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July 12, 2019
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Title: Early Intervention enrollment among infants seen in NICU Follow-up Clinic at Morgan Stanley Children's Hospital

Background:

Due to advances in perinatal intensive care, more children born prematurely are surviving into childhood, and many are found to have educational, behavioral, and neurodevelopmental disabilities.[1,2,3] Earlier gestational age (particularly less than 28 weeks gestation) and low birth weight have been associated with higher risk of cognitive impairment, and long term adverse developmental outcomes in school aged children.[1,2,3, 4] IQ scores in premature infants have been found to decrease significantly with decreasing gestational age, and children with low birthweight (VLBW, ELBW) have higher rates of educational underachievement than their normal birthweight peers.[1,4] Children can be enrolled in Early Intervention (EI) services in New York State when either a developmental delay is present (defined by two standard deviations below the mean in one functional area or 1.5 SD below the mean in each of two functional areas), or if they are diagnosed with a condition putting them at risk for a developmental delay.[5] Children born prematurely are at increased risk for developmental delay due to their prematurity.[1,4] Examples of diagnoses related to prematurity that automatically make a child eligible for EI include extremely low birthweight (<1000g at birth), grade IV interventricular hemorrhage, cystic periventricular leukomalacia, retinopathy of prematurity and sensorineural or conductive hearing loss.[5]

For all children, earlier enrollment in EI services has been shown to be helpful in overall developmental achievement,[1,4,6,7]. Many families, not only those who spend time in the NICU, experience delays in enrollment, or are not being enrolled in EI services at all, even if they are referred.[7,8,9] Children of immigrant families, children of mothers who do not speak English, and minority children are often less likely to be enrolled in EI services.[8, 10] Families with limited income, mothers with lower educational attainment, and minority families were likely to report difficulty finding out about and getting EI services started that their higher income, higher education, and non-minority counterparts.[11] There are also neighborhood factors involved in delays to enrollment in EI. Children living in New York City in zip codes where >20% of families spoke Spanish in the home, and the median household income was <$30,000 were significantly more likely to have delays in receiving services, sometimes waiting twice as long as their peers living in more advantaged neighborhoods.[7] EI enrollment in low birthweight infants shows varying rates of referral and enrollment in EI services, but even in these studies, living in a socioeconomically disadvantaged neighborhood was associated with lower rates of EI enrollment.[11, 12] Together, this information points to the barriers that many families face when trying to obtain important care for their child's development, and the great need to ensure eligible NICU graduates receive EI services. In our NICU, in 2016 58.4% of children were born to mothers of minority race, thus a large part of our population is at risk for delayed enrollment in EI. Our study will aim to determine which infants eligible for EI are actually enrolled in services, and when they are enrolled by reviewing NICU Follow-up clinic data.

Aims/Hypotheses: This study will aim to determine which infants seen in NICU Follow-up clinic at Morgan Stanley Children's Hospital are receiving EI services, and factors associated with differences in enrollment among eligible infants. We also hope to determine if patients with a higher level of impairment upon NICU discharge receive a greater number of services. We hypothesize that children of minority families, families whose primary language is not English, and those living in more disadvantaged zipcodes will receive fewer services despite eligibility for EI. Our primary outcome is the number of children seen in NICU Follow-up clinic who are eligible for and receiving services through early intervention. Our secondary outcomes include determining barriers to enrollment in EI services, and demographic differences among children receiving services.

Study Design:

This is a retrospective cohort study utilizing a convenience sample involving all children born at Morgan Stanley Children's Hospital (MSCHONY) and admitted to the Neonatal ICU with dates of birth between January 1, 2015 and December 2017. Data will be obtained from their inpatient stay as well as from NICU Follow-up clinic from January 2015-December 2017.

Inclusion criteria include birthdate between Jan 1, 2015 and Dec 31, 2017, discharge from MSCHONY NICU, eligibility for NICU Follow-up clinic (<28 weeks gestation or <1250 grams and <32 weeks or seizures, Grade 4 IVH, periventricular leukomalacia, meningitis or encephalitis). Exclusion criteria include: no comorbidities and birthweight between 1,000 and 1,250 grams as these children are not automatically eligible for Early Intervention, residing outside of New York State. For multiple gestations data will be collected on all infants in the twin or triplet gestation.

Information to be collected will include, child's gestational age, birthweight, diagnoses present upon discharge including interventricular hemorrhage (IVH), retinopathy of prematurity (ROP), postnatal growth including weight, length, Neonatal Neurobiological Risk Score (NBRS), and length of stay. Prenatal history to be collected includes ultrasound studies, infectious studies, and genetic evaluations. Outpatient data to be collected will include medical diagnoses, demographic information including zipcode of current residence, insurance status, race/ethnicity, primary language spoken at home, EI agency, and EI services received. Maternal information collected at time of a child's admission to the NICU will include age, insurance status, zipcode of residence, primary language spoken by mother, and race/ethnicity. Eligible subjects will be identified through our existing neonatal intensive care unit and maternal-fetal medicine clinical databases, and study data will be collected from review of subjects' inpatient medical records and neonatal follow-up records.

The specific systems that will be accessed for data collection include Allscripts and Sunrise Clinical Manager (Morgan Stanley Children's Hospital) which contains inpatient records as well as Clinical Records On-Line Web Network (CROWN), which is the outpatient electronic health record that contains neonatal follow-up records.

Statistical Analyses:

Analyses will include a logistic regression model looking at EI enrollment related to risk factors such as minority race, low income census tract, Medicaid insurance, and non-English as primary language spoken in the home. Will also look at neurobiologic risk score as a factor related to increased EI enrollment. Our hypothesis is that risk factors will negatively impact enrollment in EI, but neurobiologic risk score will possibly be correlated with increased EI enrollment.

A power analysis using p value of <0.05 and power of 80% showed that to determine a difference of enrollment in EI of 15%, data for 186 minority and 186 non-minority patients would need to be collected. Based on this information, the study will be powered to detect a difference of 15% between the two groups.

Study subjects: Patients seen in NICU follow-up clinic with specified birthdates and seen during the specified study period will be those included in the study analyses. No patients will be consented for enrollment in this study as it is a retrospective chart review.

Study questionnaires: There are no questionnaires as a part of this study.

Study drugs and medical devices: This study does not include use of any drugs or medical devices.

Confidentiality: The study will use a password protected secure server to store information collected from the chart review. All information will be deidentified, and will be kept on a CUMC computer in a locked room.

Conflicts of Interest: There are no conflicts of interest to report from any investigators.

Potential Risks: The main risk is the risk of breach of confidentiality, which is being protected by all possible efforts.

Potential Benefits: This study could potentially help determine gaps in care for vulnerable NICU graduates, and thus could be very beneficial for other patients in the future. Patients whose charts are reviewed for this study are not expected to benefit.

Compensation: Patients will not be compensated for participation as this is a retrospective chart review.

Cost to subjects: There will be no cost to subjects for participation in the study.

Minors as subjects: There is minimal risk to minor patients as this study is a retrospective chart review. Since this study is looking at outcomes in minors, there is no possible alternative.

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