (Mayring & Fenzl, 2014). Two trained research assistants coded the content according to a previously developed coding scheme.

Table 2: Information on data sources, utilised contents, specific research aims, analysis sample and methods of the research papers (P1-P3)

Paper	Data basis	Utilised content	Specific research aims	Analysis sample	Analysis methods
P1	Quantitative, cross-sectional, retrospective data of mothers of VLBW infants and qualitative interview data from mothers of VLBW infants	Items on birth setting, experiences with lactation support in the NICU, timing and frequency of pumping, skin-to-skin contact, etc.	<ol style="list-style-type: none"> 1. To describe how mothers perceive lactation support in NICUs in Germany 2. To identify potential barriers for effective lactation support in German NICUs 	<p><i>n</i>=533 mothers of VLBW infants (quantitative)</p> <p><i>n</i>=12 mothers of VLBW infants (qualitative)</p>	<p>Descriptive statistics with numerical data (quantitative)</p> <p>Deductive content analysis of semi-structured interviews (qualitative)</p>
P2	Quantitative and qualitative (written comments) cross-sectional, retrospective data of mothers of VLBW infants	Items on previous experiences with lactation, pressure to provide milk, sociodemographic, Parental Stress Scale (validated), etc.	<ol style="list-style-type: none"> 1. To examine how pressure to provide milk is perceived by mothers 2. To explore which factors are correlated to pressure to provide milk 	<p><i>n</i>=518 mothers of VLBW infants (quantitative)</p> <p><i>n</i>=153 mothers of VLBW infants (qualitative)</p>	<p>Descriptive und bivariate statistics with numerical data (quantitative)</p> <p>Deductive content analysis of written comments (qualitative)</p>
P3	Quantitative, cross-sectional, retrospective data of mothers of VLBW infants and qualitative interview data from mothers of VLBW infants	Items on knowledge about MOM, experiences with guilt due to prematurity and coping by providing breast milk, etc.	<ol style="list-style-type: none"> 1. To elaborate whether expressing breast milk is perceived as a resource for coping with premature birth 2. To examine factors dependent to the perception of coping with premature birth by expressing milk 	<p><i>n</i>=12 mothers of VLBW infants (qualitative)</p> <p><i>n</i>=518 mothers of VLBW infants (quantitative)</p>	<p>Deductive content analysis of semi-structured interviews (qualitative)</p> <p>Descriptive statistics and stepwise linear regression with numerical data (quantitative)</p>

6. Results

6.1 Paper 1: Lactation support in neonatal intensive care units in Germany from the mothers' perspective – a mixed-method study of the current status and needs

Published in BMC Pregnancy & Childbirth

Impact factor at the time of publication: 3,1

Abstract:

Background: Establishing successful lactation in mothers of very low birth weight (VLBW, <1.500g) infants requires structured lactation support. Little is known about mothers' perspectives on lactation support in German neonatal intensive care units (NICUs).

Methods: This paper features a convergent mixed-method approach that includes a retrospective, cross-sectional questionnaire and interview data to showcase mothers' perceptions of lactation support in NICUs. Content analysis of the interviews (n = 12) and a descriptive analysis of quantitative data (n = 533) were performed to illustrate the current status and need for lactation support in German NICUs.

Results: The results show that lactation support in German NICUs is often inadequate and does not comply with recommendations based on the existing literature to encourage pumping and breastfeeding in mothers. The data imply that even if lactation is successfully initiated in most cases, it is often not maintained over time, which may be due to a lack of personal support and consistent information.

Conclusion: The overall structures and institutional guidelines for lactation support should be encouraged to promote nutrition with mother's own milk in German NICUs.

Reference:

Schwab, I., Wullenkord, R., Eyssel, F., Dresbach, T., & Scholten, N. (2024). Lactation support in neonatal intensive care units in Germany from the mothers' perspective - a mixed-method study of the current status and needs. *BMC Pregnancy and Childbirth*, 24(1), 282. <https://doi.org/10.1186/s12884-024-06339-9>.

Link to publication:

<https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-024-06339-9>

6.2 Paper 2: Pressure to provide milk among mothers of very low birth weight infants: an explorative study

Published in BMC Pregnancy & Childbirth

Impact factor at the time of publication: 3,1

Abstract:

Background: Pump-dependent mothers of very low birth weight (VLBW, < 1.500g) infants experience specific challenges achieving sufficient milk supply in the neonatal intensive care unit (NICU) and are therefore less frequently able to achieve (exclusive) breast milk feeding. Stress due to the limitations on participating in the infant's care may contribute to this problem. Some explorative studies suggest that pressure to provide milk may be an additional stressor in mothers. However, the type of pressure to provide milk perceived by mothers of VLBW infants has rarely been examined.

Methods: A retrospective and anonymous questionnaire was conducted with mothers of VLBW infants aged 6 to 24 months at the time of data collection. Quantitative data and written comments were used to examine the mothers' perceptions. Descriptive and bivariate tests (Spearman's rho, Pearson's χ^2) were performed to show correlations between pressure to provide breast milk, parental stress (PSS:NICU: role alteration subscale), milk volume, and maternal factors. Pressure to provide milk was measured through two self-developed single items to differentiate between internal and external pressures.

Results: Data of $n = 533$ mothers of VLBW infants was analysed. More than 70% of the mothers agreed that they pressured themselves to provide milk for their infant. In contrast, 34% of the mothers agreed that they felt pressure from outside to provide milk. Higher milk volume 14 days postpartum was significantly correlated with less internal (Spearman's rho = 0.2017, $p = 0.000$) and less external pressure to provide milk (Spearman's rho = 0.2991; $p = 0.000$). Higher PSS:NICU parental role alteration scores were significantly correlated with more internal (Spearman's rho = -0.2865, $p = 0.000$) and more external pressure to provide milk (Spearman's rho = -0.1478; $p = 0.002$). Milk volume 14 days postpartum and the PSS:NICU were not significantly correlated (Spearman's rho = -0.0190; $p = 0.701$). Qualitative analyses highlighted these results and enhanced the bidirectional relationships between maternal pressure to provide milk and milk volume.

Conclusions: Especially internal pressure to provide milk is perceived by many mothers, being mutually dependent on milk supply and parental stress. Pressure to provide milk may be an

important factor to decrease maternal stress in the NICU and, therefore, lead to more positive pumping and breastfeeding experiences. More research and validated instruments are needed to adequately measure pressure to provide milk with its different psychological, social, and environmental dimensions.

Reference:

Schwab, I., Dresbach, T., Ohnhäuser, T., Horenkamp-Sonntag, D., & Scholten, N. (2024). Pressure to provide milk among mothers of very low birth weight infants: an explorative study. *BMC Pregnancy and Childbirth*, 24(1), 134. <https://doi.org/10.1186/s12884-024-06315-3>.

Link to publication:

<https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-024-06315-3>

6.3 Paper 3: Achieving sufficient milk supply supports mothers to cope with premature birth

Published in *Acta Paediatrica*

Impact factor at the time of publication: 3,8

Abstract:

Aim: To explore whether and how expressing breast milk is perceived as helpful in coping with negative emotions due to premature birth by mothers of very low birth weight (VLBW) infants.

Methods: Qualitative interviews and a retrospective cross-sectional questionnaire with mothers of VLBW infants were conducted and analysed using an exploratory sequential mixed-method design. Hypotheses were built using qualitative content analysis and quantitatively tested using multivariate regression analysis.

Results: Interviews with 12 mothers and questionnaires of 518 mothers were analysed. Coping with prematurity by expressing milk was seen as a way to maintain the caregiving role for the mothers, where three relevant factors arose: Making up for what happened, providing the best for their infant, and fear of low milk supply. Quantitative analysis showed that mothers with a high milk supply (Coef. = 1.1, $p < 0.000$) and more feelings of guilt due to premature birth (Coef. = -0.1; $p = 0.015$) perceived expressing breast milk significantly more as a resource for coping.

Conclusion: This study adds knowledge on how expressing breast milk for their VLBW infant may support mothers in coping with premature birth, by revealing the association with milk supply and feelings of guilt due to premature birth.

Reference:

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7. Discussion

7.1 Organisational determinants of lactation support in neonatal intensive care units

Establishing mother's own milk feedings in VLBW infants comes with different challenges – but also with opportunities. When mothers decide to provide breast milk for their infants, this decision is always confounded by structural circumstances, health care settings and individual and societal beliefs, regardless of whether the infant is term-born or preterm (Rollins et al., 2016). This dissertation discusses the perceptions and experiences of mothers when providing breast milk by including several of these levels. While the status quo of lactation support in NICUs is first outlined at the organisational level in order to identify potential for interventions, the second part of this thesis focuses on rather unexplored psychosocial challenges at the individual level of the mothers. In all research papers (P1-P3), the perspective of the mothers as those affected is depicted and mixed-methods are applied to create a reflection as broad as possible.

As already discussed in the initial chapters, lactation support, as well as lactation and breastfeeding success each are a synthesis of different levels, all of which should be considered. In the case of premature birth, MOM has an even greater health significance for the infant than in the case of a term birth. However, prematurity also comes with different challenges for the mother to initiate and establish lactation. Therefore, successful lactation support, in which mothers are guided, cared for and supported, plays an essential role in this process (Nyqvist et al., 2013; Ward et al., 2021). The first research paper of this dissertation (P1) shows that there is significant unutilised potential in Germany. Collaboration between wards and the standardized transfer of information is a key factor for efficient lactation support (Bixby et al., 2016; Nyqvist et al., 2013). Regarding this, mothers mostly describe their experiences as deviating from international recommendations, which could be a central reason for the often delayed or inadequate initiation of lactation (Schwab et al., 2024b). A European study showed that these discrepancies are frequent, but with strong variations between regions (Wilson et al., 2018).

Various studies have shown the positive effect of structured interventions in NICUs on maternal lactation and breastfeeding rates of VLBW infants (Gharib et al., 2018; Meier et al., 2013; Nyqvist et al., 2013). The most widely known guideline to support mother-infant bonding and enable mothers to achieve lactation was developed by UNICEF (United Nations International Children's Emergency Fund) and the WHO. It includes ten steps, also for the neonatal healthcare setting based on current research. The baby-friendly hospital initiative (BFHI) adds organisational components to fulfil a complete programme for hospitals and/or neonatal units

(World Health Organization, 2020). Its effectiveness on breastfeeding outcomes and hospital practises has been proven many times (Mäkelä et al., 2022; Pérez-Escamilla et al., 2016). However, some barriers are reported when implementing BFHI. Whereas the guideline and the ten steps are openly available, the full BFHI-programme including implementation tools and staff training is not cost-free. To facilitate access to financing options, a study elaborated effective ways to acquire funding to cover the costs of BFHI for the United States and Mexico (Arslanian et al., 2022). However, due to the different healthcare and policy structures, these findings may be hardly replicated in other countries, thus implicate the need for more international research (Arslanian et al., 2022). Other studies outlined that additional barriers to the implementation of the BFHI include the endorsement of governmental policy makers and the presence of effective leadership (Semenic et al., 2012; A. Walsh et al., 2023). In particular, within the context of neonatal care, infrastructural barriers that lead to parent-infant separation, high workloads, and interprofessional collaboration are prevalent (Benoit & Semenic, 2014). The first research paper (P1) elaborated that lactation support is suboptimal, which may stem from these missing structures and the lack of interprofessional collaboration over all hospital wards (Schwab et al., 2024b). Considering the already discussed findings, it becomes evident that apart from the ten steps within BFHI, a cost-free intervention involving the relevant stakeholders in policy and health care settings is necessary to improve the structures of lactation support.

Furthermore, the research paper P1 indicated that mothers require more information and opportunities for psychological support in the period following premature birth. The lack of structures for personalized lactation support, as reported by mothers, may lead to limited possibilities to address their individual challenges after prematurity (Schwab et al., 2024b). In general, the question arises to what extent an intervention, which aims to increase the number of infants fed with MOM should focus on the mother-infant dyad and mothers as the ones actually providing the milk (Diez-Sampedro et al., 2019; A. D. Walsh et al., 2011). In particular, they call for supporting mothers in their individual challenges after prematurity and within the situation in the NICU, as negative experiences may have an impact on the long-term psychological outcomes of preterm mothers (Treyvaud et al., 2019). To achieve optimal nutrition for infants admitted to a NICU, it may be beneficial to consider whether the goal of becoming a "baby-friendly" facility should be aligned with the objective of becoming a "mother-infant-friendly" facility. Indeed, supporting mothers in achieving their personal lactation goals may be protective against various negative psychological outcomes in mothers of VLBW infants (Boucher et al., 2011; Hoban et al., 2015; Mörelius et al., 2015). However, by describing the challenges of VLBW mothers during lactation (Chapter 3), it becomes evident that there are still gaps in knowledge which should be explored to enable healthcare providers to offer suitable support to mothers.

7.2 Findings on psychosocial (role-)challenges and opportunities during lactation

The second part of the dissertation focuses on the psychosocial challenges that arise when mothers want to provide breast milk for their infant. Therefore, the theoretical framework of maternal role attainment is used. Within this, developing the maternal role is seen as a process of transition that involves different stages. In the case of a very preterm birth, this can be interrupted and aggravated (Mercer, 1985, 1986, 2004). Preterm birth can be assumed as being a disruptive life event, leading to post-traumatic stress disorder, and oftentimes feelings of guilt, sadness and shame (Baum et al., 2012; Beck & Harrison, 2017; Rossman et al., 2013). These negative feelings can in turn produce more stress and thus have a negative impact on lactation (Lau, 2002, 2018; Zanardo et al., 2011). However, when stress is perceived, mothers may utilise various coping strategies to rebuild a connection with their infants. Little consideration has been given so far to whether providing breast milk may be perceived by mothers as a method for developing the maternal role through caregiving and which stressors or coping potentials could arise from this. The results of this dissertation suggest that the provision of breast milk may represent a way of developing the maternal role for mothers. Nevertheless, this potential is extremely fragile and dependent on a wide variety of factors.

In specific, the interruption of the first stage of maternal role attainment during pregnancy through premature birth has been identified as a potential stressor for mothers (C.-K. Lee & Huang, 2022; Spinelli et al., 2016). The early ending of the pregnancy also interrupts the bond between mother and infant. Additionally, the situation in the NICU, where mother and infant are often separated, increases the physical and emotional distance. The inability to breastfeed the infant reduces the opportunities for intensive physical contact between mother and infant. Recreating skin-to-skin contact in other ways may be central for feelings of connection with the infant, thus promoting the mother-infant bond (Ciciolla et al., 2024; Gathwala et al., 2008; Tallandini & Scalembra, 2006). Another potential way of restructuring this connection and coping with premature birth involves the provision of breast milk, which has been described in some qualitative studies (Abu Bakar et al., 2019; Flacking et al., 2006; Flacking et al., 2007; Ikonen et al., 2015; Sweet, 2008a). Nevertheless, studies have indicated that this potential is highly susceptible to the origins and levels of stress in the situation of premature birth and lactation problems (Abu Bakar et al., 2019; Ikonen et al., 2015). The second and third research papers (P2, P3) reflect these findings.

The second research paper (P2) indicated that the decision to feed the infant with breast milk often results in stress and pressure. In the majority of cases, mothers put themselves under pressure to provide breast milk for their infant, but they also feel this pressure from outside. These feelings were correlated with the amount of milk the mothers achieved and other circumstances, such as stress caused by the situation in the NICU and previous experience with expressing breast milk. Moreover, it revealed that this kind of pressure was a very common phenomenon among mothers of VLBW infants (Schwab et al., 2024a). This may be a critical issue given that stress and lactation are presumably negatively associated, thus stress should be reduced in mothers of VLBW infants (Geddes et al., 2013; Zanardo et al., 2011). The third research paper (P3) illustrated how mothers perceive expressing breast milk as a coping resource. In this regard, mothers described expressing breast milk as a way to maintain the caregiving role and making up for what happened through providing the best for the infant. These feelings of guilt due to premature birth and the achievement of sufficient lactation in terms of a high milk supply showed to be of decisive relevance in the regression model (Schwab et al., 2024c). Accordingly, the triangulation of these results reveals a picture in which lactation, stress, and coping are in constant interaction, based on striving and managing to develop the maternal role. Figure 3 outlines these interdependencies of maternal role attainment after premature birth by providing breast milk, stress and coping.

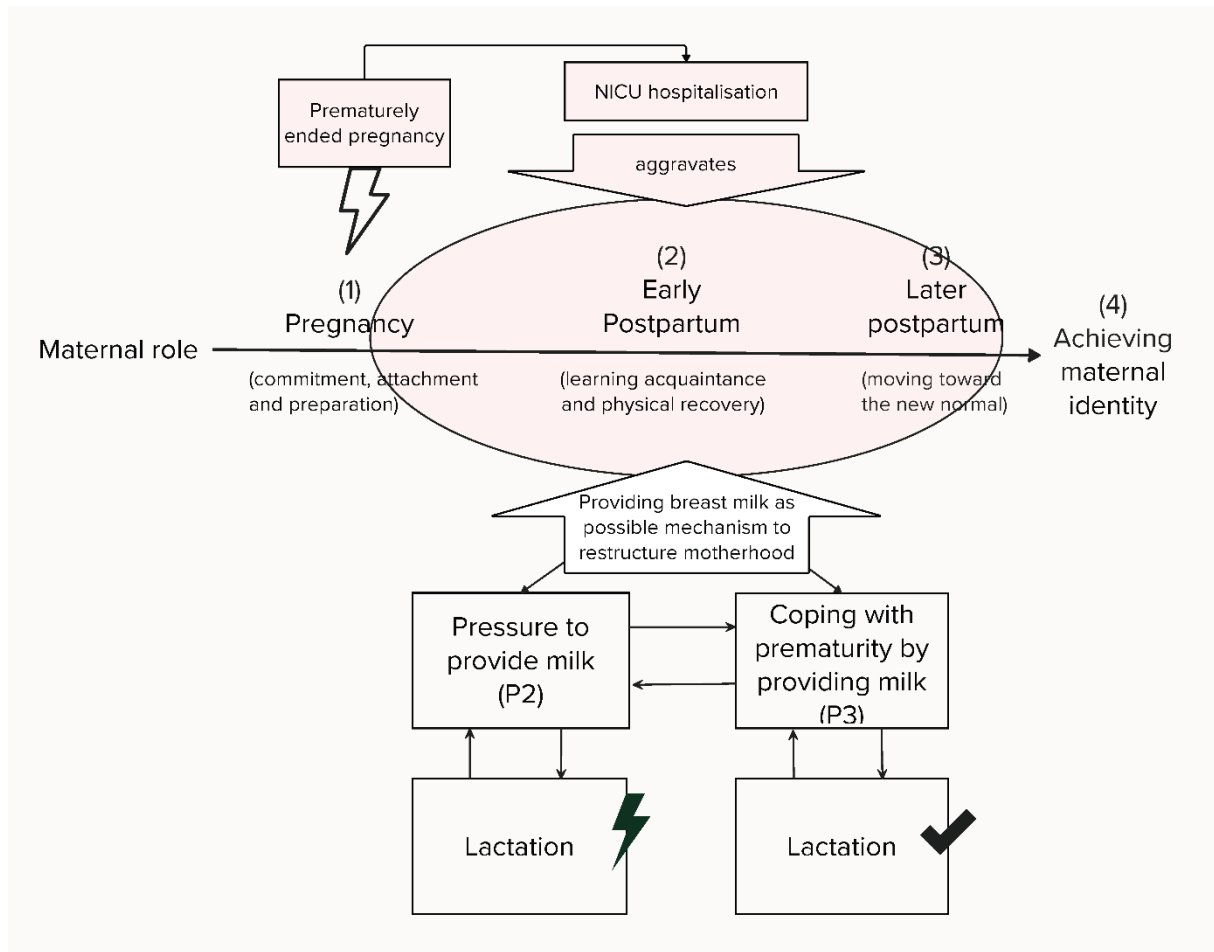


Figure 3: Interdependencies between lactation, stress and coping through the process of developing the maternal role after prematurity (own illustration)

According to the results of the research papers P2 and P3, restructuring the process of developing maternal role through the provision of breast milk could be an important determinant in explaining the context between coping, stress and providing breast milk. Nonetheless, the application of this theory to the issue addressed here must also be viewed critically. It was postulated several decades ago and may not consider the changes regarding the maternal role in the recent years. The role of women in Western society, including their role as mothers, has undergone a significant transformation as a result of the emancipatory movement. While motherhood was previously considered to be the core of a woman's role, the opportunities for women have increased as a result of social change and emancipation. This has subsequently led to an increase in women's political ambitions for gender equality (Bundeszentrale für politische Aufklärung, 2009; Meyer, 1980). This resulted, for example, in an increasing acceptance of working mothers in Germany (Alwin et al., 1992; Banaszak, 2006; Diabaté, 2021a). The advent of formula feeding has allowed the previously vital breast milk to be replaced by artificial milk as the newborn's food. This has led to a softened role for the mother as a direct nourisher (Stevens et al., 2009). Indeed, current research shows that attitudes towards motherhood changed over the last decades. However, when considering the

division of family roles, the perception of mothers as the primary caregivers remains pervasive (Diabaté, 2021b). It can be assumed that the expectation of mothers to provide breast milk is often present, although the extent to which this is seen as a mother's role is open to debate.

Nevertheless, it should be noted that the group of mothers of VLBW infants may not be comparable to mothers of term newborns. As described in Chapter 3, the theory of maternal role attainment is based on role theory as described in symbolic interactionism. Therefore, developing the maternal role is characterised by role-making, where a person is dependent on role partners. However, in the case of preterm birth, where developing the maternal role is being interrupted between its stages, inter- and intra-role conflicts due to this special situation may be dominant. The need to continuously adapt their roles to partner roles within the NICU, which include the infant, partner, and healthcare staff, may further complicate their process of developing the maternal role. Considering the provision of breast milk, it should be mentioned that the lactation initiation rate is higher than the breastfeeding rate following a term birth (Colaizy et al., 2012; Jonsdottir et al., 2022). This discrepancy may be attributed to the fact that expressing breast milk is not directly comparable to breastfeeding. It is possible that a mother may choose to express milk for her infant, yet simultaneously refrain from breastfeeding. Despite this, there is a paucity of explanations for the high initiation rate among mothers of VLBW infants. It is possible that the initiation rate is dependent on lactation support, as well as it may be influenced by education and previous experience with lactation (Niela-Vilén et al., 2016; Smith et al., 2003). Moreover, formula feeding carries higher risks for the medical outcome of VLBW infants than for term infants. This potentially may lead mothers to decide more frequently to feed their infant with breast milk or to revoke their previous decision to feed formula (Bower et al., 2017; Parker et al., 2020).

Another reason for the decision to provide breast milk could be the investigated phenomenon that mothers use the provision of breast milk as a path to develop their maternal and caregiving role, which is aggravated due to premature birth. However, it should be recognised that this mechanism does not necessarily apply to all mothers who feed their infant with breast milk and that some also decide not to express breast milk. Indeed, there are also mothers who do not feel a connection to their infant through the provision of milk, but rather feel a loss of autonomy and a lack of control (Schmied & Lupton, 2001). This indicates that in addition to providing breast milk, there have to be other processes by which mothers establish a connection to their infant after a premature birth and experience the transition to motherhood. In this regard, frequent and prolonged physical contact between mother and infant should be focused, for instance. In addition to nutritionally feeding the infant, breastfeeding also has the affective function of bonding. If breastfeeding is not possible after a premature birth, or if the mother decides not to breastfeed, this bonding function is further missing. In the case of premature birth, bonding is further complicated by the need to care for the infant in an incubator. This

again emphasizes the relevance of bonding in terms of skin-to-skin contact between mother and infant, as well as opportunities for participating in the infants care to support the transition to motherhood after preterm birth (Ciciolla et al., 2024; Flacking et al., 2006; Lupton & Fenwick, 2001).

In one of her recent publications, Mercer (2004) posits that the theory of maternal role attainment does not fully account for the social environment of the (expectant) mother, leading to a slight modification of its content. In particular, she focuses on the need to reformulate maternal role attainment into "*becoming a mother*" to indicate the transitional process of achieving maternal identity. This approach thus shifts the focus, at least in terms of language, away from the traditional role of women as mothers and towards a theory that describes the transition to motherhood in more detail (Mercer, 2004). However, role theory is a useful tool to explain interrelationships between social expectations and individual perceptions, especially in the context of parenting (Major, 2003; Mowder, 2005). Considering social roles and processes showed to have also a high relevance in lactation support for VLBW mothers. As already described at the beginning of this dissertation by using the model of Rollins et al. (2016), societal determinants are of great importance in the knowledge of the benefits of breast milk, the decision to initiate, and the duration of breast milk feeding. Moreover, the level of the family and the social environment, which characterizes the individual setting are of relevance. All these factors may have an influence on the individual perception of mothers. For example, social norms are known to have a great impact on a mother's decision to feed her infant with breast milk (Matriano et al., 2022; Russell et al., 2022). However, they can also trigger negative emotions such as failure and guilt when mothers are not able to fulfil these expectations (Hvatum & Glavin, 2017; Jackson et al., 2021). This reinforces the differences in the prerequisites of mothers, not only in terms of knowledge but also in terms of attitudes and personal resources. Therefore, it is particularly relevant to describe different views and experiences from the mothers' perspective in order to better adapt their care to their needs.

7.3 Strengths and Limitations

In this dissertation, the provision of breast milk for a VLBW infant is examined from an organisational and an individual point of view. Therefore, it adds knowledge about lactation support in NICUs in Germany, and contributes to a better understanding of the rather unexplored individual (role-)challenges of mothers after premature birth. However, the research papers included in this dissertation have some limitations. These primarily relate to the single quantitative data source, the cross-sectional study design and the one-dimensional perspective on the research questions. All quantitative analyses in the research papers (P1,

P2, P3) are based on one retrospective survey with mothers of VLBW infants after 6 to 24 months of giving birth. This time frame was chosen to reduce the risk of re-traumatization after preterm birth (Kersting et al., 2004). This may have led to recall bias among mothers (Dreier et al., 2012). Furthermore, the variance of sociodemographic characteristics in the quantitative sample (e.g. educational level) was rather low, which may be an indicator for self-selection in the responses to the questionnaire. The limitation of self-selection also applies to the qualitative sample (P1, P3), as the recruitment was based on voluntary participation of mothers, who responded to an open invitation on social media. Thus, mothers who made specific experiences in either a negative or positive manner may have self-selected themselves into the interviews. Additionally, the qualitative samples included only 12 mothers, which might further have led to lacks in data saturation (P1, P3). This also applies to the option to enter written comments after the quantitative survey (P2), which was voluntary for the mothers.

Moreover, no causal correlations could be stated, since analyses were performed on a bivariate level, using descriptive statistics (P2). The same limitations arise when performing multivariate models with cross-sectional data (P3). In addition, given that the individual, psychosocial challenges addressed in the second and third research aims (P2, P3) are rather unexplored, there were no adequate measurements available at the time of data collection. Due to this lack of scales, all items on pressure or coping by providing breast milk were self-developed. The wording of the items may have influenced the responses and, consequently, the results. Findings should be interpreted cautiously, as no validation of the items (e.g. variables on pressure and coping) took place. In the research papers of this dissertation only mothers, who initiated lactation and, therefore, made at least the initial decision to feed their infants with breast milk, were included. Thus, the findings and implications may not apply to mothers who choose not to provide breast milk for their infant. Moreover, as this dissertation focuses on the mothers' perspectives of lactation support, no other involved group was surveyed along the research papers. It would have been beneficial to gain further insight into the perspectives of other stakeholders involved in lactation support, such as NICU staff, midwives, and physicians. This could have helped to identify additional barriers and potential opportunities for improvement.

The main strengths of the underlying research papers of this dissertation are the utilisation of theoretical models to derive the research questions and empirical testing. Additionally, the dissertation utilises mixed-method approaches, which illustrate the mothers' perceptions. By applying the theory of maternal role attainment to the special situation of providing breast milk to an infant in the NICU (P2, P3), this dissertation contributes to knowledge about maternal psychosocial challenges and opportunities. Concerning the data basis, the quantitative data set with responses from 533 mothers represents a large sample, especially against the

background of a rather small group of mothers of VLBW infants. Finally, within this sensitive and individually perceived topic of providing breast milk to an infant admitted in the NICU, the triangulation of qualitative and quantitative methods allowed to illustrate a wide range of maternal experiences with lactation support (P1) and the relevance of providing breast milk to develop the maternal identity after prematurity (P2, P3).

7.4 Implications for research and practice

Implications for research

When investigating structural deficiencies in organisations, the involvement of various stakeholders is relevant. Within the first research paper (P1), the mothers' perspective was determined to explore their perceptions with lactation support. However, as mentioned before, it would be interesting to focus on the different point of views to examine further potential for improvement. Especially organisational determinants within the different NICUs may be an important factor to consider when developing possible interventions and, for instance, when implementing them. Recent research has elaborated potential facilitators and barriers for interprofessional communication in the hospital setting (L Gleeson et al., 2023). However, it is unclear whether these findings can be adapted to the specific situation of mother-infant dyads, which represent the healthcare needs of two groups of patients in a hospital setting. Consequently, further research on organisational and implementation science is required to reinforce interprofessional communication and collaboration between different hospital wards and professions, thereby facilitating consistent information sharing.

The research papers (P2, P3) explored whether providing breast milk may be one mechanism which helps VLBW mothers to develop their maternal role. As mentioned above, due to the lack of validated scales, self-developed items had to be used to measure these constructs. The transition to motherhood after premature birth has various determinants and is a multidimensional process. Besides individual preconditions, it is influenced by sociological processes and never free from norms and (role-)expectations, that are linked to them. At least, the topic of pressure linked to lactation gained more attention during the last years which is reflected by a number of publications (Diez-Sampedro et al., 2019; Jackson et al., 2024; Korth et al., 2022). However, there may still be a lack of knowledge about these processes and preterm mothers' challenges, which should be investigated in the future. Therefore, further research should focus on developing scales and validate them in order to measure these psychosocial challenges more specifically. In particular, with a focus on mothers with an infant admitted to a NICU, as this situation is hardly comparable with the transition to motherhood in term-mothers.

Furthermore, due to the aforementioned limitation of the cross-sectional design of data collection, the research papers (P2, P3) to answer the second and third research aim were limited in their statistical analyses. Therefore, neither a direction of correlation, nor any causal relationships could be stated in the results. To be more specific, it would be of interest whether pressure to provide breast milk influences the mothers' milk supply or alternatively, whether mothers only feel pressured, when their milk supply declines. In terms of the third research paper, the same question arises, whether coping by providing breast milk may predict milk supply or if only a high milk supply enables mothers to cope with prematurity by providing breast milk. Consequently, future research should focus on collecting longitudinal data to investigate possible causal relationships between pressure to provide breast milk, respectively coping by providing breast milk, and lactation. Moreover, by including more validated scales on maternal stress, further possible mechanisms with other stressors or resources could be included. This may reveal more complex relationships between, for example postpartum depression, lactation, and pressure to provide breast milk, or post-traumatic stress disorder after preterm birth and coping by providing breast milk. It becomes clear that although this dissertation brings many new insights, there is still a great need for further, knowledge-widening research in this area.

Implications for practice

With regard to the organisational gaps in lactation support in NICUs, the implementation of integrated lactation support across all wards should be encouraged (P1). Even though evidence-based interventions are available, financial requirements result in obstacles to implementation. The project Neo-MILK, within which all the used data of this dissertation were collected, aims to reach this by providing not only the evidence-based information for both parents and healthcare providers, but also strategies to implement this intervention (Scholten et al., 2023). It is a cost-free option to support NICUs in Germany to improve lactation support. Until now, however, the effectiveness of the intervention is still being evaluated and no preliminary results are available. Soon, there will be certainty about whether this intervention may be an efficient option for implementing structured lactation support in German-speaking countries. In this case, this intervention could represent an accessible option for establishing cross-ward and beyond that inter-hospital structures.

Developing the maternal role through caregiving shows to be central for many preterm mothers and providing breast milk may be one opportunity to establish their role after premature birth within the presumably stressful NICU environment (P2, P3). This potential is, however, depending on many factors. Whereas mothers should be encouraged to provide breast milk to their infants, they face barriers and challenges by doing so. When supporting mothers during

lactation, healthcare providers should be aware of the fact, that lactation and breastfeeding are always part of societal norms, role expectations, attitudes, and beliefs. Therefore, lactation support does not begin when entering the hospital, but is a societal responsibility that should be addressed earlier on. Mercer & Walker (2006) elaborated that various environments, including family and friends, community, and the society at large should be engaged to adequately facilitate the process of becoming a mother. Further, maternal care, preparing the social role, and promoting mother-infant attachment by enhancing the importance of the combination of all levels are focused (Mercer & Walker, 2006).

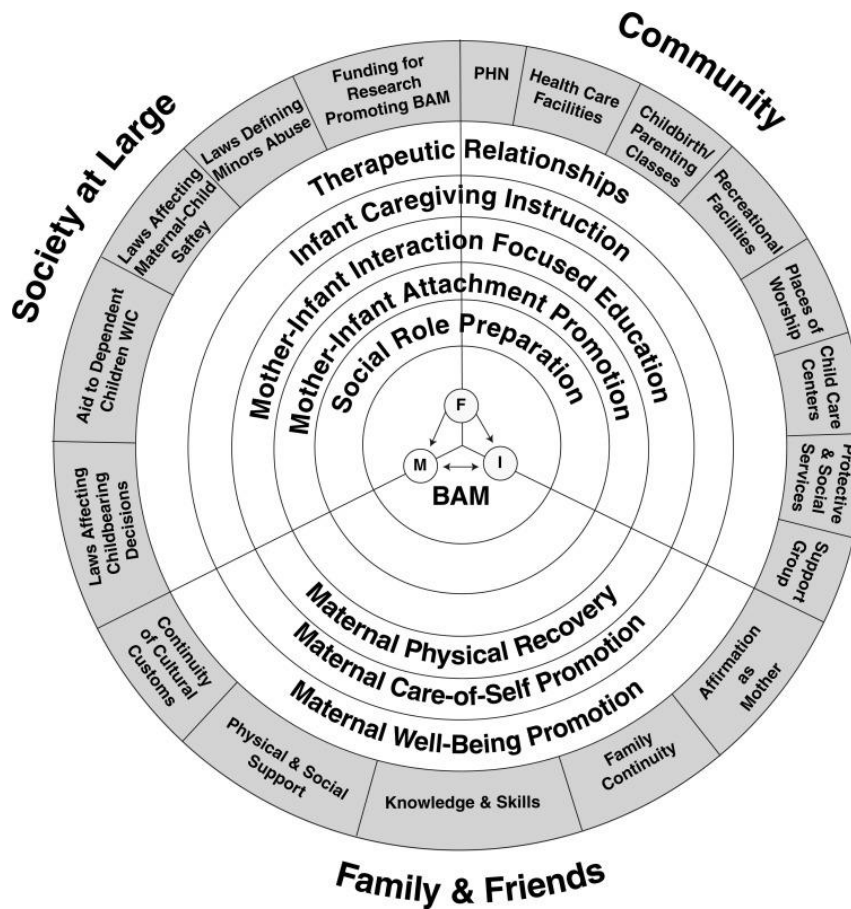


Figure 4: The interacting environments that have the potential to facilitate or inhibit the process of becoming a mother (Mercer & Walker, 2006)

If the goal is to enable mothers to feed their infants with breast milk, regardless of whether they are premature or full-term infants, policymakers need to adopt a stronger public health approach to this important issue. Despite these complex contexts in which mothers experience their reality, this dissertation demonstrates that still healthcare providers have the opportunity to make an impact on the mothers' perceptions.

However, it should be considered that healthcare providers who are working in intensive care units have to deal with a stressful working environment, where time-pressure and critical

situations are common. The NICU setting is particularly special since, although the patients to be cared for are the infants, NICU staff additionally provides emotional and practical support for the parents. Supporting mothers in lactation and their emotional challenges may therefore be difficult to implement reliably within the daily tasks. In this context, further achieving sensitive communication with regard to individual maternal perceptions at all times requires a high level of dedication by the NICU staff. However, if successful, their impact for maternal mental health, as well for nutritional outcomes in VLBW infants, can be substantial. All research papers of this dissertation implicate that the best support for mothers is personal, consistent, motivating, and valuing. NICU staff may be sensitive to pressure perceived by mothers, especially the one that stem from mothers themselves. In order to enable any coping potential by providing breast milk, presumably encouraging preterm mothers creating positive experiences with lactation is to be aimed for. These experiences may be defined positive in different ways, however, positive responses from healthcare providers and peers, and, at the same time the highest possible physical mother-infant contact seem to be central in achieving them (Flacking et al., 2021).

8. Conclusion

This dissertation focuses on how mothers of VLBW infants experience lactation after preterm birth. It includes both the organisational level of lactation support in German NICUs and the individual challenges faced by mothers. Within the first research aim, the need for improvement is discussed, especially in the cooperation between wards and the standardisation of lactation support concepts across healthcare providers. This contribution not only highlights the lack of concepts for, but above all the need for support in implementing them. The second and third research aims focus on the challenges and opportunities of providing breast milk to mothers of VLBW infants. By applying a theoretical model, explicit research questions were derived and triangulated. Using the theory of maternal role attainment, a model was developed that explains the specific interactions between lactation, stress, and coping potential by providing breast milk in the process of developing the maternal role after a premature birth. This dissertation thus emphasizes the fragility of the lactation situation for mothers after the birth of a VLBW infant. Nevertheless, the findings also show great potential and new perspectives for NICU staff in the care of mothers of preterm infants. It becomes clear that the feeding of infants with breast milk in the case of premature birth and term birth has many determinants. Thus, lactation support can never be the matter of healthcare providers alone but is a relevant public health issue with a need to also involve societal determinants. In this way, this dissertation also highlights opportunities for direct action. On an organisational level, it outlines gaps in lactation support from a mothers' perspective, some of which can be closed by interventions that already exist or are currently being evaluated. It shows a need for further research in order to include other perspectives, create a more complete picture, and identify further barriers to implementation of interventions. It also points out that there is a need for further research at the individual level. In particular, longitudinal studies to include further interrelationships and to discuss potential causal relationships between the mechanisms of stress, coping and lactation after premature birth are to be aimed for. While this dissertation presents complex challenges at the individual level, it expands the knowledge of maternal experiences. This enables healthcare providers to better address the challenges of developing the maternal role and thus offers new potential for improving maternal mental health during lactation after preterm birth.

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Declaration of contributions

The first author of all publications is the doctoral candidate Isabella Schwab (Publication 1: shared first authorship). The contributions of the first author and co-authors are as follows:

Publication 1:

This publication was realised in cooperation with project partners from Bielefeld University. Qualitative data was collected and analysed for the mixed-method study at Bielefeld University (Ricarda Wullenkord). As part of a project team, Isabella Schwab created the quantitative questionnaire and analysed the quantitative data. In cooperation with her colleague from Bielefeld University (Ricarda Wullenkord), Isabella Schwab designed and wrote the publication. Nadine Scholten supervised the conceptualisation. Friederike Eysel, Till Dresbach and Nadine Scholten reviewed the manuscript.

Publication 2:

As part of a project team, Isabella Schwab created the quantitative questionnaire, designed the research project, and analysed the quantitative data. She wrote the publication. Nadine Scholten supervised the conceptualisation. Tim Ohnhäuser, Till Dresbach, Dirk Horenkamp-Sonntag and Nadine Scholten reviewed the manuscript.

Publikation 3:

This publication was realised in cooperation with a project partner from Bielefeld University. For the mixed-method study, qualitative data was collected and analysed by the colleague Ricarda Wullenkord at Bielefeld University. As part of a project team, Isabella Schwab created the quantitative questionnaire, designed the research project, and analysed the quantitative data. She wrote the publication. Nadine Scholten supervised the conceptualisation. Tim Ohnhäuser, Till Dresbach and Nadine Scholten reviewed the manuscript.

Nadine Scholten

Prof. Dr. Nadine Scholten (Supervisor)

Appendix (copy of research papers 1-3)

Research Paper 1

RESEARCH

Open Access



Lactation support in neonatal intensive care units in Germany from the mothers' perspective – a mixed-method study of the current status and needs

Isabella Schwab^{1†}, Ricarda Wullenkord^{2*†}, Friederike Eyszel², Till Dresbach³, Nadine Scholten¹ and on behalf of Neo-MILK

Abstract

Background Establishing successful lactation in mothers of very low birth weight (VLBW, <1500g) infants requires structured lactation support. Little is known about mothers' perspectives on lactation support in German neonatal intensive care units (NICUs).

Methods This paper features a convergent mixed-method approach that includes a retrospective, cross-sectional questionnaire and interview data to showcase mothers' perceptions of lactation support in NICUs. Content analysis of the interviews ($n = 12$) and a descriptive analysis of quantitative data ($n = 533$) were performed to illustrate the current status and need for lactation support in German NICUs.

Results The results show that lactation support in German NICUs is often inadequate and does not comply with recommendations based on the existing literature to encourage pumping and breastfeeding in mothers. The data imply that even if lactation is successfully initiated in most cases, it is often not maintained over time, which may be due to a lack of personal support and consistent information.

Conclusion The overall structures and institutional guidelines for lactation support should be encouraged to promote nutrition with mother's own milk in German NICUs.

Keywords VLBW infants, Preterm birth, MOM, Mother's own milk, Lactation, NICU, Neonatal intensive care unit, Neo-MILK, Lactation support

Background

In Germany, more than 10.000 children with very low birth weight (VLBW, <1500g) are born every year [1]. The availability of mother's own milk (MOM) in neonatal intensive care units (NICUs) is particularly important for VLBW infants due to its multiple positive effects on their health outcomes [2, 3]. These include a reduced risk of bronchopulmonary dysplasia (BPD), late onset sepsis, and necrotizing enterocolitis (NEC) [2, 4]. To achieve an effective initiation of lactation and to support mothers

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during the lactation process after giving birth to a VLBW infant, structured lactation support is required [5, 6].

The current literature provides recommendations on which interventions support establishing lactation in mothers of VLBW infants [7, 8]. To initiate lactation after preterm birth, mothers need to express milk as soon as possible, at best, within 6 h after birth [9]. Infants of mothers who initiate lactation later are at a higher risk of not being exclusively fed with MOM [10]. To facilitate this early lactation initiation, mothers need to be informed about the benefits of human milk, including MOM and donor human milk, ideally before birth [11]. In addition, preterm mothers should be instructed in manual milk expression as well as the use of an electric pump [12, 13]. Early instruction is particularly important to avoid formula feeding and ensure that colostrum is the first feed that preterm infants receive [14]. To foster continued feeding with MOM, a milk volume of at least 500ml/day should be reached by day 14 post-partum [15]. Moreover, the transition from pumping to breastfeeding showed to be crucial for achieving prolonged breastfeeding for the first six months of life and is recommended by the World Health Organization (WHO) [16, 17]. Early and prolonged skin-to-skin contact raises maternal oxytocin levels and has been shown to also be important for lactation [18, 19]. This includes family centered care, which allows the mother or parents to see and touch their child at all times [20].

In addition, taking psychological issues into account is particularly important when aiming to initiate and/or enhance lactation in preterm mothers, as premature birth can lead to psychological problems and/or aggravate pre-existing psychological conditions [21, 22]. A variety of psychological factors such as post-partum depression can influence breastfeeding and lactation behaviour [23, 24]; however, negative breastfeeding and/or lactation experiences can lead to and/or aggravate mothers' psychological issues [25], especially if the experience does not meet the expectations [26]. It is, therefore, important to consider the mutual relationship between the mothers' psychological well-being and lactation as well as breastfeeding. Institutional lactation support should aim to consider both the maternal psychological and physiological resources after preterm birth. To date, little is known about how mothers of VLBW infants experience lactation support in German NICUs.

This study aims to examine lactation experiences and perceived (emotional) challenges among mothers of VLBW infants in German NICUs. The data presented in this paper were collected within the Neo-MILK project, which intends to provide human milk for every VLBW infant from the first day of life in German NICUs [27]. This paper examines the key objectives of

lactation support in the NICU in order to illustrate the status quo of lactation support in German NICUs from the mothers' perspective, as recommended by the literature. Quantitative and qualitative data will be combined in a mixed-method approach.

Methods

Both data collections were performed as part of the Neo-MILK study. This study was funded by the Innovation Fund of the Joint Federal Committee (funding code: 01NVF19027) and registered in the German Register of Clinical Trials (ID: DRKS00024799, date of registration: 04/05/2021). It received a positive ethical vote from the University Hospital Cologne (20–1547) and Bielefeld University (2020–147). The interview questions and the quantitative questionnaire were developed in parallel and reviewed by both qualitative and quantitative research teams. Data collection occurred in quick succession and analyses were mostly performed in parallel. Therefore, this study applies a convergent mixed-method research design [28].

Quantitative questionnaire

Data collection

Quantitative data were obtained from a written, anonymous survey of mothers of preterm infants with a birth weight less than 1500g, 6–24 months after birth. The time point was chosen to minimize the probability of re-traumatization [29]. The self-developed questionnaire contained questions on maternal (e.g., age, education, previous experience with pumping, number of children) and neonatal (e.g., gestational age, birth weight) factors; birth setting (e.g., caesarean section, complications during birth), and lactation support (e.g., whether they were given information about MOM, pump instructions, or manual milk expression). Data were collected from June to August 2021 in cooperation with four statutory health insurance companies (AOK Rhineland/Hamburg, DAK, Pronova BKK, and TK).

Data analysis

A total of 600 mothers participated in the survey, representing a response rate of 31,67%. After excluding data from mothers who failed to meet the inclusion criteria, the final sample included $n=533$ cases. In order to describe the current status quo, nominal data is presented in percentages. In the case of Likert scales (six-point), means and standard deviations (SD) are presented. All statistical analyses were performed using STATA 16.

Qualitative interviews

Data collection

Qualitative interviews were conducted with $n=12$ mothers of preterm infants with a birth weight of below 1500g. Recruitment methods included an Instagram post on the Neo-MILK Instagram account and information distribution about the ongoing study on the NICUs participating in the Neo-MILK projekt at the time of the data collection. Interested mothers then contacted the responsible researchers, were screened regarding the exclusion criteria (see below) and appointments were made if the requirements were met until the previously set goal of $n=12$ participants was reached. Mothers were interviewed 3 to 12 months after their child had been discharged from the hospital to balance re-traumatization risk and the ability to remember sufficient details. One mother of whose twins only one survived and who wanted to participate in the interview was excluded in order to avoid re-traumatization. Due to the COVID-19 pandemic, interviews were conducted remotely via GoToMeetings and the audio was recorded. The interviews were held in the German language. To prevent potential data loss due to equipment failure, a transcript writer was present during the interviews, given the mothers had provided consent for this. The semi-structured interviews were conducted by a psychologist to alleviate the potential experience of psychological strain. The interview guide consisted of 113 questions, covering the topics of breastfeeding intention, current breastfeeding and pumping behavior, breastfeeding and pumping attitudes and related norms, infants' stay at NICU (e.g., framework data, breastfeeding and pumping behavior during the stay), lactation and breastfeeding support (e.g., by hospital/NICU staff and partner), psychological stress factors, gender role orientation, previous breastfeeding and pumping behavior (i.e., for previous children), opinions and preferences regarding breastfeeding apps, and demographic questions (such as age, vocational status, and religion). A translated version of the interview guide including all questions that were asked can be found in the supplemental material.

Data analysis

The audio files were transcribed and anonymized for follow-up qualitative content analysis [30] by a transcription office and were coded by two trained research assistants according to a previously developed coding scheme (Additional files 1 and 2). For all key objectives of lactation support, positive and negative anchor examples were identified, with positive anchor examples illustrating cases in which the lactation support was consistent with its respective objective, whereas negative anchor examples reflected

cases in which the criteria were not met. More specifically, we focused on such quotations that gave additional insight into the reasons why the data presented a certain way, such as offering explanations. The quotations showcased in this paper were translated to English. Quotations were selected to illustrate a wide range of perceptions of mothers with different experiences in lactation support. If necessary, quotations were redacted for clarity, which is indicated by square brackets. The usage of caps lock in the quotations indicates special emphasis put on certain words.

Results

Information on sociodemographic characteristics of both data is given in Table 1. Results are structured in accordance to the aforementioned key objectives to foster lactation (Table 2).

Table 1 Sociodemographic data

Quantitative data	
	<i>n</i> , (Mean; SD [min-max])
Maternal age	500 (34.1; 4.9 [19-54])
Gestational age (weeks)	519 (28.6; 3 [22-36])
	<i>n</i> , (%)
Educational Level	
Without a graduation	11 (2.1%)
Lower secondary school	52 (9.8%)
Secondary school	119 (22.3%)
Higher education entrance qualification	124 (23.3%)
University degree	215 (40.4%)
Missing	12 (2.3%)
Native language German	
Yes	413 (77.5%)
No	110 (20.6%)
Missing	10 (1.9%)
Qualitative data	
Maternal age	12 (34.5; 3.59) [29 – 40]
Children's age at time of data collection (months)	Corrected (7.04; 2.56) [3-11] Uncorrected (9.54; 2.79) [5-14]
Educational Level	
Without a graduation	0 (0%)
Lower secondary school	0 (0%)
Secondary school	1 (8.33%)
Higher education entrance qualification	10 (83.33%)
University degree	1 (8.33%)
Missing	0 (0%)
Native language German	
Yes	12 (100%)
No	0 (0%)
Missing	0 (0%)

Table 2 Key objectives of lactation support

1. Informing all mothers and parents with a risk of premature birth about breastfeeding and pumping
2. Skin-to-skin contact in the delivery room with gradations (If skin-to-skin contact is not possible in the delivery room, touching the child and at least seeing the child directly after birth)
3. Initiation of lactation within one to four hours after birth, latest within six hours after birth with the gold standard to combine pumping and manual milk expression
4. Colostrum as the first feeding and no formula feeding
5. Maintain lactation with a pumping frequency of at least eight to ten times in 24 h three days after birth and reach at least a milk volume of 500 ml/day on day 14 days post-partum
6. Continuously checking maternal need for lactation support to enable early recognition of lactation problems and motivate mothers
7. Unlimited access to the child
8. Continuous, regular skin-to-skin contact
9. Early breast-to-mouth contact and transition to breastfeeding
10. Mother's own milk as the gold standard

Table 3 First contact between mother and child

	First time seeing the child after birth (n, %)	First time touching the child after birth (n, %)	First time of skin-to-skin contact after birth (n, %)
Directly after birth	149 (27.95%)	64 (12.01%)	29 (5.44%)
Within 3 h after birth	129 (24.20%)	229 (42.96%)	102 (19.14%)
Later than 3 h after birth	99 (18.57%)	145 (27.02%)	111 (20.83%)
Within the first day after birth	99 (18.57%)	81 (14.82%)	220 (41.28%)
Later	53 (9.94%)	14 (2.63%)	68 (12.75%)
Missing	4 (0.75%)	3 (0.56%)	3 (0.56%)

1. Informing all mothers and parents with a risk of premature birth about breastfeeding and pumping

Quantitative data show that more than one third of the mothers (37%) were not informed about the importance of MOM before birth. After birth, 22% received no information about MOM. Cross tables illustrate that 10% of the mothers ($n=53$) did not receive any information on MOM either before or after birth.

In the interviews, mothers reported to have only rarely been informed of the importance of MOM before giving birth. Nevertheless, there were also examples of where information was more prioritized:

"Before birth, I had a conversation with a neo-doctor, who then also addressed the issue or asked me [...] how my attitude towards it would be. And [...] I don't know whether on the first or second day up on the ward, the topic was addressed again by a doctor." (M2)

Some mothers received rather brief information about the topic after birth:

"Not at all before birth. After birth, they said [it], but there was no big consultation about it." (M3)

However, mothers also reported that they did not receive any information about the importance of MOM either before or after birth.

2. Skin-to-skin contact in the delivery room with gradations (if skin-to-skin contact is not possible in the delivery room, touching the child and at least seeing the child directly after birth)

More than half of the mothers reported having had the first skin-to-skin contact later than three hours after, but within the first day of birth (62%). While 28% of the mothers were able to see their child directly after birth, fewer mothers were able to have physical contact: 12% were able to touch their child directly after birth and only 5% had early skin-to-skin contact (Table 3).

To deepen these insights, the interview data illustrate that some mothers were not able to have any contact with their child (including seeing their child) until the day after giving birth (within 24 h after giving birth):

"About 13 h after that. [...] What I found in retrospect very sad. [...] I don't get it to this day why they did not show him to me for a second. I have a

Table 4 Timing of first pumping

Time of first pumping	n (%)
Within the first 2 h	30 (5.63%)
2–6 h	160 (30.02%)
6–24 h	222 (41.65%)
24–48 h	76 (14.26%)
3–7 days	24 (4.50%)
Later	2 (0.38%)
Not at all	15 (2.81%)
Missing	4 (0.74%)

really big problem with a stranger [midwife] walking through the room with my child in her arms whereas I haven't seen my son for even a second. [...]" (M2)

One mother reported having encountered her child later than one day after birth. As a result, she reported being afraid to engage with her daughter:

"Seeing her and touching her in the incubator was, I think, the next day when I was taken there in a wheelchair. But then I didn't dare to touch her yet, and I think two days after birth we were already allowed to cuddle her properly. But I didn't dare to do that either. I let my husband be the first. The first few days I wasn't quite myself yet." (M8)

However, other respondents confirmed that they had the chance to encounter their child either directly after birth or within the same day:

"I have seen him directly after the cesarean section, they lifted him up once. I was totally proud and thought: Wow. [...]" (M9)

3. Initiation of lactation within one to four hours after birth, latest within six hours after birth with the gold standard to combine pumping and manual milk expression

Only 36% of the mothers pumped within the first six hours of birth. Almost half of the mothers pumped later than 6 h after, but within 24 h after of (42%) (Table 4). Of those who initiated lactation, 57% combined pumping and manual milk expression. However, it should be mentioned that only 61% of the mothers received information about manual milk expression to win colostrum, of whom 87% then expressed colostrum and 13% did not.

The interviews deepen the findings about lactation initiation by demonstrating that the reason mothers did not express colostrum by hand was mostly because they did not receive any information about the importance of it and/or were not instructed to do so:

"Nah, I just pumped. I didn't even know how to do the expression. I only learned that later during the lactation consultation." (M9)

Apparently, communication issues between professionals from different wards emerged and posed a problem in that each had expected the other to instruct the mothers about manual milk expression:

"[On the maternity ward] So this pump was put there, a pump set was supplied and [they said] 'do it'. I was completely overwhelmed with it. Because when I then arrived on the Neo [ward] two days later [...] [they said] 'Have you not brought any milk or colostrum or something? Don't you express?'. And I was like: 'WHAT? No, and there still is no milk at all.'" (M5)

In contrast, another mother reported being instructed in detail about colostrum and was reminded several times to either pump or express milk by hand:

"They simply told us that this is enormously important, because there are still many, many, [...] antibodies, [...] and also all sorts of ingredients that a premature baby NEEDS, and that it is enormously important that you start pumping immediately after birth, because I really thought at that moment: Oh God, I have to recover after such a Caesarean section, and must somehow first get back on my feet, and my mind was not really on it at this moment, and it was good that there was always someone who came and said 'How does it look?' and 'Have you already pumped or expressed milk?'" (M4)

4. Colostrum as the first feeding and no formula feeding

More than half of the mothers reported formula feeding immediately after birth (52%). One third of those mothers (33%, $n=80$) stated that formula was provided as the main way to nourish their child during their stay in the NICU. In less than one-fifth (17%) of the cases, mothers indicated that their infants were provided with donor human milk while in the NICU.

The reported reason for why infants initially received formula was that the mothers had trouble producing (enough) milk:

"In those first three or four days, when he didn't get any breast milk from me, it was some kind of premature neo-something milk and when I pumped and that wasn't enough for them, they mixed it first. I think it was on the seventh, eighth day that he got my milk only." (M3)

While some of the interviewed mothers were able to provide MOM for their children within the first week, others reported that they were already initially able to provide milk for their children:

"I have to say it worked amazingly well. [...] I was very proud and totally happy to be able to offer that to her then, despite the situation." (M6)

5. Maintain lactation with a pumping frequency of at least eight to ten times in 24 h three days after birth and reach at least a milk volume of 500 ml/day on day 14 post-partum

Three days after birth, one fifth of the mothers (24%) pumped fewer than 6–8 times per day. Over 53% pumped 6 to 8 times a day, and only 18% pumped more than eight times within 24 h. More than half of the mothers (59%) had a milk volume of less than 500 ml/day by day 14 post-partum.

Although most mothers reported having initiated lactation within the first two hours after birth in the interviews, there was a contrasting experience in a mother who initiated pumping within the first 24 h of giving birth:

"I think that was even maybe on the next day. [...] Which I find strange now in retrospect, because you actually/ so many do it directly in the delivery room. But I think that it was on the next day, when I was able to sit up again." (M8)

Regarding the frequency of pumping in the first three days after giving birth, the mothers' experiences differed between every two to three, every three to four, and every four to five hours. Interview data implied that pumping frequency varied in some cases due to inconsistent information given to the mothers, which they perceived as confusing and/or frustrating:

"They made diverging statements. The nurse on the ward who gave me the pump said: 'pump every four hours, that's enough.' And at the intensive care ward, the nurse said: 'In any case, every two to three and a half [hours] all day'. These were just so very different statements and I was like: Huh? I don't know what to do." (M3)

6. Continuously checking maternal need for lactation support to enable early recognition of lactation problems and motivate mothers

As lactation support can be seen as a multi-faceted approach of physiological and psychological support for lactating mothers, indicators of both dimensions are shown here.

In the quantitative data, more than one third of the mothers received no personal guidance on breastfeeding and/or pumping (39%). Most mothers who received personal guidance rated it as very good or good (73%). Breastfeeding or pumping problems were reported in 73% of the cases.

In the qualitative interviews, mothers were asked about personal guidance regarding breastfeeding and pumping. Some reported satisfactory personal guidance:

"[...] I thought that was actually quite good. The nurse really, REALLY explained it very well. She was, I don't know if she was there until the end, but she was there for a relatively long time. She showed me the settings and how to scale it up and down and everything." (M1)

Some mothers did not receive any personal guidance at all:

"So for pumping there was no guidance. That did not take place." (M2)

Some of the qualitative responses implied that personal guidance did take place in general, but mothers were often supported at a time point that was deemed too late:

"I think I pumped far too infrequently [...], every maybe three, four hours, like that. No one had told me anything concrete about it. I learned it afterwards [...], always found out everything AFTERWARDS." (M2)

To illustrate the overall perception of care and support during the time in the NICU, mothers were asked if they agreed to the statement that they felt that there was always an open ear for their concerns as a mother in the quantitative questionnaire. Ranging from 1 (totally agree) to 6 (totally disagree), the mean agreement to this statement was 2.4, with an SD of 1.4. The distribution is shown in Fig. 1.

Indeed, the subjective feeling of the staff having an open ear significantly helped mothers cope with their current situation:

"So actually [the] sympathetic ear itself [has helped the most]. [Even] when it's totally stressful [...] and also when you're [at the hospital] for such a long time [it is important] that you can talk about problems. [The nursing staff] then said: 'Don't make yourself crazy.'" (M4)

"If I would talk to [the nursing staff] again, [...] I would definitely give them feedback that I experienced the emotional support as really disproportionately good. They always had an open ear, they always built me up." (M1)

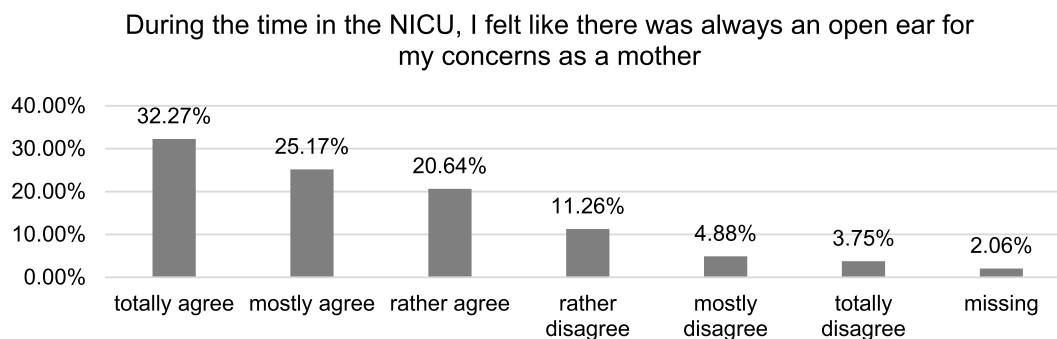


Fig. 1 Distribution of agreement to the statement that they felt that there was always an open ear for the mothers' concerns in the NICU

However, some mothers reported divergent experiences with social and emotional support after birth. For instance, they missed being able to vent their feelings and to have a safe space for this. Others complained that institutional support, like psychological counseling, was not pointed out to them. The quote by M8 illustrates this:

"No. I didn't know at the beginning that there was a psychologist in the hospital. I think that would have helped me at least for the first few days, just to somehow deal with the first shock."

7. Unlimited access to the child

The quantitative questionnaire contained no questions about the possibility of unlimited access to the child, but the mothers were asked about the options for rooming-in in their respective NICU. The possibility of rooming-in includes unlimited access to the child. Accordingly, this can be considered as an indicator of unlimited access. However, rooming-in was reported in only 3% of cases. Approximately half of the mothers (53%) reported staying at home during their child's hospitalization.

To complement the quantitative perspective, we turned to findings from the semi-structured interview. In the interviews, we asked the mothers about whether they had the option of visiting the child without any restrictions. On a positive note, most mothers reported that they and their partner had unrestricted access to their child. Take, for instance, the quote from M2:

"No, that was solved quite optimally. Me and my boyfriend, we were allowed to see our son 24 hours every minute and could also always call. So, we never felt like a nuisance or anything."

On the other hand, mothers who reported restrictions on contact with their child explicitly linked these restrictions to COVID-19:

"While the [children] were in NICU, there was a change in the hospital because the [covid] numbers went up, and then they said even though we have

TWO [babies], only one person is allowed in a day. We weren't allowed to take turns either, only one was allowed in per day [...]. We thought it was unfair because we had two children and got the same rights as for one child." (M1)

Interview data further implied that the restrictions were perceived as a burden by the parents:

"Quite awful. But I was told, it was COVID-related. We were allowed to cuddle one time a day. I think that was the worst part of the whole situation, yes." (M3)

8. Continuous, regular skin-to-skin contact

The mothers were asked how they experienced the possibility of skin-to-skin contact in the NICU. Most were satisfied with the options for skin-to-skin contact (77%).

Regarding the opportunity to engage in regular skin-to-skin contact with the child, the experiences of the interviewed mothers were mixed, with some mothers reporting positive and some reporting negative experiences. Generally, skin-to-skin contact was supported by nurses and physicians in the NICU wards and hospitals, and the extent to which these institutions supported such contact often exceeded the mothers' expectations:

"So they lie there in their incubators and the nurses go there fully equipped with everything and touch them very carefully and then we got her on the CHEST while kangarooing and were allowed to tube feed her and care for her, and change diapers, like a normal baby. So it was surprising for us that we were allowed to do that, even though she was so small." (M1)

Similarly, mothers reported that they were allowed to have skin-to-skin contact in general. However, some admitted that they were reluctant to engage in skin-to-skin contact with the newborn, because they were afraid to eventually hurt the child.

"The first time kangarooing was done by my husband. So we went there together and then the [nurse]

said, "Do you want to cuddle?". And I was like, oh God, NO. That poor little being. They want to take him out of the incubator now and my husband said "YES" directly. In retrospect, I was so glad that he did that and I can't even UNDERSTAND nowadays that I didn't really want to do that. I was just afraid of him and of everything. [...]" (M9)

However, there were also reports of problems regarding the opportunity for skin-to-skin contact. One reason was that the NICU did not find time to arrange it at first:

"At 10 o'clock was [the birth] and I think the first time I was brought over with the bed was in the late afternoon. But the ward didn't arrange it with the NICU, so they said: "No, it doesn't fit at all that you are there now". So I saw her I think once briefly and then they drove me away again. I think we had this game again the next day and then I said at some point "No matter what happens, I have to run over there myself now". Before it was physically not possible. On that day we kangarooed for the first time and spent more time together." (M5)

Another reason were restricted visiting times due to COVID-19, a problem that was further aggravated if the mothers were already discharged and had to commute:

"You then had two hours to kangaroo and if another mother sat there to kangaroo, you were often not allowed to go to the child, because it was too crowded due to the covid-19 regulations. The kangaroo time was then not made up for. I found it stressful, because if you were stuck in a traffic jam or something, you always had that time breathing down your neck: that's my kangarooing time going to waste. I was sometimes crying in the car. Or so happy to see my daughter and then drive there and the door is closed." (M10)

9. Early breast-to-mouth contact and transition to breastfeeding

Quantitative data on early breast-to-mouth contact was not available. Nevertheless, the mothers were asked in the questionnaire whether they breastfed their child, which can be an indicator of whether breast-to-mouth contact was achieved in any form. This transition from pumping to breastfeeding was achieved in almost half of the mothers (46%).

Interview data implied that mothers were rarely supported in the transition from pumping to breastfeeding, and that early breast-to-mouth contact was also rarely supported:

"[...] In the NICU when I asked if I could breastfeed [they told me]: "No, you can't, yet", and I still don't understand why. He didn't have to drink at all. He could have just sniffed or sucked and I think I just did that at some point under my snuggle blanket. I will never forget my friend saying „Today you go there and you just DO it. It 's YOUR child, you're allowed to do that", and that was incredibly good, and through that he felt me somehow. To this day, I don't understand why they weren't open to support this concrete closeness more." (M3)

Similarly, when the complete transition from pumping to breastfeeding was realized during the hospital stay, it was apparently due to the mother actively asking for support and insisting on breastfeeding:

"There are [fixed] feeding times, so there is no chance for need-oriented feeding, [...]. I always said: I have to have him with me and I'm sure I'll get him to breastfeeding, and I fought and fought and fought, and actually [...] because I was such a huge pain in the ass to them [the hospital staff], they took me in five days before [his] discharge and I could completely breastfeed him 24 h later." (M3)

Still, some mothers did not complete the transition from pumping to breastfeeding and received no support in trying to do so which in some cases led to a quick decline in the amount of breast milk they were able to provide after they were discharged from the hospital themselves:

"Quite quickly, when we were at home. [...] Somehow it just became less and less. [...] I have tried everything. But I think perhaps it is still a bit different in such a situation with such an extremely premature birth, and the clinic was 70 km away from our place, and with the commute, that is of course again stress and takes a lot of time, [...] what I really would have needed was proper help or advice." (M8)

10. Mothers own milk as the gold standard

In the survey, mothers were asked whether they agree with the statement that nutrition with MOM was promoted by physicians and nursing staff. Ranging from 1 (totally agree) to 6 (totally disagree), mean agreement was 2.3 (SD = 1.5). The detailed distributions of both the variables are shown in Fig. 2. However, 30% of mothers reported that an exclusive nutrition with MOM was achieved.

The interview data illustrated that many mothers were already highly intrinsically motivated to provide MOM for their children from the beginning:

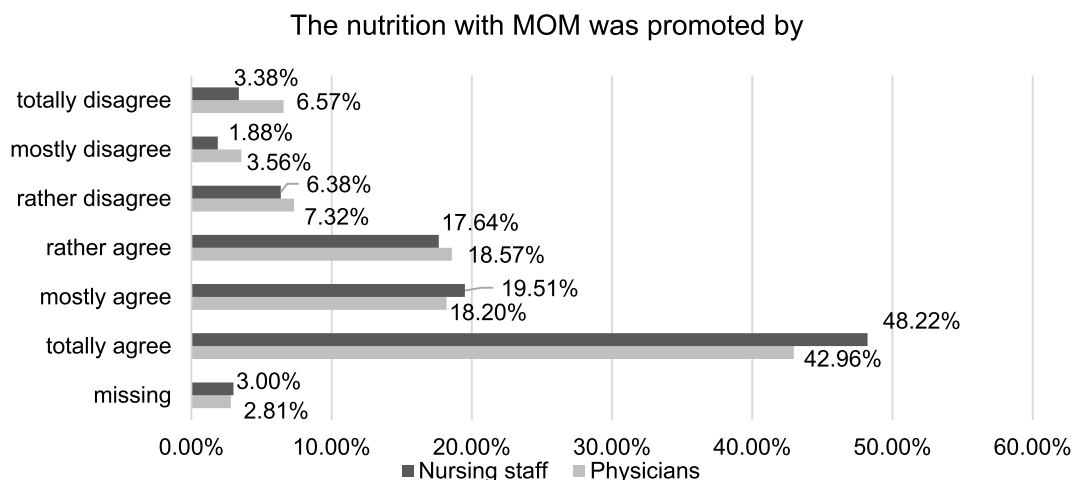


Fig. 2 Distribution of the agreement to the statement that nutrition with MOM was promoted by the NICU staff

"In general, it was ALWAYS clear to me when I would have a child that I wanted to breastfeed. So for me nothing else was worth consideration." (M2)

In most cases, the hospitals further supported this notion by explicitly communicating MOM as the gold standard for infant nutrition:

"It was always clear to me that I wanted to try, and I was very, very determined when she was born that breast milk was the best thing for her. This was also mentioned again and again on the premature infant ward that breast milk is the best, especially for premature infants, and therefore it was important to me to achieve it in any case, at least as far as possible." (M10)

In some cases, they explicitly advocated against formula as well:

"[...] In the hospital, they told me that [breast milk] was easier to digest than bottle feeding or formula. I really didn't think about that before." (M7)

In a few cases, mothers reported that the hospital did not give any information about the fact that MOM would have been the preferable form of nutrition:

"I knew about the importance of breast milk. But I think [...] if it hadn't been my third child, it wouldn't have been clear to me [...]." (M3)

Discussion

This study utilized a mixed-method approach, including qualitative and quantitative data, to examine mothers' perceptions of the lactation support they experienced around the birth of their VLBW infants. The survey and interview data were analyzed and structured according

to the key objectives recommended for lactation support in NICUs. Overall, our data show the need for improvement in lactation and breastfeeding support in German NICUs and provide insight into the specific perceptions of mothers.

While previous studies have shown the importance of providing information on the relevance of human milk to the mother prior to the birth of a preterm infant [11, 31], in many cases, mothers did not receive any information either before or after delivery. Early lactation initiation is one of the main factors leading to successful lactation after preterm birth [11]. Our data indicate that more than half of the mothers did not initiate pumping until 6 h after birth. Delayed first pumping can lead to insufficient milk supply; thus, timing is a central factor in lactation support in the NICU [32]. Interview data indicate that delayed pumping was often due to mothers not being clearly instructed regarding the usage of the electric pump, despite its importance in achieving efficient use [33]. To enable colostrum to be the first feed for infants, manual milk expression should be combined with pumping after birth [14, 34]. Quantitative data show that many mothers were not aware of manual milk expression and its methods. However, when mothers received information, nearly all of them applied it, emphasizing the need for guidance. In our study, less than half of the mothers reached the required milk supply of more than 500 ml/day on day 14 post-partum [15]. This may explain the frequent formula-feedings reported in our sample. Low milk supplies could be due to late initiation of pumping, but also low pumping frequency within the first days, which was sometimes fewer than six and often fewer than eight times in a 24-h period, despite the requirement for frequent milk expression to maintain milk supply [9]. The

qualitative data indicate that this is based on misinformation, inconsistent information, or delayed information from hospital staff. This may further explain the high rate of mothers who reported problems with pumping or breastfeeding in our data.

Although the importance of skin-to-skin contact or, if not possible, touching or seeing the newborn is well known for improving lactation success [19, 35, 36], only 5% of the mothers reported direct skin-to-skin contact after birth, 12% touching, and 28% eye contact. The qualitative data suggest that mothers could suffer from having no chance to have skin-to-skin contact with their child directly or soon after birth, indicating its importance for maternal well-being. However, the majority of mothers expressed satisfaction with the possibility of skin-to-skin contact during their child's stay in the hospital.

Furthermore, it is crucial for mothers to receive emotional and (professional) psychological support after preterm birth to protect their mental health [37]. Most mothers had a positive perception of the emotional support provided by the NICU staff; however, the interview data suggest that there may be room for improvement, as many mothers were not aware of the availability of professional psychological counselling. Given that stress can negatively affect lactation, the need for improvement is further emphasized [38].

Almost half of the mothers in the quantitative sample achieved the transition from pumping to breastfeeding, which has been shown to lead to a longer breastfeeding duration [16]. There is uncertainty as to whether the mothers in our quantitative sample chose to initiate breastfeeding rather than utilizing pumping or whether they received adequate support to facilitate the transition. However, the interview data suggest that a lack of support can hinder the transition, indicating the need for improvements to enable long-term feeding with MOM.

In summary, lactation support in NICUs in Germany shows room for improvement. On the one hand, feeding with MOM is proposed as the gold standard; on the other hand, our results reflect a lack of support for lactation and breastfeeding in actual clinical practice. Considering that beds frequently have to be blocked due to staff shortages [39], the indicated lack of lactation support in our data could be at least partly attributed to such structural issues. One central issue that repeatedly arose in our results was the lack of (personal) guidance, especially concerning consistent information through all hospital wards. This indicates missing structures and policies regarding lactation support across multidisciplinary teams of obstetrics, gynecology, and neonatology, which have been shown to be particularly relevant [40]. Previous research has shown that a consistent information policy across the various stakeholders as well as an

environment that supports nutrition with human milk are crucial for lactation support and breastfeeding promotion [41–43]. These may therefore be factors to focus on when designing future interventions for lactation support in German NICUs.

Limitations

Even though our study provided relevant insights into the status quo of lactation support in German NICUs and offers possible solutions for some of the existing issues, some limitations must be considered: Firstly, our study predominately provides data on mothers who initiated pumping. Only 3% of the mothers in the quantitative sample and none included in the qualitative sample did not initiate pumping at all. However, as mothers of preterm infants are more likely to initiate lactation than term mothers, the high initiation rate in our data hardly deviates from this [44]. Future research should, therefore, specifically target mothers of VLBW infants who do not initiate lactation to consider their insights into the topic and their reasons for not initiating lactation.

Secondly, since there are no validated and established scales on stress and/or psychological strain due to pumping and breastfeeding, especially for preterm infant mothers, self-generated items were used in the quantitative questionnaire. An expert team developed and revised these items. However, the specific choice of items may still have influenced the results, and future research should focus on validating scales for these topics. Thirdly, the interviews had to be conducted online due to COVID-19, which may have led to slightly varying answers compared to in-person interviews because the situation may feel less personal than a face-to-face interview. In addition, the interview contained many questions that may have felt more tiring in an online setting, which might have led to shorter answers at the end of the interview compared to the beginning.

Furthermore, certain particularly vulnerable populations (e.g., in this case, mothers of twins of which one child did not survive) were not contacted for the study and are not represented in the samples. Future studies could target more vulnerable populations to gain valuable insights into the topic. This also allies to mothers with low educational status or migration background, who were hardly represented in our data.

Finally, the mothers were contacted six months after giving birth. This might have led to recall bias due to mothers not recalling information correctly and/or over- and under-emphasizing certain aspects. However, as mothers who experienced premature birth are at a higher risk of depression, anxiety, and post-traumatic stress [37], this inclusion criterion was implemented in order to minimize possible re-traumatization after preterm birth.

Conclusion

This study examined the lactation support at German NICUs from the mother's perspective using a mixed-method approach, including a quantitative questionnaire and qualitative interviews with mothers of VLBW infants.

This study adds to knowledge about mothers' perceived lactation support, showing broad areas for improvement. To enhance nutrition with MOM in VLBW infants, thereby preventing health and development risks, the key objectives of lactation support should be improved. Our findings indicate the need to introduce institutional guidelines and overall structures in lactation support across all involved hospital wards to support successful lactation in preterm mothers.

Abbreviations

VLBW	Very low birth weight
MOM	Mother's own milk
NICU	Neonatal intensive care unit
BOP	Bronchopulmonary dysplasia
NEC	Necrotizing enterocolitis
WHO	World Health Organization

Supplementary Information

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Supplementary Material 1.

Supplementary Material 2.

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Authors' contributions

IS analyzed the quantitative data, RW analyzed the qualitative data. IS and RW jointly drafted a first version of the manuscript. NS, TD and FE gave feedback on the manuscript and revised it. IS and RW further revised and finalized the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding authors on reasonable request.

Declarations

Ethics approval and consent to participate

The quantitative questionnaire was approved by the ethical committee of the University Hospital Cologne (20–1547). The interviews were approved by Bielefeld University's ethics committee (2020–147). This study is registered in the German Clinical Trials register (Trial registration number: DRKS00024799). All methods were performed in accordance with the relevant guidelines and regulations. Informed consent was obtained from all participant and parents involved in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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Research Paper 2

RESEARCH

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Pressure to provide milk among mothers of very low birth weight infants: an explorative study

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Abstract

Background Pump-dependent mothers of very low birth weight (VLBW, < 1500g) infants experience specific challenges achieving sufficient milk supply in the neonatal intensive care unit (NICU) and are therefore less frequently able to achieve (exclusive) breast milk feeding. Stress due to the limitations on participating in the infant's care may contribute to this problem. Some explorative studies suggest that pressure to provide milk may be an additional stressor in mothers. However, the type of pressure to provide milk perceived by mothers of VLBW infants has rarely been examined.

Methods A retrospective and anonymous questionnaire was conducted with mothers of VLBW infants aged 6 to 24 months at the time of data collection. Quantitative data and written comments were used to examine the mothers' perceptions. Descriptive and bivariate tests (Spearman's rho, Pearson's chi²) were performed to show correlations between pressure to provide breast milk, parental stress (PSS:NICU: role alteration subscale), milk volume, and maternal factors. Pressure to provide milk was measured through two self-developed single items to differentiate between internal and external pressures.

Results Data of $n = 533$ mothers of VLBW infants was analysed. More than 70% of the mothers agreed that they pressured themselves to provide milk for their infant. In contrast, 34% of the mothers agreed that they felt pressure from outside to provide milk. Higher milk volume 14 days post-partum was significantly correlated with less internal (Spearman's rho = 0.2017, $p = 0.000$) and less external pressure to provide milk (Spearman's rho = 0.2991; $p = 0.000$). Higher PSS:NICU parental role alteration scores were significantly correlated with more internal (Spearman's rho = -0.2865, $p = 0.000$) and more external pressure to provide milk (Spearman's rho = -0.1478; $p = 0.002$). Milk volume 14 days post-partum and the PSS:NICU were not significantly correlated (Spearman's rho = -0.0190; $p = 0.701$). Qualitative analyses highlighted these results and enhanced the bidirectional relationships between maternal pressure to provide milk and milk volume.

Conclusions Especially internal pressure to provide milk is perceived by many mothers, being mutually dependent on milk supply and parental stress. Pressure to provide milk may be an important factor to decrease maternal stress in the NICU and, therefore, lead to more positive pumping and breastfeeding experiences. More research and validated instruments are needed to adequately measure pressure to provide milk with its different psychological, social, and environmental dimensions.

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Keywords Very low birth weight, Maternal stress, Pressure to provide milk, Milk volume, Lactation, PSS:NICU, Maternal mental health, Breastfeeding

Background

The first choice of nutrition in preterm infants is mother's own milk (MOM), followed by donor human milk if MOM is not available [1]. Mothers of very low birth weight (VLBW, < 1500g) infants experience specific challenges when establishing sufficient milk supply in the neonatal intensive care unit (NICU) and are, therefore, less frequently able to achieve (exclusive) feeding with MOM [2, 3]. The infant's physiological immaturity requires alternative methods of milk expression rather than direct breastfeeding [4]. The impact of preterm birth on secretory activation hinders lactation initiation, which may be further delayed by the mother's recovery from medical complications during preterm birth and absence of lactation support for mothers, thus contributing to a lower milk supply [1, 5, 6]. Many other factors have also shown to be commonly associated with milk supply and/or (exclusive) breastfeeding among mothers of preterm infants, such as maternal educational level, age, previous children, and experiences with milk expression [7–9].

In addition, mothers of preterm infants are more likely to experience stress, depression, and anxiety than term-mothers, which may be triggered by a traumatic preterm birth, separation from the infant, and limitations in participating in the infant's care in the NICU [10, 11]. The emergence of stress can be explained as a negative experience arising from distinctions between demands and resources of a person in interaction with his or her environment [12], while parenting stress describes those discrepancies connected to parenthood [13]. Considering stressors due to parenting is particularly relevant, as stress caused by the parental role alteration within the NICU setting, where finding a parent-infant bond through caregiving is hindered, may have a negative impact on maintaining breastfeeding [14, 15]. Moreover, a few explorative studies with term-mothers indicate that pressure to provide milk may be an additional stressor in mothers who want to feed their infants with their own milk [16, 17]. Given the crucial importance of MOM to medical outcomes of preterm infants, the knowledge about this topic could further increase the pressure on mothers to provide milk [18]. Therefore, especially for mothers of preterm infants, the possibility of receiving donor human milk for the infant can reduce negative emotions such as guilt and grief, when they struggle achieving their own milk supply [19]. However, to what extent pump-dependent mothers of VLBW preterm infants perceive pressure to provide milk and how

the already named factors are related to it remains rather unclear.

The objective of this study is threefold: First, we aim to measure mothers' perceptions of pressure to provide milk and illustrate its prevalence among mothers of VLBW infants. Further, factors associated with pressure in providing milk are identified. For this purpose, correlations between the perceived pressure and maternal factors, including educational level, age, previous experience with pumping, milk supply, parental stress, and the availability of donor milk in the hospital are examined. Then, in order to further explore the mother's perceptions, qualitative data in the type of written comments are assessed.

Methods

Study design

Both data were collected through a written, cross-sectional survey. It was part of the Neo-MILK project, which, amongst others, aims to describe the perceptions of preterm mothers regarding lactation and lactation support in the NICU [20]. The study was publicly funded by the Innovation Fund of the Joint Federal Committee (funding code: 01NVE19027) and registered in the German Register of Clinical Trials (ID: DRKS00024799). The study was approved by the ethical committee of the University Hospital Cologne (20–1547).

The retrospective and anonymous survey was conducted in cooperation with four statutory health insurance companies (AOK Rhineland/Hamburg, TK, DAK, Pronova BKK). Data were collected from June to August 2021. The selection criteria were a birth weight less than 1,500 g and an age of 6 to 24 months of the infant at the time of data collection (ICD10 criteria: P07.00, P07.01, P07.02, P07.10, and P07.11.). All mothers who matched these codes and were insured with these companies (1,894) were contacted by their health insurance company and invited to participate in the study. A period of at least six months after birth was chosen for the recruitment of the survey in order to minimize the risk of re-traumatization as studies have shown that post-traumatic stress after preterm birth can last for several months and produce anxiety and depressive symptoms [21, 22].

Survey instrument and measures

The survey included one subscale of a validated scale and self-developed items based on the current literature.

The perception of pressure to provide milk was divided into two sources of pressure — internal and external

pressure — and was measured agreement with two statements. Internal pressure was measured with the following statement: “During the time in the NICU, I pressured myself because I wanted to provide milk for my infant”. External pressure was measured as follows: “During the time in the NICU, I felt pressured from outside to provide milk for my child”. A six-point Likert scale (“totally agree”, “mostly agree”, “rather agree”, “rather disagree”, “mostly disagree”, “totally disagree”) was used for the responses.

Maternal perceptions of stress caused by the limited ability to care for the infant was measured using the parental role alteration subscale of the validated German version of the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU_German/2scale) [23]. The questionnaire contained only the parental role subscale, as the parental role alteration showed to be the greatest source of stress in parents and the study focuses on the parental caregiving role [24]. Furthermore, since the PSS:NICU_German/2scales score was previously used and reported at the subscale level, we applied it accordingly [25]. In short, it consists of six items, which represent possible stressors and are answered on a five-point Likert scale of “not at all stressful” (1), “a little stressful” (2), “moderately stressful” (3), “very stressful” (4), and “extremely stressful” (5) and the option of “not experienced” (0). The scale can be calculated by two metrics. For the analysis, metric 1 was used, which provides information about the stress occurrence level, meaning stress due to a specific situation. This is calculated by adding all answers on the respective subscale and dividing by the numbers of items. Therefore, higher scores indicate higher levels of stress [23].

For previous experiences with pumping, the options “yes” and “no” were given. To measure maternal milk supply, the milk volume on day 14 post-partum was chosen, as it showed to be a robust indicator for reaching sufficient lactation [3]. Milk volume 14 days post-partum was measured through pre-defined groups of “under 300ml/day”, “301–500ml/day”, “501–700ml/day”, “700–800ml/day”, and “over 800ml/day” (categorical variable). These pre-defined groups were given in order to simplify the mother’s recollection of the milk volume in case she did not document it. The mother’s educational level was measured through pre-defined groups as well, representing the different options for school qualifications in Germany, also including no qualification (categorical variable). Maternal age was openly asked (continuous variable). For the availability of donor milk, the options “Yes”, “No” and “I don’t know” were given. This variable was dichotomised, as it is presumed that if mothers didn’t know about the availability of donor milk, this option was not provided at the hospital.

At the end of the questionnaire, the option was given to enter free texts (“Do you want to tell us more? You can write it here:”). These comments were further analysed, as is described below.

Data analysis

Quantitative data were analysed using Stata 16. Descriptive data are presented with numbers and percentages in case of categorical variables, whereby continuous variables are presented with means and standard deviations.. To explore and illustrate possible associations with a variety of factors, bivariate tests depending on data distribution (Spearman’s rho, Pearson’s χ^2 /Cramer’s V) between pressure to provide milk, milk volume, previous experience with pumping, parental stress, and demographics were performed on a 95 percent significance level. Therefore, statistical significance of correlations was considered with a p-value equal or less than 5%. Spearman’s-Rho (rs) correlation test was performed in case of ordinal scales and Pearson’s- χ^2 -Test (X^2)/Cramer’s V in case of binary variables. Correlation coefficients were interpreted as recommended by the literature [26, 27].

Written comments were assessed with an inductive content analysis according to Elo et al. (2008), starting with reading all comments, setting up similar notes for every mentioned dimension, and grouping them into subcategories [28]. Then, subcategories were grouped into two larger categories. This procedure was performed by two persons separately and compared afterwards, creating the results. Quotes from the qualitative data which contained stress or pressure due to providing milk are used to give a wider understanding of the quantitative results.

Results

In total, 600 of 1,894 mothers participated in the survey, representing a response rate of 31.67%. After data correction of incorrectly contacted mothers, who did not meet the ICD-10 inclusion criteria ($n=67$) and those who did not initiate lactation ($n=15$), responses of 518 mothers remained for the following analyses. Characteristics of the participating mothers are presented in Table 1.

Quantitative results

More than 70% of the mothers totally, mostly, or rather agreed that they pressured themselves to provide milk for their infant (internal pressure). In contrast, 34% of the mothers totally, mostly, or rather agreed that they felt external pressure from outside to provide milk, whereas 33% totally disagreed that they experienced external pressure (Fig. 1).

Figure 2 presents the multifaceted correlations between internal and external pressures to provide milk, milk

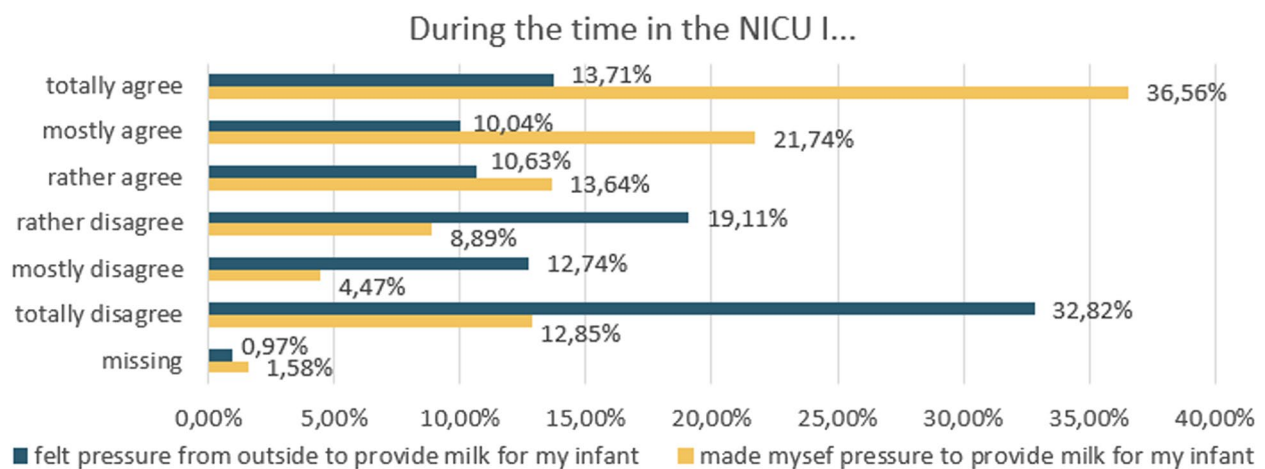
Table 1 Characteristics of the participating mothers

Characteristics	n (%)
Maternal educational level	
Without a graduation	10 (1,93%)
Lower secondary school	46 (8,88%)
Secondary school	114 (22,01%)
Higher education entrance qualification	124 (23,94%)
University degree	213 (41,12%)
Missing	11 (2,12%)
Previous experience with pumping	
Yes	97 (18,73%)
No	419 (80,89%)
Missing	2 (0,39%)
Milk volume 14 days p.p	
< 300ml/day	196 (37,84%)
301-500ml/day	115 (22,20%)
5001-700ml/day	77 (14,86%)
701-800ml/day	44 (8,49%)
> 801ml/day	68 (13,13%)
Missing	18 (3,37%)
Availability of donor milk at the hospital	
Yes	121 (22,7%)
No	403 (75,61%)
Missing	9 (1,69%)
Maternal age	(n [mean (min-max)])
	487 [34.1 (19-54)]
PSS:NICU (subscale parental role alteration)	427 [3.8 (1-5)]
Cronbach's alpha	0.8601

volume 14 days post-partum, maternal demographic factors (education, age), previous pumping experience, and the PSS:NICU parental role alteration subscale. Thicker arrows indicate higher significance, and shorter arrows between the indicators means stronger correlation.

Significant and insignificant correlations between both dimensions of pressure and factors concerning previous experience with pumping, milk volume 14 days post-partum, demographics, and the PSS:NICU subscale parental role alteration can be seen in Table 2. Bold text indicates significance. Internal and external pressure showed a weak to moderate positive correlation ($r_s = 0.3414$; $p = 0.000$). Weak significant, negative correlation appeared between the PSS:NICU and internal pressure to provide milk, where less pressure was correlated with lower PSS:NICU parental subscale scores ($r_s = -0.2865$, $p = 0.000$). Higher milk volume is positively correlated with less internal pressure ($r_s = 0.2017$; $p = 0.000$). Higher levels of parental stress are correlated to higher internal pressure. Nevertheless, positive correlations between higher milk volume and less external pressure were stronger ($r_s = 0.2991$; $p = 0.000$) than negative correlations of higher PSS:NICU subscale role alteration scores and higher external pressure ($r_s = -0.1478$; $p = 0.002$).

A higher maternal educational level was correlated with lower parental stress ($r_s = -0.1085$; $p = 0.000$). Maternal age and previous experience with pumping were significantly correlated (Cramer's $V = 0.322$), but there was no direct significant correlation between maternal age and both dimensions of pressure to provide milk ($p = 0.605$; $p = 0.769$). However, higher maternal age was positively correlated with a higher milk volume 14 days post-partum ($r_s = 0.1646$; $p = 0.000$), although previous experience with pumping was not significantly correlated to milk volume ($X^2 = 7.717$; $p = 0.103$). The availability of donor milk was significantly associated with external pressure ($X^2 = 14.410$ $p = 0.013$) and milk volume ($X^2 = 10.352$ $p = 0.035$), but not with internal pressure.

**Fig. 1** External and internal pressure to provide milk

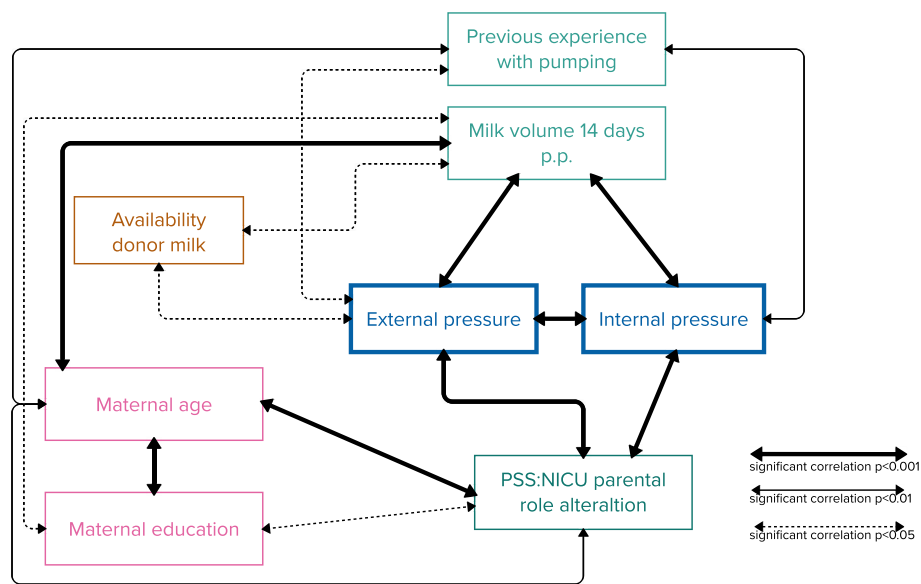


Fig. 2 Bivariate correlations

Table 2 Correlations of factors with internal and external pressure to provide milk

Variables	Maternal age	Education	Experience with pumping	Milk volume	PSS:NICU (subscale role alteration)	Availability donor milk
Internal pressure to provide milk	$r_s = 0.0238$; $p = 0.605$	$r_s = 0.005$; $p = 0.904$	$\chi^2 = 17.398$; $p = 0.004$; Cramer's $V = 0.185$	$r_s = 0.2017$; $p = 0.000$	$r_s = -0.2865$; $p = 0.000$	$\chi^2 = 2.111$ $p = 0.834$
Maternal age	-	$r_s = 0.2363$; $p = 0.000$	$\chi^2 = 50.216$; $p = 0.009$; $K = -0.124$	$r_s = -0.1646$; $p = 0.000$	$r_s = -0.169$; $p = 0.001$	$\chi^2 = 40.251$ $p = 0.080$
Education	$r_s = 0.2363$; $p = 0.000$	-	$\chi^2 = 0.2023$; $p = 0.975$	$r_s = 0.0964$; $p = 0.033$	$r_s = -0.1085$; $p = 0.027$	$\chi^2 = 3.971$ $p = 0.410$
Experience with pumping	$\chi^2 = 50.216$; $p = 0.009$; Cramer's $V = 0.322$	$\chi^2 = 0.2023$; $p = 0.975$	-	$\chi^2 = 7.7170$; $p = 0.103$	$\chi^2 = 32.9691$; $p = 0.082$	$\chi^2 = 0.051$ $p = 0.821$
Milk volume 14 days p.p.	$r_s = -0.1646$; $p = 0.000$	$r_s = 0.0964$; $p = 0.033$	$\chi^2 = 7.717$; $p = 0.103$	-	$r_s = -0.0190$; $p = 0.701$	$\chi^2 = 10.352$ $p = 0.035$; Cramer's $V = 0.145$
PSS:NICU (subscale role alteration)	Pearson's Correlation = -0.169 ; $p = 0.001$	$r_s = -0.1085$; $p = 0.027$	$\chi^2 = 32.9691$; $p = 0.082$	$r_s = -0.0190$; $p = 0.701$	-	$\chi^2 = 32.671$ $p = 0.087$
Availability donor milk	$\chi^2 = 40.251$ $p = 0.080$	$\chi^2 = 3.971$ $p = 0.410$	$\chi^2 = 0.051$ $p = 0.821$	$\chi^2 = 10.352$ $p = 0.035$; Cramer's $V = 0.145$	$\chi^2 = 32.671$ $p = 0.087$	-
External pressure to provide milk	$r_s = -0.0134$; $p = 0.769$	$r_s = -0.0434$; $p = 0.332$	$\chi^2 = 13.047$; $p = 0.023$; Cramer's $V = 0.160$	$r_s = 0.2991$; $p = 0.000$	$r_s = -0.1478$; $p = 0.002$	$\chi^2 = 14.410$ $p = 0.013$; Cramer's $V = 0.169$

Results of qualitative data

In total, comments from 153 mothers were analysed, of which 12 contained information about pressure and/or stress to provide milk. Pressure can be defined as an “excessive or stressful demand” and “often the source of cognitive and affective discomfort” [29] and is, therefore, treated as a term for stress in the analyses. The analysis of the comments resulted in two categories described below.

Internal pressure and stress to provide milk

Eight comments concerned pressure and/or stress the mothers placed upon themselves to provide milk. One mother who pressured herself to provide milk also reported high stress levels due to the situation in the NICU, leading to a lower milk supply:

“I never felt pressured to breastfeed my child by my surrounding. I put myself under pressure to do so, because it’s the best for my child. [...] My child needed an operation, and out of all the anxiety and fear I had hardly any milk, so I stopped.”

Another mother experienced stress due to a lower milk supply:

“Pumping was very stressful and a burden for me. The small amount of milk really stressed me.”

Some mothers explained that they wanted to feed their infant with their milk too much because of the importance and relevance of MOM for the infant:

“I think, at the end, I put myself under pressure because I wanted it too much.”

“The importance and impact of mother’s milk became clear to me in the NICU. With this comes responsibility, but also pressure.”

One mother reported that she did not put herself under pressure, as she already had previous breastfeeding experiences with her first child:

“I breastfed my first child only three months. Therefore, I didn’t pressure myself with the second child. I was happy about every millilitre, but as it decreased at some point, I accepted it.”

External pressure and stress to provide milk

Four comments concerned pressure from outside. The main influences on pressure to provide milk from the environment were the hospital staff and society. Some of these mothers did not want to pump/breastfeed but got pushed by the hospital staff to do so. A few

mothers reported psychological issues due to this external pressure:

“Nurses often put pressure on me that I really needed to breastfeed.”

“I was already ‘informed’ (pushed) to breastfeed four days before the caesarean section, daily pushed until two or three days after birth by different persons (physicians, midwives, nurses). [...] The extreme pressure to breastfeed, the anxiety and fear about my children, and my bad psychological condition at the time of admission led to three major breakdowns.”

“We received a lot of support with breastfeeding, but I felt under pressure, because I didn’t want to do it. The day I was discharged, I weaned immediately and felt so much better psychologically.”

Another mother felt pressure to provide MOM by society or the social environment:

“Meanwhile, it is more of a problem that women who could not breastfeed are treated rather despicably by society. As if they just don’t want it enough. There should be more acceptance when women cannot breastfeed for health reasons. I was very bad physically — that’s stressful enough — but the pressure from the outside when you don’t breastfeed is very stressful.”

The qualitative data emphasized the interdependency between milk supply, high levels of stress due to the situation in the NICU and internal pressure, which was also reflected the quantitative data. Furthermore, they indicated similar findings on the association between previous experiences with pumping and internal pressure to provide milk. In case of external pressure, the qualitative data expanded the quantitative results by showing the main sources being the NICU staff and the society.

Discussion

Our data showed that most of the mothers put themselves under pressure to provide milk. In contrast, only one third agreed they were pressured from the outside to provide milk for their infant. This coincides with recent results from Korth et al. (2022), who identified term-mothers themselves as one of the greatest sources of pressure to breastfeed apart from two external sources, which were society and lactation consultants [30]. Our results highlighted the importance of internal pressure to provide milk as a common concern also among mothers of VLBW preterm infants. Nevertheless, external

pressure should also be included as an important dimension in the perception of pressure to provide milk.

Internal and external pressures showed to be significantly correlated with each other, which indicated their interrelationship and the importance considering both dimensions of pressure. However, results reveal that some mothers did not experience pressure to provide milk, which has already been observed elsewhere [31]. Mothers with previous pumping experience reported significantly less internal pressure to provide milk for their infant than mothers without pumping experience. The qualitative data highlighted this result, as one mother who reported no feelings of internal pressure related this to her experiences with previous children. In the literature, positive previous experiences with breastfeeding showed to be protective for high breastfeeding self-efficacy and, therefore, higher breastfeeding duration [32]. Huang et al. (2019) elaborated that previous experiences with breastfeeding or milk expression encourage lactation initiation and breastfeeding duration in the actual breastfeeding event [8]. Our results indicated that the positive effect of previous experiences could also be noticeable for a lower internal pressure to provide milk and, therefore, acted like a mediator for milk volume.

Of note, whereas there was a correlation between milk volume and pressure to provide milk, on the one hand, and pressure and the PSS:NICU subscale role alteration, on the other hand, we could not find a significant correlation between milk volume and the PSS:NICU subscale role alteration. In the qualitative data, the stressful situation after preterm birth and low milk volume seemed to be mutually dependent. Stress may negatively affect lactation due to hormonal changes and maternal conditions among preterm mothers [33]. However, there are contrasting findings in the literature, where stress is both associated with lactation and shows no association [34–36]. This may be the case because stress is measured differently in those studies depending on the population of term, late preterm, or low birth weight preterm infants.

The role alteration subscale of the PSS:NICU is primarily intended to depict the situation of the lack of the parental caregiving role [11]. Although the items of the parental role alteration scale include the limited possibility to feed the infant by oneself, this terminology is not further specified. Following the concept of parental stress by Deater-Deckard (1998), the perceived discrepancy between the demand of providing MOM for the infant and the mother's resources, namely the ability to do so, would depict maternal stress [13]. The only study, to our knowledge, that examined a correlation between stress due to the parental role alteration and milk volume also did not find any significance between those two factors [15]. In our study, the correlation between higher scores

on the PSS:NICU subscale role alteration and higher internal and external pressure, and at the same time the correlation between higher internal and external pressure and lower milk volume, indicated that pressure to provide milk could be another important stressor interacting with maternal milk supply. Perhaps that is one reason why hardly any studies have been able to show a correlation between stress within the parental role and milk volume so far, as this factor has not been considered. Indeed, Dowling et al. (2012) and Ikonen et al. (2016) both identified a sufficient milk supply as a frequent concern among milk-expressing mothers of preterm infants [37, 38]. Although there are no studies focusing on pressure to provide milk among preterm mothers, Ayers et al. (2019) identified five categories of stressors in term-mothers, of which one is pressure to breastfeed [17]. Another study with term-mothers elaborated that psychological pressure to breastfeed may have the potential to contribute to postpartum depression, especially in new mothers [16]. Our findings extended these results to suggest that pressure could also be a common concern for preterm mothers, which may be even more triggered by the limited possibilities to care for and feed their infant. In particular, providing milk was described by preterm mothers as equal to "giving life" to their infants and keeping them healthy [39]. Therefore, pressure to provide milk probably should be considered when measuring stress due to the parental role in lactating mothers of preterm infants.

In addition, it should be mentioned that internal pressure was more strongly correlated to scores of the PSS:NICU subscale role alteration than external pressure, whereas external pressure was more strongly correlated to milk volume 14 days post-partum than internal pressure. This emphasises the relevance of including the different dimensions of pressure, as they seem to have various interrelationships with other determinants. However, it must be noted that no directional relationship can be specified for the correlation between internal and external pressure and milk volume or the PSS:NICU subscale role alteration. Moreover, the qualitative data showed that especially internal pressure was indeed triggered by the low milk volume, which underlines their mutual relationship.

Only 23% of the mothers stated that there was a possibility to receive donor milk for the infant. In Germany, human milk banking and usage of donor human milk is not implemented nationwide, for instance due to a lack of consistent legislative frameworks for donor milk [40]. A recent study reported a rather low utilization rate of donor milk with about 35% in their sample of German hospitals [41]. Thus, the knowledge about the possibility and availability of donor milk in general might be low in the German population. In our data, only external

pressure was significantly correlated to the availability of donor milk. It might be the case that only mothers, who struggled with achieving milk supply are informed about the alternative of using donor milk and, therefore, felt less pressured from the outside to provide their own milk. Presumably, there might be a more complex association between milk volume, internal and external pressure and the availability of donor milk. However, the data presented here does not allow further conclusions, as the availability of donor milk was not examined in detail. For future research, especially in populations where donor milk is more routinely integrated and more widely known, this might be an important factor to be included.

Strengths and limitations

The study was strengthened by using quantitative data and qualitative data to more deeply understand the pressure to provide milk among mothers of VLBW preterm infants. In this regard, it must be noted that the qualitative analyses refer to only 12 mentions. Moreover, it can be assumed that the answers are biased, as it is more likely that mothers left comments who had a traumatic or negative experience. Considering that the questionnaire included many topics regarding the time in the NICU, it is indeed surprising that 12 mentions were made regarding stress and pressure. However, a better understanding of this topic may be possible by assessing in-depth interviews with preterm mothers.

Pressure to provide milk was measured through two self-developed single-item measurements, as no validated construct was available at the time of data collection. Even though single items showed to be robust in other studies [42], the qualitative data indicated that there may be more dimensions especially of external pressure to provide milk, which could be evaluated separately in order to define specific sources of external pressure more precisely. Although the analyses showed various correlations between pressure and different variables, there may be many more influencing factors on the pressure to provide milk among mothers of preterm infants, which were not included in this study.

In addition, the retrospective character of the survey may have led to recall bias in the perceptions of mothers. This could have been the case in the retrospective reflection of stress experience during the time in the NICU, as well as in the reproduction of milk volume on day 14 post-partum. Although more than half of the mothers (56%) stated that they had documented their milk volume and did not have to provide information on the basis of memory, the other responses may be biased due to recall. Moreover, it is important to note that the PSS:NICU application was not developed for retrospective surveys due to changes in parental stress experiences over time

[23]. Nevertheless, recent research showed robust results with a retrospective use of the PSS:NICU subscale role alteration with a comparable Cronbach's alpha to our study [25]. Future studies should consider measuring all subscales of the PSS:NICU scale in order to depict more dimensions of stress.

Notwithstanding these limitations, this study provided new insights into the perception of pressure to provide milk as a possible factor being relevant for the pumping and breastfeeding experience, as well as maternal stress levels among mothers of VLBW preterm infants.

Conclusion

Many mothers of VLBW infants pressured themselves to provide milk, and some feel pressured from outside. Pressure to provide milk may be an important factor to be aware of in order to decrease maternal stress in the NICU. More research and validated instruments are needed to adequately measure pressure to provide milk with its different psychological, social, and environmental dimensions.

Abbreviations

MOM	Mother's own milk
NICU	Neonatal Intensive Care Unit
PSSNICU	Parental Stress Scale: Neonatal Intensive Care Unit
VLBW	Very Low Birth Weight
rs	Spearman's Rho-Test
χ^2	Pearson's Chi ² -Test

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Disclaimer

In this publication, while we utilize the generic feminine terms 'mother' along with the pronouns 'she' and 'her', we as authors explicitly acknowledge and recognize that individuals engaged in caregiving and lactation encompass diverse gender identities. We aim to address and include all persons, irrespective of their gender identity.

Authors' contributions

Isabella Schwab, Tim Ohnhäuser, Till Dresbach and Nadine Scholten designed the questionnaire. Isabella Schwab analysed the data and drafted the paper. All authors reviewed and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was approved and carried out in accordance with the institutional review board of the ethics committee of the Medical Faculty, University of Cologne (vote No. 20–1547). All methods were performed in accordance with the relevant guidelines and regulations. Study is registered in the German Clinical Trials register (Trial registration number: DRKS00024799). Informed consent was obtained from all participant and parents involved in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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Research Paper 3

ORIGINAL ARTICLE

Achieving sufficient milk supply supports mothers to cope with premature birth

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Abstract

Aim: To explore whether and how expressing breast milk is perceived as helpful in coping with negative emotions due to premature birth by mothers of very low birth weight (VLBW) infants.

Methods: Qualitative interviews and a retrospective cross-sectional questionnaire with mothers of VLBW infants were conducted and analysed using an exploratory sequential mixed-method design. Hypotheses were built using qualitative content analysis and quantitatively tested using multivariate regression analysis.

Results: Interviews with 12 mothers and questionnaires of 518 mothers were analysed. Coping with prematurity by expressing milk was seen as a way to maintain the caregiving role for the mothers, where three relevant factors arouse: making up for what happened, providing the best for their infant and fear of low milk supply. Quantitative analysis showed that mothers with a high milk supply (Coef. = 1.1, $p < 0.000$) and more feelings of guilt due to premature birth (Coef. = -0.1; $p = 0.015$) perceived expressing breast milk significantly more as a resource for coping.

Conclusion: This study adds knowledge on how expressing breast milk for their VLBW infant may support mothers in coping with premature birth, by revealing the association with milk supply and feelings of guilt due to premature birth.

KEYWORDS

coping, maternal mental health, milk expression, milk supply, mothers' experiences, premature birth

1 | BACKGROUND

Mothers who have delivered a very low birth weight (VLBW) infant, weighing less than 1 500g, have described it as a shocking and disruptive event in their lives.^{1,2} This can lead to feelings of grief, loss and guilt for the uncompleted pregnancy as well as anxiety and fear for the premature infant's health.³⁻⁵

After the birth of a VLBW infant, the mother and her infant are commonly separated, as the infant requires specialised care in a neonatal intensive care unit (NICU).⁶ Although important efforts have been made to enable unlimited access to the infant for parents or rooming-in, its need for medical care in an incubator may still cause physical separation.⁷ By impeding the establishment of physical and emotional closeness between the mother and the infant,^{8,9} this

Abbreviations: NICU, Neonatal Intensive Care Unit; VLBW, Very Low Birth Weight.

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could complicate the mother's ability to fulfil her maternal caregiving role.^{3,10} In addition, the mother-infant bond, which usually begins during pregnancy and continues through the process of becoming a mother after birth, is affected.^{11,12} Consequently, many mothers experience various negative emotions, including anxiety, sadness or guilt regarding the premature birth of their infant.⁵ To deal with these negative emotions and to build a connection to the infant after preterm birth, coping strategies showed to be crucial for mothers.^{13,14} However, establishing those can be challenging due to the physical separation of the mother and her infant with limited possibilities of caregiving.¹⁵

Strategies used to strengthen the maternal role as a caregiver and the mother-infant bond include skin-to-skin contact, participating in the infants care and support in providing breast milk.¹⁶ In this context, preterm mothers often describe the provision of breast milk as the only thing a mother can do, representing motherhood and a connection to the infant.^{17,18} Given the importance of breast milk for their infant's health, expressing milk might gain even more relevance for the caregiving role of preterm mothers.¹⁹ Therefore, it can be assumed to be helpful for mothers in coping with preterm birth. At the same time, however, the demand of milk expression and dealing with lactation difficulties is a recurring theme concerning mothers of preterm infants.²⁰

To our knowledge, there is a gap in research examining whether and how mothers perceive breast milk expression as a resource for coping with preterm birth. Thus, the aim of this study was to explore whether and in which way mothers perceive breast milk expression as supportive for coping with preterm birth. First qualitative interviews with mothers of VLBW infants were analysed to identify relevant factors. On the basis of these findings, hypotheses were then generated and tested in the following through quantitative data analysis.

2 | METHODS

This study applied an exploratory sequential mixed-methods design, as qualitative data were partly conducted before the quantitative questionnaire was developed. Therefore, the choice of items were influenced by preliminary results of the qualitative content analysis.²¹ All data were collected within the Neo-MILK project, which aims to implement structured lactation support and promotes the provision of human milk in NICUs in Germany.²²

2.1 | Qualitative data collection

From 4 May to 1 June 2021, narrative interviews with 12 mothers of VLBW infants at 3 to 12 months after hospital discharge were conducted. This time range was chosen to lower the risk of retraumatisation in mothers due to premature birth.² The participants of the study were recruited via the Neo-MILK social media channel and NICUs participating in the Neo-MILK project. Mothers could then contact the responsible researchers and were screened regarding

Key Notes

- There is a gap in research examining whether and how mothers perceive breast milk expression as a resource for coping with premature birth.
- Achieving sufficient milk supply showed to be crucial for coping with premature birth by expressing breast milk.
- Mothers who experienced more feelings of guilt due to premature birth perceived expressing breast milk more as a resource for coping.

the only inclusion criteria of the time of the infant's hospital discharge (3 to 12 months). One mother was excluded due to a high risk of retraumatisation since one of her twins died after birth. All interviews were conducted individually by a psychologist via video call due to the COVID-19 pandemic-related precautions at the time of the data collection. They were recorded by audio and, to prevent any data loss, were transcribed by a person who received consent from the mothers to be present.

The semi-structured interview guide was derived by psychologists, lactation consultants, nurses, and NICU physicians to capture perceived lactation support and psychological strain of VLBW mothers. The interview guide included topics such as experiences in the NICU with milk expression, previous experiences with lactation, perceived psychological strain, and if and how the mothers perceived breast milk expression as helpful in coping with perceived psychological strain due to premature birth. The interview guide can be found in Appendix S1.

2.2 | Data analyses

The audio files were anonymised and transcribed for qualitative content analysis.²³ Two trained research assistants coded the interviews according to a previously developed coding scheme. Quotes are given to better understand the mothers' perceptions. All quotations used in this paper were translated from German into English.

2.3 | Quantitative data collection

A retrospective, cross-sectional survey with mothers of VLBW infants 6 to 24 months after birth at the time of the survey was conducted. The content of the survey was developed based on the current literature and preliminary results of the qualitative interviews. Between 1 June and 31 August 2021, four statutory health insurance companies (AOK Rhineland/Hamburg, TK, Pronova BKK, DAK) sent the anonymous questionnaires to all mothers of VLBW infants, who were insured with them. They were identified by the following International Statistical Classification of Diseases

and Related Health Problems (ICD)-10 Codes: P07.00, P07.01, P07.02, P07.10 and P07.11.

Due to the lack of validated scales, all items were self-developed. To what extent expressing breast milk helped mothers to cope with their preterm birth was measured through the following statement: 'During the time in the NICU, expressing breast milk for my infant helped me to cope with preterm birth'. On a six-point Likert scale, mothers could respond whether they totally disagreed (1), mostly disagreed (2), rather disagreed (3), rather agreed (4), mostly agreed (5) or totally agreed (6) to the statement.

Reaching sufficient lactation can be defined as reaching a milk volume over 500 mL per day on day 14 of life.²⁴ In the quantitative questionnaire, milk volume on day 14 of life was measured through pre-defined groups: under 300, 301–500, 501–700, 700–800 and over 800 mL/day. Personal attitudes regarding the nutrition with breast milk were measured through two statements: 'For me it makes no difference if my infant receives my breast milk or formula'. 'Formula is of such good quality today that there is no longer any difference compared to breast milk'. A six-point Likert scale was used for the responses: totally agree (1), mostly agree (2), rather agree (3), rather disagree (4), mostly disagree (5) and totally disagree (6). As elaborated before, the premature end of the pregnancy often leads to feelings of guilt.¹³ Therefore, mothers were asked whether they had experienced such feelings through a self-developed item: 'During the time in the NICU, I experienced recurring feelings of guilt about the premature birth'. The same Likert scale as for the personal attitudes was used for responses.

2.4 | Statistical analyses

The study used the statistical software Stata 18 (StataCorp LLC, Texas, USA) to analyse the quantitative data. Descriptive data were presented with percentages, means, standard deviations and figures depending on the data distribution. After bivariate testing, multivariate regression models were calculated on a 95% significance level. Thus, associations with a *p*-value equal or less than 0.05 were considered significant.

2.5 | Ethics

The project Neo-MILK is registered in the German Register of Clinical Trials (ID: DRKS00024799). The qualitative study was approved by the ethics committee of the Bielefeld University (2020-147). The quantitative study was ethically approved from the University Hospital Cologne (20-1547).

3 | RESULTS

In the following, results of the qualitative content analysis of the 12 interviews conducted are presented first. They illustrate the mothers' perceptions on whether and how expressing breast milk helped

them cope with preterm birth. Based on these findings, hypotheses were elaborated and tested with quantitative data. These results are presented by using descriptive statistics and multivariate linear regression.

3.1 | Qualitative analyses

When asking about how mothers perceived breast milk expression and if it helped them to cope with the psychological strain of preterm birth, different themes arouse. In addition, subcategories of coping with premature birth by expressing breast milk became apparent in the interviews, which are illustrated in the following.

3.1.1 | Maintaining the caregiving role

In the interviews, the theme of maintaining a connection to their infants by expressing breast milk for them appeared. Due to the separation between the infant and mother, the caregiving role seemed to be a central issue for preterm mothers:

Yes, because you just feel needed and I think it was always somehow a connection to my daughter. It was like she needs me, so I can't let myself down. (M12)

I think that during the time when the infants were at the neo ward, you somehow functioned and you were...also proud of the fact that you could provide them with breast milk. It was, I think, also important that you still had this caregiving role somehow? ...At home you always have something to do and always can do something for the infants when they're not there. (M12)

3.1.2 | Making up for what happened

In addition to the aforementioned topic, mothers reported about experiencing negative feelings due to the premature birth, which they were trying to cope by expressing breast milk:

Yes, because of course at one moment you think: Why did my body fail, why couldn't I continue the pregnancy now? ...I definitely had the feeling that I was able to make up for what happened quite a bit with it. (M8)

In any case, I had the feeling that I could make up for a lot with it, so to speak. (M6)

Reasons for the mothers' perceptions of expressing breast milk as helpful in coping with premature birth primarily stemmed from the desire to maintain a connection with the infant. This allowed them to continue the role of the caregiver even though the pregnancy ended prematurely. Along with that, feelings of guilt, indicated by the theme of making up for what happened, may play a further role in the mothers' perception of coping by expressing milk. From this, the first hypothesis was derived:

Hypothesis 1. Feelings of coping with premature birth by expressing breast milk are positively correlated with mothers' feelings of guilt due to the prematurely ended pregnancy.

3.1.3 | Providing the best for their infant

Breast milk for premature infants was often regarded as medicine. Therefore, the possibility of being able to express breast milk for their infant made the mothers feel useful. Furthermore, some of them have seen it as a way of dealing with their negative feelings about the premature birth:

It had been conducive that you...can do something that is then also good for [the infant].
(M8)

So, I was simply able to offer my daughter the best I could and, yes, that helped me.
(M8)

But in hindsight I would say that at least something could be done for the infant and if...not even that would have been possible, I think that would have been even worse for me, yes.
(M10)

This pointed out that a positive attitude towards breast milk may be linked to feelings of coping by expressing breast milk, which resulted in the second hypothesis:

Hypothesis 2. Feelings of coping with premature birth by expressing breast milk are positively correlated with mothers' positive attitudes towards breast milk.

3.1.4 | Fear of low milk supply

On the contrary, mothers felt that the need to express a sufficient amount of breast milk may have led to even more strain. At this stage, mothers still had to come to terms with the stressful situation

of preterm birth. This seemed to be especially the case when the milk supply decreased:

So, I'm more of a success oriented person and...I was putting a lot of effort in and I wasn't getting the feedback for the success and I found that very depressing. And what really stressed me out was when I was sitting...in the pumping room and there was a mom who pumped and filled three bottles and I'm at ten millilitres and that's after half an hour. [...] So that dragged me down completely, this comparison then.
(M1)

For two or three weeks I was panicking that I would run out of milk.
(M11)

It is, therefore, assumed that the coping potential of expressing breast milk is mutually dependent on sufficient milk supply, which led to the third hypothesis:

Hypothesis 3. Feelings of coping with premature birth by expressing breast milk are positively correlated with achieving sufficient milk supply.

3.2 | Quantitative analyses

Of 1894 contacted mothers, 600 (31.6%) responded to the survey. Incorrectly contacted mothers who did not meet the ICD-10 inclusion criteria (67 mothers) and 15 mothers who did not initiate lactation were excluded. Thus, responses of 518 mothers remained for the following analyses. According to the findings of the qualitative content analysis, quantitative data were analysed to show possible associations (Figure 1). The quantitative sample is described in Table 1.

Figure 2 shows that more than half of the mothers totally, mostly or rather disagreed with the statement that expressing breast milk helped them cope with preterm birth (64%). However, 34% rather, mostly or totally agreed that they coped with premature birth by expressing breast milk. The mean agreement was 2.8 ± 1.7 . On average, the mothers (3.2 ± 1.95) agreed that they had recurring feelings of guilt due to premature birth (Figure 3). The mean agreement whether formula and mother's own milk are equal in quality for an infant was 3.5 ± 1.4 . Mean agreement to the statement whether it makes no difference to mothers if their infant receives their own breast milk or formula was lower (4.5 ± 1.5) (Figure 4). Qualitative data suggested that any feelings of coping by expressing breast milk were dependent on achieving sufficient lactation. As mentioned before, sufficient lactation can be considered when a milk volume of more than 500mL/day is reached on day 14 of life.²⁴ This was

FIGURE 1 The flow of information using an exploratory sequential mixed-method design.

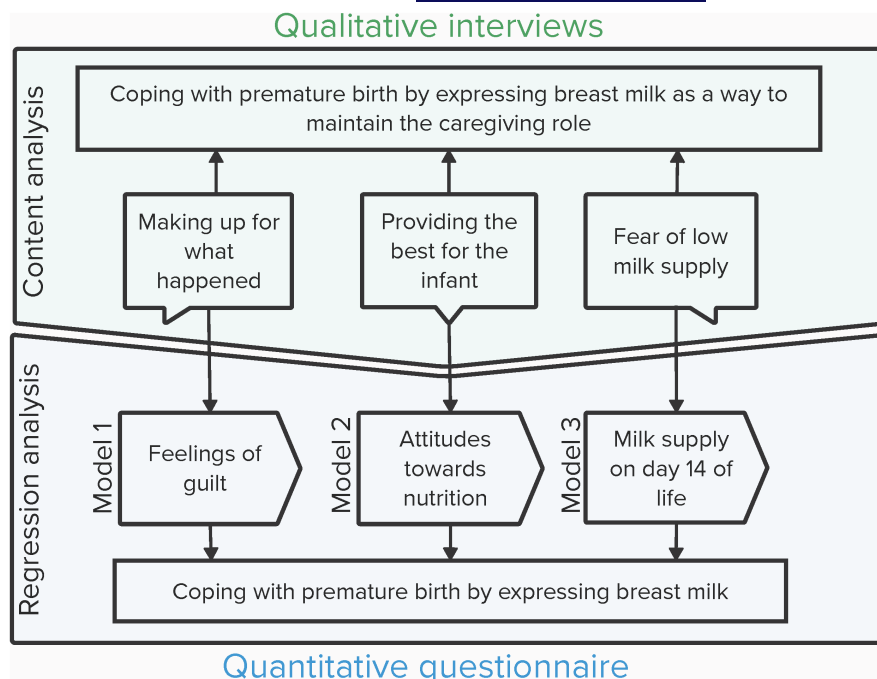


TABLE 1 Sample description.

Sociodemographic characteristics	(n [mean (min–max); SD])
Maternal age	487 [34.1 (19–54); 4.8]
Gestational age	505 [28.6 (22–36); 2.9]
	n (%)
Maternal educational level	
Without a graduation	10 (1.93%)
Lower secondary school	46 (8.88%)
Secondary school	114 (22.01%)
Higher education entrance qualification	124 (23.94%)
University degree	213 (41.12%)
Missing	11 (2.12%)
Birth weight (g)	
1499–1000	295 (56.95%)
999–5000	197 (38.03%)
<500	22 (4.25%)
Missing	4 (0.77%)
Multiples	
Yes	153 (20.54%)
No	360 (69.50%)
Missing	5 (0.97%)
Milk volume on day 14 of life (mL/day)	
<300	196 (37.84%)
300–500	115 (22.20%)
501–700	77 (14.86%)
701–800	44 (8.49%)
>800	68 (13.13%)
Missing	18 (3.47%)

achieved by 36.5% of the mothers (Table 1). The relationship between maternal milk volume and coping is shown in Figure 5.

Multivariate linear regression models were performed after bivariate analysis. Multivariate regression analysis of the final model showed a significant association of more feelings of guilt due to premature birth with more perceived coping by expressing breast milk (Coefficient = -0.105 ; $p = 0.015$). Personal attitudes towards breast milk nutrition were not significantly associated with feelings of coping (coefficient = 0.115 , $p = 0.067$; coefficient = 0.136 , $p = 0.062$) after adding the milk supply variable to the model. A milk supply higher than <300 mL/day on day 14 of life was significantly associated with more perceived coping with preterm birth by expressing breast milk. This effect was strongest for mothers with 701 – 800 mL/day on day 14 of life (coefficient = 1.099 , $p < 0.000$). The final model 3 showed an adjusted R^2 of 13.7%. However, while guilt due to premature birth explained 0.7% of the variance (Model 1), the personal attitudes (6.7%) and milk supply (6.3%) explained more variance of the final model (Table 2).

4 | DISCUSSION

This study explored whether expressing breast milk was perceived as helpful for coping with premature birth in mothers of VLBW infants. Therefore, the content from the qualitative interviews was analysed from which hypotheses were derived and quantitatively tested. The findings showed that breast milk expression was perceived to be helpful in coping with preterm birth in some cases and was mutually dependent on milk supply. The previous assumption that mothers may perceive providing breast milk as a way to fulfil a caregiving role and cope with premature birth was reflected in the interview responses. This coincides with the literature, in which milk

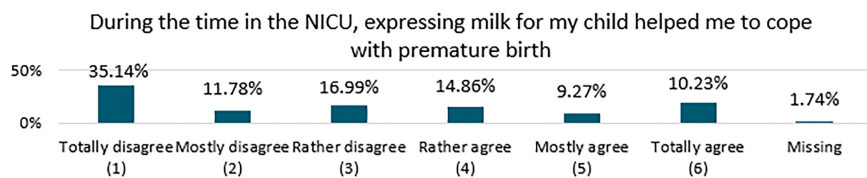


FIGURE 2 Coping with premature birth by expressing breast milk.

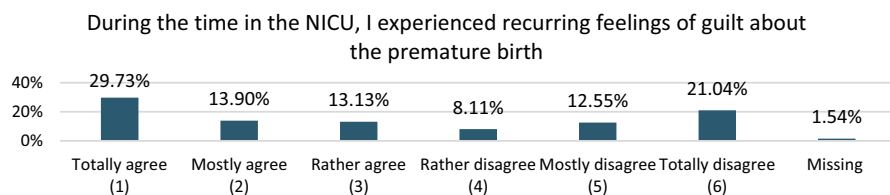


FIGURE 3 Feelings of guilt.

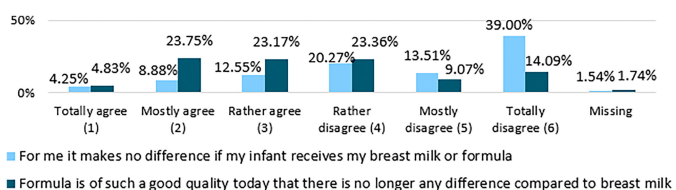


FIGURE 4 Personal attitudes towards the infant's nutrition.

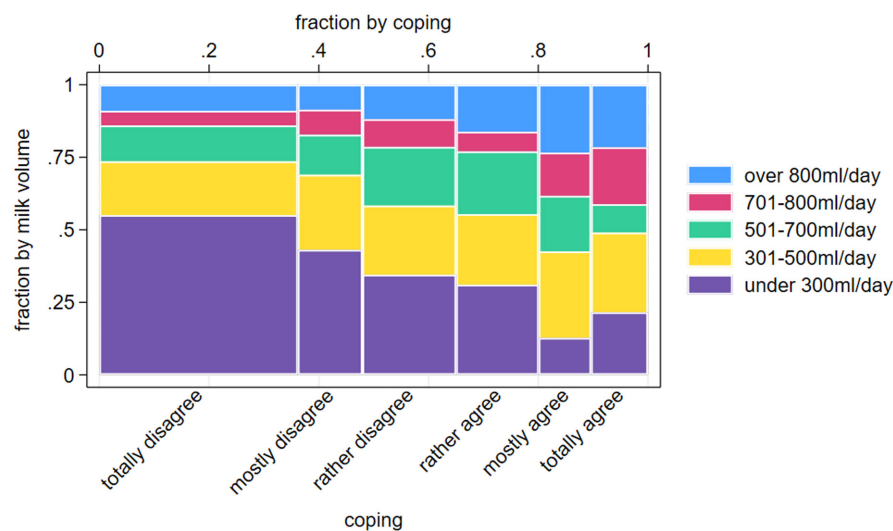


FIGURE 5 Coping with preterm birth by expressing breast milk and milk volume on day 14 of life.

expression has been shown to be one of the main aspects for the mothers to restructure motherhood after preterm birth.^{20,25} Other studies have stated that mothers associate providing breast milk with being a mother and having a connection to their infant.^{17,18} Our data indicated that particularly maintaining a connection with the infant after premature birth by providing breast milk may be a central factor in coping with premature birth. However, the mothers' perceptions were mutually dependent on other factors.

The qualitative interviews indicated that some mothers felt that they had to make up for premature birth. Other studies on the mental health of preterm mothers showed similar results: mothers thought of being responsible for premature birth and felt guilty for it.^{13,26} The multivariate regression analysis underlined these qualitative results. However, the significant association could stem from

the fact that mothers who experienced more feelings of guilt generally had a greater need for coping.

Feelings of coping by expressing breast milk were experienced by the mothers as providing the best for their infant. This is supported by other studies, where the health-promoting properties of breast milk were described as an important factor by mothers of preterm infants.^{19,27} These findings indicate that the mothers' knowledge of the health benefits of breast milk and their attitudes towards nutrition seem to be important to use expressing milk as a coping mechanism. However, this assumption was not supported by the quantitative data in this study. The data showed that the personal importance of breast milk nutrition was not associated with feelings of coping by expressing breast milk. The same findings emerged in relation to the belief that formula and breast milk are equal.

TABLE 2 Multivariate regression.

	Coping														
	Model 1				Model 2				Model 3						
	B	SE	p	CI	B	SE	p	CI	B	SE	p	CI			
			Lower	Upper				Lower	Upper			Lower	Upper		
Guilt	-0.084	0.039	0.033	-0.160	-0.007	-0.078	0.038	0.039	-0.153	-0.004	-0.105	0.037	0.015	-0.178	-0.032
Formula equal to breast milk					0.134	0.067	0.045	0.003	0.265		0.115	0.067	0.083	-0.015	0.246
Personal attitude					0.200	0.063	0.001	0.078	0.323		0.136	0.062	0.061	0.013	0.259
Milk volume (ref. <300 mL/day)															
300-500 mL/day											0.789	0.194	<0.000	0.406	1.168
501-700 mL/day											0.670	0.228	0.014	0.222	1.168
701-800 mL/day											1.099	0.278	<0.000	0.553	1.117
>800 mL/day											1.026	0.238	<0.000	0.559	1.494
Constant	3.085	0.148	<0.000	2.795	3.375	1.677	0.272	<0.000	1.143	2.211	1.589	0.266	<0.000	1.066	2.112
adj. R ²			0.007					0.074					0.137		
n			507					498					482		
BIC			1998.2					1932.9					1859.1		
AIC			1989.7					1916.1					1825.6		

Bold values indicate significance. Abbreviations: AIC, Akaike information criterion; B, regression coefficient; BIC, Bayesian information criterion; CI, confidence interval; p, p-value (Bonferroni-Holm corrected); SE, standard error.

The qualitative content analysis revealed that some mothers did not feel that expressing breast milk helped them cope with preterm birth. This appeared to be the case especially when the milk volume was low or decreased over time. In that case, the attempt to provide breast milk rather put additional strain on mothers. In the literature, concerns about sufficient milk volume seem to affect many preterm mothers.^{24,28,29} The quantitative data analysis supported these findings, as a higher milk volume on day 14 of life was significantly associated with more feelings of coping by expressing breast milk. Understanding how mothers cope by expressing breast milk may help to better support them in this process. This seems particularly relevant in the case of low milk supply when the caregiving role by providing breast milk is impaired. Enabling more positive experiences within the lactation process could be an important direction for future research to promote maternal well-being. Positive experiences may have the potential to facilitate coping with premature birth in mothers, as indicated by this study.

4.1 | Strengths and limitations

This study was strengthened by its mixed-method design. By combining qualitative and quantitative data, this study adds knowledge on the individual experiences of VLBW mothers and quantifies indicated associations. However, to better understand the coping potential of expressing breast milk for preterm mothers, more research is needed on this topic.

Despite providing insights into the interplay between the negative aspects of premature birth and the ability to cope by expressing breast milk, this study also has some limitations. The cross-sectional design of the quantitative questionnaire comes with the limitation that no causal effects could be inferred from the data. Furthermore, the retrospective nature of the quantitative survey and qualitative interviews may have led to recall bias regarding the mothers' perceptions. However, the time frame was chosen to minimise possible retraumatisation, as mothers who experience premature birth showed to be at a higher risk of posttraumatic stress and depression.^{2,30} Since no validated scales on the coping potential of expressing breast milk in the case of premature birth are currently available, self-developed items were used to quantitatively measure the extent of coping. Although the items were developed and revised with an expert team, the choice of statements may have influenced the results. For example, explicitly asking mothers about feelings of guilt in the quantitative questionnaire may have elicited guilt in mothers. Yet, many totally disagreed with having experienced this feeling. In addition, it could be possible that non-native mothers may have misunderstood the statements due to language difficulties. Future research should thus focus on the development and validation of appropriate scales. Our final model explained 13.7% of the variance, which indicates that there are other predictors of coping feelings that were not considered in the model. Due to the exploratory sequential approach of this study, only themes which emerged in the interviews were considered in the multivariate regression model.

This could have led to underestimation of other factors that might have played an important role in other study samples. Therefore, the extent to which the results can be generalised may be limited. In accordance with the literature, this study assumed that mothers perceive negative emotions due to preterm birth. As a consequence, they need coping strategies to rebuild their positive emotional state.³¹ However, this may not be true for all mothers. Indeed, some mothers, as implied by the interview data, experienced reverse feelings and felt strained due to breast milk expression.

5 | CONCLUSION

Coping with premature birth by expressing breast milk may be an important resource for the mothers' emotional state. This study showed that this potential was particularly dependent on a sufficient milk supply and feelings of guilt due to premature birth. To exploit this potential, positive experiences with the provision of breast milk should be aimed for. Therefore, mothers need support to establish lactation and reach their lactation goals. Furthermore, mothers who choose not to express breast milk or have an insufficient milk supply should be supported in their coping processes in other ways.

AUTHOR CONTRIBUTIONS

Isabella Schwab: Conceptualization; methodology; writing – original draft; writing – review and editing; formal analysis. **Ricarda Wullenkord:** Writing – review and editing; formal analysis; conceptualization; methodology. **Tim Ohnhäuser:** Writing – review and editing. **Till Dresbach:** Writing – review and editing; funding acquisition. **Nadine Scholten:** Funding acquisition; writing – review and editing; conceptualization.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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