# A Quiet Crisis: Racial Disparities and Infant Mortality

BY JESSICA TOMER

**Infant mortality. Sociologically, it is the litmus test for a nation's overall health. Emotionally, it represents unfathomable loss.**

**Nurses and other health care professionals must discuss the issue clinically, distancing themselves from the emotional ramifications. Yet, the shocking but rarely discussed statistics surrounding infant mortality in the United States merit more attention than calm discussion. Because when nearly twice as many minority babies are dying than their Caucasian counterparts, complacency is unacceptable.**

There's no dancing around the issue: African American infants are 2.5 times more likely to die than non-Hispanic white infants. Statistics are comparable among Native American babies as well. Research spanning the last 30–50 years shows these disparities have remained consistent for generations. On average, the United States has an infant mortality rate of 6.7/1,000. Among non-Hispanic African Americans, the rates today are double, with 13.4/1,000 infant deaths, as published in 2011 in *Obstetrics & Gynecology*.[1]

The CIA publishes a list of the world's countries ranked by their infant mortality rates. At the bottom, with the highest rates of neonatal deaths: Afghanistan, Angola, Somalia. At the top: Monaco, Singapore, Sweden. Where's the United States? It doesn't even crack the top 30, falling behind nearly all of its "first world" contemporaries.

In some states, including Mississippi, Alabama, and Arkansas, the infant mortality rates among African Americans are comparable to those found in third-world countries, with 18–22/1,000 live births in certain counties.

Direct causes of infant death are primarily congenital anomalies/

birth defects, followed by premature births, then sudden instant death syndrome (SIDS). (SIDS was the second-leading cause of neonatal deaths, but after years of effort and outreach, it is now third.) The solutions seem so simple: take care of women before they become mothers and teach them how to properly care for their babies. But the statistics remain stagnant, pointing to an urgent need for more education, community resources, and government action. And, as always, nurses are on the front lines.

## Spreading the word

The U.S. Office of Minority Health approached Tonya Lewis Lee, director of the 2009 documentary *Crisis in the Crib: Saving Our Nation's Babies*, to act as its national spokeswoman for A Healthy Baby Begins with You campaign about four years ago. She accepted and soon learned the seriousness of infant mortality in the United States. She says she had no idea the rates were so high, particularly among African Americans.

"I had to get involved to spread the word, to figure out why the rates are what they are," Lewis Lee says. "I've learned a lot and shared a lot." She says she is healthier now than ever before. "I really feel that taking care of yourself first is critical," she says. "We need to lead by example." And the crux of A Healthy Baby Begins with You is teaching mothers the importance of self-care and preconception health.

"Nurses have been extremely powerful in the information they give to patients," Lewis Lee says. They have a relatively intimate relationship with patients; with cross-cultural training, nurses can effectively treat those from different backgrounds.

Lewis Lee also works closely with the U.S. Health and Human Services Office of Minority Health's Preconception Peer Educator (PPE) program, which coordinates student ambassadors educating others about healthy pregnancies. "The idea of peer education is great because it goes back to understanding the community they're talking to," Lewis Lee says. The program, which started with 60 students, now has over 1,000 ambassadors. "I'm very proud of our students," Lewis Lee says. "It's a movement. It's a health movement for young people."

Yet, while such grassroots efforts are critical, higher-level changes are needed as well. "A lot depends on what goes on politically," Lewis Lee says. During the ongoing health care reform debate, infant mortality seems to be swept under the rug. Lewis Lee envisions a move toward preventable care, an improved focus on health disparities, and perhaps advances in genetic research and its affect on personal health.

Every child is an opportunity to improve the nation as a whole, she says. "I don't know that we as a nation really take the health of every citizen very seriously. . . . Some people we think are expendable," Lewis Lee says. "Somehow we need to figure out a way to make that better."

## Room for improvement

"As a public health official, we are the eternal optimists," says Garth Graham, M.D., M.P.H., F.A.C.P., Deputy Assistant Secretary for Minority Health for the Office of Minority Health at the Department of Health and Human Services.

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Graham lists three reasons he sees potential for improvement in U.S. infant mortality rates:

1. Infant mortality is related to many other factors, such as the preconception health of the mother, and with efforts to expand preventive care, "we will see healthier mothers" and subsequently, healthier babies.
2. Advances in medicine will continue to help care for premature babies and other complicated births, particularly as urban areas see improved resources.
3. A number of areas, such as Tennessee, following both local and federal efforts, has seen improved infant mortality rates, offering an imitable example and showing progress is possible.

But the eternal optimist acknowledged several obstacles as well, such as social determinants, lack of access to care, and high rates of teenage pregnancies. "The major challenge is how to deal with all of this holistically," Graham says. "Nurses, more than any other profession, are on the front lines of infant mortality."

Community resource nurses serve a key, multifaceted role in helping would-be and young mothers, Graham says. "We really want to encourage nurses . . . to be as proactive as they have been," but even more so. "Nurses are more than just healers," Graham says. They are influencers. "People who serve as role models make a huge impact."

Peter C. van Dyck, M.D., M.P.H., Associate Administrator for Maternal and Child Health for the U.S. Department of Health and Human Services' Health Resources and Services Administration

## The situation in the United States

Despite the country's wealth and technological advances, the United States' global infant mortality ranking has actually worsened since the 1960s, when the nation had the 12th-lowest infant mortality rate. Today, according to CIA estimates, the United States is approximately 46th in the world.

"This international standing is largely driven by large racial and ethnic disparities that exist in infant mortality

in the United States," says Peter C. van Dyck, M.D., M.P.H., Associate Administrator for Maternal and Child Health for the U.S. Department of Health and Human Services' Health Resources and Services Administration. "If all United States infants had the infant mortality rate of white infants, the overall infant mortality rate would decline about 15%, and our infant rate mortality ranking would improve about four places." The United States also lacks many European nations' paid parental leave, welfare, and access to health care. "According to the latest data in 2007, less than 70% of women received prenatal care in the first trimester," van Dyck says.

The clearest cause of racial disparity is the higher preterm birth rate for black infants. "Black women are four times as likely as white women to deliver very early," van Dyck says. "This racial disparity may be caused by socioeconomic disparities not just in adulthood but across the life-course, stress and discrimination, environmental quality differences as a consequence of residential segregation (e.g., pollution, crime, access to parks and supermarkets), and also differences in infant sleep practices."

Van Dyck points to the Patient Protection and Affordable Care Act of 2010 and its creation of the Maternal, Infant, and Early Childhood Home Visiting Program (MIECHV), a provision put in place "to respond to the diverse needs of children and families in communities at risk, and provides an unprecedented opportunity for collaboration and partnership at the federal, state, and community levels to improve health and development outcomes for at-risk children through evidence-based home visiting programs."


Tonya Lewis Lee, director of *Crisis in the Crib* and spokesperson for A Healthy Baby Begins With You campaign

MIECHV aims to provide comprehensive health services to these children and families, particularly expectant mothers. "Maternal health, especially the health of the mother during the prenatal period, is a critically important factor to ensure a healthy birth outcome," van Dyck says. Some of the benefits of home visits include decreased instances of smoking, substance abuse, hypertensive disorders, and domestic abuse. Regarding child health outcomes, families receiving home visits experienced lower risk of low birth weight children, higher attendance at well child visits, more prevalent health insurance coverage, higher intellectual development, and improved rates of breastfeeding, among other things.

"It is our vision that positive changes in maternal and child health outcomes will be significantly enhanced as the states implement evidence-based home visiting programs, embedded within a high-quality early childhood system," van Dyck says.

## Understanding and combating

"We strongly believe that a child needs a good beginning," says Yvonne Maddox,

Yvonne Maddox, B.S., Ph.D., Deputy Director of the National Institute of Child Health and Human Development, National Institutes of Health

B.S., Ph.D., Deputy Director of the National Institute of Child Health and Human Development, National Institutes of Health. She stresses that leaders need to take a more aggressive approach in making child health a top priority. "It is really very, very disappointing that we haven't done more."

In the infant mortality crisis, Maddox says other environmental factors must be taken into account as well, such as community and overall maternal health, the quality and accessibility of the health care system, the socioeconomic status of the community, and public health regulations. "We are targeting all the areas," she says.

Maddox focuses specifically with communities experiencing health disparities, including African Americans and Native Americans. Like the gross disparities that exist among black communities, Native American infants in some areas of the country, such as Minnesota and the Dakotas, are also twice as likely to die as their white counterparts. Routine nurse home visits to a young mother on a reservation, for example, may provide the hands-on care and continued support needed to ensure the child sees its first birthday. "It pains me" to see the extremes, Maddox says. "I don't want my country to look this way."

Long-term solutions require a deeper understanding of social and environmental determinants. "We need to really study these things in a systematic way," Maddox says. And now, with the launch of the National Children's Study, researchers are. Though still in the recruitment stages, this unprecedented study hopes to follow 100,000 children across the country from pre-birth to 21 years old. "There are a lot of things we can look at in 21 years," she says.

Researchers will monitor the environments American mothers and children occupy, and how factors such as air quality, nutrition, family dynamics, genetics, and culture affect children's health,

growth, and development. By working with expectant mothers, the study can incorporate the effects of family medical history and pre-pregnancy exposures on birth outcomes, providing important insights for the future.

Maddox says the study should shine new light on chronic issues such as obesity, autism, and depression/mental health. Though findings will be published throughout the study, researchers are years away from answers. Maddox hopes the economic downfall and recession do not damage the study's viability—or the essential health care services already in place. "It's critical that we work with our policy makers and educators," she says. "We're already working with such dismal numbers."

## Cultural competency

Minority communities may not participate in infant mortality outreach as often, Maddox says, perhaps due to lack of trust or simply not knowing the resources are available. Some may assume at-risk groups do not "get it" or don't want to try to improve the situation, but "the communities want information. They want to know. They want the facts," Maddox says. Such misunderstandings make group feedback even more essential.

"Cultural competency in messaging is critical," Maddox says. Nurses and other providers must figure out how to best interpret results of current and future studies so the message is crystal clear to patients. While pediatricians and OB/GYNs may be expected to educate their patients regarding prenatal and preconception care, information can get lost in translation. That's where nurses come in. "They are able to communicate the message very substantially," Maddox says.

Nurses of all ethnicities should understand unique backgrounds and cultural sensibilities. Hispanic communities or Native American tribal groups may require a different set of tools than a predominantly African American community. Pregnant women, women with disabilities, and other special populations also require special targeted messaging. Even nurses in the trenches of these areas may not realize the importance of translating information for patients and the community at large.

With the SIDS campaigns of the 1990's, colleges and universities teamed with health educators, faith communities, nursing organizations, and continuing education programs, working together to design a safe sleeping program. They produced literature describing proper infant dressings, approved cribs, and do's and don'ts for new mothers and even other health care professionals. Nurses who completed the program then disseminated the materials.

"We found that the way to address these issues is to launch strong education campaigns," Maddox says. Researchers also point to increased training of health care workers, like midwives and community clinic staffers, so there are enough caregivers to attend to these mothers and babies.

Government agencies like the NIH need to understand how communities interpret campaigns as well, Maddox says, making bolstering public trust another priority. And health care providers need to build a foundation of trust in their communities too. As one of the most trusted professionals, nurses can hit the ground running.

## Solutions for nurses

"Minority nurses bring a breadth of knowledge and experience to every aspect of health, contributing to excellence in health care for women and children," van Dyck says. "Public health nurses, for example, are leading the effort for community-based approaches to resolve infant mortality disparities."

There's Healthy Start; the Healthy Mothers, Healthy Babies campaign; and Lewis Lee's A Healthy Baby Begins with You. Nurses can also use the Fetal and Infant Mortality Review (FIMR) process to coordinate community dialogue and address community-specific issues related to infant mortality, from bereavement and postpartum depression to barriers to care, SIDS risk reduction, and substance abuse. "Community-based FIMR is an action-oriented continuous quality improvement process with a significant role in building community partnerships, understanding community issues, and developing culturally sensitive interventions," van Dyck says. There are roughly 200 such programs located throughout the country, in 40 states and some U.S. territories.

"Communities will address their health issues if given information and forum for resolution," van Dyck says. "FIMR teams have learned that many

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> — Karla Damus, Ph.D., M.S.P.H., M.N., R.N., F.A.A.N., clinical professor of nursing at Northeastern University in Boston and member of the CDC's preconception health expert panel and March of Dimes' Nurse Advisory Council

health messages are not culturally and linguistically appropriate, are not reaching all of the varied ethnic groups in each community, and are not being delivered by a messenger specific to each group and whom the community trusts." Consequently, FIMR has developed culturally appropriate educational materials and services.

Karla Damus, Ph.D., M.S.P.H., M.N., R.N., F.A.A.N., a clinical professor of nursing at Northeastern University in Boston and a member of the CDC's preconception health expert panel and March of Dimes' Nurse Advisory Council is looking for a paradigm shift in neonatal care.

People don't understand, Damus says, that to fully understand infant mortality rates, they must also incorporate fetal mortality rates, including miscarriages. "Families are just as devastated" and women are just as likely to experience an increased risk with subsequent pregnancies. She encourages nurses and health care providers to widen their scope as well. It's not only about the tragic deaths, but the "near-misses," the sickly infants, the NICU. We don't just want our babies surviving, but thriving, she says.

Damus says nurses and their patients can think of the uterus as a muscle subject to the same risk factors as the heart; just as with heart attacks and disease, health care providers should look at family history of preterm labor and pay attention to red flags. Doctors should also know the pregnant woman's birth weight and whether she was born early or late. "We're talking about these life-course perspectives," Damus says. "We've got to do everything we can for men and women."

Healthy start initiatives may be targeting pregnant women in black communities, but "you've got to make them healthier long before they conceive," Damus says. "It's all about wellness promotion." Damus speaks with a tinge of annoyance, perhaps anger, about the lack of advocacy for folic acid. One of the simplest, most cost-effective solutions to curbing infant mortality rates seems to be an afterthought for many health care providers. All sexually active women should be encouraged to take folic acid once a day or more, she says. "Did you take your folic acid?" should be one of neonatal nurses' first questions Social media can be used to disseminate daily folic acid reminders. She even wants to see scrub caps with that question emblazoned on it.

But what seems like the most obvious solution—ensuring the health of the mother to protect the health of her unborn child—just leads back to overarching health disparities nurses and other providers have been and must continue fighting.

"We still do lousy despite all our priorities, and that's because families aren't a priority," Damus says. "This is science as well as social justice." In addition to lackluster infant mortality rates, the racial and ethnic disparities don't seem to budge. "We should be outraged that we're not making progress," Damus says. "Yet, there are places that do, that show it is possible." Damus' former home, the Bronx, had an infant mortality rate of 15/1,000. Now, it is lower than the U.S. average, a result of years of concentrated efforts.

Damus also advocates full-term deliveries whenever possible, avoiding scheduled earlier births. She categorizes the phrase "near term" with the saying "you're a little bit pregnant." You either are or you aren't, she says.

Finally, nurses must arm themselves with adequate information, like making themselves aware of any medications that can compromise pregnancies. They can even teach expecting mothers to count kicks later in their development (a practice now back in vogue, Damus says). She also recommends healthy intervals between pregnancies and making sure fathers are involved too. "All the other stuff is just wellness!

"The nurse is key as the advocate," Damus says. But she maintains: "we can do a much, much better job."

## Life goes on

At the end of the day, perhaps the solution isn't so simple after all: we need healthier people—healthy from birth—to grow up and conceive the next generation of healthy babies. Quite the chicken-and-the-egg scenario, and one dependent on an embattled and changing health care system.

What might happen in the next 10–20 years? "I'm not sure," Damus says. "I don't expect big changes."

"If we look at the trend of the past 15 years, we expect the infant mortality rate to decline further in the coming years," van Dyck says. However, the rate of decline during past years was "modest," even largely unchanged from 2000–2007. He says recent infant mortality rates have been influenced by increased births among women over age 35 and little improvement in smoking before and during pregnancy.

"We really have to involve all the stakeholders," Maddox says: nurses and doctors, mothers and fathers, government and community leaders. With an issue as complex as infant mortality, there can never be enough resources and research.

"A country's infant mortality rate is one of the most important indicators of health," Maddox says. "We have a lot of work to do." MN

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**Resource**

Spong, C.Y., Iams, J., Goldenberg, R., Hauck, F.R., & Willinger, M. (2011). "Disparities in Perinatal Medicine: Preterm Birth, Stillbirth, and Infant Mortality." *Obstetrics & Gynecology.* 117(4) 948-955.