A Prospective Study of Parent Health-Related Quality of Life before and after Discharge from the Neonatal Intensive Care Unit

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Objective To determine how infant illness and parent demographics are associated with parent health-related quality of life (HRQL) during and 3 months after hospitalization in the neonatal intensive care unit (NICU). We hypothesized that parents of extremely preterm infants would report lower NICU HRQL than other parents, and that all parents would report improved HRQL after discharge.

Study design This prospective study of parent–infant dyads admitted to a level IV NICU for ≥14 days from 2016 to 2017 measured parent HRQL before and 3 months after discharge using the Pediatric Quality of Life Inventory Family Impact Module. Multivariable regression was used to identify risk factors associated with HRQL differences during hospitalization and after discharge.

Results Of the 194 dyads, 167 (86%) completed the study (24% extremely preterm; 53% moderate to late preterm; 22% term). During the NICU hospitalization, parents of extremely preterm infants reported lower adjusted HRQL (−7 points; $P = .013$) than other parents. After discharge, parents of extremely preterm infants reported higher HRQL compared with their NICU score (+10 points; $P = .001$). Tracheostomy (−13; $P = .006$), home oxygen (−6; $P = .022$), and readmission (−5; $P = .037$) were associated with lower parent HRQL 3 months after discharge, adjusted for NICU HRQL score.

Conclusions Parents of extremely preterm infants experienced a greater negative impact on HRQL during the NICU hospitalization and more improvement after discharge than parents of other infants hospitalized in the NICU. Complex home care was associated with lower parent HRQL after discharge. The potential benefit of home discharge should be balanced against the potential negative impact of complex home care. *(J Pediatr 2019;213:38-45)*.

The neonatal intensive care unit (NICU) is a stressful place for families.[1,2] Parents in the NICU experience a markedly altered caregiving role, which impacts their quality of life.[3-5] At discharge, parents assume all caregiving needs for their infant, many of whom may have complex home health needs. Complex home care has also been associated with lower caregiver health-related quality of life (HRQL).[6,7] The impact of child health on parent wellbeing is an important outcome in healthcare.[8] Parents' physical, emotional, and psychological health affects their caregiving ability, which in turn affects child health.[9-12] Therefore, understanding parent HRQL before and after NICU discharge is crucial to supporting at-risk families.

Quality of life research in neonatology has led to important insights on quality of life for child and young adult survivors of prematurity compared with full-term controls.[6,7,13-20] HRQL has been shown to be lower for parents of preterm infants than parents of healthy term infants after the NICU during infancy[11] and continuing into early childhood; parent HRQL is influenced by the NICU hospitalization itself,[21] later childhood morbidities,[22-24] and parental factors such as coping, stress, and mental health.[3,11,21-28] HRQL for parents of full-term infants requiring NICU care has not been described. Also, the change in parent HRQL from NICU hospitalization through subsequent discharge has not been studied across a cohort of infants of all gestational ages and diagnoses. Understanding parent HRQL before and after the transition home could help to target interventions to better support NICU discharge.

Our objective was to determine how NICU illness, parent demographics, and post-NICU healthcare use are associated with parent HRQL in the NICU and after discharge. We hypothesized that parents of extremely preterm infants would report lower HRQL in the NICU than parents of other infants, adjusted for illness and demographic factors, and that all parents would report higher HRQL after discharge compared with in the NICU.

HRQL	Health-related quality of life
LOS	Length of stay
NICU	Neonatal intensive care unit
PedsQL	Pediatric Quality of Life Inventory

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Methods

We conducted a prospective study among parents of infants hospitalized for ≥14 days in a level IV NICU from November 2016 to July 2017. This NICU admits infants of all gestational ages requiring intensive care born at a co-located birth hospital and receives patients transferred for medical and surgical subspecialty evaluation. The unit has single patient rooms, psychologists, case managers, social workers, and a family support coordinator. We excluded non–English-speaking families because of personnel limitation in obtaining interviews; we also excluded nonbiological parents who could not provide consent, infants previously discharged home, infants transferred to cardiac intensive care, or infants for whom death was imminent. Parents of multiples chose 1 child to enroll. If an infant died, the family was excluded from further assessments.

The primary outcome was parent HRQL, measured using the Pediatric Quality of Life Inventory (PedsQL) Family Impact Module.[29] This 36-item self-report tool assesses parent HRQL related to their child's illness among 8 domains: physical, emotional, social, and cognitive functioning; communication; worry; family relationships; and daily activities.[29] A 5-point Likert scale is used; mean scores are transformed to a 0-100 scale with higher scores indicating higher HRQL. Based on pilot data from our NICU, we determined that a sample size of 214 patients would provide 80% power to detect a 5-point difference in between-group HRQL pre- vs post-discharge, accounting for 8-10 covariates, with 80% follow-up at 3 months.

The primary exposure was infant gestational age based on best obstetric estimate by groupings: extremely preterm, 23-28 weeks gestation; moderate to late preterm, 29-36 weeks; and term, 37-42 weeks. We reviewed the chart for variables that would reflect NICU illness, comorbidities, parent demographics, and discharge medical needs across all gestational ages (variables shown in **Table I**). Insurance type was identified by chart review. Healthcare use after discharge was determined by chart review and confirmed with the parent. This information included the number of subspecialty appointments, emergency room visits, hospital readmissions, and use of durable medical equipment.

Study Procedure

Eligible parents were approached by a research assistant to complete questionnaires using a tablet into a secure database.[30] Upon enrollment, parents answered demographic questions. Parents completed the PedsQL Family Impact Module within a few weeks of anticipated discharge, once the infant's anticipated care needs were becoming clear. Our pilot work showed this timing to be critical to enrollment, because parents are often too stressed to participate in research immediately before going home. The timing of HRQL assessment was determined by weekly screening by the study team and confirmed with the primary clinical caregivers. A post-NICU discharge assessment was completed 3 months after discharge by phone or in person.

Statistical Analyses

We compared demographics, infant illness, and post-NICU healthcare use between gestational age groups. Next, we compared NICU and 3-month parent HRQL scores by demographics, infant illness, and post-NICU healthcare use. We also compared subdomain scores of the PedsQL between NICU and 3 months after discharge by gestational age group. Between-group comparisons were performed with Kruskal-Wallis tests, χ^2, or Fisher exact tests; within-group changes in HRQL were compared with paired-samples Wilcoxon signed-rank tests. Nonparametric comparisons were used to avoid assumptions about the HRQL distribution.

We calculated a clinically relevant change in HRQL from NICU to 3 months after discharge. Because an illness-specific measure was not available, as an anchor-based method of determining clinically relevant change we asked parents to respond to the question "How sick is your child?" on a 5-point Likert scale at both time points.[31,32] This question was chosen to reflect the parent's perception of infant illness severity, which has been linked to perception of an infant's future quality of life.[33] We considered a clinically relevant change to be the median HRQL change for parents who responded that their child was ≥1 point different after discharge compared with the NICU. As an alternative distribution-based measure of change, we calculated twice the standard error of the mean of NICU HRQL scores.[32] We determined whether the proportion of parents reporting a clinically significant change in HRQL was different for any parent or infant risk factor, using χ^2 or Fisher exact tests.

Because the bivariate analyses were normally distributed, we developed multivariable linear regression models to assess associations between risk factors and parent HRQL. To assess NICU HRQL, we first developed a model including all covariates that had bivariate association with HRQL differences at a P value of <.2. To assess HRQL 3 months after NICU discharge compared with the NICU, we adjusted for the parent's NICU HRQL score, then entered all potentially significant risk factors that were identified on bivariate analysis. Because of the collinearity between related risk factors, we reduced each model to include only risk factors with a P value of <.2, also assessing for <15% change in effect size of the remaining factors before dropping a variable. In both models, moderate to late preterm infants (29-36 weeks) were used as the gestational age reference group because they had the highest HRQL scores at both time points. We assessed the assumptions of the linear regression model by examining whether the residuals from the final models were normally distributed as well as examining diagnostic plots. A P value of <.05 was accepted for statistical significance. STATA version 14 (StataCorp, College Station, Texas) was used for analyses. This study was approved by the Medical College of Wisconsin Institutional Review Board.

Table I. Infant and parent characteristics of study sample by gestational age

Characteristics	≤28 weeks (n = 52)	29-36 weeks (n = 114)	≥37 weeks (n = 48)	*P* value
Parent				
Age, years	31 (25-35)	29 (26-33)	30 (23-34)	.820
Race/ethnicity				
Black	17 (33)	25 (22)	9 (19)	**.042**
White	27 (53)	78 (68)	34 (71)	
Hispanic	2 (4)	4 (4)	5 (10)	
Other	6 (10)	7 (6)	0	
Education				
Have not finished high school	6 (12)	3 (3)	3 (6)	.170
High school graduate	25 (48)	66 (58)	23 (48)	
College/technical school graduate	21 (40)	45 (39)	22 (46)	
Has a car	40 (77)	93 (81)	41 (85)	.550
Staying at Ronald McDonald House	14 (27)	42 (37)	12 (25)	.200
Single parent household	8 (15)	6 (5)	2 (4)	**.040**
No. of siblings (for child)				
0	23 (44)	34 (30)	22 (46)	.200
1	13 (25)	34 (30)	9 (19)	
>1	16 (31)	46 (40)	17 (35)	
History of mental health concerns	16 (31)	40 (35)	18 (38)	.900
Public insurance	29 (56)	63 (55)	22 (46)	**.044**
Infant clinical characteristics				
Birth weight, grams	745 (581-1000)	1805 (1468-2213)	3113 (2735-3557)	**.001**
Male sex	21 (40)	52 (46)	28 (58)	.200
Congenital or chromosomal anomaly present	5 (10)	32 (28)	33 (69)	**<.001**
Multiple gestation	11 (21)	24 (21)	1 (2)	**.008**
Cesarean delivery	31 (60)	70 (61)	15 (31)	**<.001**
Outborn delivery	34 (65)	32 (28)	29 (60)	**<.001**
Number of surgeries	1 (0-2)	0 (0-1)	1 (0-2)	**<.001**
Number of consultants	4 (2-7)	1 (0-3)	3 (2-6)	**<.001**
Required mechanical ventilation	27 (52)	39 (34)	19 (40)	.096
Ventilator days	59 (3-77)	0 (0-1)	1 (0-6)	**<.001**
Received vasopressors	18 (35)	10 (9)	9 (19)	**<.001**
Day of life at assessment, days	97 (67-140)	20 (17-47)	19 (16-40)	**<.001**
Total LOS, days	123 (87-177)	42 (27-59)	34 (23-47)	**<.001**
Post-NICU healthcare use	n = 36	n = 92	n = 39	
Home oxygen	20 (59)	12 (13)	6 (15)	**<.001**
Home gastrostomy tube feedings	7 (20)	11 (12)	11 (28)	.080
Home nasogastric tube feedings	1 (3)	0	5 (13)	**<.001**
Tracheostomy	7 (13)	3 (3)	3 (6)	**.004**
Medications prescribed				
0	8 (23)	53 (58)	19 (49)	**.003**
1-2	14 (40)	27 (30)	13 (33)	
>2	13 (37)	11 (12)	7 (18)	
Emergency department visits (≥1)	12 (33)	25 (27)	13 (33)	.680
Acute care visits (≥1)	10 (28)	24 (26)	10 (26)	.970
Hospital readmission (≥1)	9 (26)	16 (17)	18 (46)	**.003**

P values in bold represent those with a value significant at $P < .05$.

Parent and infant characteristics of the study sample, by gestational age. Data in the table represents number (%) or median (IQR). *P* values indicate χ^2 or Fisher exact tests for differences between proportions, and Kruskal-Wallis tests for differences in medians, as appropriate. Post-NICU healthcare use is calculated for the 167 infants with 3 months of follow-up. There were no differences in other clinical characteristics between eligible infants who did and did not receive 3-month follow-up.

Results

We enrolled 214 parent–infant dyads. Twenty dyads were ineligible for follow-up owing to death (n = 8), social reasons (n = 7), or ongoing hospitalization at the study conclusion (n = 5 extremely preterm patients with tracheostomy and long-term ventilation). Of the remaining 194 eligible dyads, 167 (86%) completed an interview 3 months after discharge (**Figure 1**; available at www.jpeds.com). Mothers were the primary respondents (88%). There were no significant differences between eligible subjects who completed follow-up and those lost to follow-up.

Of the study cohort, 52 infants (24%) were born extremely preterm, 114 (53%) were moderate-late preterm, and 48 (22%) were term. **Table I** shows infant and parent characteristics stratified by gestational age. Parents of extremely preterm infants were more likely to report black race and single parent households. At discharge, extremely preterm infants were more likely to be discharged with home oxygen, whereas term infants were more likely to be discharged with tube feedings. By 3 months, term infants had the highest proportion of hospital readmission. Emergency room visits and acute care visits were not different by gestational age groups. Most extremely preterm infants had diagnoses consistent with complications related to prematurity; most full-term infants had either a congenital anomaly or required neurologic evaluation (**Table II**; available at www.jpeds.com).

Table III. Associations with parent HRQL in the NICU and 3 months after discharge

Characteristics	n	NICU HRQL	*P* value	3-Month HRQL	*P* value
Parent					
Race/ethnicity					
Black	32	74 (57-81)	**.03**	70 (61-82)	.229
White	116	69 (58-82)		73 (61-85)	
Hispanic	8	50 (44-64)		67 (45-71)	
Other	11	71 (63-89)		74 (68-84)	
Education					
Did not graduate high school	8	74 (62-80)	.112	74 (68-92)	.289
Graduated high school	82	75 (62-84)		78 (64-88)	
Graduated college	77	65 (56-80)		70 (57-80)	
Single parent household					
Yes	10	53 (43-58)	**.002**	64 (57-77)	.129
No	157	70 (59-82)		72 (62-84)	
History of mental health disorder					
Yes	58	63 (52-78)	**.007**	70 (58-83)	.127
No	109	73 (61-85)		74 (62-85)	
Infant NICU characteristics					
Gestational age, weeks					
≤28	36	60 (51-77)	**.004**	72 (63-83)	**.007**
29-36	92	74 (61-85)		76 (65-86)	
≥37	39	67 (59-79)		63 (56-80)	
Major anomaly					
Yes	47	67 (56-81)	.336	68 (57-81)	**.015**
No	120	70 (56-81)		75 (63-86)	
Delivery location					
Inborn	96	73 (59-84)	**.04**	74 (63-85)	.182
Outborn	71	67 (53-79)		69 (60-82)	
Multiple surgeries					
No	94	76 (61-85)	**.005**	76 (64-88)	**.002**
Yes	73	65 (53-78)		67 (58-81)	
Multiple consultants					
No	102	76 (61-85)	**<.001**	76 (65-87)	**<.001**
Yes	65	63 (51-76)		64 (57-79)	
Mechanical ventilation					
No	102	76 (61-85)	**<.001**	76 (65-88)	**<.001**
Yes	65	62 (53-73)		65 (58-81)	
Vasopressors					
No	140	70 (58-83)	.15	72 (61-85)	.269
Yes	27	65 (58-79)		69 (61-80)	
Length of NICU stay, days					
<28	43	77 (63-85)	**.04**	72 (65-85)	.635
29-60	66	69 (59-81)		74 (58-84)	
>60	58	65 (53-79)		71 (61-83)	
Postdischarge healthcare use					
Home oxygen					
No	124			73 (62-85)	.227
Yes	43			68 (60-81)	
Gastrostomy tube					
No	137			74 (63-85)	**.001**
Yes	30			63 (51-76)	
Nasogastric tube					
No	155			72 (61-84)	.551
Yes	9			68 (57-80)	
Tracheostomy present					
No	156			73 (62-84)	.070
Yes	9			64 (48-69)	
Medications prescribed					
No	100			75 (63-88)	**.008**
Yes	67			68 (60-81)	
Emergency department visits					
No	113			74 (63-85)	**.040**
Yes	51			69 (58-81)	
Hospital readmissions					
No	121			76 (64-85)	**<.001**
Yes	43			64 (56-76)	

Values are median (IQR) unless otherwise noted.

Comparisons with parent and infant NICU characteristics and median parent HRQL scores. NICU HRQL is the parent health-related-quality of life as measured by PedsQL Family Impact Module within a few weeks before NICU discharge. Higher scores indicate higher HRQL. The 3-month HRQL is the parent HRQL as reported 3 months after the infant's NICU discharge. *P* values represent nonparametric comparisons of between-group differences at each time point. Additional variables not shown here included access to a car, number of siblings for the child, insurance status, multiple gestation, and mode of delivery; these variables were not significant at the $P > .2$ level and were dropped from further analysis.

Table VI. Multivariable associations with parent HRQL during NICU and 3 months after discharge

Covariate	HRQL Coefficient	95% LCI	95% UCI	*P* value
During NICU admission				
Parent race/ethnicity				
Black	4.0	−1.5	9.5	.152
White	0.0			(ref)
Hispanic	−11.1	−20.9	−1.3	**.026**
Other	6.7	−1.7	15.0	.116
Single parent household	−18.0	−27.1	−8.9	**<.001**
History of mental health disorder	−9.2	−13.4	−4.9	**<.001**
Gestational age, weeks				
23-28	−7.0	−12.6	−1.4	**.015**
29-36	0.0			(ref)
37-43	−1.0	−6.3	4.4	.721
Multiple surgeries	4.4	−1.2	9.9	.122
Multiple consultants	−5.7	−10.6	−0.8	**.023**
Mechanical ventilation	−7.2	−11.7	−2.6	**.002**
3 months after NICU discharge				
Enrollment HRQL (every 1 point)	0.6	0.4	0.7	**<.001**
Gestational age, weeks				
23-28	10.6	4.7	16.4	**<.001**
29-36	0.0			(ref)
37-43	−5.1	−9.9	−0.4	**.036**
Mechanical ventilation in NICU	−3.5	−7.7	0.7	.101
Tracheostomy	−10.0	−19.0	−1.0	**.030**
Readmission	−4.9	−9.7	−0.1	**.044**
Home oxygen	−6.6	−11.8	−1.5	**.012**

LCI, lower confidence interval; *UCI*, upper confidence interval.
Reduced linear regression models for multivariable associations with parent HRQL before NICU discharge and parent HRQL 3 months after NICU discharge, adjusted for NICU HRQL within the same parent. HRQL coefficient is the adjusted difference in total PedsQL Family Impact Module score.

Demographic characteristics, NICU illness, and post-NICU healthcare use were associated with parent HRQL (**Table III**). Demographic factors including Hispanic ethnicity, a single parent household, and a history of mental health concerns were associated with lower NICU HRQL; no demographic factor was associated with differences in 3-month HRQL. NICU illness variables associated with lower parent HRQL both in the NICU and at 3 months after discharge included gestational age, mechanical ventilation, multiple surgeries, and multiple consultants involved in care. Post-NICU healthcare use variables associated with lower parent HRQL included gastrostomy tubes, multiple prescribed medications, emergency department visits, and hospital readmissions.

When estimating a clinically significant change in parent HRQL based on response to the question "How sick is your child?" on a 5-point Likert scale, a 1-point difference in parents' response corresponded to a median HRQL difference of 4 points on the PedsQL Family Impact Module (**Table IV**; available at www.jpeds.com). This anchor-based estimate of a 4-point difference in HRQL was more conservative than a distribution-based approach using twice the standard error of the mean (2.5-point difference). Using a 4-point difference in total PedsQL score as a clinically significant change in parent HRQL, **Figure 2** shows the proportion of parents of infants in each gestational age group who reported a clinically significant change in HRQL between the NICU hospitalization and 3 months after discharge. For parents of extremely preterm infants, 67% reported clinically significant improvement in HRQL at 3 months, compared with 31% of parents of term infants. Conversely, 22% of parents of extremely preterm infants reported lower HRQL after discharge, compared with 41% of parents of term infants ($P < .001$). No other parent or infant risk factor was associated with significant bivariate differences in pattern of HRQL change over time.

Analysis of HRQL subdomains (**Table V**; available at www.jpeds.com) revealed that during the hospitalization parents of extremely preterm infants reported lower emotional functioning and lower worry scores compared with parents of later gestation infants. At 3 months, parents of term infants reported lower emotional and cognitive functioning, communication and worry scores than parents of earlier gestation infants. By 3 months after hospitalization, parents of extremely preterm infants reported significant improvement in physical, emotional, and cognitive functioning, as well as family relationships. In contrast, parents of term infants reported lower scores in cognitive functioning and family relationships after discharge, and no improvement in any subdomains.

Table VI shows reduced regression models of factors associated with parent HRQL. During the NICU hospitalization, Hispanic ethnicity, a single parent household, and a history of a mental health concern were significantly associated with lower HRQL. Significant clinical risk factors included extreme prematurity, multiple subspecialty consultants, and use of mechanical ventilation. At 3 months, parents of extremely preterm infants reported an increase in HRQL compared with their score at enrollment. No demographic factor was significantly associated with change in HRQL after discharge home. Multiple gestation or having other children at home were not associated with differences in baseline HRQL or change in HRQL over time. Postdischarge healthcare use, including home oxygen, tracheostomy, and inpatient readmission, were significantly associated with lower HRQL. Full models including all risk factors that were significant on bivariate analysis did not change the direction or significance of the association between gestational age and HRQL. Residuals from the models were normally distributed.

Discussion

This study prospectively examined how demographics, NICU illness, and post-NICU healthcare use impact HRQL for parents of infants of all gestational ages requiring a prolonged NICU stay. Our major conclusions are that parents of extremely preterm infants experience the most negative

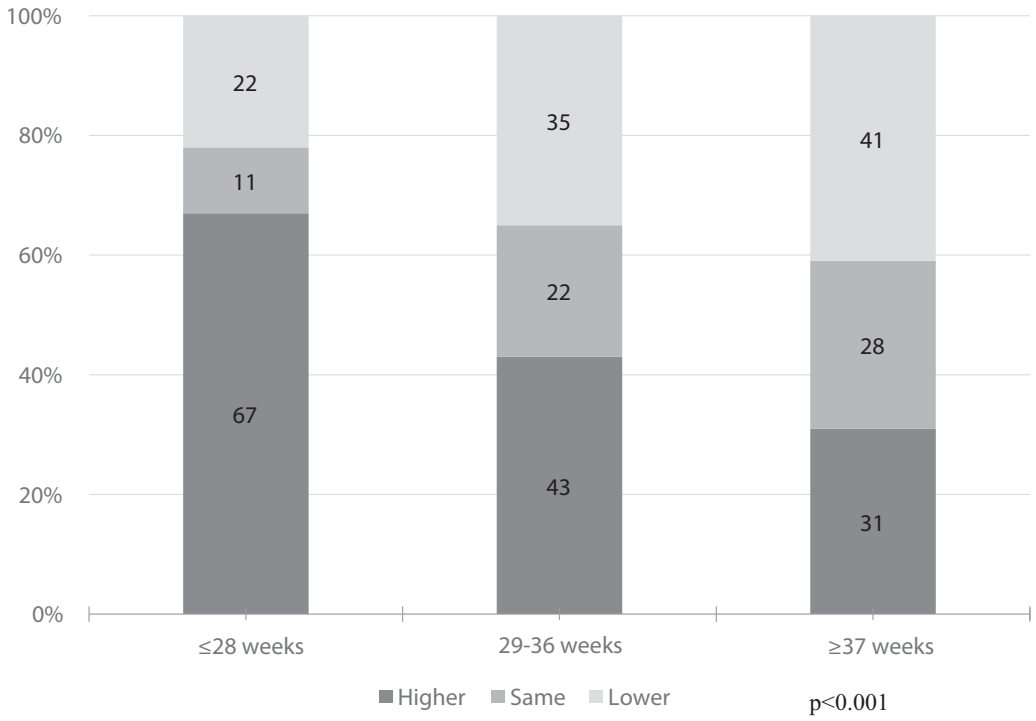

Figure 2. Clinically significant change in parent HRQL between NICU and 3 months after discharge. Numbers in each colored box indicate the n of parents responding. The *P* value was calculated by χ^2 tests.

impact on parent HRQL during the NICU hospitalization as well as the most improvement after discharge. Demographic risk factors are associated with lower parent HRQL in the NICU, but these differences do not persist after NICU discharge. Postdischarge healthcare use, including home oxygen, tracheostomy, and inpatient readmission, is associated with lower parent HRQL 3 months after NICU discharge.

Parents of extremely preterm infants reported the lowest HRQL during the NICU hospitalization. Parenting an extremely preterm infant has been associated with a higher incidence of stress and depressive symptoms, which are correlated with HRQL.[2,34] Mothers of preterm infants have been reported to have lower HRQL at 8 weeks postpartum than parents of healthy term controls. Indeed, research on parent HRQL of term infants has been limited to those who did not require a NICU stay[35] or those with later childhood diagnoses.[36] This study extends those findings by comparing parent HRQL for extremely preterm infants to that of other parents requiring an extended NICU stay.[35] Term infants who are sick enough to require a 2-week NICU stay often have major anomalies, a known cause of psychological distress to parents.[37] Nonetheless, extremely preterm infants experience the highest risk of mortality, comorbidities, and long length of stay (LOS), even compared with critically ill term infants.[38] Whether gestational age itself, the long LOS, or its associated comorbidities are responsible for the impact on parent HRQL is probably less important than recognizing the impact of extreme prematurity on parents.

After discharge, parents of extremely preterm infants reported the greatest improvement in HRQL. A Brazilian study of parents of preterm infants reported that HRQL improved over time.[39] We found that this pattern was distinctly different than parents of later gestation infants requiring an extended NICU stay. It seems unlikely that the higher HRQL for parents of extremely preterm infants results entirely from regression to the mean, because parents of term infants had a similarly low NICU HRQL score yet were more likely to experience lower HRQL after discharge. Although we adjusted for some measures of post-NICU healthcare use, sick term infants may have other unmeasured medical needs causing stress for parents. Also, neonatal care providers typically describe an array of medical and developmental outcomes for survivors of extreme prematurity, but in a heterogeneous term infant population, even less prognostic information may be available.[40-43] Lakshmanan et al found that time off work, financial worry, and social isolation were associated with lower parent HRQL in preterm infants; parents of term infants with extensive home care needs and uncertain prognosis may be impacted to an even greater extent.[44] In addition, there were important differences in subdomain HRQL changes between preterm and term parents, with preterm parents reporting the greatest increases in emotional functioning and family relationships compared with term parents. This finding may be due to better known support programs in place in the hospital and community for families of preterm children and an overall better understanding of prematurity through programs such as the

March of Dimes; parents of sick term infants who may have less well-known diagnoses may also have fewer perceived support systems. Another key difference between parents of extremely preterm and term infants is that parents of term infants have a shorter NICU LOS. Witt et al found that longer NICU LOS in preterm infants was a risk factor for lower parent HRQL.[22] In our cohort of infants of all gestational ages, we did not find that LOS was an additional risk factor for lower HRQL. In the postdischarge period, parents of sick term infants paradoxically may have less time for teaching and adaptation to the infant's condition, which may contribute to a relative lack of discharge readiness and resulting lower HRQL after discharge.[45] Parents of preterm infants may have already mourned the prospect of having a healthy child during the hospitalization, whereas parents of term infants may have had less time to cope with the lost expectation of a healthy child. Future research is important to understand the specific psychosocial and educational needs of parents of term infants in the NICU.

We found several demographic factors associated with lower parent HRQL during hospitalization. These demographic factors impacted HRQL in the NICU but did not affect parents' change in HRQL after discharge home. Single parents and parents with a history of mental health concerns may have delayed discharge to ensure adequate teaching and comfort with cares; mothers with a history of mental health disorders previously have reported less perceived discharge readiness.[46-48] Our results suggest that high-risk parents may benefit more from earlier teaching and discharge planning when possible, rather than delaying discharge, if clinical criteria are met and adequate home support is available. Family-integrated care models and transition-to-home programs report improved outcomes and decreased parental stress.[49-51] Future work in NICUs serving families with different demographics than ours, or in communities with different follow-up structures, will be important to understand the potential applications of these findings. Earlier discharge planning integrated with ongoing family education may be essential to optimizing both parent HRQL and infant safety.

Parents of children with more post-NICU healthcare use reported lower HRQL after discharge. Lakshmanan et al similarly found that readmissions and home technology were associated with lower parent HRQL in parents of preterm infants 2 years after discharge.[44] Our study extends those findings by comparing NICU with post-NICU HRQL in the same parents over time. For parents of preterm infants, some of the potential negative impact of complex home care may be offset by the potential positive impact of home discharge. In a pediatric transplant population, positive predischarge hospital processes were associated with higher parent HRQL at home.[52] Parents of preterm infants may uniquely benefit from strategies to expedite discharge, if empowered early to ensure safe transition home, but the positive impact of home discharge needs to be balanced against the negative impact of complex home care.

Our study has important limitations. Our follow-up period was 3 months, so we did not capture parent HRQL changes in the long term. Parents of medically complex children may adapt to their child's illness over time, resulting in higher HRQL; conversely, parents of preterm infants may experience lower HRQL later if school problems emerge.[53] Defining clinically meaningful change in HRQL is difficult in the absence of a quantitative illness measure that changes with time.[31] Anchor-based methods of assessing HRQL change have gained increasing importance in the literature, but to our knowledge have not been applied to caregiver HRQL previously. We did not include healthy newborn infants, although this has been done in prior studies of parents of preterm infants.[11] Some demographic factors are hard to interpret; for example, staying at Ronald McDonald house implies both living far away and having the life flexibility to stay away from home. A previous history of a mental health concern was assessed via parent report rather than with a separate screening tool. Our study design of comparing parent HRQL after discharge with their own score during hospitalization may partially mitigate these issues, but future studies incorporating more detailed maternal health measures will be important for future research. ■

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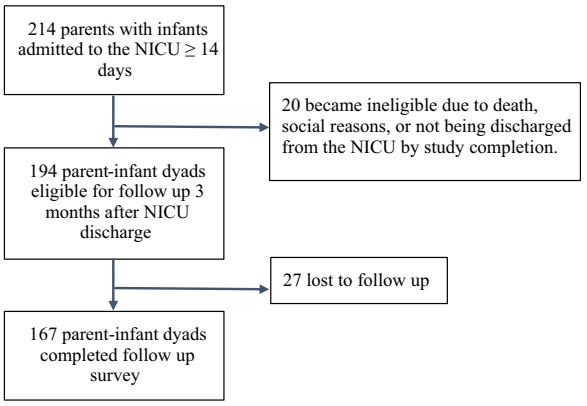

Figure 1. Flow of participants through the study.

Table II. Common diagnoses for infants admitted to the NICU by gestational age

23-28 weeks (n = 52)		29-36 weeks (n = 114)		37-43 weeks (n = 48)	
Diagnosis	**n (%)**	**Diagnosis**	**n (%)**	**Diagnosis**	**n (%)**
Moderate-severe BPD	39 (75)	Moderate-severe BPD	24 (21)	Genetic syndrome*	11 (23)
PDA	22 (42)	NEC	9 (8)	Pulmonary hypertension	7 (15)
Late-onset sepsis	16 (31)	Genetic syndrome*	9 (8)	Seizures	7 (15)
Surgical ROP	11 (21)	Other anomalies	9 (8)	Hydrocephalus requiring reservoir or shunt	7 (15)
Severe IVH	7 (13)	GI anomalies (gastroschisis, bowel atresia, TEF)	8 (7)	Pulmonary anomaly (CDH, CPAM)	6 (13)
NEC	7 (13)	Pneumothorax	7 (6)	GI anomaly (Bowel atresia, omphalocele)	5 (10)
Surgical NEC	5 (10)	Late-onset sepsis	6 (5)	CNS anomaly (myelomeningocele, encephalocele)	5 (10)
Congenital anomaly or genetic syndrome*	5 (10)	Cardiac anomalies (VSD, TOF)	6 (5)		
		Hydrocephalus requiring reservoir or shunt	5 (4)		
		PDA	5 (4)		

BPD, bronchopulmonary dysplasia (defined as mild if required >21% after day of life 28, moderate if required <30% FiO_2 at 36 weeks GA and severe if required ≥30% FiO_2 and/or positive pressure at 36 weeks GA); *CDH*, congenital diaphragmatic hernia; *CNS*, central nervous system; *CPAM*, congenital pulmonary adenomatoid malformation; *GI*, gastrointestinal; *IVH*, interventricular hemorrhage (defined as grade 3 or grade 4 IVH, unilateral or bilateral); *NEC*, necrotizing enterocolitis (defined as Bell's stage 2 or greater); *PDA*, patent ductus arteriosus that required medical therapy or surgical ligation; *TEF*, tracheoesophageal fistula; *TOF*, tetralogy of Fallot; *VSD*, ventricular septal defect.
Late-onset sepsis was defined as culture positive bacteremia, meningitis, or urinary tract infection obtained >3 days after birth and treated with antibiotics >5 days.
Table II provides the most common diagnoses encountered in each gestational age group, listed in order from most to least common, for all diagnoses present in ≥5 infants in that gestational age group.
*Genetic syndrome refers to an identified syndrome confirmed by testing. Seven infants had trisomy 21. The rest were individually identified syndromes consistent with the infant's congenital anomalies; specific types are not listed to protect patient confidentiality for infants with rare diseases in a single center. Other listed anomaly categories reflect infants without an identified genetic syndrome. An infant with multiple anomalies may be represented more than once.

Table IV. Anchor-based calculation of clinically significant change in HRQL between NICU and 3 months after discharge

Changes in response to "How sick is your child?"	n	Median HRQL change
3 points better	11	+8
2 points better	27	+5
1 point better	**39**	**+4**
No change	70	+1
1 point worse	13	−1

Table IV presents the median change in HRQL at 3 months after discharge compared with the NICU associated with each interval change in a parent's response to the question "How sick is your child?" on a 5-point Likert scale. Categories of change that reflected ≥5 respondents were included. This method has been used to anchor patient-reported outcomes in the absence of a numeric illness scale.

Table V. Parent HRQL subdomains between NICU and 3 months after discharge by gestational age

Parent HRQL subdomains	23-28 weeks	29-36 weeks	37-42 weeks	*P* value
NICU				
Physical functioning	58 (46-75)	67 (54-79)	67 (50-75)	.365
Emotional functioning	55 (43-70)	70 (55-90)	65 (45-80)	**.007**
Social functioning	69 (50-88)	75 (63-88)	75 (53-91)	.222
Cognitive functioning	70 (50-90)	80 (60-95)	70 (53-90)	.127
Communication	67 (50-83)	75 (67-92)	67 (54-83)	.065
Worry	60 (43-80)	75 (55-90)	55 (45-75)	**<.001**
Daily activities	58 (42-75)	50 (42-75)	50 (42-67)	.673
Family relationships	75 (55-95)	90 (65-100)	80 (70-100)	.081
3 Months				
Physical functioning	67 (63-79)	71 (58-81)	63 (50-75)	.124
Emotional functioning	80 (70-90)	80 (70-90)	70 (55-80)	**.006**
Social functioning	75 (63-88)	75 (63-94)	69 (56-94)	.473
Cognitive functioning	80 (63-98)	75 (60-95)	65 (50-90)	**.020**
Communication	75 (58-84)	75 (67-96)	67 (58-83)	**.035**
Worry	70 (55-80)	80 (70-95)	60 (45-80)	**<.001**
Daily activities	50 (33-71)	58 (42-75)	50 (33-67)	.161
Family relationship	80 (65-100)	80 (70-95)	75 (60-90)	.316
Change				
Physical functioning	+8 (−4 to +25)	+4 (−8 to +13)	0 (−13 to +8)	**.048**
Emotional functioning	+25 (0 to 40)	+5 (−5 to +25)	0 (−15 to +15)	**.003**
Social functioning	+13 (−13 to +25)	0 (−13 to +13)	0 (−13 to +6)	.088
Cognitive functioning	+10 (0 to +25)	0 (−10 to +10)	−5 (−10 to 5)	**<.001**
Communication	+8 (0 to 17)	0 (−8 to +17)	0 (−17 to +8)	.053
Worry	+10 (0 to +20)	0 (−10 to +10)	0 (−10 to +10)	.098
Daily activities	0 (−17 to +17)	0 (−17 to +17)	−8 (−17 to +8)	.555
Family relationship	+10 (−3 to +25)	0 (−15 to +5)	−5 (−20 to +0)	**.001**

Table VI *HRQL*, health related quality of life. presents median (IQR) HRQL subdomain scores in the NICU and at 3 months, as well as the median (IQR) change from NICU to 3 months within individual patients. The *P* values represent nonparametric Kruskal-Wallis tests between gestational age groups.