Referral of Very Low Birth Weight Infants to High-Risk Follow-Up at Neonatal Intensive Care Unit Discharge Varies Widely across California

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Objectives To determine rates and factors associated with referral to the California Children's Services high-risk infant follow-up (HRIF) program among very low birth weight (BW) infants in the California Perinatal Quality of Care Collaborative.

Study design Using multivariable logistic regression, we examined independent associations of demographic and clinical variables, neonatal intensive care unit (NICU) volume and level, and California region with HRIF referral.

Results In 2010-2011, 8071 very low BW infants were discharged home; 6424 (80%) were referred to HRIF. Higher odds for HRIF referral were associated with lower BW (OR 1.9, 95% CI 1.5-2.4; ≤ 750 g vs 1251-1499 g), higher NICU volume (OR 1.6, 1.2-2.1; highest vs lowest quartile), and California Children's Services Regional level (OR 3.1, 2.3-4.3, vs intermediate); and lower odds with small for gestational age (OR 0.79, 0.68-0.92), and maternal race African American (OR 0.58, 0.47-0.71) and Hispanic (OR 0.65, 0.55-0.76) vs white. There was wide variability in referral among regions (8%-98%) and NICUs (<5%-100%), which remained after risk adjustment.

Conclusions There are considerable disparities in HRIF referral, some of which may indicate regional and individual NICU resource challenges and barriers. Understanding demographic and clinical factors associated with failure to refer present opportunities for targeted quality improvement initiatives. *(J Pediatr 2015;166:289-95)*.

Infants discharged from neonatal intensive care units (NICUs) frequently have complex medical issues and are at risk for neurologic and developmental challenges. Although advances in perinatal and neonatal care have resulted in substantially improved survival rates for very low birth weight (VLBW, <1500 g) and extremely preterm infants,[1-3] they remain at risk for neurologic and developmental sequelae,[4-6] and require significant outpatient services.[7] High-risk infant follow-up (HRIF) programs provide multidisciplinary evaluation and care, usually offering a range of coordinated specialists and services including neurodevelopmental follow-up.[8,9] The American Academy of Pediatrics (AAP) Committee on Fetus and Newborn has emphasized the critical need to integrate HRIF into a NICU discharge plan to assure early identification and intervention.[10]

Unfortunately, even if infants are identified and referred to HRIF, successful follow-up is not assured, with recent studies showing less than 70% compliance.[11,12] Furthermore, high-risk infants who failed to keep follow-up appointments, or were followed only with great difficulty, were more likely to have severe disability, cognitive impairment, or adverse sensorineural outcomes.[13-15] Of great concern are the social and demographic disparities associated with poor HRIF participation,[11-13,15-17] not only because children and families who could potentially benefit most from supports and services are more likely to be lost to follow-up, but also because bias may be introduced to follow-up studies.

But the first crucial step toward improving participation in follow-up is to assure that HRIF referral is made at NICU discharge. We do not know the factors that may influence such referral patterns. The California Perinatal Quality of Care Collaborative (CPQCC) is a population-based dataset of perinatal variables and short-term outcomes for >95% of infants discharged from NICUs in California. The CPQCC partnered with California Children's Services (CCS) to revitalize and enhance the existing HRIF Program, which was begun in the late 1970s, creating the CPQCC-CCS HRIF Quality of Care Initiative. The program provides for a series of visits through 3 years of age for eligible infants in California, including all VLBW infants. With the linked CPQCC and CCS HRIF databases, a better understanding of factors associated with HRIF referral in a California population-based cohort of VLBW infants can be gained, allowing for identification of disparities and barriers to referral, and ultimately for development of targeted quality improvement (QI) initiatives.

AAP	American Academy of Pediatrics	IVH	Intraventricular hemorrhage
BW	Birth weight	NEC	Necrotizing enterocolitis
CCS	California Children's Services	NICU	Neonatal intensive care unit
CPQCC	California Perinatal Quality of Care Collaborative	PMA	Postmenstrual age
		QI	Quality improvement
GA	Gestational age	SGA	Small for gestational age
HRIF	High-risk infant follow-up	VLBW	Very low birth weight

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Our objectives were to determine referral rates to the CPQCC-CCS HRIF, and factors associated with referral and nonreferral to CPQCC-CCS HRIF among VLBW infants born in 2010 and 2011, and surviving to discharge home.

Methods

This was a retrospective analysis of prospectively collected data of VLBW infants in the CPQCC born in 2010 and 2011, who survived to discharge home, from the linked CPQCC and CPQCC-CCS HRIF databases. During the study period, greater than 90% of California's VLBW infants were cared for in 127 CPQCC hospitals. Data for the CPQCC database are abstracted by NICU personnel including physicians, nurses, and other trained staff. The CCS partnered with CPQCC to restructure the statewide HRIF Program, and to develop a completely web-based reporting system to collect data for the CPQCC-CCS HRIF Program. The CPQCC-CCS HRIF provides for a series of visits through 3 years of age for all infants meeting eligibility criteria and cared for at a CCS-approved NICU. The revitalized statewide CCS HRIF Program was launched in 2009, and has created online tools and reports to allow NICUs and HRIF programs to assess their successes and challenges compared with other programs in California. During the study period, there were 64 CPQCC-CCS HRIF participating programs throughout California. Eligibility criteria for the CPQCC-CCS HRIF Program encompass a number of criteria for both preterm and term infants. However, all VLBW infants, regardless of gestational age (GA), are eligible. Annual statewide training sessions for both the CPQCC and the CPQCC-CCS HRIF personnel promote accuracy and uniformity in data reporting and abstraction.

The CCS Program standards for NICUs require that each CCS-approved NICU ensure the follow-up of neonates and infants discharged from the NICU who are at high risk for neurodevelopmental delay or disability. The CCS mandates that all certified NICUs are part of the CPQCC and are responsible for identifying and referring eligible infants to the CPQCC-CCS HRIF Program. The individual HRIF clinics and programs are CCS "Special Care Centers" with required team members to perform diagnostic services including neurologic and developmental assessments. The assigned personnel at the CPQCC NICU complete a Referral/Registration Form via the web-based CPQCC-CCS HRIF Reporting System, referring the infant to a HRIF program. The HRIF program then accepts the case via the web-based system and is responsible for contacting the family, arranging follow-up appointments, tracking compliance, and completing web-based HRIF Visit Forms. The CPQCC and the CPQCC-CCS HRIF Reporting Systems operate independently, and the databases were linked for this analysis. The linkage process matches cases on the CPQCC patient identification number, then by a matching algorithm based on patient and maternal data including date of birth, sex, birth location, reporting NICU, birth order, birth weight (BW), GA, and other factors.

This study was approved by the Stanford University Institutional Review Board. We evaluated numerous factors potentially associated with referral and nonreferral to HRIF for VLBW infants. Maternal, sociodemographic, neonatal clinical, and NICU-related data were obtained through CPQCC records, using definitions as described in previous publications.[18,19] For the purposes of this analysis, prenatal care was defined categorically, maternal age was grouped as ≤19 years, 20-29 years, and subsequent 10 year intervals to 40+ years, and maternal race/ethnicity was categorized according to CCS guidelines (African American, Hispanic, white, Asian/Pacific Islander, native American, other). Other factors included morbidities that may have contributed to severity of illness, such as necrotizing enterocolitis (NEC), late sepsis, or meningitis (culture-proven sepsis and/or meningitis after day 3), surgery for retinopathy of prematurity, patent ductus arteriosus, or NEC, presence of congenital anomalies, oxygen use at 36 weeks postmenstrual age (PMA) (continuous or intermittent), and severe intraventricular hemorrhage (IVH). Severe IVH was defined as grade 3 or 4.[20] Mechanical ventilation was defined as need for conventional or high frequency ventilation at any time during NICU stay. NICU level of care was based on CCS guidelines, which classify NICUs into 3 levels—regional, community, and intermediate NICUs—according to the services provided at each center, with designations based on the AAP definitions in place during the study period.[21] "Regional" NICUs were equivalent to the AAP levels IIIC and IIID designation, "community" NICUs equivalent to AAP level IIIA and IIIB, and "intermediate" NICUs being equivalent to AAP level II designation. Hospitals with licensed NICU beds that do not choose to participate in the CCS program do not receive a CCS level designation, and were defined as "non-CCS" for the purposes of this analysis. NICU volume was based on the average annual VLBW discharged volume for 2010 and 2011 for each NICU. NICUs were then grouped according to quartile of VLBW discharged average annual volume. California geographical regions and subregions were defined according to the California Department of Public Health Regional Perinatal Programs of California scheme.

For maternal, demographic, and neonatal variables, rates of referral to CPQCC-CCS HRIF by NICU and by California geographical region were calculated by dividing the number of referrals received by the number considered eligible or expected (ie, VLBW infants surviving to discharge home). A multivariable logistic regression model was constructed to identify factors associated with referral to HRIF using backward selection with an exit criterion of $P < .15$, which included variables prospectively identified as relevant, and factors determined to be significant in unadjusted analyses. Because BW and GA are highly correlated, the final model included BW only. Small for GA (SGA) was included in the model. Although referral to CPQCC-CCS HRIF is required only for those infants cared for in a CCS NICU, infants who were never cared for in a CCS NICU during any point in their hospitalization were not included in the final model. For unadjusted analyses, categorical variables were analyzed