AOGS
Acta Obstetricia et Gynecologica Scandinavica

AOGS ORIGINAL RESEARCH ARTICLE

Why babies die in unplanned out-of-institution births: an enquiry into perinatal deaths in Norway 1999–2013

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Key words
Out-of-institution births, causes of death and associated conditions, perinatal mortality, Norwegian Institute of Public Health, Medical Birth Registry of Norway

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Conflict of interest
The authors have had no relationships with any company that might have an interest in the submitted work in the previous 3 years and no financial interests that may be relevant to the submitted work.

Please cite this article as: Gunnarsson B, Fasting S, Skogvoll E, Smárason AK, Salvesen KÅ. Why babies die in unplanned out-of-institution births: an enquiry into perinatal deaths in Norway 1999–2013. Acta Obstet Gynecol Scand 2017; 96:326–333.

Received: 22 June 2016
Accepted: 19 November 2016

DOI: 10.1111/aogs.13067

Abstract

Introduction. The aims were to describe causes of death associated with unplanned out-of-institution births, and to study whether they could be prevented. *Material and methods.* Retrospective population-based observational study based on data from the Medical Birth Registry of Norway and medical records. Between 1 January 1999 and 31 December 2013, 69 perinatal deaths among 6027 unplanned out-of-institution births, whether unplanned at home, during transportation, or unspecified, were selected for enquiry. Hospital records were investigated and cases classified according to Causes of Death and Associated Conditions. *Results.* 63 cases were reviewed. There were 25 (40%) antepartum deaths, 10 (16%) intrapartum deaths, and 24 neonatal (38%) deaths. Four cases were in the unknown death category (6%). Both gestational age and birthweight followed a bimodal distribution with modes at 24 and 38 weeks and 750 and 3400 g, respectively. The most common main cause of death was infection (n = 14, 22%), neonatal (n = 14, 22%, nine due to extreme prematurity) and placental (n = 12, 19%, seven placental abruptions). There were 86 associated conditions, most commonly perinatal (n = 32), placental (n = 15) and maternal (n = 14). Further classification revealed that the largest subgroup was associated perinatal conditions/sub-optimal care, involving 25 cases (40%), most commonly due to sub-optimal maternal use of available care (n = 14, 22%). *Conclusions.* Infections, neonatal, and placental causes accounted for almost two-thirds of perinatal mortality associated with unplanned out-of-institution births in Norway. Sub-optimal maternal use of available care was found in more than one-fifth of cases.

Abbreviations: AC, associated condition; CODAC, causes of death and associated conditions; OOI birth, out-of-institution birth.

Introduction

Norway has a total area of 385 000 km^2 and a population of just over 5 million. It is one of the most sparsely populated countries in Europe. The travel times from home to hospital in rural areas can be hours, and the travel may include ferries or obstacles such as winter-closed mountain passes. Seven of 1000 births in Norway are unplanned out-of-institution (OOI) births. These are associated with increased perinatal mortality compared with hospital births (1), though the causes have not been studied in detail. The perinatal period begins at 22 completed weeks of gestation (154 days) and ends 7 days after birth (2), and the perinatal mortality rate is defined as stillbirths and live births that die within this period, per 1000 births, although other definitions exist (3). The perinatal mortality rate in Norway is very low, at 4.9 per 1000 births (gestation ≥22 weeks or birthweight ≥500 g) in 2013 (4). Nevertheless, studies from Norway and elsewhere indicate that perinatal deaths are associated with sub-optimal care, suggesting that improvements in outcomes are attainable (5–8).

Frequent causes of perinatal mortality include preterm birth, congenital malformations, infections, and various forms of placental dysfunction or abruption. Factors such as maternal disease, obesity, smoking, low or advanced age, and socioeconomic status are all associated with increased perinatal mortality. Complications during delivery and multiple pregnancies are also significant contributors. Stillbirths account for the majority of perinatal mortality in Norway; whereas the total incidence has fallen, the proportion of stillbirths among all perinatal deaths has increased from half in 1967 to three-quarters in 2013 (4,9). We undertook an enquiry of perinatal deaths associated with unplanned OOI births in Norway over a period of 15 years. The aims were to describe the causes of death (COD), and to study whether they could have been prevented.

Material and methods

The Medical Birth Registry of Norway is a population-based registry containing information on all births in Norway since 1967. It is based on compulsory notification of every birth or abortion from 12 completed weeks of gestation onwards. Between 1 January 1999 and 31 December 2013, a total of 884 355 births with gestational age ≥22 weeks and birthweight ≥500 g were registered (1). In this period there were 6027 (0.68%) unplanned OOI births (place of birth registered in the Medical Birth Registry as "unplanned at home", "during transportation" or "unspecified") and 69 (1.14%) perinatal deaths among those unplanned OOI births (1). These were subjected to enquiry.

The first author (B.G.) reviewed medical records and extracted anonymous data into a semi-structured case summary that included information about background, medical history (including use of tobacco, alcohol and recreational drugs), obstetric history (previous births, gestational age, and birthweight and prenatal, intrapartum, postnatal and neonatal care), along with information about patient transport, laboratory values, placental histology, and autopsy reports.

The Causes of Death and Associated Conditions (CODAC) system was designed for the classification of perinatal deaths (10) and has been used widely around the world (11–15). It has a three-level hierarchical tree to code the underlying COD. The 10 level I categories for the primary COD and associated conditions (AC) are:

- Infectious COD (referred to as infection below)
- Conditions, diseases and events specific to neonatal live (neonatal)
- Mechanisms and events of parturition or its complications (intrapartum)
- Congenital anomalies, chromosomal anomalies, and structural malformation (congenital anomaly)
- Fetal conditions, diseases and events (fetal)
- Cord conditions, diseases and events (cord)
- Conditions, diseases, and events of the placenta and membranes (placenta)
- Maternal conditions, diseases and events (maternal)
- Unknown, unexplained and unclassifiable COD (unknown)
- Terminations of pregnancy (termination).

There are two additional categories in AC:

- Associated conditions and complications in the perinatal period (associated perinatal)
- Associated maternal conditions and identified risk (associated maternal).

Each level I category is sub-divided in level II and allocated another digit; this occurs again at level III, giving each case at least a three-digit code for the main COD. Cases may receive up to two additional codes of three digits each for AC, including codes for sub-optimal availability and appropriateness of care. The order of codes should preserve the relative significance and sequence of events, and it is important to note that deaths caused by infections affecting the mother, neonate or intrauterine structures are coded by the causative agents as the main COD, with the locus of infection coded in subsequent positions (10). The coding rules are listed in Table 1. The publication that introduced CODAC has examples of coding and the following link to an EXCEL file with the

Key Message

Infections, extreme prematurity, and placental conditions are major contributors to perinatal mortality in unplanned out-of-institution births in Norway. Sub-optimal professional management contributes to a small proportion of deaths. One important, potentially modifiable, factor is sub-optimal maternal use of available care.

Table 1. Coding rules in CODAC (10).

1	To be a COD, the condition(s combined) should have significant lethality (≥0.05) in the clinical setting it was observed
2	If no COD was found, code antepartum stillbirths and neonatal deaths as 8xx and intrapartum deaths as 29x
3	If two (or more) conditions could be COD, select the most significant contributor to death
4	If two equally significant conditions could be COD, code the first to occur if this can cause the latter (related conditions)
5	If two equally significant conditions could be COD, code the last to occur if this cannot cause the first (unrelated conditions)
6	If two equally significant conditions of unknown timing could be COD, code the first among codes 0 to 7 (hierarchically)
7	If COD was infectious, code as 0xx (000 if unknown agent) and report the locus as AC in 19x, 49x, 59x, 69x or 79x
8	If any act to advance death was performed (termination), code as 9xx, and conditions leading to termination as AC
9	To be an AC, the condition(s combined) should contribute significantly in explaining the circumstances of death
10	Do not code any condition(s) unrelated to the causes or circumstances of death

AC, associated condition; COD, cause of death.

classification system, http://www.biomedcentral.com/content/supplementary/1471-2393-9-22-S1.xls (10).

The first author (B.G.) classified all cases in the CODAC system. Case summaries were discussed with the last author (K.Å.S.) and coding results reviewed. The two authors came to a consensus about the coding in all but eight cases (13%), which were subsequently discussed by all authors until a joint decision was made.

The Regional Committee for Medical Research Ethics, Region South-East, Norway, approved the study (Project #2011/1619/REK sør-øst D).

Continuous variables are provided as median (range) and modes, and categorical variables as percentages.

Results

Sixty-nine cases were eligible for enquiry. After preliminary review, we excluded three cases misclassified as out-of-hospital births, and three with gestational age <22 weeks, leaving 63 cases for full analysis. One birth was at an unknown site, one in a public building, four at a community health care clinic, 14 during transportation, and 43 in a home. Attendance could not be determined for nine births, 23 were unattended by healthcare providers, 16 were attended by ambulance personnel only, and 15 attended by midwife or physician.

Median maternal age was 28.9 years (range 15.6–44.9). Fifty-nine (94%) cases were singleton births and four (6%) were twins. Thirty (48%) were born to primiparous women, 17 (27%) to mothers with one previous birth, and 16 (25%) to mothers with two or more previous births. Two were born to mothers who had previously undergone cesarean section.

Thirty-eight (60.3%) babies were born in cephalic presentation and 16 in breech (25.4%); presentation was not registered in nine cases (14.3%). Thirteen were preterm breech presentations (nine between 22 and 25 gestational weeks and four between 26 and 37 weeks). Figure 1 shows a bimodal distribution of gestational age, with modes at 24 and 38 weeks and a median of 28 weeks (range 22–40). Figure 2 shows the bimodal birthweight distribution, with modes at 750 and 3400 g, and the median at 905 g (range 510–4146 g). Thirty-five (56%) cases were stillborn. In 25 cases the fetus died before onset of labor and in 10 cases during labor. Twenty-four (38%) babies were born alive. In four (6%) cases, time of death could not be determined. There were 16 (48%) live births among those with gestational age 22–28 weeks and

Figure 1. Histogram with overlaid density plot showing bimodal distribution of gestational age (11 missing values).

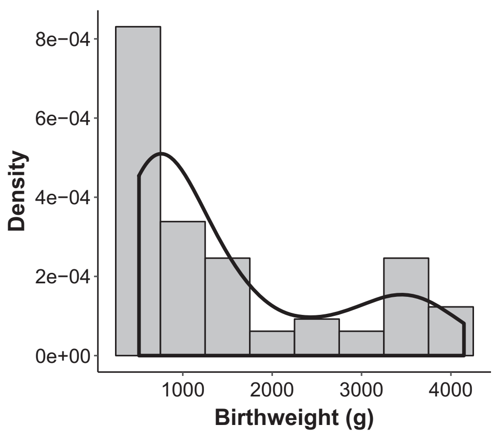

Figure 2. Histogram with overlaid density plot showing the shape of birthweight distribution.

Table 2. Subcategories for the main cause of death (COD, n = 63) and associated conditions (ACs, n = 86). Shaded areas: not applicable.

Cases caused or associated with	COD n (%)	ACs n (%)
Infection (agent)	**14 (22)**	**2 (3.2)**
Unknown agent	8	1
Group B Streptococci (GBS)	2	0
Common bacteria of maternal flora, non-GBS	2	1
Bacteria – other	2	0
Neonatal	**14 (22)**	**11 (17)**
Extreme prematurity	9	5
Cardiorespiratory	1	2
Trauma or suffocation	2	0
Inadequate care	2	3
Infection		1
Intrapartum	**9 (14)**	**5 (7.9)**
Malpresentation	4	1
Extreme prematurity	1	3
Excessive contractions/hypertonic labor	0	1
Unknown (fetal respiratory failure/ asphyxia)	4	0
Congenital anomaly	**2 (3.2)**	**2 (3.2)**
Genito-urinary	1	0
Respiratory and diaphragm	0	1
Gastrointestinal tract	0	1
Trisomies	1	0
Fetal	**0**	**0**
Cord	**2 (3.2)**	**1 (1.6)**
Loops (cord compression)	2	1
Placenta	**12 (19)**	**15 (24)**
Abruption or retroplacental hematoma	7	1
Infarctions and thrombi	4	4
Small for gestation placenta	1	0
Infection/inflammation of the placenta/membranes		10
Maternal	**5 (7.9)**	**4 (6.3)**
Unspecified or other	1	0
Hypertensive disorder	2	0
Uterus and cervix	1	1
Diabetes	1	0
Infection		3
Unknown	**5 (7.9)**	
Unknown with no placental PAD nor autopsy	2	
Unknown/lacking documentation	3	
Termination	**0**	
Associated perinatal		**32 (51)**
Small for gestational age		1
Multiple births		2
Preterm prelabor rupture of membranes		1
Vaginal hemorrhage		2
Sub-optimal care[a]		26
Associated maternal		**14 (22)**
Other or unspecified		7
Smoking		5
Maternal characteristics[b]		2

PAD, pathological-anatomical diagnosis.
[a]Subcategories at level III are shown in Table 3. One case had two accounts of sub-optimal care.
[b]BMI >40 in one case and young maternal age in another.

eight (27%) among those with gestational age ≥29 weeks, but the difference was not statistically significant.

The results of CODAC classification at levels I and II are presented in Table 2. This includes the main COD for all 63 cases as well as 86 AC. In 14 cases, the main COD was infection affecting the mother (n = 3), neonate (n = 1) or intrauterine structures and compartments (n = 10). Eleven babies were born preterm and seven at gestational age ≤25 weeks. Five were born alive, but died within hours. Fourteen cases were neonatal deaths, all but two born preterm and nine with gestational age ≤25 weeks). Most died within few hours after birth. There were nine intrapartum deaths, four of which were likely caused by breech presentation. The third most common COD was placental, affecting 12 cases. Seven were born preterm and two at gestational age ≤25 weeks. Two babies were born alive but both died a few minutes after birth.

Associated conditions are listed in the last column of Table 2. Nine cases had no AC, 22 had one, and 32 had two. The most common ACs were perinatal (n = 32), placental (n = 15) and maternal (n = 14). The largest level II subgroup was associated perinatal conditions/sub-optimal care, which involved 25 (40%) cases. Sub-optimal maternal use of available care (n = 14) was the largest subgroup in level III (Table 3), including eight cases in which pregnancy and delivery were concealed or possibly denied or undetected. Sub-optimal professional management was relevant in seven cases due to failure or delay in diagnosing medical conditions (for instance preterm labor) and/or failure or delay in referring to a higher level of care. Two cases were due to failure or delay in dispatching an ambulance with appropriate healthcare personnel. Associated maternal conditions included four cases where language or communication difficulties between mothers and care providers contributed to the circumstances of death.

Discussion

Infections along with neonatal (mainly extreme prematurity, gestational age 22–25 weeks) and placental causes

Table 3. Subcategories for associated perinatal conditions/sub-optimal care.

Cause	*n*
Sub-optimal maternal use of available care	14
Sub-optimal detection of complications	3
Sub-optimal employment of available care	3
Sub-optimal referral to adequate care	4
Other	2

accounted for 63% of perinatal mortality associated with unplanned OOI births. Sub-optimal maternal use of available care was found in 22% of cases.

We noticed a marked bimodal distribution of gestational age and birthweight among the cases of perinatal deaths, suggesting that they represent different groups or populations. One peak represents very low gestational age and birthweight, with infections and prematurity as the predominant underlying COD. Many were live births, and proper pre-hospital emergency medical response might have altered the clinical course of those cases. A second peak of age and weight was seen at term, where placental and maternal conditions dominated and most cases were stillbirths. For this group, better pre-hospital care would have been unlikely to improve outcome.

Confidential enquiries and audits have investigated various aspects of perinatal morbidity and mortality (5,7,8,14–23) but we are not aware of other research addressing the topic of this study in detail. It was not surprising to find many sub-optimal factors, and it is possible that we may have overlooked important issues, as studies have suggested that adverse events and near misses in out-of-hospital care often go unreported (24,25).

We tried to identify groups or clusters of COD that could indicate human or systemic factors amenable to intervention. AC contributing to the circumstances of death were common and can be prevented. The challenge of identifying them and intervening in an appropriate and timely fashion, is far more complicated. In particular this applies to the eight concealed or possibly denied or undetected OOI perinatal deaths. We are not aware of any studies looking into concealed pregnancies in Norway. However, this important condition may be more common than is appreciated and is known to be associated with poor neonatal outcome (26–28). We found a few examples of factors that are more easily amenable to change, for example sub-optimal detection of complications/referral to adequate care and sub-optimal employment of available care. Intrapartum causes explained nine (14%) deaths in our study, including four breech presentations. It is likely that some of these deaths might have been averted. Preterm fetuses are frequently in breech presentation. However, since nine of 13 perinatal deaths with breech presentation were born at 22–25 gestational weeks, it is difficult to determine the importance of the fetal presentation on its own. We find it noteworthy that CODAC classifications of stillbirths and neonatal deaths for 2013 in the UK revealed a lower proportion of intrapartum causes at just under 9% for stillbirths and 6.5% for neonatal deaths (14).

A particular strength of this study is that, due to the Norwegian personal identification number, we were able to identify perinatal deaths among OOI births from the Medical Birth Registry of Norway over a period of 15 years. However, the registry does not define the attributes of the birthplace variable, and we discovered cases in which hospital births were erroneously coded as births during transportation. We are not aware of studies assessing the validity of this variable. The validity of several other variables has been studied and found to differ from poor to very good (29–34). It is therefore possible that unplanned OOI births are under-reported. We found the CODAC classification to be a good information management tool that assigned the most likely COD, given available information about the case and a competent user (10). CODAC has been shown to perform well in terms of retaining important information and ease of use (11), although some find the system complex (35). A potential downside of the classification system is that only stillbirths were classified when CODAC was tested and refined (10,11). Still, the system is used by the MBRRACE-UK program for classification of all perinatal deaths in the UK (14,23).

To qualify as a proper COD, the condition or combined conditions should have significant lethality in the clinical setting under observation. The assignment of codes was clearly a matter of judgment and sometimes difficult to verify due to the retrospective nature of our study. This also applies to the assignment of the time of death as antepartum or intrapartum, which can be particularly difficult in pre-hospital settings without the presence of healthcare personnel. All cases were classified by two authors (B.G. and K.Å.S.) with proficiency in neonatology and obstetrics. The two authors agreed in most cases, and inter-rater agreement was not measured. However, a kappa of 0.82 has been reported for CODAC when the coding rules are followed (10). The complexity of some cases required input from different medical specialists and a multidisciplinary panel, with extensive collective experience in obstetrics, neonatology, anesthesia, and pre-hospital emergency medicine, added considerable strength to our study. It is possible that other specialists would have arrived at different decisions in some cases, but we do not believe the coding was a source of a large bias.

The implications of our findings are as follows. Pre-hospital perinatal emergencies may present dramatically, and the outcome can be lethal. Infections, extreme prematurity, retroplacental hematomas, and abruptions all carry poor prognoses, even in the hospital setting. However, these are rare events, and our findings suggest that poor outcome is seldom due to sub-optimal performance of healthcare workers immediately around the time of birth. However, much remains unknown about errors in clinical judgment, communication, and reporting of adverse events in pre-hospital perinatal health care.

Despite data showing higher incidence of unplanned OOI births in Norway than in other European countries, there is no evidence of a decline (1,36–42). The national guidelines for antenatal care have no information on when and how to seek care when labor starts (43), and the Norwegian healthcare system appears to lack the ability to learn and share safety lessons about unplanned OOI births. We acknowledge that this can be difficult, but our study has revealed that there is room for improvement, in particular regarding the signs of preterm labor in late second trimester (from 22 to 28 weeks).

Since 2010 the regional health authorities have been responsible for offering an escort for women in labor, if the transport time to hospital is 1.5 h or more (44). This arrangement was triggered by a study from Norway in 2008 revealing that 25% of unplanned OOI births were not attended by a midwife (45). In this study, five (9%) of 53 maternity institutions had a formal midwife service agreement for OOI births, whereas 247 (79%) municipalities claimed to have no such assistance. Of these, 33 were located at least 90 min away from the nearest hospital. It is time to explore whether the new arrangement from 2010 has met its goals in different parts of Norway.

Fortunately, most OOI births result in survival of the mother and neonate, but they are nonetheless unintended or unexpected incidents that must be reported systematically and reviewed to ensure that lessons are learned. A key strategic action could be to implement obligatory reporting of critical details for all unplanned OOI births to the Norwegian Institute of Public Health to ensure follow up of each case and to aid further research on the quality of pre-hospital perinatal care.

Conclusions

Infections along with neonatal and placental conditions accounted for almost two-thirds of perinatal mortality associated with unplanned OOI births in Norway between 1999 and 2013. Sub-optimal maternal use of available care was found to be a contributor in more than one-fifth of cases.

Funding

Financial support was received from the Norwegian Air Ambulance Foundation, which operates a commercial air company for the Norwegian and Danish emergency medical services. However, the funding had no influence on study design, completion or data analysis.

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