Parent Language: A Predictor for Neurodevelopmental Follow-up Care Among Infants With Very Low Birth Weight

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ABSTRACT

OBJECTIVE: Preterm/very low birth weight infants may suffer neurodevelopmental delays. Pediatricians should monitor neurodevelopment and pursue timely referrals. Yet parents who speak non-English primary languages (NEPL) report worse health care communication and fewer appropriate specialty referrals for their children. We sought to determine whether infants of NEPL parents receive recommended outpatient follow-up care for neurodevelopment. We hypothesized that these infants received less care than infants of English speakers.

METHODS: We linked paid claims from California Children's Services to clinical data from California Perinatal Quality Care Collaborative (58% linkage rate, 1541 subjects) for publicly insured infants with birth weight <1500 g or gestational age ≤32 weeks. Our primary outcomes were completion of 1) preventive visits and 2) ophthalmology visits; and receipt of 3) influenza vaccination and 4) palivizumab. To compare group differences, we also assessed 5) hospital length of stay and 6) readmissions. Analyses were adjusted for medical severity and sociodemographic characteristics.

RESULTS: A total of 433 infants (28%) had NEPL parents. Infants of NEPL parents had 38% higher odds of receiving influenza vaccination (95% confidence interval 9–75, $P = .008$) and completed 8% more preventive visits (95% confidence interval 1–64, $P = .019$) than infants of English speakers. Infants of NEPL parents did not have longer lengths of stay or more readmissions.

CONCLUSIONS: Infants of NEPL parents were more likely than infants of English speakers to receive some aspects of recommended outpatient follow-up care. Regardless of language, all infants received far lower rates of follow-up care than recommended by national guidelines. Future study should address the causes of these gaps.

KEYWORDS: health care disparities; infant, premature; infant, very low birth weight; language; minority health

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WHAT'S NEW

Preterm/very low birth weight infants born to non-English-speaking parents were more likely to receive outpatient neurodevelopmental follow-up care than infants of English speakers. Regardless of language, all infants received far less care than recommended by national guidelines.

PRETERM BIRTH AND very low birth weight (VLBW) are common causes of infant mortality and morbidity,[1] generating an annual socioeconomic burden exceeding $26 billion.[1] Beyond their birth hospitalizations, these infants are at high risk for neurodevelopmental problems, including impaired growth, vision, hearing, motor, cognitive, behavioral, and social-emotional functioning.[1–3] While timely outpatient referrals to early intervention services may reduce these risks,[4,5] effective care requires coordinated communication between parents and health care providers.[3]

Language barriers may impede this coordinated communication and, consequently, how high-risk infants receive appropriate outpatient care. In the United States, 15% of infants are born into families in which one or both parents speak a non-English primary language (NEPL).[6] NEPL parents commonly report poor communication with health care providers,[7–11] lower parental satisfaction with care,[7] and fewer outpatient referrals to specialists and early intervention programs.[7,12] In one study, Spanish-speaking parents

whose infants were discharged from a neonatal intensive care unit (NICU) lacked knowledge about their infants' conditions and awareness of early intervention programs.[10] In other studies, parents with NEPL were less likely to report that health care providers elicited their developmental concerns[8] or discussed developmental assessments.[7]

Primary care providers play an important role in supporting growth, neurodevelopment, and other health outcomes for high-risk infants.[2,3] No studies to date, however, have examined the relationship between parent NEPL and appropriate receipt of outpatient neurodevelopmental follow-up care by preterm/VLBW infants. To address this gap, we examined 3 years of clinical, sociodemographic, and paid claims data for a representative sample of preterm/VLBW infants in California. We hypothesized that infants of NEPL parents received less outpatient follow-up care, had longer birth hospital stays, and were at greater risk for hospital readmission compared to infants of English speakers.

METHODS

DATA SOURCES AND PROBABILISTIC LINKAGE

We extracted data for all episodes of inpatient and outpatient use of care for all infants with preterm birth/VLBW diagnoses who were enrolled in California Children's Services (CCS) from January 1, 2009, to June 20, 2012. For each infant, we linked comprehensive (inpatient and outpatient) paid claims from California's Management Information System/Decision Support System with clinical and sociodemographic data from the California Perinatal Quality Care Collaborative (CPQCC) using probabilistic linkage techniques. CCS is a Title V program that provides diagnostic, treatment, and case management services to California children with eligible medical conditions (including VLBW) and income standards: family income <$40,000, or family income >$40,000 with medical costs >20% of income, or qualification for Medi-Cal.[13] Parent primary language and residential zip code are self-reported at the time of CCS enrollment.[13] CPQCC is a hospital collaborative that collects data for >90% of infants in California's NICUs to improve health care quality and outcomes.[14] Clinical data included dates of birth, hospital admission and discharge, gestational age, singleton or multiple gestation, and medical complications. Sociodemographic data included maternal age, race, ethnicity, and receipt of prenatal care.

We performed probabilistic linkage techniques[15] using infants' dates of birth, gender, birth hospital name, hospital length of stay, and city/county of residence (Online Appendix Figure 1). We linked 58% of subjects across data sets. Comparing linked and unlinked subjects, we found no group differences in rates of parent NEPL, male gender, or median family income <200% of the federal poverty line (based on residential zip code). Linked subjects were more likely than unlinked subjects to reside in Los Angeles and less likely to reside in the Farm Belt. Analyses were conducted by SAS 9.4 software (SAS Institute, Cary, NC). We obtained Stanford institutional review board approval before we initiated study activities.

We included infants with billing codes for birth weight <1500 g and/or gestational age ≤32 weeks (Online Appendix Table 1) who were continuously enrolled in CCS through their first birthday. We excluded infants for whom language was unknown and those not linked.

KEY INDEPENDENT VARIABLES AND PRIMARY OUTCOMES

Our key independent variable was parent NEPL. For descriptive analyses, we compared clinical and sociodemographic characteristics by parent ethnicity and language: Hispanic English speakers, Hispanic Spanish speakers, and non-Hispanic other NEPL to the reference group of non-Hispanic English speakers. For bivariate and multivariable analyses, we grouped NEPL speakers (Spanish and other) and compared their outcomes to those of English speakers.

We assessed 5 measures as indicators of the primary outcome: receipt of outpatient neurodevelopmental follow-up care. We selected measures from evidence-based quality indicators.[2] For each measure, subjects either had the event or were censored if they unenrolled from CCS, died, or had no event. 1) Timeliness of first outpatient visit after hospital discharge was assessed as a binary variable (any physician visit within 7 days) and continuous variable (days to first physician visit) as demonstrated by a paid claim for any outpatient physician. 2) Completion of recommended preventive visits up to 24 months of age was assessed using the American Academy of Physicians (AAP) Bright Futures schedule.[16] Eligible intervals for preventive visits were based on a 30-day month and counted by day of life (Online Appendix Table 2). We then determined the number of eligible intervals with a completed visit as demonstrated by a paid claim with a preventive visit billing code (Online Appendix Table 1). If a subject was hospitalized for >7 days during a preventive visit interval, this interval was removed from the number of eligible intervals. 3) We assessed completion of at least 1 influenza vaccination[17] during the first 12 months of life as a binary variable, demonstrated by a paid claim with an influenza vaccination billing code (Online Appendix Table 1). 4) We assessed completion of palivizumab prophylaxis for prevention of respiratory syncytial virus (RSV) infection on the basis of AAP guidelines.[18] The number of eligible outpatient doses was based on the subject's gestational age and chronological age at the start of RSV season, up to 5 doses (Online Appendix Table 3).[18] Accounting for age at hospital discharge, we counted the number of completed outpatient doses within the first 12 months of life as demonstrated by paid claims with palivizumab billing codes occurring at least 21 days apart (Online Appendix Table 1). 5) We assessed completion of at least 1 ophthalmology visit during the first 12 months of life as a binary variable, demonstrated by a paid claim with ophthalmology national provider identifier numbers.

We assessed 2 measures as indicators of a secondary outcome: use of inpatient care. These measures were selected from national guidelines for reduction of preventable inpatient care.[19] First, we assessed the length of hospital stay for the birth hospitalization as a continuous