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Part C early intervention utilization in preterm infants: Opportunity for referral from a NICU follow-up clinic

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ABSTRACT

Objective: Early Intervention (EI) services promote development for preterm infants. In the state of Illinois, Child and Family Connections (CFC) is the intake agency that determines qualification for EI services. In Illinois, all extremely low birth weight (ELBW) infants are eligible for and referred to CFC at discharge from the Neonatal Intensive Care Unit (NICU). This study investigated: (1) patterns of CFC and EI enrollment, and; (2) predictors of CFC enrollment, need for CFC referral, and high EI therapy use among preterm infants seen in a NICU follow-up clinic.

Methods: 405 preterm infants, including 169 ELBW infants, were seen in a NICU follow-up clinic at 4-, 8- and 20-months corrected age. CFC/EI data were collected at each visit. Multiple regression analyses adjusted for the effect of medical, sociodemographic and neurodevelopmental risk factors on CFC/EI outcome.

Results: Despite the high rate of EI utilization and routine care by primary pediatricians, up to 28% of ELBW infants required a CFC referral from a NICU follow-up clinic. Medical and neurodevelopmental risk factors were associated with CFC enrollment while medical, sociodemographic and neurodevelopmental risk factors were associated with need for CFC referral.

Conclusion: NICU follow-up clinics facilitate appropriate CFC/EI services for preterm infants.

What's this paper adds?

The field of pediatrics recognizes, and in fact, explicitly states that best medical practice for preterm infants includes enrollment in NICU follow-up clinics. In statement of purpose, NICU follow-up clinics serve to monitor growth and development, provide continuity of medical care and provide assurance of appropriate therapeutic interventions. Preterm infants' development is known to benefit from enrollment in agencies such as CFC and services such as EI. However, to date, very little is known about the role that NICU clinics can play in referring and enrolling preterm infants into CFC and EI.

To our knowledge, this study is the first to investigate patterns of preterm infants', including ELBWs', enrollment in CFC and EI, and predictors of CFC enrollment, need for referral to CFC, and predictors of high levels of EI therapy use

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(i.e., enrollment in more than 1 EI therapy) *from a NICU follow-up clinic. Therefore this is the first study to investigate the role of NICU clinics in assuring appropriate CFC/EI services*. Despite the fact that 25% of all preterm infants seen in the NICU clinic were high EI therapy users, and despite the fact that these same preterm infants were regularly followed by primary care pediatricians, 14–28% of preterm infants seen in a NICU follow-up clinic needed a referral to CFC by the NICU follow-up physician. Sociodemographic risk factors, in addition to medical and neurodevelopmental risk factors, are significantly associated with the need for CFC referral.

1. Introduction

Preterm births (born < 37 weeks gestational age) represent 11.7% of all live births in the United States (March of Dimes, 2014). As such, medical management of children born prematurely is an important aspect of pediatric medicine. The American Academy of Pediatricians has recognized the unique needs of preterm infants and recommends preterm infants follow-up with physicians affiliated with a neonatal intensive care unit (NICU; Verma, Sridhar, & Spitzer, 2003). The National Institute of Child Health and Human Development has issued similar guidelines, and recommends that all extremely low birth weight (ELBW, subset of preterm infants born weighing less than 1000 g) infants receive follow-up care post-NICU discharge (Ballentyne, Stevens, Guttmann, Willan, & Rosebaum, 2012). In accordance, the vast majority of academic NICUs (93%), and, by mandate, all level III NICUs, have established NICU follow-up clinics, designed to meet the aforementioned guidelines and the clinical needs of NICU graduates (Kuppala, Tabangin, Haberman, Steichen, & Yolton, 2012).

NICU follow-up clinics are directed by neonatologists and/or developmental behavioral pediatricians. Preterm infants are typically scheduled for their initial appointment in a NICU follow-up clinic at 2–4 months corrected age (CA) and are regularly re-assessed through quarterly to annual return appointments until 2–3 years CA (Bockli, Andrews, Pellerite, & Meadow, 2014; Kuppala et al., 2012; Patra, Greene, Perez, & Silvestri, 2014). Follow-up clinics primarily serve to identify problems with growth and development, provide continuity of care, and provide assurance of appropriate therapy, including policy-governed developmental intervention (Bockli et al., 2014; Kuppala et al., 2012; Patra et al., 2014). While a large role of NICU follow-up clinics is to assure appropriate therapies, NICU follow-up clinics and policy-governed early intervention (EI) therapeutic services are two entirely separate systems. The United States' 2004 Individuals with Disabilities Act, Part C, provides federal financial support for state-wide creation of agencies that oversee provision of early intervention (EI) therapeutic services for children ages 0–3 (Individuals with Disabilities Education Improvement Act, 2004). EI services are typically provided in a child's home after NICU discharge. The creation of agencies and implementation of EI varies by state. In Illinois, Child and Family Connections (CFC) acts as the coordinating intake agency that determines qualification for EI services through a comprehensive evaluation process. Many states EI services are coordinated by intake agencies such as CFC. In Illinois, ELBW infants are automatically eligible to be enrolled in CFC and subsequently, to receive a comprehensive evaluation. In Illinois, any child aged 0–3 with a developmental delay of greater than 30% or more in 1or more developmental domains qualifies for EI services. It is important to note that given the structure of the system, infants may be eligible for and enrolled in CFC, and therefore be appropriately and actively monitored and re-evaluated, but may not qualify for EI therapies given their developmental functioning. EI services are uniquely tailored to each child's set of developmental needs, but are typically comprised of enrollment in one, or a combination, of: developmental, physical, occupational and speech therapy.

Appropriate EI enrollment is of great importance as services are known to promote development among preterm infants (McManus, Carle, & Poehlmann, 2012). In fact, review of standard practice among NICU follow-up clinics indicates that assurance of enrollment in appropriate EI services appears to be a nearly universal, important, yet under-funded aspect of NICU follow-up clinical care (Bockli et al., 2014; Kuppala et al., 2012). As many as 99% of NICU follow-up programs are reported to refer to an agency such as CFC for EI (Kuppala et al., 2012), yet as many as 1 in 4 follow-up clinics report that if they were to receive additional financial resources, they would allocate them to assurance of EI services (Bockli et al., 2014).

Despite the prevalence and importance of appropriate EI enrollment for preterm infants, the relevant literature remains sparse. Existing studies have used regional research cohorts or linked, state-wide databases from the mid-to late 1990s and early 2000s to examine medical and sociodemographic predictors of enrollment of preterm infants who qualified for EI services (McManus, Robert, Albanese, Sadek-Badawi, & Palta, 2013; Wang et al., 2009). To our knowledge, patterns of enrollment in EI services, predictors of need for referral to an agency such as CFC for EI services, and predictors of high levels of therapy use *from NICU follow-up clinics remain unknown.* Therefore, despite NICU follow-up clinics' stated intent and mission to assure appropriate therapeutic services for their preterm infants, *the actual role of NICU clinics in assuring appropriate CFC/EI services for preterm infants is unknown.* Thus, the present study seeks to describe: (1) patterns of CFC and EI enrollment across NICU appointments in the first two years of life, by which age nearly half of NICU follow-up clinics end (Kuppala et al., 2012), and; (2) medical, sociodemographic and neurodevelopmental predictors of CFC enrollment in the second year of life, need for CFC referral in the second year of life, and high level of therapy use (defined as enrollment in more than 1 therapy at any point over the first or second years of life). These associations will be calculated for all preterm infants attending the NICU follow-up clinic (preterm-ALL). Additionally, the aforementioned associations also will be calculated separately for two sub-groups of the preterm-ALL group: (1) ELBW (preterm <1000 g) infants, who, as previously stated, are automatically eligible for CFC enrollment in Illinois and who are automatically referred to CFC by NICU staff prior to discharge home from the NICU, and; (2) preterm infants born weighing more than 1000 g (preterm >1000 g).

The study hypothesizes that birth and medical variables (i.e., birthweight, presence of severely abnormal head ultrasound) and sociodemographic risk variables (i.e., public insurance status as a proxy of income) would predict CFC