

Fetal and Infant Mortality Review: A Tool That Communities Can Use To Identify and Address Issues Related To Disparity in Infant Health Outcomes.

Introduction

Unique among all health outcomes, infant mortality has always been viewed as a sentinel event that serves as a measure of a community's health as well as its social and economic well being. It is also a measure of the organization and abilities of a community's health and human services resources. Infant mortality is associated with a variety of factors including quality of and access to pregnancy and pediatric health care, socioeconomic conditions, family stressors, the strength of high risk safety nets, the quality of community resources and the cultural competence of local service systems.

In 2002, the United States' infant mortality rate increased to 6.95 deaths per 1,000 live births. This unexpected increase in infant mortality was the first in more than 40 years. In 2003, the infant mortality decreased to 6.84 deaths per 1,000 live births, the same rate seen in 2001, although the decrease was not statistically significant.¹

When examined for race and ethnicity, infant mortality rates vary significantly. The African American community experiences the greatest disparity in infant mortality with the rate, at least, double that for white infants.² Native American infant deaths due to Sudden Infant Death

Syndrome (SIDS) are the highest in the nation - 2.4 times higher than non Hispanic white infants.³

According to the March of Dimes, the percentage of deaths occurring to infants born premature or with low birth weight increased 9% between 1995 and 2003.⁴ The rate of preterm births among African American women is also about four times higher than non Hispanic white women. The low birth weight rate for Puerto Rican women was more than twice the rate for non Hispanic white women.⁵

Very little is actually known about what underlies these racial and ethnic health differences in low birth weight and infant mortality.⁶ However, in the year 2000, one out of three Americans was African American, Latino, Middle Eastern or Asian/Pacific Islander.⁷ This means that a growing number of women, infants and families may face adverse outcomes of pregnancy.⁸

Today, community-based Fetal and Infant Mortality Review (FIMR) is an action-oriented continuous quality improvement process that is playing a significant role in building community partnerships, understanding community issues associated with health disparity and developing culturally sensitive actions to address disparities.

What is FIMR?

The overall goal of Fetal and Infant Mortality Review is to enhance the health and well-being of women, infants and families by improving the community resources and service delivery systems available to them. Through FIMR, key members of the community come together to review information from individual fetal and infant deaths. The purpose of these reviews is to identify the factors associated with these deaths, determine if they represent system problems that require change, develop recommendations for change and assist in the implementation of change.⁹

The recent findings of the national evaluation of FIMR indicate that this process is an evidence-based, effective perinatal systems initiative. The evaluation also documents that local health departments sponsoring FIMR compared with those without FIMR were more likely to report six improved core public health functions:¹⁰

- Data collection and analysis,
- Client services and access,
- Quality improvement for systems of care,
- Partnerships and collaboration,
- Population advocacy and policy development and
- Enhancement of the labor force.

How FIMR Can Help

Three components of the FIMR process are especially valuable in discovering and addressing community factors related to infant health disparities:^{11, 12}

1. The diverse coalition/community **partnership** building component of the process,
2. Inclusion of the **voice of local families** who have lost their babies, and
3. FIMR **actions** based on decisions pertaining to the whole community and the families who live there

1. The coalition/community partnership building component of the process.

A first step in addressing issues related to health disparities must be for each community to develop a greater understanding and appreciation of its diversity.

FIMR includes a community coalition/partnership building component that can bring together the array of ethnic and cultural views in the community and promote a climate of respect and understanding.

Successful FIMR projects include a wide variety of culturally diverse partners in their activities. Typically, FIMR engages about 30 to 50 active community members, including policymakers, representatives of organizations, families and consumer advocacy groups.

Bringing all these partners together to address community issues is a success story in itself. FIMR meetings and discussions about the health and well being of women, infants and families provide a real opportunity for community members to grow in understanding and appreciation of cultural beliefs and behaviors that differ from their own.

During the past three years, the FIMR team [members] have grappled with many difficult issues. Racial and ethnic sensitivity of all team members has increased. We believe the CRTs have worked well together and have all grown in understanding of others who are not of their sex, race, ethnicity or profession.

— Mary Hibbard, MD, Former Commission of Health, Suffolk County, N.Y.

2. Inclusion of the voice of local families who have lost their babies.

The FIMR process includes a home interview with the mother who has suffered a loss. The mother describes health and human services and other resources she received or wished for, her cultural view of the experiences surrounding her pregnancy and the birth and death of her child, background information about her relationship with the father and other support persons, physical/emotional stressors and grief reaction to the loss. For many mothers, this may be the first and only opportunity to talk to another person about the loss of her infant.

The home interviewer then conveys the mother's story to the FIMR members.

Thus, the home interview lets the true voice of each bereaved parent speak to the community at large. FIMR projects find that this home interview almost always provides the most valuable information in the review. It is extremely important to their understanding of whether or not services and community resources are available, accessible and culturally appropriate for the community. Findings in a pertinent study¹³ support the view that, "Intervention programs that listen to the voice of the community and especially the women themselves ...

may be the most successful in improving pregnancy outcomes."

FIMR teams can also more readily identify issues of racism and other forms of discrimination in service delivery systems through the interview and can effectively begin to address them.

Maternal interviews give a voice to the disenfranchised in my community, those without clout or power. FIMR provides a rare opportunity for the 'providers' in a community to hear from the 'consumers'.

— Patt Young, FIMR Interviewer, Alameda/Contra Costa Counties, CA

3. FIMR Actions/Interventions based on the documented needs of the community and the families who live there.

FIMR is an action oriented, community process leading to creative and culturally sensitive interventions. The actions result from the decisions of broad-based, culturally-diverse FIMR coalitions and partnerships. Thus, they represent the collective wisdom and expertise of the entire community, not just a part. The actions grow out of a broad-based, culturally-diverse perspective. They are crafted to address the needs of many local families, not just a few.

The process that brings together diverse people to learn from the story of a family that experienced a fetal or infant loss helps awaken both commitment and creativity. The stories illustrate community needs that are clearly concrete, local and significant, while the interaction among diverse community participants generates ideas for action that might lie beyond the imagination and power of an individual provider or agency.

— Seth Foldy, MD, Former Commissioner of Health, Milwaukee WI

Conclusion

FIMR is an evidence-based perinatal systems initiative that is being implemented to understand and intervene to correct factors that may contribute to disparity in infant health outcomes. Specifically, FIMR can: 1) bring diverse community members together to participate in a process that provides an opportunity for them to grow in understanding of others who are not of their age, sex, race, ethnicity or occupation; and 2) develop local interventions from FIMR reviews that are culturally sensitive, community specific and family-oriented. FIMR empowers the community to develop creative, culturally relevant maternal, infant and family health policies, programs and resources.

Gradually through our FIMR reviews, we have come to realize that infant mortality is not an isolated problem, but an indicator of deeper issues and stresses in our community: poverty, social isolation, divisions of race and class and barriers to equal access to health care. We knew we must begin to focus on those broader issues.

— Karen Papachoudo, FIMR coordinator, Aiken, South Carolina

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