

Program Brief: Retrospective Review of Cases and Factors Associated with 76 Neonatal Deaths in six EMAS-supported Hospitals

January 2016

BACKGROUND

Decades of supportive policies and programs focused on reducing maternal and neonatal deaths led to declines in Indonesia's neonatal mortality ratio (NMR) from the early 1990s. Data shows declines in NMR from 30 deaths per 1,000 births in 1994 to 19 deaths per 1,000 by 2007.¹ Yet, further reductions since this time have not materialized. The most recent Indonesia Demographic and Health Survey (2012) indicates that the NMR has remained stagnant at 19 deaths per 1,000 live births, with 60% of all infant deaths and nearly 50% of all under 5 deaths occurring during the first month of life.² Indeed lowering NMR has proven more difficult than lowering the infant or under 5 mortality rate.

The challenges of delivering adequate neonatal health care in Indonesia include limited access to quality facilities, limited availability of health staff capable of managing complications, lack of awareness and cultural constraints regarding newborn care, low nutritional and health status of women, and a frail system for recording neonatal deaths.³ Policies, programs, and clinical standards intended to address some of these challenges have been in place for some time, yet these investments have not yet resulted in expected declines in neonatal deaths.

The limited availability of data has made it challenging to fully understand the reasons behind persistently high neonatal death rates. Record-keeping in facilities, data recording and reporting structures are often inadequate and are believed to not fully capture all deaths. In September 2014, EMAS initiated a retrospective maternal death review process to help shed light on potential contextual factors impacting 112 maternal deaths in EMAS-supported hospitals. When that review proved to be both feasible and very informative, in April 2015, EMAS collaborated with the Perinatology Working Group of the Indonesian Pediatricians Society (*Ikatan Dokter Anak Indonesia*, or IDAI UKK *Perinatologi*) to undertake a similar process to review neonatal deaths in selected EMAS-supported facilities.

In Indonesia, WHO estimates that prematurity is the leading cause of neonatal death, accounting for 44% of deaths, followed by birth asphyxia and birth trauma (21%), congenital abnormalities (13%) and sepsis and other infections (11%).⁴ Data from EMAS-supported hospitals generally reflects this pattern. In the period reviewed, neonatal deaths in Phase 1 and 2 hospitals were most commonly associated with low birth weight (43%), followed by asphyxia (24.5%), and sepsis (12%). A relatively large proportion of neonatal deaths (20%) were also associated with "other" causes.⁵

PURPOSE OF REVIEW

IDAI and EMAS jointly conducted a retrospective review of individual charts in selected EMAS-supported hospitals to:

- Better understand the causes of death among neonates greater than 2000 grams who die in the first week of life, including the associated contextual factors such as the source of referral and pre-hospital care, the quality of care provided at the facility and related barriers that may have contributed to neonatal death (e.g.

¹ Indonesia Demographic and Health Survey (IDHS) 2007.

² Indonesia Demographic Health Survey (IDHS) 2012.

³ (BAPPENAS) MoNDPNDPA. Report on the Achievement of the Millennium Development Goals Indonesia 2010 Jakarta, Indonesia: Ministry of National Development Planning/National Development Planning Agency (BAPPENAS), 2010:10160.

⁴ http://www.who.int/maternal_child_adolescent/epidemiology/profiles/neonatal_child/idn.pdf

⁵ Based on EMAS monitoring data, which is drawn from standard registers in facilities. "Other" causes include birth trauma, neonatal tetanus, congenital deformities and diarrhoea.

timeliness of care, availability of personnel or equipment, or appropriate administration of treatment and monitoring);

- Determine whether or not the deaths may have been preventable;
- Review the quality of medical records; and
- Inform future research and interventions to reduce preventable deaths.

PROCESS AND SCOPE OF REVIEW

Neonatologists from IDAI collaborated with EMAS to define the purpose, scope and details of the review. Hospitals were selected for the review based on relatively high numbers of neonatal deaths.⁶ In total, six district hospitals in five EMAS-supported provinces took part in the review process: RSUD Karawang (West Java); RSUD Jombang (East Java), RSUD Banyumas and RSUD Margono Soekarjo (Central Java); RSUD Rantau Prapat (North Sumatra), and RSU Tangerang (Banten).⁷ Formal permission for the review was obtained from participating hospitals, which were cooperative and gave permission to be included in the review process.⁸

A standardized form was developed in *Bahasa Indonesia* based on existing maternal-perinatal audit forms and materials. This form was designed to be user friendly, as well as sufficiently comprehensive to capture the medical case characteristics⁹ and contextual factors¹⁰ contributing to deaths of neonates. The review form was verified and refined, before being finalized by IDAI UKK Neonatology Chair and the review team.

The review was undertaken in June 2015 by a team of five IDAI neonatologists. A ‘no blame, no shame’ approach was taken for the review, and the specialists traveled, to and reviewed records from, hospitals outside of their own provinces to reduce possible bias. Three hospitals were visited by a one member of the review team, while reviews in two hospitals were done by a team of two team members.¹¹

Cases selected for review were neonates weighing over 2000 grams at birth who died within the first seven days of life. These criteria were established in order to review the cases that had the strongest likelihood of survival, and yet did not survive. Cases with major congenital anomalies were excluded. The neonatologists reviewed individual case level medical records for neonatal deaths that occurred in the six selected hospitals from January to June 2015. The reviewers examined available chart information and made a determination regarding the factors associated with the neonatal death for each case reviewed. Newborn nursery and newborn intensive care (NICU) environments were also assessed through observation and general review of documentation. Data was cleaned, checked for logic, and analyzed using Spotfire Analytics software.

The review is limited in that it was retrospective and based on a single source of data—the available chart documentation varied in completeness, with numerous examples of missing documentation and data, which limited the ability of the reviewers to draw definitive conclusions regarding all factors associated with each death.

⁶ Death data was drawn from EMAS’s routine monitoring data.

⁷ Pinrang (South Sulawesi) was excluded due to low numbers of neonatal deaths during the review period.

⁸ This openness and willingness may be related to improved clinical governance, and facilities becoming ‘learning organizations.

⁹ Case characteristics included data on patient demographics (age, gender, referral source), medical information (maternal and obstetric history, quality of care etc), plus data on referral and timing of admission/birth and death of newborn.

¹⁰ Contextual factors were categorized according to the “three delays”: delay in care seeking, delay in reaching care in time and delay in receiving adequate and appropriate care.

¹¹ The review team met to develop a common interpretation and completion of the form, but it is possible that the medical records and contents of the review form were open to interpretation some extent.

FINDINGS

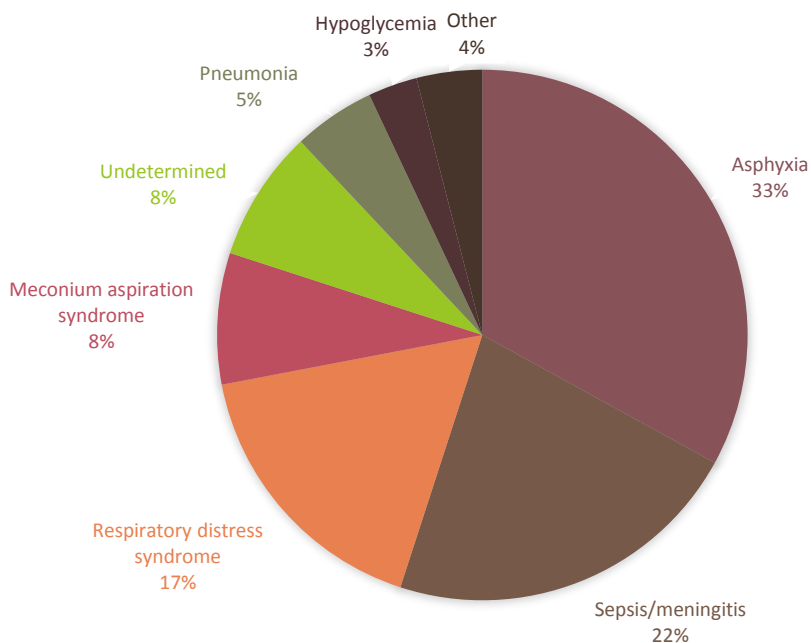
In total, individual charts from 76 neonatal death cases had sufficient information to be included in the review, with a range of 8 to 15 cases per facility. These cases represent 9.6% of the 789 neonatal deaths¹² weighing over 2000g recorded in the 71 EMAS-supported hospitals during the time period reviewed. Overall, 49% of cases (37/76) were born in the hospital where the review occurred, and 51% of the cases were referred from outside after birth.

While there were gaps in the medical records reviewed, the review process highlighted several important insights into the common characteristics of these 76 cases which can be used to focus future investigations and inform programming.

CAUSES OF NEONATAL DEATHS

- As shown in Figure 1 below, the leading cause of death in the cases reviewed was asphyxia (33%, 25/76), followed by sepsis/meningitis (22%), respiratory distress syndrome (17%) and meconium-aspiration syndrome (8%). The cause of death was undetermined in 8% of cases.

Figure 1: Complications associated with 76 neonatal deaths in 6 EMAS-supported hospitals, January – June 2015.



BASIC CASE CHARACTERISTICS

Maternal and obstetric history

- Age of mother:** The majority of mothers (49%, 37/76) were between 20 and 35 years old; 13% were older than 35 years, and only one (1%) was under 20 years of age. However, over one third of cases (37%) did not have the age of the mother recorded.¹³
- Gestational history of mother:** In around one-third of cases, this was the mother's first pregnancy (34%, 26/76) and delivery (30%, 23/76). In 17% of cases the mother had had more than three pregnancies.

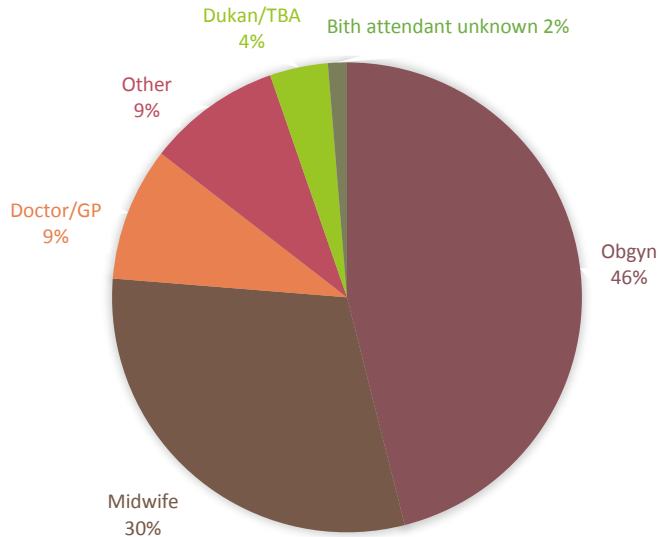
¹² 0-28 days.

¹³ Including all cases in RSUD Tangerang.

However there was incomplete gravida and partus data for approximately 20% of cases. Antenatal care history was only provided for 22% of cases.

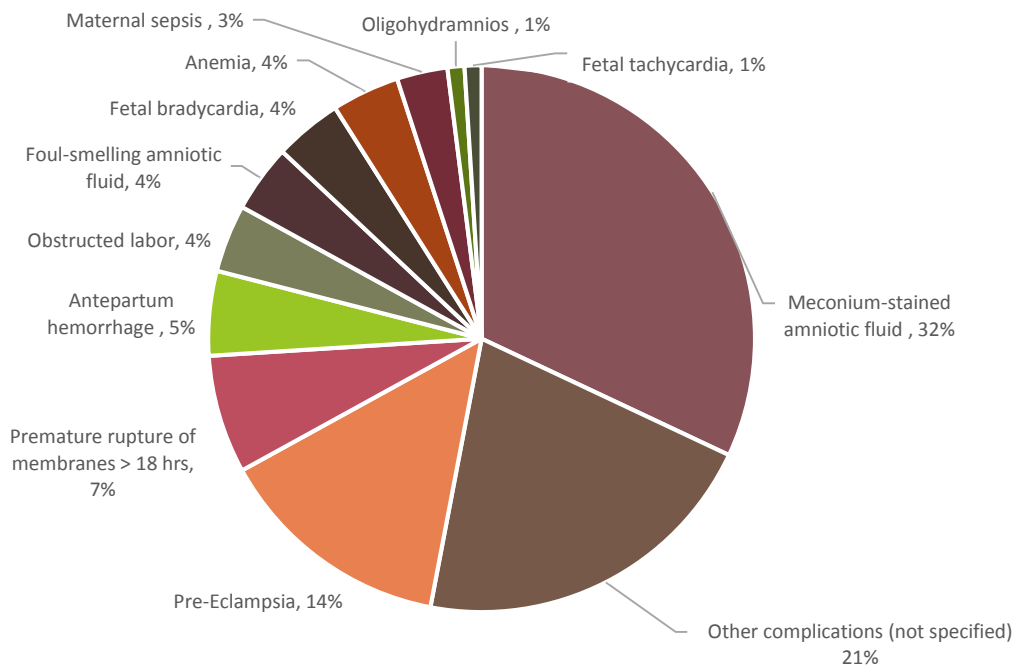
- **Mode of delivery:** In half (50%) of the cases reviewed, the neonates were born spontaneously, with a further 29% delivered by emergency caesarian section (CS), 9% by elective CS, 7% via vacuum extraction and 4% by forceps.
- **Birth attendant:** The majority (85%) of births in the cases reviewed were attended by a doctor or midwife.

Figure 2: Birth attendants for cases of neonatal deaths reviewed.



- **Ante/perinatal complications:** As shown in Figure 3 below, the most common ante/perinatal complication was meconium-stained amniotic fluid (32%, 24/76), followed by pre-eclampsia (14%), premature rupture of membranes for over 18 hours (7%) and antepartum hemorrhage (5%).

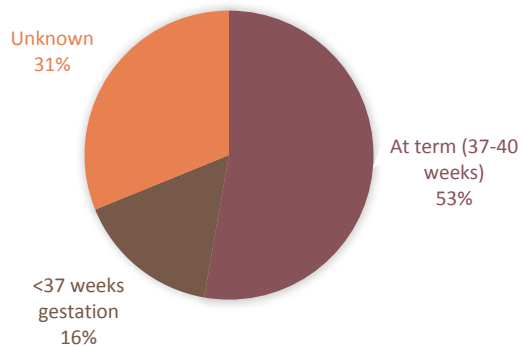
Figure 3: Perinatal complications for the 76 neonatal deaths reviewed.



Neonatal characteristics

- *Gender:* Two-thirds (66%, 50/76) of cases were male neonates.
- *Weight at birth:* The majority (67%, 51/76) of cases weighed over 2500g at birth, with approximately one-quarter (23%) weighing 2000-2500g and 7% classified as large for gestational age. Three percent had no birth weight recorded.
- *Gestational age:* The majority (53%, 40/76) of cases were born at term (37-40 weeks gestation), with 16% born at less than 37 weeks gestation. However, gestational age was unknown for 31% of cases. Analysis showed a moderate positive correlation between gestational age and birthweight.

Figure 4: Gestational age of 76 cases of neonatal deaths reviewed in 6 hospitals



- *Number of fetuses:* Most (96%, 73/76) were singleton babies, with the remaining 4% being twin babies.
- *Apgar scores:* Over one-third of cases (34%, 26/76) had been given an Apgar score of 4-6 at 1 minute, with 28% scoring 0-3, and 21% scoring 7-10. There was no Apgar score at 1 minute recorded for 17% of cases.¹⁴ At 5 minutes, over one-third (36% 27/76) of cases had scored over 7, 34% scored 4-6, and only 12% scored under 3. A similar number (18%) of cases had no 5 minute Apgar score recorded.¹⁵

TIMING OF NEONATAL ADMISSIONS AND DEATHS

- *Timing of birth/ER admission:* Most cases (64%, 64/76) were born¹⁶/admitted to the hospital's ER¹⁷ on weekdays, with 36% born/admitted on weekends and 8% on public holidays. The highest number of admissions/births (42%, 32/76) were during the physicians' morning shift (07:00-14:00)¹⁸ with 22% during night shift.
- One-fifth (21%, 8/39) of the cases spent between under 60 minutes at the ER, while 13% spent over 2 hours there. However the duration in ER was unknown for 51% of cases. The highest number of cases (43% 33/76), were admitted to the neonatal unit in the day shift, with 22% admitted during the night shift.

¹⁴ The majority of these (12/13) were referred cases.

¹⁵ Again, all but one of these cases had been referred from outside the hospital.

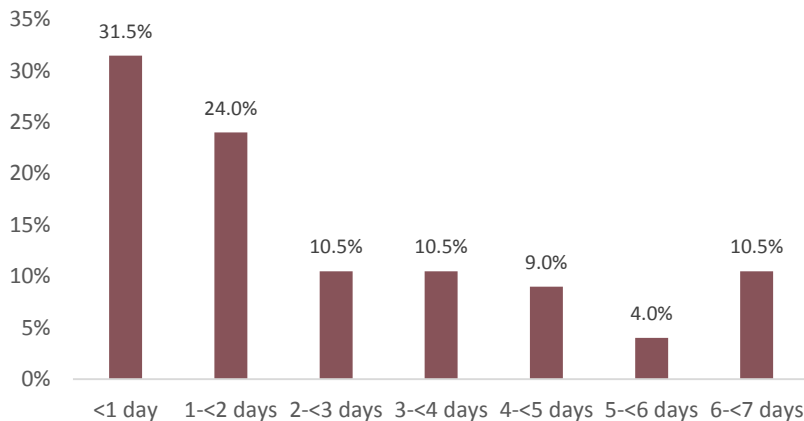
¹⁶ For those born at the hospital audited.

¹⁷ For those born elsewhere and referred to the hospital.

¹⁸ The highest number of cases (15/76, 20%) occurred on Thursdays, which had the most public holidays in the period reviewed, followed by weekends (14 births/admissions, or 18% per day). The peak time for birth/admissions were 8-9am, 12-1pm, and 4-6 pm.

- *Timing of neonatal deaths:* The highest percentage (32%, 24/76) of cases died in the first 24 hours after birth, followed by 24% between 1-2 days of age.¹⁹ The distribution of deaths over the first seven days is shown in Figure 5 below. Most deaths (68%, 52/76) occurred on weekdays, with just under one-third on weekends.²⁰ Slightly more deaths (39%) occurred during the night shift, followed by the afternoon shift (36%) and morning shift (25%).

Figure 5: Timing of neonatal deaths in terms of days after birth for 76 cases



CARE BEFORE REFERRAL AND REFERRAL PROCESS

- *Source of referral:* Approximately half (51%, 39/76), of cases were referred from outside the RS. Of these, most cases (26%, 10/39) were referred by a private midwife practice, followed by maternity and general hospital (21% each), private clinic (13%), and *puskesmas* (3%). Ten percent were 'self-referral' (i.e. family made the decision to bring them directly to the hospital), and 8% were referred by 'other' sources. In the majority of cases, the referrer was a doctor or midwife (pediatrician (41%, 16/39), midwife (33%), GPs (10%)).
- *Stabilization before referral:* In 28% of referred cases, the reviewers concluded that the neonates were not adequately stabilized prior to referral. The vast majority (90%, 35/39) of referred cases arrived at hospital in 'severe' condition/severely ill, with 10% described as 'critical' upon arrival/admission to the emergency room.
- *Referral-related factors contributing to neonatal deaths:* The decision to refer the neonate was made too late by the medical provider in almost one-third (31%, 12/39) of cases. In 26% of referred cases, there was a delay in seeking medical help, and for 13% there was a lack of communication between health facilities. There was no documented refusal of referral, or cases of multiple referrals.

QUALITY OF CLINICAL CARE PROVIDED AT HOSPITAL

Based on review of the medical charts, the review teams determined that the care provided to the neonates was substandard and contributed to their deaths. Findings are summarized in Figure 6 below. In many cases reviewed, there were multiple contributing factors.

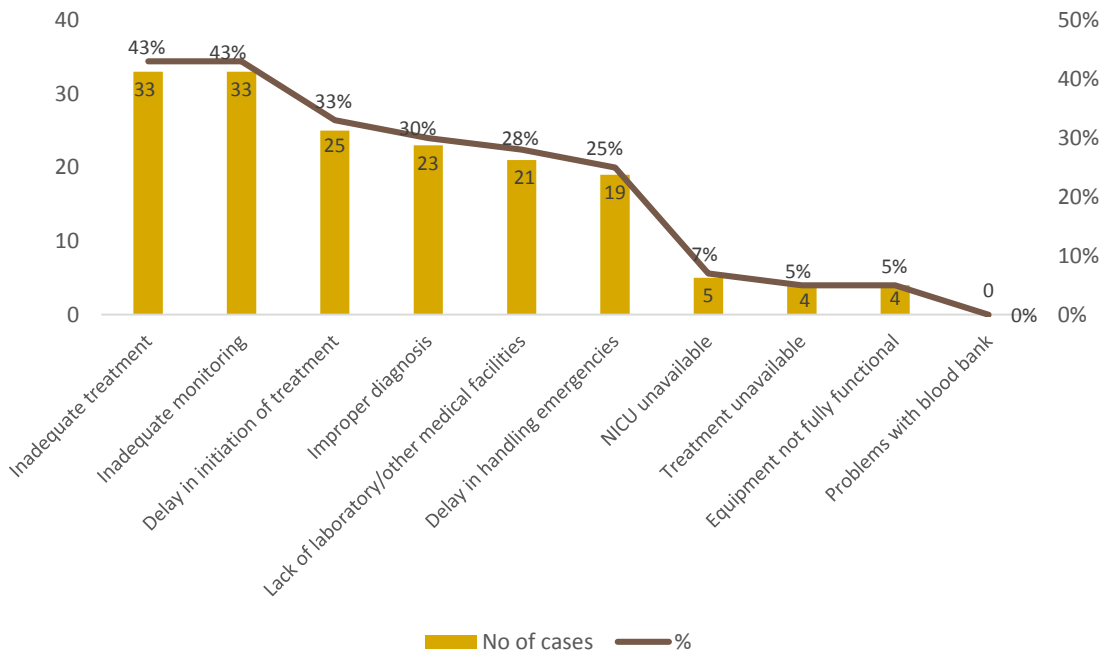
- The most common finding was **inadequate treatment** and **inadequate monitoring**, which each occurred in 43% (33/76) of cases), as shown in Figure 6 below.

¹⁹ WHO estimates that globally 75% of all neonatal deaths occur during the first week of life, with between 25% to 45% of these occurring within the first 24 hours. <http://www.who.int/mediacentre/factsheets/fs333/en/>

²⁰ The least deaths occurred on Wednesdays, otherwise reasonably even across the week, with no significant increases over weekends or public holidays.

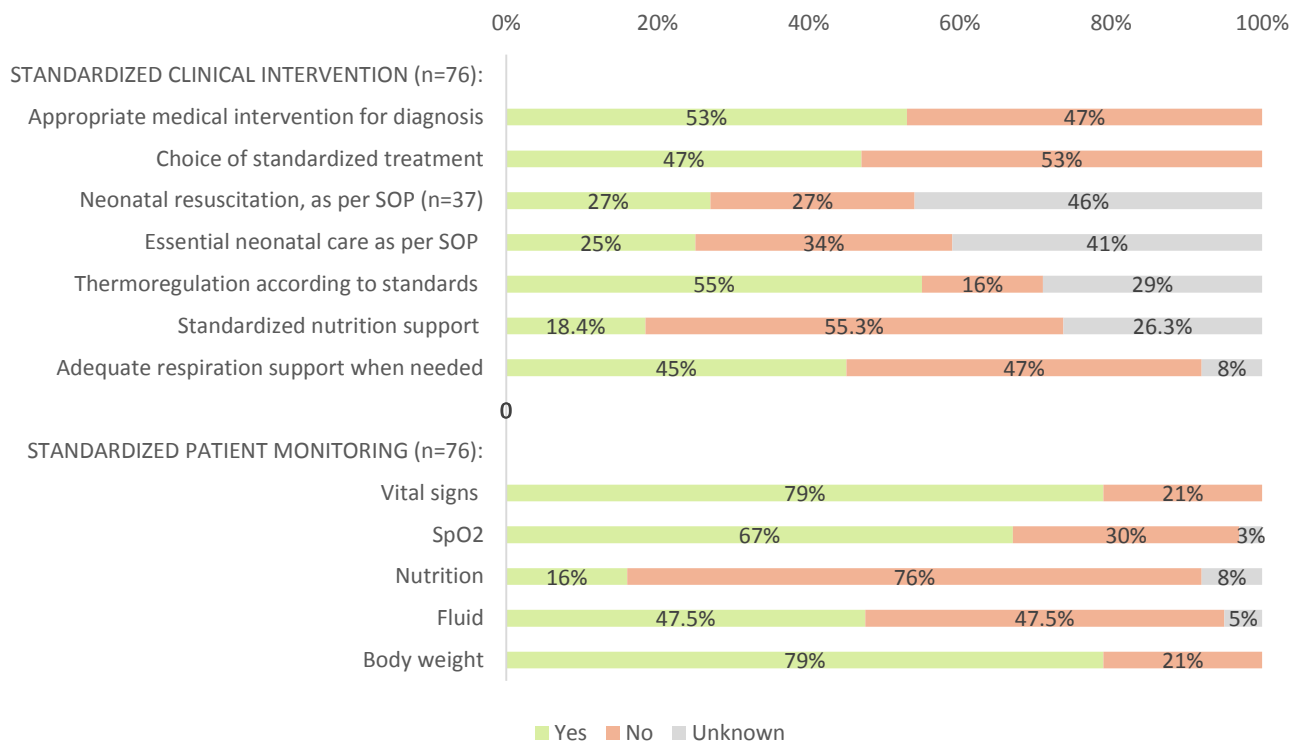
- In one-third (33%, 25/76) of cases there was a **delay in initiating treatment**. Inaccuracies in clinical decision-making were found to be common, with reviewers determining that an **improper diagnosis** had been made in 30% (23/76) of cases. This may be related to other findings that the appropriate diagnostic test was not provided in 51% (39/76) of cases, and over half (55%) of cases were not evaluated on site by a pediatrician prior to death (data not shown in graph)

Figure 6: In hospital contributors of death for the 76 neonatal deaths reviews, as determined by auditors.



- Figure 7 below shows that in 47% of cases (36/76), the appropriate medical intervention for the diagnosis was not provided. Furthermore, a number of clinical interventions were not performed to the correct standard for a high proportion of cases. This ranged from 55% for standardized nutrition support, to 16% for thermoregulation.
- Inadequate patient monitoring was found to be a contributing factor to death in 43% (33/76) of cases. As shown in Figure 7 above, the percentage of cases not monitored across the various categories ranged from 76% for nutrition and bodyweight to 21% for vital signs. However, many cases (42%) had incomplete daily documentation.

Figure 7: Provision of standardized clinical interventions and patient monitoring



- There were no apparent differences in these variables between neonates born in the hospital and those referred from other sources.

MOST NEONATAL DEATHS FOUND TO BE PREVENTABLE

- Overall, the review team concluded that 70% (53/76) of the deaths were preventable in the hospital.²¹ In 14% of the deaths, the neonates' condition was too severe upon arrival at the hospital to be saved. The auditors were unable to determine whether or not the death was preventable for the remaining 16%.
- Neonatal deaths from referred cases were considered more preventable than non-referred cases (97% compared to 67%).

MEDICAL RECORD QUALITY

- As noted in sections above, there were numerous gaps in the medical records of cases reviewed. Overall, 21% of cases had no daily records in the medical records, and 42% had incomplete daily records in the medical records.

²¹ Cross-tabulation between the cause of death and possibility of prevention indicated that neonatal deaths from hypoglycaemia, birth trauma, hypoxic ischaemic encephalopathy were 100% avoidable; sepsis/meningitis deaths were 88% avoidable; meconium-aspiration syndrome 83%; respiratory distress syndrome 78%; asphyxia 75%; and pneumonia 67% avoidable.

SUMMARY AND CONCLUSIONS

In lieu of a more formal and comprehensive death review process, it is possible to gain valuable insights retrospectively from individual charts in a relatively short time period, even with the limitations previously noted.

- **The majority of neonatal deaths were preventable.** Expert opinion determined that 70% of the deaths could have been prevented with more accurate diagnoses and more appropriate clinical and referral management. For 14% of the cases, the auditors determined that the neonatal death was unavoidable. In the remaining 16% of the cases, a determination was unable to be made.
- **Clinical care and documentation provided in hospitals is often of substandard quality.** Almost one-third of cases had an incorrect diagnosis, and in around half of the deaths, the neonates had received inadequate clinical management, with a number of clinical interventions not performed as per SOP. Monitoring and follow up of neonates throughout their stay in hospital was also found to be poor. Auditors made several recommendations directly to hospital staff around improving the management of neonates, and standardized care for common complications. There were significant information gaps in the medical record for a number of variables reviewed, and incomplete daily medical records for 42% of cases.
- **Medical providers at the hospital are not providing timely care.** In one-third of cases, delays in the provision of care and clinical decision-making in the hospital were found to have contributed to death. In one-quarter there was a delay in handling an emergency. There were also delays in receiving care by specialists, with more than 50% of cases dying without having been evaluated on site by a pediatrician.
- While **delays in initially seeking care were seen in 27% of referral cases**, most families sought care from a qualified medical provider in a timely fashion.
- A high percentage of deaths occurred in neonates referred from a doctor or midwife, yet **pre-referral decision-making and care appears to be inadequate.** The majority (84%) of referred cases were referred by a midwife or doctor, yet 30% were not adequately stabilized prior to referral, and the decision to refer was made too late in almost one-third of the cases.
- Many findings of this review are similar to those of the earlier maternal death review. This review further highlights the gaps in access to specialists and substandard quality of care in facilities as contributors to death.

NEXT STEPS

This review has resulted in a raised awareness amongst the leading IDAI neonatologists regarding the quality of care and availability of pediatricians in district hospitals. IDAI presented the results to each hospital that participated in the review, and they presented the results to the Child Health Directorate. Together with the maternal death review, these findings and related analyses will enable IDAI, POGI, MOH and EMAS to determine what additional targeted inputs and innovations are required to improve care seeking behavior, pre-referral processes, and hospital care and follow up.

IDAI and EMAS will continue to focus on examining cases of neonatal deaths. In particular, EMAS is examining the quality of care more comprehensively as part of the EMAS program evaluation, in order to provide further and more conclusive evidence in this regard.