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Implications of a NICU Perinatal Follow Through Program for the Primary Care Physician

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Perinatal follow through: Implications for primary physicians

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Neonatal intensive care unit follow-through programs provide early evaluation information for the primary care physician. This article describes such data for 339 graduates of St Joseph's Special Care Nursery, 78% of whom were preterm and 70% were of low birth weight. At six months, 7% of the infants were diagnosed with cerebral palsy, based on a 15-month follow-up. Other neurological and respiratory problems were common. A normal neurodevelopmental outcome was found for the majority of the infants. Referrals to medical specialists (eg, ophthalmology) and early intervention programs were required for many infants. The case management role of the primary physician is highlighted along with specific recommendations for care of the medically at-risk or developmentally delayed infant. *Wis Med J* 1990;89(3):111-114.

FOLLOW-UP MONITORING clinics have a positive effect on infants served through neonatal intensive care units (NICU).¹ The important role of the primary care physician in following NICU graduates has been described.² The role of the primary care physician in following NICU graduates will be affected by recently enacted legislation, namely, Public Law 99-457, The Education of the Handicapped Act Amendments of 1986. Under the provisions of this law, states are provided funding to develop programs for infants and children from birth to 3 years old with handicapping conditions.

The American Academy of Pediatric's Committee on Children with Disabilities has published a statement regarding the physician's role in this expanded service delivery system.³ One key responsibility is to address the effect of the condition on the child

and family and to act as a family advocate to ensure that the child receives appropriate therapeutic services. To assume this case management role, physicians need to be aware of the array of medical and related difficulties experienced by NICU graduates and the evaluation data available through follow-up monitoring clinics.

Our paper highlights this information base using birth-outcome and follow-through data from St Joseph Hospital's Special Care Nursery and Perinatal Follow-Through Program (PFTP).

Subjects and methods

Our study included 339 neonates (38% girls, 62% boys) admitted to St Joseph's Special Care Nursery from June 1985 to July 1986, and who subsequently enrolled in the PFTP. The racial breakdown was 88% white, 11% black, and 1% Hispanic. Most were born to married parents (78%) of middle socioeconomic levels; 14% had unmarried parents. Enrollment was based on meeting at least one of the criteria shown in Table 1.

Appointments were scheduled at 6, 15, and 30 months (corrected age). Some infants were seen earlier if deemed necessary at the time of discharge from the hospital, and more frequent visits were scheduled if the

evaluations produced questionable findings. During the PFTP appointment, a pediatric nurse practitioner completed a health history and physical exam. The corrected age was used to plot the infant's body measurements on the Babson and Benda Growth Chart for preterm infants. The Denver Developmental Screening Test, a language questionnaire compiled by the pediatric speech therapist, the Denver Eye Screening Test, and the High Risk Register for Hearing Loss were administered. The physical therapist completed a neurodevelopmental assessment using a tool⁴ that combined the Primitive Reflex Profile,⁵ French Angles,⁶ and a method described by Milani-Comparetti and Gidoni.⁷ The preliminary diagnosis of cerebral palsy was based on this latter evaluation.

Table 1. Criteria for enrollment in the perinatal follow-through program

Birth weight less than 1500 grams.
Gestational age less than 32 weeks.
Small for gestational age (below 2nd percentile)
Mechanical ventilation required > 5 days (eg, severe RDS, severe sepsis).
Apgar score < 4 at five minutes.
Seizures.
Meningitis.
Intracranial hemorrhage.
Hydrocephalus.
Abnormal neurologic exam at discharge.
Congenital viral infection.
Congenital anomalies or genetic disease with uncertain prognosis.
Drug withdrawal symptoms/maternal drug abuse (especially cocaine).
Thrombocytopenia/polycythemia.

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Table 2. Birth outcome data for perinatal follow-through program infants

Variable	\bar{x}	SD	n	%
Birth weight (g)	2112	923		
less than 1,500			89	30
1,500-2,499			120	40
2,500 or more			90	30
Gestational age (wk)	33.4	4.6		
36 or less			232	78
37-43			67	22
Apgar score at 1 min	5.7	2.3		
3 or less			63	21
4-6			99	32
7-10			134	45
Apgar score at 5 min	7.7	1.6		
3 or less			10	3
4-6			36	12
7-10			251	85
Birth length (cm)	44.3	6.1		
Head circumference (cm)	30.6	3.6		
Pneumogram result				
normal			69	28
borderline			13	5
abnormal			162	67

At 15 months, the Bayley Scales of Infant Development were administered by an occupational therapist. Near the conclusion of each PFTP evaluation, a neonatologist examined the infant and joined the family and other evaluation team members to discuss the results. Families were provided resources for identified problems. The results of the evaluation were sent to each family's primary care physician along with recommendations for special program referrals when warranted (eg, programs for newborn to 3-year-old children).

The PFTP serves an eight-county area; evaluation services were provided at no cost to the families.

Results

Birth outcomes. Birth outcome data regarding the sample are shown in Table 2; 78% of the sample were preterm, and 70% were of low birth weight. In addition to prematurity, the most common discharge diagnoses

were respiratory distress syndrome, meconium aspiration syndrome, asphyxia, apnea, seizures, and congenital anomalies. Most infants required a home monitor when discharged (69%).

PFTP outcomes. Outcome data obtained through the PFTP are shown in Table 3 for the 6-, 15-, and 30-month visits. At the 6- and 15-month visits, nearly one out of five infants' birth weights were below the second percentile when plotted for corrected age. Regarding the early diagnosis of cerebral palsy, 16 of the 23 infants with positive diagnoses at six months returned for a 15-month visit. Of these, 13 retained the diagnosis (81%); two children were reclassified as equivocal and one as normal (false positives). Two children considered equivocal and one child classified as normal at the six-month visit, were diagnosed as having cerebral palsy at the 15-month visit (false negatives).

Of the 10 hypotonic children who returned for a 15-month visit, seven (70%) retained that diagnosis; three were reclassified as equivocal or normal (false positives). Seventeen children diagnosed as equivocal or normal at the six-month visit, were reclassified as hypotonic at the 15-month visit (false negatives).

The average Bayley Mental Development Index at the 15-month visit was 104 (SD = 22). Infants diagnosed with cerebral palsy at 15 months (n = 18) had the lowest Bayley scores (p < .001) in the sample (\bar{x} = 66; range, 50 to 105); ten had scores in the delayed range, six in the borderline range, and two in the normal range. Children considered hypotonic or equivocal at 15 months had the next lowest Bayley scores (\bar{x} = 87 and \bar{x} = 89, respectively) followed by the "normal" children (\bar{x} = 112). Of the children seen at the 30-month visit (n = 60), the average Bayley score was 114 (SD = 18).

The infants spent an average of 4.8 months on the home monitor (SD = 2.8; range, 1 to 30). Of the 196 infants on monitors, 12 had apparent life-threatening events (ALTES), with ten infants requiring vigorous stimulation when the alarm sounded and two requiring cardiopulmonary resuscitation; only 3% of the parents reported having persistent anxiety over the presence of the monitor in the home, and 5% felt dependent on the monitor when it was discontinued. There were no deaths.

Data on other services provided to the infants are summarized in Table 3. A number of infants (7%) were already enrolled in various early intervention programs (eg, special education, speech, occupational or physical therapy) before their six-month visit. By 15 months, nearly one out of five infants (19%) were either enrolled in or referred for therapy; four infants were discharged from therapy by 15 months. Common reasons for physician visits included upper respiratory infection, otitis media, bronchiolitis, and gastroenteritis.

Discussion

Our data showed that a significant majority of NICU graduates have a normal neurodevelopmental outcome, even those with very low birth weights or very low gestational ages. This is encouraging to parents and professionals in view of the emotional and economic costs involved to achieve these goals. The data also showed, however, that the NICU graduate is at increased risk for growth and neurodevelopmental sequelae. High-risk infant follow-through clinics provide early detection of these handicapping conditions, particularly cerebral palsy. Most level III perinatal centers in Wisconsin are associated with such a clinic.

The data also showed that cerebral palsy was accurately diagnosed in more than 80% of the cases by the six-month visit. These children present dilemmas for the primary care physician. They often have subtle symptoms and may require a detailed, time-consuming neurologic evaluation to elicit findings suggesting emerging neurodevelopmental problems. Timing is important as these children benefit most from early intervention programs the sooner they are enrolled.

Families of NICU graduates require continued care and support as they encounter myriad therapeutic agencies and services. The family's primary care physician is ideally suited to assume a case management role with these families to provide continued medical management of the infant, to support the family through this stressful and often extended experience, and to serve as an advocate to ensure that appropriate therapeutic services are delivered in a timely manner. Armed with the data provided by follow-through clinics and the advice of experienced colleagues,² the primary care physician will be better prepared to fulfill these responsibilities.

Recommendations

The following recommendations apply to the primary care of medic-

Table 3. Perinatal Follow Through Program outcomes at 6, 15 and 30 month visits.

Variable	6 months		15 months		30 months	
	n	%	n	%	n	%
Weight percentile						
16th or less	174	51	124	50	15	25
50th or more	165	49	126	50	45	75
Length percentile						
16th or less	134	39	90	36	21	35
50th or more	205	61	160	64	39	65
Head circumference percentile						
16th or less	86	25	77	31		
50th or more	253	75	173	69		
Diagnosis						
cerebral palsy	23	7	18	8		
hypotonia	18	5	25	10		
equivocal	71	21	25	10		
normal	224	67	173	72		
Bayley Mental Development Index						
normal (85 or more)			208	83	57	95
borderline (69-84)			20	8	2	3
delayed (below 69)			22	9	1	2
Therapy program						
enrolled	25	7	39	16	9	12
referred	19	6	8	3	0	0
none	295	87	199	81	68	88
Number of visits to physician						
none	161	47	41	16	7	12
1-2	134	40	107	43	32	53
3 or more	44	13	101	41	21	35
Specialists						
ophthalmology	55	45	33	32	4	25
neurology	20	16	7	7	1	6
orthopedics	19	15	19	18	2	13
surgery	16	13	11	11	1	6
cardiology	8	7	10	10	3	19
ENT	5	4	23	22	5	31
Number of hospitalizations						
none	270	80	206	83	54	90
1	57	17	30	12	6	10
2 or more	12	3	13	5		

ally at-risk or developmentally delayed infants:

- plot growth at the "corrected age," using the Babson Graph, which is available from infant formula company representatives;
- use "corrected age" when screening infant development;

- coordinate the management of the home apnea monitor using the Perinatal Center Apnea and High Risk Infant Follow-Through programs as resources;
- if multiple specialists are involved, coordinate and interpret findings for the parents;

- become familiar with the therapeutic and educational resources in your community (eg, birth to three programs) and refer patients to these programs as soon as problems are identified or suspected; use these programs as resources for the more detailed and time-consuming developmental evaluations; and maintain open lines of communication with these programs, share pertinent medical information, and request that the child's goals, plans, and reports be sent to you; and
- ask families for an assessment of their situation and what they see as their greatest needs. Public Law 99-457 emphasizes the family's role in problem identification and decision making related to services for their children.

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