A Process to Address Disparities in Rates of Sudden Infant Death Syndrome

SARAH J. MCDERMOTT SHAEFER, RN, PHD,
ELLEN HUTCHINS, SCD, MSW,
KATHLEEN BUCKLEY, MSN, CNM

Fetal and Infant Mortality Review (FIMR) is a continuous quality improvement program that leads to improvements in services and resources for families and, ultimately, a decrease in infant mortality. It is an action-oriented process that combines medical data with the mother's report of experiences during the life and death of her infant. The FIMR has proven to be especially important in addressing community issues associated with infant deaths related to sudden infant death syndrome.

Unique among all health outcomes, infant death is viewed as a sentinel event that serves as a measure of the community's overall health and economic well being. It is also a measure of the organization and abilities of the local health and human services organizations and the robustness of community resources.

In 1988, the U.S. Public Health Service proposed a review of infant deaths as a local strategy to address infant mortality. This approach features a community-based examination of a broad array of factors that might contribute to fetal and infant death and the mobilization of community resources to prevent future deaths.[1] The process was developed by the federal Maternal and Child Health Bureau and became known as Fetal and Infant Mortality Review (FIMR).

Many communities across the United States have now established FIMR programs as a way of gaining insight into the causes of such deaths and of devising and implementing ways to improve the health of pregnant women and their infants.[2,3] The program embodies many of the principles of continuous quality improvement (CQI), including the use of teams, a focus on the team mission, and the examination of processes rather than individuals.[4] It involves public heath agencies, health care providers, institutions, policy makers, community leaders, and community advocates in the processes of data review, planning, and action implementation to improve local systems' ability to respond proactively to fetal and infant mortality.[5]

KEY STEPS IN THE FIMR PROCESS

The FIMR is a community-oriented action process that results in improved service systems and resources for women, infants, and families.[6] It is a CQI cycle that involves data collection, case review, community action, and change in community systems (Figure).

The first step of the process is data collection. A two-pronged

Dr. McDermott Shaefer is Past President, Association of Sudden Infant Death Syndrome and Infant Mortality Programs, and Founder, Health Care Answers, Baltimore. Dr. Hutchins is Chief, Perinatal and Women's Health Branch, Maternal and Child Health Bureau, Rockville, Maryland. Ms. Buckley is Director, National Fetal and Infant Mortality Review Program, American College of Obstetrics and Gynecology, Washington, DC.

The development of this document was supported by a grant to the National Fetal and Infant Mortality Review Program, American College of Obstetricians and Gynecology, from the Maternal and Child Health Bureau, Health Resources and Services Administration Grant #U08 MC 00136. The opinions expressed herein are those of the authors and do not necessarily reflect the views or policies of the Maternal and Child Health Bureau, the Health Resources and Services Administration, or the U.S. Department of Health and Human Services.

approach is used to learn as much as possible about the circumstances surrounding the fetal or infant death. Data concerning the pregnancy, child's health, and death event are obtained from medical records and other sources, such as social services and emergency medical transport records. In addition, the mother is interviewed to gain her perspective on the death. The home interview is a unique and special part of all FIMR programs.[7] It provides a window into the mother's life and sheds light on the factors associated with her baby's death. The interview yields community-specific information that cannot be gathered from vital statistics alone. For example, the mother provides a wealth of qualitative information about her encounters with community service systems, how they were helpful, how they could be improved or expanded, and what additional services might be useful. This combination of quantitative and qualitative data provides a comprehensive picture of the medical, social, and environmental factors that might have contributed to the death and offers insight on what can be done to prevent future deaths.[8]

The next step is the case review. A multidisciplinary team of professionals meets to examine the de-identified data collected from official records and the maternal interview. The team evaluates the death to determine whether it is unique or part of a pattern of deaths in the community. This information forms the basis for community action, which is the hallmark of the FIMR process. A community-action team composed of community leaders, businesses, elected officials, providers, advocates, and consumers develops recommendations for changes and innovations that can improve local service systems and resources. The effects of these changes in the community systems are monitored to assess progress in reducing fetal and infant deaths and to direct future planning efforts.

The South Dakota FIMR experience illustrates the CQI approach that is the cornerstone of this program. In 1998, the Regional Infant and Child Mortality Review Committee's annual report noted an alarming increase in deaths from sudden infant death syndrome (SIDS) in the region.[9] This information was then submitted to the community-action team, which determined that a "Back to Sleep" message—advising parents to lay young infants on their backs to sleep, rather than their stomachs—needed to be specific to the area's American-Indian population. To determine the effectiveness of changes made to the educational campaign, the Committee continued to review SIDS deaths in the community. As this case demonstrates, one important outcome of the FIMR process has been to develop SIDS risk–reduction messages that are culturally appropriate, relevant, and accessible to underserved members of the local population. Although SIDS is a leading cause of death among infants of all racial and ethnic groups, the rates of SIDS among African Americans and American Indians are higher than among Caucasians.[10–16] Part of this racial disparity in SIDS rates can be attributed to a failure to reach these racial and ethnic minority groups. A key goal of the FIMR process is to collect data that can be used to develop educational messages and outreach strategies specifically targeting the community groups at greatest risk for fetal and infant death.

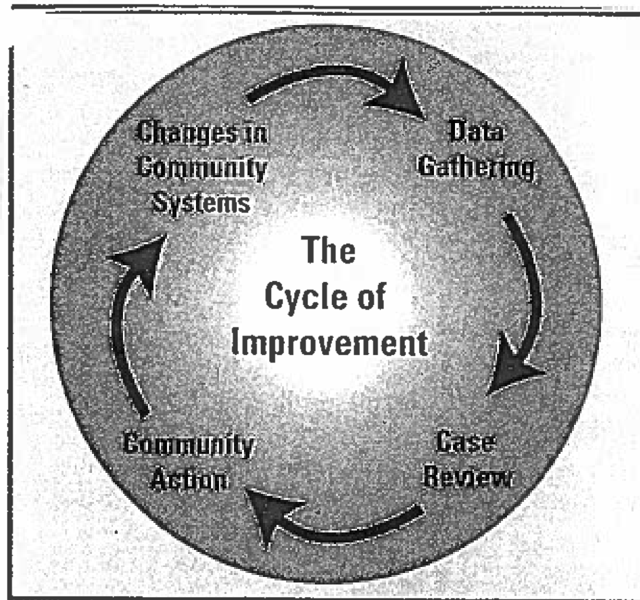

Figure. The National Fetal and Infant Mortality Review process of continuous quality improvement.

DISPARITIES IN SIDS RATES

Although the United States has made progress in reducing its infant mortality, the rate of decline has slowed in the past 10 years.[16] Twenty-two percent of all infant deaths are attributable to SIDS.[16] Sudden infant death syndrome is defined as the sudden death of an infant under one year of age that remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history.[17] It is the leading cause of death for infants older than one month of age. Rates of SIDS are highest among African Americans and American Indians, and lowest among Asians and Hispanics (Table).[10–16]

Infant sleep position, exposure to smoke, and overheating

during sleep can increase the infant's risk for SIDS.[18–20] Additionally, the mother's health and behavior during her pregnancy and the infant's health before birth influence the occurrence of SIDS. Mortality from SIDS has declined significantly since the 1994 initiation of the "Back to Sleep" campaign. Although overall SIDS rates have declined, the racial disparity persists. The rate of SIDS among African Americans remains twice that of Caucasians.[16]

Parents and caregivers can reduce the risk of SIDS. Recent studies report that the sleep environment is a significant risk factor for SIDS in the African-American community.[18] Soft bedding, pillows, and bed sharing increase risk and should be eliminated. Cultural explanations[19] for specific infant-care practices must be understood to decrease SIDS risk factors. Sheers and colleagues[20] reported that infants sleeping on adult beds, sofas, or chairs have a significantly higher risk of dying of suffocation, and that such deaths are increasing (Table).

TABLE **MORTALITY FROM SIDS (PER 100,000 LIVE BIRTHS) BY RACE AND HISPANIC ORIGIN OF MOTHER, PER YEAR**

Race	1995	1996	1997	1998	1999	2000	2001
All races*	87.2	78.5	77.2	71.7	66.8	62.1	55.5
Caucasian	72.3	64.3	64.8	59.5	55.6	51.8	45.6
African American	166.6	153.8	143.2	137.9	129.9	122.1	113.5
American Indian†	206.6	203.3	155.6	151.5	146.9	120.0	145.7
Asian & Pacific Islander	49.9	44.0	51.2	39.4	31.0	29.4	18.5
Total Hispanic‡	47.7	48.5	46.5	37.4	37.2	34.3	27.1

*Includes races other than African American and Caucasian.
†Includes Aleuts and Eskimos.
‡Includes Cuban and other and unknown Hispanics.
SIDS = Sudden infant death syndrome.
Note: The linked birth/death data set is from birth and infant death certificates registered in all States, the District of Columbia, Puerto Rico, the Virgin Islands, and Guam. Race is based on birth certificate data. Race and Hispanic origin of mother are reported as separate items on the birth certificates and therefore a mother of Hispanic origin can be of any race.

MORTALITY REVIEW TAKES ACTION

The 220-plus FIMR programs in 40 states reported common characteristics of families most at risk for SIDS. Many families have not been exposed to SIDS risk-reduction messages or are unaware that the messages relate to them. In addition, some families do not trust the risk-reduction messages or those that communicate them.

The FIMR programs make significant inroads to these problems by tackling each issue. They increase community awareness about SIDS, use culturally appropriate messages that are locally significant, and ensure that a trusted messenger delivers the SIDS risk-reduction messages. The following community examples illustrate actions that typify FIMR's risk-reduction approach.

Community Awareness. The Palm Beach County, Florida, FIMR noted an increase in SIDS rates. The program worked with the medical examiner and a local health alliance on a "Safe Infant Sleeping Program" to identify messages about safe sleeping environments. The chief medical examiner spearheaded a public education campaign, with the message, "The survival of your child will depend more on where and how he or she sleeps during the first year of life than any other action or care issue during childhood." Palm Beach's coalition also developed an ongoing strategy to institutionalize SIDS education for child-care workers, hospital staff, physicians, their office staff, prenatal and postnatal care agencies, parents, and family members.

Culturally Appropriate Messages. In Oakland, California, the FIMR team found that SIDS risk-reduction literature was available only in English. The languages used in the community included English, Chinese, Vietnamese, Spanish, Amharic, Thai, Croatian, and Laotian. The FIMR team members worked together to produce SIDS educational materials in all eight languages. A low reading level was used and a special message included for grandparents. These materials are distributed throughout the community.

After reviewing many African-American SIDS deaths, the Richmond, Virginia, FIMR found that many new mothers, family members, and community day care providers did not know about SIDS risk–reduction practices. The program worked with the city's Health Department to design culturally appropriate materials and developed a door hanger with the "Back to Sleep" message using a picture of an African-American baby. The Healthy Start Consortium and the regional perinatal council distributed these throughout the community. This campaign continues today and has been adopted by several other states.

The Siouxland, Iowa, Health Department serves diverse residents, including American-Indian families. The FIMR team found that many families did not have a crib at home for the newborn. Local American

Indians believe that a pregnant woman should not make plans for the baby or buy a crib before the birth; it is considered unlucky and is forbidden by tradition. The local hospitals and home visiting agencies developed a postpartum nursing protocol to ask each new mother, "Where will your baby sleep?" A local foundation agreed to provide cribs for needy families.

Trusted Messenger. In sections of Milwaukee chosen for FIMR reviews, the FIMR team noted that some groups, including African-American, Latino, and Hmong residents, were less likely to place their infants on their backs to sleep. The health department asked faith communities in these sections of Milwaukee to help reach these families. Nineteen parish nurses coordinated a church-based Back to Sleep campaign. These nurses also integrated the SIDS message into their ongoing teaching plans. Thus, the message continues.

In Jacksonville, Florida, FIMR revealed that African-American infants accounted for nearly 50% of sleep position/location-related deaths. Nearly 80% of these deaths happened to babies who were sharing a bed or who were in an inappropriate bed. The FIMR community members initiated "Project Moses" to reduce sleep position/location-related infant deaths in the African-American community. The AME Ministerial Alliance and other community members are part of the project. Initial data revealed pregnant women needed bassinets to ensure a safe-sleep environment. Senior church members, some of whom are grandparents, were enlisted to construct the needed bassinettes. The goal is to distribute 500 bassinets.

Project Moses also provides education about risk factors associated with SIDS and sleep position/location deaths. Each bassinet contains information about the importance of a safe sleeping environment, SIDS risk reduction, and related topics. This information is also given to the church volunteers who construct the bassinets, providing an opportunity for seniors to learn about safe sleep as well.

Cultural explanations for specific infant-care practices must be understood to decrease sudden infant death syndrome risk factors.

IMPLICATIONS FOR MANAGED CARE

Beyond the toll on families and communities, infant death has significant social, programmatic, and economic implications for managed care systems. Participation in the FIMR initiative to improve service delivery and enhance prevention efforts offers significant benefits to MCOs, their members, and the community as a whole. For example, an MCO might request that all participating obstetricians, pediatricians, and birthing hospitals provide safe-sleep education to expectant parents. Additionally, the MCO could partner with community projects, such as Healthy Start, to support their clients in appropriately accessing prenatal care.

Data from FIMR can inform educational programming and service planning for the MCO. For example, Amerigroup Corporation (Virginia Beach, VA) has recently expanded its education program as a direct result of its involvement with the local FIMR program. It targets grandparents and nonlicensed care providers of infants for SIDS risk-reduction information. Amerigroup also has expanded its awareness and coordination of services for clients through community linkages. In specialized circumstances, such as infant death and its prevention, MCOs may need to rely on ancillary service referrals to support their programs. Through its involvement in the FIMR case review and community-action processes, Amerigroup learned about valuable community resources, such as home visiting by a local health department program and a residential program for substance abusing mothers and their children. In addition, the firm has been able to impress on other team members in the FIMR process the importance of case management through MCOs in achieving their goals of enhancing the health and well-being of women, infants, and families.

Participation in FIMR also can benefit MCOs' quality-assurance efforts by providing a systemwide perspective of available services and unmet service needs. The program provides a unique picture of how all the local maternal and child health systems work together on behalf of families. This helps MCOs to better define their role in this effort and determine how well they are achieving their goals. Managed care organizations can refine their programming to capitalize on existing strengths, eliminate redundant or inefficient services, and add new services to meet clients' needs.

In addition, participation in FIMR may help MCOs show improvement in Health Plan Employer Data Information Set (HEDIS)-related reporting areas, such as access to prenatal care, length of stay of newborns, and community SIDS rates. Although implementation of FIMR recommendations has not been directly studied in relation to HEDIS scores, linking the two may be one approach to evaluating FIMR's effect on both programming quality and community outcomes.

Involvement in FIMR also offers potential marketing and cost-containment benefits to MCOs. Connections to FIMR and broader community efforts to promote health and reduce infant mortality would be excellent marketing tools to attract clients of childbearing age. The expanded base of resources and services made available through FIMR-centered community networking also would be attractive to these clients. The mandate to control costs may be another incentive to participate in the FIMR process. An infant loss is often followed by another pregnancy that may be more costly, owing to additional preventive measures taken, such as special prenatal tests, maternal–fetal medical evaluations, and maternal and infant hospitalizations.

By working with FIMR to safeguard the health of fetuses and infants, MCOs can help reduce the rate of high-cost pregnancies subsequent to infant death. Data from FIMR can help MCOs make informed decisions about the cost effectiveness of different measures for protecting the fetus and preventing infant death.

The FIMR offers MCOs an important opportunity to network and solve problems with a large system of agencies, institutions, and providers. Managed care programs can use this forum to speak about issues that are important to them. One of the important findings of the FIMR national evaluation is the usefulness of the FIMR method in building local public and private sector partnerships.[5] Information collected in all components of the evaluation points to FIMR's important role in bringing diverse community members together to focus on issues related to fetal and infant deaths. The evaluation states that the subject of infant deaths inspires concern and a call to action in the entire community of medical care providers, public health professionals, policymakers, consumers, and other activists alike in ways that many other topics of public health concern have not.[5] Managed care organizations can become valued members of the community-action team working to improve family services and prevent infant death in their service areas.

Participation in the Fetal and Infant Mortality Review program can benefit MCOs' quality assurance efforts by providing a system-wide perspective of available services and unmet service needs.

CONCLUSION

Using CQI strategies, FIMR develops creative and innovative local actions to improve services and resources for women, infants, and families. Key steps in the FIMR action-oriented process include data gathering, case review, community action, and implementing changes in local community systems. The FIMR provides a structure for the community to improve the health and well-being of its youngest citizens.

Through the FIMR process, community-specific data are used to identify local system issues, promote solution identification, and gain community support. Though not limited to SIDS-prevention efforts, FIMR demonstrates effective methods for developing and disseminating culturally appropriate health-education messages about this important health concern. These strategies are able to increase community awareness of SIDS and, ultimately, decrease racial disparities in these tragic deaths.

As valued members of the community and the cornerstone of the modern health care industry, MCOs are in a unique position to both support and benefit from the FIMR process. Through data sharing and the cooperative use of resources, managed care and FIMR can become powerful partners in the effort to reduce infant deaths in local communities.

[*Editor's Note:* For more information about FIMR programs and how to start a local program, contact the National Fetal and Infant Mortality Program at (202) 863-2587 or visit www.acog.org/goto/nfimr.]

REFERENCES

1. Davidson EC Jr: A strategy to reduce infant mortality. *Obstet Gynecol* 1991; 77:1-5.
2. Baltay M, McCormick MC, Wise PH: Implementation of Fetal and Infant Mortality Review (FIMR): Experience from the National Healthy Start Program. *Maternal and Child Health Journal* 1999;3: 141-150.
3. Buckley K, Chapin JL: Fetal and Infant Mortality Review: An evolving process. *Maternal and Child Health Journal* 1999;3: 173-176.
4. Klerman LV, Cleckley DC, Sinsky RJ, et al: Infant mortality review as a vehicle for quality improvement in a local health

department. *Comm J Qual Improv* 2000;26:147-159.
5. The evaluation of FIMR programs nationwide: Early findings. Johns Hopkins University, Bloomberg School of Public Health, September 2004 (www.jhsph.edu/wchpc/pub/Brochure.pdf).
6. Buckley KA, Koontz AM, Casey S: *Fetal and Infant Mortality Review Manual: A Guide for Communities*. Washington, DC, American College of Obstetricians and Gynecologists, 1998.
7. Shaefer J, Noell D, McClain M: *Fetal and Infant Mortality Review: A Guide for Home Interviewers*. Washington, DC, American College of Obstetricians and Gynecologists, 2002.
8. Fogarty C, Sidebottom A, Holtan N, et al: Project LID (lower infant death): Lessons learned from a local infant mortality review project. *Minn Med* 2000;83(8):43-49.
9. Randall B, Wilson A: An illustrative example of infant and child death review in South Dakota: The 1998 annual report of the Regional Infant and Child Mortality Review Committee. *S D J Med* 1999;52:423-427.
10. MacDorman MF, Atkinson JO: Infant mortality statistics from the linked birth/infant death data set—1995 period data. *Mon Vital Stat Rep* 1998;46(6 suppl 2):1-22.
11. MacDorman MF, Atkinson JO: Infant mortality statistics from the 1996 period linked birth/infant death data set. *Mon Vital Stat Rep* 1998; 46(12 suppl):1-24.
12. MacDorman MF, Atkinson JO: Infant mortality statistics from the 1997 period linked birth/infant death data set. *Natl Vital Stat Rep* 1999;47(23):1-23.
13. Mathews TJ, Curtin SC, MacDorman MF: Infant mortality statistics from the 1998 period linked birth/infant death data set. *Natl Vital Stat Rep* 2000;48(12):1-25.
14. Mathews TJ, MacDorman MF, Menacker F: Infant mortality statistics from the 1999 period linked birth/infant death data set. *Natl Vital Stat Rep* 2002;50(4):1-28.
15. Mathews TJ, Menacker F, MacDorman MF: Infant mortality statistics from the 2000 period linked birth/infant death data set. *Natl Vital Stat Rep* 2002;50(12):1-28.
16. Mathews TJ, Menacker F, MacDorman MF: Infant mortality statistics from the 2001 period linked birth/infant death data set. *Natl Vital Stat Rep* 2003;52(2):1-28.
17. Willinger M, James LS, Catz C: Defining the Sudden Infant Death Syndrome (SIDS): Deliberations of an expert panel convened by the National Institute of Child Health and Human Development. *Pediatr Pathol* 1991;11:677-684.
18. Hauck FR, Herman SM, Donovan M, et al: Sleep environment and the risk of Sudden Infant Death Syndrome in an urban population: The Chicago Infant Mortality Study. *Pediatrics* 2003;111:1207-1214.
19. Rasinski KA, Kuby A, Bzdusek SA, et al: Effect of a sudden infant death syndrome risk reduction education program on risk factor compliance and information sources in primarily black urban communities. *Pediatrics* 2003;111:e347-354.
20. Sheers NJ, Rutherford GW, Kemp JS: Where should infants sleep? *Pediatrics* 2003;112:883-889.

DISCLOSURE
Dr. McDermott Shaefer, Dr. Hutchins, and Ms. Buckley have indicated they have no financial arrangements or affiliations with commercial or equipment companies to disclose.

Address for correspondence: Kathleen Buckley, MSN, CNM, Director, National Fetal and Infant Mortality Review Program, American College of Obstetrics and Gynecology, 409 12th Street SW, Washington, DC 20024. E-mail: Kbuckley@acog.org.

To obtain reprints, please contact: Kevin Chamberlain, Medicom International, at (914) 337-7878, ext. 202, or visit our website at www.medicomint.com. Copyright 2004 by Medicom International. All rights reserved.

CALL FOR ORIGINAL RESEARCH PAPERS

MANAGED CARE INTERFACE is seeking original papers in the following research areas:

- Clinical health outcomes
- Managed care vs. fee-for-service environments
- Health policy decision making
- Health care delivery systems
- Patient satisfaction
- Pharmacoeconomics
- Disease management
- Pharmacy practice

If you or your institution is conducting research in any of these areas (as well as related fields), MANAGED CARE INTERFACE would be pleased to consider original papers for possible publication. All submissions are rigorously peer reviewed. Please see page 47 for information for authors.