A QUALITY STUDY OF FETAL AND NEONATAL AUTOPSIES AT OSLO UNIVERSITY HOSPITAL

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Abstract

Background A post mortem examination can establish an accurate cause of death. Of all post mortem examinations performed at Oslo University Hospital (OUS), approximately 50% are performed on foetuses and children. The conclusions and findings of this examination often provide parents and clinicians with an explanation for the child's death. Furthermore, the findings are reported to national registries that use this data to assess how well public health funding is spent when it comes to diagnostics, treatment and prevention. The SNOMED coding system is used in pathology departments worldwide, including Oslo University Hospital. Over 80 different systems for classifying and coding causes of death in the perinatal setting exist. Both the systems' ability to correctly capture a cause of death in code and their applicability to different settings vary greatly. This makes the data collected about perinatal mortality hard to access and use. In an effort to organize all the data on pre- and neonatal deaths, the World Health Organization (WHO) proposes a universal classification system, the ICD for perinatal mortality (ICD-PM), which takes into account factors related to both mother and child and chronological aspects. This system is designed to be used in both high and low-income countries. It is an important tool in the realization of the new Sustainable Development Goals set by the WHO. Another step taken to address maternal and perinatal health is the foundation of the Norwegian Competence Centre for Paediatric and Pregnancy-related Pathology in 2004.

Goal The goal of this study is to explore the main causes of perinatal mortality at Oslo University Hospital (OUS) and any possible changes in trends over time by comparing data from before and after the establishment of the Competence Centre for Paediatric and Pregnancy-related Pathology. We also wish to assess the quality of post mortem reports and test the user-friendliness and reproducibility of the ICD-PM in a post mortem examination context.

Methods and material Our material comprises all autopsy reports on foetuses and infants up to seven days of age in 2005 and 2015. The reports were reviewed and recoded according to ICD-PM coding standards. Inter-observer analysis was performed. As a negative quality marker for a post mortem report, "unknown cause of death" in either SNOMED or ICD-PM was used.

Results The majority of deaths in our population occurred antepartum. The two most frequent causes of death were congenital malformations or chromosomal defects leading to termination of pregnancy and hypoxia and intrauterine death caused by a dysfunctional placenta. Between 2005 and 2015, the number of reports concluding with "unknown cause of death" has decreased, suggesting an increased quality in the post mortem examinations. Finally, ICD-PM is easy to use in a perinatal post mortem setting. It is simple and specifically designed for the perinatal post mortem setting.

Conclusion An improvement in the establishment of clear causes of death was seen over the investigated ten-year period. This could be explained by a multidisciplinary approach. The main maternal condition is a failing placenta. This last finding underlines the importance of examining the placenta when investigating intrauterine deaths, which OUS has implemented as a systematic approach from 2005. ICD-PM's strength lies partly in that it accounts for maternal conditions. It is intuitively easy to use, reliable and, with adequate training, it allows a more accurate registration and classification of perinatal deaths on both a national and an international level.

Introduction

Between 1990 and 2015 the global mortality for children under the age of 5 years has decreased (from 12,6 million deaths in 1990 to 5,6 million in 2016). The neonatal mortality has also decreased, but the first 28 days of life remain the most vulnerable time in a child's life, with 46% of under 5 deaths happen in this period. In the last century, the main causes of childhood and perinatal mortality have changed from infectious diseases and malnutrition to prematurity-related problems and congenital malformations. In developing countries, infections still contribute to childhood and perinatal mortality, more so than in developed countries. [1] (UN IGME, 2017, p. 1).

In Norway, mortality has decreased sharply from 1900 to 1970 and more slowly so after 1970. Vaccination programs, improved hygiene and quality of life have nearly eradicated infectious diseases like measles, tuberculosis, pneumonia, enterocolitis as causes of perinatal and paediatric death. The main causes today are problems related to prematurity, congenital malformations and events occurring in relation to birth. [2] (SSB, 2003).

According to the Public Health Institute's statistics [3] (FHI Statistikkbank), the number of births in Norway has been relatively stable from 2005 to 2015 (57.479 in 2005 and 59.931 in 2015). This is true also for the number of perinatal deaths as well with 322 in 2005 and 290 in 2015. This number includes stillbirths (gestational age over 22 weeks or weight over 550g), and neonatal deaths in the first six days of life. In most perinatal deaths, a post mortem examination is requested by the clinicians. Hospital post mortem examinations are performed at OUS on foetuses >12 weeks' gestational age (Norwegian abortion legislation and routines will be further discussed).
Sometimes a hospital post mortem examination is not performed, e.g. if the parents refuse for religious causes or if the clinician believes that no further insight will be gained. In some unexpected deaths, especially intrapartum deaths with possible legal implications, a forensic post mortem examination is requested by the police.

At Oslo University Hospital, there has been an increased focus on perinatal post mortem examinations, all beginning with the establishment of the Competence Centre for Paediatric and Pregnancy-related Pathology in 2004. The centre was established after general demands from pathologists across the country to improve and standardize perinatal autopsy and reporting. It is one of few that are entirely government-funded. The goal of this study is to explore the main causes and any possible changes in perinatal mortality in this period. We also wish to assess the quality of post mortem reports.

The Public Health Institute (FHI): communication and registration for statistical purposes

In a high-income country like Norway we have highly advanced resources at our disposition and are able to do a thorough post mortem examination. This work has to be properly reported and reflected in the mortality statistics.

The post mortem results are entered into the patient's/subject's medical record, under the label of post mortem report (Obduksjonsrapport). This document has a section of written text stating the main findings and conclusions drawn from the macro- and microscopic

examinations, the medical history and any additional tests. The Public Health Institute receives this information and effectively translates it into ICD-10 codes.
SNOMED codes are also assigned to the post mortem report, but these are not registered by the Public Health Institute.

Worldwide chaos of classification systems

Globally, more than 80 systems for classification of cause of death in the perinatal setting exist. These systems are designed for different parts of the perinatal period and for different subject groups. However, most are poorly suited for use in low-income countries with few technical resources. Furthermore, the systems vary greatly in terms of their ability to capture a cause of death in their codes. According to V. Flenady et al (2009)[4], the reported contribution of unexplained stillbirths varied as much as 56% (15% unexplained in the most effective system, 71% unexplained in the least effective).

In 2000, the WHO started a global effort to tackle poverty, focusing on child mortality, maternal health as well as sanitation and income poverty. These were the Millennium Goals, which in 2012 were replaced by the Sustainable Development Goals. Accurate information about the main causes of maternal and perinatal death are essential to address this global health problem. This requires both a global standardization of the classification and a system that is applicable to an environment where the only information available is oral recounts of the events as well as one where highly advanced imaging and sampling technology is available.

SNOMED

The registration and coding system currently used at OUS was developed by the Norwegian Association of Pathologists in 1992-1994 and was based on the SNOMED nomenclature originally developed by the College of American Pathologists in the 70s. The ambition was that there would be a nationally unified system for coding.

After its introduction, the chief complaint about the system was that it was far too complicated to use. However, little organized effort has been made to systematically improve the system. The main organ responsible, a sub-group of the Directorate for electronic health services, has merely registered any comments or complaints from the regional centres where the system is in use – a last revision/update of the Norwegian SNOMED (also called NORPAT) was done in 2002. (Direktoratet for e-Helse, 2017)[5]

SNOMED as a medical terminology represents a system of concepts. It is designed to structure both the information in electronical records and the exchange of this information. The concepts are divided into concept models, each with its own hierarchy. Each concept has a unique numerical ID within the hierarchical structure and can have synonyms.

A SNOMED code frequently used within perinatal pathology is the one for “post mortem examination of foetuses >12w gestational age”, T89000. There are further code specifications for medical abortions and depending on grade of development. Stillbirths are also coded T89000 but perinatal deaths of live-born babies are coded T00010 (entire

individual).

Another example of SNOMED codes are the F codes, used for specific events or complications during pregnancy and birth. Intrauterine death is coded F31600 (abortion, no further specifications) in in 1st and 2nd trimesters and F35330 (intrauterine foetal death) for 3rd trimester. Absence of malformations is indicated by M00100 (insignificant morphological deviation).

When the placenta has been examined, this is indicated by T88000 (placenta, cords and membranes). Lesions in the substructures (cords, membranes) can be coded with T-code for the structure and relevant M-code, preferably in combination with T88000 and M01000 (abnormal morphology). (Den Norske Patologforeningen/The Norwegian Association of Pathologists, 2004, p107-109)[6]

The challenges in using SNOMED lie mainly in that the system is very complicated and detailed, especially in a post mortem setting, making it weak in terms of global applicability and reliability. This was also an issue in our material, where different pathologists had been involved in the writing and coding of the reports.
In order to study mortality trends in a standardized matter we therefore decided to recode the reports and test the user-friendliness and reproducibility of the WHO's newly proposed system for classification of cause of death, ICD for perinatal mortality (ICD-PM).

ICD-PM

The World Health Organization has been responsible for the International Classification of Diseases since the organization's creation in 1948, although the system itself dates from 1893. It is a diagnostic classification system used to report diseases and identify health statistics and trends globally. In August 2016, WHO proposed an extension of ICD10, focused specifically on perinatal mortality: the ICD for perinatal mortality (ICD-PM). An important part of the international public health agenda beyond 2015 is to end preventable stillbirths and neonatal deaths. Thus, the ICD-PM was designed to ensure accurate capture and classification of the causes of death across all settings – a globally applicable and comparable system being a vital first step in this process.

The codes in ICD-PM reflect the close relation between maternal conditions and the outcome of the pregnancy. Documentation and coding of maternal condition that may have influenced the pregnancy is mandatory in every perinatal death. Another defining element of ICD-PM is that it identifies the time of death in relation to onset of labour: antepartum, intrapartum or neonatal.

The multi-layered approach to classification of cause of death makes the system applicable to a wide range of settings where the information available varies greatly in quality and detail. This is of great importance to the system's global applicability.

As stated in the annex to the document, standardization of attribution of cause of death will improve interpretation of data on perinatal mortality and the maternal condition in this

setting, analysis of the causes of perinatal mortality and allocation of resources to programmes aimed at both maternal and perinatal mortality. [7] (WHO, 2016, p.1-2)

Main perinatal causes of death, ICD-PM groups		
Antepartum death	**Intrapartum death**	**Neonatal death**
A1 Congenital malformations, deformations and chromosomal abnormalities	**I1** Congenital malformations, deformations and chromosomal abnormalities	**N1** Congenital malformations, deformations and chromosomal abnormalities
A2 Infection	**I2** Birth trauma	**N2** Disorders related to foetal growth
A3 Acute antepartum event	**I3** Acute intrapartum event	**N3** Birth trauma
A4 Other specified antepartum disorder	**I4** Infection	**N4** Complications of intrapartum events
A5 Disorders related to length of gestation and foetal growth	**I5** Other specified intrapartum event	**N5** Convulsions and disorders of cerebral status
A6 Antepartum death of unspecified cause	**I6** Disorders related to foetal growth	**N6** Infection
	I7 Intrapartum death of unspecified cause	**N7** Respiratory and cardiovascular disorders
		N8 Other neonatal conditions
		N9 Low birth weight and prematurity
		N10 Miscellaneous
		N11 Neonatal death of unspecified cause
	Maternal conditions	
	M1 Complications of placenta, cord and membranes	
	M2 Maternal complications of pregnancy	
	M3 Other complications of labour and delivery	
	M4 Maternal medical and surgical conditions	
	M5 No maternal condition	

Methods and material

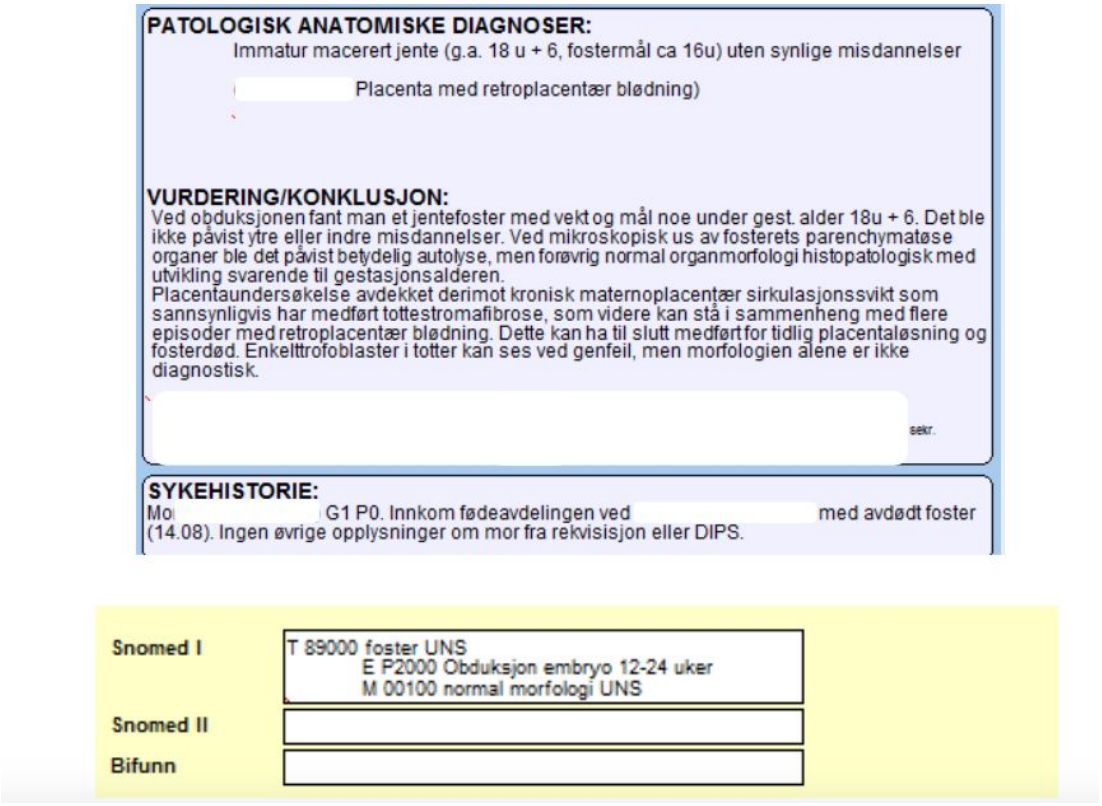
Through this work the causes of death in foetuses and infants examined/autopsied at Oslo University Hospital (OUS) were reviewed. Because the project was started in 2015 and one of the goals was to look at changes over time we chose to look at reports from 2015 and 2005, a period with increased focus on perinatal pathology at OUS.

Autopsy material

The basis of this study comprises all post-mortem reports on foetuses and infants up to seven days of age in 2005 and 2015. The age-limit is set in accordance with the WHO's definition of the neonatal period. The number of reports amounted to a total of 249, of which 101 dated from 2005 and 148 from 2015.
The information gathered from the reports included: information about the foetus/infant like length, weight, malformations, presence of photographic or radiographic documentation, abnormal genetic findings, gestational age, prenatal diagnostic procedures performed and their findings, mother's obstetrical history and any complications. We also recorded the SNOMED codes used to describe the findings and cause of death.

Assigning ICD-PM codes to the material

In order to study mortality trends in a standardized manner, an ICD-PM code was assigned. In the recording process, the information in the summary text of the post-mortem report was used. This includes a written-out description of the events leading to death and how they relate to the findings and it is this information that is sent to the Public Health Institute (Dødsårsaksregisteret og Medisinsk Fødselsregister).



PATOLOGISK ANATOMISKE DIAGNOSER:

Immatur macerert jente (g.a. 18 u + 6, fostermål ca 16u) uten synlige misdannelser

Placenta med retroplacentær blødning)

VURDERING/KONKLUSJON:

Ved obduksjonen fant man et jentefoster med vekt og mål noe under gest. alder 18u + 6. Det ble ikke påvist ytre eller indre misdannelser. Ved mikroskopisk us av fosterets parenchymatøse organer ble det påvist betydelig autolyse, men forøvrig normal organmorfologi histopatologisk med utvikling svarende til gestasjonsalderen.
Placentaundersøkelse avdekket derimot kronisk maternoplacentær sirkulasjonssvikt som sannsynligvis har medført tottestromafibrose, som videre kan stå i sammenheng med flere episoder med retroplacentær blødning. Dette kan ha til slutt medført for tidlig placentaløsning og fosterdød. Enkelttrofoblaster i totter kan ses ved genfeil, men morfologien alene er ikke diagnostisk.

sekr.

SYKEHISTORIE:

Mo G1 P0. Innkom fødeavdelingen ved med avdødt foster (14.08). Ingen øvrige opplysninger om mor fra rekvisisjon eller DIPS.

Snomed I	T 89000 foster UNS E P2000 Obduksjon embryo 12-24 uker M 00100 normal morfologi UNS
Snomed II	
Bifunn	

Figure 1 Example of post-mortem report at Oslo University Hospital. The blue section includes the written conclusion, final diagnoses and a brief history of the mother. The yellow section at the back of the written report contains the SNOMED codes

We defined which codes were to be interpreted as a failure to establish a specific cause of death and that did not confer any information about the chain of events leading to death. In ICD-PM this would mean A6 (Antepartum death of unspecified cause), I7 (Intrapartum death of unspecified cause), N11(Neonatal death of unspecified cause) and M5 (No maternal condition).
In SNOMED we defined a group of codes to be unspecific/inconclusive when appearing alone, without further specific coding. These codes do not confer any information about the chain of events leading to death. The following SNOMED codes were defined as unspecific/inconclusive: M 28050 (immature foetus), M 00100 (normal morphology), F 31680 (spontaneous abortion/miscarriage), M 28130 (macerated foetus), F35330 (intrauterine foetal death), E P4000 (autopsy, child).

Statistics

In order to examine the statistical significance of some of our observations, we put them through a series of analyses. Chi-square test was used to assess the significance of the changes in the number of placenta- and hypoxia-related deaths between 2005 and 2015. The change in number of antepartum deaths of unknown cause and the difference between the number of inconclusive codes in 2005 and 2015 were also assessed with a chi-square test. In these aforementioned tests, there were two independent, categorical variables and outcomes. To determine the variability between the two coding systems, we calculated a Cohen's Kappa coefficient. Intraclass correlation coefficient was calculated to test interobserver variability.

Results

A randomly selected 10% of the reports were blindly assigned ICD-PM codes, by two independent coders. To test the interobserver variability, we calculated the intraclass correlation coefficient, which was considered to be strong (0,942) for the foetal codes and moderate (0,553) for the maternal codes (where a coefficient of one would mean total agreement and 0 would mean chance agreement).

In the process of assigning ICD-PM codes to all our reports, we were, in a standardized manner, able to register at what time and of what the baby died.

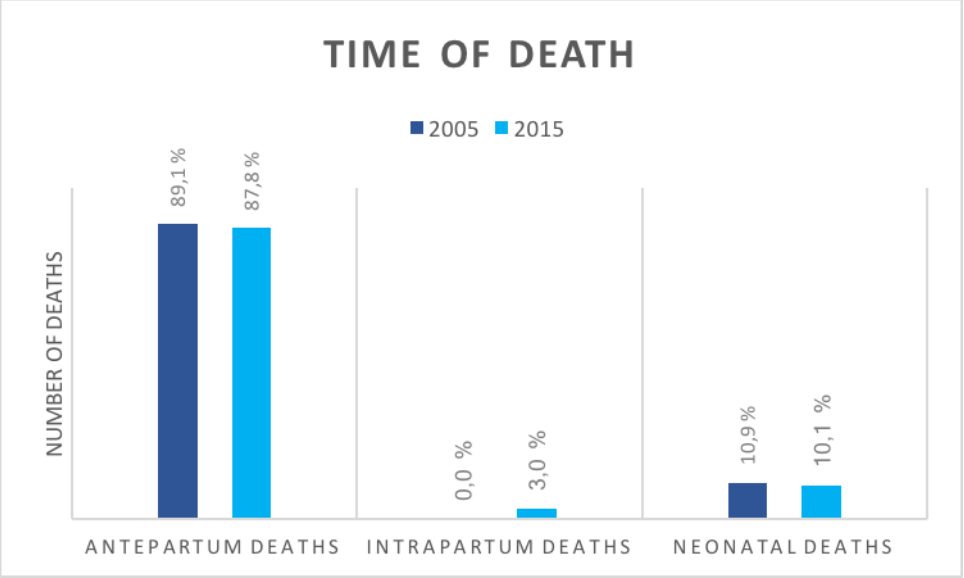
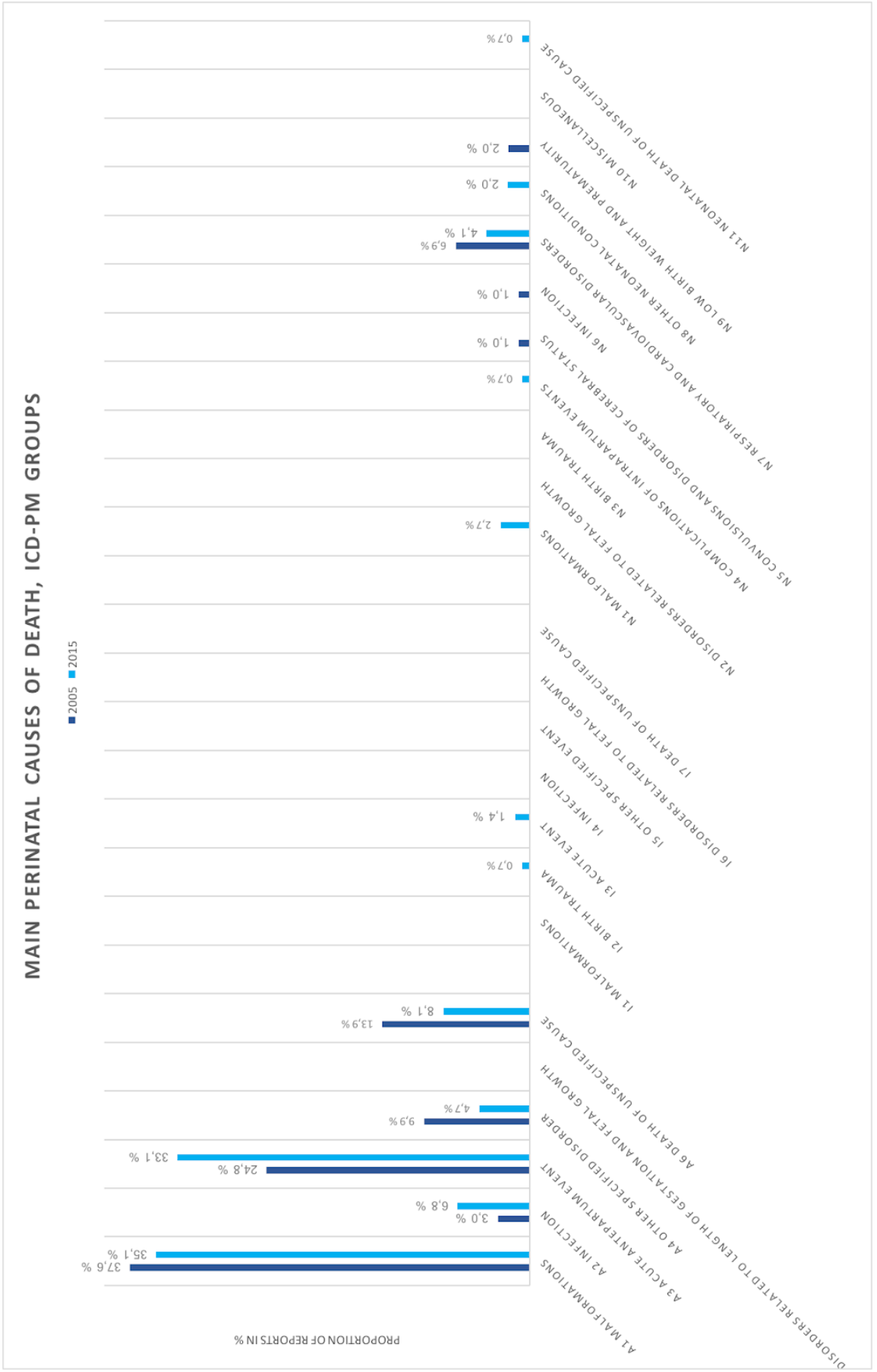


Figure 2 Time of death in relation to onset of labour

The majority of the babies examined at OUS died antepartum and only three (1%) died intrapartum or because of an intrapartum event. The number of neonatal deaths was 11 (11%) in 2005 and 15 (10%) in 2015 (Figure 2). Most of these were deaths due to complications of prematurity (immature lungs, necrotizing enterocolitis).

The main foetal conditions leading to death in both 2005 and 2015 are malformations (37% and 35%) and antepartum hypoxia (24% and 33%). The majority of “Other specified antepartum disorders” are problems relating to amniotic fluid (e.g. preterm rupture of membranes). The “Respiratory and cardiovascular disorders” in the neonatal period are most often related to prematurity (Figure 3).
The changes in the A3 and A6 categories were found to be statistically insignificant (p=0,157 and p=0,145 respectively).

Figure 3 Perinatal causes of death in 2005 and 2015



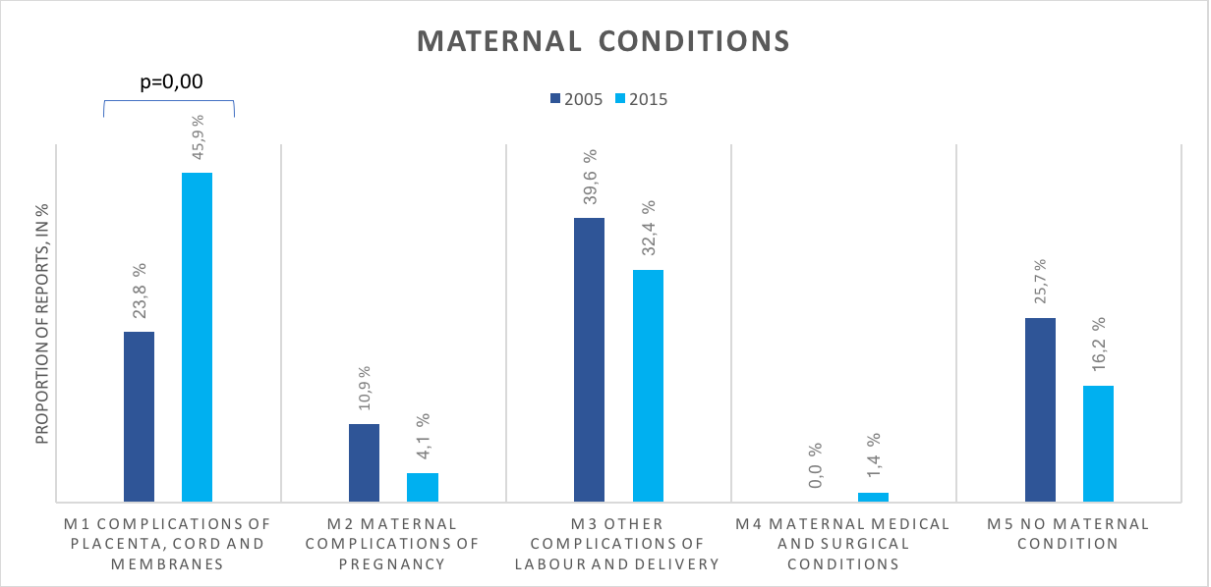


Figure 4 Maternal conditions (M1 - M5) in 2005 and 2015. The chi-square test performed to assess the change in number of placenta-related deaths yielded a p-value of 0,00.

The maternal conditions recorded in our material mostly fall in to two categories: M1, complications of placenta, cord and membranes (23,8% in 2005, 45,9% in 2015) and M3, other complications of labour and delivery, including termination of pregnancy (39,6% in 2005, 32,4% in 2015). The proportion of mothers with no maternal condition in our material was 25,7% in 2005 and 16,2% in 2015 (Figure 4).

The maternal conditions can be seen in relation with the foetal conditions in a multifactorial process leading to death. Foetal conditions in A1 (congenital malformations, chromosomal abnormalities) are often detected during the antenatal screening program in Norway and subsequently a great part of these foetuses was aborted, maternal condition M3 (other complications of labour and delivery, including termination of pregnancy). The other, most common maternal condition is complications related to placenta, M1. This in turn leads to asphyxia in the foetus, A3.

Our findings underline the importance of always examining the placenta when doing a post-mortem examination on a foetus or neonate. This was not a systematic part of the examination in 2005, but has been implemented between 2005 and 2015.
The increase in number of deaths related to placental pathology was significant; a chi-square test yielded a p-value of 0,00.

To study quality, we compared the two systems with regards to their ability to capture a specific cause of death (see Material and Method).

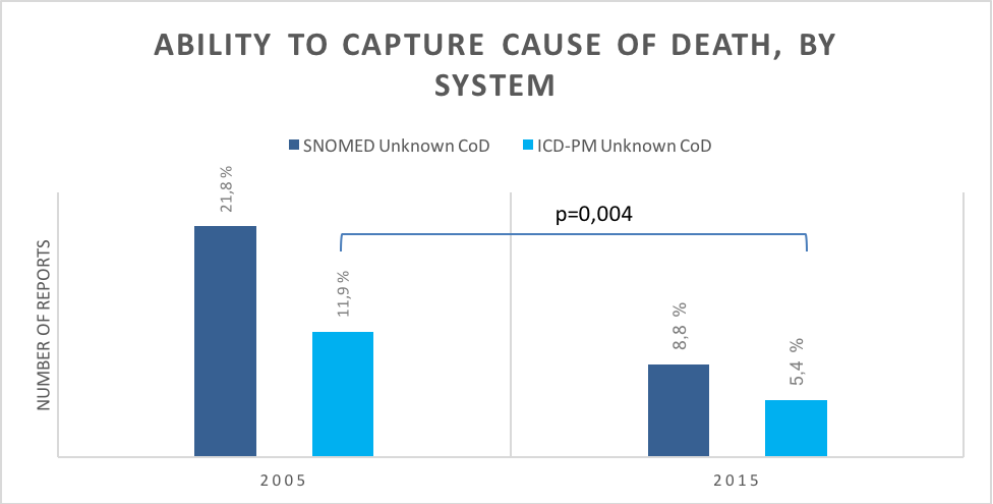


Figure 5 Number of reports coded with "unknown cause of death" in SNOMED and ICD-PM, in 2005 and 2015. The chi-square test performed to assess the reduction in number of reports concluding with "unknown cause of death" yielded a p-value= 0,004.

Looking closer at each case where the two coding systems were not of accord we find that it is mostly SNOMED that fails to capture the cause of death in its codes, compared to ICD-PM (Figure 5).
We examined the circumstances under which the two systems differed in capturing a cause of death. We found that in 14 of 17 reports a specific cause of death was captures according to ICD-PM coding, but not according to SNOMED. Although the conclusion was not captured in the coding, the written section of the report did, however, conclude.

Between 2005 and 2015 the number of reports concluding with an unknown cause of death has significantly decreased; the chi-square test performed yielded a p-value of 0,004.

Cohen's kappa was run to determine the variability in coding between the two classification systems on the entire material. In 2005, the agreement between the systems was substantial, kappa=0,65. In 2015 it was moderate, kappa=0,51.
Since the variable we considered was whether the code assigned was specific for a cause of death or not, this test merely tells us that the two systems are equally good at establishing a cause of death. This, however, does not take into account the ease of use and experience of each classification system.

Discussion

Oslo University Hospital material compared to the Norwegian population

In the OUS material, the majority of deaths occurred antepartum and two causes of death stood out in terms of frequency: congenital malformations/chromosomal defects leading to termination of pregnancy and hypoxia and intrauterine death caused by dysfunctional placenta.

According to the Public Health Institute's (FHI) data, the number of births and perinatal deaths has been quite stable between 2005 and 2015. Our material comprises data from post mortem examinations done at a hospital. A post mortem examination for medical purposes (as opposed to a forensic examination) should be done upon indication, but this indication is not clearly defined in any law. Most parents want the foetus/child to be autopsied in these cases [6](Den Norske Patologforeningen/The Norwegian Association of Pathologists, 2004, p.17). The fact that our material comprises only post mortem examinations in itself represents a narrow selection of the national data. Between 2005 and 2015 the number of post mortem examinations on foetuses/infants has been 25-35% of deaths. The autopsy rate on the rest of the population is estimated to be 8-10%. [3] [8] (Helse- og omsorgsdepartementet /Ministry of health and social care, 2011, pg4.3.3.3)

Norwegian legislation allows women to get an abortion upon their own request, before 12 weeks gestational age (estimated by ultrasound examination and measurements) – these are not included in the material as these foetuses are not autopsied. Terminations after 12 weeks gestational age (before 18 weeks) have to be approved by a medical tribunal ("Abortnemnd") and certain conditions must be met: the abortion can be approved based on socioeconomic grounds, threats to the mother's health or if it is reasonable to assume that the child will suffer serious health problems (most often hereditary diseases or malformations) [9] (Abortlova/Law on termination of pregnancy, 1975, § 2). Thus, the post mortem reports in our material are mostly from foetuses with malformations (leading to them being aborted), as these are the ones that are autopsied at OUS.

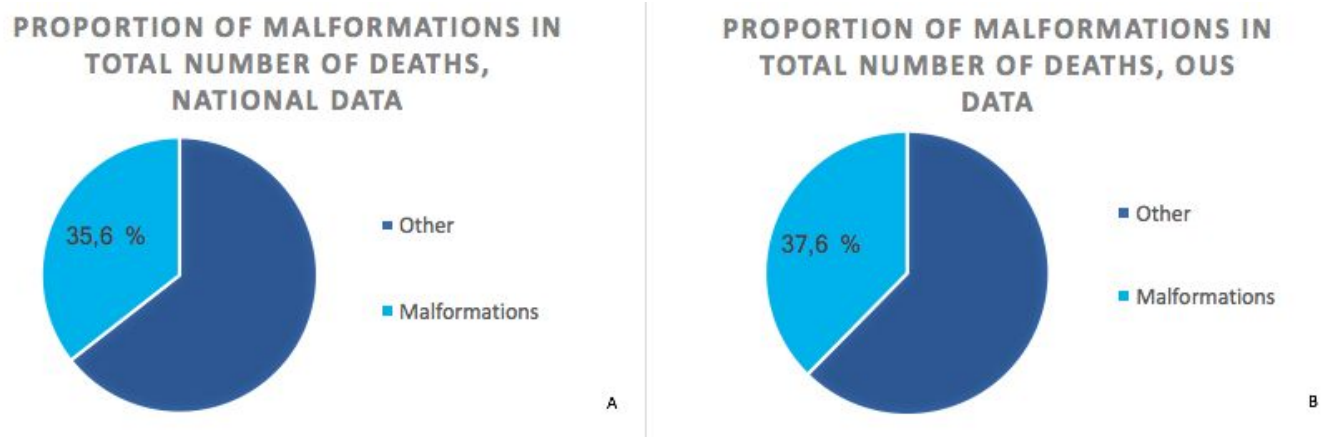


Figure 6 This figure shows the proportion of deaths with malformations, in 2005, in the OUS data (A) and national data (B). In 2015, the proportions are 37,8% at OUS and 38,8% nationally.

When comparing OUS data with data from the Public Health Institute, we can conclude that our data is relatively representative of the general population. The proportion of lethal malformations is the same in the local and national data-sets (around 37%) and is fairly stable over time (Figure 6).

We also looked at the number of terminations in our material, and their relation to the number of malformation. A majority of terminated pregnancies both in the OUS and Public Health Institute material had malformations: 210 of the 245 terminated foetuses (86%) had a malformation in 2005 and 228 out of 260 in 2015 (88%). In OUS's data, in 38 of the 40 terminated pregnancies there were malformation in 2005 (95%). In 2015 the number of malformations surpasses the number of terminations – this can be explained by the fact that some malformations were so severe that the foetus died spontaneously in utero.

Oslo University Hospital material compared to other populations

When publishing the ICD-PM, WHO did studies applying the system to populations in the UK and South Africa. The UK results show some similarities to ours and most deaths occured antepartum, main maternal complication was related to placenta, cord and membranes and a great part of antepartum deaths were due to congenital abnormalities. The neonatal deaths were also mostly due to complications of prematurity.

However, there are far more neonatal and intrapartum deaths than in our material (5% intrapartum and 46,7% neonatal deaths in UK, 0% intrapartum in 2005, 2% intrapartum in 2015, and 10% neonatal deaths both years in Norway) [10] (ER Allanson et al, 2016, p.2023-2025).
This can be partly explained by the fact that in Norway, most deaths occurring intrapartum lead to inquiries at the wards and the neonates are sent to forensic pathology labs for examination, rather than to the hospital's pathology lab.

In the pilot studies done by the WHO in the UK and South Africa, it is clearly stated that ICD-PM codes were assigned retrospectively by trained coders. In our study, however, the coders were not trained. The main challenge with SNOMED is therefore, to a certain extent, seen in ICD-PM: namely that reliable coding across coders and centres can only be achieved by training the coders and setting standards for how to code.

The coders at OUS agreed on a set of "rules" for coding certain chains of events.

In the case of IUFD without any obvious foetal cause of death, foetal cause was coded as asphyxia (A3) and maternal factor as placenta/chord/membrane dysfunction (M1).
A foetus with a malformation/chromosomal abnormality that was aborted would be coded A1 (congenital malformations and chromosomal abnormalities) and M3 (other complications of labour and delivery, including termination of pregnancy).
In the case of chorioamnionitis, attention was payed also to the grade of foetal response: a chorioamnionitis with only maternal response would subsequently be coded A3M1 (foetal

hypoxia and placental dysfunction) whereas a chorioamnionitis with foetal response would be coded as A2M1 (infection in foetus and placental dysfunction).

This is thought to be the source of one of the greatest differences between the Norwegian and UK material. In the UK, no antepartum deaths were coded as "due to hypoxia", which, in the Norwegian material is one of the main foetal causes of death. This is an important difference in coding techniques, which would most likely be avoided by training the UK and Norwegian coders to code in the same way.

Among the coders at OUS there was a discussion around how termination of pregnancy should be coded. As per our coding, a termination because of a malformation in the foetus is coded with the maternal code M3 (Complications of labour and delivery). It was discussed whether it would be more appropriate to code it differently, seen that if the only pathological factor in the pregnancy is the foetus's malformation, the mother should be considered healthy.

Over a ten-year period (2005-2015), the number of reports concluding with "unknown cause of death" has decreased, in the Norwegian material.
A great part of the antepartum deaths in the UK material fall under what we define as "unknown cause of death": unknown foetal condition and no maternal condition. In the Norwegian material, this number is very small, both in 2005 and 2015. This makes one wonder whether there is any significant difference in procedures, investigations or technology around the post-mortem examination. Norway and the UK are on a relatively equal level in terms of development and resources. The difference might then lie in the organization of the perinatal and maternal health services. The Norwegian and UK guidelines for post mortem examination are very similar and place equal weight on the examinations that should be included. [11] (The Royal College of Pathologists, 2017, p.6-10)

Classification systems in Norway - challenges

SNOMED is being used by pathology labs, the National Cancer Registries (Kreftregisteret), forensic pathology labs and for other biobanking purposes. These centres use the coding system differently and have different needs. The first SNOMED-draft proposed was meant as a maximum-system, where each centre could choose to use as many or as few codes needed for their work, and not have to create any "local" codes. However, there is no national consensus and unity around the codes in the system. This gives rise to two main challenges in the registration, classification and exchange of information:

About the importance of structuring data for analysis

Information, such as post-mortem findings and results, has to be organized and structured to be properly stored and interpreted. One of the ambitions of the Norwegian Society of Pathologists is for all of the pathology centres to have one common set of codes for cause of death. A given diagnosis would then have the same form and code in Oslo and e.g. Tromsø. A board of professional exists, under the Norwegian Doctors' Association (Legeforeningen), to develop and update the national guidelines and recommendations so that these also meet the international standards.

About the importance of standardizing data-collecting

The research centres, hospitals and public health institutions (FHI, SSB, MFR) collecting and exchanging data each use different templates and codes. This means that information that OUS gathers and transfers to FHI looks different at the two institutions. Data and information exchanged includes referrals, test results and hospital reports.
The templates are not accurate enough to ensure that important details are reliably and securely transmitted from the sending party to the receiving party. This is true particularly within the field of pathology, where the reports are in written text, making the information hard to use and systematically interpret. [12] (Direktoratet for e-Helse, 2016, p.14)

In order to capture chains of events leading to death in perinatal pathology, "locally modified" SNOMED codes have been implemented at OUS, which do not exist at other centres (E codes). This information is in practice not accessible to other centres wishing to do research, unless the centres themselves reassign codes to the material.

Specificity of a classification system to its material

We found that ICD-PM was easy to use and reproducible in a perinatal post mortem setting. Contrary to SNOMED and ICD-10, ICD-PM has been developed with specific focus on the perinatal setting. This makes it easier to use in the setting of perinatal death. When comparing the ability of each system to capture a cause of death in their codes we found that ICD-PM and SNOMED do not differ statistically significantly (see Cohen's kappa coefficient).

Markers for quality in post mortem examinations and reports at OUS

Through this study, we gained important insight into changes in trends and possibly development and implementation of new routines and technology at the department.
In 2004, Bjugn et al (2002) [13] published an adaptation of the quality markers defined by the Royal College of Pathologists ("Guidelines for post-mortem reports"), a set of markers to assess the quality of post mortem examinations and their reporting. Before that time, local guidelines were used, but the work of Bjugn and co-workers was the first to set a national standard. Now, external examination, examination of the major organ systems, histological sampling, photographic documentation, blood samples and examination of placenta are always done. In specific cases of unexpected intrauterine death, genetic analysis, microbiological testing or screening for metabolic diseases are sometimes indicated. This development was enforced by the establishment of the Competence Centre for Paediatric and Pregnancy-related Pathology at OUS in 2006, and the focus on this field of pathology was greatly increased.

Using our negative marker for quality, the number of reports concluding with "unknown cause of death", we observed that between 2005 and 2015, the quality has increased at OUS. As mentioned earlier, we believe that the systematic examination of the placenta has played an important role in this development – a theory based on the observation that reports from 2005 often did not include any mention of the placenta, which the reports from 2015 systematically did. This is thought to be the result of the gradual implementation of

new routines at OUS after the publication of the national guidelines for post mortem examination as well as the increased focus on perinatal pathology.

It might be interesting to further expand this study to look at greater periods of time rather than just sampling, like we have done. More needs to be done to establish whether SNOMED-coding should be abandoned, or further adapted to the perinatal setting.

Conclusion

Over the ten-year period looked at, the quality of post mortem reports at Oslo University Hospital has seen an improvement in terms of how often a clear cause of death was established. This is partly due to an increased focus on perinatal pathology through a multidisciplinary approach and a systematic implementation of histopathologic examination of placenta. In our material, a dysfunctional/failing placenta is the most frequent maternal condition associated with foetal mortality.

The ICD-PM and SNOMED systems for classification of cause of death seem equally able to capture a cause of death, however the SNOMED system has been criticized for being far too complicated and poorly suited to the perinatal pathology setting. The ICD-PM classification system is easy to use, reliable and, with adequate training, it allows an accurate registration and classification of perinatal deaths on both a national and international level. Its specificity also lies in that it accounts for maternal conditions.

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