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A Community-Wide Infant Mortality Review: Findings and Implications

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SYNOPSIS

The authors present the results of a community-wide infant mortality review, describe implications for the delivery of maternal and child health services, and discuss the value of such reviews in addressing local public health concerns. The review included an analysis of birth and death certificates and medical record data; maternal interviews; review of cases and development of recommendations by provider panels; and convening of community groups to develop strategies to improve the health and health care of women and infants. The review focused on 287 infant deaths during 1990–1993.

More than half of all neonatal deaths were attributable to "pre-viable" or "borderline viable" births. Sexually transmitted infections were the most frequently identified underlying risk, and smoking was the most frequently identified prenatal risk. Homelessness, physical and sexual abuse, and alcohol use were at least twice as likely among women whose babies died than among a high risk comparison group. Panelists identified fragmented health care over the course of women's reproductive lives as a predominant theme. The authors conclude that: (*a*) The focus of maternal and child health care should shift to a model of women's health care that addresses the chronicity of social and clinical risks. (*b*) Infant mortality reviews are a valuable tool for community education, systems review, and policy development and can be applied to other public health issues with local significance. (*c*) Expectations about the review process's ability to produce conclusions about causality or recommendations narrowly geared to reducing infant mortality rates need to be reframed. (*d*) The model will be strengthened by greater participation of families affected by infant death.

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Infant mortality, recognized as an indicator of a society's general health and socioeconomic well-being, remains higher in the United States than in most other developed nations and continues to show wide disparities across ethnic and class lines. Most notably, the chance of survival to the age of one year has been close to twice as high for white infants as for black infants for almost three decades.[1] Conventional research methods have gone a long way toward identifying socioeconomic, biologic, and behavioral risk factors that contribute to these disparities, including poverty, prematurity, and poor access to prenatal care. However, conventional methods fail to address the interplay of these factors in the context of women's lives and of the health services designed to serve them. To understand this interplay and identify preventive strategies, we need research that combines quantitative and qualitative data about the clinical and social context of infant death and engages residents and providers in high risk communities in the research process.[2-3]

Within the field of maternal and child health, there is a long and valued, albeit debated, tradition of using regional mortality reviews as a tool for understanding maternal and perinatal deaths and identifying preventive measures.[4-15] This tradition, with its reliance on cases of death only, is not etiologic research but is akin to review and surveillance of sentinel health events.[16,17] Most recently, in 1988, the Maternal and Child Health Bureau (MCHB) of the U.S. Health Resources and Services Administration launched eight city-, region-, and state-based fetal and infant mortality reviews (FIMRs) and went on to mandate and support community-wide FIMRs as an integral part of the Federal Healthy Start Initiative in 15 target areas. In 1990, the American College of Obstetrics and Gynecologists (ACOG) began a similar initiative, the National FIMR Program, in partnership with MCHB, making grants to 14 cities and counties to establish such reviews, investing a total of about $1.5 million over six years. Funds for this initiative came from MCHB, the March of Dimes, the Robert Wood Johnson Foundation, Carnation, and ACOG, District IV. Since that time, the FIMR method has been widely disseminated and institutionalized as a way to understand and reduce infant mortality rates in high risk communities.[18] According to an ACOG survey of all state maternal and child health directors in 1995 and more recent updates of that survey, FIMRs are being conducted in about 200 locales across 35 states, many of them now funded by state and local health departments (Personal communication, Kathleen A. Buckley, MS, Director, National FIMR Program, ACOG, October 1998).

Only two reports of the FIMR model and findings have been published to date.[19,20] although a number of abstracts and reports are available.[21-28] The purpose of the present paper is to describe the methods and findings of the Boston Infant Mortality Review (IMR) Project. We discuss implications for maternal and child health practice and system change as well as the applicability of the method for other issues of local public health significance.

THE BOSTON IMR

The FIMR model expands the scope of traditional hospital-based clinical mortality reviews, regional mortality reviews, and surveillance of sentinel health events to include broad community participation and an examination of the social, environmental, and human service context of fetal and infant deaths. Although application of the FIMR model varies widely site to site, key features include: (*a*) medical record reviews; (*b*) interviews with mothers; (*c*) case reviews by provider panels; and (*d*) convening of community groups to translate findings and recommendations into action plans.

The Boston IMR began in 1990 and continued through 1993 with funding from MCHB's original initiative (Phase I). During this period we collected data on all infant deaths that occurred in Boston to Boston residents within two 18-month periods: January 1990–June 1991 and January 1992–June 1993. Since the target population and study methods were very similar during these two almost contiguous time periods, we pooled the data for reporting purposes.

The Boston Project did not address fetal deaths (that is, deaths of fetuses of 20 or more weeks' gestation, identified by not breathing or showing any other evidence of life at the time of extraction from the mother), and therefore it is referred to as an "IMR" rather than an "FIMR."

From July 1993 through March 1996, the Project continued under the auspices of the Federal Healthy Start Initiative (HSI), again with funding from MCHB (Phase II). During these later years, we studied only cases from the highest risk neighborhoods in Boston, designated as the "HSI target areas." Data on the deaths from Phase II are not included here due to the difference in the source population.

The objectives of the Boston IMR were: (*a*) to understand the clinical and social context in which infant deaths occur; (*b*) to generate public health and clinical policy recommendations to improve services for women

Sixteen percent of the women whose infants died had not received needed clinical services.

and infants at risk; and (*c*) to stimulate community-wide education and action on the problem.

Case identification. IMR Project staff identified infant deaths using the Infant Death Surveillance System, an automated record of all infant death certificates maintained by the City's Department of Public Health (now called the Boston Public Health Commission). To be counted as an infant death, the birth must have met the eligibility criteria for a live birth and the death must have occurred to a child whose age was less than one year (365 days). For purposes of birth registration, the Massachusetts Department of Public Health defines a live birth as "the birth of an infant who breathes or shows any other evidence of life (such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles) after separation from the mother's uterus, regardless of the duration of gestation."[29] Project staff identified 287 infant death cases for the combined study periods.

Medical records review. We obtained approval from the institutional review boards of nine hospitals, 13 community health centers, and one health maintenance organization in Boston to review the prenatal, maternity, and pediatric records for the 287 cases. Trained perinatal nurses abstracted detailed information, using a standard form adapted from one developed by the Multi-State Infant Mortality Review Program. The form included data on the sociodemographic characteristics of mothers; their medical conditions prior to and during pregnancy; the amount and content of prenatal care; labor and delivery; neonatal medical conditions and services; post–hospital discharge pediatric conditions and services; and the death event.

Maternity medical records included copies of the birth certificate. This allowed us to compare the characteristics of the infants who died with those of all infants born to the source population (Boston residents giving birth in Boston) based on birth certificate data.

Our quantitative analyses of data from the medical record review focused on the conditions prior to and during pregnancy that may be associated with poor pregnancy outcomes. In addition, we reclassified the causes of death into more clinically meaningful categories than those appearing on the death certificate. One of the authors (ERB), a neonatal specialist, derived a cause of death from combined birth and death certificate data and autopsy reports and, as needed for clarification, information from medical records and maternal interviews.

Interviews with mothers. Using the identifying information found on death certificates, we attempted to contact each woman whose infant had died during the study periods and request her consent to participate in an in-depth interview. Ten women from a range of ethnic, cultural, and linguistic communities in Boston (three African American women, two Latinas, and two women of Haitian, one of Chinese, one of Cape Verdean, and one of Irish descent) were trained to locate these mothers and conduct interviews in their homes or at other community sites.

As a first step, we sent a letter to each of the mothers of infants who had died, expressing condolences and requesting her participation in an interview at a later date. During time period one, these letters were sent four months following the death; during time period two, they were sent within six weeks of the death to initiate contact as soon as possible. For women who did not respond to the letter in writing or by telephone, interviewers hand-delivered duplicates of the letters and made up to 10 visits to the home addresses named on the death certificate to try to locate the women and personally request their participation in the study. During time period one, these visits were initiated between six and eight months after the death of the infant, and during time period two, between three and four months after the death.

Intense case finding efforts were required to reach this group of women, typically characterized by high medical risk, social isolation, and extreme mobility. In many

Surveys of panel participants revealed numerous changes in organizational policies and practices that came about as a result, at least in part, of IMR findings.

cases, interviewers followed word-of-mouth leads from neighbors, which often meant finding women in homeless shelters and at other community locations.

Interviewers were trained to listen with empathy to a woman's story and were prepared to make referrals on a wide range of needs, but were instructed not to offer extensive counseling or services themselves. The interview included closed- and open-ended questions about the woman's life circumstances in the year prior to pregnancy, during pregnancy, at the time of the infant's death, and immediately following the death, as well as her experience with medical and social services. The mean time between the infant's death and the interview was six months. The interviews lasted an average of two and a half hours. During the first time period, each woman was reimbursed $25; the amount was raised to $50 during the second time period. The majority (70%) of women gave their consent for interviews to be taped. When women agreed for interviews to be taped, interviewers used the tapes to check their verbatim recording of the responses to open-ended questions; the study coordinator (CAH) also used the tapes during her routine quality checks of all completed interview forms. Due to the sensitivity of the subject matter, standard reliability checks such as repeated interviews were not employed.

Our analyses of quantifiable data from the interviews focused on the social characteristics and life circumstances of the mothers during pregnancy and the prior year, particularly on factors with a demonstrated or theoretic link to poor birth outcomes. We took advantage of data collected from a random sample of women who delivered their infants at Boston City Hospital from June 1992 through August 1993 ($N = 229$) as a comparison. At the time, Boston City was a municipal hospital serving a low-income, largely African American, Haitian, and Latina population. Based on their social and demographic characteristics, these women may be considered a representative sample from the source population for the IMR. For purposes of a study of the predictors of lack of prenatal care,[30] these women were interviewed immediately following their delivery by members of the IMR interview staff, using a format similar to the one developed for the IMR. Variables available for a comparison of these women with those whose infants had died included housing status, experience of abuse, material need, life stresses, pregnancy planning, substance use, and use of prenatal and primary care.

Provider review panels. Project staff prepared summaries of the 128 cases for which both medical record reviews and interviews were completed. These summaries were reviewed by interdisciplinary provider panels whose members came from the city's teaching hospitals, health centers, and community agencies as well as the local and state health departments. Over time, 96 individuals from 36 institutions and organizations were represented on these panels, including obstetricians, perinatologists, neonatologists, pediatricians, maternal and child health nurses and nurse-midwives, social workers, and community-based health and social service providers with expertise in substance abuse, housing and homelessness, domestic violence, family planning, adolescent health, nutrition, child welfare, and entitlement programs. For each case, the panel identified: (*a*) the clinical and social conditions present during the preconceptional, prenatal, postnatal, and pediatric periods; (*b*) whether risk conditions had been identified and treated in a timely way; and (*c*) the clinical and public health policy implications inherent in each case.

From the panels' findings, we calculated the proportion of cases for which clinical and social risk conditions were not identified by medical and social service providers or were identified and not matched by services. We also performed content analyses of the policy recommendations derived from these cases. We entered each recommendation into a textual analysis software program, HyperResearch, and coded them according to the following categories developed for this purpose: content area addressed (such as prenatal care, housing), area of intervention needed (such as advocacy, clinical protocol), and other recurring and cross-cutting themes (such as system linkages, provider-patient communication). We then created a large grid using these categories to classify the recommendations and found that the cross-cutting themes were the most useful categories by which to organize and present the panels' recommendations.

At the end of each study period, we conducted a follow-up survey of panel participants to assess the impact of their participation and IMR findings on their own and their institutions' practices and policies related to infant mortality.

Policy working groups. The final step of the IMR process is to communicate the findings of the data analyses and provider panel reviews to a broad group of community members and leaders, health and social service providers, and policy makers and to involve them in developing recommendations for policy and practice.

At the end of the second study period, we convened two broad community working groups, one focused on "improving health care for women and infants from low-income communities in a managed care environment" and the other on "the prevention of prematurity in low-income communities." Among the 200 members of these groups were women whose infants had died as well as representatives of hospitals, health centers, managed care organizations, health insurers, community-based organizations, and local and state health departments and legislative offices. The groups' task was to translate the findings of the IMR, the published literature on infant mortality, and their collective experience into a set of key principles and recommendations for improving birth outcomes in low-income communities in the city of Boston.

Following these meetings, a subset of 15 members formed a policy action group to take these principles and recommendations to the next step: a blueprint for change in the organization and content of managed care services for women and their infants at risk of infant death. The emphasis was on the risk of prematurity, the primary antecedent of infant death in Boston. This group met monthly for one year.

FINDINGS OF THE BOSTON IMR

Medical records.

Capture rate. Project staff obtained and abstracted at least one medical record for all 287 cases of infant death (274 pregnancies).

Causes of death. Figures 1 and 2 show the distribution of causes of death for all neonatal and postneonatal cases of death for both time periods. These data make clear the large percent of neonatal deaths of infants in the "pre-viable" category (< 24 weeks and ≤ 500 grams) or "borderline pre-viable" (< 24 weeks and > 500 grams). In some other states and in many other countries, many of these infants would not have been given a birth certificate due to the early gestational age, and thus would be counted as fetal deaths rather than infant deaths.

Clinical risk factors. According to medical records, the most frequently reported clinical risks existing prior to pregnancy were: sexually transmitted infections (32% of cases); chronic illness, including asthma, hypertension, and others (28%); urinary tract infections (25%); prior preterm birth (20%); and a history of illicit drug use (20%). During time period two, 22% of women had a history of genital infections (not measured during time period one). The most frequently identified prenatal risk factors were: smoking more than 11 cigarettes a day at any point during pregnancy (33%); bleeding in the second trimester (22%); urinary tract infections (19%); alcohol use (19%); sexually transmitted infections (19%); and any illicit drug use during pregnancy (19%).

Maternal interviews.

Response rate. Of the 126 women eligible for a maternal interview in time period one, 55 (44%) were interviewed, and of the 134 women eligible in time period two, 73 (54%) were interviewed. The improved response rate was attributable to several changes in protocol that were instituted in time period two, including earlier contact and larger payments to respondents. A comparison of the sociodemographic profiles of mothers who were and were not interviewed revealed few differences; none were statistically significant (data not shown).

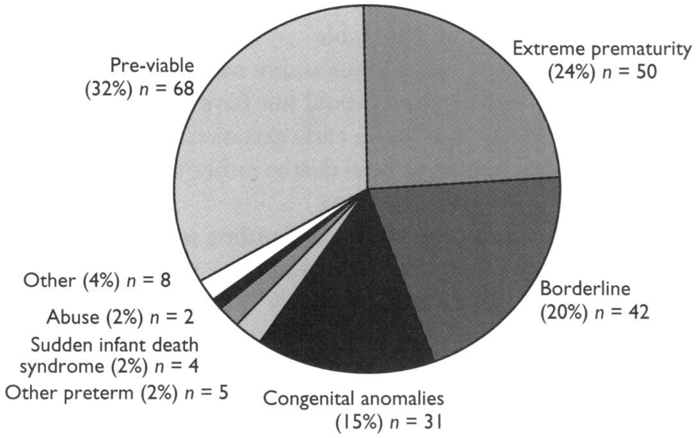
Comparison with high risk group. The Table shows the social and economic characteristics of mothers whose infants died, as self-reported in interviews, and those of the comparison group, a random sample of women who delivered at Boston City Hospital and were interviewed immediately postpartum using a similar interview format. Those whose infants died were almost three times as likely as their high risk counterparts to have unstable housing, four times as likely to report being abused during their pregnancy, and almost three times as likely to have used alcohol during pregnancy. The two groups were similar in terms of other measured characteristics.

Provider review panels. In one-quarter of the 128 cases, the panels judged underlying and pregnancy-related clinical risks not to have been identified in a timely way. The panel also found that 16% of these women did not receive needed clinical services. Examples of crucial missed clinical opportunities include failure to administer a routine *alpha*-fetal protein test during a prenatal visit at 16 weeks, inadequate treatment for chlamydia for women and their male partners, and failure to recognize and treat a prior diagnosis of incompetent cervix. The proportion of cases in which needed social services were not received was far higher (50%); and in half of these cases the social service problem had not been documented in the medical record. Examples of crucial missed social services included drug treatment, appropriate child protective services, and counseling and referrals for women with a history of sexual abuse and ongoing battering.

See pages 173–175 for a summary of the five cross-cutting themes most commonly discussed by the review panels. Each is associated with a set of specific recommendations developed by the panels. Issues related to the lack of continuity in women's and infants' health care—before, after, and between pregnancies, between clinical and social services, and between mainstream health care organizations and community-based services—were by far the most frequently noted (73% of cases).

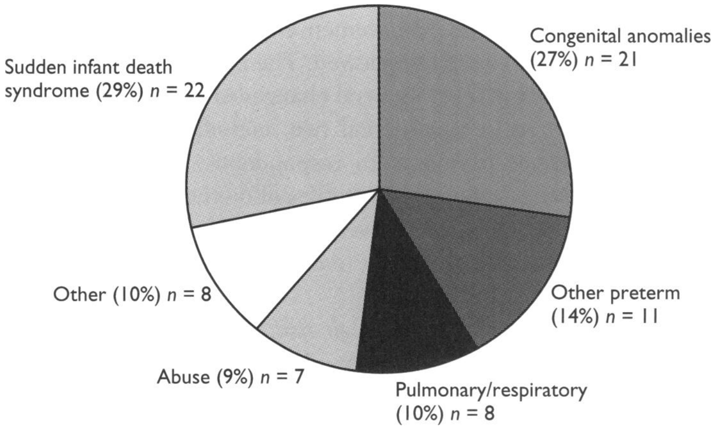
Follow-up survey of panel participants. The recommendations made by the panel members were distributed

Figure 1. Distribution of causes of death for neonatal deaths, Boston Infant Mortality Review, January 1990–June 1991 and January 1992–June 1993 (*n* = 210)



Pre-viable = ≤ 500 grams and < 24 weeks' gestation
Borderline = > 500 grams and < 24 weeks' gestation
Extreme prematurity = < 1500 grams and not meeting the criteria for pre-viable or borderline

Figure 2. Distribution of causes of death for postneonatal deaths, Boston Infant Mortality Review, January 1990–June 1991 and January 1992–June 1993 (*n* = 77)



NOTES: Abuse is defined as a diagnosis of abuse by the medical examiner or, in the case of a "pending" diagnosis by the medical examiner, a determination of abuse by case reviewers. Pulmonary/respiratory is defined as pulmonary or respiratory disease not directly attributable to pneumonia bronchiolus or bronchial dysplasia or respiratory distress syndrome due to prematurity.

The findings of the project have specific implications for how maternal and child health services are delivered to those at highest risk.

widely in Boston, and many are being applied in health care institutions and community organizations throughout the city. Surveys of panel participants revealed numerous changes in organizational policies and practices that came about as a result, at least in part, of IMR findings. The most frequently named changes were: (*a*) greater emphasis in the teaching of obstetrical and pediatric residents on clinical and social risks that repeat themselves between pregnancies (for example, vaginal infections, unplanned pregnancies, battering); (*b*) development of new, more comprehensive risk assessment tools and resource directories for prenatal care providers, WIC sites, mobile clinics, school health programs, and community health centers; (*c*) development of protocols for intensified follow-up of women who miss prenatal care appointments; (*d*) institution of hand-held records at a hospital's women's health clinics and affiliated community health centers; and (*e*) enhanced training in family planning for community health outreach workers.

Table. Social risks during pregnancy self-reported by mothers whose infants died (January 1990–June 1991 and January 1992–June 1993) compared with those self-reported by women giving birth at Boston City Hospital (BCH), June 1992–August 1993

	Mothers in infant death cases n = *128*	*Women giving birth at BCH* n = *229*
Social risk	*Percent of women*	*Percent of women*
Homeless (strict definition)[a]	5	8
Homeless (broad definition)[b]	30	11
Abused by partner[c]	25	6
Unable to pay for basic needs ≥ 1 month	35	31
Death of family member or friend	30	26
Had not intended or planned pregnancy	63	41
Unintended pregnancy and no birth control use	38	33
Considered termination of pregnancy	23	24
Smoked	34	36
Used alcohol	23	8
Used illicit drugs	14	12
Received no prenatal care	6	5
Had no regular medical provider	20	26

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[a] Women without homes of their own, living in shelters or on the streets

[b] In addition to those meeting strict definition, includes women doubled and tripled up with relatives or friends

[c] Includes physical and emotional abuse

Not surprisingly, the themes that emerged from the case reviews in Boston are remarkably similar to those noted in reports of FIMR projects throughout the country.

Policy working groups. Some recommendations were deemed by the two policy working groups described above as compelling, far-reaching, and timely enough to warrant a concerted community-wide effort (see items in bold print in the box on pages 173–175). The policy action group, which grew out of the two broader community working groups, produced a position paper entitled "Beyond Prenatal Care: Improving Birth Outcomes through Enhancements to Clinical Services For Women." This document describes an enhanced model of care for women from low-income communities who are considered at highest risk for preterm delivery. It includes a rationale for integrating women's primary health services with prenatal and postnatal care within managed care organizations; definitions and outcome measures for "case management" and "community-based outreach"; and guidelines for building partnerships between managed care and community organizations. The paper was distributed widely to constituencies throughout the city and state and provided the basis for discussions at Boston's second mayoral Infant Survival Summit, convened in June 1997. As a result of the Summit, insurers and managed care providers made commitments to work closely with the city's Public Health Commission and maternal and child health advocates to develop and apply standards of care for high risk women and infants. The IMR was a primary catalyst for a growing collaboration.

The Commission has convened a follow-up Task Force on Women's and Infants' Health, which has classified the IMR recommendations according to the core public health functions of assessment, assurance, and policy development and has identified recommendations 3a and 3b as priorities (see p. 174).

LESSONS FROM THE BOSTON EXPERIENCE

Boston's experience with a community-wide IMR raises important lessons on two levels. First, the findings of the project have specific implications for how maternal and child health services are delivered to those at highest risk for poor birth outcomes in Boston and similar urban settings. Second, our experience provides insight into the value of this multitiered method of review and its applicability to other public health issues.

Implications for maternal and child health services. Not surprisingly, the themes that emerged from the case reviews in Boston are remarkably similar to those noted in reports of FIMR projects throughout the country.[19,23-28] First, three-quarters of women in our sample had important medical risk factors before their pregnancies began, such as a history of prior preterm delivery or vaginal infections. The review panels found that in about three-quarters of the cases reviewed there were serious discontinuities in the health care of women over time, such as the lack of continuity between women's primary care and prenatal care and the absence of interconceptional care informed by high risk events of prior pregnancies. Such lapses argue for a system of women's health care that is continuous throughout a woman's reproductive years regardless of pregnancy status.[31]

Second, the social needs of women, even when identified in the clinical setting, appear to have been inadequately addressed in about half of the cases. This may have resulted from a lack of sufficient social service resources within clinical settings, women's failure to follow up on referrals, or providers' reticence to take on complex social problems such as the lack of stable housing and domestic abuse. The social and economic circumstances of patients' lives are not and should not be considered the responsibility of physicians to solve, yet they are the context in which clinical outcomes occur. Thorough risk assessment, followed by counseling and referrals, must be more consistently integrated into prenatal and primary health care.[32]

The review panels identified provider-patient communication issues to be problematic in almost 40% of cases. Interviews with women of color, in particular, revealed how differences in ethnicity, class, culture, and comunication styles between patients and providers can lead to

PROVIDER REVIEW PANEL FINDINGS: THEMES AND RECOMMENDATIONS, BOSTON INFANT MORTALITY REVIEW, JANUARY 1990–JUNE 1991 AND JANUARY 1992–JUNE 1993

THEME	RECOMMENDATIONS
1. Fragmentation and discontinuity in the health care of women and infants, even those with high risk histories (73% of cases reviewed)	a. **Apply the model of enhanced prenatal care services for high risk women to a system of comprehensive and continuous primary care for women. Use interdisciplinary care teams, with community-based health worker as the "connector" to a wide range of services over time.**
	b. Develop a regionalized system that uses the critical event of a perinatal loss or a prior preterm labor or birth as a starting point for intensive, ongoing, services for women.
	c. Develop a mechanism to monitor and improve: (*i*) the quality of documentation in medical records, particularly regarding pregnancy risks and outcomes, and (*ii*) tracking of medical records across clinics and hospitals.
	d. **Promote cross-training and referrals between maternal and infant providers and other specialists, including those in fields of substance abuse, family planning, and domestic violence.**
	e. Intensify efforts to reach women who miss appointments or do not return for services, especially after a pregnancy test.
	f. **Promote better coordination among different systems of care, including managed care organizations, community-based services, family planning and obstetric clinics, emergency departments, and obstetrics departments.**
	g. Develop, and monitor regionally, protocols for communication with patients regarding early signs of preterm labor, particularly for telephone triaging and emergency room care of pregnant women with bleeding and pain during second trimester.
	h. Following perinatal loss or near loss, incorporate counseling and education regarding the prevention of repeated losses within postnatal care and primary care for women.
2. Severe social risk unrecognized and/or unmatched by needed services in the health care context (50% of cases reviewed)	a. **Standardize use of interdisciplinary care teams, with patient advocate/case manager as core member of team, to assist women in navigating the health care system and understanding health information and services.**
	b. **Develop and monitor the use at all ob-gyn care sites of protocols for ongoing comprehensive history taking and risk assessment. Protocols**

PROVIDER REVIEW PANEL FINDINGS (CONTINUED)

THEME	RECOMMENDATIONS
	should include universal screening for conditions often not noted in medical records, including history of sexually transmitted infections, history of sexual abuse, father's health status, nutritional assessment, housing assessment. Risk assessment should be repeated at least twice during pregnancy and at all primary care visits.
	c. Include as a quality assurance standard: a minimum of one comprehensive risk assessment and one risk-based counseling session in the woman's own language, with a member of her cultural background present as provider or interpreter.
	d. Include family mental health services in maternity care, especially to address effects of chronic losses and chronic exposure to violence.
	e. Substance abuse should be viewed as a possible symptom of a history of or current exposure to sexual abuse and/or domestic violence.
	f. Ensure the immediate connection to an advocate when there is evidence of domestic violence or sexual abuse during maternity or primary care visits.
3. Recurring urinary tract infections, genital infections, and sexually transmitted infections (44% of cases reviewed)	a. Develop and apply guidelines for more aggressive screening, diagnosis, and treatment of bacterial vaginosis and other genital infections during routine gynecology visits and during pregnancy.
	b. **Better educate women about the links between genital infections and sexually transmitted diseases and poor reproductive outcomes. This should include community-wide education campaigns and advice during clinical encounters.**
4. Repeated unintended and closely spaced pregnancies (40% of cases reviewed, with over half these preceded by difficult sexual histories, including childhood sexual abuse)	a. Incorporate age- and culture-specific "life planning"/"life option" counseling into family planning services. Include this counseling at all points of health care for women from low-income communities.
	b. **Training in family planning/life planning should target: nurse practitioners and nurse-midwives, physicians who are primary care clinicians in managed care settings, and all community-based health workers.**
	c. Develop linkages between family planning and other services such as detoxification programs, homeless shelters, Head Start, and WIC.
	d. Make available at all ob-gyn settings mental health and trauma counseling for women with histories of sexual abuse.
5. Low satisfaction with interpersonal aspects of health care, particularly	a. Promote the use of ongoing patient satisfaction survey geared toward provider-patient communication.

PROVIDER REVIEW PANEL FINDINGS (CONTINUED)

THEME	RECOMMENDATIONS
among women of color (38% of cases reviewed)	b. Increase the availability of continuing education for health care professionals in (*i*) listening to patients' concerns regarding their health and the health of the infant; (*ii*) the dynamics of race and racism in health care; (*iii*) attitudes regarding substance abuse and information about the effective management of women who are substance abusers; (*iv*) cultural beliefs about birth defects; (*v*) the meaning of death and dying for families of diverse backgrounds; and (*vi*) mutual respect in the doctor-patient relationship.
	c. Institute training programs for patients to educate themselves about obtaining information from and sharing information with their providers.

NOTE: Recommendations in bold print are those seen by community working groups as being of highest priority, warranting a concerted community-wide policy initiative.

interactions that leave women feeling disrespected or not listened to. If a woman experiencing a high risk pregnancy or an infant death feels her concerns and questions are minimized, she may be less likely to seek regular medical care for herself and her children. A growing literature in medicine demonstrates that the style of care influences health outcomes by affecting how patients seek care, comply with advice, and care for themselves.[33–36]

Limitations and strengths of the method. Several limitations of the IMR method constrain its ability to provide sufficient information for the design of targeted interventions to reduce infant mortality. First, as a "critical case series analysis," the IMR does not produce information about causality or etiology. In the absence of a controlled research design, it is not possible to draw conclusions about particular risk factors and their association with the outcome of infant death. The goal of an IMR should be framed, then, not as a method to achieve reductions in infant mortality rates per se, but as a method of engaging community members in a process of collecting and reviewing detailed information about how existing systems and services fail and can be improved for the good of women's and infants' health.

Second, the in-depth data collection and review process required for an IMR is time-, labor-, and cost-intensive. Locating and abstracting medical records requires approximately six to ten hours of abstractors' time per case, amounting to $120 to $200 per completed case, although close to a 100% "capture rate" can be achieved. Obtaining maternal interviews is almost as labor- and cost intensive, requiring about eight hours of interviewers' time per completed interview (about $120 to $140 dollars per case) and an average of four hours for each case for which there was no interview. However, the response rates are much lower for interviews than for medical records abstractions. Less intensive case finding may lead to an incomplete picture of the social context in which infant deaths occur in a community.

Third, the model relies on an enormous amount of in-kind time and cooperation from all community participants. As a result, it is difficult to maintain consistency in the panel review process, and conclusions and recommendations may vary according to who attends these meetings regularly.

Fourth, these projects are often limited to using data from medical records and interviews and would be enhanced by data from other service systems, such as Medicaid, WIC, and special perinatal initiatives. However, such data are difficult to obtain, and issues of security and confidentiality limit the likelihood of linkage.

Finally, the model cannot succeed without strong leadership guiding the long-term effort required to turn recommendations into policy and action. Leadership within local public health departments and community-based agencies changes frequently, and, in addition, resources may not be available for the implementation phase. If local health departments do not have the internal or external grant support to sustain this level of activity in-house, they can collaborate with schools of public health and medicine or decentralize data collection and review, shifting the IMR to a multi-institutional collaboration.

In about three-quarters of the cases reviewed there were serious discontinuities in the health care of women over time.

The chief promises of the method are threefold. First, the method yields useful insights for clinical practice. Individual providers may not routinely come in contact with the larger realities of patients' lives or understand the impact of these realities on their compliance with medical advice and on their health and well-being. Second, the IMR provides information about the social, clinical, and human service context in which infant deaths occur in a given community. This leads to recommendations for how service systems and public policies can better match the real life circumstances of women and infants at risk. Third, the in-depth review of cases highlights the multiple, interwoven, and complex pathways that precede the majority of infant deaths in high risk communities, as well as the gaps in existing human service systems. This kind of information is not routinely available through other data sources or other research methods, such as analyses of vital statistics data, medical record audits, or hospital-based mortality reviews. It allows for the generation of hypotheses about the underlying mechanisms of the social inequalities seen in infant death statistics that can be tested in further research.

This capacity of the IMR method to combine data about individuals and systems is particularly valuable in the case of infant mortality in the 1990s. The distribution of infant death in any community reflects deeply entrenched social, economic, and health care disparities that become manifest in clinical disease of women and their infants.[37] Such realities require national public policy solutions and local systems changes, guided by more than a list of risk factors amenable to individual clinical interventions. This may be contrasted with the situation surrounding maternal death in the 1930s to 1970s. At that time, regional maternal mortality reviews could make a difference by identifying and addressing causes of death directly linked to specific clinical practices, such as anesthesia mistakes or the treatment of pre-eclampsia.

Based on our experience in Boston, we believe the IMR model can be applied to other issues of public health significance at the local level. The criteria for selecting appropriate topics should include: (*a*) sufficient political weight attached to the problem in the community; (*b*) the availability of population-based data on the problem and the capacity to collect detailed information from people affected and from relevant service systems; (*c*) reasonably high prevalence; (d) acceptance of the issue as a warning signal that the quality of care may need improvement at the local level.

The method makes a valuable contribution to understanding in an in-depth way how social, clinical, and system factors interact to produce risk and infant death. It is also a powerful tool for ongoing systems review. However, it is the application of this understanding to local system change through a process of community-wide education and participation that distinguishes the IMR process most from conventional methods of analyses. The impact of the method on short-term infant mortality rates is not likely to be great or easily determinable; however, system changes may result in long-term improvements in maternal and infant health. The objectives of the FIMR/IMR projects should be reframed to reflect this broader goal. In addition, the method would be strengthened by fuller participation at all stages of review and analysis by "consumers," those whose lives are directly affected by infant death.

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