Discharge of Medically Complex Infants and Developmental Follow-Up

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Learning Objectives

Upon completion of this article, readers should be able to:

• Identify commonly encountered morbidities in preterm and term infants discharged from the neonatal intensive care unit

• Recognize that the discharge planning process begins early during the NICU hospitalization

• Describe the need for coordinated and comprehensive post-discharge care of infants with multiple medical problems.

• Develop discharge plans that are individually tailored to each infant based on his or her comorbidities, need for technology support outside the NICU and risk of future illness or impairment

• Identify infants who may be at risk for neurodevelopmental delays and impairment and who may benefit from neurodevelopmental follow-up and early intervention services
Scope of the Issue

• Survival of preterm and critically ill infants has increased over time
  • Improvements in maternal and neonatal care
  • Increased availability of advanced technologies in the NICU

• More infants are being discharged from the NICU with unresolved and active medical issues that require ongoing multidisciplinary care

• Some infants with medical complexity are dependent on technology at NICU discharge

• Primary care physician plays critical role in coordinating care across multiple subspecialties, creating family-centered medical home for the infant with medical complexity
# Infants with Medical Complexity

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- Any congenital or acquired condition or complication that may impact long-term health, function and/or neurodevelopment.
Discharge Planning and Care Transition

• Begins early during NICU hospitalization
  • Assess family’s goals for their infant
• Requires participation from all care team members
• Tailor discharge criteria to each infant
• Contingency planning if/when criteria are not met
Special Circumstances

• Infants discharged from the NICU dependent on technology
  • Pulse oximetry monitoring
  • Oxygen
  • Chronic invasive ventilation via tracheostomy
  • Nasogastric or gastrostomy tube feeding
  • Parenteral nutrition

• Home palliative care
  • Life-limiting disorders: chromosomal abnormalities and genetic syndromes, severe inborn errors of metabolism, CNS malformations, severe HIR
  • Advanced directives, bereavement support
Pulmonary

• Bronchopulmonary Dysplasia
  • One of the most common morbidities in preterm infants
  • Infants with moderate to severe BPD may require prolonged respiratory support
    • Oxygen via nasal cannula, continuous positive airway pressure, chronic invasive ventilation via tracheostomy
  • Treated with diuretics, inhaled steroids and bronchodilators
  • Complications: Pulmonary hypertension, pulmonary vein stenosis, growth failure from increased metabolic demand, developmental delay and neurodevelopmental impairment
  • Coordinated care in BPD clinic, if available (Neonatology, Pulmonology, Cardiology, ORL)
Pulmonary

• Other pulmonary disorders requiring coordinated care after NICU discharge
  • Meconium Aspiration Syndrome with Persistent Pulmonary Hypertension of the Newborn
  • Congenital lung anomalies (i.e. Congenital Diaphragmatic Hernia)
  • Infants who required extracorporeal membrane oxygenation (ECMO)
    • Higher risk of poor oral feeding, neurologic complications, developmental delay and long-term neurodevelopmental impairment
Cardiovascular

• Congenital Heart Disease
  • ASD, VSD, PDA: close follow-up based on defect size, location and direction of shunt; monitor for heart failure symptoms and determine need/timing of surgical closure
    • Close follow-up after transcatheter PDA closure, endocarditis prophylaxis 6mo post-procedure
  • May require supplemental oxygen, pulse oximetry monitoring, tube feeding after discharge
  • Complex Critical CHD: coordinated follow up with Cardiology, Cardiothoracic Surgery and neurodevelopmental specialists
    • Infants who require early surgical repair or palliation with cardiopulmonary bypass are at even higher risk for developmental delay and neurodevelopmental impairment

• Hypertension: Multifactorial etiology
  • BP monitoring at all well-child visits, need infant-sized cuffs
Feeding and Nutrition

• Mother’s own breast milk is optimal nutrition for most infants
  • Exceptions include some inborn errors of metabolism (i.e. galactosemia)

• Preterm infants with appropriate growth who feed >180 ml/kg/d may not require fortification of breast milk with transitional formula
  • Infants with growth restriction, metabolic bone disease or intake < 170ml/kg/d should receive fortification or supplementation (22 to 26 kcal/oz) for 12 weeks past term age
    • On-demand breastfeeding with one to two formula feeds per day
    • Transitional formula powder added directly to expressed breast milk

• Preterm infants with decreased feeding efficiency/endurance may not be able to feed to empty breast until 4-6 weeks after discharge
  • Mother should continue to pump after breastfeeding to maintain adequate supply
Metabolic Bone Disease

• Osteopenia due to prematurity
  • Decreased calcium and phosphorus accrual in utero (majority occurs during 3rd trimester)

• Reduced incidence and severity with fortification of breast milk

• Serial monitoring of serum calcium, phosphorus and alkaline phosphatase
  • 2 weeks after discharge if infant feeding unfortified breast milk or standard infant formula
  • Alkaline Phosphatase > 800 IU/L: begin transitional formula supplementation, > 1000 IU/L: begin calcium and phosphorus supplements

• Minimum Vitamin D supplementation for VLBW infants: 400 IU per day
Tube Feeding and Parenteral Nutrition

• Post-discharge Tube Feeding
  • Infants with poor feeding efficiency/endurance, increased metabolic demand, neurologic impairment or congenital anomalies
  • 2-3mo trial of supplemental nasogastric feeds if full oral feeds anticipated
  • Gastrostomy tube placement prior to NICU discharge or if trial of nasogastric feeds fail

• Intestinal Failure: Short Gut Syndrome due to necrotizing enterocolitis or congenital GI anomalies; malabsorptive syndromes
  • Inpatient intestinal rehabilitation vs home parenteral nutrition
    • Extensive parental teaching/training, central line care, home nursing
  • Coordinated follow-up with gastroenterologist, nutritionist, PN pharmacist
Renal

• Acute Kidney Injury (AKI)
  • Increasingly recognized as common in preterm and critically ill infants in NICU
  • Associated with poor long-term health outcomes
    • Chronic kidney disease in childhood/adolescence
    • Hypertension
  • BP monitoring at all well-child visits, need infant-sized cuffs

• Congenital renal and urologic anomalies require coordinated follow-up after NICU discharge with pediatric nephrology and urology
Hematologic

• Anemia of Prematurity
  • Due to shortened red blood cell lifespan, blunted erythropoietin response, decreased iron stores, iatrogenic blood loss from phlebotomy
  • Physiologic nadir occurs earlier and is more severe in preterm infants
  • Preterm infants should receive at least 2mg/kg of ferrous sulfate until 12mo
    • Breastfed infants may require more
  • Serial hematocrit monitoring for infants with low pre-discharge hematocrit, history of multiple packed red blood cell transfusions or slow weight gain
Infectious Disease

• Timely vaccination critical for infants with medical complexity to prevent vaccine-preventable illnesses
  • Follow CDC guidelines schedule based on chronologic age (regardless of gestational age at birth)

• Respiratory Syncytial Virus prophylaxis for high-risk infants
  • Prematurity, chronic lung disease, congenital heart disease, neuromuscular disorders, immunodeficiency
  • Must be cognizant that infants discharged during late spring and summer will be candidates for prophylaxis during up-coming RSV season

• Infants with history of recurrent infections, immunodeficiency, perinatal HIV, Hepatitis B or C exposure may require close follow-up after NICU discharge
Ophthalmologic

• Retinopathy of Prematurity: Abnormal growth of retinal vasculature, may lead to retinal detachment and blindness
  • High-risk infants born < 31 weeks or < 1500g are screened by pediatric retina specialists until retina is fully vascularized (often occurs after NICU discharge)

• Preterm infants at higher risk for myopia, amblyopia and strabismus later in infancy/childhood, require close ophthalmologic follow-up

• Other eye issues requiring close follow-up: congenital eye disorders (glaucoma, cataracts), systemic illness with eye involvement (TORCH infection)
Neurologic - Intracranial Hemorrhage

• Intraventricular Hemorrhage: More common in preterm infants
  • Serial cranial ultrasounds from first days of life through term-equivalent
  • Associated with developmental delay, neurodevelopmental impairment (cerebral palsy)
    • Highest risk with Grade IV (intraparenchymal) hemorrhage and periventricular leukomalacia

• Subdural and subarachnoid hemorrhages: Often asymptomatic or incidental finding
  • Severe catastrophic hemorrhages associated with poor long-term outcomes

• Neonatal Stroke: Cerebral arterial infarction or sinovenous thrombosis
  • Increased risk for developmental delay, neurodevelopmental impairment (cerebral palsy, focal neurologic deficits)
Neurologic - Hydrocephalus

• Congenital (aqueductal stenosis) vs Acquired (post-hemorrhagic, post-infectious)

• Severe or rapidly progressive hydrocephalus requires CSF diversion to mitigate permanent parenchymal injury
  • Ventriculo-peritoneal, ventriculo-atrial, ventriculo-pleural, ventriculo-subgaleal shunts
  • Temporary vascular access device or reservoir in infants too small for definitive shunting

• Risk of shunt complications (infection, malfunction, need for revision) and poor neurodevelopmental outcomes
Neurologic - Immaturity

- Apnea of Prematurity: CNS respiratory immaturity leading to pauses in spontaneous respiration
  - May also have component of airway obstruction
  - Associated with oxygen desaturation and/or bradycardia
- Typically resolves by 37 weeks’ PMA but persists longer in extremely preterm infants and those with BPD
- Often used as discharge criteria (no apneic, bradycardic or desaturation events for 5-7 days), frequently delays discharge
  - Some infants discharge with home pulse oximetry monitoring or caffeine treatment but no evidence-based guidelines for duration or weaning criteria
  - No evidence for improved outcomes with home monitoring
Neurologic

• Infants with neurologic conditions or complications require close coordinated follow up with pediatric neurology and neurodevelopmental specialists
  • Seizures are common presenting sign of underlying CNS or systemic disorders, often treated with antiepileptic medication beyond NICU discharge
    • Require close monitoring of drug levels and adverse drug effects
  • Specialized clinics for infants with myelomeningocele, neuromuscular disorders provide coordinated, comprehensive care from multiple pediatric subspecialties in one location
Neurodevelopmental Assessment

• Infants with medical complexity at higher risk for developmental delay and neurodevelopmental impairment
  • Require close coordinated follow-up, serial assessments, physical, occupational, speech and feeding therapy, if indicated, to optimize outcomes and function

• Assessment prior to NICU discharge to identify infants at highest risk for impairment, assist in discussing long-term prognosis
  • Brain Magnetic Resonance Imaging: detection of more subtle findings not visible on cranial ultrasound
    • Diffuse PVL, ischemic injury, cerebellar hemorrhage, brain atrophy
  • General Movements Assessment: clinical assessment performed serially, highly sensitive and specific for predicting spastic cerebral palsy
Neurodevelopmental Follow-Up

• Routine surveillance at well child visits, formal assessment at 9, 18 and 30mo with PCP
  • High-risk infants should be referred for Early Intervention services at discharge, followed by a neurodevelopmental specialist within 3-4mo of NICU discharge and have more frequent serial assessments

• Monitor for developmental delay in all domains; motor, coordination or tone abnormalities; cerebral palsy; vision and hearing deficits, cognitive impairment; problems with sensory processing, communication and behavior

• Infants with medical complexity have higher risk for autism and ADHD
  • Autism screening at 18 and 24mo
  • ADHD screening at 4y
References

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