PRESS RELEASE
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CPQCC initiative boosts HRIF referral rates throughout the state

At the start of the last decade, nearly 1500 very low birth weight infants born in California each year and discharged to home were not referred for High-Risk Infant Follow-up (HRIF) care despite their eligibility by California Children's Services (CCS) criteria. To address this gap, the California Perinatal Quality Care Collaborative (CPQCC) launched a statewide initiative designed to boost referral rates at all CPQCC-member neonatal intensive care units (NICUs).

The overall referral rate for this group jumped from 83% prior to the initative to 94% following the initiatve, and improved substantially across all sociodemographic, perinatal, and clinical variables. Today, the percentage of NICUs referring >95% of eligible infants has increased from 41% to 84% of CPQCC NICUs.

Findings are reported in a study published in the January 2020 issue of The Journal of Pediatrics. Vidya Pai, MD, MS Epi, is the lead author.

"It's good to know that regardless of which NICU a baby was discharged from, they at least have a better chance of being referred to high-risk infant follow up," says Dr. Pai. "Because CPQCC exists, we have the opportunity to implement this huge initiative that impacts 140 NICUs and several thousands of babies, which isn't something that is available in any other state."

HRIF REFERRAL PROCESS AND VARIATIONS IN CARE

Since 2009, CCS partnered with CPQCC to restructure statewide follow-up. Together, they created a web-based reporting system, with linkages to CPQCC NICU data to ensure infants born at risk for developmental delays and neurologic problems receive additional care once they are discharged from the NICU. This statewide program mandates that NICUs refer CCS eligible infants to one of nearly 70 HRIF clinics in California. Eligible infants include all those born before 32 weeks gestation, or with very low birth weight (less than 1500g or 3.3lb), as well as infants with other clinical risk factors.

Multi-disciplinary care teams at local HRIF clinics track the development of these infants over three visits for up to three years. In addition to assuring access to providers with expertise in functional and neurodevelopmental challenges, these programs provide support for parents, assist with coordination of complex care, and provide additional referrals to medical and supportive services when needed.

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Susan Hintz, MD, MS Epi, CPQCC's HRIF Medical Director, led a study published in 2015 that showed wide variation of HRIF referral rates across the state for very low birth weight infants. Referral rates differed dramatically depending on region (8-98%), and NICU (<5-100%).

Of great concern to Dr. Hintz and colleagues was the fact that failure to be referred to HRIF was associated with sociodemographic and NICU-level disparities in addition to neonatal clinical factors. Maternal African American and Hispanic race or ethnicity was associated with lower odds of referral. Infants with greater birthweights or born at a later gestational ages were referred at lower rates compared to those born smaller and earlier. Overall, lower volume and lower level NICUs referred eligible infants less often than higher level regional and academic NICUs that care for more infants annually.

"Referral rates for all of those groups improved significantly likely as a result of the initiative," says Dr. Pai.

Aiming to improve continuity of care for at-risk infants, the initiative relied on raising awareness and incentivizing NICUs to improve referral rates.

In 2013, each NICU involved in the initiative received a confidential report showing how many NICU discharges resulted in confirmed referrals to HRIF clinics. Education about the report was provided in 2013 and 2014 to all CPQCC-member hospitals during CPQCC annual data training sessions.

In 2014, the expectation was communicated that all CPQCC NICUs achieve 100% referral rates to HRIF. Leadership from CPQCC annually awarded NICUs that met this goal and exacted a small penalty fee from any NICU that failed to refer all eligible infants.

Variation in HRIF referral rates decreased for specific groups following the education that CPQCC provided to member hospitals and its performance-based rewards. After the initiative, Hispanic ethnicity, small for gestational age status, congenital anomalies, and major morbidities were no longer associated with a decreased odds of referral. Lower birth weight, outborn status, and higher NICU volume were no longer associated with increased odds of referral.

Still, higher level NICUs remained associated with higher odds of referral while African American race was associated with lower odds of referral. Dr. Pai speculates the disparity persists because African American infants may be more often cared for at lower level NICUs that may lack the infrastructure or resources to facilitate the HRIF referral process. Encouragingly, there was a greater magnitude in improvement in referral rates for African American infants compared to white infants between the two periods. Further investigation is needed to evaluate the persistent racial disparities related to referral.

WHERE DO WE GO FROM HERE?

While Dr. Pai and colleagues have demonstrated systemic improvement in HRIF referral rates at the NICU-level throughout the state, this does not necessarily mean more children are being seen in HRIF clinics.

Dr. Hintz investigated the programmatic and administrative barriers to HRIF care as well as factors associated with a successful first visit at one of the 68 HRIF clinics in California. During 2010 and 2011, only 76% of very low birth weight infants who were referred to HRIF actually attended a HRIF visit within the first year. The team again found that maternal, sociodemographic, and home- and program-level disparities were associated with HRIF non-attendance, as well as some clinical factors. Higher odds of attendance at HRIF programs was associated with older maternal age, lower birth weight, private insurance, history of severe intracranial hemorrhage, two-parent household, and higher volume at HRIF program. Similar to the wide range of HRIF referral rates between NICUs pre-initiative, attendance rates varied across HRIF programs throughout the state.

Drs. Hintz and Pai plan to investigate HRIF attendance rates for very low birth weight infants in the time period after the CPQCC initiative took place, in addition to attendance rates of other groups of high-risk infants including those with severe congenital heart disease. Finding ways to tackle the identified barriers and challenges for families and HRIF clinics in assuring successful follow up is a critical next step. To this end, the team is in the process of creating work groups with NICU, HRIF clinic, and parent stakeholders to develop interventions to ease the transition from NICU to home and community.

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Other authors of the paper include Peiyi Kan, MS, Mihoko Bennett, PhD, Suzan Carmichael, PhD, and Henry C. Lee, MD, MS Epi.

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