ORIGINAL RESEARCH: EMPIRICAL RESEARCH - QUANTITATIVE



Symptoms of depression in parents after discharge from NICU associated with family-centred care

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Abstract

Aims: The aim of this study was to examine the potential association of family-centred care as perceived by parents during a NICU stay with parents' depressive symptoms at discharge and at 4 months corrected for infant age.

Design: A longitudinal, multicentre cohort study was conducted from 2018 to 2020 in 23 NICUs across 15 countries.

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Methods: Parents (n = 635 mothers, n = 466, fathers) of infants (n = 739) born before 35 weeks of gestation and admitted to the participating NICUs were enrolled to the study during the first weeks of their infants' hospitalizations. They responded to Digi-FCC daily text messages inquiring about their perception of family-centred care provided by NICU staff. In addition, they completed a questionnaire assessing their overall perception of family-centred care at discharge. Parents' depressive symptoms were measured by the Edinburgh Postnatal Depression Scale at discharge and again after discharge when their infants were at 4 months corrected for age.

Results: The mothers' and the fathers' perceptions of family-centred care were associated with their depressive symptoms at discharge and at 4 months corrected age, controlling for gestational age, multiple birth, parent education and relationship status. Parents' participation in infant care, care-related decisions and emotional support provided to parents by staff explained the variation in the parents' perceptions of family-centred care. The factors facilitating the implementation of family-centred care included unlimited access to the unit for the parents and for their significant others, as well as amenities for parents.

Conclusions: Our study shows that family-centred NICU care associates with parents' depressive symptoms after a NICU stay.

Impact: Depression is common in parents of preterm infants. The provision of family-centred care may protect the mental well-being of parents of preterm infants.

KEYWORDS

depression, family-centred care, health promotion, intensive care units, longitudinal study, neonatal parents, nursing, predictive research, preterm infant, prospective cohort

1 | INTRODUCTION

Current evidence indicates that parents of preterm infants are at high risk for developing depression, which has negative consequences for parents, the parent-infant relationship and infant development (de Paula Eduardo et al., 2019). Depressive symptoms result from parents' stress, separation from the infant and inability to realize a parental role in an unfamiliar and often professional-centred neonatal intensive care unit (NICU) environment (Flacking et al., 2012). Family-centred care (FCC) aims to include parents as partners in infant care during the infant's hospitalization in the NICU and may therefore play a role in reducing the risk of parental depression (Ding et al., 2019). Existing evidence on the association between parents' depressive symptoms and FCC is sparse. This study focuses on the global challenge of reducing depressive symptoms among mothers and fathers of preterm infants by examining the association of FCC practices and parents' depressive symptoms in the contexts of 15 countries. This will give us an indication if supportive care culture can play a major role in decreasing parents' depressive symptoms.

2 | BACKGROUND

The hospitalization of a newborn in a critical care unit is typically unexpected, highly stressful and generally traumatic for parents.

Preterm birth is one of the most common reasons for NICU hospitalization. A systematic review and meta-analysis of 26 studies conducted in 18 countries between 2008 and 2018 found an association between preterm birth and postpartum depression in mothers (de Paula Eduardo et al., 2019). Across these studies, rates of maternal depression varied from 6.6% to 42.9%. Compared with mothers of full-term infants, the mothers of preterm infants were 1.2-18.4 times more likely to experience postpartum depression. Although the timing of measurements differed, most studies assessed depressive symptoms during the NICU hospitalization. In studies measuring symptoms up to 3 months postpartum, mothers' symptoms decreased over time; however, studies that assessed symptoms for longer than 3 months did not reveal a consistent pattern. Mothers of preterm infants were at increased risk compared with mothers of full-term infants up to 3 months after birth (de Paula Eduardo et al., 2019).

Although less is known about the effects of preterm birth on fathers, some studies suggest they are also at-risk for depression, and their symptoms diminish over time in a pattern similar to that of the mothers' symptoms (Pace et al., 2016; Winter et al., 2018). Prevalence estimates for clinical depression in fathers of preterm infants range from 6% to 36% (Pace et al., 2016; Winter et al., 2018). Fathers of preterm infants have more depressive symptoms at 9 months of corrected age of the infant compared with fathers

of term infants (Cheng et al., 2016). Understanding fathers' depressive symptoms and associated factors are important due to their increasing presence and role during NICU care (He et al., 2021).

Both mothers' and fathers' depressive symptoms may have adverse effects on the parent-infant relationship or interaction, as well as on child development. Maternal depressive symptoms were associated with less optimal mother-infant bonding (Rados et al., 2020). Longitudinal studies found that the infants of mothers who were depressed at 4 months corrected infant age had lower cognitive functioning at 16 months, controlling for various socioeconomic factors (McManus & Poehlmann, 2012b); clinically significant depressive symptoms at 9 months corrected infant age was also related to lower infant cognitive functioning at 16 months (McManus & Poehlmann, 2012a). Fathers' depressive symptoms were associated with poorer cognitive development in preterm children (Çelen Yoldaş et al., 2020) even when adjusted for mothers' symptom levels and children's biological and social risk factors (Cheng et al., 2016). Fathers' psychological well-being was also associated with behavioural problems in 3-year-old children born very preterm (Huhtala et al., 2012).

Given the high rates of depression in parents of infants requiring NICU care, researchers have sought to understand which parents might be at greater risk. Evidence from a scoping review indicated that intrapersonal, interpersonal, and institutional factors influence NICU parents' mental health (Loewenstein, 2018). Intrapersonal risk factors include being a first-time parent, lower maternal education and low self-esteem. Interestingly, the severity of an infant's medical condition was not consistently related to parental depressive symptoms. Interpersonal risk factors include single parenting and a lack of support available from family and friends. The intrapersonal and interpersonal risk factors for depressive symptoms are similar to those for parents of full-term infants (Vigod et al., 2010).

Institutional risk factors refer to the stressful NICU environment and lack of FCC practices, such as healthcare providers' negative attitudes toward parent presence, participation and parent-infant skin-to-skin contact; poor information provision from healthcare providers to parents and the low quality of infant pain management during hospitalization (Loewenstein, 2018). Free access for parents is the corner stone of family-centred care, as the other FCC aspects cannot be realized without parents' presence. FCC interventions that provide educational or psychosocial support for parents and include them as partners in infant care may play a role in reducing the risk of parental depression (Benzies et al., 2013; Ding et al., 2019). Despite the benefits of FCC, actual unit practices and policies (Gooding et al., 2011) and parents' depressive symptoms vary across the world (de Paula Eduardo et al., 2019). Little research has explored the role of institutional factors, such as parents' perceptions of FCC, in parents' depressive symptoms.

3 | THE STUDY

3.1 | Aim

The aim of this study was to examine whether parents' perceptions of FCC during a NICU stay were associated with their depressive symptoms at discharge and 4 months of corrected infant age. This international study allowed us to examine the association in a large group of neonatal units with different FCC practices and variations in parental depressive symptoms after hospitalization.

3.2 | Design

A longitudinal, prospective multicentre cohort study was conducted from March 2018 to May 2020 with parents from 23 participating NICUs in 15 countries (13 in Europe, 1 in Australia and 2 in Canada). This report adheres to the STROBE guidelines for reporting observational studies (von Elm et al., 2007).

3.3 | Participants

Parents were recruited in the NICUs in which their preterm infants were admitted between March 2018 and December 2019. Each participating NICU was to recruit the parents of 30 eligible infants. This sample size was chosen so that data collection at each site could be completed in a reasonable amount of time and the actual time ranged from 2 to 12 months (M = 8 months). It was possible for both parents of an infant to participate, or the mother or the father/partner could participate alone. Thus, more than 30 parents participated at a site if more than one parent per infant chose to take part.

Parents were included if (a) their infant was born before 35 weeks of gestation and was admitted to the NICU and (b) they had a mobile phone that could receive text messages and they agreed to receive messages from the research team for the purposes of data collection. The gestational age limit was set to 35 weeks which is the usual limit to routinely admit preterm infants to neonatal units. Parents were excluded if (a) their infant's estimated hospital stay was less than 3 days (insufficient time for data collection), (b) they had triplets or higher-order multiples, (c) they were unable to read English or the local language at the study site and (d) the infant's medical condition was so critical that survival was uncertain. Recruitment took place as soon as appropriate before the sixth day after birth, except for two units where the local ethics committee did not permit recruitment until the second week following birth.

During the study period, a log of all admissions of infants younger than 35 gestational weeks was kept at each participating unit. Data about the infants' gestational age, birthweight, length of hospital stay and driving time to the parent's home were recorded, as well as reasons for ineligibility for this study.

3.4 | Data collection

3.4.1 | Depressive symptoms

Parents' depressive symptoms were measured with the Edinburgh Postnatal Depression Scale (EPDS; Cox et al., 1987). The scale consists of 10 screening questions concerning a respondent's feelings during the previous week and the absence or presence of symptoms such as insomnia, mood, tearfulness and thoughts of self-harm. Parents respond to each question on a scale from 0 to 3 related to the frequency of feelings or symptoms, with total scores ranging from 0 to 30. Higher scores reflect greater symptomatology. Studies across different populations and cultures used cut-off scores ranging from 9–10 to 13–14 (Norhayati et al., 2015; de Paula Eduardo et al., 2019). In this study, the mean score was computed, as well as the proportion of respondents scoring in the range indicating possible clinical depression (cut-off score ≥13).

3.4.2 | Family-Centred Care

We employed two methods to capture parents' experiences of family-centred care during NICU hospitalization to increase the validity of our findings. Both measures have operationalized parent-staff partnership and parent support as the essential element of FCC (Mikkelsen & Frederikssen, 2011).

3.4.3 | Digi Family-Centred Care (DigiFCC)—parent version

Parents' perceptions of FCC were assessed daily over the course of hospitalization using the Digi Family-Centred Care: Parent (DigiFCC-P) version survey (Axelin et al., 2020). Nine items assess the following aspects of FCC: (a) active listening by staff, (b) parent participation in infant care, (c) staff provision of individualized parent education, (d) parent participation in making decisions, (e) parents' trust in the staff with respect to infant care, (f) parents' trust in staff for infant care, (g) parents' participation in medical rounds and decisions concerning medical care, (h) information received from staff and (i) emotional support provided by staff.

A random selection of one of the nine items was sent daily as a text message to parents in the evening via a protected website until infant discharge or until the parent chose to stop responding. If a parent did not respond within one evening, then the same question was sent again as a reminder the next day. Parents of twins received only one item per evening. Parents responded by selecting a response from 0 to 7 to the text message, with higher values reflecting better quality FCC, according to their experience during that specific day. Respondents selected 0 if they had not been in the NICU that day. They could also choose to add brief comments to explain their response. A mean score was computed for each parent for the nine items, not including 0 values that indicated parent absence from the unit.

3.4.4 | Family-Centred Care Questionnaire

To capture the parents' overall impression of FCC at the end of the hospitalization, parents responded to a paper version of the 20-item Family-Centred Care Questionnaire (FCCQ): Parent version in the week prior to discharge (Shields & Tanner, 2004). The FCCQ assesses parents' perceptions of the staffs' ability to provide their child and family with FCC during their child's hospitalization. This self-report measure consists of 20 items. The subscales assess three dimensions of family-centred care: respect (6 items), collaboration (9 items) and support (5 items). Parents rate items on a 4-point scale (never, sometimes, usually and always), and higher scores reflect a more favourable perception of the staff's family-centred care. In this study, a mean score was calculated for each of the subscales, as well as the total score.

3.4.5 | Other measures

A background questionnaire was developed to collect data about the sociodemographic characteristics of the parents (e.g. age, education, employment status prior to the birth and parity) and their infants (e.g. gestational age at birth). Moreover, at each participating NICU, the site investigator and a unit manager (e.g. head nurse or medical director) responded to a unit background questionnaire to collect data about unit characteristics, practices and amenities for parents. This included the level of neonatal care (2, 3 or 4), annual number of admissions, number of physicians and nurses working on various shifts, types and number of other professionals on staff (e.g. a psychologist or social worker), amenities for parents (e.g. number of single-family rooms, showers, kitchens and lounge facilities) and practices (e.g. parents' 24-hour access to their infants, couplet care and visits by significant others).

From the unit background questionnaire, the following variables were calculated to describe unit characteristics: (a) average daily census (the annual number of care days divided by the number of days in a calendar year), (b) average daily census per nursing staff on a weekday day shift and (c) single-family rooms per average daily census. A unit was considered to have limitations on parents' presence if parental presence was restricted or if parents were not able to be with their infants during procedures.

3.4.6 | Data collection procedures

Parents participated from the time of their enrolment until approximately 4 months after discharge. We were interested in prolonged depressive symptoms of parents of preterm infants since the prolonged depressive symptoms of mothers have been shown to associate with less optimal mother-preterm infant interaction (Korja et al., 2008). Text messages assessing family-centred care were sent to parents throughout their hospital stays or until they stopped responding. During the last days of their infants' hospitalization, they completed paper versions of the EPDS and FCCQ. Finally, when their

infants were 4 months corrected age, the EPDS was sent to them via email or mail as parents preferred.

In cases when an infant was transferred to a step-down unit, data collection continued if that unit was also participating in the study. For example, in Tallinn and Tartu, three units participated in each. These were considered one unit, although they have different locations. If this was not the case, data collection ended at discharge from the study NICU. Nonetheless, post-discharge measures were sent to these parents because they had provided their consent and contact information.

3.5 | Ethical considerations

Ethics approval was obtained at the principal investigator's site (the Hospital District of Southwest Finland, Registration number T08/011/18). In addition, each study site sought approval from their local research ethics board and/or hospital as required. Data collection began at each site after local approval was obtained. Eligible parents were given oral and written information about the study procedures, and those who agreed to participate provided written informed consent. Study questionnaires and documents (i.e. electronic or paper versions) were identified with an arbitrarily numbered identification code to conceal participants' identities. The local researchers entered the anonymous data into the Research Electronic Data Capture (REDCap) system, and they were stored in the secure cloud service provided by the University of Turku. All electronic platforms used in this study required passwords for access.

3.6 | Data analysis

Continuous variables were reported as means and standard deviations (SD), medians and quartiles (Q1, Q3) and categorical variables with counts and percentages. Mean values were calculated for the DigiFCC-P and FCCQ. Any responses to text message items that parents returned after their infants' discharge were not included in the analysis. When less than 30% of the items were missing in EPDS and the subscales of FCCQ, we replaced the missing values with the mean values of answered items, such that a small amount of missing data would not lead to exclusion from the analysis.

We investigated the associations between parents' perceptions of FCC and unit background variables using linear mixed models with family as a random effect. Only unit background variables for which p < 0.10 in univariate models (indicating some possible association with perception of FCC) were included in the multivariable analysis. We assessed the association between FCC and parents' depressive symptoms for mothers and fathers separately using linear mixed models with unit as a random effect, while controlling for gestational age, multiple birth, parent education and relationship status. Considerable right skew in EPDS scores made it necessary to square root transform those prior to analysis to meet the residual normality requirement in linear

mixed models. The analyses were carried out using SAS for Windows, version 9.4. *P* values below .05 were considered statistically significant.

3.7 | Validity, reliability and rigour

The EPDS is a well-established measure used most frequently in studies of depression in the perinatal period (Norhayati et al., 2015; de Paula Eduardo et al., 2019). The EPDS has demonstrated high internal consistency and validity for detecting major depression in the perinatal period. A review of measures to identify postpartum depression concluded the EPDS has good diagnostic performance (Hewitt et al., 2009). The EPDS is considered a valid method to measure depressive symptoms in both mothers and fathers (Castle et al., 2008).

The DigiFCC—Parent Version tool was developed in an iterative process in 15 NICUs. Its content validity was established based on a review of the literature and with an interdisciplinary expert panel of NICU professionals. The functionality of the text message system, the clarity of items and the scaling have each been tested (Axelin et al., 2020). The tool was used in a previous international survey (Raiskila et al., 2016). The validity of the FCCQ measure was established, and reliability is adequate (Shields & Tanner, 2004). Cronbach's alpha for the parent questionnaire has been 0.72 (Aggarwal et al., 2009).

Most of the standardized measures and any questionnaires developed specifically for the purposes of this study were developed and available in English. For measures without a validated translation in any of the required languages, we undertook translation from English to the target language (e.g. Croatian, Danish, Dutch, Estonian, Finnish, French, Icelandic, Lithuanian, Norwegian, Polish, Russian, Spanish and Swedish). Following guidelines for translation and cultural adaptation of research questionnaires (Wild et al., 2005), the material was first translated by a professional translator to the target language. Next, the site investigator made minor modifications to reflect the local cultural context, and this version was subsequently translated back to English by another independent translator. After back-translation, the accuracy of the translation was verified by the first author, and any discrepancies discussed until consensus were reached. The FCCQ was translated in collaboration with one of its original developer, Dr. Linda Shields.

4 | RESULTS

4.1 | Participant and unit characteristics

The 23 participating units were from 15 countries: Australia, Belgium, Canada, Croatia, Denmark, Estonia, Finland, Iceland, Lithuania, the Netherlands, Norway, Poland, Spain, Sweden and the United Kingdom. The number of units per country ranged from one to three. The median admission rate of the neonatal units was 494 (range 128–1115) infants per year. Five units (22%) limited parental presence; for example parents' presence was not allowed during

procedures such as intravenous cannula insertion or intubation or during nursing shift change or medical rounds.

Out of 1384 eligible families, 691 (50%) agreed to participate, while 405 (29%) were not approached and 288 (21%) declined. Families who were uninformed did not differ from those approached with respect to their infants' gestational ages. However, the travelling time to the hospital was significantly longer among those who were not approached when compared with those who were approached: M = 56 (SD 80.3) and 42 (SD 44.5) minutes respectively (F = 15.59; p = <.001). Participating families did not differ from those who declined with respect to infant gestational age, but those who declined had a longer travelling time to the hospital than participants did: M = 58 (SD 78.7) and 42 (44.5) minutes respectively (F = 5.52; p = .019). Figure 1 shows the flow chart for recruitment and participation.

The goal was to recruit 30 families per unit; the final number varied from 19 to 48 (Supplementary material S1). Parents (n=635 mothers, n=466, fathers) of 739 infants (n=202 twins) participated in the study. The median age of mothers and fathers was 31 and 33 respectively. The vast majority of mothers and fathers were cohabiting (Table 1). The infants' median gestational age at birth was 31.8 weeks (range 28.7–33.7) and the length of NICU stay varied from 13 to 42 days, with a median of 23 days (Table 2).

4.2 | Parents' depressive symptoms

The mothers' mean EPDS score was 9.19 (SD 5.0) at discharge and 6.66 (SD 4.73) when the infant was 4 months corrected age. The fathers' mean EPDS score was 6.34 (SD 4.41) at discharge and 4.45 (SD 4.21) at 4 months. The EPDS scores exceeded the cut-off (\geq 13) for 25.3% of the mothers at discharge and for 12.3% at 4 months, as well as for 8.3% and 5.8% of fathers respectively.

4.3 | Parents' perception of family-centred care

Overall, parents reported a favourable perception of FCC measured via daily text messages during their hospital stay with the DigiFCC-P. The mothers' and fathers' mean total scores were 5.92 (SD 0.77) and 5.84 (SD 0.83), respectively, out of 7. Mothers and fathers rated the following items below the mean: participation in infant care 5.81 (SD 1.63) and 5.46 (SD 1.77), participation in making decisions 5.53 (1.74) and 5.55 (1.81), participation in medical rounds 4.63 (2.35) and 4.74 (2.30) and emotional support provided by staff 5.28 (1.87) and 5.31 (1.83) respectively. The means and SDs for each DigiFCC-P item and total scores for the mothers and fathers are reported in Table 3.

The parents' perceptions of FCC over the entire course of hospitalization, measured with FCCQ at discharge, were equally positive. Mothers and fathers' mean total scores were 3.37 (0.38) and 3.32 (0.40) out of 4. The support provided by the staff was rated lowest by both mothers (3.19, SD 0.38) and fathers (3.12, SD 0.58) on the subscale. The means and SDs for each FCCQ subscale are reported in Table 4.

4.4 | The association of family-centred care with parents' depressive symptoms at discharge and at 4 months of infant corrected age

The DigiFCC-P total score had a significant association with mothers' EPDS scores at discharge (F = 11.20, p = .0009), and at 4 months corrected age (F = 6.60, p = .0105). At discharge, the rescaled EPDS score decreased by 0.16 (SE = 0.05) when the mean DigiFCC-P score increased by 1. The relationship status of the mother was also associated with EPDS (F = 3.17, p = .0427): rescaled EPDS scores of single mothers were 0.52 (SE= 0.21) higher compared with those who were cohabiting or married. At 4 months, the rescaled EPDS score decreased by 0.18 (SE = 0.07) when the mean DigiFCC-P score increased by 1. Mothers' education was associated with the EPDS (F = 3.58, p = .0141): Mothers with primary school education or secondary school education had higher rescaled EPDS scores compared with those with a master's or PhD degree; rescaled EPDS scores decreased by 0.75 (SE = 0.31) and 0.33 (SE = 0.13) respectively.

The total DigiFCC-P score also had a significant association with the fathers' EPDS scores at discharge (F = 4.68, p = .0313), but not at 4 months (F = 0.62, p = .4311). At discharge, the rescaled EPDS score decreased by 0.14 (SE = 0.07) when the mean DigiFCC-P score increased by 1.

The total FCCQ score had a significant association with the mothers' EPDS scores at discharge (F = 40.90, p < .0001) and at 4 months (F = 4.38, p = .037). At discharge, the rescaled EPDS score decreased by 0.65 (SE = 0.10) when the total FCCQ score increased by 1 point. At discharge, gestational age was also associated with the mothers' EPDS scores (F = 4.71, p = .0304): each additional week of gestational age decreased the rescaled EPDS score by 0.03 (SE = 0.01).

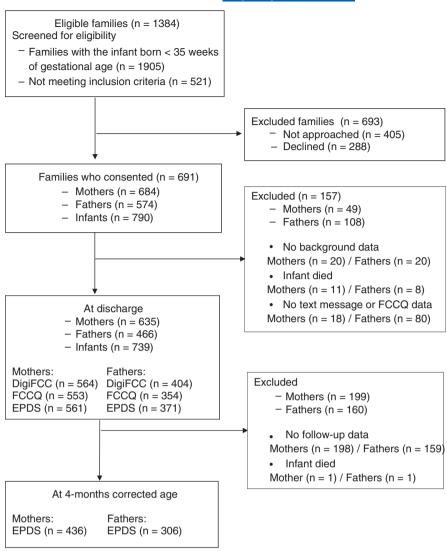
The total FCCQ score had a significant association with the fathers' EPDS scores at discharge (F = 54.10, p < .0001) and at 4 months (F = 14.52, p = .0002). At discharge, the rescaled EPDS score decreased by 0.99 (SE = 0.13) when the total FCCQ score increased by 1 point. At discharge, the relationship status of the fathers was associated with EPDS (F = 5.86, p = .0031). For fathers who were in a relationship but not cohabiting, the rescaled EPDS score was 0.58 lower (SE = 22) compared with those who were cohabiting or married. At 4 months, the rescaled EPDS score decreased by 0.76 (SE = 0.20) when the FCCQ total score increased by 1.

4.5 | Unit characteristics associated with the parents' perception of family-centred care

The variation in the total DigiFCC-P scores was explained by the following unit characteristics: (a) amenities for parents (F = 21.10, p < .0001), (b) visits permitted by significant others (F = 7.20, p = .0075) and (c) limitations on parent presence in the unit (F = 4.06, p = .0442).

Each additional amenity for parents in the unit was associated with a 0.10 (SE = 0.02) increase in the mean DigiFCC-P score. Each additional subgroup of significant others who could visit was

FIGURE 1 Flow chart



associated with a 0.08 (SE = 0.03) increase. Any limitation on parents' participation was associated with a 0.18 (SE = 0.09) decrease in the mean DigiFCC-P score.

Variation in the FCCQ scores was explained by the same unit characteristics: (a) limitations on parent presence (F = 11.08, p = .0009), (b) amenities for parents (F = 8.55, p = .0036) and (c) visits by significant others (F = 5.06, p = .0250).

Any limitations on parents' participation were associated with a 0.14 (SE = 0.04) decrease in the FCCQ scores. Each additional amenity for the parents was associated with a 0.03 (SE = 0.01) increase in the FCCQ scores and each additional subgroup who could visit was associated with a 0.05 (SE = 0.02) increase.

5 | DISCUSSION

Our study showed that parents' positive perceptions of family-centred NICU care were associated with fewer depressive symptoms in parents of preterm infants. This suggests that institutional factors, such as FCC culture, may significantly contribute to parents'

mental health. The key aspects of FCC were staff-parent partnership and emotional support. These aspects of FCC appear to be better implemented in units with amenities and with unlimited access for the parents and for their significant others.

In our study, mothers reported more depressive symptoms than fathers did, which is in line with previous studies assessing the postpartum period, including studies focusing on NICU parents (Ouwendijk-Andréa et al., 2020; White-Traut et al., 1999). The proportion of mothers and fathers exceeding the screening threshold on the EPDS fell within the wide range (6.6–42.9%) reported in a recent systematic review (de Paula Eduardo et al., 2019) and decreased over time, which is consistent with three previous reviews (Norhayati et al., 2015; Pace et al., 2016; de Paula Eduardo et al., 2019). However, the proportion of parents at risk for depression was still high, particularly at discharge. A recent longitudinal study suggested that the postpartum months might play a crucial role in the risk of parental depression during the first year after the birth (Neri et al., 2020), which calls for preventive approaches during the infant's NICU care.

Our findings about the role of supportive FCC bring new information about practical approaches to prevent parental depression.

TABLE 1 Characteristics of parents

	Moth	m/m 42E\		Cother	Faller of the ACC		
	Motne	Mother (n=635)		Father (n=466)			
	n	Median	IQR	n	Median	IQR	
Age (years)	630	31.0	[28.0, 35.0]	457	33.0	[29.0, 37.0]	
	n	%		n	%		
Education	616			447			
Primary school	30	4.9		26	5.8		
Secondary school	259	42.0		199	44.5		
Bachelors	119	19.3		72	16.1		
Masters/doctoral	208	33.8		150	33.6		
Employment status	625			453			
Paid employment	519	83.0		431	95.1		
Unemployed	43	6.9		14	3.1		
Student	22	3.5		5	1.1		
Homemaker	41	6.6		3	0.7		
Smoking	626			454			
Yes	39	6.2		78	17.2		
No	587	93.8		376	82.8		
Speaks local native language	630			459			
Yes	556	88.3		418	91.1		
No	74	11.7		41	8.9		
Partner relationship	623			455			
Single	24	3.9		2	0.4		
In relationship, not cohabiting	44	7.1		20	4.4		
In relationship, cohabiting	555	89.1		433	95.2		
Other children in the home	616			448			
Yes	268	43.5		182	40.6		

Abbreviation: IQR, Interquartile Range.

TABLE 2 Characteristics of infants

n	%	Median	IQR
739		31.86	[28.71, 331]
739		1584	[1108, 2033]
733		23	[13, 42]
322	43.6		
417	56.4		
738			
422	57.2		
316	42.8		
537	72.7		
202	27.3		
	739 739 733 322 417 738 422 316	739 739 733 322 43.6 417 56.4 738 422 57.2 316 42.8 537 72.7	739 31.86 739 1584 733 23 322 43.6 417 56.4 738 422 57.2 316 42.8 537 72.7

Abbreviation: IQR, Interquartile Range.

Important elements in FCC were staff–parent partnership and emotional support. Partnership included respect, trust, involvement and collaboration. Earlier evidence shows that parent education and support, including psychological counselling and social support, are effective in preventing depressive symptoms in mothers (Benzies et al., 2013). In addition, individual cognitive behavioural therapies have been shown to improve parents' depressive symptoms (Mendelson et al., 2017). Because individual therapies reach only a select group of parents, healthcare professionals need more approaches that are universal. We suggest the optimal approach would be to provide FCC to support all parents and possibly prevent the development of clinical depression rather than reacting to manifested depression (Ouwendijk-Andréa et al., 2020).

The central elements explaining the variation in FCC between the units were parent participation in care and in care-related decision making as well as emotional support provided to parents. In their review, Loewenstein (2018) listed parent participation, information provision, staff's supportive attitudes and infant-centred care as

TABLE 3 The means and standard deviations for each DigiFCC-P item and total scores for the mothers and fathers

	Mother (n=564)		Father (n=404)	
	М	SD	М	SD
To what extent did the staff listen to you today?	6.18	1.24	6.21	1.26
2. To what extent did you participate in your baby's care today?	5.81	1.63	5.46	1.77
3. To what extent did the guidance provided by the staff meet your needs today?	6.02	1.37	6.22	1.20
4. To what extent was your opinion considered in decisions made about your baby today?	5.53	1.74	5.55	1.81
5. To what extent did you trust the staff in the care of your baby today?	6.28	1.18	6.27	1.19
6. To what extent did the staff trust you in the care of your baby today?	6.30	1.26	6.33	1.15
7. To what extent did you participate in discussions during the doctor's round/visit?	4.63	2.35	4.74	2.30
8. To what extent did the information provided by the staff meet your needs today?	6.09	1.30	6.10	1.31
9. To what extent did the staff offer you emotional support today?	5.28	1.87	5.31	1.83
Total	5.92	0.77	5.84	0.83

Note: M and SD indicate mean and standard deviation respectively.

TABLE 4 The means and standard deviations for each FCCQ subscale and total scores for the mothers and the fathers at discharge.

	Mother (N = 553)		Father (N = 354	
	М	SD	М	SD
Respect Subscale Total	3.47	0.47	3.44	0.51
Collaboration Subscale Total	3.41	0.43	3.35	0.44
Support Subscale Total	3.19	0.55	3.12	0.58
FCC Measure Total	3.37	0.38	3.32	0.40

Note: M and SD indicate mean and standard deviation respectively.

significant elements of institutional support, but implementing these beneficial practices in day-to-day care remains challenging. For example, emotional support and shared decision making have been shown to be difficult to implement (Raiskila et al., 2016; Vetcho et al., 2020) because they require a profound change in the care approach, shifting from professional-centred care to FCC (Oude Maatman et al., 2020). These changes can be achieved by training the healthcare team so that staff in the unit can better provide individualized support and truly collaborate with parents (Toivonen et al., 2020).

The implementation of effective FCC seemed to be supported by unlimited access for parents and significant others as well as amenities for parents to support their presence in the unit. Enabling parents' presence is a necessary component of FCC. Therefore, the implementation of FCC involves the overall organization of care, the architectural design and policies of the unit and the bedside care provided to infants and parents (Al-Motlaq & Shields, 2017). An interesting result in the current study was the importance of

significant others' access to the unit. The presence of other family members and friends may be an important source of social support for parents that might mitigate the adverse effects of NICU hospitalization on parental mental health (Vigod et al., 2010). This is an area for improvement and further research, because the presence of significant others is traditionally limited (Flacking et al., 2019) and their role has not been well studied.

A strength of this study is the longitudinal, prospective, multicentre design. We measured depressive symptoms using a uniform measure and cut-off value at the end of hospitalization and again several months after discharge. We were able to control for gestational age, multiple birth and parents' level of education and their relationship status in the analyses. Parents' perceptions of FCC were measured with prospective and retrospective measures that provided similar results supporting their convergent validity.

5.1 | Limitations

Our study has some limitations. We did not collect data on parents' histories of depression and thus could not control for them in the analyses (Vigod et al., 2010). We also did not collect data on the diagnoses of the preterm infants. We assumed a higher degree of complications of prematurity with lower gestational age. Gestational age was controlled for in the analyses. Although parents found the use of text messages to collect data on FCC convenient and easy to use, technical problems with the text message delivery occurred in Iceland, Estonia and Spain, reducing the volume of data from those areas. The psychometric properties of both FCC measures require further testing, and they have an observable ceiling effect.

The generalizability of our results to different countries is supported by the large international multicentre design of the study and the inclusion of a wide variety of units. The results may be applicable to parents of other neonates treated in neonatal intensive care units, but this study was limited to parents of preterm infants. In some NICUs, fewer fathers participated. Nonetheless, given the number of units in the study, the number of fathers was large. It is also notable that fewer parents who lived further away from the NICUs participated in the study. In addition, most participants were employed and in relationships; therefore, future studies should examine whether our results are representative among more socially disadvantaged parents.

In conclusion, our study showed that staff-parent partnership and emotional support, as elements of FCC, were associated with fewer depressive symptoms in parents of preterm infants. This information can be used to develop practical approaches to preventing depression in parents of preterm infants. Preventive strategies would improve the well-being of parents themselves and benefit infants needing neonatal hospital care, because parental depression puts their healthy development at risk.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

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Anna Axelin, Nancy Feeley, Marsha Cambell-Yeo, Bente Silnes Tandberg, Tomasz Szczapa, Joke Wielenga, Janne Weis, Anita Pavicic Bosnjak, Rakel B. Jonsdottir, Kendall George, Ylva Thernström Blomqvist, Kajsa Bohlin and Liisa Lehtonen made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; Anna Axelin, Nancy Feeley, Marsha Cambell-Yeo, Bente Silnes Tandberg, Tomasz Szczapa, Joke Wielenga, Janne Weis, Anita Pavicic Bosnjak, Rakel B. Jonsdottir, Kendall George, Ylva Thernström Blomqvist, Kajsa Bohlin and Liisa Lehtonen involved in drafting the manuscript or revising it critically for important intellectual content; Anna Axelin, Nancy Feeley, Marsha Cambell-Yeo, Bente Silnes Tandberg, Tomasz Szczapa, Joke Wielenga, Janne Weis, Anita Pavicic Bosnjak, Rakel B. Jonsdottir, Kendall George, Ylva Thernström Blomqvist, Kajsa Bohlin and Liisa Lehtonen given final approval of

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