

Mother-Infant Bonding and Breastfeeding in Neonates with Hypoxic Ischemic Encephalopathy and Seizures

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ABSTRACT

Mother-infant bonding and breastfeeding are critical factors in the long-term outcomes of neonates. This is a first-of-its-kind exploratory study that reports the maternal bonding status and provision of breast milk for families whose infants suffered from Hypoxic Ischemic Encephalopathy (HIE) or neonatal seizures. Eighty-six mothers who participated in the NEOLEV2 neonatal seizure clinical trial were interviewed. Researchers surveyed mothers using the Parent Bonding Questionnaire (PBQ) and subjects provided additional qualitative comments on their experiences bonding and breastfeeding in the hospital as well as at home with their high-risk newborns. Participant interviews highlighted the impact of stressors surrounding the health and progress of their neonates that negatively impacted maternal-infant bonding as well as contributed to their inability to provide breast milk. New mothers, in particular, reported a desire to continue breastfeeding, but felt that there was inadequate support for them. Further considerations of Whole Person Care in maternal-infant bonding, breastfeeding, mental, and postpartum support for parents of high-risk neonates could reduce long-term challenges for this vulnerable population.

Keywords: Breast milk; Breastfeeding; Maternal bonding; Hypoxic Ischemic Encephalopathy (HIE); Neonatal seizures

INTRODUCTION

Parent-infant bonding is a crucial predictor of cognitive outcomes and behaviors in children as is the provision of breast milk [1,2]. An add-on study to the NEOLEV2 neonatal seizure study was conducted to evaluate maternal-infant bonding and breastfeeding in a high risk critically ill population. Two hundred and eighty neonates recruited to NEOLEV2 across six sites with 200/280 receiving breast milk within the first week of life (71.0%), the remainder received formula or parenteral nutrition. Eighty-six families whose neonates had Hypoxic Ischemic Encephalopathy (HIE) or neonatal seizures agreed to participate in this study from four of six NEOLEV2 sites: University of California San Diego (UCSD), Sharp Mary Birch Hospital for Women and Newborns, Rady Children's Hospital-San Diego, and Auckland Starship Hospital, New Zealand. Parents were interviewed *via* telephone for basic information, nutrition practices,

and completion of the Parent Bonding Questionnaire (PBQ).

Most parents who participated were non-white (55%), less than 36 years of age (71%) with some neonates having profound disability (15%). Here we report the trends of maternal bonding and breastfeeding, maternal support for breastfeeding during a time of unexpected stress (secondary to their baby's hospitalization in the NICU with brain injuries and/or seizures). Additionally, we report on these trends following discharge home and breastfeeding duration. Neurodevelopment in this cohort and its determinants, including breastfeeding, are under evaluation in a complementary study.

Maternal-infant bonding

Multiple factors of the Neonatal Intensive Care Unit (NICU) experience impact maternal-infant bonding. The inability of neonates to receive their nutrition in the ideal baby-to-breast format can

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influence maternal bonding in the NICU [3]. Stress of having a NICU newborn can impact expression of breast milk. Newborn birth trauma that results in NICU care likely negatively affects maternal bonding [4]. Maternal depression (which is often associated with the NICU experience) has been correlated with a disruption of maternal bonding which may have an impact on neonatal risks for adverse outcomes [5,6]. Furthermore, suboptimal maternal bonding has a negative impact on neurodevelopmental outcomes [7].

Bonding may be more successful when infants are breastfed even when breastfeeding does not correspond to decreased fussiness [8]. However, the relationship between positive bonding and nutrition type has recently been disputed [9]. Further investigation into the relationship between bonding and breastfeeding is needed.

Breast milk provision

The World Health Organization (WHO) recommends breast milk as the sole source of infant nutrition for the first six months with recommendations that it continue to be part of a baby's nutrition up to two years of age [10]. Despite these recommendations, even in developed countries, rates of exclusive breastfeeding up to 6 months are very low [11]. In 2016, a telephone interview in California revealed that the introduction of breast milk for all neonates was quite high at 88.1%; however, the rate of exclusive breastfeeding at 6 months was significantly lower, at 25% https://www.cdc.gov/breastfeeding/data/nis_data/rates-any-exclusive-bf-state-2016.htm. The length of breastfeeding and exclusive breast milk provision up to 6 months has been found to be significantly correlated with breastfeeding support [12]. There are a number of medical benefits for breastfed infants. Breast feed infant lower risk of hospitalization for asthma, atopic dermatitis, gastroenteritis, obesity, leukemia, diabetes, respiratory tract infection, otitis media, and sudden infant death syndrome [13]. Furthermore, the benefits of breast milk include protection against necrotizing Enterocolitis, critically contributing to healthy infant microbiome, facilitation of brain development, positive neurodevelopmental outcomes through childhood (even in the preterm population) [14-18]. Generally, prolonged breastfeeding confers the greatest benefits to child health, including a reduced risk of being overweight or obese later in life. Finally, breast milk is preferred over infant formula as improper preparation or contamination of infant formula can cause sickness [19,20].

Length of stay in the NICU impacts the long-term success of breastfeeding with negative correlation between longer NICU stays and long-term breastfeeding success [21]. Skin-to-skin and holding experiences experienced through baby-to-breast feeding supports optimal long-term neurodevelopmental outcomes [22]. However, early-onset breast milk provision is a key to mothers' ability to provide breast milk over a longer period as well as successful coaching in hand-expression and pump use [23]. In the case of infants diagnosed with HIE, therapeutic hypothermia requires that nutrition be provided enterally through which breast milk is still the preferred source of nutrition, even though it is not always available [24-28].

What requires further investigation is the breastfeeding experience of mothers with high-risk term infants with neurological diagnoses. This exploratory study is a first-of-its-kind in the examination of breast milk provision in term neonates with HIE or seizures a high risk cohort for both difficult and delayed establishment of breastfeeding as well as jeopardized maternal-infant bonding.

MATERIALS AND METHODS

Parents whose infants had participated in the NEOLEV2 study at the Sharp Mary Birch, UCSD, Rady Children's and Auckland Hospital sites, with neonates who had had neonatal seizures and/or HIE were contacted *via* telephone by a research investigator or research staff member. Since the original study happened over a 5-year period, the timing of the interviews relative to the age of the originally enrolled neonate varied from 8 months to 70 months with an average of 37 months. Consenting parents completed questionnaires regarding their breastfeeding experience, about their child's health and the Postpartum Bonding Questionnaire (PBQ) instrument. General information pertaining to their child's health, whether the parents themselves had been breastfed, and notable factors about their child's health were also recorded. The Postpartum Bonding Questionnaire (PBQ), a 25 question self-report questionnaire, was selected for this study to assess a mother's emotional connection to her infant. The PBQ has been validated as having good sensitivity and specificity for detecting problems in maternal infant bonding [25,26]. Researchers have demonstrated that the rates of abnormal maternal-infant bonding reduce and then stabilize over the first 6 months postpartum. In a group of mothers who themselves had suffered childhood abuse and neglect, there was a 20% rate of abnormal bonding as measured by the PBQ at 6 weeks postpartum, improving to 11% by 6 months of age. Compared to their healthy control group, rates of abnormal bonding as measured by the PBQ in 17 % at 6 weeks postpartum, dropped to 7% at 6 months [27,28].

Information was entered into the RED Cap database, including data on breast milk feeding duration, reasons for breastfeeding termination, infant medical diagnoses, whether infant was profoundly disabled, whether the infant had epilepsy outside the neonatal period and current anti-seizure medications, number of days in the NICU, days of non-sucking nutrition (duration of requirement for nasogastric or intravenous nutrition), birth order of baby ,maternal age at delivery, whether mother was herself breastfed, maternal medications at delivery, breastfeeding support in the NICU and breastfeeding support at home. In addition, chart review and review of data from the NEOLEV2 database complemented this study interview. Important qualitative data were captured from the additional comments sought from mothers during these deeply personal interviews. A general inductive approach was used to analyze these comments. The consents and instruments were translated into Spanish and a graduate nursing student whose native language is Spanish interviewed the Spanish-speaking families. At the conclusion of each call resources were provided for parents who demonstrated a need for child development support and/or social and mental health services.

Statistical analysis

Data were analyzed using JMP Ver 14 (SAS Inc.). The sample size of 86 had an estimated power of 90% to detect a difference in two proportions of 25% or more (power analysis of a 2-sided test assuming proportions of 5% and 30% respectively and N=43 for each group). Weighting was applied to all analyses to adjust for the differences in the participation rates between the two locations, and between the two ethnic groupings. The weighted proportions of the study factors with 95% confidence intervals (95% CI (Confidence Interval)) were determined. Associations to breastfeeding duration (dichotomized at 26 weeks) and the PBQ (dichotomized to abnormal or not) were investigated by logistic regression, and Odds Ratios (OR) with 95% CI presented. The weighted proportions of the study factors for

breastfeeding less than 26 weeks and for abnormal PBQ were calculated using contingency table analysis.

RESULTS

Participation

Of the total 215 infants who participated in the NEOLEV2 study at one of the four sites participating in this follow up study, 37 infants had neither neonatal seizures nor hypoxic ischemic encephalopathy, 10 patients had died, and 1 patient had withdrawn consent. Extensive efforts were made to enroll the 170 potentially eligible subjects in this follow up study. Reasons for failure to recruit to the follow-up study included surrogate delivery (1), move of family out of the country (1), child not in parent custody (1) language barrier (1) and no working contact information or unable to contact (76). Two parents declined to participate.

Eighty six of 170 eligible families (51%) consented to and participated in this study. Seventy-five families were primary English speakers (85%), eight families from the San Diego region were primary Spanish speakers (9%) with others identifying primary or secondary fluency in other languages (Cantonese, French, Tagalog, Mandarin, Amharic, Tongan, Samoan, Maori, Hindi, Swahili, and Afrikaans) who were also fluent in, and consented, in English. The New Zealand participation rate was significantly higher than in San Diego (83% vs. 38%, $p < .001$), and the minority family (all except white non-Hispanics) participation rate was significantly lower compared to the white non-Hispanics (41% vs. 62%, $p < .001$). The NEOLEV2 database collected information regarding problems in pregnancy including pre-existing maternal mental health or substance abuse issues, and other psychosocial risk factors. Among those eligible there was no significant difference in the participation between those with and without any pre-existing maternal mental health or substance abuse issues. However, of 13 eligible families identified as having other psychosocial risk factors (primarily identified by a noted lack of pre- or ante-natal care), none were able to be recruited to this study. Table 1 presents the weighted distributions of the factors investigated for this study.

Table 1: Weighted† distributions of child and maternal factors in neonates with hypoxic ischemic encephalopathy or neonatal seizures. **Note:** †: Weighting was applied to all analyses to adjust for differences in the participation rates between the two locations, and between the two ethnic groupings, ‡: Weighted N are rounded to whole numbers for presentation, §: Data was complete (total N=86) for all measures except Mother Breastfed (N=81), Non-suckling feeds (N=74) and PBQ (N=80).

Demographics		N‡	% (95%CI)
Study location	USA	62	72 (61-80)
	New Zealand	24	28 (20-39)
Gender	Boy	58	67 (56-76)
	Girl	28	33 (24-44)
Ethnicity	Minority	47	55 (44-65)
	White (Non-Hispanic or Latino)	39	45 (35-56)
Birth			
Maternal age at delivery	>35 years	15	17 (11-27)
	>20-35 years	71	83 (73-89)

Mode of delivery	Scheduled C-section	14	16 (10-25)
	Other	43	50 (40-61)
	Spontaneous vaginal	29	34 (25-44)
Birth order	First	51	60 (49-69)
	Not first	35	40 (31-51)
Profoundly disabled	Yes	13	15 (9-24)
	No	73	85 (76-91)
Time in NICU	>14 days	31	36 (27-47)
	2-14 days	55	64 (53-73)
Seizure			
Seizure anytime	Yes	39	45 (35-56)
	No	47	55 (44-65)
Received phenobarbital	Yes	32	37 (28-48)
	No	54	63 (52-72)
Breastfeeding			
Breastfeeding duration	<26 weeks	33	39 (29-49)
	>=26 weeks	53	61 (51-71)
Mother breastfed§	No	19	24 (16-35)
	Yes	61	76 (65-84)
NICU lactation consultant	No	22	26 (18-36)
	Yes	64	74 (64-82)
Breastfeeding home support	No	46	53 (43-63)
	Yes	40	47 (37-57)
Non-suckling feeds§	>28 days	6	8 (3-16)
	>7-28 days	16	22 (14-33)
	0-7 days	52	70 (59-80)
Maternal bonding and mental health			
Parental Bonding Score (PBQ)§	Abnormal	15	19 (12-28)
	Normal	65	81 (72-88)
Maternal mental health issues	Yes	19	15 (9-24)
	No	67	85 (76-91)

Maternal bonding

There was a 19% (95%CI 12%-29%) rate of abnormal maternal bonding as measured by the PBQ (Table 1). Table 2 presents the weighted counts, proportions and odds ratios for mothers who scored in the abnormal range for maternal bonding across the factors investigated for this study. The odds of abnormal bonding were higher for those mothers who had not been breastfed themselves as babies (OR 4.3, $p = 0.02$). There were no other statistically significant differences, but in addition to the previously stated increased odds for breastfeeding less than 26 weeks, there were notably decreased odds (OR<0.5) for abnormal maternal bonding for scheduled C-section delivery (OR .26, $p = .23$), Non-white and Hispanic mothers (OR .33, $p = .07$), no lactation consultant (OR .38, $p = .24$), and baby having a seizure at any time before discharge from NICU (OR .43, $p = .17$).

Table 2: The weighted† distributions and Odds Ratios (OR) of child and maternal factors in neonates with hypoxic ischemic encephalopathy or neonatal seizures in those neonates who were breastfed for <26 weeks and those neonates whose mother had an abnormal Parental Bonding Score (PBQ). **Note:** †: Weighting was applied to all analyses to adjust for differences in the participation rates between the two locations, and between the two ethnic groupings, ‡: Weighted N is rounded to whole numbers for presentation. Some rounding errors are apparent, §: Data was complete (total N=86) for all measures except Mother Breastfed (N=81), Non-suckling feeds (N=74), and PBQ (N=80), ¶: Odds Ratios (OR) are for neonates who were breastfed for <26 weeks vs. neonates who were breastfed ≥26 weeks, and for neonates whose mother had abnormal PBQ scores vs. neonates whose mother did not have abnormal PBQ scores, respectively, ††: p-values are for a weighted logistic regression.

	Breastfeeding duration<26 weeks				PBQ Abnormal		
	N‡ (%)		OR (95%CI)¶	p††	N (%)	OR (95%CI)¶	p††
Demographics							
Study location	USA	28 (45)	2.7 (.92-7.7)	0.07	10 (17)	.69 (.21-2.3)	0.54
	New Zealand	6 (23)	-	-	5 (23)	-	-
Gender	Boy	23 (39)	1.0 (.42-2.6)	0.92	11 (19)	1.1 (.32-4.0)	0.85
	Girl	11 (38)	-	-	4 (17)	-	-
Ethnicity	Minority	21 (46)	1.9 (.78-4.7)	0.15	5 (11)	.33 (.10-1.1)	0.07
	White (Non-Hispanic or Latino)	12 (30)	-	-	10 (27)	-	-
Birth							
Maternal age at delivery	>35 years	8 (51)	1.8 (.59-5.6)	0.3	4 (25)	1.6 (.44-6.2)	0.46
	>20-35 years	26 (36)	-	-	11 (17)	-	-
Mode of delivery	Scheduled C-section	8 (60)	3.0 (.80-11.4)	0.1	1 (8)	.26 (.03-2.3)	0.23
	Other	15 (35)	1.1 (.41-2.9)	0.86	7 (18)	.70 (.21-2.3)	0.56
	Spontaneous vaginal	10 (33)	-	-	7 (24)	-	-
Birth order	First	18 (34)	.64 (.27-1.6)	0.32	10 (21)	1.4 (.43-4.6)	0.57
	Not first	16 (45)	-	-	5 (16)	-	-
Profoundly disabled	Yes	6 (47)	1.5 (.44-4.8)	0.53	2 (21)	1.2 (.25-5.8)	0.82
	No	27 (37)	-	-	13 (18)	-	-
Time in NICU	>14 days	16 (50)	2.1 (.86-5.2)	0.1	4 (15)	.65 (.19-2.2)	0.48
	2-14 days	18 (32)	-	-	10 (21)	-	-
Seizure							
Seizure anytime	Yes	14 (36)	.84 (.35-2.0)	0.7	5 (12)	.43 (.13-1.4)	0.17
	No	19 (41)	-	-	10 (24)	-	-
Received phenobarbital	Yes	11 (36)	.82 (.33-2.0)	0.67	5 (15)	.66 (.20-2.2)	0.51
	No	22 (40)	-	-	10 (21)	-	-
Breastfeeding							
Breastfeeding duration	<26 weeks	-	-	-	8 (35)	2.1 (.69-6.7)	0.19
	≥26 weeks	-	-	-	7 (16)	-	-
Mother breastfed§	No	6 (33)	.74 (.25-2.2)	0.58	8 (39)	4.3 (1.3-14.4)	0.02
	Yes	25 (40)	-	-	7 (13)	-	-
NICU lactation consultant	No	10 (44)	1.3 (.50-3.5)	0.58	2 (10)	.38 (.08-1.9)	0.24
	Yes	24 (37)	-	-	13 (22)	-	-
Breastfeeding home support	No	20 (43)	1.5 (.61-3.5)	0.39	8 (20)	1.2 (.38-3.6)	0.78
	Yes	14 (34)	-	-	7 (17)	-	-
Non-suckling feeds§	>28 days	3 (61)	2.7 (.45-16.1)	0.28	1 (20)	.75 (.08-6.6)	0.8
	>7-28 days	8 (49)	1.6 (.52-4.9)	0.41	1 (8)	.27 (.04-1.9)	0.18
	0-7 days	19 (37)	-	-	13 (24)	-	-
Maternal bonding and mental health							
PBQS§	Abnormal	8 (55)	2.1 (.69-6.7)	0.19	-	-	-
	Normal	24 (37)	-	-	-	-	-
Maternal mental health issues	Yes	5 (27)	.52 (.17-1.6)	0.25	5 (26)	1.8 (.50-6.2)	0.38
	No	28 (42)	-	-	10 (17)	-	-

Many mothers said they had had concerns regarding their bonding to their child. EEG monitoring, separation from baby acutely, and sedating medications were factors identified by mothers as that negatively impacted bonding. Breastfeeding, baby massage and skin-to-skin were identified by mothers as things that helped with their bonding. One mother described her postpartum experience as “I was too stressed to leave the ward, too stressed to cross the street. I was initially told the baby might die, and nobody announced when that danger was past. I was too scared to look at the list of names in NICU in case the baby was dead overnight.” The “zombie” medication meant the baby was asleep and NICU nurses told me the baby should be left to rest.”

Mothers reported not getting enough information regarding their babies’ prognosis, “I was initially told the baby would die but then not informed when her prognosis improved” and getting inaccurate and discouraging advice e.g., “the nurse said not to bother breastfeeding.” There were multiple reports of the stress of discharge. “It was stressful to go from such a highly monitored environment to home with no input.”

Many others spoke of their concerns regarding their children’s disabilities soon after their birth as well as how their development would be delayed or progress and some expressed guilt that their neonates had not developed normally in utero.

Breastfeeding

Thirty nine percent (95% CI 29-49%) of mothers participating in this study breastfed for less than 26 weeks (Table 1). Seven percent breastfed for less than 2 weeks, 14% 2-11 weeks, 18% 12-25 weeks, 23% 26-51 weeks, 25% 52-103 weeks, and 13% 104 or more weeks.

When considering the entire NEOLEV2 cohort of 280 neonates, baseline breast milk provisions revealed 200/280 receiving breast milk within the first week of life (71%) with the remaining receiving formula or parental nutrition. Interview of the 86 mother subset population, breastfeeding duration was found to be greater than 26 weeks for many of the participants (61%) with most mothers reporting NICU lactation consultant support (74%) but the majority reporting a lack of breastfeeding support once they were home (53%).

Table 2 presents the weighted counts, proportions and odds ratios for mothers who breastfed less than 26 weeks across the factors investigated for this study. There were no statistically significant differences, but there were notably increased odds (OR>2.0) for breastfeeding less than 26 weeks for scheduled C-section delivery (OR 3.0, p=.10), San Diego location (OR 2.7, p=.07), more than 28 days of non-suckling feeds (OR 2.7, p=.28), more than 14 days in NICU (OR 2.1, p=.10), and abnormal maternal bonding (OR 2.1, p=.19). Non-white and Hispanic mothers also had lower rates of breastfeeding to 26 weeks or longer (OR 1.9, p=.15). The odds for breastfeeding no more than 2 weeks (data not shown), were notably further increased for scheduled C-section delivery (OR 10.0, p=.10) and abnormal maternal bonding (OR 6.0, p=.06)

Mothers were asked to provide a reason why they stopped breastfeeding. All mothers who breastfed for less than 26 weeks and 75% of mothers who stopped before one year gave reasons which indicated that it was not the mothers’ preference to stop and with better breastfeeding support, including in the work environment, longer breastfeeding might have been achieved. Reasons given included “baby not interested, biting or hungry”, “poor supply”, “difficulty expressing”, “too difficult”, “stress” and “work” with a few unique reasons, eg: “mother unwell

with shingles” and “undergoing IVF” and “inadequate supply related to history of breast reduction surgery.” There were many mothers who commented that there was inadequate support for breastfeeding, both in the NICU and more so after discharge. Many commented that there was a lack of support for breast milk pumping. Many reported stresses and some attributed their milk drying up to this stress.

Maternal mental health

Ten mothers reported diagnoses of depression, anxiety, or postpartum depression. In seven of these mothers these were antenatal diagnoses, three diagnoses were made following births. Two mothers had substance abuse issues. An additional nine mothers reported other mental health issues postpartum including “baby blues,” a need for counselling, and self-diagnosis of “a kind of post-traumatic stress disorder.” Tragically, two fathers had committed suicide. Maternal mental health overall was not significantly associated with either breastfeeding duration or postpartum bonding (Table 2). However, separating the mothers with diagnoses of substance abuse from the mothers with other mental health issues postpartum, revealed differences in the odds. Mothers with a mental health diagnosis or substance abuse had lower odds of breastfeeding less than 26 weeks (OR=.26 p=.07) and lower odds of abnormal bonding (OR=.72, p=.71), whereas mothers with other mental health issues postpartum had higher odds of breast feeding less than 26 weeks (OR=2.0, p=.41) and of abnormal bonding (OR=4.3, p=.09).

We believe this to be an indication that diagnosis and appropriate input for antenatal mental health problems can prevent negative impact on breastfeeding and bonding. Conversely the postpartum mental health issues were not adequately diagnosed and supported, and therefore did impact negatively on breast feeding and bonding.

DISCUSSION

Maternal-infant bonding

This study provides a first exploratory evaluation of the maternal-infant bonding development in a high-risk neonatal population. The rate of abnormal bonding measured in this cohort was as high as that reported in a very high-risk group of mothers who had themselves experienced child abuse and neglect. Our administration of the questionnaire was retrospective and therefore less accurate. Nonetheless, this supports the hypothesis that mothers of infants with neurological issues are at high risk for bonding difficulties. The association between longer breastfeeding with lower rates of abnormal bonding is a complex and reciprocal interaction. It is however reasonable to hypothesize that lack of breastfeeding to 2 weeks may be a useful identifier of risk for subsequent difficulty with abnormal bonding, and that longer breastfeeding may indeed be protective of maternal-infant bonding. The qualitative data also suggested this.

Breast milk provision

Three of the four hospitals in this study are considered “Baby friendly”, meaning the hospitals are accredited as actively supportive of breastfeeding by the WHO program Baby Friendly Hospital Initiative <https://www.babyfriendlyusa.org/for-facilities/practice-guidelines/>.

This study provides a first exploratory evaluation of breastfeeding support for high-risk neonates with hypoxic ischemic encephalopathy and seizures in such “baby friendly” accredited hospitals. The standard NICU lactation support is critical to making early breast milk

provision successful, but the lack of support once discharged from the NICU was notable in most mothers who stopped breastfeeding prior to 26 weeks. All mothers who stopped breastfeeding before 26 weeks indicated that it was not their preference to do so and perhaps would have breastfed longer had more support been provided.

Lack of resources, once at home and the stress of having a neonate with long-term challenges were noted by one of the two mothers who reported that their baby's father died by suicide. The attention of healthcare providers in critical care (NICU) was not sustained after discharge from NICU, and the continuity of care that is health-promoting for both baby and family is a crucial ingredient to long term health. The inadequate post-discharge breastfeeding support is likely not unique to San Diego and New Zealand. Public health campaigns to promote breastfeeding have always focused on knowledge acquisition education. Despite the savvy use of social media, there has been a lack of physical support for the continuation of breastfeeding post-hospital due to lack of available funded lactation consultants. In the U.S., a few states have targeted programs to promote community-based breastfeeding but these are rare (<https://www.cdc.gov/nccdphp/dnpao/state-local-programs/breastfeeding.html>). Presently, there are no national funded programs to promote and guide community-based breastfeeding, particularly for high-risk mothers and infants.

Higher rates of breastfeeding past 26 weeks in NZ women are multifactorial. Notably many NZ women take 12 months maternity leave, 26 weeks supported by government funded parental leave payments and postpartum care for mother and baby is provided by midwives who are strong advocates for breastfeeding.

Whole-person care

There are two team-based care systems known for whole-person, whole-family care in the world of healthcare: rehabilitation and hospice. Home-based care from a multidisciplinary team can address the physical, social, psychological and spiritual needs of both child and family. Seamless continuity of ongoing care should start with admission to the NICU (including those with newborn hypoxic ischemic encephalopathy and seizures) and incorporate care for mothers at risk for maternal bonding problems.

Currently, post-NICU care includes periodic medical visits to high-risk infant follow-up clinic for developmental assessments. These standard of care visits, that are out-of-home and occur 4-6 months post discharge, provide inadequate support, are burdensome for families and results in many of these infants being lost to follow-up. To optimize maternal bonding and the ability for many to breastfeed beyond the minimum of 26 weeks, a team-based homecare or visiting nursing service could identify and address early problems of perinatal and postpartum depression and anxiety, new onset comorbidities in high-risk infants, as well as provide support for the continuation of breastfeeding.

A limitation of this study was the sample size. Although adequately powered to detect large effects (proportional differences of 25% or more) in the presence of a 50% frequency of short breastfeeding duration and abnormal PBQ scores, the reality was that the effects observed were not of that magnitude and short breastfeeding duration and abnormal PBQ scores were not that common. However, the sample population may be biased as some mothers may not have participated in this study because they harbor feelings of guilt around discontinuation of breastfeeding. Other NEOLEV2 families that were not able to be sampled include those affected by homelessness, drug addiction, and psychiatric diagnoses of either parent. Consequently,

these data should be considered exploratory.

CONCLUSION

This study has helped to highlight the specific breastfeeding and bonding difficulties faced by mothers of infants with neonatal neurological disorders. Further research in this cohort is needed. This study highlights the necessity of identifying and addressing social determinants of health which are exacerbating health inequities in Southern California and in New Zealand. This first-of-its kind research study was performed to heighten awareness of the inadequate support available for optimal maternal bonding and infant nutrition, particularly in the highest risk NICU population.

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