The Voice of the Infant.

Cause of death coding does not always reflect what really mattered in the life of the infant who died suddenly and unexpectedly.

Julie McEniry and Diane Cruice, on behalf of the Infant Mortality Sub Committee of the QPQC.

Background

- The Infant Mortality Rate (IMR) in Queensland (QLD) is higher than the rest of Australia and the reasons for this are unclear1. This is also true for QLD’s post-neonatal infant mortality (see graph)1.
- IMR differences between states and within QLD are not explained by QLD’s geography or demographics, and QLD non-indigenous as well as indigenous IMRs are raised1. This does not support unmodifiable reasons (specific to QLD) for the higher IMR. It is more likely that the excess QLD infant deaths are preventable.

Results

- 51 deaths met the definition of SUDI. The SUDI IMR in QLD was higher than NSW. Rate Ratio (QLD vs NSW) = 1.5 (95% CI 1.002-2.150)4.
- 4 were excluded from further review (2 incomplete from Coroner, 2 false abusive injury). 47 remaining SUDI were re-classified as follows.

SUDI Re-Classification using San Diego-Krous, Avon-Blair, NSW CDRT, CDC-Shapiro Mendoza Classifications

<table>
<thead>
<tr>
<th>SUDI</th>
<th>Description</th>
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<tbody>
<tr>
<td>SIDS IA</td>
<td>“classic” age 3-9m and safe sleep</td>
</tr>
<tr>
<td>SIDS B 1</td>
<td>IA SUDI – Information not collected</td>
</tr>
<tr>
<td>SIDS B 2</td>
<td>IA SUDI – factors possibly contributed</td>
</tr>
<tr>
<td>SIDS B 3</td>
<td>IA SUDI – factors sufficient to provide cause of death</td>
</tr>
</tbody>
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The subgroup of SIDS was the group most commonly recorded (76%) – mostly to USD

Conclusions

- The word “infant” comes from the Latin “unable to speak”. An infant who dies suddenly and unexpectedly relies on others for a voice to speak in the circumstances of the death.
- What really mattered in the life of the infant who died suddenly and unexpectedly was the complex interplay of multiple social, intrinsic and extrinsic factors that combine with unsafe sleep factors, to minimise risk.
- With the help of forensic and scientific investigations this has to be done will be very few SUDI can be correctly coded as SIDS. In our series, half the death codes were inappropriate. A mislabelled diagnosis of SIDS may be more comforting to parents than "undetermined" as a cause of death but this does no justice to the infant.
- ICC10 coding to a “beyond reasonable doubt” forensic standard serves legal requirements, but results in a unidimensional descriptor which fails to describe preventable factors in infant death.
- Whilst research progress is being made to better understand SIDS, comprehensively that "SIDS is just something that unfortunately happens" persists. SUDI classification which accounts for multiple factors offers opportunities to prevent further infant deaths.

Acknowledgements

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References


Key Message

- SUDI is multifactorial

Key Message

- Unexplained sleep remains a factor in most SUDI