Prevention of Acute Bilirubin Encephalopathy and Kernicterus in Newborns

Position Statement
#3049

NANN Board of Directors
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Assessment and management of hyperbilirubinemia in the newborn is critical in order to prevent associated complications, including acute bilirubin encephalopathy (ABE) and bilirubin-related brain damage, or kernicterus.

As the professional voice of neonatal nursing, the National Association of Neonatal Nurses (NANN) recommends the practice of universal screening using total serum bilirubin (TSB) or transcutaneous bilirubin (TcB) measurements, as well as efforts by neonatal nurses to educate parents and identify strategies within their institutions and practices to enhance the processes of diagnosing and managing hyperbilirubinemia.

National Association of Neonatal Nurses

Association Position

Neonatal nurses must be proactive in the assessment and management of hyperbilirubinemia in the newborn, and screening is a key intervention in the prevention of ABE and kernicterus. NANN supports universal screening using TSB or TcB measurements, which help to assess the risk of subsequent severe hyperbilirubinemia. A top priority for neonatal nurses is to provide written and verbal information about newborn jaundice so that all families are educated about this condition. Neonatal nurses must continue to take steps to increase awareness and identify strategies within their institutions and practices to enhance the processes of diagnosing and managing hyperbilirubinemia.

Background and Significance

During the first week after birth, more than 60% of apparently healthy full-term and late-preterm newborns develop hyperbilirubinemia, and most are discharged from their birth hospitals before the usual peak of TSB (age 72–120 hours). Hyperbilirubinemia typically resolves by 7–10 days of age, and the outcome is usually benign. However, approximately 5%–11% of infants will develop severe hyperbilirubinemia, defined as having TSB above the 95th percentile for age in hours, that requires treatment with phototherapy (Bhutani, Johnson, & Keren, 2004; Ebbesen et al., 2005; Manning, Todd, Maxwell, & Platt, 2007). Without appropriate intervention, a progressive increase in hyperbilirubinemia to TSB values greater than 25 or 30 mg/dL (above the 99th percentile for age in hours) places otherwise healthy neonates at risk of kernicterus (Smitherman, Stark, & Bhutani, 2006). In 2002 the National Quality Forum declared kernicterus and TSB concentrations greater than or equal to 30 mg/dL to be "never events," adverse, preventable medical occurrences that should never happen. The relationship between the extremely high levels of hyperbilirubinemia and bilirubin neurotoxicity is not known because routine surveillance is not available. It has been estimated that the risk of kernicterus in infants with TSB greater than 30 mg/dL is about one in seven infants (Ebbesen et al.; Manning et al.).

Neonates at risk for the development of severe hyperbilirubinemia include

- those of 35–36 weeks' gestational age
- those with indications of inadequate breast-feeding or dehydration
- those having siblings who had jaundice
- those having predischarge TSB or TcB in the high-risk zone
- those in whom jaundice was observed in the first 24 hours
- those having isoimmune or other hemolytic disease (e.g., glucose-6-phosphate dehydrogenase [G6PD] deficiency)
- those with significant bruising or cephalhematoma
- those with G6PD deficiency (which may be present in as many as 12.8% of African-American males [Kaplan, Herschel, Hammerman, Hoyer, & Stevenson, 2004])
- those of East Asian or Mediterranean heredity.

The initial neurotoxicity of extremely elevated bilirubin levels results in ABE, which may progress to kernicterus. No evidence exists that neurotoxicity occurs at a specific bilirubin concentration. The critical level in an otherwise healthy neonate is likely influenced by postnatal age, maturity, duration of hyperbilirubinemia, and rate of TSB rise (Bhutani, Johnson, & Keren, 2005). The presenting signs of ABE are subtle and nonspecific and can be discerned by assessing the infant's mental status, muscle tone, and cry. Some signs are feeding difficulties; lethargy, with an altered awake-sleep pattern; irritability, fussiness, being difficult to console; and intermittent arching.

Advanced signs of ABE are cessation of feeding, bicycling movements, inconsolable irritability and shrill crying, seizures, fever, and coma. Long-term morbidity—including choreoathetoid palsy, sensorineural hearing loss, gaze paresis, dental hypoplasia, and cognitive impairment—can result if the elevated bilirubin levels are not reduced during the time when neurotoxicity may be reversible (Johnson, Bhutani, & Brown, 2002; Soorani-Lunsing, Woltil, & Hadders-Algra, 2001).

In 2001, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO, known since 2007 simply as the Joint Commission) issued a sentinel event alert notifying hospitals and healthcare providers that kernicterus threatens otherwise healthy newborns (JCAHO, 2001). A warning on the danger of kernicterus was also issued by the Centers for Disease Control and Prevention (CDC) in 2001, and the National Quality Forum (2002) declared kernicterus and TSB concentrations equal to or greater than 30 mg/dL "never events." In July 2004, the Subcommittee on Hyperbilirubinemia of the American Academy of Pediatrics (AAP) published its clinical practice guideline "Management of Hyperbilirubinemia in the Newborn Infant 35 or More Weeks of Gestation," and a similar guideline was published in 2007 by the Canadian Paediatric Society. In a commentary on and update of AAP's 2004 guideline, Maisels and colleagues recommended universal discharge screening, combined with an assessment of clinical risk factors (of which gestational age and exclusive breast-feeding are the most important) and a targeted follow-up (Maisels et al., 2009).

In 2004 JCAHO released a second sentinel event alert regarding hyperbilirubinemia and the prevention of kernicterus in which it recommended that all hospital and healthcare professionals caring for newborns follow the 2004 AAP clinical guideline (JCAHO, 2004).

Recommendations

NANN supports the recommendations of JCAHO (2004), AAP (2004), the Canadian Paediatric Society (2007), and Maisels and colleagues (2009), the key elements of which are listed below:

1. Successful breastfeeding should be promoted and supported because research shows that frequent breast-feeding (8–12 times per day) decreases the incidence of severe hyperbilirubinemia.

2. Nursery protocols for the identification and evaluation of hyperbilirubinemia should be established.

- Hospitals should adopt facility-wide policies and procedures that maintain an adequate standard of care for all newborns in order to prevent ABE and kernicterus.
- Bilirubin levels should be carefully monitored in infants found to be jaundiced in the first 24 hours of life.
- Jaundice should be assessed regularly at least every 8–12 hours, and nurses should have independent authority to obtain a TSB or TcB level.

3. Education for healthcare providers must emphasize that visual inspection is not reliable as the sole method for assessing jaundice.

4. Bilirubin levels must be interpreted according to the infant's age in hours.

5. Closer surveillance of infants with a gestational age of less than 38 weeks is necessary because of their higher risk for severe hyperbilirubinemia.

6. All infants should be assessed for adequacy of breast-feeding and for the risk of severe hyperbilirubinemia before discharge. Universal discharge screening should be combined with an assessment of clinical risk factors (of which gestational age and exclusive breast-feeding are the most important) and a targeted follow-up.

7. Parents should receive written and verbal information about jaundice.

8. Follow-up care should be based on time of discharge and risk assessment.

9. Phototherapy or exchange transfusions are to be used for treatment when indicated.

- All nurseries should have the equipment to provide intensive phototherapy.
- Breast-feeding should continue if possible for the infant receiving phototherapy or nutritional supplementation.

Conclusions

Neonatal nurses should be knowledgeable about identifying, tracking, and, when necessary, testing and treating infants for severe hyperbilirubinemia in order to prevent ABE and kernicterus. Predischarge measurement of the bilirubin level by TSB or TcB, combined with an assessment of clinical risk factors, should be used to assess for the risk for severe hyperbilirubinemia for all full-term and late-preterm infants discharged from an institution. Nursing leaders can promote patient safety by ensuring that their facility's protocols support nurses in performing a TSB or TcB measurement without an order from a physician or neonatal nurse practitioner. Neonatal nurses should ensure that protocols have been established for the routine assessment of jaundice, reporting

of bilirubin levels according to a newborn's age in hours, and documentation through the use of an hour-specific bilirubin nomogram.

Neonatal nurses should also promote breast-feeding and provide lactation support to mothers and families. Neonatal nurses play a pivotal role in providing discharge instructions to the family. Written and verbal instructions should include basic facts about jaundice, the risk factors for jaundice, the significance of jaundice, instructions on checking for jaundice, information on follow-up appointments, and conditions or changes in the infant about which the family should notify healthcare providers.

Further prospective research is needed to identify the potential long-term outcomes of infants with hyperbilirubinemia and the risk of undertreatment. Optimal breast-feeding is an important preventive strategy for severe hyperbilirubinemia. Neonatal nurse researchers should continue to focus on conducting well-designed studies that produce evidence needed to guide best practice on improving breast-feeding support for mothers.

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