

Position Statement #3040

Prevention of Bilirubin Encephalopathy and Kernicterus in Newborns

The National Association of Neonatal Nurses (NANN) believes neonatal nurses must be proactive in the assessment and management of hyperbilirubinemia in the newborn. NANN also believes parents should be educated about the risks of untreated hyperbilirubinemia and the need for close follow-up of their infant(s) after discharge. NANN further believes neonatal nurses must take steps to increase awareness and identify strategies within their institutions and practice to enhance the process(es) of diagnosis and management of hyperbilirubinemia.

Kernicterus

Kernicterus is an entirely preventable, yet devastating neurologic syndrome with life long complications. It is caused by severe and inadequately treated hyperbilirubinemia during the neonatal period. Kernicterus is a post mortem pathologic disease finding, but early signs of bilirubin encephalopathy may include extreme jaundice, alterations in level of consciousness (lethargy) and tone (hypotonia and / or hypertonia), abnormal movement, such as arching of the back (opisthotonos) or arching of the neck (retrocollis), poor feeding, and high pitched crying. The long-term sequelae include cerebral palsy, sensorineural hearing loss, gaze paresis, dental dysplasia and mental retardation ⁶ and carries a mortality rate of ~ 10%.

In the 1940-50's, kernicterus was noted as a complication of erythroblastosis fetalis or other forms of hemolytic disease ¹. With the use of Rh immunoglobulin (Rhogam TM, Ortho-Clinical Diagnostics, Inc.; Raritan, New Jersey) as well as the introduction of exchange transfusions and phototherapy, kernicterus all but disappeared in full term babies. In the 1990's, physicians began to debate the need to identify or treat hyperbilirubinemia in full term infants without hemolysis ^{2, 7-9}. Increases in breastfeeding rates (with subsequent ineffective feeding and suboptimal intake) as well as earlier hospital discharges may have contributed to the resurgence of kernicterus ^{5, 10}. Phototherapy and exchange transfusions continue to effectively prevent kernicterus if treatment is timely ⁶. Extreme hyperbilirubinemia is a medical emergency requiring prompt and intensive treatment.

Since kernicterus is not a reportable condition (to the Centers for Disease Control (CDC)) in the United States, its true prevalence is unknown. A volunteer registry at Pennsylvania Hospital in Philadelphia reported there were 90 documented cases in 21 states from 1984-June, 2001 ². NANN strongly supports research to:

- determine current prevalence/incidence of kernicterus,
- determine antecedents of bilirubin encephalopathy (duration, safe vs. unsafe levels)
- determine role of other confounding factors, such as infection, on risk for bilirubin encephalopathy.

Risk Reduction

The American Academy of Pediatrics (AAP) Practice Guidelines for Management of Hyperbilirubinemia in the Healthy Newborn ⁴ provides guidelines for identifying at risk newborns and treatment strategies. These guidelines are currently under revision ¹. In April 2001, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) issued a Sentinel Event Alert regarding kernicterus. Some proposed risk reduction strategies include:

- Pre-discharge bilirubin measurement for all newborns, with standing orders allowing nurses to order total serum bilirubin levels (TSB) or transcutaneous bilirubin levels (TcB) for jaundiced or at-risk newborns.
- An hour-specific, percentile-based nomogram may be used to predict the risk of hyperbilirubinemia in term and near term infants and to guide follow-up ¹⁴ .
- Support for early, frequent and unrestricted breastfeeding with evaluation of feeding technique and adequacy of intake prior to discharge.
- Follow-up for all newborns within 48 hrs after discharge by a nurse or trained health care provider experienced in the care of newborns to provide:
 - follow-up physical assessment and weight check
 - feeding history and on-going lactation support to assure adequacy of intake for breast-fed infants
 - Continued education and support for parents ^{1, 5-6}If timely follow-up cannot be achieved, timing of discharge must be based on risk assessment.
- Providing all parents with adequate educational materials at discharge regarding jaundice, feeding adequacy and symptoms to watch for ^{5, 10-11, 13}.
- Develop a coordinated program to educate all staff that may encounter newborns, including risk factors, identified root causes and early signs of bilirubin encephalopathy ^{12, 15}.
- Assuring adequate equipment--bilirubin lights and blankets, measurement device or lab services for timely TSB test as well as policies and procedures on jaundice management that specifically cover the nurse's role, documentation, charting requirements, and monitoring of jaundice pre-discharge ⁵.

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