Perinatal Periods of Risk: Using Data and Community Involvement to Prevent Infant Mortality

Introduction & Overview

CityMatCH Mission: Improving the health and well-being of urban women, children and families by strengthening the public health organizations and leaders in their communities

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Infant mortality is complex

- Health care system
- Built Environment

Important time periods
- Preconception health
- Prenatal
- Neonatal
- Post-neonatal
  - Life course
  - Inter-generational

Why do we need PPOR?

Infant mortality is complex

Goes beyond obstetrics
- Chronic disease
- Mental Health
- Social determinants
- Health care system
- Built Environment

Infant Mortality Rates are HIGH, and even in cities where they have decreased, racial disparities persist

Why not use both pieces of information to learn more about why babies are dying?

Communities needed help!

Dr. Bill Sappenfield, CDC’s first assignee to CityMatCH, and Dr. Magda Peck, founder of CityMatCH, teamed up!

INTERNATIONAL EXPERTISE

Dr. Brian McCarthy and colleagues at the Centers for Disease Control and Prevention and the World Health Organization knew that causes of perinatal death are closely related to both age at death and birthweight.

Why not use both pieces of information to learn more about why babies are dying?
The PPOR approach examines fetal and infant mortality in two dimensions.

Why Include Fetal Deaths?
(1) they are important to their families
(2) there are almost as many fetal deaths as there are infant deaths
(3) these deaths can provide us with a lot of information

Standard Infant Mortality Rates do not include fetal deaths. PPOR is about using every bit of information we have.

Experts used statistics to combine boxes with similar causes of death and risk factors.

The dividing lines had been chosen so deaths in the same “box” had similar PROBLEMS:
- Causes of death
- Maternal risk factors

...which means they also had similar SOLUTIONS.
Each period of risk is associated with its own set of risk and prevention factors.

The four periods provide a framework that helps communities:
- Move from having data to using data
- Prioritize limited resources
- Use evidence to maximize impact

To use the risk periods, SORT the Fetal and Infant Deaths:
* Example: Girl born weighing 2499 grams died at 22 days old

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Community stakeholders in “Urban County” sorted their 2000-2003 fetal and infant deaths in this way, and made a PPOR map that looked like . . .

To judge these counts, we need to know how many pregnancies there were altogether.

Answer: There were 23,282 fetal deaths and live births meeting PPOR criteria.

To calculate mortality rates, Urban County divided each count by the number of live births and fetal deaths 23,282 then multiplied by 1,000

**There were 4.2 deaths for every 1,000 live births and fetal deaths.**

They calculated the rate for each period of risk the same way, using the same denominator:

To calculate mortality rates

Urban County divided each count by the number of live births and fetal deaths 23,282 then multiplied by 1,000

Quick side trip #1:

How do we find out about the deaths to count them?
A certificate of death is required by state law for every death in the United States. Fetal deaths are also recorded, though state laws and practices vary. All these are entered into computer data files as are live births records.

The US Vital Records System

Which deaths do we count?

- The mother resided in the geographical area we are studying when the baby was born (or the fetus delivered).
- The birth occurred during our study time period.
- The baby died before its first birthday.
- Infant deaths NOT counted if under 500 grams birth weight; Fetal deaths NOT counted if under 500 grams or earlier than 24 weeks gestation (PPOR criteria).

Back to Urban County’s PPOR Map of Fetal-Infant Deaths

Back to Urban County’s PPOR Map of Fetal-Infant Deaths

What rates can we expect to see in each Period of Risk?

PPOR answers this question using a reference group, a real population of mothers that experience best outcomes: low fetal and infant mortality rates.

Examples of Reference Groups

Examples of Reference Groups

The Reference Group is about Justice

The underlying assumption is that if the reference group can have low mortality, our study group should be able to reach that goal.

Community stakeholders choose the reference group. They agree that it is an appropriate standard or goal for their community.
Urban County stakeholders chose the US Reference Group 2000-2002

- Defined by *maternal demographics*
  - 20 or more years of age
  - 13 or more years of education
  - Non-Hispanic white women
  - Residents of the US at the time of baby's birth

They compared the study and reference populations by subtracting rates in each period of risk.

Urban County: 4.2, 2.1, 1.9, 2.0
Reference Group: 2.2, 1.5, 1.1, 0.9

4.2 - 2.2 = 2.0

Interpretation: 2.0 excess deaths for every 1,000 live births and fetal deaths

Urban County also estimated the number of preventable deaths

2.0 x 23,282 = 46 estimated preventable deaths in the Maternal Health/Prematurity Period of Risk

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<th>White non-Hispanic</th>
<th>Black non-Hispanic</th>
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<tr>
<td>Excess Rate</td>
<td>Excess Number</td>
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<tr>
<td>2.0</td>
<td>46</td>
</tr>
<tr>
<td>0.6</td>
<td>13</td>
</tr>
<tr>
<td>0.8</td>
<td>18</td>
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<tr>
<td>1.1</td>
<td>26</td>
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2.0 + 0.6 + 0.8 + 1.1 = 4.4 Overall excess mortality rate

46 + 13 + 18 + 26 = 103 Estimated preventable deaths
A simple calculation showed that two periods of risk accounted for 70% of their excess mortality. The second phase of the Urban County investigation focused on these two periods.

\[(2.0 + 1.1) / 4.4 = .70 \text{ or } 70\%\]

SUCCESS! Urban County completed Phase 1 of PPOR analysis. Their rewards...

SUCCESS! They had eliminated many potential causes and narrowed the scope of their investigation.

SUCCESS! The community stakeholders were still on board. They understood the numbers and saw how the data could help them prioritize further investigation.

Some stakeholders simply do not believe in infant mortality statistics, and sometimes they are right!

No data source is perfect. Data quality must be checked. For example, even a few deaths without birth weight information will make PPOR rates look artificially low.

It is important to listen to and address data concerns THROUGHOUT the process.

Yes, Urban County celebrated these successes, but they didn’t stop there.

Phase 2 analysis helped them prioritize among the remaining potential causes of excess mortality.
“She’s got to be kidding! There’s more?”

There are three helpful steps in Phase 2 Analysis

1. Identify the most important probable causes or mechanisms for excess mortality
2. Examine risk factors for those causes, by comparing the study and reference populations
3. Estimate potential impact of risk factors

How does Phase 2 work?
We’ll show you some of Urban County’s investigation of its Infant Health Period of Risk.

• Other risk periods have different methods
• Other cities have different results
• The overall strategy is the same

Step 1: In the infant health period of risk, PPOR uses “underlying cause” ICD-10 Code from the death certificate to investigate causes. Here is a partial list for Urban County.

<table>
<thead>
<tr>
<th>ICD code</th>
<th>Count of Deaths</th>
<th>Code description</th>
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<tbody>
<tr>
<td>Q208</td>
<td>1</td>
<td>Other congenital malformations of cardiac chambers and connections</td>
</tr>
<tr>
<td>Q232</td>
<td>1</td>
<td>Congenital mitral stenosis</td>
</tr>
<tr>
<td>Q249</td>
<td>2</td>
<td>Congenital malformation of the heart, unspecified</td>
</tr>
<tr>
<td>Q909</td>
<td>1</td>
<td>Down’s syndrome, unspecified</td>
</tr>
<tr>
<td>Q913</td>
<td>1</td>
<td>Edwards’ syndrome, unspecified</td>
</tr>
<tr>
<td>V485</td>
<td>1</td>
<td>Passenger injured in traffic accident</td>
</tr>
<tr>
<td>W75</td>
<td>2</td>
<td>Accidental suffocation and strangulation in bed</td>
</tr>
<tr>
<td>W84</td>
<td>1</td>
<td>Unspecified threat to breathing</td>
</tr>
<tr>
<td>R96</td>
<td>15</td>
<td>SIDS</td>
</tr>
</tbody>
</table>

Step 1. The dozens of ICD-10 codes were grouped, and mortality rates calculated for each group in both the study and reference populations.
SUCCESS!
Urban County Stakeholders had discovered that most of their Infant Health Period excess mortality was due to sleep safety issues.

They had eliminated causes that were not large contributors to their excess infant mortality, and further narrowed the scope of their investigation.

Step 2: In Urban County, how common are the known risk factors for sleep related deaths? Compare study and reference groups if possible.

- Sleep position
- Maternal smoking
- Passive smoke
- Bedding
- Co-sleeping
- Crib availability and use
- Parental substance abuse
- Death scene investigation

But they could do better!

Step 2: Since more mothers in Urban County smoked, this could be contributing to the gap.

Step 2: Over 70% of Urban County babies were put to sleep on their backs, which is as good as the best states. Prone sleep position is less likely to be contributing to the gap.

Step 2: Other important information

Child abuse investigators on the team reported that couches, blankets, and parental drug use had been factors in several "SIDS" death cases.

A survey of local obstetricians revealed that
- Most doctors did not discuss safe sleep with expectant mothers
- Most were not aware of available smoking cessation services
Step 2: Guided by PPOR findings, the Fetal Infant Mortality Review team focused on sleep-related deaths for six months.

The FIMR Case Review Team reported that the physical and mental health of mothers was a factor in many of these deaths, including:
- chronic stressful conditions
- lack of social support

Quick side trip #2:

What is FIMR?

FIMR can give us answers when we don't even know what the question is yet!

FIMR can identify cause and effect relationships.

FIMR works in small neighborhoods.

FIMR “Paints faces behind the numbers”

What is FIMR?
Fetal Infant Mortality Review

- The Case Review Team (CRT) examines records of fetal and infant deaths, including chart abstractions and maternal interviews
- Finds patterns, systems issues
- Makes recommendations to the Community Action Team (CAT)

Step 3: Urban County estimated the impact of risk factors, and the potential impact of interventions

Statistically estimated how many lives could potentially be saved if certain risks were reduced (Population Attributable Risk)

- Which factors are modifiable?
- Do evidence-based interventions exist?
- What are our community assets, capacity, and commitment?

The stakeholders weighed the evidence and sought more information as needed.

Phase 2 investigations can continue as questions arise and more data becomes available.
Urban County’s Community Stakeholders decided on these initial action steps:

- Message changed from “sleep on back” to a broader “safe sleep” message
- Physician education about smoking cessation services for pregnant women
- Partnered with a group that was already working on maternal mental health issues

SUCCESS!
Urban County had still more rewards...

- Their time investment was focused
- They found some answers
- Action steps were more appropriate than initially envisioned (“back to sleep”)

SUCCESS in Outcomes
PPOR 1993-2009
Urban County

Fetal-Infant Rate=10.7

The decrease in mortality rates can't necessarily all be attributed to PPOR

Can everyone use the Perinatal Periods of Risk approach?

What do you need?

--You need at least 60 deaths--

- At least 60 fetal and infant deaths, for each population being studied
- May combine up to five years (no more, due to changes in medical practice and public health systems)
- Phase 2 analyses require even more deaths

You need a clearly defined study population

A small area may not have enough deaths, and population-based data may be available only down to the city or county level
You need 3 vital records data files

1. Fetal deaths
2. Infant deaths, linked to birth records
3. Live births

You need someone who knows what to do with the data files

What is PPOR?

. . . It’s more than just the data!

It’s a community tool for decreasing infant mortality

6-stage PPOR approach following the community planning cycle

Stage 1: Assure Community and Analytic Readiness
Stage 2: Conduct Analytic Phases of PPOR
Stage 3: Develop Strategic Actions for Targeted Prevention
Stage 4: Strengthen Existing and/or Launch New Prevention Initiatives
Stage 5: Monitor and Evaluate Approach
Stage 6: Sustain Stakeholder Investment and Political Will

PPOR is designed for integration with your community planning cycle

PPOR should be used with any existing efforts

• FIMR
• Healthy Start
• Community Health Assessments

But if you are just starting out, the PPOR approach can frame and guide your whole infant mortality prevention process.

Stage 1: Assure Community and Analytic Readiness

“Data analysis alone does not produce community change.”

• Because infant mortality has many social and medical causes, many stakeholders are needed
• Everyone has a different piece of the puzzle
Who are your stakeholders?

Source: NACCHO’S MAPP Clearinghouse

You need to be ready and have committed leadership

- If communities are not ready for change, or leadership is not engaged or committed, they will have a difficult time being successful.
- Planning helps avoid failure, which can be discouraging.

Tools for Assessing & Evaluating Readiness

- Help engage partners, reach consensus, identify assets, reveal gaps, develop strategies
- Evaluate efforts of the collaborative

Stage 2: Analysis – Phase 1

- Calculates period-specific mortality rates in the study population
- Compares them with rates in the reference population
- Identifies the periods of risk that contribute most to "excess mortality" or preventable deaths

Stage 2: Analysis – Phase 2

- Identifies the most important probable causes of local excess mortality
- Examines risk factors for those causes, by comparing the study and reference populations
- Estimates potential impact of risk factors

Stage 3: Develop Action

The community stakeholders decide how best to address the specific areas found to be contributing most to preventable deaths

- Assess relevant community assets
- Find existing evidence-based programs
- Adapt or design new programs
- Determine appropriate policy changes
Stage 4: Implementation

New programs are implemented or existing ones strengthened

Based on

- Results of PPOR previous 3 stages
- Stakeholder knowledge
- Community assets

Stages 5 & 6: Close the Loop by Evaluating, Monitoring, and Assuring Sustainable Community-Involved Work

Visit us at www.citymatch.org or call 402-561-7500

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