Current Status of Fetal Death Certificate Reporting

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Erica Lee, MPH
Quality Improvement Coordinator
Bureau of Vital Statistics
New York City Department of Health and Mental Hygiene
Overview

• Fetal Deaths in NYC
• Perinatal mortality
• Data Quality Gap: comparing fetal deaths to neonatal deaths
• Research Question: Fetal Death Reporting Barriers
  – Methods
  – Selected Results
  – Conclusions/Next Steps
### NYC Fetal Deaths 2011

<table>
<thead>
<tr>
<th>Attribute</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total fetal deaths</td>
<td>14,947</td>
</tr>
<tr>
<td># of reporting facilities</td>
<td>52</td>
</tr>
<tr>
<td>% reported electronically</td>
<td>&gt;99%</td>
</tr>
<tr>
<td>Gestational age</td>
<td></td>
</tr>
<tr>
<td>&lt;13 weeks</td>
<td>81%</td>
</tr>
<tr>
<td>13-19 weeks</td>
<td>12%</td>
</tr>
<tr>
<td>20-27 weeks</td>
<td>5%</td>
</tr>
<tr>
<td>≥ 28 weeks</td>
<td>2%</td>
</tr>
</tbody>
</table>
Perinatal Mortality

Perinatal continuum

Conception  1\textsuperscript{st} trimester  2\textsuperscript{nd} trimester  3\textsuperscript{rd} trimester  BIRTH  28 days

Perinatal deaths

Third-trimester fetal deaths

28 weeks

Neonatal deaths
Perinatal mortality

• Third-trimester fetal deaths:
  – 28% of US perinatal deaths
  – 25% of NYC perinatal deaths

• Close in time along the perinatal continuum
  – Causes and preventative targets likely very similar
  – Research/programming gap between fetal and neonatal deaths
Fetal vs. neonatal deaths

• Both events captured by vital events registration systems
  – Viable data source: low-cost, representative

• Comparing fetal to neonatal deaths allows for:
  – Comprehensive assessment of fetal death data quality and viability for research
  – Insight into fetal vs. neonatal death reporting and data quality disparities
Sample: third trimester fetal deaths (n=1930) and neonatal deaths (n=735)

1. Frequencies of missing/unknown on fetal vs. neonatal

2. Frequencies of ill-defined causes of death on fetal vs. neonatal

3. Pre/post revision data completeness for fetal deaths

4. Fetal death data completeness by reporting facility
## Selected results: Completeness

<table>
<thead>
<tr>
<th>Fetal Death Certificate Item</th>
<th>% Missing/Unknown, 2011</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>General Information</strong></td>
<td></td>
</tr>
<tr>
<td>Zip code</td>
<td>27</td>
</tr>
<tr>
<td>Primary payer</td>
<td>14</td>
</tr>
<tr>
<td><strong>Maternal Information</strong></td>
<td></td>
</tr>
<tr>
<td>Ancestry</td>
<td>25</td>
</tr>
<tr>
<td>Pre-pregnancy weight</td>
<td>13</td>
</tr>
<tr>
<td>Level of education</td>
<td>22</td>
</tr>
<tr>
<td>LMP date</td>
<td>9</td>
</tr>
<tr>
<td>FPNC date</td>
<td>20</td>
</tr>
<tr>
<td><strong>Maternal risk factors and morbidity</strong></td>
<td></td>
</tr>
<tr>
<td>Pregnancy risk factor</td>
<td>18</td>
</tr>
<tr>
<td>Alcohol use during this pregnancy</td>
<td>9</td>
</tr>
<tr>
<td>Illicit or other drug use during this pregnancy</td>
<td>21</td>
</tr>
<tr>
<td>Smoking during pregnancy</td>
<td>8</td>
</tr>
</tbody>
</table>
### Selected results: Ill-defined Cause of Death

<table>
<thead>
<tr>
<th>Event type</th>
<th>% Ill-defined, 2007-2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neonatal</td>
<td>5</td>
</tr>
<tr>
<td>Fetal</td>
<td>67</td>
</tr>
</tbody>
</table>

**Written causes (fetal deaths)**
- Intrauterine fetal demise
- Unknown
- Stillbirth / Stillborn

75%
Selected results: Summary

• NYC late-term fetal death certificates lack maternal, pregnancy, and cause of death information compared with neonatal records

• Implementation of electronic reporting system/revised certificate impacted data completeness and COD

• Variability by hospital suggests opportunities for improvement exist
Research Question

What are the causes of deficient data at fetal death reporting facilities?
Methods

Survey

• One respondent with primary responsibility for fetal death reporting at each of 50 NYC reporting facilities in 2011
• 17 content questions regarding fetal death reporting
  – Knowledge
  – Attitudes
  – Practices
  – Barriers
• 2 researchers independently categorized open-ended questions into themes
Methods

Association between survey responses and 2011 fetal death data quality indicators at each facility

• Data completeness: “Any Unknown” - Maternal risk factor; Date of last normal menses; Date of first prenatal care visit; Fetal weight

• Ill-defined causes of fetal death
  • Unspecified cause (P95)
  • Prematurity (P07.2, P07.3)
SELECTED RESULTS
Respondent Characteristics

Final response rate: 78% (n=39), reporting 84% of all 2011 fetal deaths

• Facilities
  – 36 hospitals (92%)
  – 2 private physician offices/clinics (5%)
  – 1 birthing center (3%)

• Respondents
  – 23 administrative staff (59%)
  – 11 birth registrars (28%)
  – 3 nurses (8%)
  – 2 midwives (5%)
Reporting Requirements and Data Use

• 32 (82%) understood NYC requires reporting for all gestational ages

• 34 (87%) considered fetal death reporting ‘very important’

• 20 (51%) knew how fetal death data are used
Variation in Reporting Practices

- Median time to register a fetal death: 15min (0-45 min)

- Median number involved in collecting information required to file a fetal death: 4 persons (0-40 persons)

- 12 (31%) use the fetal death worksheet for >50% of cases
  - 23 (59%) use it for <25% of cases
Revision and Electronic Reporting

Transition to Electronic Reporting (EVERS)
• 21 (55%) considered electronic reporting easier
  – 10 (26%) considered it more difficult

• 17 (45%) thought EVERS reduced the time to report
  – 12 (32%) thought it increased reporting time
  • Reported longer filing times on average (21min vs. 14min, p=0.051)

Revised Cause of Death Section
• 15 (38%) thought revisions were similarly clear and easy to understand as previous versions
  – 9 (24%) thought revisions are clearer and easier to understand
Reported Barriers

• 6 (15%) reported “no substantial barriers” to timely reporting

• 11 (28%) reported difficulties accessing physician’s time and attention

• 9 (23%) thought forms were lengthy, overly detailed, had too many questions

• 8 (21%) thought reporting took too much time
Data Quality Linkage – Registrations with Missing Information

Reported barriers vs. “no substantial barriers”
• 37.5% versus 7.9%  RR: 4.7   95% CI: 1.6–14.2

Said form was too long/detailed vs. did not mention that barrier
• 46.4% versus 30.5%  RR: 1.5   95% CI: 1.1–2.1

Considered fetal death reporting ‘very important’ vs. ‘somewhat important’
• 30.4% versus 58.1%  RR: 0.52   95% CI: 0.38–0.71
Data Quality Linkage – Ill-Defined Cause of Fetal Death

Reported difficulty accessing physicians to complete Cause of Death section and certify registrations vs. those who did not

- 70.9% versus 56.6%  \[ \text{RR: 1.3} \]  95% CI: 1.1–1.5

Reported that revised Cause of Death section was clearer and easier to understand vs. those who did not

- 48.0% versus 65.7%  \[ \text{RR: 0.73} \]  95% CI: 0.57–0.94
Lessons Learned – Mitigating Barriers

• Reduce certificate length
  – Focus on high quality items actively used for research or surveillance
  – Minimize information required for early fetal deaths in NYC (<20wks)

• Facilitate data collection
  – Mandate worksheet use
  – Linkage between EMR’s and electronic vital events systems
  – Integrate fetal death reporting into physician workflow
Lessons Learned – Mitigating Barriers

85% of respondents requested some sort of training

• Reporting requirements
  – Difference between elective abortion, fetal death, live birth, and when to report each event

• Importance and use of fetal death data
  – Perceived importance was linked to better data quality

• Physician training
  – Role in reporting as best source of data
  – How to correctly complete the revised cause of death section
Limitations

• Respondent may not be primarily responsible for fetal death reporting

• Socially desirable responses

• Restriction to NYC facilities
  – Reporting requirements
  – Electronic reporting system
Conclusions

• Fetal death data is poorer than data for other, similar vital events

• Reporting barriers exist for fetal deaths that may explain poor data quality

• Taking action to mitigate reporting barriers may improve fetal death data quality

• funding is needed to operationalize improvements and prioritize fetal deaths
“This is a stressful burden on an overworked system. No additional money has been allocated to dedicate more time to this Required filling [sic].”
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Thank you!

Erica Lee, MPH
Quality Improvement Coordinator
Office of Vital Statistics
646-632-6730 | elee7@health.nyc.gov
Questions?