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Jorge César Martínez

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Neonatal Jaundice: Building a Culture of Safety (An Argentinean Perspective)

Jorge César Martínez*

The practice of modern medicine requires us to provide safe care for our patients; that is, to do the right thing, for the right person, at the right time, and in the right place. Many times we have wondered if this practice is what we are offering to jaundiced newborn infants, who make up 70% of the newborn infant population of the world. How many newborn infants develop neurologic damage secondary to hyperbilirubinemia? Are we treating newborn infants excessively? Are we really preventing damage with screening? Is screening essential? Is it worth managing many patients, to detect only a very few with potential damage, especially considering the costs this monitoring entails? An answer can be obtained by asking the parents of a child with bilirubin encephalopathy. Inquiries have changed with advances in science, but the original questions are still there. Advances in the science of evaluation are essential to finally give an answer that satisfies everyone, not just doctors, but particularly the parents of these children, who are just beginning their walk through life.

Without a doubt, we have greatly improved our strategies and technologies for treating jaundiced newborn infants. If we look back, as we always should do to learn from mistakes and successes, we must recognize that the contributions of Hsia, Diamond, Mollison, Gellis, and many others pointed the way toward deciding when and at what levels treatment must be initiated in these children who have hyperbilirubinemia. The indication for exchange transfusion when the bilirubin level reached 20 mg/dL drastically reduced the incidence of neurologic damage, which up to that point was very important. Later, we realized that we were not classifying patients by gestational age and hours of life, and in this regard we might be treating some newborns too aggressively. Indications for treatment changed and we started to use bilirubin level ranges rather than absolute levels to determine therapeutic behaviors. After an apparent "quiet" period, new reports revealed that kernicterus had come back. Have we been neglectful?

After consensus groups met and performed careful studies of the literature, the American Academy of Pediatrics provided us with management guidelines in 1994. These guidelines were updated in 2004 and were clarified in 2009. Maisels and Bhutani proposed an algorithm providing recommendations and follow-up according to predischarge bilirubin measurements, gestational age, and risk factors for subsequent hyperbilirubinemia. This algorithm appeared to be complete, thoughtful, and above all, easy to implement all over the world. Of course, re-emerging controversy resulted: the increased incidence of kernicterus was questioned, as were screening examinations. It should be mentioned that the current recommendations could lead to additional testing and increase inappropriate use of phototherapy.

During my "medical life," I witnessed (and participated in) the development of how we tackled the

*School of Medicine, University del Salvador, Buenos Aires, Argentina; and R. Sarda Mother-Infant Hospital, Buenos Aires, Argentina.

problem of jaundice. My point is that we have certainly made much progress: we have guides; we have clear definitions of populations at risk; we have a useful technology (apparently without producing adverse effects); and the technology is accessible worldwide, but in my opinion the main problem is the lack of adherence to guidelines in different health care centers. We have no long-term evaluations of children with hyperbilirubinemia that allow us to draw valid conclusions and sustainable evidence.

Even if the quality of evidence of the recommendations is not high and based on expert opinion, we must remember that we are dealing with a devastating condition, and these tools could help us to prevent it while we design and implement long-term studies to support high-quality evidence. Jaundice of the newborn is not an in-patient problem; it has become an outpatient problem because serum bilirubin levels rise during the first days after discharge. Not all of the related costs can be measured directly; disabilities produce not only physical but also psychological damage to the whole family. The fragmented characteristics of health care systems contribute to unsafe conditions and sometimes serve as an impediment to establishing the standardized follow-up care that is absolutely critical in the first days after birth.

Primum Non Nocere ("First, Do No Harm": Hippocrates)

The health system needs to offer patients an approach to improve prevention and to avoid harm using thoughtful responses while getting more knowledge and evidence. Failure of the planned action to be completed as intended according to guidelines could happen in all stages in the process of care, from diagnosis to risk assessment, treatment, and preventive measures.

Building safety into medical processes of care is more effective than blaming individuals because of the failures. The focus must shift from blaming to a focus on preventing future damage by designing safety into the system as well as strong and visible leadership that encourages recognition and learning from errors and stimulates effective safety programs.

Designing safe systems requires an understanding of the sources of errors and how to use design concepts to minimize these errors or allow detection before harm occurs. Institutional interventional strategies should be designed for the purpose of creating a safety system based on teamwork, by sharing knowledge so that each safety officer promotes health, minimizes memory usage, emphasizes the use of standards, and includes parents as members of the child care team.

While we are still looking for answers to our questions, I think that we can offer safe medicine for the management of neonatal jaundice by adhering to the proposed management of neonatal jaundice provided in the American Academy of Pediatrics guidelines. This concept must be clear to managers of health care systems and to all members of the health care team, particularly to front-line providers, because this method is currently the main tool used to avoid the risk of damage. Human factors engineering is defined as the study of the interrelationship between humans, the tools they use, and the environment in which they live and work.

Behaviors To Be Encouraged

It also should be clear that there are fundamental behaviors needed to avoid the risk of hyperbilirubinemia and neurologic damage that should be encouraged, such as the following:

1. Organize and facilitate individualized monitoring of the newborn, on a daily basis if necessary, with clinical assessment and rechecking of the risk factors to detect immediately newborns who should be treated, avoiding dangerous rises in bilirubin levels and potential neurologic damage.
2. Provide adequate information during the prenatal period to parents regarding neonatal jaundice. Parents should be considered by doctors and nurses as important team members in providing safe care for their child.
3. Encourage leaders in each institution to guide and continually assess and encourage adherence to the guidelines for all staff for the safe care of the newborn.
4. Report all children who have bilirubin levels exceeding the recommended levels to be evaluated by the safety committee of the institution that evaluates causes of failure in prevention. The purpose should not be to blame, but to establish a safety culture. Performance of root-cause studies leading to the implementation of changes or reinforcing safe and effective behavior should be undertaken in the future.
5. Take into account the flaws in human factors engineering, in which communication (or rather, lack of communication) is most important.
6. Establish communication systems: personal, written, or electronic, enabling rapid understanding of the status and risk of newborns so as to enable clinicians to perform the necessary care 24 hours a day.

It is understandable that there are differences between countries and among different institutions around the world, but the incorporation of defined behaviors driven by considerations that are not financial but instead are focused on commitment can and should be universal, despite the cost pressures, liability constraints,

and resistance to change. Reports of long-term studies conducted by international expert groups will be very useful, because they will provide us with answers to our questions and ratify or amend the currently proposed management of newborns with hyperbilirubinemia. Since the publication of the Institute of Medicine report "To Err Is Human" (*errare humanum est*), we must realize that "to err is part of human nature, but [it] must also be part of human nature to create solutions, find better alternatives and face the challenges ahead."

Errors We Must Avoid

- Failure to recognize jaundice or its severity, based on visual estimation.
- Failure to measure serum bilirubin levels in a jaundiced child in the first 24 hours of life.
- Failure to measure serum bilirubin levels before discharge or in follow-up visits when a newborn appears to be jaundiced.
- Discharge of a newborn before 48 hours after birth without arranging for him or her to have a visit 1 or 2 days later, particularly if the child is <38 weeks of gestation.
- Failure to include children for follow-up even if their bilirubin values correspond to low-risk areas of the nomogram at discharge.
- Failure to provide support for breastfeeding to ensure adequate caloric intake and to inhibit the enteropathic cycle.
- Failure to provide adequate information to parents about newborn jaundice.
- Failure to respond adequately to the concerns of parents regarding the evolution of neonatal jaundice, poor feeding, breastfeeding difficulties, or changes in behavior or activities of the newborn.
- Failure to measure the effectiveness of phototherapy equipment.
- Failure to recognize immediately and to treat properly children with bilirubin levels that are rising rapidly.
- Failure to treat appropriately severe hyperbilirubinemia without taking into consideration the child's age in hours after birth.
- Failure to use intensive phototherapy or exchange transfusion if either is indicated.
- Failure to consider hyperbilirubinemia >25 mg a medical emergency.

Conclusions

Apparently, if we could avoid all these errors, there would be few cases of bilirubin encephalopathy in relation to total live births (there are still no reliable data), but this concept should not downplay the issue or be a factor when considering the cost-benefit equation. Perhaps we could get the best conclusion if we answer these two questions: (1) from the perspective of the parents of a child affected by bilirubin encephalopathy (a child who was healthy at birth and subsequently developed severe neurologic damage), what did they expect that we should have done better? And the second question is (2) when we, the health care providers, were newborns, how would we wish to have been cared for, if we were jaundiced? I believe the answers are obvious and would help us to improve care systems, behaviors, and adherence.

American Board of Pediatrics Neonatal–Perinatal Medicine Content Specifications

- Know the AAP guideline for the management of neonatal hyperbilirubinemia in term and preterm infants, including prevention strategies and management of severe hyperbilirubinemia.

Suggested Reading

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