

Patient Safety

Barriers to First-Week Follow-up of Newborns:

Findings from Parent and Clinician Focus Groups

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In response to continued reports of kernicterus, a potential and devastating consequence of extreme hyperbilirubinemia, recommendations for follow-up of discharged newborns have been substantively updated. In the full-term newborn, bilirubin levels peak at 72–120 hours of life. However, most infants are now discharged before this time, so this critical period occurs while they are without professional observation.¹ Although predischarge assessment for risk of severe hyperbilirubinemia is desirable, it is not currently possible to determine exactly which infants will develop significant hyperbilirubinemia by the time of discharge.² Early discharge with no short-term follow-up has been identified as an important root cause of failure to prevent kernicterus.³ Therefore, in 2001, the Joint Commission on Accreditation of Healthcare Organizations issued a *Sentinel Event Alert*,³ which recommended that organizations implement procedures for follow-up of all newborns within 24–48 hours by a physician or pediatric nurse.

In July 2004, the American Academy of Pediatrics (AAP) released an update to its existing clinical practice guideline on the management of hyperbilirubinemia in the newborn.⁴ The guideline recommends that all infants be examined in the first few days after discharge to assess their well-being and the presence/absence of jaundice, on a schedule determined by their length of

Article-at-a-Glance

Background: Monitoring newborns within the first week is critical to assess the adequacy of feeding and weight gain and to identify instances of hyperbilirubinemia. As systems of maternal and newborn care have become increasingly fragmented, infants are at increased risk of poor outcomes because of poor follow-up. Structured focus groups were conducted in June–July 2001 to provide information about the barriers to timely newborn follow-up and strategies to address them.

Methods: One focus group for physicians and one for nurses were held at the Henry Ford Health System, Detroit, and two focus groups of parents were recruited by Blue Cross Blue Shield of Texas, Dallas.

Results: Barriers were identified in communication and information, systems and processes of care, and parental knowledge and education. Concerns raised by clinicians and parents were consistent and complementary. Some organizations have begun implementing some of the suggested strategies to achieve timely follow-up.

Discussion: Implementing the AAP guideline and improving safe care in the first week of newborn life will require attention to linkages and transitions between these various microsystems.

hospital stay (that is, age at discharge), and risk factors for hyperbilirubinemia.

First-week follow-up is not currently the norm for newborn care.^{2,5,6} With this misalignment between the recommendations and the state of routine practice in mind, focus groups were held as a part of the Making Advances Against Jaundice in Infant Care (MAJIC) project, in which two large managed care organizations volunteered to work to improve care for infants with hyperbilirubinemia. We convened focus groups of parents and clinicians to explore existing barriers to timely newborn follow-up and strategies to address them.

Methods

Focus groups, as discussions designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment,⁷ are intended to create an interactive process to explore what is known about a problem and the predisposing, enabling, and reinforcing factors that determine behavior related to the issue.⁸⁻¹⁰

Sample

In June–July 2001 four focus groups were held across the two MAJIC project sites—one each for physicians and nurses who were recruited from the Henry Ford Health System (HFHS), Detroit, and two for parents recruited by Blue Cross Blue Shield of Texas (BCBSTX), Dallas. Project resource constraints precluded conducting clinician and parent focus groups in both sites. The Human Subjects Committees of the Harvard School of Public Health and HFHS approved the protocol. To recruit providers, the HFHS division head of neonatology sent invitations to 16 hospital- and community-based physicians with affiliations to HFHS or St. Joseph Mercy Hospital, Pontiac, Michigan. Nurses were recruited from the newborn nurseries of both hospitals and from affiliated home care agencies. Separate dinner sessions were held for nurses and physicians.

Parents were recruited via an e-mail from the BCBSTX president to employees which invited them, their friends, or family who had had a baby in the past 6 months to participate. Two groups were held during breakfast and lunch at the BCBSTX corporate offices. Participants received a book about well-child care as a thank you gift.

Focus Group Sessions

Groups ranged in size from 7 to 9 participants and lasted 1.5–2.0 hours. They were tape recorded and led by an experienced facilitator [S.S.S.], with a second facilitator [L.E.P.] serving as observer/recorder. Clinician sessions began with a brief overview of the importance of first-week newborn follow-up. In response to “key questions,” clinicians were asked to share their perspective on barriers to and strategies for detecting hyperbilirubinemia and following newborns in the first week of life. They were instructed to reflect on their experience throughout their careers, not just in their current positions. Also in response to key questions, parents were asked to describe their experiences with their recent newborn or past care for any older children irrespective of where they received newborn care. In addition to discussing barriers, emphasis was placed on eliciting feedback on what could have made it easier for them to have their baby seen during the first week after discharge.

Analysis

Tapes of each session were transcribed. Written summaries based on the tapes and transcriptions were created by one author [S.S.S.] and reviewed by a second [L.E.P.]. Results from the two parent groups were combined, resulting in three sets of reports—physicians, nurses, and parents. Responses were classified into categories on the basis of the themes that emerged. These groupings included communication and information, systems and processes of care, and knowledge/education.

Results

Eight physicians participated, including a chief pediatric resident, inpatient and community pediatricians, and a family practitioner. All reported regularly seeing and treating infants with hyperbilirubinemia; none had seen an infant with kernicterus. Nine nurse participants worked in newborn nurseries, neonatal intensive care units, or home care programs. Across the two parent groups, participants included 14 mothers with babies who ranged in age from 1 to 13 months. All parents had health insurance. Infant age at discharge ranged from 38 to 77 hours. Five infants had had visible jaundice; three had been treated.

Table 1. Communication and Information Barriers and Strategies*

Barriers	Reported by
1. Obstetrician and hospital pediatrician give mother conflicting information about readiness for discharge	M.D.
2. Communication gaps during "hand-offs" between hospital and community-based provider: <ul style="list-style-type: none"> ■ Community-based provider not notified that baby has been born ■ No clear mechanism for communication between hospitalist and community-based provider ■ Unclear who is responsible for baby in first days following discharge ■ Delays when home care nurses can't identify or reach a responsible clinician ■ Community-based provider may receive a bilirubin result without knowing one was drawn 	M.D., R.N.
3. Key information needed to evaluate newborns after discharge may not be readily available to community-based provider, including the following: <ul style="list-style-type: none"> ■ Exact time of birth ■ Gestational age ■ Results from tests conducted in hospital 	M.D., R.N.
Strategies	Reported by
1. Improve communication between hospital pediatricians and obstetricians regarding readiness for discharge	M.D.
2. Notify community-based provider by e-mail that the baby was born	M.D., R.N.
3. Quick easy access (on-line or from patient) by community-based providers to lab results	M.D., R.N.
4. Give parents list of "early warning signs" to report (perhaps as a refrigerator magnet)	M.D., P
5. Continued contact from birth hospital to parents: <ul style="list-style-type: none"> ■ Call-in number for questions ■ Follow-up call from nursery to mother 	P

* M.D., physician; R.N., nurse; P, parent.

Communication and Information

Providers identified gaps in communication that can occur between the various clinicians involved in the care of mother and baby before and after delivery (Table 1, above). Obstetric and pediatric clinicians may give conflicting information to the mother about discharge timing:

The OB makes rounds before I do in the morning. And they've already told Mom it's fine for her to go home today. Mom doesn't want to hear from me ... you know, I think your baby ought to be watched for another 24 hours.

Community-based clinicians expressed frustration that at times they are not even notified of the baby's birth:

There's a lot of times where there's a mother—who even as a family doctor—the mother's been my patient—and I know she's pregnant. But I don't get any notification that she's delivered. And so, I don't know if there's a baby hanging out there yet—waiting to be seen.

Clinician opinion differed as to who is responsible for the newborn in the first week of life. Some hospital physicians reported a sense of ongoing responsibility in the days immediately postdischarge, while others indicated the "handoff" to a community-based clinician should occur at the time of discharge. This lack of clarity can leave new parents uncertain about whom to contact and home care nurses unclear where to direct bilirubin test results.

Relevant information needed to evaluate newborns and to support prompt decision making after discharge may be lacking. Data easily accessible to hospital-based clinicians that may be needed to make subsequent evaluation and treatment decisions, such as gestational age and exact time of birth, may not be available to the post-discharge clinician.

Strategies recommended by all groups included improved systems for communication between pediatric

and obstetric clinicians in the hospital, and a system (perhaps fax or e-mail) for notifying clinicians about the birth and discharge of infants in their care. Clinicians also expressed the desire for better access to laboratory results. Parents expressed a desire for opportunities for increased postdischarge communication with clinicians.

Systems and Process of Care

Physicians and nurses observed that existing systems for collecting, processing, and reporting bilirubin levels do not keep pace with the newborn's rapidly shifting physiology in the first week of life and therefore do not allow for timely decision making (Table 2, pages 597–598). Many home care agencies lack standing orders for the nurse to obtain a bilirubin for infants they assess as jaundiced, thus delaying the blood draw until a physician order can be obtained. After a sample is drawn, the home care nurse's workload of other visits can delay getting it to the lab, labs may be geographically dispersed, or the nearest lab may not be a "network provider" under the infant's insurance plan. Physicians also may not have arrangements with suitable laboratories to have "STAT" processing for specimens drawn in their office. Clinicians report engaging in a number of "work-arounds" for these barriers, including having parents take the sample to the lab and wait there until results are available or sending infants back to the newborn nursery or birth hospital's lab to have blood drawn.

Physicians expressed concern about a lack of reliability of some home care services, with visits not scheduled in a timely manner or not conducted by pediatric nurses. Home care nurses, for their part, reported that phone numbers or addresses in the hospital referral information they receive may not actually be the ones where the mother is available after discharge:

Sometimes we forget to ask the moms if they're going to be at the residence that they say they live. Because a lot of times, they'll go and stay at their mom's house. And when home care goes to see them, they'll either be at the other residence, or no one's answering the phone.

Even when the parents can be reached, they sometimes refuse offered home care services.

Follow-up in physician offices is also not without frustration. The ability to provide prompt follow-up in a physician's office or clinic can be hampered by overloaded practice schedules and "normal hours" of operation.

Babies who go home on Friday may not be seen until the following week. Although some physicians reported altering their practice styles to account for this, others did not:

Just the timing and the place—and what day of the week it is. And we teach the residents now—Friday Rules—you know? You can practice medicine a certain way but you practice different on Fridays—because it's the weekend.

Some parents do not have a primary care clinician for their newborn by the time of discharge. Among those who have a timely follow-up visit scheduled, some do not complete the visit. This may be in part because mothers report that going anywhere is difficult in the first week home and that making it to an appointment on time often feels impossible. They report feeling physically exhausted, sore, and generally overwhelmed. Trying to organize an excursion around baby's feeding and sleeping schedule is a major challenge. Additionally, many mothers were told by their physicians not to drive a car for up to two weeks:

And the nursing makes it difficult too, because they need to eat so often...because it feels like once you're done, they want to eat again.

My [difficulty in getting out of the house] was getting dressed. Because you don't want to wear your maternity clothes. You can't fit into the clothes you wore before you were pregnant. You get yourself dressed. You're finally comfortable with what you're wearing—and you pick him up, and he spits up on you. So now you have to go back, and try and find something new.

Some mothers also expressed concern about taking their well newborn to the physician's office for fear of exposure to sick children.

Barriers due to insurance requirements were reported by members of all three groups. Parents indicated that out-of-pocket cost is a consideration in deciding whether to accept a home visit. Clinicians noted that insurers may not cover a home visit for newborns whose inpatient length of stay exceeded 48 hours. Insurance can also affect the continuity of care. The pediatrician who sees the baby in the hospital may not be able to see him or her as an outpatient because of inconsistencies in insurance coverage:

I'm on call, and I get a baby on my service phone. I don't know the mom. On top of that, our system doesn't take their insurance. Or, I don't take their insurance, either. And this baby, you know, it is my responsibility and I discharge them. And then I tell them that you really need to be seen.

Table 2. Systems and Process of Care Barriers and Strategies*

Barriers	Reported by
1. Delays in outpatient bilirubin testing and reporting: <ul style="list-style-type: none"> ■ Home care nurse may not have standing orders to draw a sample ■ Time to get sample to lab from home or office (may be due in part to home care nurse workload) ■ Nearest lab isn't covered by patient's insurance ■ Difficulty getting a covered lab to run tests STAT, especially after hours or weekends 	M.D., R.N.
2. Barriers to home visits in the first week of life: <ul style="list-style-type: none"> ■ Mother and baby may not be at home address postdischarge (e.g., went to stay with her mother) ■ Some home care agencies won't commit to next-day or weekend visits ■ Some home care agencies do not have pediatric nurses ■ Mother asks nurse to delay visit because home is untidy or disorganized ■ Some mothers insist on physician follow-up and won't accept a home care nurse ■ Some mothers reluctant to receive home visit by a "stranger" not previously known to them 	M.D., R.N., P
3. Barriers to office visit in first week of life: <ul style="list-style-type: none"> ■ Lack of weekend office hours for Friday/Saturday discharges ■ Some community-based providers have a 3-4 week backlog for next available appointment ■ Mother may not have chosen post-discharge provider by time of discharge (some M.D.s don't do pre-natal interviews if it is not reimbursable) ■ Mother told in hospital not to drive for anywhere from 3 days-2 weeks ■ Lack of transportation to office ■ Difficulty in getting self and baby ready to leave the house ■ Maternal concern about exposing newborn to "germs" outside the house and from sick children in the physician's office 	M.D., R.N., P
4. Insurance coverage constraints: <ul style="list-style-type: none"> ■ Some insurers do not cover a home visit if hospital length of stay was > 48 hours ■ Eligibility for a home care visit may be unclear depending on whether insurer counts length of stay in days or hours ■ Hospital staff may not be on insurance panel to provide outpatient care 	M.D., R.N.
Strategies	Reported by
1. Home visit by a physician (or someone designated by primary care physician)	P
2. Encourage home care; present as the normal routine	R.N., P
3. To address barriers to follow-up office visits: <ul style="list-style-type: none"> ■ Obstetrician to provide parents with list of pediatricians at prenatal visit to encourage timely identification of a pediatric provider ■ Hospital nurses to encourage parents to choose pediatrician prior to discharge ■ Book follow-up appointment before baby is discharged 	M.D.
<ul style="list-style-type: none"> ■ Separate times, waiting room for well children in pediatrician's office (separated from "sick" children) ■ Make follow-up office visits more flexible: <ul style="list-style-type: none"> — Drop-in visits ("come between 8:00 and 12:00") 	P

continued

Table 2. Systems and Process of Care Barriers and Strategies* (continued)

Strategies	Reported by
<ul style="list-style-type: none"> – Fill out paperwork ahead of time – No long waits ■ Provide assistance for mother to get to follow-up office visit: <ul style="list-style-type: none"> – Someone to accompany – Transportation 	
4. To address barriers to follow-up home visits: <ul style="list-style-type: none"> ■ Hospital to verify family's postdischarge location prior to discharge to facilitate subsequent home visit ■ Home care nurse to conduct educational visit with mother before delivery 	R.N., P
5. To address barriers to timely bilirubin testing and reporting <ul style="list-style-type: none"> ■ Have standing orders for home care nurse to draw bilirubin ■ Ensure quick, easy access to lab (location, hours, insurance) 	M.D., R.N.

* M.D., physician; R.N., nurse; P, parent.

A number of strategies for improvement in systems and processes of care were identified. Physicians suggested sweeping changes, such as bilirubin-screening tests for all babies at 72 hours of age, but also simple strategies, such as providing parents with a refrigerator card with “early warning signs” of newborn hyperbilirubinemia. Most physicians agreed that an outpatient visit a day after discharge should replace the more common two-week visit and were indifferent as to whether it occurs in the home or office. Both groups of clinicians suggested implementing mechanisms for quick and easy access to laboratory results and an accurate address and telephone number where the mother will be postdischarge.

Nurses would like to see home care presented more frequently as an expected standard of care and suggest an additional educational visit before delivery:

When you have a mom who's just delivered—and she is absolutely exhausted, and she is going to go home the next day, and you are trying to do that whole critical teaching in that short span of time. How much does she really retain? That's why I was saying prenatally. If you can get some of the things in, and you talk about newborn care, and actually teach a little bit more and then you can reinforce it.

Mothers varied as to their preference for site and type of provider for a follow-up visit. Some mothers would want a home visit only if it were conducted by their own

pediatric primary care provider, but others would welcome a knowledgeable nurse, especially if associated with the provider. Some mothers were very enthusiastic about a home visit to avoid leaving the house with the newborn.

Mothers who were less comfortable with a home visit proposed assistance in getting to the physician's office, including someone to accompany them and transportation. Mothers also suggest flexible appointment scheduling, drop-in visits, and separate office hours or waiting areas for well babies.

Knowledge and Education

Both clinician groups identified gaps in both clinician and parent education (Table 3, page 599). Nurses commented that shorter hospital stays leave less time for the education that traditionally occurs after the birth of a baby. Physicians noted that the evaluation of hyperbilirubinemia can be difficult for the lay person to understand because bilirubin levels are only meaningful in the context of the baby's age and particular bilirubin level:

And then you try to say that it is normal for babies to be jaundiced up to a certain point. But it is a hard thing to explain to parents. Because it is hard to give up that idea, of well, doesn't a little bit hurt a little bit? Versus a little bit doesn't hurt but (a lot) hurts a lot. And it's very hard to get that across.

Table 3. Knowledge and Education Barriers and Strategies*

Barriers	Reported by
1. Shorter hospital stays leave less time for important education of parents: <ul style="list-style-type: none"> ■ Lots of visitors impedes access to mother ■ Maternal fatigue and/or pain makes learning difficult ■ No time for repetition ■ Information about jaundice may get "lost" in flood of information given at discharge 	R.N.
2. Clinicians may be reluctant to educate families about hyperbilirubinemia prenatally: <ul style="list-style-type: none"> ■ Concern about scaring parents ■ Clinicians think concepts are difficult to understand ■ Parents may not be ready to consider potential problems in advance 	M.D., R.N.
3. Poor understanding by clinicians of increased risk of jaundice in near-term babies and therefore no adjustment in time of discharge or first follow-up visit	M.D.
4. Lack of clinician awareness of the recommendation for early follow-up (especially in areas where the community standard has historically been a first visit at two weeks of age)	M.D.
5. Hard for parents to remember hospital staff's instructions once they are home and overwhelmed	P
Strategies	Reported by
1. Increase professional awareness <ul style="list-style-type: none"> ■ Increase awareness among obstetricians ■ Create guideline card to cover near-term infants ■ Inform physicians about risk factors and train to identify hyperbilirubinemia in nonwhite populations 	M.D., R.N.
2. Parental education throughout continuum of care <ul style="list-style-type: none"> ■ Obstetricians to begin education about hyperbilirubinemia ■ Offer education in prenatal classes <ul style="list-style-type: none"> – Lists of local pediatricians – Information about hyperbilirubinemia ■ Continue hyperbilirubinemia education in hospital <ul style="list-style-type: none"> – During bath demonstrations – In-room video – Educational posters about hyperbilirubinemia in newborn nursery – Written instructions at discharge 	M.D., R.N., P
3. Support groups for new and expectant parents	M.D., R.N.

* M.D., physician; R.N., nurse; P, parent.

Nurses also expressed concern about discussing possible negative outcomes (such as hyperbilirubinemia) before delivery, and some physicians acknowledged that they have refrained from prenatal discussions of newborn hyperbilirubinemia to avoid scaring or worrying parents.

Topics suggested for clinician education include risk factors for severe hyperbilirubinemia, identifying

hyperbilirubinemia in dark-skinned populations (which are increasing), and a guideline card that covers near-term infants. Suggestions for parent education include support groups for new and expectant parents, breastfeeding support (since unsuccessful breastfeeding may lead to poor intake of calories and fluids, promoting newborn hyperbilirubinemia),¹¹ and educational posters in the

newborn nursery. Education could be provided during prenatal home visits and OB visits.

Discussion

Although the release of updated recommendations for follow-up of newborns is encouraging, the issuance of guidelines alone does little to influence practice.¹²⁻¹⁴ Recent discussions of health care quality have described the health care system as composed of front-line clinical microsystems, overarching macrosystems, and patient subpopulations needing care.¹⁵ Nelson and others suggest that to move toward a “perfected” system of care, the performance of each individual microsystem must be optimized, and the linkages between them must be made seamless, timely, efficient, and thoroughly reliable.¹⁶ The updated AAP hyperbilirubinemia guideline echoes the Institute of Medicine’s call for safe systems of care and highlights the relevance to newborn care.¹⁷ Over the years, the system for caring for expectant mothers and newborns has evolved into a variety of distinct and discrete enterprises (prenatal care, in-hospital care, home care, pediatric office care) that function largely independently of one another and do not share information easily, if at all.

Findings from these focus groups were consistent and complementary. Clinicians display awareness of many ways in which the health care system, at both the micro and macro level, can interfere with their efforts to provide appropriate care. Communication may be incomplete, untimely, or even absent between the clinicians who care for women and their newborns before, during, and after the birth hospitalization. Parent descriptions of their experiences highlight ways in which the “workings” of the health care system failed to meet the needs of patients and families. The participants’ reports highlight potential complexities of implementing seemingly straightforward recommendations, such as follow-up for all infants based on the risk assessment and time of discharge (guideline recommendation 6.1.1),⁴ and interpretation of bilirubin levels according to the infant’s age in hours (recommendation 3.2). Strategies implemented by the two MAJIC managed care organizations (Sidebar, page 601), as well as those identified by focus group participants, serve as a starting place for organizations seeking organizations to improve follow-up for newborns. The updated guideline also suggests several strategies, including standing orders for

bilirubin testing, educational materials for parents, and provider check lists and reminders. An accompanying commentary¹⁸ acknowledges the complexity of clinical practice improvement and announces a new AAP initiative, “*Ensuring Safe and Healthy Beginnings*,” that will promote a variety of strategies targeting early follow-up and other aspects of a safe beginning for newborns.

In addition to discrete improvement strategies, emphasis must be placed on improving the linkages between organizations, or microsystems, to implement these guideline recommendations. Transitions must be accompanied by thoughtful planning, systems that support and encourage the sharing of information across care settings, and flexible options for follow-up which address the families’ preferences and physical and emotional needs (for example, share information on jaundice before delivery rather than at discharge, when parents report being overwhelmed by print and verbal instructions).

The steps to improving newborn follow-up will vary by type of organization (hospital, managed care organization, pediatric practice, obstetric practice, or home care agency) and by the relationships between these in various communities. Our hope is that the findings shared here will provide a starting point for conversations between organizations seeking to improve the follow-up and safe care of newborns. **I**

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Sidebar 1. Lessons from the Field

Strategies from the Two MAJIC Project Managed Care Organizations

Understand your patients

- Case review and root cause analysis of members reaching "target" bilirubin levels or readmitted for jaundice

Understand your processes

- Review current care processes to identify opportunities for systems improvement

Educate providers

- Distribute laminated pocket cards to hospital-based physicians and community pediatricians for reference

Educate parents

- Provide articles on newborn follow-up, jaundice, and early identification of pediatric providers in newsletters

Improve systems and processes

- Add advice to the prenatal care manager telephone script to identify a primary care pediatric provider before delivery

- Ask mother for information on jaundice, time of birth, and discharge during postdischarge phone call

- Give home care nurses cell phone numbers for newborn nursery staff to facilitate prompt contact

- Add weekend clinic hours to follow up newborns discharged on Thursday and Friday

- Assist new mothers in identifying a pediatric provider prior to discharge

- Revise forms for newborns to include time of birth and time of discharge (rather than dates alone)

Enhance benefits

- Encourage employers to include a prenatal case management program as a benefit selection

- Cover home care visits for all newborns, including those discharged after 48 hours

- Cover additional hospital days if necessary

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