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Early Therapy Services Following Neonatal Intensive Care Unit Discharge

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Abstract

Aims—To (1) characterize early therapy services for preterm infants in the first two years of life, and (2) define factors related to accessing early therapy services.

Methods—Therapy utilization after discharge from the neonatal intensive care unit (NICU) was tracked in 57 infants born 30 weeks gestation from 2007 to 2010. Participants returned for developmental testing at two years. Factors related to early therapy utilization were explored.

Results—Fifty-two (91%) infants received a referral for therapy at NICU discharge but only 44 (77%) received at least one type of therapy during the first two years of life. Infants who received early therapy services were more likely to have more days on ventilation ($p = .005$), have single mothers ($p = .047$), and exhibit abnormal neurobehavior at term equivalent age ($p = .03$). On average, infants first received occupational therapy at a mean age of 5.1 ± 4.6 months with a median of 2.6 (1.3–9.0), physical therapy at a mean age of 4.3 ± 4.1 months with a median of 3.7 (0.1–5.5), and speech-language pathology services at a mean age of 14.0 ± 6.1 months with a median of 15.0 (11.3–17.7) months corrected age. Of the 13 children who did not receive any therapy in the first two years after NICU discharge, seven (53%) had a developmental delay at an age of two years.

Conclusions—In spite of high referral rates for therapy services, there is a delay in therapy activation following NICU discharge, and some infants who warrant services do not obtain them.

Keywords

Developmental delay; early intervention; occupational therapy; physical therapy; prematurity; speech language pathology

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Declaration of Interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

Introduction

One in nine infants is born prematurely in the United States each year (Center for Disease Control and Prevention (CDC), 2014). Preterm infants have a high risk of medical complications, including respiratory distress, sepsis, and gastrointestinal problems (Butler&Behrman, 2007; CDC, 2014). In addition, preterm infants have a heightened risk of developmental delays, including motor, cognitive, and language difficulties as well as psychiatric, behavioral, and learning problems later in life (Bruder, 2010). Subsequently, preterm infants are often referred for early therapy services after discharge from the neonatal intensive care unit (NICU) (Curry et al., 2012).

Preterm infants can receive therapy services after NICU discharge through various delivery models, including early intervention and outpatient therapy. Therapy services provided by early intervention, a federally mandated program, are for children at risk of developmental delay and are often conducted in the infant's home (U.S. Department of Education, 2007). Health care professionals, teachers, or parents can be referral sources for early intervention programs. Outpatient therapy services are usually based on a medical model. Physicians are the referral sources for outpatient therapy services. Therapy programming can include occupational therapy (OT), physical therapy (PT), and/or speech-language pathology (SLP).

Early intervention and therapy programs are beneficial for improving developmental outcomes in children born prematurely (Cameron et al., 2005). Therapy programming is related to improved developmental, behavioral, psychosocial, and cognitive outcomes (IHDP, 1990; Kaaresen et al., 2008; Koldewijn et al., 2009; Nordhov et al., 2010; Spittle et al., 2010; Verkerk et al., 2011). In addition, improved cognitive and motor functions have been observed in children receiving OT, PT, and SLP (Blauw-Hospers et al., 2011; Lekskulchai & Cole, 2001; McManus et al., 2012).

In spite of the mandate of early intervention services for high-risk children under IDEA Part C and evidence supporting the use of therapy services, low rates of early therapy utilization have been reported, and many preterm infants are delayed in receiving therapy during early childhood (McManus et al., 2012). Barriers for accessing early therapy services include low income, low maternal education and single family households (McManus et al., 2013). Caucasian children are five times more likely to access early intervention services than African-American children (Feinberg et al., 2012). Some studies have shown that children with Medicaid are less likely to access early intervention and early therapy services (Barfield et al., 2008; Rosenberg et al., 2008); while other studies suggest that children with public insurance, or specifically Medicaid, are more likely to enroll in therapy services than children with private insurance (McManus et al., 2013; Shapiro-Mendoza et al., 2013). Low referral rates, lack of family follow through, and stigma associated with utilizing services are also suggested to be the factors influencing under-enrollment for services for extremely low birth weight children (Wang et al., 2009). However, patterns of early therapy utilization and barriers to services are not well understood. By understanding gaps in services and factors related to accessing therapy, interventions and policies can be implemented to improve service utilization for high-risk infants. The aims of this study were two-fold: To (1)

characterize early therapy services in the first two years of life following NICU discharge, and (2) define factors related to accessing early therapy services among preterm infants.

Methods

Design and Study Site

This study was approved by the Human Research Protection Office at Washington University in St. Louis, and informed consent was obtained from the parents of all preterm infants enrolled in the study. This study used data from a preterm infant cohort that was prospectively enrolled to understand early brain development in NICU. Consecutively admitted infants in the level III–IV NICU at St. Louis Children’s Hospital in St. Louis, Missouri from 2007–2010 were recruited. Medical factors and socio-demographics were collected from the electronic medical record, and a parental questionnaire was administered at NICU discharge. At term equivalent age, neurobehavioral testing was administered at the bedside in NICU, and infants underwent magnetic resonance imaging (MRI). Naturally occurring therapy utilization was retrospectively tracked across the first two years of life through outpatient therapy medical records and the state-run early intervention provider billing documentation. At two years of age, infants returned for developmental testing.

Subjects

Inclusion criteria for the original study included infants born ≥30 weeks estimated gestational age (EGA) and free of congenital anomalies. Additional exclusion criteria for this study included residence outside of Missouri and failing to return for developmental testing at the age of two years. As St. Louis borders the state of Illinois, infants who resided in Illinois were excluded due to differences in the provision of early intervention services between Missouri and Illinois. One hundred and thirty-six infants were enrolled. Twenty infants expired during NICU hospitalization, one was later excluded due to a congenital anomaly, one was transferred to another hospital, and seven withdrew from the study leaving 107 participants at NICU discharge. Following discharge, one infant withdrew and two expired, leaving 104 eligible participants. Of those, 86 (83% of the surviving cohort) returned for developmental follow-up testing. Of these, 57 (66% of those returning for follow-up) met the other inclusion criteria of being a Missouri resident and were included in this retrospective analysis. There were 29 infants who were part of the original cohort who were excluded due to being an Illinois resident. There were no differences in key perinatal factors, such as EGA at birth and cerebral injury, among those included and excluded from the cohort.

Variables

Early Therapy Utilization

Infants received standard care in the study site NICU, which included routine NICU-based therapy services starting at 30 weeks postmenstrual age. Neonatal therapists conducted parent education, in which they discussed the infant’s strengths and weaknesses as well as recommendations for therapy at discharge. In addition, the discharge process included a referral and a written script for therapy, when appropriate, based on the decision of the

medical team. Naturally occurring therapy utilization was tracked using the therapy records from the NICU discharge hospital, which provides outpatient therapy services to high-risk infants, and from the billing records of First Steps, Missouri's early intervention provider. Dates of evaluation, the Individualized Family Service Plan (IFSP), and therapy sessions were differentiated in the data obtained.

In Missouri, the requirement for eligibility for early intervention services for the newborn population is that children are born less than 1,500 g and have one of the following additional conditions diagnosed within 30 days of birth: APGAR score of 6 or less at 5 min, intraventricular hemorrhage (grade II, III, or IV), any positive pressure ventilation greater than 48 h, or resuscitation/code-event requiring chest compressions. Almost all ($n = 56$; 98%) of the infants in the cohort qualified for early intervention services based on the established criteria.

Information from outpatient and early intervention providers was compiled together, cross checked, and included: (1) the age of initial OT, PT, and SLP activation (corrected age in months), (2) duration of services (in weeks), (3) frequency of services (days per week), and (4) total hours of therapy received. The age of the IFSP was also documented.

Neurobehavioral Assessment at Term Equivalent

Neurobehavioral testing prior to NICU discharge was conducted to identify abnormal behavior. At term equivalent age, a single certified examiner administered the NICU Network Neurobehavioral Scale (NNNS) at the infant's bedside. The process of certification entails a check of reliability on the NNNS. The NNNS is a newborn assessment designed to examine the neurobehavioral organization, neurologic reflexes, motor development, tone, and stress signs of high risk infants, including premature infants (Lester & Tronick, 2004). The NNNS takes 20–30 min to administer, and it yields the following 13 subscales: habituation, attention, handling, arousal, self regulation, quality of movement, excitability, lethargy, asymmetrical responses, hypertonicity, hypotonicity, stress/abstinence signs, and non-optimal reflexes (Lester & Tronick, 2004). The NNNS summary scores were used in this study to determine abnormal behavior prior to NICU discharge. If an infant had three or more summary scores that were 2 standard deviations (SD) outside the published norms for full term infants, he/she was labeled as having abnormal behavior at NICU discharge (Lester & Tronick, 2004). The NNNS scores were not routinely communicated to therapy providers at discharge.

Medical Factors

Medical factors during the infant's NICU hospitalization were collected from the electronic medical record, and included: EGA, birth weight, necrotizing enterocolitis (all stages), patent ductus arteriosus, days on ventilation, postmenstrual age (PMA) at discharge, and brain injury. Routine cranial ultrasound and MRI at term equivalent age were used to determine brain injury. A trained neuroradiologist interpreted and scored images to determine the absence or presence of brain injury. Brain injury was defined as the presence of grade III or IV intraventricular hemorrhage (IVH), cystic periventricular leukomalacia (PVL), and/or cerebellar hemorrhage.

Socio-Demographic Factors

Socio-demographic factors that were collected from the medical records were the infant's gender and race (Caucasian or not Caucasian), maternal marital status (single or married), and insurance type (public or private). Insurance type was used as a proxy for socioeconomic status. Maternal education (college education or no college education) was obtained from a questionnaire that the mother completed prior to discharge from the NICU.

Developmental Testing at Age of Two Years

Developmental testing was conducted at two years of age using the Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-III). The Bayley-III was designed for children aged 1–42 months, and is considered the gold standard for assessing the developmental function of infants and toddlers (Bayley, 2006a). The Bayley-III has test–retest reliability ranging from 0.86–0.98 and an internal consistency for the subtests ranging from 0.86–0.93 (Bayley, 2006b). Concurrent validity between the second and the third editions of the Bayley in language, motor, and cognitive composite scores has been reported ($r = 0.47, 0.60, \text{ and } 0.60$ respectively) (Bayley, 2006b). A trained psychometrician administered, scored, and interpreted the Bayley-III for all study participants. The examiner was blinded to what therapy the infant had received during the first two years of life. The language, motor, and cognitive composite scores were used to investigate associations with early therapy utilization at two years of age. In addition, developmental delay was defined by having one or more composite scores and 1 SD below the norm (<85).

Data Management and Statistical Analysis

All data management and statistical analyses were conducted using IBM Statistical Product and Service Solutions (SPSS) 21 (IBM Corporation, 2012) under the supervision of a biostatistician. Descriptive statistics were used to report the utilization of early therapy services. The relationships of medical factors, socio-demographic factors, and developmental scores with early therapy utilization were investigated using independent samples t -tests and chi-square analyses. All analyses were run using $\alpha = 0.05$.

Results

Sample descriptives and their relationships to early therapy utilization are summarized in Table 1.

Early Therapy Utilization

Early therapy characteristics are summarized in Table 2. Of the 57 infants, 52 (91%) infants received referrals for early therapy services at NICU discharge. Forty-four (77%) received therapy services in the first two years of life, leaving 13 (23%) participants with no documented therapy services within the first two years of life. Of the 57 infants in the cohort, 26 (46%), 41 (72%), and 23 (40%) participants received OT, PT, and SLP services, respectively. Thirty-six (63%) participants had developmental delay at the age of two years. Of the 13 participants who did not receive therapy after NICU discharge, 11 (85%) received

a referral at NICU discharge, eight (62%) already had abnormal behaviors at NICU discharge, and seven (54%) had a developmental delay at the age of two years.

Among those who received therapy in the first two years of life, on average, infants first received OT, PT, and SLP at 5.1 ± 4.6 , 4.3 ± 4.1 , and 14.0 ± 6.1 months corrected age respectively. The median age of therapy activation was 2.6 (1.3–9.0), 3.7 (0.1–5.5), and 15.0 (11.3–17.7) months corrected age for OT, PT, and SLP respectively. Among the 26 participants who received OT, 10 (39%) participants started receiving OT by two months of age, 16 (62%) participants started receiving OT by six months of age, and 23 (89%) participants started receiving therapy by 12 months of age. Among the 41 participants who received PT, 16 (39%) participants started receiving PT by two months of age, 28 (68%) participants started receiving PT by six months of age, and 39 (95%) participants started receiving PT by 12 months of age. Among the 23 participants who received SLP, one (4%) participant started receiving SLP by two months of age, four (17%) participants started receiving SLP by six months of age and seven (30%) participants started receiving SLP by 12 months of age.

Of the 44 participants who received OT, PT, and/or SLP services, 12 (27%) received only one type of therapy service, 17 (39%) received two types of therapy services, and 15 (34%) received all three types of therapy services.

Of the 43 infants who received therapy through early intervention, documentation of the initial IFSP was available on 17 (39%) of the cohort. Among the 17 initial IFSPs that were documented, 12 (71%) had therapy initiated within two weeks of the IFSP date, three (18%) had therapy initiated within two to four weeks of the IFSP date, and two (12%) had therapy initiated at more than one month after the IFSP date.

Of the 26 children who received OT services, 18 (69%), 1 (4%), and 7 (27%) participants received OT services at home only through early intervention, outpatient only, or at more than one location (early intervention and outpatient) respectively. Of the 41 children who received PT services, 31 (76%), 1 (2%), and 9 (22%) participants received PT services at home only through early intervention, outpatient only, or at more than one location respectively. Of the 23 children who received SLP services, 17 (74%), 0 (0%), and 6 (26%) participants received SLP services at home only through early intervention, outpatient only, or at more than one location respectively.

Of the 57 children in this study, 26 (46%) children received special instruction through early intervention and 31 (54%) children did not receive special instruction. Of the 13 children who did not receive OT, PT, or SLP services, four (31%) received special instruction.

Among the entire sample, there were 18 participants (32%) with a cognitive or motor developmental delay who received OT services. There were 23 (40%) participants with cognitive or motor delay who received PT services. There were 15 (26%) participants with a language delay who received SLP services.

Predictors of Early Therapy Service Utilization

Infants who had more days on ventilation were more likely to receive any therapy services in the first two years of life ($p = .005$). Infants who received any early therapy services were more likely to have abnormal behavior at term-equivalent age ($p = .03$) and were more likely to have mothers who were single ($p = .047$). In addition, children who activated SLP services were more likely to have lower language ($p < .001$) and cognitive scores ($p < .001$) on the Bayley-III scale. There were no other medical or socio-demographic factors that were related to early therapy utilization in the first two years. Predictors of use of early therapy services are summarized in Table 1.

Discussion

The key findings of this study disclose a significant issue in the provision of therapy services to at-risk infants with the following findings: (1) Only approximately three-fourths of infants at risk received therapy services in the first two years of life; (2) there was lack of utilization of therapy in the first two years among participants with a defined delay at two years of age; (3) participants initiated PT services earlier and more often than OT and SLP services; and (4) therapy utilization in the first two years after NICU discharge was more common in infants who were ventilated longer, had abnormal behavior at NICU discharge, and had single mothers.

In Missouri, weighing 1,500 g at birth and having either a low APGAR, brain injury, prolonged respiratory distress, or need for resuscitation are the criteria for eligibility for early intervention, which includes early therapy services (Nicastro, 2013). In spite of almost all of the infants in the cohort being referred to early therapy services, nearly a quarter of this sample never activated therapy services in the first two years following NICU discharge. Reasons for low enrollment were not identified in this study but are likely multifactorial and could include lack of parental education and preparedness for post-discharge therapy services (Griffin & Abraham, 2006; Sneath, 2009). While the study site took great effort to provide a therapy script and educate parents prior to discharge, improved programming about transition from NICU therapy services to outside therapy services in a fashion that can be understood and implemented by parents, who have many stressors, is warranted.

A delay in therapy activation across all three disciplines was evident and appears to be timed with when components of functional delay are evident. Physical therapy was the earliest therapy initiated and the most utilized of the three therapy services. However, the average time for PT activation, in spite of referral among most infants at NICU discharge, was four months corrected age. Although gross motor delays are common in preterm infants (Cameron et al., 2005), the lack of progression of gross motor skills becomes evident around four months of age when infants are expected to hold their head upright, prop on elbows, and initiate rolling (Bayley, 2006a). In this cohort, it appears that the mean age of PT activation occurred at a time when gross motor delays may be more apparent to parents. The average age of OT activation was five months of age. Similarly, fine and gross motor delays, as well as problems with self-regulation and behavior, which are problems occupational therapists traditionally address, may be more apparent to parents at five months of age. Finally, the average age of SLP activation was 14 months, an age that parents may be more

aware of poorly progressing language skills. However, there are standardized assessments and trained clinicians who are skilled at evaluating and treating infants at birth. By extending services earlier, it is plausible that more marked improvements in optimizing outcomes can be made. In addition, the use of neonatal therapists in the NICU is increasing (Sturdivant, 2013). At the study site, a dynamic team of OTs, PTs, and SLPs provided services to the infants daily during hospitalization. However, the infants in this cohort did not continue to receive this level of intervention for at least several months following NICU discharge. The gap in provision of therapy services between NICU discharge and when therapy was activated occurred at a critical period of development when foundational skills are setting the stage for an optimal developmental trajectory.

Factors related to early therapy utilization could aid our understanding of groups that may need more supports as well as potential interventions that may improve timely and consistent therapy services following discharge. Preterm infants with abnormal behavior, using standardized neurobehavioral assessment, at term-equivalent age were more likely to receive therapy services compared with those without abnormal behavior. This finding suggests that neurobehavioral testing can be an important tool for detecting infants with altered developmental pathways at NICU discharge to inform targeted interventions at home. Preterm infants who were on the ventilator for longer were more likely to access therapy services compared with those on shorter periods of ventilation. This finding suggests that sicker infants may have easier access to therapy services, whereas infants who are more medically stable, although still having high rates of developmental problems, may be more likely to have difficulties accessing therapy. Mothers who were single were more likely to enroll their children in early therapy services; this is inconsistent with the existing literature stating that single mothers have limited access to early therapy services (McManus et al., 2013). The reasons for this finding are unclear; however, it is possible that better surveillance and support are given to mothers with fewer resources, including those who do not have the social support of a partner, making this group more likely to access services in the first two years of life.

While this study defined predictors of poor therapy utilization in a high-risk group of infants following NICU discharge, it is imperative that the gaps in services are addressed to enable better utilization and continuity of services that are aimed at optimizing outcomes of this vulnerable population. Such programming must aim to enable a smoother transition of services from NICU to home by decreasing the burden of lack of accessibility on parents, promote better early identification and targeted interventions, educate non-trained therapists and parents on early programming as well as build the evidence to support the use of early programming on promoting better outcomes of preterm infants following NICU discharge.

The original intention of this study was to define the relationships between early therapy usage and developmental outcomes; however, this was a difficult relationship to untangle. Infants/children with more impairment were likely to receive more therapy services. In addition, there were likely naturally occurring barriers to therapy, such as education and family resources, that could affect therapy usage in addition to impacting developmental outcomes. In addition, the quality of early therapy is likely important but was unable to be documented/quantified. Finally, there were different pathways of early therapy utilization,

with very few infants receiving continuous therapy from discharge until two years of age. Some had large breaks in therapy services, others had lower frequency but more continuous therapy services, and still others had combinations of different therapies across different time periods. Future research can better untangle the relationships between early therapy and outcome by comparing standard of care (what therapy happens based on the current system) to consistent, quality, and timely intervention during vulnerable periods of development. In addition, the preference of therapy provider was the state-run early intervention provider, and most infants received services through early intervention. More research is needed to understand the effect of different models of care in terms of both ability to provide consistent services and quality of therapy.

Limitations of this study include it being an observational study with a small sample size. This urban St. Louis cohort was diverse with a large number of infants of low socioeconomic status. In addition, this study was conducted in Missouri, where service eligibility and criteria may differ from other states. Thus, these findings may not generalize to all children aged zero to three years across the United States. There is a possibility that the participants received services at other locations that could not be accounted for in the comprehensive review of medical records within the hospital system that treated the infant and the statewide early intervention system. However, infants with a high likelihood of receiving services from other sources, i.e. children residing outside of Missouri, were excluded. Finally, this was a retrospective review of therapy utilization that relied on accurate documentation.

Conclusions

In this study, the researchers characterized early therapy utilization patterns and defined factors related to accessing early therapy services. There were gaps in early therapy services following NICU discharge in preterm infants who have high rates of developmental challenges. Therefore, improving programs to ensure early and continuous care following NICU discharge should be made a priority.

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Table 1

Sample descriptives and relationships with therapy utilization.

	Whole sample	Did not receive any therapy*	Did receive therapy	
	Mean (SD); median (IQ); N (%) (N = 57)	Mean (SD); median (IQ); N (%) (N = 13)	Mean (SD); median (IQ); N (%) (N = 44)	p value**
<i>Medical factors</i>				
—EGA (in weeks)	26.8 (±1.7)	27.5 (±1.1)	26.6 (±1.8)	.06
—Birth weight (in g)	959.8 (±267.4)	958.9 (±244.7)	960.1 (±276.4)	.98
—Necrotizing enterocolitis (NEC)	3 (5.3%)	1 (7.7%)	1 (2.3%)	.30
—Patent ductus arteriosus (PDA)	29 (50.9%)	5 (38.5%)	24 (54.6%)	.30
—Brain injury (moderate/severe)	9 (15.8%)	0 (0%)	9 (100.0%)	.08
—Abnormal behavior	23 (40.4%)	5 (38.5%)	18 (40.9%)	.03
—Days on ventilation	2.0 (1.0–12.5)	1.0 (1.0–2.0)	3.0 (1.0–23.3)	.005
—PMA (in weeks)	39.6 (±3.8)	38.8 (±3.1)	39.8 (±4.0)	.37
<i>Socio-demographic factors</i>				
—Gender (male)	26 (45.6%)	3 (23.1%)	23 (52.3%)	.06
—Race (Caucasian)	32 (56.1%)	7 (53.9%)	18 (40.1%)	.40
—Marital status (single)	40 (70.2%)	12 (92.3%)	28 (63.6%)	.047
—Maternal education (some college)	17 (29.8%)	4 (33.3%)	13 (29.6%)	.93
—Insurance (public)	36 (63.2%)	10 (76.9%)	26 (59.1%)	.24
<i>Developmental performance</i>				
—Developmental delay	36 (63.2%)	7 (53.9%)	29 (65.9%)	.42
—Bayley-III cognitive	85.1 (±9.7)	87.3 (±8.3)	84.4 (±10.1)	.35
—Bayley-III language	87.7 (±11.3)	92.4 (±9.5)	86.3 (±1.5)	.08
—Bayley-III motor	84.4 (±11.2)	87.3 (±8.3)	81.0 (±11.6)	.07

* Any therapy is defined as any PT, OT, and/or SLP in the first two years of life following NICU discharge.

** *p* value for independent samples *t*-test and chi-square analyses investigating associations between medical factors, socio-demographic factors, and developmental outcomes with early therapy utilization.

Table 2

Early therapy utilization.

Early therapy service	Age at therapy activation (months)		Age of therapy activation (months)		Duration (weeks)		Frequency (days/week)		Hours	
	Range	Mean (SD)	Median (IQ)	Mean (±SD)	Mean (±SD)	Mean (±SD)	Mean (±SD)	Mean (±SD)	Mean (±SD)	Mean (±SD)
OT	0.4–14.9	5.1 (±4.6)	2.6 (1.3–9.0)	57.8 (±24.0)	0.6 (±0.2)	31.0 (±22.2)				
PT	0–15.2	4.3 (±4.1)	3.7 (0.1–5.5)	61.3 (±23.0)	0.6 (±0.4)	33.3 (±29.6)				
SLP	1.9–21.6	14.0 (±6.1)	15.0 (11.3–17.7)	33.0 (±22.6)	0.5 (±0.3)	13.3 (±13.4)				

Note. All months relate to corrected age.