

Premature Abandonment?

Multidisciplinary Experts Consider How to Best Meet Premies Needs at “Preterm Infants: A Collaborative Approach to Specialized Care” Roundtable

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In June 2006, the Institute of Medicine (IoM), released a comprehensive study, *Preterm Birth: Causes, Consequences, and Prevention*. The report was a result of the IoM’s efforts, in particular the Committee on Understanding Premature Birth and Assuring Healthy Outcomes, to better understand and prevent preterm birth and improve care for babies born prematurely.

After its publication, a group of health care professionals came together in a roundtable session, “Preterm Infants: A Collaborative Approach to Specialized Care,” to discuss the implications of the report. The following article captures the group’s April 2007 discussion about the clinical and societal problems of preterm birth. It should be of interest to hospital administrators, pediatricians, third-party payers, policy makers, public health officials, academic researchers, funding agencies, allied health professionals, and others with a vested interest in curbing healthcare costs as well as what needs to be understood and done to safeguard the short- and long-term health of a most vulnerable population.

Premature birth in the United States is growing at an alarming rate. Since 1981, it has increased by 30 percent. In 2004, one-eighth of all infants were born preterm, that is, at less than 37 full weeks of gestation.

Due to advances in treatment, preterm babies are more likely than ever before to survive infancy. But they remain at risk for a wide range of health and developmental problems that can last a lifetime. These problems exact a medical, economic, and emotional toll on the babies, their families, communities, and public health systems. No single solution to this crisis exists. Rather, many groups with a stake in these issues must work together to advocate for and implement change in the way premies are treated and cared for.

“Preterm Infants: A Collaborative Approach to Specialized Care,” a multidisciplinary roundtable of neonatal experts, convened at the Department of Health Care and Public Administration in the School of Public Service within the College of Management at the C.W. Post Campus of Long Island University. The objective of the roundtable was to discuss the short- and long-term consequences of preterm birth and what can be done now to address the special health care needs of premies. Co-chaired by Dr. Richard E. Behrman, editor of the Institute of Medicine’s (IoM) report *Preterm Birth: Causes, Consequences, and Prevention*, and Dr. Richard Martin, division chief, Neonatology, Rainbow Babies Children’s Hospital, the roundtable

included leaders in neonatology, pediatrics, pulmonology, neurodevelopment, infectious disease, pediatric nutrition and epidemiology.

“My motivation for being involved in this important and timely discussion relates to the fact that one of the things we were trying to do at IoM was draw attention to the range of problems that affect premature births and the care of premature infants,” Behrman commented at the start of the discussion. “Prematurity is a major public health problem because the number of preterm deliveries is increasing. We thought it would be worthwhile to make various publics aware of the pressing problems premies face about which something more



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could be done.”

Among the recommendations of the 2007 roundtable: Physician leaders and professionals must work together to raise awareness and educate themselves and their colleagues about the special needs of preemies. They must advocate for change and call attention to prematurity as a lifelong condition that requires a continuum of care from the neonatal

intensive care unit (NICU) to the family, the pediatrician, the school system and beyond. With an enhanced understanding, all involved can work collaboratively to ensure preemies receive the care they need.

SPECIALIZED CARE AND HEALTH CONSEQUENCES FOR PREEMIES

Disrupted Development

Preemie children are among the most “complicated” patients, Martin said. They may take several medications and have several health or growth problems. The medium and long term implications of which are potentially enormous.

“Prematurity is really disrupted development,” explained Phyllis Dennery, MD, chief of neonatology at Children’s Hospital of Philadelphia. “There’s a continuum of development that was disrupted by an early birth. The resulting onslaught of environmental and other stimuli – infection and so forth – and now the path of development no longer follows the course it should, but gets twisted and changed, and organs change as a result of that, your brain changes and your lungs change, and so it becomes a different, unique problem.”

“I think there’s a dearth of understanding that people who are born prematurely, who have had health issues, will carry those issues well into adulthood, and they are not like everybody else,” echoed Howard Panitch, MD, a pediatric pulmonologist at Children’s Hospital of Philadelphia.

Lung development is one example of how preemie physiology differs, according to Panitch. Chronic lung disease, also known as bronchopulmonary dysplasia (BPD), is associated with lung immaturity as well as the use of ventilators for preterm babies. Both can lead to growth, health, and neurodevelopmental problems during childhood. But “the movement in pediatrics is to ignore the diagnosis and say, ‘well, that was a neonatal diagnosis; when in fact that’s the bedrock of what happens to children forevermore,” Panitch said. “We have young adults who have a history of BPD who have chronic radiographic changes and clinical changes, and our concern

Preemie Health and Mortality

- Mortality risk declined more than 30 percent between 1985 and 2000 for births at 24 weeks gestation or greater. Mortality risk declined 40 percent or more for births at 26-31 weeks.
- Unfortunately, the rate of complications from preterm birth has not shown a similar decrease. In a study of extremely low birthweight children who reached age 8, 69 percent had one or more functional limitations such as a developmental delay, difficulty seeing or hearing, or an inability to socialize. (Extremely low birthweight means below 1 kilogram.)
- In the same study, 16 percent suffered from neurosensory impairments such as cerebral palsy, deafness and blindness. Thirty-eight percent suffered from IQs below 85; 21 percent had asthma.
- Infants with a principal diagnosis of prematurity or low birthweight stayed in the hospital an average of 24.2 days, versus 2.0 days for newborns without complications.
- Eighty percent of infants born before 27 weeks gestation will develop respiratory distress syndrome (RDS).
- The challenges extend to near-term children. Children born between 32 and 36 weeks account for 16 to 20 percent of children with cerebral palsy.

SOURCE: *Institute of Medicine*





should be that as their organs go through the aging process, we may have the issues of the elderly in a much younger population.”

Similarly, Heidelise Als, PhD, an associate professor of psychology at Harvard Medical School, raised the issue of how the brain is affected by premature birth: “The first time I was invited into a NICU, I was struck by the baby’s competence, by these little, at that time, 28-week fetuses that came from the delivery room and then were being literally bombarded by the positive intention of the physicians to keep those lungs of those babies together. From a development perspective: I asked, ‘Can we understand what that fetal brain in the last trimester attempts to accomplish and expects to help its development?’ I set out to understand neural development better and the impact of the environment on the immature brain.”

Scott Denne, MD, professor of pediatrics at Indiana University Medical School offered another perspective: “The growth of preterm infants, especially the extremely preterm infants remains probably one of our most significant problems both within the NICU and after these babies leave the NICU. I do believe, both from long-term growth outcome perspective and in terms of improving neurodevelopmental outcomes, that focusing on nutrition may yield significant returns.”

The Near-Term Preemie

Severe complications are less frequent in infants born near-term, that is between 33 and 36 weeks of gestation. This is by far the largest group of preterm infants, accounting for 8.9 percent of all births between 1995 and 2000. (By contrast, only about 3 percent of infants were born on or before the 32nd week.) Many of these babies have normal birth weights, and most receive routine care in well-baby nurseries. But they are still more vulnerable to mortality and complications than full-term infants.

Participants expressed concern that near-term preemies are not getting the attention they need. “They’ve fallen below my radar screen,” said Caroline B. Hall, MD, an infectious disease

specialist at Strong Children’s Research Center at the University of Rochester. “I never see these children. We’re not called about them and suddenly they’re transferred to the care of their private doctor who is not informed about what to expect. So there’s no way to assure they’re going to get the specialized care they might need. I worry about those [cases], mainly because they’re so frequent.”

Many pediatricians do not realize that near-term preemies are also more susceptible to infections such as respiratory syncytial virus, or RSV. “They think it’s just another baby that has bronchiolitis or a cold. They don’t realize that this may be the exceptional child,” Hall said.

Behrman also reported that compared to full-term babies, near-term preemies have more problems with breathing, feeding, maintaining temperature, jaundice, hyperactivity, fine motor skills, mathematics, speaking, and reading and writing. Paul Checchia, MD, a pediatric cardiologist and director of the pediatric ICU at St. Louis Children’s Hospital, said that many pediatricians report that they cannot get reimbursed for the extra visits children born at 34 weeks or later

Populations Vulnerable to Preterm Birth

- In 2003, non-Hispanic African-American women suffered the highest rates of preterm birth in the United States, 17.8 percent.
- Also in 2003, white women had an 11.5 percent rate of preterm birth. Asian and Pacific Islander women had 10.5 percent preterm birth rates.
- African-American women deliver their infants before 37 weeks of gestation twice as often as women of other races. They deliver infants before 32 weeks of gestation three times as often as white women.
- The most notable increases in preterm birth rates from 2001 to 2003 were for white non-Hispanic, American Indian and Hispanic groups.
- Rates of preterm birth vary markedly by state, regardless of ethnic background. For example, in Texas and some other Southern states, white women had preterm delivery rates of about 11 percent in the late 1990s. In Oregon, Washington and some other Northern states, rates were between 8 percent and 9.4 percent.
- Infant mortality for preterm births also varied considerably. For example, Georgia, Illinois and the Carolinas had 45 to 57 deaths per 1,000 live births in the late 1990s. Several Western states had 28 to 35 deaths per 1,000 live births during the same period.

SOURCE: *Institute of Medicine*

need. (Checchia was scheduled to participate in the roundtable, but was unable to attend. He was interviewed at a later date.)

Transitioning Out of the NICU

“There’s what I would call a premature abandonment which occurs after the nursery experience. I think with exceptions mainly for research purposes, kids are not followed much beyond two and three years of age, and you’re not at a point where you can actually determine if in fact a lot of things are

going to impact these people later in life in the educational systems and so forth,” said David K. Stevenson, MD, Harold K. Farber Professor in Pediatrics, Lucile Packard Children’s Hospital at Stanford University.

“There are safeguards written into healthcare guidelines that say this child should receive the services once he or she goes home... [But] there are usually months of delays before people in the community are available to make assessments and then pick up on that program,” said Panitch.

Martin added that the general pediatrician is an important advocate for the preemie during this period. But the pediatrician faces obstacles as well, including time pressures and reimbursement challenges. To alleviate some of these roadblocks, a different approach towards preemie care needs to be adopted.

“Perhaps prematurity should be thought of as something that doesn’t happen for a period of time and then is over with. It’s a condition that is extended over a lifetime, and if you’re fortunate and things go well, you can live a very good life, indistinguishable from your friends and the rest of your family. But you are at risk for a lot of other things unless you pay attention over the long term,” Stevenson said. “If you change the conceptual framework from something that’s over and done with in the nursery to something that actually is a condition, like cancer, that needs to be attended to vigilantly, you’ll maximize the return on that original investment.”

Preemies and the Pediatrician

How can pediatricians optimize treatment for preemie children? Here are a few recommendations from panel co-chair Richard E. Behrman:

- Establish a strong line of communication with the neonatal unit. Neonatologists can provide a wealth of information on the unique physiology of preemies—for example, on how their bodies may respond differently to infection.
- Be aware of what resources are available in the community for preemies. Staff at neonatal units may be able to point you in the right direction.
- Be acutely aware of whether the child is developing properly using growth charts specially designed for preemies. Even if they’re not on the normal chart, you should still expect them to grow.
- Take continuing education courses about the special needs of preemie children. Many pediatricians were trained at a time when preemies rarely survived infancy. But because the number of preemie children coming through your practice will continue to grow, it’s never too late to learn more about them.

“If you ask how we’re going to change this, it could be to somehow educate parents and the world that this is like oncology or any other disease – a lifetime problem that’s going to be recurrent.”

Dr. Hall



Hall agreed: “It occurred to me that oncology is a very good model because it has the blessing, if it can be called that, of being recognized as a disease that kills. There is an absolute understanding that should a cancer patient survive, it’s not survival forever. It’s survival for five or ten years. They’re given a lifetime protocol. What we need to do then for prematurity, is the opposite of what has been done. Now, it is considered that once they’re out of the NICU, they survive. If you ask how we’re going to change this, it could be to somehow educate parents and the world that this is like oncology or any other disease – a lifetime problem that’s going to be recurrent.”

Als, too, thought that the way cancer patients are treated is a model to strive for. “When you look at how patients are treated in oncology, they’re all known as individuals. They have an identity and are greeted as individuals. Our babies have certain needs, but instead of treating them as individuals, we care for them systematically. We provide the care and wrap them up in three-hour intervals. That’s not how a baby can function, and that’s not how a mother can function.”

The oncology model is even applicable for tracking premies after they leave the NICU. “We all agree that there’s been striking success over the last 20 years or so in pediatric oncology, and one of the major reasons from my point of view is that they’ve established an absolute model in pediatrics for clinical trials, and you can virtually not be a pediatric oncology patient and not be in a study, and often in a large national study. I think we have too many lost opportunities,” Barbara Schmidt, MD, PhD, a pediatrician and epidemiologist at McMaster University noted.

Early Development and Longer-Term Issues

In the time after hospital discharge, the home environment and the school becomes crucial to a child’s development. This can put premies at a disadvantage, as a disproportionate number of them are raised in poverty. “For those of us who serve an inner-city population, it’s concerning to see babies leave our doors and go into an environment that is well documented to make their outcome worse,” Schmidt said.

The burdens on teachers are especially onerous in the most impoverished school systems, said Linda Vila, an assistant professor of health care and public administration at the C.W. Post Campus at Long Island University and host of the roundtable. “You have a classroom of 40 kids with three ex-preemies who are disruptive and have learning problems. These children are getting none of the resources they need to excel in that environment,” she added.

Schmidt, who is doing a five-year follow-up study of premies, said she frequently hears from parents who had been told that their children were okay at the end of their second year after leaving an early intervention program. But as they prepared to enter school at age five, they were found to have behavioral, cognitive, or speech and language deficits. “When the clinical psychologist sits down with the parent, their world



comes tumbling down because they have no clue,” she said.

“The transitions between the NICU and the outlying hospital, the practice, even the adult world, are inherently difficult,” said Denne “Focusing time and resources on these transitions may be a real opportunity to improve life for this population.”

OTHER CONSEQUENCES OF PREMATURITY

In addition to discussing the specialized care premies need and the effects of preterm birth on their health, the roundtable

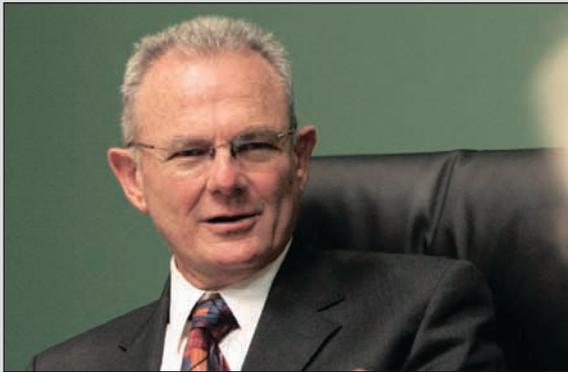
The Costs of Preterm Birth

- The societal economic burden associated with preterm birth in the U.S. was at least \$26.2 billion in 2005, or \$51,600 per preterm infant.
- The largest cost was medical care (\$16.9 billion). More than 85 percent of medical care services were delivered in infancy.
- Lost household and labor market productivity totaled \$5.7 billion. Other costs include maternal delivery (\$1.9 billion), special education services associated with cerebral palsy, retardation, hearing and vision loss (\$1.1 billion), and early intervention (\$611 million).
- These estimates are likely too low as there is insufficient data on several categories of cost, such as the cost of caregivers to individuals with disabling conditions or other special education services.
- Forty percent of preterm births are reimbursed by Medicaid.
- Although extremely preterm births comprise just 6 percent of all preterm births, these infants accounted for more than one-third of total medical costs associated with preterm birth through 7 years of age.

SOURCE: *Institute of Medicine*

participants talked about other consequences of prematurity including emotional and financial burdens.

“I think within the neonatology group worldwide, we’ve been shooting ourselves in the foot because some of us have been so eager to show good outcomes, [to show] that disabilities aren’t so bad after all, and people have good quality of life despite them. While this is factually true, Schmidt said, “we as a community have to get past this because we all agree around this table that prematurity affects you lifelong and is a potential disability. But there are other people out there that are on almost a crusade to quote the opposite.”



“Parents don’t have paid leave for the time that their child is in the NICU,” Als noted. With a typical six-week leave, many parents have to return to work when their baby may need them the most. “We would like the parents to be at the NICU 24 hours, and they would like to be there 24 hours, and the baby wants them to be there 24 hours, but they are caught. I think that’s a major policy issue if we want to move ahead in getting support to the baby.”

While a preemie baby is emotionally and financially taxing on a family, taxpayers and providers also shoulder some of the costs associated with prematurity. The annual cost of lost household and labor market productivity from families of preemies is estimated at \$5.7 billion.

MOVING FORWARD

Toward A Continuum of Care

“Neonatologists are still inclined to look for their clinical slam-dunk finding, and that’s no longer likely to be the case,” said Stevenson. “I used to think of prematurity as a fairly straightforward condition that might even have a singular cause. Now I’m convinced that it’s actually a very complex syndrome. It has many contributing causes and highly variable outcomes, and the only way then to address it is in a

Effects of Prematurity

Preemies face a variety of problems related to their disrupted development.

- **Central Nervous System.** Incomplete formation of the central nervous system makes preterm infants vulnerable to CNS injury, whether through delivery, infection or exposure. Short-term complications include bleeding in the brain; longer-term outcomes include cerebral palsy, mental retardation and more subtle disorders of CNS function such as learning and behavioral disorders.
- **Immune System.** Preterm infants’ immature immune systems are inefficient in fighting off bacteria and viruses that can cause infection. Infection is related to many of the complications of immaturity, including pneumonia, sepsis and meningitis. Immunity is further compromised when caretakers must insert catheters, needles or other invasive devices. As many as 65 percent of infants with birth weights under one kilogram contract at least one infection during their first hospital stay.
- **Cardiovascular System.** Congenital heart defects may prompt premature delivery. Fortunately, mortality in babies born with heart lesions has greatly declined due to advances in surgery.
- **Pulmonary System.** Preterm babies with immature lungs often require a ventilator to breathe. Disrupted lung development and ventilation can both increase the risk of lung injuries such as chronic lung disease. Long-term effects include asthma and risk of respiratory infection.
- **Gastrointestinal Tract.** Very premature babies have undeveloped GI tracts and must be fed intravenously. Underfeeding of these babies can stunt their physical and neurodevelopmental growth, says panelist Denne. Evidence is mounting that babies should receive larger feedings, especially of protein, he says.
- **Auditory System.** Preterm infants are 10- to 50-fold more likely to suffer from neonatal hearing disorders. Immaturity is a risk factor, as is infection and use of certain medications. Later, hearing impairment can interfere with speech production.
- **Visual System.** Preterm infants’ retinas may not be fully developed, leading to significant abnormalities of all parts of the visual system, including retinopathy of prematurity (ROP), in which blood vessels and scar tissue grow within and over the retina.



multi-faceted, multi-discerning way, and not with a singularity of focus.”

Many questions about what the future will be for this growing generation of preemies remain unanswered. But it would be unwise for the healthcare community to shrug its shoulders and wait for answers. The panelists agreed that while there is an important research agenda to be pursued, much can be done to expand services to *today's* preemies and increase the odds that *their* future will be as healthy as possible.

Als suggested striking a balance when talking to parents about the challenges preemies face. “We ought to be careful that we don’t devastate people. I think that negative predictions just pull the rug out from under parents. And while these children are at very high risk, on the other hand they are very special children. They are really extraordinary. When you point out that they have survived against all odds and they will always stay special, they’re going to have a special way of processing their environment.”

Several participants suggested that thanks to the establishment or expansion of NICUs in many hospitals, more preemies are surviving into childhood. “Hospitals,” Stevenson argued, “should therefore consider it their responsibility to help the physicians and other specialists who are doing this

very, very important work on the follow-through of newborn infant care. It’s not only morally correct, but I think it’s fiscally an appropriate thing to do.”

Hall called for more education. “I took it that our charge was to answer what we can do right now and what is the most cost effective and the cheapest way. And to me, that answer is education. Education of our house staff, our personnel, our parents, our doctors, our hospital administrators. We can’t always have all the added personnel we want, but as part of our accreditation as physicians, as NICUs, as any of these other residencies, additional education should be required.”

Stevenson recommended tying reimbursement more closely to longer-term outcomes. This can be difficult, but “there is something rational and moral about looking at your whole spectrum of work product,” he said. “In other words, if you are going to invest so much on one end, why don’t we have an easier way to transition to the baby’s home, and the community and the resources that reside there.”

The participants had several immediate suggestions for bridging the gaps in premie care from the NICU through adulthood:

- Ensure that pediatrics residents are given more extensive training in the post-discharge needs of preemies.
- Expand eligibility criteria for early intervention services to include near-term preemies and underserved populations (for example, families located in rural or outlying areas, poor families, or families with inadequate insurance coverage).
- Extend the duration of developmental screening and monitoring throughout childhood, not just through NICU discharge or the first three years.

“Physician leaders and professionals have been reluctant to lobby, to be involved,” Dennery told the panel. “But we are all responsible to educate and to fight for change. We as leaders, have to educate the public and the policymakers that things can’t go on as they have.”

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Dr. Dennery

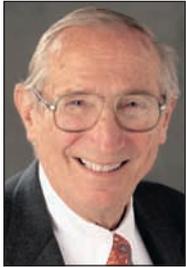
Roundtable Participants



Heidelise Als, Ph.D.
Associate Professor of Psychology
Harvard Medical School/Children's
Hospital Boston



Richard Martin, M.D.
Director, Division of Neonatology
Drunsinsky-Fanaroff Chair in Neonatology
Rainbow Babies & Children's Hospital



Richard Behrman, M.D.
Chair, IoM Committee on Understanding
Premature Birth and
Assuring Healthy Outcomes



Howard Panitch, M.D. **
Pediatric Pulmonologist
Division of Pulmonary Medicine
Children's Hospital of Philadelphia



Paul Checchia, M.D.
Chief, Pediatric Cardiac Critical Care Service
Co-director, Pediatric Intensive Care Unit
St. Louis Children's Hospital
Assistant Professor of Pediatric Critical Care and
Cardiology Washington University School
of Medicine



Barbara Schmidt, M.D., Ph.D.
Professor, Departments of Pediatrics and Clinical
Epidemiology & Biostatistics
McMaster University



Scott Denne, M.D.
Professor of Pediatrics;
Associate Chairman – Clinical Research
Indiana University School of Medicine



David K. Stevenson, M.D.
Harold K. Farber Professor in Pediatrics
Lucile Packard Children's Hospital at
Stanford Neonatology



Phyllis Dennery, M.D.
Chief, Division of Neonatology and
Newborn Services
Children's Hospital of Philadelphia
Attended on behalf
of March of Dimes



Linda Vila, J.D.
Assistant Professor, Health Care and
Public Administration
College of Management, School of
Public Service
C.W. Post Campus of Long Island University



Caroline B. Hall, M.D. *
Professor, Pediatrics and Medicine in
Infectious Disease
Strong Children's Research Center
University of Rochester Medical Center

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