CHAPTER 8

Sudden unexpected deaths in infancy

This chapter provides details of sudden unexpected infant deaths.

KEY FINDINGS

• Sudden unexpected death in infancy (SUDI) is a category of deaths where an infant (aged under one year) dies suddenly usually during sleep and with no immediately obvious cause. Deaths from SUDI are recorded as 'cause pending' until an official coroner’s investigations or post-mortem examinations provide an official cause of death.

• There were 30 SUDI cases in 2016–17, a rate of 47.9 deaths per 100,000 infants. The number and rate of SUDI deaths have fluctuated over the last 13 years; ranging between 29 and 55 deaths each year.

• Aboriginal and/or Torres Strait Islander infants are over-represented in SUDI deaths. Over the last 3 years, Indigenous infants died suddenly and unexpectedly at 2.3 times the rate of non-Indigenous infants.

• Encouragingly the numbers of Aboriginal and/or Torres Strait Islander SUDI deaths in the last two years have been lower than the numbers in most earlier periods since 2004 (4 deaths in 2015–16 and 3 in 2016–17).

• Children known to the child protection system had SUDI rates over three times those for all children over the last 3 years.

• Six of the 12 deaths with an official cause of death were attributed to SIDS and undetermined causes. Official causes of death were still pending for 18 deaths.

• Six of the SUDI deaths were found to have an explained cause of death. Four children died as a result of infant illnesses or conditions unrecognised prior to their deaths and 2 died as a result of sleep accidents.

• In 2015–16, when all but 2 SUDI deaths had recorded causes of death, the rate of death for SIDS and undetermined causes was 24.0 per 100,000 infants (15% of infant deaths from all causes), representing the third highest cause of death after perinatal conditions and congenital anomalies.

• Compared to other explained causes, SIDS and undetermined causes are a much more common contributor to infant deaths in the post-neonatal period (28 days to 11 months), accounting for 24% of all deaths in this age group in 2015–16 (14 of 59 post-neonatal infant deaths).

• Findings of Queensland Paediatric Quality Council’s expert panel reviews of SUDI cases, presented in this chapter, revealed the following themes:
  – for SUDI, there is rarely a single cause in isolation
  – the SUDI infant’s family environment is complex and vulnerable
  – for SUDI families, safe sleeping messages have not been acted on

• Growing evidence indicates the Pepi-Pod® Program, currently being rolled out as a portable sleep space with safe sleep education in Indigenous communities, improves the safety of infants in high risk sleep environments. Consideration could be given to extending the program into other settings in which vulnerable families and their babies are displaced from their homes or have complex needs, including: young mothers’ programs; domestic violence and homeless shelters; drug and alcohol support services; and as part of emergency responses in cyclone, flood and fire-affected locations. There would also be value in developing studies which would map the impact of targeted programs for vulnerable families on infant mortality patterns.
## Sudden Unexpected Deaths in Infancy 2014–17

An expanded version of Table 8.1 containing data since 2004 is available online at [www.qfcc.qld.gov.au](http://www.qfcc.qld.gov.au).

### Table 8.1: Summary of SUDI in Queensland 2014–17

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<td>2</td>
<td>*</td>
<td>2.1</td>
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</tbody>
</table>

Data source: Queensland Child Death Register (2014–17)

* Rates have not been calculated for numbers less than four.

1. Data presented here is current in the Queensland Child Death Register as at August 2017 and thus may differ from those presented in previously published reports.
2. Rates are based on the most up-to-date denominator data available and are calculated per 100,000 children (in the sex/age/Indigenous status/children known to child protection/ARIA+ region/SEIFA region categories) in Queensland each year. Rates for 2014–15 use ERP data as at June 2014, The 2015–16 and 2016–17 periods use the ERP data as at June 2015.
3. ARIA+ and SEIFA exclude the deaths of children whose usual place of residence was outside Queensland.
4. The number of children known to the child protection system represents the number of children whose deaths were registered in the reporting period, who were known to the DCCSDS within the one-year period prior to their death. The denominator for calculating rates is the number of children aged 0–17 who were known to the DCCSDS, through either being subject to a child concern report, notification, investigation and assessment, ongoing intervention, orders or placement, in the one-year period prior to the reporting period.
5. Rates of SUDI for “Known to the child protection system” are calculated per 100,000 children aged 0–17 years in Queensland, known to the child protection system instead of per 100,000 infants under the age of one year known to the child protection system.
6. Yearly average rates have been calculated using the ERP data as at June 2015.
THE CLASSIFICATION OF SUDDEN UNEXPECTED DEATHS IN INFANCY

Sudden unexpected death in infancy is a research classification and does not correspond with any single medical definition or categorisation. Rather, the aim of this grouping is to report on the deaths of apparently well infants who would be expected to thrive, yet, for reasons often unknown, die suddenly and unexpectedly. Identifying deaths in this way assists in the identification of possible risk factors for and associations with sudden infant death and, most significantly, those factors which may be preventable or amenable to change.

The Police Report of Death to a Coroner (Form 1), which includes a summary of the circumstances surrounding the death as initially reported,33 is used to identify SUDI deaths. The circumstances of the death must meet all of the following criteria to be included in the SUDI grouping:

- child less than one year of age
- sudden in nature
- unexpected, with no previously known condition which was likely to cause death
- no immediately obvious cause of death.

The SUDI grouping includes deaths found to be associated with infections or anatomical/developmental abnormalities not recognised before death, sleep accidents such as inhalation of gastric contents, and deaths that initially present as sudden and unexpected but are revealed by investigations to be the result of non-accidental injury. It also includes deaths due to SIDS and infant deaths where a cause could not be determined.34

Death certification

A high proportion of SUDI cases (18 of 30 in 2016–17) are pending death certification at time of reporting. Paediatric autopsies are amongst the most complex forms of autopsies undertaken, and the complexity contributes to the length of time required to undertake and report on autopsies. Following the development of a new definition of SIDS in 2004 (termed the San Diego definition), all cases of SUDI optimally require the performance of a complete autopsy (including toxicology, microbiology, radiology, vitreous chemistry and metabolic screening studies).35

There is also an additional focus on establishing there is no evidence of unexplained trauma, abuse or unintentional injury before a classification of SIDS can be assigned. This frequently involves more extensive gross and microscopic examination during autopsy than in cases of explained infant and child deaths.

SUDDEN UNEXPECTED DEATHS IN INFANCY: FINDINGS 2016–17

During 2016–17, there were 30 SUDI cases in Queensland, at a rate of 47.9 deaths per 100,000 infants. The number and rate of SUDI deaths have fluctuated over the last 17 reporting periods; however, the 2016–17 number of deaths is the second lowest recorded since reporting began in 2004. The number of SUDI cases since reporting commenced in 2004 ranges from 29 to 55 per year, with an average of 43 per year.36

Sex

During 2016–17, there were 17 SUDI deaths of female infants, compared to 13 male infants. There is minimal difference between the 3-year average SUDI mortality rates for females and males (5.6 deaths per 100,000 female infants, compared to 50.8 deaths per 100,000 male infants). In the 13 years since reporting commenced, male children are slightly over-represented in SUDI cases.

36 In Queensland, section 8 of the Coroners Act 2003 requires all violent or unnatural/unusual deaths be reported to a coroner. All unexpected infant deaths fall within that description. All cases of SUDI require a comprehensive investigation, which should include a full autopsy, examination of the death scene and review of clinical history.
37 Cases of SUDI that were explained at post-mortem are also counted and discussed in the chapter appropriate to their cause of death. Deaths found at autopsy to be caused by previously unrecognised illnesses or congenital anomalies are counted in Chapter 2, Deaths from diseases and morbid conditions. Deaths found at autopsy to be caused by accidental suffocation in bed are counted in Chapter 5, Other non-intentional injury-related death.
39 Tables with data for 2004–17 are available online at www.qfcr.qld.gov.au
Age

Figure 8.1 shows SUDI by age at death during 2016–17. Infants’ age ranged from 1 day to 11 months. The majority (80%) of sudden unexpected deaths occurred among infants aged under 6 months (24 of the 30 deaths).

**Figure 8.1: SUDI by age at death 2016–17**

Data source: Queensland Child Death Register (2016–17)

**Aboriginal and Torres Strait Islander status**

Of the 30 SUDI deaths during 2016–17, 3 were of Aboriginal and/or Torres Strait Islander infants. This is the lowest number of Indigenous SUDI deaths since reporting commenced in 2004. Over the past 13 years the number of Indigenous SUDI deaths has ranged from 3 to 18 each year, with an average of 10 per year.

Over the last 3 years, the average annual SUDI rate of mortality for Indigenous infants was 2.3 times the rate for non-Indigenous infants (108.7 deaths per 100,000 Indigenous infants, compared to 46.7 deaths per 100,000 non-Indigenous infants).

**Geographical area of usual residence (ARIA+)**

Of the 30 SUDI deaths during 2016–17, 14 were of infants from regional areas and 15 were of infants from metropolitan areas. There were no deaths of infants who resided in remote areas of Queensland. One infant death is excluded from regional analysis as their usual place of residence was outside Queensland.

**Socio-economic status of usual residence (SEIFA)**

Of the 30 SUDI deaths during 2016–17, 17 were of infants who resided in Queensland areas of low-to-very-low SES, 6 were of infants from moderate-SES areas and 6 were of infants from areas of high-to-very-high SES.

Over the last 3 years, the average annual SUDI rate of mortality for infants from areas of low-to-very-low SES was approximately 2.4 times the rate for children from areas of moderate and high-to-very-high SES (79.5 deaths per 100,000 infants from areas of low-to-very-low SES, compared to 35.5 deaths per 100,000 infants from areas of moderate SES and 31.7 deaths per 100,000 infants from areas of high-to-very-high SES).

**Children known to the child protection system**

Of the 30 SUDI deaths during 2016–17, 7 were of infants known to the Queensland child protection system within the year before their death. Children known to the child protection system had a SUDI rate over three times that for all Queensland children over the last 3 years (rates per 100,000 aged 0–17 years of 10.7 and 2.9 respectively).
CAUSE OF DEATH 2015–16

Predominantly, deaths from SUDI are recorded as ‘cause pending’ until the outcomes of post-mortem examinations or coroner’s investigations are concluded. At the time of reporting only 12 of the 30 SUDI cases in 2016–17 had an official cause of death. To present more detailed information on cases for which an official cause is available, the following sections provide data from the period 2015–16, when all but 2 SUDI deaths had a cause-of-death finding.

Cases of SUDI are grouped broadly into two categories:

- **Unexplained SUDI**—those infant deaths for which a cause could not be determined (including SIDS and undetermined cases and SUDI deaths pending a cause of death).
- **Explained SUDI**—infant deaths for which a cause was not immediately obvious; but for which post-mortem examinations were able to identify a specific reason (including unrecognised infant illnesses, sleep accidents and non-accidental injury).

In 2015–16, 29 deaths were SUDI cases. Following post-mortem examinations, 12 deaths were found to have an explained cause (41%). The remaining 17 deaths were unexplained SUDI cases: For 15 deaths, the official cause was SIDS or undetermined (52%), and for 2 deaths the cause had not been ascertained (7%).

Unexplained sudden unexpected deaths in infancy

Unexplained SUDI cases includes deaths for which post-mortem examinations and coronial investigations indicate the causes to be SIDS or undetermined causes, as well as deaths which were pending the outcome of post-mortem examinations and coronial investigations.

**Sudden Infant Death Syndrome and undetermined causes**

The definition of Sudden Infant Death Syndrome (SIDS) applied in this report and currently accepted by most experts within Australia is as follows:

> The sudden, unexpected death of an infant under one year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation including performance of a complete autopsy and review of the circumstances of death and the clinical history.

Cases of SUDI are classified as having undetermined causes if:

- natural disease processes are detected and are not considered sufficient to cause death but preclude a diagnosis of SIDS
- there are signs of significant stress
- non-accidental, but non-lethal, injuries are present
- toxicology testing detects non-prescribed but non-lethal drugs, or
- a full autopsy has not been performed and a cause is not otherwise identified.

Further classification of the 17 unexplained SUDI cases in 2015–16 identified that 9 deaths resulted from SIDS and 6 from undetermined causes. Two deaths which were pending outcomes of post-mortem examinations and coronial investigations.

The rate of death for SIDS and undetermined causes in 2015–16 was 24.0 per 100,000 infants (15% of infant deaths from all causes), representing the third highest cause of death after perinatal conditions and congenital anomalies. As noted in Chapter 2, compared to other explained causes, SIDS and undetermined causes are a much more common contributor to infant deaths in the post-neonatal period (28 days to 11 months). In 2015–16, SIDS and undetermined causes were the leading causes of infant death in the post-neonatal period (1–11 months). In 2015–16, SIDS and undetermined causes, along with congenital anomalies, were the leading causes of death in the post-neonatal period (14 deaths each of 59 post-neonatal infant deaths).

Analysis of longer-term trends in SUDI deaths is problematic because of changes in classifications and, more importantly, changes to the pathological investigations carried out on SUDI deaths. SUDI deaths now require a full autopsy be carried out, and this has enabled improved identification of underlying illness and other explained causes of death. Notwithstanding these caveats, SIDS deaths recorded prior to 2000 may provide a reasonable match to deaths in the SUDI research category. ABS data indicates in 1982–86

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58 ABS (1998), *Causes of Infant and Child Deaths, Australia, 1982–96*, Cat. 4398.0
there were on average 66 SIDS deaths in Queensland each year, dropping to an average of 47 in 1992–96. Reductions in SIDS numbers in the late 1980s, both nationally and internationally, are attributed to public health campaigns such as Back-to-Sleep, as well as increased awareness of the importance of a safe sleep environment.

There were approximately 40 SUDI cases each year between 2004 and 2007; 50 cases each year from 2008 to 2012, and fewer than 40 cases each year in the last few years.

**RISK FACTORS FOR SUDI DEATHS**

A number of factors have been associated with an increased risk of unexplained SUDI deaths. These can be classified according to whether they are associated with the infant, the sleep environment or the family or household:

**Infant factors**: prematurity and low birth weight, multiple gestation (twins, triplets), neonatal health problems, male sex and recent history of minor viral respiratory infections and/or gastrointestinal illness.

**Sleep environment factors**: sleeping on soft surfaces and loose bedding, prone (on stomach) sleeping position and side sleeping position, some forms of shared sleeping and overwrapping or overheating.

**Family factors**: cigarette smoking during pregnancy and after birth, young maternal age (< 20 years), single marital status, high parity (number of births by mother) and short intervals between pregnancies, poor or delayed prenatal care, high-risk lifestyles, including alcohol and illicit drug abuse and low SES (social disadvantage and poverty).

Safe sleeping programs specifically emphasise ways to minimise risk factors, and include some of the following prevention messages:

- Sleep infants on their back from birth
- Ensure the infant’s head and face remain uncovered
- Keep baby smoke free before and after birth
- Ensure infants have their own safe sleep environment. This means ensuring the cot meets the Australian safety standards and contains a firm mattress which is the appropriate size for the cot, and the environment is free from objects such as pillows, soft toys, and doonas.
- Sleep infants in the parents’ bedroom for the first 6–12 months
- Breastfeed infants.

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Infant sleep position

Table 8.2 shows the position when placed for sleep and when found, for the 17 infants whose deaths were classified as unexplained SUDI.

Table 8.2: Unexplained SUDI by sleep position and position when found 2015–16

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<th>Sleep position</th>
<th>SIDS n</th>
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</tr>
<tr>
<td><strong>Total</strong></td>
<td>9</td>
<td>6</td>
<td>2</td>
<td>17</td>
</tr>
</tbody>
</table>

Data source: Queensland Child Death Register (2016–17)

**SHARED SLEEPING WITH OTHER RISK FACTORS**

Eleven of the 17 infants whose deaths were classified as unexplained SUDI were sharing a sleep surface with one or more people at the time of death (5 SIDS, 4 undetermined, and 2 cause pending).

Sharing a sleep surface with a baby increases the risk of SIDS and fatal sleep accidents in some circumstances.61 Some studies have found there is an increased risk of SIDS only when mothers who smoke share a bed with their infant, although such findings are insufficient to enable complete reassurance bed sharing is safe for non-smokers. Risks are also associated with shared sleeping if infants are sharing a sleep surface with a caregiver who is under the influence of alcohol or drugs which cause sedation, if the caregiver is excessively tired or there are multiple people in the bed with the infant.

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PEPI-POD® PORTABLE SLEEP SPACES

The Pepi-Pod® Program (the program) provides a way to ensure infants have their own safe sleeping environment, if safe sleep principles are followed, while at the same time allowing infants to co-sleep with their parents if this is the cultural or family preference or circumstance. The Pepi-Pod® Program originated in New Zealand as a sister program to the Maori wahakura and was part of the Safe Sleeping public health initiative to address rates of SUDI deaths. Its first significant use was as part of the emergency response to the Christchurch earthquake.

The program has been introduced in Queensland with a specific focus on regional and remote Aboriginal and/or Torres Strait Islander communities in collaboration with government and nongovernment services (n=14 services as of September 2017). The program comprises three essential elements: a portable infant sleep space, safe sleep education and a family commitment to using the Pepi-Pod® as intended and spreading safe sleep messages within their priority social networks. All Queensland families recruited have identified risk factors for SUDI; approximately 75% of families had ≥2 known risk factors. Pepi-Pod® Program acceptability has been supported by parent responses which relate to three key themes: safety, convenience and portability.

Preliminary findings suggest the use of the Pepi-Pod® reduces the interaction between parental smoking and direct bed-sharing for a vulnerable infant by over 50%. Safe sleeping awareness has been raised within families and in community networks. Health service feedback relating to program implementation in Queensland has indicated the program is feasible, accessible, and flexible and has built local workforce capacity with integration into current service models. The Program has also played a part in a community emergency response in Queensland during tropical Cyclone Ita. Further studies are needed to map infant mortality patterns in areas which have health services which have implemented the Pepi-Pod® Program.

A New Zealand study indicates SUDI mortality rates in New Zealand decreased by 29% since 2009, after a decade long plateau in rates. While the study does not attribute the change directly to the program, it notes there have been no other significant changes in health services or campaigns, and no changes in immunisation or smoking rates during pregnancy which may explain the decrease.

Given the growing evidence the Pepi-Pod® Program improves the safety of infants in high risk sleep environments, consideration could be given to extending the program into other settings in which vulnerable families and their babies are displaced from their homes or have complex needs, including: young mothers’ programs; domestic violence and homeless shelters; drug and alcohol support services; and as part of emergency responses in cyclone, flood and fire-affected locations. There would also be value in developing studies which would map the impact of targeted programs for vulnerable families on infant mortality patterns.

64 Mitchell E, Cowan S, Tipene Leach D (2016). The recent fall in perinatal mortality in New Zealand and the Safe Sleep programme. Acta Paediatrica. ISSN 0803-5253
Explained sudden unexpected deaths in infancy

In 2015–16, 12 of the 29 SUDI deaths were classified as having an explained cause of death following post-mortem examination. Eleven infants died as a result of illnesses unrecognised prior to their deaths. One infant died as a result of a sleep accident. These 12 deaths are included in this chapter (as sudden and unexpected); however, they are also included in the chapters relating to the specific causes of death. Table 8.3 shows the breakdown of explained SUDI by cause of death.

Table 8.3: Explained SUDI by cause of death 2015–16

<table>
<thead>
<tr>
<th>Cause of death</th>
<th>Total n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unrecognised infant illness</td>
<td>11</td>
</tr>
<tr>
<td>Bacterial pneumonia, not elsewhere classified (J15)</td>
<td>3</td>
</tr>
<tr>
<td>Benign neoplasm of other and unspecified intrathoracic organs (D15)</td>
<td>1</td>
</tr>
<tr>
<td>Cardiac arrest (I46)</td>
<td>3</td>
</tr>
<tr>
<td>Congenital malformations of great arteries (Q25)</td>
<td>1</td>
</tr>
<tr>
<td>Other benign neoplasms of connective and other soft tissue (D21)</td>
<td>1</td>
</tr>
<tr>
<td>Streptococcal sepsis (A40)</td>
<td>1</td>
</tr>
<tr>
<td>Viral pneumonia, not elsewhere classified (J12)</td>
<td>1</td>
</tr>
<tr>
<td>Other non-intentional injury/sleep accident</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>12</td>
</tr>
</tbody>
</table>

Data source: Queensland Child Death Register (2016–17)
1. ICD-10 underlying cause of death code included in parentheses.

The QFCC supports research into the causes and prevention of child deaths by providing detailed child death data to researchers under sections 26 and 28 of the Family and Child Commission Act 2014. The QFCC was pleased to collaborate with the Queensland Paediatric Quality Council (QPQC) and provide data for the Infant Mortality Subcommittee of the QPQC to conduct a detailed review of SUDI deaths 2013-2015. The following case study presents their preliminary findings.

**CASE STUDY: THEMES FROM AN EXPERT PANEL REVIEW OF SUDI CASES IN 2013**

Author: Queensland Paediatric Quality Council Infant Mortality Sub-Committee

Queensland’s infant mortality has been persistently higher than the national average. Since 2003 the state-national gap differences have been as high as 21%. “Sudden Unexpected Death in Infancy” (SUDI) accounts for half of the deaths of infants in the post-neonatal period (28 days to less than one year old) (QFCC, 2016). Most SUDI occur in the setting of an unsafe sleeping environment. Some of these deaths may be preventable, and careful review of each SUDI death can reveal modifiable risk factors, which if addressed, may reduce some of the excess mortality.

**Methodology**

The Infant Mortality Subcommittee (IMSC), of the Queensland Paediatric Quality Council (QPQC), conducted a multidisciplinary expert panel review of case notes of infants who died in Queensland from January 1 2013 through December 31, 2013. The eligible population included all post-neonatal infants whose death had been referred to the Coroner for investigation as it had been sudden and unexpected. Selected neonates (age at death 0-27 days) were also included in the review if they had been discharged from the hospital setting and subsequently died suddenly and unexpectedly.

The IMSC requested all data and records from multiple sources in order to fully understand not only each infant’s death, birth, and life events, but also the mother’s pregnancy and health and the relationships and social structures that existed between the infant, mother and other significant carers. Information collected included relevant medical records for the infant and mother, infant emergency and hospital presentations, perinatal data records, police death scene investigation forms, forensic autopsy reports, Coronial findings and other relevant documentation. Although not all records were available, a core group of records was obtained for each infant. Members were allocated cases for review (two reviewers per infant) and the case was discussed at a monthly review meeting with all members contributing to the final findings. A detailed review tool was completed for each review.

65 The IMSC was convened in 2015 by the Queensland Paediatric Quality Council (Queensland Health) to examine Queensland’s persistently higher infant death rates. IMSC members have expertise ranging from critical care, neonatology, forensic paediatrics, forensic pathology, university research in the area of infant deaths, community child health and non-government service provision. More information on the IMSC can be found at www.childrens-health.qld.gov.au/chp/health-professionals/QPQC.

Findings

A total of 100 infant deaths were reviewed. Nine of the infants died whilst neonates (0-27 days of age), and 91 infants died in the post-neonatal period. The age at death ranged from 3 to 341 days of age (Median, 74 days).

Nearly half the deaths met the definition of SUDI (47 cases), a category of death where an infant (aged under one year) dies suddenly with no immediately obvious cause (QFCC 2016, p 57). The circumstances of death must meet all of the following criteria to be included in the SUDI grouping: child less than one year of age; sudden in nature; unexpected, with no previously known condition that was likely to cause death; no immediately obvious cause of death (p.59)

In addition to these 47 SUDIs, were a further 5 infants who died from inflicted injury. The coronial investigation has not yet been finalised for these. These deaths did not meet the definition of SUDI; the injuries were immediately obvious at the time of sudden death for four of the infants, and for one infant the death was not sudden.

Theme: For SUDI, there is rarely a single cause of death in isolation

After a SUDI occurs, a single unequivocal cause of death was rarely identified by the IMSC. For most infants, the forensic post mortem report documented multiple accompanying factors of relevance to the death, several of which may have contributed to the death, in addition to a single “final” cause of death (which was usually not changed as a result of the broader coronial investigation). It is this single final cause of death which is coded and reported nationally. In the 2013 SUDI cohort, only a minority of deaths were unequivocally “explained” by the findings at post mortem. For the remaining “unexplained SUDI”, the Krous et al. 2004 definition of SUDI, including “Sudden Infant Death Syndrome” (SIDS), in use throughout Australia since 2004, was used as the reference.

Frequently the committee identified genuine lack of certainty of cause of death, at variance to the certified cause of death. Examples included many deaths which did not meet the criteria for SIDS; or where “alternative diagnoses of natural or unnatural conditions were equivocal” (Krous et al, 2004); or where multiple different factors existed any of which might have caused death; or where doubt existed as to whether a single factor provided sufficient cause. The committee re-categorised such deaths, mostly to “Unclassified Sudden Infant Death: (USID) This decision was taken regardless of whether a single explained cause of death had been stated or whether the death was certified as due to SIDS.

The intent in this re-categorisation is to more precisely adhere to the accepted international classification, and to clearly demonstrate the multiple and modifiable risk factors, rather than leaving these hidden beneath a more conventional but debatable, or even incorrect, diagnostic label.

From the original “Explained SUDI” group of 19 deaths:

- 2 deaths were re-categorised to SIDS ;and
- 5 were re-categorised to USID (most commonly because the pathology described at post mortem was insufficient to have caused death, and one or more alternative diagnoses was possible but equivocal); and
- 12 deaths remained as explained deaths, of which 3 were due to asphyxiation in an unsafe sleep or other environment.

From the original “Unexplained SUDI = SIDS” group of 21 deaths:

- 4 deaths were re-categorised to “explained” (all due to asphyxiation in an unsafe sleep environment); and
- 11 were re-categorised to USID (including several deaths in which a full, internal post mortem examination was not completed thereby disallowing the definition of SIDS, and other cases where one or more than one alternative diagnosis was possible but equivocal); and
- 6 deaths remained as SIDS

From the original “Unexplained SUDI = USID” group of 7 deaths:

- one death was re-categorised to “explained” (due to asphyxiation in an unsafe sleep environment); and
- one was re-categorised to SIDS; and
- 5 deaths remained as USID.

Queensland Family & Child Commission
The impact of this re-categorisation was as follows. Deaths categorised as Explained SUDI reduced from 19 to 17 infants. Of the final 17, 8 deaths were due to asphyxiation (five of these newly categorised as such) and 9 due to natural cause. Deaths categorised as SIDS reduced from 21 to 9. Deaths categorised as USID increased from 7 to 21.

**Theme: The SUDI infant’s family environment is complex and vulnerable**

The remainder of this review will examine 38 infants which the committee categorised as either unexplained SUDI (SIDS=9 and USID=21) or as explained deaths that were coded as asphyxiation (n=8). These 38 cases shared multiple risk factors, many of which were modifiable. Eighteen (47.4%) infants were male and 20 (52.6%) were female. Indigenous status was identified for all cases with five (13.2%) identified as Aboriginal, two (5.3%) Torres Strait Islander and three (7.9%) as both Aboriginal and Torres Strait Islander.

One of the key themes to emerge from the reviews was the importance of the infant/carer dyad. The infant, being totally dependent on a responsive carer, cannot be reviewed without consideration of the primary carer and family circumstances. The mother was the main caregiver for 36 (94.7%) of the infants. In the period prior to the infant’s death (day or evening of) 11.4% of primary carers had taken prescribed drugs, 8.3% disclosed they had consumed alcohol and for 2.9% there was documentation of illicit drug use. However, detailed record review indicated that 14 mothers (38%) had a history of illicit drug use prior to the infant’s death and 5 of these mothers had hepatitis C. There was a history of family violence reported in 36.8% of cases with 35.1% having a history of police involvement with the parents. Just under half the infants’ families (45.9%) were already known to the Department of Communities, Child Safety and Disability Services. In three cases (8.1%) a previous infant of the mother had died in unexplained circumstances.

Protective factors were also examined. The majority of infants (67.2%) had been breastfed at some time in their lives, and 45.9% were reported to be either fully or partially breastfed at the time of their death. Reviewers found recorded evidence of safe sleeping advice being discussed with the mother in 15 cases (42.9%). Around half of the families had recorded access to primary health care for their infant (51.6%), however for a large number of infants, information regarding primary health care use and/or safe sleeping advice could not be ascertained from the records examined (37.1%). The IMSC has noted from this finding the importance of obtaining and reviewing primary health care records for both the infants and mothers in any future infant death reviews.

Complicating the review of the infant and carer dyad, was the paucity of documentation about important risk factors. Even when documented, this was often only recorded in either the mother or the infant’s records; rarely in both. This may have meant that the maternal health care providers and infant postnatal health care providers were unaware of each other’s concerns. This presents a barrier to identifying escalating concerns in real time in order to flag the need for intervention prior to an infant’s death.

**Theme: For SUDI families, safe sleeping messages have not been acted on.**

As documented in previous QFCC reports, there was a very high prevalence of unsafe sleeping practices relating to environment and /or infant care in the SUDI group. Supine (placed on the back) is the recommended safe sleeping position for infants aged ≤ 12 months, however only one third (12, 32.4%) of the infants were placed to sleep in this position. Over 40% (16, 42.1%) were placed to sleep in positions not considered safe for infant sleeping (e.g. prone, side-lying, propped up). In a further 24% of cases the position in which infant was put to sleep was not documented in enough detail in the records available to be classified by the reviewers. The position of the infant when found was better documented (86.5%). Infants were found prone (on their stomachs) (12, 32.4%), side-lying (7, 18.9%) and in other positions (8.1%, such as in a sling or mother’s arms). Only 10 (27%) infants were found lying on their back. Thirteen infants (35.1%) were found in a different position from how they were placed to sleep. Concerning the position when placed to sleep or when found was inadequately described in 29.7% of the infant records.

The majority of the infants reviewed (72%) routinely slept on a surface not specifically designed for infant sleeping and 55.5% of these commonly shared that sleep surface with one or more adults or siblings. The most common sleep surface was an adult bed or adult mattress on the floor (50%). Many of the infants were placed to sleep with pillows or on soft bedding (22, 59.4%) and smoking in the house was reported to occur for 67.6% of infants. With so many reported unsafe sleeping practices it is not surprising that in every SUDI case, there was at least one unsafe sleep factor and most (32, 86.4%) infants had two or more of these well-known unsafe sleeping risk factors reported. One of particular note was smoking in the house which was reported in 92% of infants who were sharing a sleep surface at the time of their death.
Discussion

This review of 2013 SUDI deaths highlights the complex interplay of multiple factors that leads to SUDI. This review has also raised concerns around the certification of infant deaths, with a number not conforming to the internationally accepted Krous et al. (2004) definition of explained SUDI, SIDS and USID. This can impact on the accuracy of subsequent cause of death coding. Coding cause of death to an international standard enables the comparability of statistics overtime and between jurisdictions (both within Australia and internationally) and enables the effectiveness of public health measures to be monitored.

Even when death is correctly certified, by channelling the complex set of factors which are active in the infant’s death event down to one underlying cause, we reduce the ability to fully understand the importance and interplay of these factors. As such, this review also demonstrated the benefit of a multidisciplinary team approach to SUDI death reviews, in which a range of information sources are used to identify the contributory risk factors, that go beyond a single underlying cause of death.

The IMSC reviewed infant deaths with a particular focus on preventability and avoidability, especially looking for modifiable risk factors which can be identified and then reduced or eliminated by existing interventions. The major finding from this review is the ongoing contribution of unsafe sleeping practices to SUDI, particularly in the presence of other known risk factors such as smoking and drug use. This is especially worrying given the range of safe sleeping education initiatives, and the evidence that uptake of these recommendations by infant caregivers is associated with a reduction in many SUDI deaths.

The review also highlighted many of the infants were living in socially and physically challenging environments, and this may mean the universal public health and community messages about safe sleeping are not leading to change where it is needed most. There is evidence of the effectiveness of more targeted and practical intervention strategies working in conjunction with these universal messages to reduce infant deaths (Mitchell et al 2016, Cowan et al 2013). An example of such a program in the Queensland context is the Pepi-Pod® Program which aims to reduce SUDI through practical, culturally appropriate engagement and education for families with a high risk of infant death. The program includes the provision of an actual portable sleep pod for young infant’s age 0-4 months (Young et al 2017) which reduces the interaction between sleep environments and infant vulnerabilities which place them at an increased risk of asphyxiation. Ongoing review of SUDI deaths will provide valuable information on how such programs may be targeted effectively to those most at risk.

Conclusion

A detailed review of SUDI deaths in Queensland has revealed modifiable risk factors and opportunities for early intervention, which could save infant lives. In order to identify these factors, timely and detailed case death reviews are essential, utilising multiple sources of information, and harnessing the critical analysis skills of content experts from a wide range of speciality disciplines. Findings and recommendations from these detailed reviews complement the broader death reporting by QFCC and together provide a more complete picture of opportunities to further reduce infant mortality in Queensland.

References


Mitchell E, Cowan, S, Tipene-Leach, D, (2016). The recent fall in postperinatal mortality in New Zealand and the Safe Sleep programme. 105:1312-1320
