

Commentary

What, how and when should we instruct mothers about neonatal jaundice

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Most parents in affluent countries receive information about neonatal jaundice from instructional pamphlets and/or verbally from nurses before discharge. Predischarge protocols, content and delivery of information for parents, and screening for jaundice vary among hospitals. Newborns are usually screened either visually or with a transcutaneous monitor to estimate the intensity of jaundice. The timing of follow-up is guided by the newborn's clinical status, age at discharge and risk of developing significant hyperbilirubinemia based on an hour-specific bilirubin level [1,2].

The jaundice management system is primarily provider directed and works well in affluent countries resulting in a very low incidence of kernicterus spectrum disorder (KSD) [3]. The incidence of KSD in European countries where population data is available is 1.1 to 1.2 cases per 100,000 live births [4,5]. But KSD still occurs in Western countries. Interviews with parents of affected children reveal that most did not know that jaundice could produce brain injury or when to worry, and few were armed with the knowledge to challenge bad advice from their baby's health provider [6].

The situation is much worse in many low-middle income countries (LMICs) [7], especially those with a high incidence of G6PD deficiency [8]. Post-delivery surveillance is inconsistent, amplified by poorly trained community workers, low knowledge of jaundice and its risks among mothers, early discharge, and out-of-hospital births, all contributing to delayed recognition and care-seeking for jaundice. Although population-based data on the incidence of KSD in LMICs is lacking [9], testimony to the magnitude of the problem is a multi-center 15.3% incidence of acute bilirubin encephalopathy (ABE) observed in 800 serial admissions for jaundice [10].

The majority of babies with irreversible bilirubin encephalopathy are already affected when admitted to institutions capable of treating severe hyperbilirubinemia. Thus, timely care-seeking and effective treatment are critical

More Information

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irrespective of the cause of jaundice. Multiple barriers to timely care have been well documented in LMICs and apply to affluent countries as well [7,11]. These include failure to recognize jaundice, inappropriate response to jaundice (e.g., jaundice is ignored, trials of traditional medicines and drugs, unfiltered sun exposure), social/economic impediments, inability to screen for hyperbilirubinemia or measure serum bilirubin, poor coordination of primary and tertiary care centers, and ineffective phototherapy.

The first barrier, recognition of jaundice and appropriate action, depends on timely intervention by providers and/or timely care-seeking by parents. International guidelines for jaundice management provide rather detailed recommendations for providers, but the limited direction for instructing parents.

The World Health Organization (WHO) 2022 guidelines [12], recommend that "written/digital education booklets, pictorials for semi-literate populations and job aids should be available," but no advice on content except to encourage parents to seek health care early if they identify danger signs between postnatal care visits. Danger signs listed by WHO include not feeding well; no spontaneous movement; convulsions; fever; any jaundice in the first 24 hours after birth, and yellow palms and soles at any age. TSB is frequently greater than 20 – 25 mg/dL when hands and feet are jaundiced [13] and "early" care is first recommended when mild to severe ABE is observed.



The American Academy of Pediatrics (AAP) 2004 guidelines for the management of hyperbilirubinemia [14], recommend only that “explicit educational materials be provided to parents concerning the identification of newborns with jaundice.”

NICE guidelines (2016) [15], recommend parents be provided information “that is tailored to their needs and expressed concerns...Care should be taken to avoid causing unnecessary anxiety ... [and] include [that] neonatal jaundice is common and is usually transient and harmless” (<https://www.nice.org.uk/guidance/cg98>). Parents and caregivers should be educated on how to check their baby for jaundice and what to do when jaundice is suspected. However, Information for parents explaining specific risks of severe hyperbilirubinemia or how to recognize signs of ABE is not specified. The reason we treat jaundice – to prevent brain injury – is not explicitly addressed in either AAP or NICE parent instruction recommendations, and all guidelines assume that mothers will be taught about jaundice between birth and discharge.

A recent multi-center observational study in Nigeria, a country with a very high rate of KSD, examined the impact of introducing maternal instruction into *antenatal* parent classes [16]. 659 jaundiced newborns were admitted at 2 - 28 days of age during a 6-months observation period. 625 mothers had attended antenatal clinics (95%). They were retrospectively divided into groups depending on whether mothers received jaundice instruction and attended antenatal care clinics. Newborns of mothers who attended jaundice classes with postpartum reinforcement had a 3% incidence of ABE (mild), and those with good antenatal clinic attendance but received no jaundice information had a 22% incidence of ABE, reduced to 19% if they received post-natal information (the standard practice in most hospitals). A small group of 22 mothers who received no antenatal care and no instruction had a 95% incidence of ABE when admitted.

This was not a randomized prospective study, but the association of training mothers with favorable outcomes was dramatic and challenges the way mothers are currently taught about jaundice, especially in regions with high rates of out-of-hospital deliveries, early discharge, and limited jaundice screening before discharge.

What, when and how should maternal instruction be provided? Because KSD is a present danger in Nigeria (and many LMICs), the content of teaching materials and discussion specifically addressed how to identify jaundice, the need to seek evaluation immediately, and the consequences of delay (KSD). Breaking with tradition, instructions were presented as interactive group discussions in antenatal clinics with brief one-on-one reinforcement following birth. Providing antenatal rather than postpartum training recognized that nearly 95% of mothers in the region attending antenatal clinic sessions,

while only 66% of mothers delivered in hospitals where they could be presented with jaundice information. Furthermore, by introducing jaundice training into the antenatal support classes, mothers were able to learn without the stress of postpartum physical and emotional adaptation and early discharge. Training was facilitated by group interactive sessions offered in participating antenatal clinics and lasting 20 - 40 minutes. In contrast, post-delivery reinforcement consisted of brief one-on-one verbal instruction and distribution of written/graphic materials or was postponed until follow up clinic 2 - 3 days post discharge. Updated video and slide training modules in multiple languages based on materials used in this study are available on the Stop Kernicterus International website [17].

In summary, there is increasing evidence that empowering mothers to participate in jaundice management using antenatal interactive group training coupled with postpartum reinforcement will promote early care seeking and lower the incidence of ABE.

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