Recurrent sudden unexpected infant deaths in families: causes and concerns.

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Care of Next Infant Programme (CONI)

- Enhanced Health Visitor (HV) service for families with infants born following sudden infant death in England, Wales, Northern Ireland
- HV trained and supported by CONI HQ based at Lullaby Trust
- Families referred antenatally and followed for at least 6 months
- HV provide regular home visits, apnoea monitors, life support training.
- If a CONI infant dies HV notify CONI HQ
  - Families are offered a detailed case review by specialist CONI paediatricians and pathologists; this happens after all standard coronial and child death review investigations are complete
Sudden Unexpected Death in Infancy (SUDI)

- 300-400 cases of Sudden Unexpected Death in Infancy (SUDI) annually in the UK
  - Death that could not have been reasonably predicted 48 hours before
  - 1/3 SUDI have cause of death subsequently determined (including accidental asphyxia)
  - 2/3 SUDI remain unexplained = Sudden Infant Death Syndrome (SIDS)/unascertained death
- SIDS risk factors: social deprivation, smoking, alcohol or drug misuse, unsafe sleep environment.
- Child protection concerns in 5-10% of SUDI cases
- 1990s ‘one SIDS is a tragedy, two are suspicious, three are murder’

Objectives

- 1. To determine the SUDI rate for infants born after a previous SUDI in the same family
- 2. To establish the causes of death and risk factors in families with recurrent SUDI
- 3. To determine the frequency of child protection concerns in families with repeat SUDI
Methods

• We reviewed all case files for CONI infants registered between January 2000 and December 2015, who died unexpectedly before the age of 1 year.
• Information extracted on cause of death and SIDS risk factors
• Risk factors:
  • maternal smoking
  • maternal mental health problems
  • Unsafe co-sleeping
  • maternal alcohol or drug misuse
  • poor parenting and child protection concerns

Consistency of Review

• Cause of death based on information in the case file including parental accounts, death scene findings, post-mortem reports and specialist reviews.
  • SIDS determined according to San Diego definition, if inadequate information classified as unascertained.
  • Accidental asphyxia determined where both the autopsy findings and the circumstances of death were supportive, or if the infant was found under a parent or at the bottom of the parents’ bed under bedding, or if there were other significant suffocation hazards.

• Case files were reviewed twice by different pairs of researchers using a standard template then discussed by the whole team.
Results

• There were 6612 live-born infants registered on CONI in the years 2000-15
• 29 deaths in 26 families
  • 23 with 2 deaths (including the index case)
  • 3 with 3 deaths (including the index case)
• Detailed clinical information was available for 18/26 index deaths and 25/29 sibling deaths.
• Mortality rate on CONI = 4.39 per 1000 live births.

![Cause of death](chart.png)
Maternal smoking habits for index and CONI cases

<table>
<thead>
<tr>
<th>Smoking CONI pregnancy (22 total)</th>
<th>Non smoking CONI pregnancy (4 total)</th>
<th>CONI pregnancy smoking unknown (2 total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking index pregnancy (15 total)</td>
<td>15</td>
<td>0</td>
</tr>
<tr>
<td>Non smoking index pregnancy (6 total)</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Index pregnancy smoking unknown (22 total)</td>
<td>5</td>
<td>0</td>
</tr>
</tbody>
</table>

Maternal smoking in pregnancy in 15 index cases and 22 siblings

Final sleep position for index and CONI cases

<table>
<thead>
<tr>
<th>CONI case co-sleeping (10 total)</th>
<th>CONI case safe sleeping (7 total)</th>
<th>CONI case unknown sleeping (9 total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Index case co-sleeping (9 total)</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Index case safe sleeping (6 total)</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Index case sleep unknown (11 total)</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

9 index and 10 CONI cases were co-sleeping in hazardous situations
## Maternal mental health problems for index and CONI cases

<table>
<thead>
<tr>
<th>Mental health problems in CONI case (13 total)</th>
<th>No mental health problems in CONI case (6 total)</th>
<th>Mental health unknown in CONI case (7 total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental health problems in index case (6 total)</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>No mental health problems in index case (7 total)</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Mental health unknown in index case (13 total)</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

Mental health problems either antenatally or postnatally in 6 index and 13 CONI cases

## Poor parenting in index and CONI cases

<table>
<thead>
<tr>
<th>Parenting concerns in CONI case (15 total)</th>
<th>No parenting concerns in CONI case (7 total)</th>
<th>Parenting concerns unknown in CONI case (4 total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parenting concerns in index case (5 total)</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>No parenting concerns in index case (12 total)</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Parenting concerns unknown in index case (9 total)</td>
<td>5</td>
<td>0</td>
</tr>
</tbody>
</table>

Parenting concerns in 5 index and 15 CONI cases
Child abuse or neglect in index and CONI cases

<table>
<thead>
<tr>
<th></th>
<th>Abuse or neglect in CONI case (7 total)</th>
<th>No abuse or neglect in CONI case (14 total)</th>
<th>Abuse or neglect unknown in CONI case (3 total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abuse or neglect in index case (3 total)</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>No abuse or neglect in index case (15 total)</td>
<td>2</td>
<td>13</td>
<td>0</td>
</tr>
<tr>
<td>Abuse or neglect unknown in index case (6 total)</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
</tbody>
</table>

Child abuse or neglect in 3 index and 7 CONI cases

Conclusions

- SUDI rate for siblings at 4.39/1000 is 9 fold greater than UK SUDI rate of 0.45/1000 live births.
- Homicide was very rare, but child protection concerns were common (7/29 CONI cases)
- Smoking and unsafe sleep remains a significant risk factor despite the enhanced Health Visitor programme, 11 CONI cases were co-sleeping and 6 CONI deaths were due to accidental asphyxia
- Genetic mechanisms are likely to be important as well as modifiable risk factors
Remembering Prof Bob Carpenter 1930-2016

And thank you to all at CONI